

Federal/State Partnership Meeting
Transition from Pediatric to Adult Primary Care
Hearing from Youth with Special Health Care Needs

October 25-27, 2009

SABRINA MATOFF-STEPP: Thank you for coming to this session. This is a very exciting project that my colleague, Anna Lenhart, and I are going to talk about this afternoon. My name is Sabrina Matoff-Stepp. And I'm the Director of the HRSA Office of Women's Health. And you may be asking yourself what is that, because it's like is that MCHB? Is that HRSA? What is that?

So in your notebooks under Tab 7, I think it's Tab 7 where some of the materials are as well as a PowerPoint for today you can certainly read about Ann and I. We won't bore you with telling you our life story up here.

Basically I just wanted to share a little bit about the HRSA Office of Women's Health because it's something that oftentimes people aren't as familiar with. You know MCHB. You know the Title V Block Grant but you may not be as familiar with the HRSA Office of Women's Health.

Really briefly the HRSA Office of Women's Health has been in existence since 1996. We were created in the late '90s, obviously. We were created administratively in the Office of the Administrator.

We are not legislatively mandated. What that means is a number of things. It means that we can be moved. And in 2000, when the administration changed, we were moved, and we were put administratively under the Maternal Child Health Bureau. So that's where we've been ever since in terms of the structure.

But our name has not changed. It's not the MCHB Office of Women's Health. It's the HRSA Office of Women's Health. That has implications and that's essentially we're charged with women's health policy and programming across the entire agency.

So my office, and I think I saw my two staff wave in the back there, Marissa Rice and Eisha Cody. We're an office of three. I know you all know what it's like to work with few resources. We have this amazing charge and we have three staff people to do this across all of HRSA.

We're collaborating and coordinating all the time. We do absolutely nothing by ourselves. We really are looking at how to empower, engage and create new ways of dealing with issues that women are facing across the life span so that this new sort of philosophy that we've been hearing about this morning and certainly that you'll continue to hear about throughout this conference about looking at MCH from a life span perspective is so perfect because really the Office of Women's Health at HRSA has always taken a life span approach.

We are concerned about women as they grow, as they become mothers or not. And as they continue to have hopefully healthy satisfying lives. So we do a number of different things within MCHB. We also do a lot of things within the other bureaus at HRSA.

And we work quite a bit with the other agencies in HHS. So our colleagues in FDA and CDC and NIH, the Office of the Secretary, so there's a lot that goes on in women's health at HHS, and increasingly more, which is always good, I think, given that we've had sort of a little bit of a lack of things going on in women's health over the last couple of years.

We're really excited now to have some new energy and some new charge to be working with all of you and to be working with our colleagues and our sister agencies.

So again the HRSA Office of Women's Health, we are a resource to you, if you would like to contact me or my staff, we are very interested in working on issues that affect women and their families. And taking that sex and gender perspective on issues that perhaps in the past you've only sort of looked at from one perspective, like one-size-fits-all may have worked before but it might not work still.

So that's really sort of a very brief introduction about the office. There's more information if you want to learn about the office on the MCHB website. But I just wanted you to know again where we come from and if you would like to work with us, I'd be happy to follow up with you.

This particular project, again, was born out of a lot of discussions, collaborations, trying to get our arms around looking at an issue that perhaps all of you know a lot more about than I do.

I'm still learning here. But we really wanted to take a look at this issue of youth with special healthcare needs as they transition to adult primary care.

And you all know again, I'll defer to all of you, you know more about this than I do, I really began to see this uninvestigated niche which was as these young people grow and they live longer and longer lives with better technology and medicine and supports, what are some of the issues that they face from a sex and gender perspective.

Is it all the same? Or are there some issues that perhaps the young women experience differently than the young men, are there some things that they all say. They all share. And we really went into this sort of not knowing. We knew that there continues to be a lot of work around transition issues.

This is something that is important. It's part of the performance measures for the block grant. But, again, how do you look at this just a little differently and learn from the youth themselves? Because we can all assume, but when you go to the youth themselves, they'll tell you exactly what's going on.

It may be interesting. It may give you some new insights. So this project, we started this. We started putting this together, and I went to Dr. Van Dyck and asked for a little money.

And at first he was like what are you talking about? And I had to kind of sell it to him. But he came around, and he agreed. And I did this and then on the next slide I'll show you this is again an example of a partnership and a collaboration. This is certainly not something that we could do by ourselves. And we're very interested in hearing from you about your thoughts, maybe your experiences on how you've worked with transition from a sex and gender perspective, what are other ideas you have about taking this work a little further.

Because this is just a start. We certainly have only touched on the tip of the iceberg. So I'm going to do a little bit of the presenting and my colleague Anna Lenhart from New Additions Consulting will talk about some of the work that we did actually with youth themselves.

New Additions, this is the workgroup. We have a number of people involved with this project. Certainly MCHB Division of Children With Special Healthcare Needs. I'm sure all of you know Dr. Bonnie Strickland and her team. We've certainly worked with them on this. My office, the HRSA Office of Program Planning and Evaluation, the Office of Women's Health at the Secretary's level. Within the structure of the department, there are other offices in women's health and there's one at the secretary level. So we worked with them.

The Office on Disability at HHS. Many of you know them very well. They also have a strong interest in helping young people grow and be healthy.

And, of course, again New Additions consulting which is where Anna came from. And we started to talk about this study, and there's Bonnie, just waved at Bonnie, and how wonderful it's been to work with Bonnie on this project.

I'm always, you know, as a federal employee, you know, we do a lot of work collaboratively and a lot of work with different contractors. And we all struggle at times to find really good contractors and people who can do what we envision.

And I have to say -- and I'm so glad -- it's easy for me to say this -- that working with Anna has been nothing but a pleasure. This is an amazing project that we started and it couldn't have happened without Anna and her colleagues at New

Additions and you'll see why as we go through. But Anna has been great, and it's been just a great collaboration.

So what are we trying to do here with this project? So, again, what we were trying to set out to do is really sort of look at what are some of these challenges, barriers and opportunities for young people?

And we're going to define what we defined as young people. And there's all kinds of ways, of course, to put parameters around what's youth, what is middle -- young adult, et cetera, and there's all kinds of ways to justify that.

And we'll tell you why we chose this certain age group that we did, too. So we looked at some of these barriers and opportunities for male and female, youth with special healthcare needs as they transition from pediatric to adult primary care.

And again this sort of slant that we wanted to take a look at was, what are some of those similarities and differences in their experience? Were they -- were there some things that they could teach us as we try to improve their experiences to try to support them, help them better, as they make that transition as they grow.

So this slide, some of this again will probably be very familiar to you. This is a quote from the National Survey of Children With Special Healthcare Needs. But

this gets at. I won't read it word for word to you, you can certainly see it, but it makes a case for we're talking about a significant number of young people that are living with a special healthcare need.

And, again, there's technology and medical treatments and cures, even continued to be found, young people are not dying young. They're continuing to live perhaps with this particular chronic condition and to become hopefully independent adults.

And that presents, of course, a number of challenges to the young person themselves, but it also presents, of course, challenges to the provider teams, to their families, to their communities. Ultimately, of course, we are -- we'd all like to see young people become independent, healthy adults, and to not be judged by that particular special need they have. But just to maximize their ability to really integrate and to become part of meeting their own healthcare.

When I first started working on this project, again, very little knowledge, just the kernel of an idea. I was just amazed about we're not talking about a few young people here. We're talking about a lot of young people who really need to be understood from where they're coming from.

And hopefully that is something that we've begun to take a look at here. One of the things that again all of you know very well, so it goes without saying, but just

Bonnie always drums this home and I'm continuing to learn from her about this, is the importance of a medical home.

Certainly when we're trying to develop this project, one of the sort of the key pieces that we were trying to sort of use as a framework was the importance of looking at a medical home, where some of the elements that the transition that young people with special healthcare needs were going through, what are some of their care coordination markers that we try to ask them about in the discussion groups, was that reflective of a medical home.

So, again, just some brief background here but we really wanted to just give you that piece. So what did we do here? We did a number of things with this again very exploratory, small study, a little bit of resources, lots of collaboration. And, again, it's an example that you don't need a lot of money sometimes to do something. You need interests. You need will. You need commitment. Not a lot of money mere here. I can share it was a lot less than you probably think. But what we did, we did two major things with this particular study.

We did a lit review, a focused lit review. It wasn't an exhaustive lit review. But we did a lit review where we focused on youth with special healthcare needs and we looked at ages 14 to 30. We wanted to get at some young people as they started to go through that transition as they started hopefully to be making those transition plans with their healthcare provider and also continue and look at the

overlap. Okay, now as you start to become a young adult, you're going to college, you're leaving home.

You're becoming a member of the larger community, and perhaps then you're going into your young adulthood and starting families. You're starting other parts of your life. We wanted to look at sort of that continuum.

So age 14 to 30, you know, it's not the only way to look at this age group, but we really wanted to look at some of the sort of the younger people as they started to transition, think about transitioning and then hopefully people who had gone through it or who were still going through it actually, because one of the things we learned was that not everyone goes through this transition.

Some are still working at it. Some never did it. So interesting. And Anna and her team, we worked with them. We looked at about 20 different articles focusing on these four domains. General health and well-being, behavioral health. Mental health and reproductive health. Those four domains.

And then -- am I on your slide yet? Is this your slide? Anna will tell me when -- we're going to divide it up. And then that informed, then -- and Anna is going to talk about what we found from that literature review. -- that informed then we went on to doing a number of discussion groups. And this is where it really got interesting. Because we had four discussion groups.

We then brought in essentially the youth themselves. We wanted to hear from them. And for this part we included young people between the ages of 18 and 27. The 18 essentially was our way to get around informed consent from a parent.

That's the only really logical reason why we didn't go younger, because that hassle of needing a parent to provide informed consent, as much as important, I have to say we took that shortcut. We just didn't have the time to do that. It's another piece that I hope we might be able to do at some point is to ask younger people and do repeat this discussion through process.

But that's why we did 18. As far as the 27, I think that, again, was just a matter of trying to keep it a little bit within sort of that young adult group. We really didn't have, as I recall, a more definitive way of 27. It was just where the oldest person who was able to participate, that was as old as they were.

We wanted to keep it kind of up to about 30. Not a whole lot more than 30. It just so happened the oldest person was 27.

So we did four groups. Two groups of men. Two groups of women. And then again these are small groups. These are discussion groups. So not a lot of

people. This is exploratory, qualitative, whatever you want to call it. But again start us thinking about what are some of -- what are some of these questions.

Okay. So I'm going to now turn it to Anna who really was the key behind doing a lot of the work here, and she's going to sort of talk and share with you what we found with some of the literature review, what we found with some of the discussion groups. Some of what we actually want to now share with you and in your binders under Tab 7 I think you'll really see -- we're going to talk about this -- what some of those quotes, some of what the young people shared with us that really sort of taught us more than what we had got.

So I'll turn it over to Anna here.

ANNA LENHART: Hi, I'm Anna Lenhart. Moving right along. We'll talk a little bit about what we found during the lit review. Sabrina said we did 20 articles. Part of this was a focus issue. The other thing you'll find by reading these four bullet points is what we found through the research was a lack of research.

When you type in transition models focusing on sex and gender needs for adolescents with special healthcare needs/disabilities, really nothing comes up.

So we kind of went through, tried different terms. And we found some things but what we really found was there's a need out there for more research, for more

focused research, especially on the sex and gender needs for the youth in our target demographic.

So moving on to the research portion of the project. We conducted the lit review. We used what we found from there to kind of move forward and develop a research framework. And what we decided was what was missing was the actual input from youth themselves, while they're going through the transition process.

We found some studies that had interviewed parents of youth with special healthcare needs. Had maybe done a retrospective on what was your transition process like.

What we didn't have was I'm transitioning right now, this is what it's like, this is what I'm going through, here's my story, and that's what we wanted to capture through our small study.

So just a little look at our group. 18 to 27. We had nine males and seven females. We had four discussion groups, and two supplemental interviews. One with a young man and one with a young woman.

The youth were self-selected. We sent out notices through different listservs and relevant organizations and the youth signed up. So that presents some limitation we'll talk about later.

But the other thing that was interesting, for as small of a sample as we had they were really representative of a variety of disabilities across the spectrum. It's important just to note that they were peer leaders, if you will, or they were opinion leaders within their separate groups.

We did the informed consent. And they received I think \$25 for participating.

They did have an incentive. So another note about our demographic is that they did have a higher than average education level. We had a high representation of college students, college graduates, and two students who were pursuing advanced degrees.

So what we found that was common among the different groups were misconceptions in the healthcare community. Some of our participants felt that their healthcare providers kind of project their own limited expectations upon the youth.

The youth, when we compared the goals from our youth with the goals from just general adolescence, they don't have goals or expectations for life they just need different strategies how to get there.

I think that's really important to carry through. We're not talking about changing expectations, we're just talking about a new way to get there. And that's what the youth really focused on.

Another thing we learned was that despite everything, they're still seeing their specialist as their primary care provider. One of my favorite quotes from the youth was: You know what I got from my primary care provider, I got a referral to my specialist.

So despite kind of trying to do the primary care, we still see the specialist being the provider they most associate with.

And the third thing was the shift from parent to patient-centered care. I think every single participant in our groups said some version of, hey, I'm in the room, don't talk to my mom, talk to me. I make my own decisions. I'm 24 years old. This concept of taking ownership of their own care isn't something like we'll see if they can or can't do, it's something they want to do and are able to do they need their providers to cooperate and help them move along that direction.

So next, with our focus groups, with the young women, we found these three themes. The diet and exercise and violence and reproductive healthcare to kind of emerge is as the most frequently talked about. Touching on the first one, diet

nutrition and exercise. What they really focused on with these three issues were kind of the long-term effects, not kind of dieting for tomorrow but cardiovascular health, learning the behaviors to carry over to adulthood.

So long-term health impacts about these behaviors, which was interesting to see comparing it to some of the general adolescent literature on female views of diet and exercise.

So the second thing we talked about was violence. And this was something in the literature that was more closely associated with young men as being a prominent issue. And what we found with our young women was the existence of verbal and emotional abuse in relationships as well as bullying between women. So that's what they talked about as far as their concerns with violence.

And one individual kind of said something that was interesting about women with disabilities and special healthcare needs being their own bullies or kind of having a projection of self-worth that might make them more vulnerable to tolerating it from other people.

And then the third thing was reproductive healthcare. And this was pretty interesting, because it wasn't, again, just immediate choices. It was pregnancy planning. We'll talk about some of the quotes in a little bit. But planning for

families. Switching medication now to something that would be able to be taken during pregnancy.

Talking about genetic testing. Well, my child had my disability kind of really looking forward, which was great to hear and very interesting.

So the next thing we talk about are the male-specific themes. So the guys in our focus groups were really focused on long-term family supports, kind of the role of the provider, kind of some things we see in the literature as traditional gender-specific themes but they really were interested in how their health benefits would change if they're on public benefits, if they get married. If they have children. What does that mean?

I think one of our young men was talking about getting a 401(k), where does you do that, where are the support classes to help me learn about this. And throughout the group this really looking long term was a great theme that we saw.

So some of the lessons that we learned that were not gender-specific was the definition of transition and how this differed. The research really talks about transition as a shift from pediatric to adult-oriented care. That's how they defined it in the research articles we looked at and that's how we defined it going into

this. What we found when we talked to youth about transition, they were talking more about navigating within the adult healthcare system.

We asked if they had issues with transitioning and they said things it's easy to get an insurance card. It's hard to get a doctor. We also have, because a lot of them were in college, so you have public in California but you're a college student in Massachusetts.

How does that affect your life? What kind of transition tools are needed. So that was kind of an interesting difference between what we expected going in and what we found coming out.

We also had the inclusion of youth in the decision-making process. They were really interested in participating in our study. They were really interested in learning about more opportunities to participate and inform the debate since it's about them. And they want to be included while they're involved with it.

Concerns about healthcare system fragmentation, care coordination, cost.

These are concerns that everybody has, but when you're dealing with a variety of specialists, different medications, these are very real concerns to these young adults.

Gender-specific. We saw long-term healthcare issues with the women and supporting families with the young men. What we have in common is kind of related back to these misconceptions in the healthcare community or maybe misconceptions in the community in general. They're not just thinking about tomorrow. They're thinking 10, 15 years down the line. That's so important to consider as we make strategies, we help providers learn more about our population.

So I think that's kind of the biggest finding that we found was that there really is no difference between the goals of young adults without disabilities and the goals of young adults with disabilities.

It's just a different means of getting there.

So some of the limitations from our study. It was self-reported information. So you kind of -- this is a small sample size. We had self-reported information.

These were highly educated young adults who were very involved with their own youth leadership groups.

So these were not just kind of randomly selected young adults. The small size is all selection bias. Again they're not representative of all youth with special healthcare needs and then our limited resources.

So here's some snippets of what the youth taught us. So we have the -- they do studies about us but shouldn't they include us. This goes back to what I said a few slides ago. The youth are interested in doing more, helping to inform more studies about them. There's a lack of research out there and there's a population willing and eager to participate in generating more research.

So I think there's a disconnect there that doesn't need to be. The transition itself went fine. It's easy to get an insurance card but hard to get a doctor. Maybe the focus needs to shift to helping youth navigate within the system versus just transferring them to it and then saying good luck.

So if I get married, would I need to start paying for my own medical insurance? How much does it cost? Do I need a job with healthcare and a 401(k)? These are young adults thinking well beyond just marriage and children, we're talking 401(k). Kind of providing more information outside of just health. More quality of life.

So I'm trying find a doctor to be completely open with me. Can I get pregnant? Can I have kids? Will they have my disability too?

One of my favorite quotes from one of the young woman was my gynecologist wouldn't talk to me about it so I got a new gynecologist.

So they're not just going to sit there and wait for their provider to tell them. They're going to ask questions. And if those questions aren't addressed, they're going to move on.

So that's all for our presentation for today. We'd like to open up for questions or suggestions or interesting comments since you're kind of the experts and know more about it than I do. And then for more information, or if you want to see the full study you can e-mail Sabrina or Lauren Sokowski who is in the Office of Disability. Thank you.

SABRINA MATOFF-STEPP: So as Anna said, we ran through this a little quickly, because we really wanted to save more time to really have a discussion. What I can say again is we handed out to you the slides and in your notebook under Tab 7 I think we gave you the Study At a Glance with some great quotes and they're hopefully very informative and useful as you think about the young people that you're dealing with as they transition.

But and the other thing I want to tell you is we're hoping to get the study posted on the HRSA website. It of course has to go through the wonderful bureaucratic clearance process, but that has started, and hopefully it's not going to take much longer.

So it will be posted and when it is we'll make sure that everyone who is here today and certainly at this meeting will have access to it. It's not a huge, long, 100 pages. It's about 20 pages or so. It will give you more background on like, okay, who was in the group. Of course, we can give you a little bit more about their marital status. Some of the race ethnic breakdown. Again, it was small. We wanted to make sure we protected their confidentiality.

So we didn't ask them a lot of demographic questions. But, again, if you really want to see more details and look at more about the lit review, et cetera, we can provide it to you. We just wanted to give you that sort of overview here. But, again, certainly I know Bonnie's very interested from the perspective of working on this in much more in depth in her division and her staff.

I see Linda who is back there part of the workgroup as well and [indiscernible]. And I think what we tried to do here is open, start opening a crack of this topic of transition, particularly for young people who have issues that may or may not be being addressed the way we think they are or what has been typically done.

And then overlay, again, this -- okay, all young people have issues and questions around reproductive health, mental health, et cetera. But are there some things that young women are going to have more of a concern about than young men. And if so what are they. How can we then hopefully work together to better address those issues, because it's not all the same, you know. They're not

cookie cutters. They're going to deal with things differently regardless of what health issue they're dealing with.

And so it was kind of rewarding to see almost in a way that you know you get women together. These young women together and they're going to talk about diet and exercise to some extent. Because that's what they see. And they're concerned about it just as much as anybody else.

Or another topic. Men particularly were the provider role. Okay, a little bit maybe predicted. But again there's some very specific, I think, and more issues that if we had had some more resources and some more time I'm sure we could have found, dug a little deeper, found out a few more things, and we're hoping, I think one of our hopes -- and again we'd like to engage with you all, where you see what are some ways to replicate to expand this kind of work further. Because this is just the beginning. We'd really like to continue this work.

It's got I think a lot of potential to reach out to young people, include them, empower them as they make these changes and become really thriving adults.

So Bonnie, is it -- open kind of a discussion, maybe, if you wanted to -- if there's anything else we didn't say about this study that you wanted to add from your perspective?

BONNIE: Not really anything to add, but I do think is that we've been talking about transition for a while, conceptually. We all know that this is something that needs to take place. And what we see right now is a lot of models of preparation.

And if someone prepares the pediatric community to transfer our youth to adulthood, the adult healthcare system is way, way [indiscernible]. So just comparatively speaking, I see a lot of wonderful -- I'll stand up -- a lot of wonderful preparation materials out there, programs for preparing youth to transition to adulthood.

For me, and what I'm hearing, the transfer from a provider perspective -- I want to get back to what the youth are saying -- is that transfer of how you actually, when the time comes to move to that adult healthcare provider, how do you do it. And how do you co-manage it? I don't like that word, but it's really what it is. It's not just off you go. It's how do we make this transition together so it's seamless for the youth.

But one of the things I found fascinating about this is that the youth really don't see it the same way we see it. Why does that surprise me, I don't know. But they really do see it as a more fluid process rather than an event.

So what I would say from that is, one, we need to put some time and focus on this process of, number one, implementing the great materials we have in place.

As I said, I've seen lots of very nice preparation programs. I think our National Center on Healthy Getting Ready to Work here, we need to make sure that they're cataloged. I think we have a lot of them. But make sure we have all of them. Rather than inventing more, share in the models that are there.

And focus a lot on how do we effect the transfer so that it really is a process for the youth going through it. But for us it's still how do you make sure the transfer takes place. And beyond that, how do you make sure it's quality. Because if it's not a quality move, it prevents keeping the kids with their pediatrician. On that point, we need to focus on the transfer and making sure it's a quality transfer and that families tell me -- I'd just as assume stay with my pediatrician, they're not saying I want my son or daughter to keep a pediatric model of care throughout their entire life, they're saying I don't see a viable option, I don't see an adult healthcare system that provides the same level of care. Choice, there has to be quality viable choices. That's the first thing.

The second thing is this notion of a medical home. Whatever you want to call it. I think part of the problem is that we tend to take youth with special healthcare needs and we put them in a disability box, a chronic care box, a sick person box, and you can't get out of it. You can't be a typical person. You can't be healthy if you have a chronic healthcare issue or if you have a disability.

I think medical home is a transformative model that's really going to help us in the area of children and youth and adults with special healthcare needs by promoting that concept that we can be healthy, that people with disabilities, special healthcare needs, need good primary care. Need to focus on well-being and participation and they also need the good chronic care to address the special healthcare needs.

But it's not one or the other. It's not sick care or well care and once you're in this box you're in it forever. And I think that's what medical home is going to do for us.

I also think in this world right now it's time for health reform. We have an incredible opportunity to address some issues that we -- I didn't think I'd ever see the day in my career where we would be talking about extending the age for coverage under the family health plan. Looks like it could be to 26. 28. Maybe it's more than that. No pre-existing conditions. There's some things in the new health reform legislation that are really going to help youth. And there's more -- using the medical home model to do that. Patient centered medical care collaborative. That's one of them. If you don't know about that, I can give you the website and you can follow up on what they're doing.

The only other thing I would want to say, and that this isn't just a healthcare transition. This healthcare transition precipitates and influences every other

transition that a young person is going to make. It could make being healthy and able -- you can't live in your community if you're not healthy enough to live in your community. You sure can't participate if you're not healthy enough to participate. Sharing in what goes on in that community.

If we can contribute to the health of a young person by making them healthy, enabling them to live in the community, it affects their educational transition. It affects their employment transition. It affects their social leisure transition.

So I think we have our piece is much bigger than the healthcare piece. We've got to do it because I think healthcare is the component that's going to make it possible to achieve all of that public policy that's been around for decades. ADA.

IDEA, all of that federal legislation that's set public policy for decades. But we've never been able to achieve it. And I do think if we can create a model that optimizes health for people with a chronic health condition then we will have done our part.

I think the voices of young people -- I love this group. I think we need a more systematic way of routinely getting to the voice of youth. I think CASA is one that we need to do that. We need to be able to -- I think one of the things that happened in this project that Anna talked about but didn't dwell on was going to the decision-maker groups of youth around the country and getting their voice.

That's one of the pieces we want to further develop with our national center is having, pulling that group, those groups. Not just one group, but those groups together and making sure we have ready access to them when we need them, because we really got a different point of view. Not a lot of it surprising, but aha, sort of those aha moments.

We were excited about it. As was pointed out it was a small effort, but we plan to do a lot more with it. And I'm more convinced than ever now that we've really got to focus on this in our strategic planning work.

So that's my two cents.

SABRINA MATOFF-STEPP: At least 10 cents. So with that, questions about the work or other ideas, dialogue, how we can continue to help you? Questions, yes.

UNKNOWN SPEAKER: I'm sure you guys have had discussions about had you chosen a different population for your discussion, socioeconomic, about higher education, would have perhaps gotten a totally different set of themes.

SABRINA MATOFF-STEPP: Yes.

UNKNOWN SPEAKER: Sort of looked at the best case in this study. Is that one of the things you're considering of doing as the next phase?

SABRINA MATOFF-STEPP: I would love to do that. I'm sure Anna might want to help, and Bonnie. But I would love to do that. I think this was as Anna said, we tried to recruit. We put the word out on various listservs of organizations and probably those who were most -- who have the time, the availability, the interest, who are more maybe, had a little bit more practice with participating in speaking might have volunteered more than groups of young people who may be more shy or again in other groups more rural or more isolated groups.

I think, you're right. We get a very probably different perspective. Maybe it's similar, but probably some different -- and I think it would be fun and again to overlay the sex and gender perspective, again I think we'd get some very interesting aha moments, because then you'd start having other overlays of geographic, how the geography of where they live or their family or if they're living in more strained economic households or having difficulty making other types of -- I think it would be very interesting.

So hopefully we'll be able to do something like that and get more of a diversity of people, of young people who would want to give us their opinions.

I think I saw your hand. Yes.

UNKNOWN SPEAKER: Just a question around when you look at particularly females between 18 and 22, a lot of them get their primary care from an obstetrician, particularly developing teens at that young of an age.

So have we done anything around working with ACOG and their ability to respect youth with disabilities in preparing them? Because the one point you said that was striking to me was that the primary just refer the youth back to the specialist.

And I'm just wondering, have we done anything with those primary care physicians who typically will take care of youth and prepare them to accept youth with disabilities?

SABRINA MATOFF-STEPP: If I'm not mistaken, and others in the room may -- I think ACOG, the Academy Of OB/GYN they have on their website either a position paper, a white paper, a principle around women and disabilities.

I'm pretty sure they do. That's not to say that they implement it or they actualize it enough. I'm sure they don't. Because I think of course we heard from even these young people some of the stories about those who have more physical disabilities. They don't have exam tables that they can easily access or they use other kinds of equipment that is not disability-friendly.

So I think you have a really good point as far as engaging more with the primary care group such as ACOG or AWAN or these other nurse groups who are probably going to be, as Bonnie was saying brought more into the picture now with healthcare reform, that they're going to need to be trained. I think that was the other thing, the whole issue around training. We didn't go much into depth with that because we were focused on the youth here. We really wanted to know what they were thinking.

But I think again another variation of this could be having, talking to the providers. And again we get a very different perspective, but again I think the providers, too, you know, they have a whole catching up sometimes to do. They're not used to thinking about these young people -- they have a voice. They're sort of not used to that.

So I think it's a challenge to get the provider groups aware, familiar and then actually doing what they need to do when it comes to providing that primary care, just the general quality comprehensive quality care for young people and being sensitive to their, whatever issues that they're coming in with, because we all have something. I mean, none of us are perfectly healthy.

But like Bonnie said, I really like what she said there. Again, I'm sure you all do this, too. This idea if you start with the person and not their disability, they're not their disability. They're this person. They have other wonderful qualities to them.

If they have a disability, okay, you work with that. But it's the person and they have a voice. And that's what's really important.

UNKNOWN SPEAKER: Just as kind of a follow-up, one of the interesting things that came across in discussion groups was that the youth felt that they have to be their provider's disability resource, kind of. If it's not their specialist then they go see like a primary care provider. They're expected to be the expert on their disability, which isn't something as a patient you would want to experience.

You're not usually required to bring like your expert subject matter to the doctor's office. So I think that was kind of like an interesting finding that goes along with how that might translate when you go to your OB/GYN or someone who is not your specialist.

SABRINA MATOFF-STEPP: Other questions?

UNKNOWN SPEAKER: I want to talk as a mother of a young adult with cystic fibrosis rather than my organizational position. One is that your findings are very consistent with how I experienced my son who is now 22 years old progressing through his early adulthood. And I would refer to them as young adults and not youth.

As he starts to grapple with his longevity, his ability to form lasting relationships and work toward some form of a partnership and [indiscernible]. So it was -- I would say, boy, it looks like it was very responsive, but he very much fits your demographic group.

So one of my various comments would be that probably to reach the other youth that are not represented in this group, you're going to have to go searching in other -- using other methods. But you're not going to find kids as tightly affiliated with organizations that cater to that population.

Another thought and comment is that you know this tension of a medical home happening within the primary care. It's not that way.

When you are dealing with a specialized chronic condition it seems natural and normal to turn to specialty care. We did it -- I did it as a mother with my son. We bypassed the pediatricians all the time. And they in fact turned to me as the expert on CF.

So I wouldn't expect that to change in primary care. I would never expect a primary care provider to be able to be that expert, but, rather, to rely on standards of care, procedures that are available to them to know when they need to refer or to be aggressive in their screening and referral processes.

So I'm putting an amalgamous step, but the pressures that we put on primary care or adult care primary care are proportionate to their capacity and to not expect more than they can really give but rather to give them the age that lets them carry out that referral process.

And I had another comment.

SABRINA MATOFF-STEPP: We'll come back -- it will come back to you. Do you have a question?

UNKNOWN SPEAKER: I remembered it. (Laughter).

SABRINA MATOFF-STEPP: Okay, we'll come back.

UNKNOWN SPEAKER: And watching the most important thing in his life is studying the course of his work and discover his own longevity is partnering, that they're going to need not just making babies or supporting them, but how then as young adults began to work together doing partnerships is supports that are there for them to work together around that and explore that together.

SABRINA MATOFF-STEPP: You mean partnering in terms of having really strong social relationships.

UNKNOWN SPEAKER: Strong, intimate social relationships they may want to take into a lifelong partnership. There are some questions that come up that, you left a new field, a new arena for a lot of these people to deal with.

SABRINA MATOFF-STEPP: No, it's really important. I think that's again something else that we think youth or young adults with special healthcare needs don't want to be married or don't want to be in partnerships or relationships, and that's absolutely not true. I mean, all of them voice how important that was in one way or another.

So I think the dark shirt.

UNKNOWN SPEAKER: Two things. One, I'm wondering if there's a way to take a protocol that you used of your methodology and offer it up to the state that it may not be the right time right now but in the midst of their needs assessment, if there's a way to use the protocol to -- I know in May we're using youth as part of the needs assessment. And the HRTW team designed tools for the states to use to engage youth as part of the needs assessment. There may be a way to take that protocol, give it to the states to offer up to get some broader information and certainly widen that demographic that you have. I think that would be of great interest.

The other thing I wonder, tying into the keynote last night, was you didn't talk about any of the inequities, and I wonder if that slope that we learned about last night, if kids with special health -- when we talk about access and coverage and the sort of the issues that are being discussed at the primary care level, my guess is that there's some differences there as well between kids with special healthcare needs and the general population of youth.

Some that aren't going to be very different and some that are going to be very different. And I wonder if it would be important or valuable. I think it would be valuable to look at what typical kids are saying as different, kids with special healthcare needs. Access of coverage are just two things. That age group is the group of people in this country that are most likely to be uninsured.

Thankfully special healthcare needs are more likely to be insured because of public options.

SABRINA MATOFF-STEPP: Interesting.

UNKNOWN SPEAKER: So I think you would find some differences that would relate to those inequities and disparities that we're looking at also. So I just throw that in there.

SABRINA MATOFF-STEPP: No, good point. I think with small -- we didn't do a comparison, but I think you're right. There are probably some interesting findings there that if we were to be able to take a control group or a group that does that, a group that doesn't have special healthcare needs and look at their transition for lack of a, to go from a pediatrician to an adult care, what are some of the same different et cetera issues.

Why don't we keep switching off here.

UNKNOWN SPEAKER: I like the composition of your group, because it's obviously a collaborative across programs. And I think it leads to some opportunities. Again, as someone mentioned before, we have obviously have the school system that's operating and has the individual transition planning, and one of the things we've worked to try to do in our state, Texas, is working to deal with the health component of that transition planning and to bring that to the educational table (shuffling papers) to support the health and cross that bridge. And some questions you might want to ask if you have a future opportunity is if any of these individuals had any health issues brought up in that transition planning component, where you're transitioning in the educational realm, adult job opportunities or quicker educational opportunities.

The other thing is, I think we have an opportunity now in what you mentioned Bonnie about the patient centered primary care collaboratives, develop arenas in

medical home is ramping up really quick with multi-payor involvement and many states have these pilots.

And as a Title V entity I think we need to bring to the table is to try to partner in those initiatives as quick as we can to say fundamental to any medical home environment is the recognition, I mean, adult pediatric family pages, is the recognition of the importance of this transition ability and to be engaged in it and partner in it because I try to make it a little bit more than just a subset and intent subset is when you go to pediatric to adulthood with someone with special healthcare needs. That stresses that situation to the max and part of that is critical there.

Oftentimes that gets minimized. That's a small population. We don't want to deal with that right now. What I try to say is implement in the sense of being a medical home. Fundamentally, you have to understand what it means to transition from medical home to medical home. And that environment can occur in other arenas that may be more prevalent, or more volume that lies in an adult practice. Pediatric medical home to adult medical home, how does that work? What's the partnership to even measure that in terms of evaluating medical home.

Fundamentally, if you're an adult-oriented project or pilot with medical homes, you should not ever be able to put aside transition. So you could have an adult

primary care transition to an adult primary care transition. The components of partnership with another medical home is critical, but especially with people with special needs.

So I think we have opportunities to try to bridge and collaborate, and with your being and people who are in the adult realm as well, I think building that up fundamentally is so critical, not being left off the table. Then if you say you're medical home, you have to have these things that you embrace.

SABRINA MATOFF-STEPP: Interesting. Thank you.

Few other questions, the light's shining in my eyes so if I don't see you. Yes.

UNKNOWN SPEAKER: Actually, I have a scenario that I want to draw for you and ask for some advice. I have a family right here. We're transitioning care from one -- the cause is metabolic studies. We're transitioning care from one facility to another to provide that care from across the state. We don't have a metabolic geneticist for our state. There's a family very upset. The mother is very upset.

She declined to bring her child in. Her son has TB. But he is 18. I can't call the Office of Children's Services. I'm very concerned about this child's phenylalanyl levels, because she's brought him in routinely. And he's always been in control

with his diet with his formula. I don't know if there's anything that I can do since her child is 18. I planned to call her. She won't return my calls anymore.

Anybody have any advice what I might do for the family?

SABRINA MATOFF-STEPP: Linda?

LINDA: I would actually find another family. Just I think Debbie would recommend-- all the speakers. I would find another family to reach out to that family right away, or another young adult, in the same demographic.

UNKNOWN SPEAKER: I was very concerned because I know transitioning into adult care. Mom stops controlling things. I wasn't sure what steps to take.

SABRINA MATOFF-STEPP: Good, other questions? Comments? Interests? Ideas? Patty.

UNKNOWN SPEAKER: You also passed from one issue in front of you. But look systemically at what's been done differently for you to have an opportunity at this level.

So ask your agency to self-reflect. Many times we assume if the family and young person, we set that scenario up, didn't realize, oh, there's potential, and [indiscernible]. Now thinking about males, (Laughter), and traditionally, with no

diagnosis, they go to the pediatrician in their teens. They get their college or sports physical, and then show up for a colonoscopy at 60. Are we going to take a look at the intervention of our young men with special healthcare needs and who is the spokesperson? Because had we set up this gender, well, mom makes my appointments. My mother knows this. Does that happen a little bit more in the males than the females? And if so, can we break that pattern that seems to be with or without a disability: Don't worry my wife makes that appointment for me, my secretary does this. I just feel this gender issue has not been looked at, nor has the male been given that voice. So as an employer at a university with a young man who was not disabled, I said: Looks like your sick, when is the doctor's appointment. He said my mother will let me know.

So that's the kind of question. I think you need to look back at what are we creating. And there was a wonderful book on women and wellness, it has five objectives. The book --

SABRINA MATOFF-STEPP: Which one is it?

UNKNOWN SPEAKER: You did this a couple of years ago, the decade of wellness, what's the benefit.

SABRINA MATOFF-STEPP: Might have been out of the Office of Women's Health.

UNKNOWN SPEAKER: Says what decade.

SABRINA MATOFF-STEPP: I know what you're talking about. It's out of the office of the secretary, yes.

UNKNOWN SPEAKER: We get that for the car, but we don't get it for our population that takes a look at the well cost. My son had a neuromuscular disease, but his liver was well. There were things that were well, but we weren't looking at the wellness part. I thought that document was great. And we've been using it as we look ahead. And you've got one for males, but there's no malehealth.gov. So you find that under the women's section, too.

But take a look at that. And I think we show that to our young people, say here's your road map for later on, get your checkup so you can stay ahead of some issues. But I thought the work you did was great beginning the discussion. I really appreciate it.

SABRINA MATOFF-STEPP: What Patty is talking about, there's an information center resource, for lack of -- it's called the National Women's Health Information Center, which is www.womenshealth.gov, which is essentially the federal government one-stop shop for information about all things related to, in a sense, women. But it also has pages and information related to men's health.

And there have been -- I know that the Agency for Healthcare Research and Quality did a campaign recently where they were trying to get at men's health. And there was some really funny ads of trying to get men to go into their preventive, into preventive appointments and some really catchy things, because you're right, men sometimes, not all men, have that sort of break between going to the doctor, who is going to take care of it.

Because women are the healthcare gatekeepers. Even as adults, oftentimes that's done by the women, the spouse, the wife, the mother.

So I think that's important to look at how as part of this effort to get young men to take on the responsibility for their health, forget the disability. That should be part of that transition, too, that men need to take on some of that hopefully for themselves and they become more empowered that way, which could be scary, but it gives us more time to do some other things. Right?

UNKNOWN SPEAKER: The lit review that we did, one of the findings we did come across was however limited the results were for secondary issues in general, they were that much more limited for young men. A lot of what we found was really focused on young women, particularly young women and their reproductive health. There wasn't really anything on young men, what they go

through as far as gender issues or sex specific issues. It was very much focused on young women.

UNKNOWN SPEAKER: So there's a gap there.

UNKNOWN PERSON: I want to try to standardize some things.

SABRINA MATOFF-STEPP: Right. This is purely, as Anna said, lots of limitations. We can't generalize. This is certainly -- we can --

UNKNOWN PERSON: It's a good place to start.

SABRINA MATOFF-STEPP: But it's a starting point, you're right. Discussion group, focus group. Some of it that is semantics, some of it -- there are some differences.

And we did have some set questions. I mean, we did.

ANNA LENHART: We did.

SABRINA MATOFF-STEPP: It wasn't just a random discussion. The moderators did have some specific questions and then the youth, you know, discussed and took it. But you're right. This is not, you know -- you're right. We

can't say the young men were more likely to be interested in provider issues than the young women. I mean, for this group, yes. But not -- certainly not across any other population we couldn't say that.

So we're not making generalizations. It is just a start to look at. But very important point we need to keep looking at this many more times and in different ways. Linda, in the back?

LINDA: Just a couple. When we had first related to the studies, just so people might know, it was a very demographically limited group. What but we really did cast a wide net. We really did contact a lot of different organizations. And I think we have to remember that there are certain type of young adults that are going to join those organizations.

And so I would challenge all of us -- and I know it's hard to reach out to groups that don't typically join those kind of organizations.

So I don't want people to think that we purposely limited it. We did but we gave kind of a wide --

SABRINA MATOFF-STEPP: Lots of attempts to reach out.

LINDA: Lots of attempts. [Indiscernible] and we talk about the whole issue of health insurance and know that this group is in the highest group of uninsured. And I would actually say, it's true for youth with disabilities as defined by the guidelines have insurance, but in terms of young adults with special healthcare needs, they're uninsured at probably the same rate as all young adults.

And as we talk about healthcare reform, I think we all have to remember that this is the group that we need to bring into the insurance pool in order to balance things out. And if you talk to some young adults in terms of the mandate, some of them are not too happy with it, because they think they can have the risk and they're uninsured.

On the other hand, I personally experienced this whole issue with my son who doesn't have special healthcare needs. We were panicked because our insurance dropped him like that. We have Tricare. The minute he graduated college he was out. We did have health insurance for him and they dropped him without any notification.

But I think this is a good time for all of us to be highlighting on the fact that so many young adults are uninsured and anytime you also note that this is the group that has the highest rate of traumatic brain injury and accidents. So therefore they're at incredible high risk to have incredible medical debt.

And then my favorite hat to wear, which is as a parent of a young -- I guess can I call her a young adult?

SABRINA MATOFF-STEPP: Yes.

LINDA: We're working on it. My 17-year-old has special healthcare needs. And a lot of these issues really resonate with me. But I think the hardest thing for parents and for youth is to know what is the same for all kids and what's different because you have that special need.

So my daughter's really, and has continued to grapple with so when her girlfriends stop being friends with her, is it because they no longer want to hang out with her because she looks different or is it because, I hate to say it, but we all know, adolescent girls can be mean girls and they just do that to each other.

So I would love to see kind of the bullying and that whole friendship issue, or I don't have a boyfriend, is it because you have friends who don't have boyfriends, or is it because I have this special need or I'm not seeing my other friends who don't have boyfriends. So I think there's a lot of issues to explore around gender. Again, this was just meant for us to kind of tease out on this discussion, because we really haven't done a about it.

And then also just the whole issue of the medical transition is very real. Sara keeps saying: Who am I going to go to? Because she also knows that a lot of her doctors are like her mom, retirement.

So I think that supply issue is a real issue. And for her next hospitalization, her request is do I have to be put with the two-year-olds? (Laughter). And last time it was a two-year-old who Sara heard the diagnosis of full-blown leukemia and it still brings back to Sara what happened to Saidie, she asks all the time.

So I don't know if there are any hospital models that really -- where do you put these kids? They're not adults. And she actually goes to a hospital that has, is its own hospital with pediatric wings.

I don't know if there are any models for inpatient care that can really focus on this type of issue.

SABRINA MATOFF-STEPP: Interesting. Yes.

UNKNOWN SPEAKER: I just wanted to draw a concept about medical home.

UNKNOWN SPEAKER: Good I knew you were. (Laughter).

UNKNOWN SPEAKER: I was going to say Kathy has to say --

UNKNOWN SPEAKER: In Colorado, we're really trying to focus on messaging, because I don't necessarily think people have as much trouble with the definition of medical home.

We know it has [indiscernible] et cetera, and what is shaping out for us in Colorado is that medical home is a team. And that begins to allow for every single situation that anyone can face.

Someone that's relatively healthy, even a healthy man that has insurance, or a child with special healthcare need, youth with special healthcare need, adult with special healthcare need.

If you think of medical home as a team and all providers are responsible for being part of a team so everyone is responsible for talking with each other, and consumers, especially, if they feel like they're leading a team and they're responsible for building a team, every single person's team could look different.

It could be a different type of provider. Then you get away from a medical home is a place. A medical home is a provider. But, rather, it is going to comprise a number of different people. And that's going to help this transition issue.

If you're used to having your healthcare, whether you're relatively healthy or if you're entering into a chronic condition where you need specialists and you need care coordination, you're going to be used to thinking about a team and therefore it doesn't matter if your new team member is an adult healthcare provider. So the word team is what we're really trying to focus on, because we think team is inherent in that word or all those quality components of a medical home. So I just throw that out.

SABRINA MATOFF-STEPP: That's great. So it's not the place, it's the people.

UNKNOWN SPEAKER: It's a team concept.

SABRINA MATOFF-STEPP: Great. Yes, you had a question.

UNKNOWN SPEAKER: Back to that. I was thinking about the partnership and the team. And one thing it would be nice to talk with young adults about it is how to maximize -- have the skills what to do to build that team from their point of view building.

Because there has to be that partnership. And sometimes they're walking into maybe a healthcare provider who may not be that atune to health home concepts or whatever, especially [indiscernible] transition period. So what communication

issues are critical to building that partnership and establishing that primary care home, so to speak.

And the reason, another reason, not just for quality issues, is that if you're a young person, typically you may have limited resources financially. You may or may not have health insurance. What I've seen and I've seen this example you get your person young person into the person to see your primary care but they get five minutes and they're out and they lost their money to that session and it hasn't been as productive as it could have been and a golden opportunity sort of back fired when they walk out and go that wasn't important. I didn't get what I wanted and here I am out this money or maybe I made the effort.

There has to be some almost assertive qualities in a way that isn't antagonistic, but to say, hey, I really need to get this from this relationship. We really need to have this, because if you have to hunt, hunt, hunt, a lot of people don't have the money to hunt, hunt, hunt.

So anyway, it has to come both ways. The providers have to be prepared. But if you're coming into an arena sometimes where there aren't that many prepared. You have to have the skills to bring that out in them somehow.

SABRINA MATOFF-STEPP: Good. Good. Absolutely. Other questions?

Comments? Anything else? Okay. Well, I think we're probably a little early. But

we really thank you for coming. And, again, if you'd like the report, we can certainly send it to you. E-mail me and I'll be glad to send it to you or leave me your card. Just keep in touch with us.

We really would like to do more with this work. So knowing that you would like us to continue, we would want to partner with you, will help justify that as we go forward. So thank you.

(Applause)