AMCHP Annual Conference, 2010

Moving Ahead Together:

Celebrating the Legacy, Shaping the Future of Maternal and Child Health

Promoting Medical Homes for CYSHCN through Strengthened Partnerships

March 6-10, 2010

CINDY CAMERON: Welcome to the roundtable, which I was going to tell you the name of it and I have my program at the wrong page, but now I will, Promoting Mental Home through CSHCN and Strengthen Partnerships. So we have two different presentations today. One from Seattle, Washington and or the state of Washington I should say and one from the Region Four Genetics Collaborative and the Washington presentation is going to talk about some state initiatives that they've worked on and the Region Four Genetics Collaborative is going to talk about a tool that they've developed for families to use when looking at medical homes. So I am the moderator. I am the timekeeper and the introducer and I'm actually going to talk for like two minutes at one point about the Region Four Genetics Collaborative. So I'm Cindy Cameron. I'm from the Michigan Public Health Institute and I'm also the director of the Region Four Genetics Collaborative, which is why I'm going to talk about it for a minute.

So I'm going to present our… You're going to go first Linda apparently, since you're up here. Our first two presenters I will introduce both of them and then I will introduce Bob Cook and Jane Turner. After they finish we will take question at the end and we're going to try and plan for 20 to 30 minutes for questions. So Linda Barnhart is a Public Health

Nurse Consultant with the Washington State Department of Health. She received her Bachelor of Science in nursing from Seattle University and Master of Science from Saint Martin's University. She worked as a family nurse practitioner at a rural clinic providing care for families including children with special healthcare needs. Ms. Barnhart has a primary focus in working to improve the number of children with special healthcare needs who have a medical home. She has worked with stakeholders to develop a medical home state plan and is an active participant on the Committee for the Washington State Department of Health Patient-Centered Medical Home Collaborative. She also works through an interagency agreement with the University of Washington Medical Home Project to support pediatric practices and their efforts to become a more comprehensive medical home as well as providing supports and resources to providers and families.

Reilly Peters is director of the Office of Maternal and Child Health at the Washington State Department of Health. He received his BS in physiology from UC Davis, master's degree in healthcare administration from University of South Carolina… Southern California. I'm sorry. I don't know why I said South Carolina. I made that up. And doctorate from the University of Washington in epidemiology. An office director is responsible for guiding vision, direction and oversight for the Office of Maternal and Child Health to carry out its mission of protecting and improving the health of people with a focus on women, infants, children, adolescents and families. He provides leadership and mentoring for managers and staff of MCH administration and oral health assessment, child and adolescent health, children with special healthcare needs,

genetic services section, immunization program, child profile and maternal and infant health programs. He also manages and monitors the Office of Maternal and Child Health programs in close partnership with federal, state and local agencies and consumers to promote effective health policies and quality systems of care. He works with DOH office directors and other state agencies to develop programs and performance measures that relate to issues affecting the MCH population and children with special healthcare needs. So please welcome our folks from Washington.

LINDA BARNHART: Thank you. So can you hear me okay? This is good. All right, so thank you very much for the introduction. So I'm not going to go through too much to say more about that except that I do work closely with her medical home project, but first, little poll here. How many of you are with the Children with Special Healthcare Needs Program anywhere? This is going to be easy. Okay, so you are embedded in some of the things I'm going to talk about and you will see what I mean.

So the goals of our presentation are to share with you methods to assure children with special needs are included in statewide Medical Home activities, to show how Medical Home is spread beyond children with special needs and to identify activities that strengthen partnerships between state, CSHCM programs and new Medical Home partners. So in Washington our Department of Health houses our Title V CSHCM program, just as background for you.

So what you're going to learn in the next couple of minutes or 20 minutes or so is a brief history of the Medical Home in Washington, brief history of the learning collaboratives in Washington, the Washington State legislative mandates around Medical Home, current Medical Home learning collaborative, the role of our program and how it all ties together, but what you're not going to learn, so I hope you're not expecting to learn anything about details for the Patient-Centered Medical Home Collaborative, details of learning collaborative methodology, change package or chronic care model. I have to say I'm learning all of those things as we've become part of this new movement going on in our state. I would love to come up here and talk confidently about all of them, but I'm still in learning mode for a lot of it.

So I want to start out by saying life is really simple, but somehow I have learned we insist on making it complicated. So who are children with special needs and all of you know that, so I don't even really probably have to do this except to say they are children who have or are at increased risk for a chronic physical, developmental, behavioral or emotional condition and who also require health and related services of a type or amount beyond that required by children generally. So these two adorable children both have a special healthcare need. The little girl on the right had release of the tethered cord at Nationwide Columbus Children's Hospital a couple of years ago, still has significant bowel and bladder residual, spends more time at urology appointments than any little girl should have to do and has you know kind of a lifetime, so she is not… doesn't have severe special needs, but she has them that affect her everyday life. And the little guy on the right at the time of this picture he was six, but he has ADHD. He has

learning disabilities. He has a number of issues also that make him a child, a special needs. You can't see it on either of them and I happen to think they're extremely cute because they're my grandchildren and there is another picture that you will see that also has a picture of my grandchild, so you know you have to be fair and they're all in here, but I do have to say as their grandmother that neither of these kids have a very good medical home, so the little guy on the right lives in Seattle and the little girl on the left lives in Columbus and I have gone with them to doctor's appointments, to pediatrician appointments and I just get the sense that it doesn't quite mesh and I think you all know exactly what I mean and their parents, the little girl on the left her mother is graduating from medical school shortly. Yes, I'm very proud, but she is graduating shortly, so she goes into these appointments expecting I think more than she is getting.

So our national performance measures, which once again I won't go through for all of you on detail, but you know that most important to us, all of them are, but that children have ongoing comprehensive care within a medical home, families are participating in the decision making and will be satisfied with the services, so all six of them are here. Handouts by the way are in the back. And we know from our data that really less than half of the kids in our state and nationally have a medical home. So I wish there was an easier way to do this, but I want to get you to what Reilly and I are talking about today and that's that we're part of a medical home learning collaborative that is not geared toward children, so what I want to do is get you up to the point we're at today and to tell you how we are really challenged with making sure our kids are included in all the current work, which is phenomenal, but that our kids are still included in all of the work.

So Medical Home in Washington has been going on since 1994. It started as an MCHB grant, as a demonstration project. We collaborated with the University of Washington, our Title V CSHCM program, our Washington chapter of the AAP, Seattle Children's Hospital, which is a huge regional center that serves our five state region. This was at the time called the Medical Home Training and Resource Project. Our program started a little bit of funding after the MCHB grant and we continue to fund that program, which is now called… We just call it our Medical Home Project. They do a number of statewide Medical Home activities for us. We were so on it back in '94 as soon as websites started coming up that we actually snagged MedicalHome.org, which we still like to go we were just so ahead of our time. At the time this project has helped us also to lead to a strategic plan for children with special needs. Our project supports the Medical Home Leadership Network, which the next slide I'll tell you a little bit more about it, but it is a group of primary care pediatric providers. The project develops a number of tools for providers one of which I have in the back, but yeah, that I wanted to bring out. A number of tools for providers, such as something called "Child Health Notes". It's a quarterly publication that we distribute to all members of our Medical Home Leadership Network. It's also available online to anybody that wants it. Its target audience for now is primary care providers. We're talking about developing one for families. It covers topics from developmental screening to how to help develop the child in your practice, how to help develop the IEP, the IFSP, so they just do a range of topics specific to kids with special needs. We also do tools for families. We developed a brochure. I have a copy of an English and Spanish version back there. We developed a checklist for families. I'm sure

a lot of you have done these same kind of tools. You know you sort of take somebody else's, make it your own or you develop one and share it with everybody, but we've really been involved in tools to help families and providers.

Our project also shares information to communities. They act as TA. They… I don't know if I put it in the next slide or not. They every year for Seattle Children's, the pediatric residents that come, we make sure in year one. We used to do it year two. We've bumped it to year one. That they get a "Talk about Medical Home", so right from the start the residents hear about Medical Home and how they can be part of that.

Our Medical Home Leadership activities currently has 18 teams across our state. We go anywhere from 18 to 22. These 18 have been there from minute one though. They have really been there since '94. Each team consists of a primary care provider, a public health nurse, an FRC family resources coordinator who are the care coordinators for our Birth to Three Part C Program and a parent. Examples of activities that they do, we give them a small stipend, not very much money, but we give them a small stipend and ask them to choose an activity that they might do to be a resource to other physicians, either pediatricians, nurse practitioners, family practice, whoever in their community, so that's what we ask them to do and so it's not really a contract. It's just an informal stipend with them. Activities they have chosen are such as developing or trying to implement ages and stages in their practice. We currently have an autism grant and one of them is using their stipend to go to our autism grant council meetings, so they've

decided to focus on autism. All activities, they are to assure that they have a family member on the team.

We do activities from Medical Home like other states in addition to our project. Our governor, and Reilly is going to talk about this in a minute, but our governor when she was elected wanted to implement healthcare reform. One of the things she was particularly interested in was Medical Home, so she asked the Department of Health to convene a strike team. We love the name, the Medical Home Strike Team, and we convened partners of other stakeholders, AAP, Washington Chapter, our Medicaid organization, some of our nonprofits, so we gathered a group together to talk about Medical Home, what we could do, not just for children with special needs, but to promote it beyond that, so we actually developed a strategic plan for all children based on the strategic plan that we had done for children with special needs.

Just briefly, and the reason I'm showing you these tools is to tell you as you all know, you're involved in this, but to show you the amount of work we've done to promote Medical Home in Washington. So some of the tools we did was this statewide group developed a key message document, so this key… The important thing about this is this group of stakeholders came up with a definition. We looked at the AAP. We looked you know at all of the definitions of Medical Home. We came up with one that worked for us and some of the points behind it, so this was our definition we came up with. So it's, "A medical home is an approach to delivering primary healthcare through a team

partnership that insures healthcare services are provided in a high quality and comprehensive manner."

We also developed a care coordination… Let me get my props. I don't have Vanna White up here to keep my props inline. But care coordination, same thing, key message document. It was the group that went together decided on a definition we could all live with. We wanted to help our partners be able to talk to their community partners and other organizations, specifically our parent groups or anybody that is interested about Medical Home, but we wanted to supply them with data, so that it would be useful and easy for them to do that, so we came up with the Medical Home Data Monograph, which has a lot of data on you know where do you find information about Medical Home, what's really… what do we know.

We developed… I told you about our brochures. We had a translation grant that we used to translate this into the seven languages I mentioned. We developed a factsheet and this… The purpose of this was for people to take it to their legislatures or whoever might be interested in Medical Home, so they had quick talking points because as we all know you can go out there and someone can say, "Well what is a medical home?" And we hope we all have it at the tip of our tongues, but likely we do not and our partners certainly don't, so we developed these tools to help our partners and stakeholders have quick reference talking points to feel comfortable when they're talking about it.

So now I'm going to turn it over to Reilly because I've told you we're involved in Medical Home. We care. We feel this degree of ownership in it for children with special needs and Reilly is going to tell you about other programs going on.

REILLY PETERS: Hi there, so I think my job as… if you go back to Linda's original slide about life is really simple and we tend to complicate it, my job is to tell you how complicated it got and maybe describe how or why it got complicated. So as Linda indicated earlier, their program has been working on Medical Home since 1994 and really doing wonderful work with a very defined population and trying to, at the same time, promote Medical Home to a larger community of policymakers and until our governor, our new governor was elected and came into office that Medical Home Strike Team designation was really the first outside reinforcement from our own office that Medical Home was important to Washington State. So I want to put this all in context of what else is happening within the state. So the Office of Maternal Child Health is one of three offices in our division. There is another office called Community Wellness Prevention, which houses all of our chronic disease programs. In 1999 they took their diabetes categorical grant from CDC and one of the activities implemented was a diabetes collaborative to promote the different interventions that had been coming out from **** and measured to the HEDIS measures, etcetera and got wonderful success. They were able to demonstrate with their first two waves of physician offices that they recruited that physicians were able to change their practice and were able to see early significant outcomes in their diabetic patients.

So before I go on to make sure, does everyone know what a learning collaborative is? Everyone involved in learning collaboratives? Half, okay, so for those of you who aren't, just a quick couple of keynotes. It really is meant to be a bridge between what the science says and how to apply it in your everyday practice. It offers essentially learning sessions, hopefully in a team approach, so the provider, the nurse, the office manager, all the key people can learn how to change how your practice works to facilitate this intervention. Bottom line is it's a quality improvement process. It's important to note that because they focused on diabetes and remember diabetes has got some very strong evidence bases interventions that they built on, so I mentioned earlier that they had a lot of success and from that success they began to expand. The first expansion was in their third wave of recruiting physicians into the practice. They also expanded the conditions, so they also took on what they call the adult preventive services and hypertension in their third wave.

In their fourth wave they brought on heart disease as another condition and so with each success of wave and each additional condition they had to develop new intervention tools or go to the science to how apply those. In what was wave six then became complicated, so again, all throughout this time they were developing a reputation for deploying highly successful learning collaboratives that were disease specific using known interventions that are out in the science. With that reputation our state Medicaid agency came to them and said, "Gee, we would like to participate too and we can bring state funding and we can also bring you a way to match into federal Medicaid dollars." At the same time we had another Medical Home initiative sponsored

through University of Washington I think was probably key sponsors, that focused on child health and it targeted Medical Home, asthma and childhood obesity. They also came to the learning collaborative and said, “We want to participate too.” So those three learning collaboratives all kind of merged and in that next wave of recruitment they then offered physicians a choice of which condition they wanted to choose amongst.
And then in the phase seven recruitment the health plans of Washington State then came onboard as well and they brought funding to the table. This is was really kind of a serious or a significant change to the process because all along it had been funded through CDC grants or as I mentioned earlier, a little bit of state money with Medicaid. This was health plans bringing their dollars, which really then started talking about sustainability of this project. So that’s what has been going on with other learning collaboratives. At the same time the notion of Medical Home also become quite popular, so for the first 15 years we were championing Medical Home from the bureau and the AAP perspective and other people started using Medical Home from the chronic care model that CDC is promoting, same language, some overlap, but yes, some significant differences.

With the new governor one of the things she did was to appoint what she called the Blue Ribbon Commission, which was our Washington State healthcare reform legislation. This Blue Ribbon Commission had the agency secretaries from state Medicaid, Healthcare Authority, also had a number of key legislators and from… The governor chaired it herself and some of her key staff and that commission report turned into legislation and that legislation recommended 16 areas of improvement in the

healthcare system. One of the areas was Medical Home. That was in 2007. Another significant bill that passed that year was a bill that was just called Access to Children's Health or Children's Health Access, something like that and the important pieces of that legislation is expanded eligibility to 300% of federal poverty. It inserted a lot of language about performance measures, gathering data and it charged the Department of Health and the state Medicaid agency to work together to develop performance measures, etcetera.

In 2008 then there was a lot of concern about not enough physicians in primary care practice in our state and so they started off with legislation that was really meant to shore up primary care providers in this state and it actually got turned into again, more legislation about Medical Home and promoting primary care… a primary care collaborative. They used the collaborative words again piggybacking onto now the reputation that the learning collaboratives had been developing over chronic disease, all the basic chronic diseases. And then finally last year another significant piece of legislation came into place that probably the most important thing of it is that throughout this process they had been trying to get the health plans to play more of a significant role in the process and other than putting up funding there was concern that if they all sat at the table and planned on joint interventions and joint strategies that there could be some antitrust implications, so in 2009 the state legislature passed a bill the governor signed that specifically exempted learning collaborative work from both state and federal antitrust legislation.

So our current collaborative now is on phase seven. As I mentioned before there are a number of conditions that providers can choose to target. There are no state funds included. The funding comes from various CDC categorical grants, so diabetes, stroke, heart disease, asthma, etcetera. We brought on a new or there was a new partner that came into this, the Washington Academy of Family Physicians. They had previously received a grant from Robert Wood Johnson to train coaches in the Medical Home model and so they were actually offering their resources of the coaches and then with all the various slightly independent or slightly different Medical Home models there was just this intent or an agreement to let's merge all of our forces.

So I think the bottom line message, I'm going to turn it back over to Linda, is you know I think in my mental model for 15 years we're pushing the rock up the hill trying to get Medical Home recognized. We reached it. Now that that boulder is rolling downhill quickly and we're scrambling to stay on because there is so much movement going on in Medical Home, but not exactly the way we would have taken it and so our challenge is to now tweak it in the direction we're trying to get it to go instead of kind of pushing it by ourselves. Linda?

Linda Barnhart: Okay, so as Reilly said, so we had these three paths going on. Medical Homes in Washington, learning collaboratives in Washington, legislative activities and our challenge as Reilly said was to assure the needs of children, especially children with special healthcare needs remain visible and included in the legislative mandated Medical Home learning collaboratives.

So the current collaborative, this 2008 legislation, has 33 primary care practices, urban and rural, large and small. They were to commit to five learning sessions over two years, about a third of the patients in this collaborative are under the age of 18. And the only reason I put this slide up… By the way, these initials on the left, Washington Patient-Centered Medical Home Collaborative and we couldn't come up, you know bureaucracy. We like to have sort of an acronym we can rattle out to somebody. We couldn't come up with it, so we just call it the collaborative, but the reason I put this here is I'm part of the planning committee. I'm part of the faculty. I've been very fortunate to be as part of this a now adult family and family practice focused movement. The first meeting I went to they talked about lean principles. They talked about team building within the practice. They talked about open access. I mean just some great things that needed to happen in a practice to make it redesigned to be more efficient and then I went to a faculty meeting and it was great. All the breakouts we're going to be about once again, the lean design, lean principle. If you're not familiar you know go look it up. I'm learning a lot about lean principles, all these great things and it struck me as it would strike all of you well gee where is family centered care? You know I mean it's sort of like not even there. It's not even talked about. It wasn't even on anybody's radar screen and this is not a fault of anybody's. It's just we are so embedded in comprehensive, coordinated, compassionate, family-centered. I mean we can rattle them off and I'm not even getting a sense of it at the meeting, so it was very, very interesting and I realized we in our program have our work cut out for us.

It’s exciting though to have these new partnerships to work with our new… our chronic disease program. They’re great partners to have and they are very open and so it’s a great new partnership. It’s great to meet all these family physicians. The Washington Academy of Family Physicians are a great group. They all want to do the right thing, but what I’m there is Title V sitting in these meetings. Come to find out most of them have never heard of Title V. It’s nice to be able to say this is what Title V can do for you. As you all know this is what we do when we go these partnership meetings.

By the way, this daughter I mentioned earlier is going into family practice. Now she is currently in Ohio and we’re hoping on match day, which is in a week and a half that she matches back in Washington closer to her mother where she belongs, but whatever, but anyway, she has been to a few Medical Home meetings with me and she said, “Washington is very family centered.” “They welcome family practice.” “You know I feel this real sense there that this will be a good move for me to go into this.” But anyway, just a little bit of an **** chart. I know my time is about over, so I want to just quickly say so what did our program bring? Well we brought… We participate on the planning committee. We participate on the faculty in the ways that I’ve mentioned. I mention Medical Home AAP components whenever it seems to fit and try to bring those up. I go with our coaches on clinic visits and suggest such things as when they’re talking about their new office redesign and rearranging the waiting room as their first step toward Medical Home I suggest that perhaps they want to do a walkthrough and pretend they have a patient in a wheelchair and try to park in the lot. I mean we all know how this can

go, and get in there and just feel friendly. I mean from minute one. Let's try that or what would it look like. People are very open to these suggestions.

Our second learning session is coming up end of March and I'm going to do a breakout session and facilitate how to talk to your patients and their families about Medical Home. We recommended that their advisory board have a family member on it and they've actually… They've considered that and decided to do that, so she has been to one meeting and she said, "I felt very welcome." So it was great. We brought them resources that they weren't familiar with, CSHC and data.org. You know my world is of course she would know that. That's such a great place to go and get data on Medical Home, but it was new to them. It was a great resource. MedicalHomeinfo.org, you people… All of you know about these resources.

One of clinical outcome measures is going to be well child visits and so I was asked to find something that would be evidence based, so I pulled out the AAP Bright Futures Guidelines. It was great. Our own MedicalHome.org, this decision tree, I have a few in the back that say, "Primary care, what do you do if you have a child that raises concerns?" "This is how you refer them."

At the end of the day though what has really mattered here is the relationships, hiring the right person to manage the Washington Patient-Centered Medical Home Collaborative. I was on the interview committee. We interviewed a lot of people interested in this position. The woman we hired was just a natural fit. She got it. I mean I

hate to say that, but she really did. She absolutely got patient-centered care, family-centered care.

We have a great collaborative planning team with new partners. We do regular temperature checks, but you know who is missing? We don't have a family member in our planning committee yet, so I'm feeling like that's the push I'm starting to make, but I have to go slow, so that they keep an eye… their eye on the prize. The practices, I feel like we want them all the keep their eye on the prize. A family is a unit composed not only of children, but of men, women, an occasional animal and the common cold. So thank you very much. We're going to have questions at the end of it.

Cindy Cameron: Do you want to bring that up and I'll introduce you? Okay.

Bob Cook: Yes, ma'am. Well I'm not first, but that's okay.

Cindy Cameron: No, I know. I'm going to introduce both of you.

Bob Cook: Yeah, okay.

Cindy Cameron: Wait, I'm leaving the mic though. I'm going to do that. So while Bob is bringing up the next presentation I'm going to introduce our next two folks and I'm just going to ask all four of you now I will get another chair, but when they get done if you'll move up to the table, so you'll all have a mic for questions.

So the next presentation is the… We refer to it as the guide. I realize that's not the name of it anymore, Partnering with Your Doctor. You should all have one I hope. And Jane Turner, all right, is going to talk and also Bob Cook. Jane is a general pediatrician with many years experience caring for children with typical and special healthcare needs. She serves as a consultant to Michigan Children's Special Healthcare Services Program. Her primary assignment for CHSCS is to develop an integrated system of care for children and youths with special healthcare needs by helping practices become family-centered medical homes. As a medical educator she has developed curriculum to prepare students for individuals and populations who are covered by public insurance. Jane is currently working on developing curriculum about the family-centered medical home for pre-doctoral medical students and pediatric residents.

And our other presenter is Bob Cook from Taylorville, Illinois. He is the father of three children, Elizabeth, age 22; Katelyn, age 7 and Seth who died in 1999 at age 15. Seth had multiple disabilities from a drowning accident at age 5 and Kate was recently diagnosed with ADHD. Bob has worked for 34 years with families and individuals with disabilities. Over 20 years were in vocational rehabilitation including 10 years as the director of 2 vocational training centers. For 9 years he has worked in early intervention as local and statewide parent liaison for families enrolled in early intervention. For the last 5 years he served as the statewide family liaison for the Division of Specialized Care for Children. Bob has a Bachelor of Arts in human development.

And I am actually going to begin this presentation very briefly just to give you an idea of what the genetic collaboratives are.

Audience: Who are you?

Cindy Cameron: I'm Cindy Cameron. I'm from Michigan. Jane is from Michigan. Bob is from Illinois and I just briefly because all of you live in a state where there is a genetic collaborative and I just want to say upfront that while these collaboratives were developed to address needs of children with heritable conditions we have found especially when we work with families that the work that comes out of our collaborative applies to children with special needs, not just heritable conditions, so it's not that narrow.

So the collaboratives were established in 2000 and the language is the secretary shall award grants to eligible entities to enhance, improve or expand the abilility of state and local public health agencies to provide screening, counseling or healthcare services to newborns and children having or at risk for heritable disorders. The role of the collaborative is to ensure that children with heritable disorders and their families have access to quality care and appropriate genetic expertise and information in the context of a medical home that provides accessible family-centered continuous, comprehensive, coordinated, compassionate and culturally effective care, which is of course the AAP language. And this is map of the regional collaboratives. You can see Region Four. That is where the three of us are from, but you will see that everybody has a regional

collaborative and all of them have family involvement. Some of them are more focused on Medical Home than others.

So the Region Four vision is that all newborns will receive state of the art newborn screening and follow up and that children and youth with heritable disorders will have access to genetic expertise and coordinated care in the context of a medical home and our mission has lots of words; to increase access to information about newborn screening and genetic resource services and family support systems; to facilitate data collection and analysis; to guide decision making regarding screening cutoffs, diagnosis and long term treatment of heritable disorders; to support state public health agencies in improving infrastructure for genetic service delivery with heritable disorders; to provide a forum for families, public health and clinical providers; to share best practices and models for improving newborn screening, follow up and genetic care coordination and to link region four states with regional and national initiatives for improving the quality of newborn screening and genetic service delivery. And so Jane is going to describe the work of this particular workgroup that developed this tool and then Bob is going to tell you more about it.

JANE TURNER: Thanks Cindy and it's a pleasure to be here. It's a pleasure to see you. As you can see from my card I'm a first time attendee at this meeting and I'm so glad I came. This is a wonderful, wonderful meeting. I'm going to talk a little bit about a particular project. We're the Education… Medical Home Education Workgroup and our mission was to come up with something to help families really understand what a

medical home is, so that they could be more informed, work with families to help inform other families, so that they could be better at choosing a doctor or help their doctor, their practice provide more of a medical home, so with the idea that if families know what they're looking for that's going to help move the whole system and starting with the premise that families do know.

We really applied… We went to the principles of family- centered care as we did this and families, family representatives were the driving force on this workgroup. I am one of a couple of other physicians on the group. We were kind of the token pediatricians on the group and because it really was driven very much by the families and that was appropriate. I like that. The membership included several Region Four staff folks who really helped with all of that, all the coordination, getting us together. We had conference calls once a month, took care of all the paperwork, doing a lot of the work in between. We had two co leads. One was a parent and professional and one was a professional. We started off with a parent, who did not have another professional role, but she moved to Colorado and they're not in our region, so she couldn't do that anymore, so then we had a parent professional, recruited another parent to be on the core group working on this. There were another five parents, a genetic counselor. There were professional public health representatives and I guess I was the one pediatrician.

We started in December of 2007. We developed a work plan and our goal was to identify, review and select existing initiatives and materials to educate region four families and providers and I want to just emphasize something that Cindy said in that

the focus of the Region Four Genetics Collaborative is on genetics or heritable disorders, but that was just… that was a nice way… that's the… everything we did is applicable to children with special needs and in fact, is applicable to kids with typical needs as well. I mean everybody benefits from a medical home, but those with special needs and those with heritable disorders benefit… have more to lose if they don't have a medical home.

Okay, one of the things that was important in this in terms of making it happen and having real parent input, it was very helpful that three of our parent members were also professionals and worked for their CSHCN departments in their states and why that was really helpful was that they could do a lot of the work in their day job as well because we had a payment structure that if you participated in it on the conference calls you got a certain fee. I think it was maybe up to $20 an hour honorarium. Co leads got more because of the work in between the calls, but there was an awful lot of homework and they were able to do it not at night after putting the kids to bed. I'm sure they did that too because people were passionate about this work, but they could do it as part of their day job and I think that really, really helped to have a good product and meaningful input from the parents on the team.

We started by researching existing resources and materials and got here… There was a handout here that lists some of the materials that we looked at. We looked across the country to try to pull out some materials and low and behold we picked one that we thought was the best template for it and that was Michigan's Children's Special

Healthcare Services Guide. I don't know who came up with that suggestion, but the group agreed that the Michigan guide was really… We did have a guide… had developed… Michigan's Children's Special Healthcare Services had developed a very nice manual about the medical home and so we took that and so instead of starting from scratch we were able to tweak things, adjust things, improve on things and work through on that.

We developed our own reviewing tool and asked everyone to do that. We developed… We came up with a draft as a reviewing tool then the staff helped kind of polish it up, sent it out. We sent in our reviews. We got reminders when we were late, so that we could get them in and then the staff of the Region Four Collaborative and as well as some of the parents that really could put some time into it then digested that material and came up with you know kind of pulled it down to say what we can really use and we have that ****. We used the Michigan guide. We began to modify it to fit the goal of the educating families and you know some things… The guide specifically uses the language about a genetic condition, but again, it's not limited to that. Unique features, we added a section on advocating for your child. We added some parent to parent tips. There are some copies of the guide here. I don't know if there is enough for everyone. There should be. We brought lots of copies and we also have lots of resources about the medical home.

The tips for parents, parent to parent tips were really from parents on our group and kind of highlighted things because by the time you get a several you know what is it, 20

page guide going it's hard to pull out the really important information and we definitely utilized AAP definition, the medical home and we used that as a way to organize our thoughts and put it all together.

So we met… How much did we put into this? We met 17 times by phone, over 100 administrative hours to create, edit and produce the guide and volunteers from the group were utilized to create a webcast about it and that was kind of neat the way we did the webcast. The way that was recorded is that we all sent in headshots and then we could record it just you know over the web or over the phone, so I was recovering from a fracture of my acetabulum, that's the socket of my hip and wasn't very mobile, but I was able to participate in this webcast from my nest in the living room. We aired the webcast in December and here is a link to… you can take a look at it. It kind of walks you through it. The finalized guide, we completed our work in August and finalized the guide at that point.

I just wanted to comment a little bit from my perspective. I love this guide. I think it's terrific and I have seen some things about the medical home that kind of scare me because it's just the expectations are way up there and it looks like it's all my job that you know as the practice has to do all these things and this really is a guide about partnership between parents and physicians and is not about oh, your doctor has to do this and your doctor has to do that, but about how parents can work effectively with their doctors. I'm not saying it puts me off the hook. There is an awful lot that my practice needs to do, but it really… it doesn't scare me away. I love the part about getting the

most out of an appointment, great advice about preparing for a visit. As a pediatrician I just love it when parents come in prepared for the appointment because then we can make the most of the time and most parents do come in prepared, if only give them a chance to you know tell what they need. And though I said this before, it's a useful tool for everyone.

Our distribution plans, we're sending them out to all the region four states. Those are the states… You may have noticed on that map all of the other regions have a name and we have a number. Why are we number four? Well because we're the Great Lake States and what is that other one? Kentucky, so we all touch the Great Lakes except Kentucky, but you add Kentucky in there and you can't call us the Great Lakes region, so that's why we are Region Four. Many states they have some direct mailing for the families. This is available also it's on the web, so you can download all this information if you don't have this glossy guide and we had a lot of discussion about when is the best time to give the guide out to families. Is it at diagnosis? Is it when they get to the genetics clinic? What is the best time? And we did not reach a consensus. Well our consensus was there is no one best time. Different families are going to be at the right place to get this information at a different time, so we need to have it available in a number of different venues.

They are available for purchase or you can download and this is… You can find the… There are links through the Region Four Genetics website and you know we might talk about this a little later. We might come up in the question and answer, other

suggestions about what is the best way to help us distribute the guide. We did have quite a bit of discussion about this because there is no point in putting all these hours into creating something if it's not going to get into the hands of the people that can use it.

Cindy Cameron: This is Bob's turn.

Jane Turner: This is Bob's turn.

Bob Cook: She is on a roll.

Jane Turner: Yeah, I'm on a roll.

Bob Cook: Thank you. Thank you Jane. For those of you who don't know me I'm Bob Cook. I'm from Illinois. I'm not from Michigan. I was adopted for a number of months during this project.

Cindy Cameron: I think you still are.

Bob Cook: Yeah, I think so, but it was an interesting and still is an interesting experience and originally I wasn't quite sure what I got into, but I was happy to participate in this as we go along. One of the things that I want to talk about, and I'm sure that nobody has been looking through the guide while we've been talking, right? I

think everybody has, but and we'll have some time where you can ask some questions about it if you so desire. We're also looking for input too. On our website if you have questions or you see maybe something that we missed. I'm sure we didn't miss a thing, but if you did just please let us know. But really the guide is designed to provide advice on how to actively and effectively partner with your child's doctor.

My son was diagnosed with autism at age two and then later was in a near drowning accident as they mentioned and all the time of trying to meet with the doctors and physicians and trying to figure out you know how we're going to coordinate his care really took a lot of our time and really what we're trying to do through the book and as you look through that and I would just say you know if you want to open it up to the table of contents. As you look at all the different material we tried to include so much stuff. Really I also want to emphasize too and we went over it real quickly was that sheet where we looked at lots and lots of materials. There is so much information on Medical Home. We really tried to condense and to pick out some good parts and just really try to identify as much as we possibly can. We really tried to identify what family-centered care is and demonstrate that, the benefits of that for our families and also to demonstrate issues on culture effectiveness and compassionate care. In the webinar I do the compassionate care section and again, that was an interesting… When she talked about headshots I almost sent in Brad Pitt's picture for me because I figured you know the likelihood of people knowing what I look like might be slim, so I figured at least they might look at Brad Pitt for awhile, but I didn't, but the webinar was really useful. It was really helpful and I encourage you to go to that website and to take a look at that.

What also assists families through their transition process? At the time of my son's death he was 15 and although he was very medically involved and used a wheelchair and couldn't move. He had quadriparesis, fed through a tube in his stomach. We were dealing with issues of transition of we're trying to figure out maybe where he was going to live. We knew he wasn't going to get a job, but there were issues in regard to transition which became real important and we got to remember as parents that we have to let go, maybe let go of kids, maybe you know hoping they might come to Washington, but you know we have to let go sometimes and transition becomes a real big issue and transition process because really transitions occurs through our entire life. It's just not at age 14. There are so many different aspects of transition and we tried to incorporate that and we tried to provide a list of lots and lots of resources as much as we could. And see, I skipped this first one, but it was really a source of specialized information for parents to help them advocate for their child.

There is nothing… I you know personally you know to saying anything negative about doctors. However, when my son had his… Shortly after his near drowning accident I had what I considered medical flyovers where they just sort of circled my son and then pulled me out in the hall to talk to me and never really communicated with my child and basically just told us what we had to do and I really didn't know how to advocate for my son and I apologize for that, but after awhile as you can see I probably gained my voice and really tried to advocate for him as much as possible, so the more that I really wanted to make sure that we tried to include strongly advocating and how to work with

your doctors and just within the system. It also for us helped lay the definition of a medical home. When I started working on Medical Home back in 2000 I went to the first Medical Home conference. It was not in a great location. It was in Hawaii and it was tough. It was really tough. But when I talked to my wife about Medical Home she says, “Well Bob, we have a medical home.” You know my son was in a hospital bed. We had all kinds of equipment. If we don’t have a medical home you know nobody does. Well it’s not that and we all know that medical home means a lot more than that, but it’s still very confusing out there. People don’t understand what it is, so we tried to be as clear as possible. We tried to be I don’t want to say as simple as possible, but in very clear language what some of these concepts were.

We tried really to provide as many tools as possible and as you look through the book there are places where you can… actually there is a question and you can fill it out like you know when you’re interviewing a doctor or you’re asking doctors questions. There are some sample questions in there, so you can write on these and it brings attention to linking families and children to a medical home, but I also want to emphasize as you look through the book we tried to put our parents tips in blue. A number of places we included quotes from parents and those are located for example on page 13 in a light blue box with dotted lines. We tried to include parent’s quotes as much as possible because who can better tell the story about what it means to have a medical home or a child with a chronic health condition than parents? We have lots of checklists. We have lots of materials that families can use. I think it’s a real good tool that I encourage you to go to our website. You can download it, the whole handbook, the whole guide as much

as possible. So I want to make sure I got all of those and I keep going up and I should go down.

Okay, this is just one parent's perspective on the guide, "I believe we have provided a very family friendly guide with useful information and resources that would help all families who have a child with chronic health conditions better understand that concept of a medical home, partnering with your doctor." So I want to thank you and we will take questions. Now you can clap for everybody else. I can stay there. I can stay here see, families over here. Questions, come on this is the audience participation section of the… Yes.

Audience: Hi, Bob. I have a question as far as did you experience any families feeling very empowered in going in and talking to their doctors and the doctors is sort of feeling like they… like where is this coming from and you know?

Bob Cook: Who did you talk to?

Audience: **** and saying well you know gee now that this family is coming to us you know kind of having them taken aback and you know maybe they need to make some changes ****.

Bob Cook: Yeah, I can't speak specifically about this guide and the families, but I know in Illinois and I'm sure that others here in the room know that again, and I was trying to… I thought about this last night. There was a research study done by Robert

Liptak about 10 years ago and where there was a list of 10 things and they asked doctors and parents and the doctors thought the parents needed services and the parents want information, so it's really different, so I think it's really important in regards to your question about the… We've had doctors who you know who told you this and why are you asking me these kinds of questions, but I think it's just all empowering. That's really what we're supposed to do. I mentioned you know I do have a bachelor's degree. I don't have a master's, but I do have an MS and that was a master in Seth who is my son and I don't have a PhD, but I work with a lot of MDs, but I'm a DAD and as a dad I knew my kid better than anybody else, so on a team I feel I'm at the same level and I think all parents need to, so the more information we can interact with the physician I think it's better and I'm sure that there were probably a number of physicians. We work with lots of physicians in Illinois and part of the idea of distributing this guide throughout our region and throughout the country is to start saying to parents, it's okay to ask questions. You know its okay to say stuff. So there was somebody over here who had a question. Go ahead. You want to say yours in the back?

Audience: Yeah, I think this is from the first folks that are doing the learning collaborative, but to what extent can you address the real challenging issue of the transition from pediatric to adult healthcare? It's more than infusing sort of the medical home concept within the pediatric or within the adult practices. I'm interested in the extent to which the collaboratives have tackled the transition issue between the two.

Linda Barnhart: And I wish I could give you the answer. There… Is this on? You know it really isn't addressed yet. I mean when you think about it family practice across the lifespan you know they really should be in the position, but as we know most of these kids unless you're very rural that go to a pediatrician because they have high needs and they still need to transition it isn't being addressed yet. As I said there is a lot of challenges that we have ahead of us to make sure those issues are talked about, but we really haven't yet.

Jane Turner: Can I comment a little bit on experience in Michigan?

Linda Barnhart: Please.

Jane Turner: We have a Medical Home learning collaborative also and demonstration project with some pilots and we're working on transition. We have a long way to go. There is at least the perception that the adult providers don't want to take care of these kids. I don't know how true that is. It's a very strong perception, so we often don't even ask. I do know that some of our families when they make the transition they are a little disappointed because the expectations are different, but I also have had families that have made the transition and have been absolutely thrilled because it has opened up new world of resources, of other specialists and other resources. One of the things that we have found, in our practice we have a medical home demonstration project, one of the things, as we worked on the materials for transition. We decided to develop materials for transition that are not only for children. They're not targeting only special

needs. This transition is an issue for all kids. It's just it's more challenging if you have special needs and you have more to lose if you fall in the gap between pediatrics and a provider for adults, but this is something for all kids, so we start something at about age… I think we're handing it out at age 14, a checklist for families to fill out and then keep.

Bob Cook: Can you get closer?

Jane Turner: I'm not loud enough, okay. A checklist on things that apply to all kids. You know can you make your own appointment? Do you know how to get your own medicine? Can you call for a refill if you're on medication? Do you have any clue how your healthcare is paid for? I don't think we use that language exactly, but we should. So anyway, this is a **** thing and we have found in a university setting our family physician and internal medicine colleagues are very interested in training their residents in this issue, so there is a glimmer of hope there that it's going to get better and again, I'm not sure that what the real barriers are versus the perceived barriers.

Linda Barnhart: Did you want to say something?

Bob Cook: Let me pull the mic closer. Pull the mic closer.

Linda Barnhart: And I'd like to add onto that just a little bit because we in Washington two years ago we did a survey of adult providers, not necessarily family practice. We tried to target adult primary care providers and the question we asked were, what are

the barriers because rumor has it you know the perception is that you're not taking these kids and we know this from our parent groups and focus groups and the interesting thing. Now you know when you send out a survey that the people… when you get it back you have a select group. I mean it's not that everybody responds, but it's interesting out of the 300 we sent out we got 100 back. We thought not bad for physician groups. Pardon me.

Jane Turner: Yeah, that's good.

Linda Barnhart: But we thought we did okay, so but interesting though, the information was from most of these is that we do take them. Money is an issue. Paperwork for our Medicaid and I don't think our state is alone that has significant paperwork in order to get Medicaid approval for stuff. It's not easy. The kids are now 18, so unless they're on SSI they don't have paperwork or Medicaid, so you know there is a lot of those barriers, but we found even though they said we take them the big barrier is not the money and it's not the paperwork. It's that a lot of these kids are living a long time. They have conditions we're not familiar with and our question was you know, so unfortunately the parent really has to be the person that educates them, which doesn't always seem quite so fair, but it is the reality of it and we have an adolescent health transition project that we're developing tools for adult… I like to say adult providers. Okay, all providers are adults, but you know however we want to look at that, but just say okay, what are the conditions that you most want to know more about, what are those that you just can't seem to get your arms around, so we're working on some of those tools if that is some

of the issues that they're facing and that they're waiting rooms aren't setup. I mean there is a lot of funny little things that you didn't really think about. Our exam tables are not set so that you know we can really do exams on some of these kids. We're not setup that way, so those are the things that are our next project is to tackle for our adolescent health transition project.

Bob Cook: And I would just say in regards to Illinois' CHCN program we have on our website just a whole section on transition. We have tip sheets for kids and EI, real young. There is some transition things in regards to that for kids, so there is lots of information out there and to me it's really critical that we address transition throughout the lifespan.

Jane Turner: There is also… You know going back to this morning's plenary talk about switch, one of the big elephants in the room with transition is the emotional one that the doctors don't want to let go and we get really attached to these families. The families are attached to us, so it's like you know we kind of talk about it, but nobody really wants to do it.

Audience: One **** issues are not used to **** can come in and ****, but it's not easy and you know we're so used to always being kind of in charge **** two people ****.

Linda Barnhart: Yes, that's a good point.

Bob Cook: Mary, you got to let go.

Cindy Cameron: She is your ****.

Audience: Was the guide that you all created, is it in Spanish as well?

Bob Cook: Not yet.

Jane Turner: Not yet. It really needs to be in Spanish and Arabic and other… and really for different parts of the country.

Cindy Cameron: It kind of depends on our region. With the seven states we have many populations that it needs to be translated for.

Jane Turner: Yes, many, yeah.

Bob Cook: And this is a… I see it as a living document too that I think we're going to be making some changes to at times, so additional things like that will happen.

Cindy Cameron: Our next workgroup up is on transition. They're going to start meeting shortly, so we expect **** work.

Bob Cook: Other questions?

Linda Barnhart: I have one more comment though. I see Tony and it reminds me of those, is that one of the TA centers, Healthy and Ready to Work, has information on adolescent transition, although you're all nodding, so you probably know the site, but just as a reminder that we do have some information and it refers to our adolescent health transition project, I'm sure to Bob, so there is a lot that is going on.

Bob Cook: Well and also the National Healthy Read to Work, which is a national site on transition, is a wonderful resource, so okay. Yes.

Audience: Two things, one in terms of this have you ever taken some of the tools that are in here and just given the checklist to someone rather than the entire? I'm just wondering for some families if this would be kind of overwhelming and have you tested it in terms of?

Jane Turner: We haven't, but that's a good idea.

Bob Cook: I mean we haven't tested it. I mean I know that within our group and I was at the end as the co chair, the parent co chair. The parents can use it any way they want and also we're trying to get it through our genetic centers and stuff and that we even said that they could actually go to the website, the professionals working with it and just use just the checklist or just use certain sections, whatever because for some families it might be too much and you know we leave that up to the professional feelings on that

because that could be very possible, but part of it too from a parent's viewpoint you know I might not be ready to do that, but it's nice to know that that stuff is here, so when I do need I can get it and I might not be ready today, but maybe next week I can deal with some of that, so okay. Yes.

Audience: Have you worked with practices that **** clinics that don't have pediatricians on **** or on ****? I know there is a whole network of public funded or publically supported community health centers, especially in the rural areas and **** and some of them **** and what has been your experience in working with them?

Jane Turner: We're in the early stages of working with some QHCs to become a medical home, so I really can't tell you their responses yet. Part of it is kind of understanding the hierarchy. For me at least it is understanding the hierarchy ****. Where **** working with a federally qualified health center there is a lot of interest, but some… We're not quite sure how you get things done yet. To transform a practice is one thing, but when it's coming from there is so much… so many rules in coming from above it's a little complicated, so I really can't help you with ****. It's complex.

Bob Cook: Yeah and I can't say about genetic centers, but in Illinois in our medical home project we have a number of HQFCs as medical homes where we use Carl Cooley's method of quality improvement teams where we use physicians and staff and parents and we have… and they're wonderful because part of their federal funding is quality improvement and Medical Home really fits into that, so they're very excited about

it. In fact, some of the teams that do the most work are those, so I mean we have worked… There is one especially in Rockford, Illinois that is just super excited, so.

Linda Barnhart: And we have a number of community health centers in the current learning collaborative.

Audience: For children?

Linda Barnhart: Well they serve all. They're family practice clinics, but we do have a number of federally qualified health centers and one of our partners is, if I can ever say it right, the Washington Association of Community and Migrant Health Centers that are a partner in the planning the collaborative.

Bob Cook: Another question.

Audience: I actually almost have the opposite question actually. Putting on my parent hat here and I just came from a meeting. My daughter has a genetic condition. I just came from a meeting in Atlanta where we brought together teams from around the country who the base of which is… **** specialty here because we're almost in academic medical centers and I feel like there is this tension between these centers wanting to take care of the whole child, but that's really not what we're talking about in terms of medical home because medical home should be in the community, but at least you know my daughter. I mean she has had 26 surgeries, so you know she gets a lot of

care in an academic medical center. I just don't know if anyone is… You know we talk about Medical Home and the ideal being in that community center, but the reality of it is and then I had a lot of conversations with the geneticist **** because they feel they are the ones that should be providing that primary care, but again, the reality is when we talk about it, it really should be in the community.

Jane Turner: You're right. There is a huge tension here and often it's the multidisciplinary team or the geneticist or the neurologist or the cardiologist who really does know the child the best and interacts with the family the most and then they see the pediatrician or the family physician just for immunizations and the occasional ear infection or something. There is a lot of talk about it. I mean in my head one of the ways to put these together is the team perhaps, particularly if they have a team, not just a geneticist, but a full team can serve to come together, pull together a care plan that then can be carried out in the community with the primary care physician as the implementer of that care plan. I'm not talking about who gets paid for what because that is way too complicated, but that would be one way to reconcile those roles. It really helps to have a team to put together a comprehensive care plan.

Bob Cook: Just briefly, in our Children's Special Healthcare Needs Program a number of our families because we ask families to identify their Medical Home provider, have identified specialists because they do see their doctor quite a bit. A key component to Medical Home is communication among all the parties, so if that specialist is

communicating on some of the things and is communicating with the pediatrician, the families going to the pediatrician it’s you know that kind of fits in, so anyway.