

MCH/CSHCN Director Webcast

June 9, 2005

Transition to Adulthood: the Outcome of all Outcomes, Healthy and Ready to Work, Phase II Project

CHRIS DeGRAW: Good afternoon and welcome to mchcom.com webcast coming to you from the Maternal and Child Health Bureau in Maryland. For state and Maternal Child Health directors, I'm Chris DeGraw. Before I introduce today's speakers I would like to review technical information about the webcast. Please note that in response to your suggestions, the speakers Power Point presentations and other handouts are available on the mchcom.com so you can download the slides before the webcast. Slides will appear in the central window. Slide changes are synchronized with speakers presentation. You may need to adjust the timing of the slide changes to match the audio by using the slide delay control at the top of the messaging window. We encourage you to ask the speaker's questions at any time during the presentation. Simply type your question in the white message window on the right of the interface, select question for speaker from the dropdown menu, and hit send. Please include your state and organization in your message so we know where you're participating from. The questions will be relayed onto the speakers periodically throughout this broadcast. If you don't have the opportunity to -- if we don't have the opportunity to respond to your questions during the webcast we'll email you afterwards. We encourage you to submit questions any time during the webcast and we'll field the questions toward the end of the webcast. You can adjust the volume of

the audio using the volume control slider that you can access by clicking on the loudspeaker icon. Those of you who selected accessibility features when you registered will see text captioning underneath the video window. At the end of the broadcast interface will close automatically and you'll have an opportunity to fill out an online evaluation. Please do so, your responses will help us plan future webcasts in the future and improve your technical support. I would like to turn the webcast over to Scott Snyder who will moderate the webcast and introduce the rest of our speakers.

SCOTT SNYDER: Good afternoon. I'm Scott Snyder. I'm a public health analyst and program officer for the healthy and ready to work initiative. I thought we could go around the table and introduce ourselves.

CECI SHAPLAND: I'm Ceci Shapland.

TANIS BRYAN: I'm from the southwest institute for families with special needs in Scottsdale, Arizona.

KAREN RICHARDSON: I'm from the southwest institute in Scottsdale.

DANIEL BIER: I'm from the University of Wisconsin Madison.

SARA RENNER: I'm Sara Renner and work for the employment policy group at the University of Iowa.

SAM GLEESE: I'm Sam Gleese project director from the citizens for disability program in Jackson, Mississippi.

DEBBIE GILMER: Debbie Gilmer at the main support network and the Title V program.

PATTI HACKETT: I'm Patti Hackett.

SCOTT SNYDER: Good afternoon. It's great to see with all the hi-tech -- technology we're passing a round a microphone by hand. Today's topic is: Transition to Adulthood: The Outcome of all Outcomes, Healthy and Ready to Work, Phase II Project.

The next slide. This afternoon we'll be discussing how transition outcomes can be achieved in the national performance measures, some of the lessons learned from the healthy and ready to work Phase II project and some of the tools and resources that have been developed.

Next slide. Currently the initiative provides funding for the healthy and ready to work national center located in Washington, D.C. and five projects located in Arizona, Iowa, Maine, Mississippi and Wisconsin.

Next slide. If you wish to obtain some more information regarding the initiative, you can either email me or go to the healthy ready to work center website.

Next slide. The conceptualization of the ready to work initiative grew out of many mandates and initiatives. Under the 1989 omnibus budget reconciliation act, Title V was revised directing states to provide and promote family-centered, community-based, coordinated care for children with special healthcare needs and facilitate the development of community based services for children and their family. We begin to see a shift in the paradigm. It was during these die am I can times the healthy and ready to work initiative emerged in 1996 and the Phase II projects received funding in 2001. Since 2003, states have been required to report on their transition efforts as one of the 18 national performance measures for their MCH Title V Block Grants and I'll have more later. To learn more about the history of the initiative go to this website.

Next slide. I would like to expand a little bit on some of the mandates and initiatives. The 1999 Olmstead Supreme Court decision was a landmark decision which affirmed the right of people with disabilities to live in the community rather than in institutions whenever possible. In February 2001 President Bush announced the New Freedom Initiative, a comprehensive program to promote full participation of people with disabilities in all areas of society by increasing access to technologies, expanding educational and employment opportunities and promoting inside access into daily community life.

Next slide. In a status report on this executive order entitled delivering on the promise it was determined that HRSA as Maternal and Child Health Bureau would take the lead in implementing a plan to achieve community based system with children and youth with

special healthcare needs and their families. Barriers identified from this report could be overcome by providing access to comprehensive family-centered care, affordable insurance, early and continuous screening for special children and transition services.

Next slide. Consensus statement on healthcare transition was approved as policy by the board of the American Academy of Pediatrics, American academy of family physicians and the American Society of internal medicine. This policy statement press a consensus on the critical first step that the medical profession needs to take the realize the vision of a family-centered, continuous, comprehensive, coordinated, compassionate and culturally competent healthcare system as developmentally appropriate as sophisticated. It calls on physicians to understand the rationale for transition from child oriented healthcare and to create a written healthcare transition plan by age 14 that takes into account what services should be required and who might provide them and how these services would be financed. Next slide. As mentioned previously, the national performance measure number six is transition to adulthood. Transition is a process, not an event. A transition process should begin at the day of diagnosis. A child, youth or young adult should be involved in the decision process. Providers and parents should prepare to facilitate movement from one state to another. Coordination of services and providers is essential.

Next slide. First steps are used to measure the development of community-based systems and services for children with special healthcare needs and their families. These send four outcomes adopted by MCHB and later reiterated in the president's New Freedom Initiative. Early and continuing screening, family and youth involvement, medical home,

healthcare insurance, community-based service systems and transition to adulthood.

These outcomes for children with special healthcare needs are also incorporated under objective 1623 of Healthy People 2010. The target is to reach 100% success for each outcome by 2010.

Next slide. For the healthy ready to work projects to be successful they must integrate their activities and address each of these four measures. Today's presentation will illustrate how the healthy and ready to work Phase II projects attempts this in your own words. Now your next presenter is Ceci Shapland discussing transition and screening.

CECI SHAPLAND: Thank you. Performance measure number one focusing on transition and screening focuses on children and youth and will be screened early and continuously and the operative word here is continuous. To continue the screening that is needed throughout adolescents and into adulthood. Here at healthy and ready to work we always get the question about what has health got to do with transition? We feel it has everything to do with transition. Transition is about real life, about employment and having fun in the community and living in the community, playing in the community, and so we really want to focus on the health needs and how young people can have a quality life. Along with that, we also look at teaching young people about their health because they can only remain healthy if they know how to make healthcare decisions and they know about their healthcare.

Next slide. What should we focus on with transition and screening? Well, first of all secondary disabilities, of course, that's monitoring preventive care as well as mental healthcare and any high risk behaviors that will come up during this time. The other piece is aging and any deterioration. There is not a lot of knowledge right now about aging aspects of a lot of young people with special health needs because only now some of them are beginning to live into old age. There is a body of knowledge building and it is something that really needs to be focused on and more research. But the aging issues are very, very important. Also we want to look at transition as it focuses on those real life things like employment and leisure and recreation. How does health impact what kind of job a person has or what kind of recreational activities? How will it impact where they live? The transportation they use? The housing choices. Finally, how is it going to impact their higher education and training for the job?

Next slide. Finally, another important part of screening and transition, of course, is the general preventive healthcare. We need to think about hygiene and nutrition and exercise, the sexuality issues I mentioned the mental health issues. Any routine immunizations. We need to teach young people about the routine types of tests they need to have. Pap smears, etc. I'll turn it over to Debbie Gilmer for transition and family involvement.

DEBBIE GILMER: It's a pleasure to be here. I think it's pretty typical that we focused a lot of efforts over a number of years on family involvement. I'm going to talk more specifically today about our emphasis on youth involvement and hopefully will pepper some of my comments with the importance of families but today I'm going to talk more particularly

about the youth involvement. In Maine, our healthy ready to work initiative. This is our Phase II projects. They are in a partnership with the community with a number of folks. We've addressed all six areas of the national performance measures thinking that's critical. But I think what I wanted to talk about here was the importance of -- and the critical role that it's impossible to do this work alone. Our partners likely number well in excess of 50 organizations and agencies at this point in terms of independent living centers and family organizations and youth organizations, different branches of state government. Non-profit organizations and all that it really takes a village, if you will.

Next slide, please. Maria is a young woman who has been involved in our project for a number of years. I would like to suggest to folks out in the states that despite some myths there is no problem finding youth willing and able to assist advise, and contribute to these efforts. Maria is a high school graduate and currently left two weeks after she graduated from a small high school in Maine and moved to southern California where she's enrolled in college and living on her own. She remains on our children with special health needs advisory committee thanks to the power of technology as we're seeing today, we can do that.

Next slide. Youth are talking, are we listening? The efforts are founded with the belief that youth and family are the experts and over the years they've demonstrated their able ability to serve as fellow researchers, policymakers. Certainly they have been our teachers. Their work is obviously and necessarily compensated. They've served as change agents and they've become dear friends.

The purpose -- next slide. The purpose of the youth educators and advocates of Maine is our Youth Advisory Committee with the children with special needs program in our state. They wrote this purpose statement and exist to review and -- to develop and review policies and procedures for services served by the program. Next slide. I would encourage all states to adopt a similar Youth Advisory Committee and liken it after your family advisory committee. The youth group is a sister group to that. Next slide. They've educated and informed a wide audience of colleagues in our state and our materials are available on our website.

Next slide. Influencing change. They're recognized now as a go-to group on a number -- from our CMS grants, Secretary of State is working with them on addressing driver's education and accessible vehicles, for example. Next slide. They've certainly served as mentors not only to other young adults with and without disability and special healthcare needs but certainly to us as well.

Next slide. I've talked briefly about the fact that it really does take a village. It is not necessarily easy. It involves a significant commitment and changing the way we do business, the outcome is absolutely invaluable and the final slide, Stephen King, one of our most famous residents of our state, did the commencement at the university recently and as he finished his address he said let me tell you a secret. Right now you're all sitting on the ground floor of the greatest place on earth and the elevator doors are open. Mr. King here is talking about the great State of Maine but I would like to end with the notion

that all of our nation's youth are deserving that all doors be opened and that healthcare and transition are a critical area to address. Thank you. Tanis Bryan, medical home.

TANIS BRYAN: One of the goals of our project was to establish a consortium of primary care pediatricians, specialists and adult care providers to develop medical homes for youth as they transition into young adulthood. First slide, please. You all know the definition of a medical home. Children and youth with special healthcare needs will receive coordinated, ongoing, comprehensive, culturally competent care within a medical home. As I go through the lessons we've learned and make suggestions, one of the things we've learned is that everyone needs a medical home and as we age, all of us, youth and ourselves including, medical home becomes even increasingly important. My comments today focus on what pediatricians and specialty care can do to help prepare youth and families for this transition. But we still have a major issue of how to get adult care providers to adopt the concept of medical home.

Next slide, please. And so we start, although technically the consensus statement suggests that youth should have a transition plan when they reach age 14, we have learned that transition is a life span process that really starts at birth in the hearts and minds of parents. And families beliefs, what they think about, what they learn about their youth, their values, what they think is important, the expectations they set for the future of their children determine whether youth will acquire the self-determination skills necessary for transition to adult healthcare, education, career and independent living. So the dye is cast very early. And maybe it gets recast when the family gets asked the crisis of learning

that their child has special needs. And this is an incredibly important time because they set up family routines on how they will deal with this child and those routines reflect what they believe is possible. Next slide, please.

So primary care and specialty care physicians play a very significant role in helping families shape their expectations and the skills that foster youth and parents acquisition of self-determination skills. Note that I include parents as an equal partner in the physician's responsibility because the parents, of course, take home the attitudes they pick up from physicians, the advice that physicians give them is very, very critical to them. So helping them to transition to adult care can be complicated because families get very comfortable with the pediatricians that have been caring for their children and the pediatricians become very attached to the youth as well. And many times they've been through some life threatening events that make this bonding even stronger. The only one in the picture eager to leave the childcare is usually the youth. Seeing the railroad trains and getting suckers at the end of the visit is not what they want for their life span.

Next slide, please. Some of the strategies that we've been trying to work with to help the physician process along, we're working with the state Medicaid directors to try to pilot ways to change reimbursement schedules so that -- so that physicians -- adult care physicians will be more willing to take the kids. A critical thing is to get residents into training to learn about kids with special needs so that they feel comfortable, that they know the resources in communities are available. Another thing we found very, very critical was developing ways for healthcare providers to communicate with one another.

Systems are not set up for easy communication and without that, it doesn't work. Next slide, please. Systems that are supposed to be helping provide the process need to dedicate staff to be responsible for facilitating the transition process. One issue is providing care coordination, the next is linking community resources. Linking families and youth to other resources and again, starting the process early. We would like to see a specialty care providers develop age and developmentally appropriate condition-specific list of what you could do to start to assume independence to themselves.

Next slide, please. A critical issue, most doctors feel that they attend to the cultural differences and dang differences in the families they choose. The evidence would suggest otherwise. And so we would plead with providers to pay very careful attention to the cultural and literacy issues that make it more or less likely that families will follow through on the suggestions that physicians advise. For youth, we had a youth day. Am I supposed to understand this when attending a session on SSI benefits? And I reverb rated on that because my question is, why are you asking the questions? We clearly haven't -- this group had no notion whatsoever that she was responsible, that she had rights and responsibility and just going briefly through what some of these are. Learning what you have to do by yourself to navigate the healthcare and other systems. Having knowledge about what your issues are, what you need and your health history, X, Y, Z. A system for recording medical advice and follow through. We all need that. It's very hard to remember all the instructions that you may be given and having something in writing or on tape so that you can review it later is very helpful. And a transition plan. We're falling down in getting transition plans and I think an issue for discussion is who and where should the

transition plan be developed? Because it falls -- the comprehensive need to develop a plan that cuts across different areas then makes no one area of professional services is responsible for all these areas. So this is something that we need to talk about.

Next slide, please. We need to include families and youth in activities where they take control. Families should be giving -- very critical to respect their privacy from an early age on and one of the things we find is doctors certainly talk to the youth but all medical information gets directed to parents and we would strongly hope that professionals and primary care providers would be able to shift their communications to the youth especially if the family is sitting there and gets the information directing the comments to the children from an early age would help. And finally, last slide, the physician's prime responsibility is the medical management of the young person's disease but the outcome of this medical intervention is irrelevant unless the young person acquires the required skills to manage the disease and her life and that's the bottom line for medical home and now I'll pass it on to Patti.

PATTI HACKETT: The next session is transition and healthcare. The national performance measure number four requests that adequate private or public insurance to pay for the services that youth need, next slide. I don't need to tell you that what happens if we don't plan ahead. Most of us think there aren't that many options but there really are. Without pre-planning youth will be destined to at least one year without insurance.

Next slide. The next couple slides is a whole presentation by itself so I'll whip through them but just introduce the topic that there are some options. We know in a public-funded program such as Medicaid there are three possibilities. Maintaining Medicaid to 18. Dropped from Medicaid because you are no longer considered that disabled before 18 and at 18 and one day you are no longer disabled or new to Medicaid because your parents income was too high and this is the first time you're on. What it will require is good documentation and financial record planning. The loophole in this, it's not usually used but one we would like to promote and continue the dialogue. There are possibilities at age 17 if you feel there is going to be a youth that might be in jeopardy during redetermination to think about applying for what they call section 301. By developing a relationship with voc rehab and developing a vocational plan the youth can maintain their S.S.I. and Medicaid benefits as long as they are compliant with their employment plan. Keep that in mind. On the slide is the actual website which is the S.S.I. rules. If you share this web link with your office they'll know it's real.

Next slide. The other option is Medicaid while working. It is not easy and it can be hard. But the idea is understanding what the systems could offer. It's new in the process and we still are optimistic. Next slide. There are some options under private insurance with either family, employer or solo pre-pay. You can maintain benefits two ways, the adult disabled dependent child can extend benefits lifelong with annual documentation. This law is effective in 40 states. There are other possibility of student status. The problem with that is if kids get sick, one you're off the plan you don't bounce back on. Then there is the other options of college plans which doesn't offer very much but offers something better than

nothing, employer or group plan or self-pay. If you choose to do a self-pay it could be a tax deduction for your premium. This ticket to work and Cobra.

Next slide. As we take a look now. As you as a state Title V program what can you do to influence Medicaid changes in your state.

DEBBIE GILMER: I'll talk for a very brief moment about a couple of things that we did in Maine. I need that last slide back. The opportunities to influence change. Many states, if not all states have medical infrastructure grants focused on various topics but in most states all around Medicaid eligibility with workers with disabilities. We've been able to address a number of issues, including the cash cap on the S.S.D.I. side for young adults who might be receiving D.I. Those are the Medicaid buy-in programs but every state has a Medicaid buy in program. You don't need to lose your insurance benefits, Medicaid immediate necessarily when you go to work. In Maine we use a non-categorical single no children program eligibility for youth -- for individuals 16 to -- 18 to 64. Our largest group of enrollees are the 18 to 24-year-olds. That's another option for health insurance for those folks who are getting their feet wet, getting their first physician and so there are opportunities to stay engaged with your state. And transitioning community is next.

DANIEL BIER: I would like to just read that performance measure there on the next slide, please. Community-based service systems will be organized so that families can easily use them. This is where the rubber hits the road and where we really see how is our success from the previous performance measures really played out in the lives of families

and youth? I think the primary message that I would have in this is that transition is a community-based process. It is something that we have to do with all the different partners in the community, within the healthcare system and outside the healthcare system connected with youth and connected with families. It is certainly a message that Debbie has said a few times as she talked and acknowledging in the beginning from the perspective of a children with special healthcare needs program we have a really good opportunity to build capacity in the local communities to -- through advocacy training and technical assistance efforts. We don't often have the dollars to do these things and the dollars are in so many other systems.

Through advocacy training, technical assistance we can increase capacity. That's the model that we really worked on in Wisconsin. The key part of this was helping everyone realize that it was currently positioned in the community that they have a healthy vision for what a successful transition is. We need to state that with them and have them have ownership of that vision and then listen to them to help them tell us what they need us to do in training technical assistance and advocacy to help them be more successful in doing the things they want to do. In order to -- next slide, please. As we took that approach, we identified a series of six activities, six elements that are listed in this slide that we have been implementing a series of activities in each of these elements and together depicted here separately. They're so interdependent in practice. I'll go through the six elements in the next slides.

The first one focuses on what we do with communities and with individuals. And these are actually going to work together. The first one is really we've been working with others at the asset based community development institute at northwestern using that model to go into communities, map communities, find out what is going on in those communities, where is the action? Who are the people? How does this community move? Not just in areas of health but to make the community successful at multiple levels. We get to know that community and they get to know us and figure out how can we begin to connect with them? Parallel to that is a different process going on focused with specific young people with disabilities. And using a lot of the different tools that we've all known about for persons under planning. Through that process we get a better idea where do the young people themselves want to go? What is their vision for the future? Then we go through a connection process of what does the community want to do and what are their strengths and what contributions can they make to making communities successful and merging those with the young people themselves and saying where do they want to go? It's an asset-based model where you have communities and youth moving in directions that they want to do and it is a very strength-based model. Next slide, please.

This next slide really focuses on once you have mapped the community and know the youth you really want to connect people in ways that maximize their strengths and increase their skills. So we are involved in a variety of training and technical assistance to promote skill development for youth, families, providers, help them learn together, create a variety of materials. The things we've developed have really come from what they tell us they want to do. We have engaged with them through the other processes. They tell us I

would like more information on this. And then by our community assets model we often find people who are good connections with that. We've had some of the same people in the community help develop curriculum for -- to meet some of the needs that other people have said they need developed. So a variety of activities and skill development. Medical home I really need to stress here in the model because there are so many things going on in transition within and outside of the healthcare systems. We need to rely on to make successful. For us as directors and as staff and people who are so close to the state children with special healthcare needs program, we need to keep recognizing our unique role is to advance the medical home.

For individuals with special healthcare needs who are experiencing problems because of the health issues, being the obstacle transition, medical home offers a tremendous opportunity to work in -- with that constellation of services and it's a healthcare framework that is something we need to make sure we're grounding all of our efforts within that medical home. That's an important part of the model. The next slide finishing up on the other two elements of our model is strengthening linkages. We have a variety of ways where we connect state and local community groups through a statewide transition consortium now facilitated by our state children with special healthcare needs program. Youth advisory groups. You can see the other structures on our slide here. Then we're continually talking and thinking and looking to ourselves and asking how are we doing? We have just specific ways where we are, I think, really looking at continuous quality improvements. Which is an important thing and do it in a positive way where we're

identifying our deficits, strengths and moving forward in ways we're all very comfortable with.

A final couple of comments on the next slide, the first quote here was one of the conclusions with a meta-analysis done a number of years ago looking at primarily successful transition in the school system and through -- this is a quote out of that literature where they were seeing that positive outcomes for youth are increased with strong collaborative approaches across program and agency lines. That was coming a lot from the educational perspective. I think it is something that we've been seeing in our own work in Wisconsin these past four years and at the next meeting isolated transition efforts in Wisconsin benefit from an organized effort to strengthen connections, incorporate youth input and align transition initiatives with similar statewide redesign activities. Just in conclusion, we're not alone in this work. It's exciting. There is a very effective and efficient opportunities for children with special healthcare needs programs. We expect in Wisconsin to be able to prepare a toolkit of all of our materials and get it out to each of the state programs. We hope that you'll find some tools and some ways that you can use some of our material. I would now turn it to Sara from Iowa.

SARAH RENNER: Thank you very much. I'm Sarah Renner from the healthy and ready to work project in Iowa. A pleasure to be here today to talk about the young people we're working with you and to join my colleagues. My colleague, Sam Gleese from Mississippi and I will talk a little bit about transition.

Next slide, please, as a reminder the national performance measure number six that goes along with the states youth with special healthcare needs will receive the services necessary to make transitions to all aspects of adult life including adult healthcare, work and independence. And I would like to turn it over to Sam.

SAM GLEESE: Thank you, Sarah. In Mississippi, transition has taken the form of a collaborative partnership between Title V, the coalition for citizens with disabilities, a statewide advocacy group and living independence for everyone which stands -- which the key phrase is life. Where we do a statewide effort to empower young people with special needs to become independent, productive citizens in society.

Next slide. And to do that, we employ what we call-in dependent living transition specialists. These transition specialists, in addition to promoting the concept of a medical home, provide information, referral, peer counseling, life skill training and also training the young people and their families on how to be advocates for themselves. From taking this approach we're able to better empower young people with special needs to become healthy, productive citizens of society prepared to enter the workforce and to become taxpayers rather than tax burdens. And now back to you, Sarah.

SARA RENNER: Thank you. I wanted to talk about -- next slide, a little bit about the Iowa project. The first part, the medical component, we had a slightly unique approach, I guess, to the whole care coordination component. We have a two-person care coordination team composed of one woman who is a nurse and another who was a masters in social work.

Together they're really able to address all of the -- both the physical and the emotional healthcare needs for simple conditions as well as complex conditions for all of the young people that they worked with. One of their missions was to help the young people increase their understanding of their own medical conditions, be able to talk about that and, you know, be able to talk with medical providers and others in their community about their medical condition. They were working toward the attainment of self-management of their own health conditions. Many of the young people we worked with were in various degrees of management, self-management of their own health condition.

One of the things our care coordination team focused on is helping young people manage their own healthcare. To that end each of the young people in our project had a medical binder that was sort of a compendium of all the information related to their medical conditions. What medications they're taking. When their next appointment would be. Any emergency information that would be important to know. And the goal for that medical component was the transition of these young people from pediatrics to adult healthcare services and along with that the attainment of independence. Another facet of our project was the employment component which in Iowa is a real important part of our healthy and ready to work project. We always thought of our project as being both the transition from pediatric to adult healthcare and the transition from school to work. So a lot of our project was focused on employment skills assessment and training and developing job opportunities in the Waterloo, Iowa area which was our demonstration project. We involved lots of people in the community. Lots of other providers in the community to collaborate and work with our young people with us.

What we found from our youth advisory council is we asked our young people and the participants what they want and what we found was what was kind of important and interesting for you to hear. We found 37.8 of our young people said they wanted employment. That was the big goal for them. Next to that, 26.7 in the yellow say they wanted to go to college. 20% in blue said they wanted to understand their medical condition. 8.9% wanted to live independently and 6.7% had other. That included things such as understanding their medications, making accommodations so they could go on to college and making accommodations so they could transition from pediatric to adult healthcare. Next slide, please. What we saw, what we have found is that the medical community is much more aware and responsive to health-related issues produced because of the healthy and ready to work project. We found youth and families are more aware of these issues and what opportunities exist in their community that they can avail themselves of. And we also found that a higher percentage of youth move on to post secondary education. 25% of our youth in Iowa were able to go on to employment opportunities. That's after they were able to learn skills with help and self-management of their own healthcare. And with that I would like to turn it to Patti.

PATTI HACKETT: As we develop systems and services and new activities around transition are we really looking at the outcomes? That brings us back to transition to the adulthood is the outcome of all outcomes. We know the data that has been around for years is not good. So our only direction is up.

Next slide. We know transition to adulthood is successful when youth have a voice and they're heard in their own healthcare decisions. When those who want leadership roles are brought to the table. When they have a medical care plan that meets their needs and developmental issues and when youth have insurance that is not in jeopardy because they're working or getting older. Next slide. We know transition is successful when they have an opportunity to try. When their aspirations are supported, when they're financially supported to learn new skills. When they're working. One part that we always fail to remember is that family members get to work the jobs they're entitled to because service systems are in place. The last slide for this part of the presentation features our website and we encourage you to come visit. It's a cut and paste kind of deal. Take what you want and if you adapt it, please let us know.

The remaining slides in today's presentations are for your review later on. It identifies some activities and some materials that may be of interest. We'll open it at this time for questions and I thank you very much for joining us today.

CHRIS DeGRAW: Thanks a lot, Patti. We do have a couple of questions to start with. First comes from Kentucky and is -- relates to the medical home presentation which I believe was Tanis. The question is, what is the difference -- as the speaker defines it -- between care coordination and case management?

TANIS BRYAN: Case management is what many organizations do to shuffle people through their agency. Care coordination is a way of helping families and youth coordinate

all the services that they need. So when they come into a primary care or specialty of care office and the plan is that they need this service and that service and another service, that those -- the family knows where those services are and has provided all the support necessary and possible to help that family make the contact with the services, then to be the place where all the records are kept so that all the services that have been given can then be coordinated through that medical home.

CHRIS DeGRAW: Thank you. There are a couple of questions that relate to the availability of forms that were -- the first are there examples of communication forms that can be mailed?

PATTI HACKETT: We're proud to say several of our projects have created some forms. If you go to tools and solutions section you'll see the materials that Arizona healthy and ready to work have developed and practiced in the field. Kentucky Title V program uses around their life maps and other projects such as that.

CHRIS DeGRAW: Are there templates of forms available for the medical home binder?

UNKNOWN SPEAKER: The medical home binder? There are plenty of forms available at our website and we have sent them to you called the child health data assessment as part of the medical home file.

TANIS BRYAN: We also have a communication form the family fills out the top of when they go to the physician's office and then the bottom part is filled out by the physician and

family and has the directions that the family is to follow through and instructions they can take to the specialty care and bring back to primary care. We have evaluation data showing that the families find extraordinarily helpful.

CHRIS DeGRAW: That's all the questions we have at this point. The contact information, of course, is available in the slide presentations. So in the handout on the website so you can follow up with any questions if you have any and they'll try to answer them for you. I want to thank all of our speakers today for a very interesting presentation. Thank you for coming in under the wire time wise. Even with time to spare. I want to thank all of you for participating in our monthly mchcom.com. Like to thank the Center for the advancement of distance education at the University of Illinois in Chicago. Today's webcast as with all of our webcasts will be archived and available in a few days on the website

WWW.mchcom.com. We encourage you to let your colleagues know about the website and hope they'll find it useful as well. We want to make these webcasts as responsive to your informational needs as possible. If you have any suggestions on topics that you would like to have addressed on future webcasts or any comments in general, please email them to us as info @ mchcom.com. Thank you again and we look forward to your participation again next month.