

**Seminars on Adolescent Health: What's Health Got to Do With It?
Transitions for Youth with Special Health Care Needs**

June 23, 2004

TRINA ANGLIN: Welcome to the Maternal and Child Health Bureau, Office of Adolescent Health webcast. "What's Health Got To Do With It?" transitions for youth with special healthcare needs. This is the first of two webcasts we're sponsoring this year as part of the national initiative to improve adolescent health. The national initiative, which is simultaneously based on Healthy People 2010 critical adolescent health objective and a youth development is the CDC adolescent and school health and our Office of health. This webcast has been planned by state health coordinators. Our audience includes professionals from public health, personal healthcare and education arenas as well as family representatives. Technical support for our webcast is provided by the Center for the advancement of distance education from the University of Illinois at Chicago. I am Trina Anglin from the Office of Adolescent Health and will serve as moderator. Before I introduce our panel, I would like to review some technical information.

You will see Power Point slides on your computer screens and hear the voices of our panel. Slides will appear in the central window and should advance automatically. The slide changes are synchronized with the speaker's presentations. You do not need to do anything to advance the slides. 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 speakers 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 or organization in your message so that we know from where you are participating. The questions will be relayed to the moderator periodically throughout this broadcast. The panel will respond to your questions during the discussion period which follows the four presentations. If we don't have the opportunity to respond to your question during the broadcast, we will email you an answer afterwards. Again, we encourage you to submit questions at any time during the broadcast.

On the left of the interface is the audio control. You can adjust the volume of the audio using the volume control slider which 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 audio control window. At the end of the broadcast the interface will close automatically and you will have the opportunity to complete an online evaluation. Please take a couple of minutes to do so. Your responses will help us to plan future broadcasts in this series and improve our technical support. So now, we are ready to roll. Our first panelist is Mr. Todd Lewis, the medical home and transition program manager for the Arizona Department of Health Services, Office of children with special healthcare needs. Before joining Arizona's health department, Todd was the special education teacher for a local high school district. He has also provided consultation to a wide range of public and private agencies and organizations working with families and children with special healthcare needs and developmental disabilities. Todd will discuss Arizona's Tsunami program. You can type in questions at any time during Todd's presentation. Todd.

TOD LEWIS: Good morning and good afternoon. Again, I would like to welcome everyone. I'm Todd Lewis and I work for the Arizona Department of Health Services, Office for Children with Special Health Care Needs. We have developed over the course of several years something called the Tsunami program. What is the Tsunami program? It's really a statewide network composed of youth with special healthcare needs and families with children with special healthcare needs. Many of these individuals work alongside staff in order to build a more family system of healthcare. The key component of this network is training and leadership development. We provide training and leadership development through a variety of sources of the raising special kids is a family information network here in Arizona as well as family voices. Also what is the Tsunami program? They are compensated for their expertise, time and expenses. We've been able to carve out money set aside for -- to pay the youth and families. They're compensated \$12 per hour that comes out of our block grant monies. Again, the Tsunami youth and families are provided to training to their services related to Office for Children with Special Health Care Needs. We have family members as well as youth that participate in strategic planning meetings for the office and the various sections within the office.

As well as activities related to other agencies, Department of education, governor's council on developmental disabilities and the governor's council on injury prevention. Who are children with special healthcare needs? In Arizona this has been defined as any child have been diagnosed with the chronic disease. Also their condition is health related

functional limitations for regular activities of daily living and also has required for the past year or will require for more than one year health services beyond those received by the average child. Who are Tsunami youth? Many of our youth and families come from -- we have four regional clinics, specialty clinics that provide medical services for children and youth with special healthcare needs up to age 21. Those are called children's rehabilitative services. Those are located in YUMA, Flagstaff, Phoenix and Tucson. There are eight teams located across Arizona in urban and rural areas. Our parent groups raise special kids. And family voices. Several of the youth groups, best buddies has a strong presence in Phoenix as well as some of the youth groups from the high schools. Also non-profits such as southwest institute for families and children with healthcare needs. Family centered involvement.

The main reason that the Tsunami program was developed was in response to a need for family involvement throughout the office in our activities and strategic planning. The first principle that we have adopted for the office, parent/child involvement which is meaningful involvement of children, youth and families in the development and planning and implementation and evaluation of programs and policies of the system of care. Next. Partnerships and collaborations. This is really key to our Tsunami program and one of the larger elements of the program. Effective policy and service delivery systems are best developed through relationship development and building on the strengths of existing systems and communities, partnerships and collaboration within the Arizona Department of Health Services and will it be defined in all of our work with providers and other systems of care. Many of the community development teams have multiple parent leaders. These

parent leaders are also partially funded through the Tsunami program and work with the different levels of hierarchy with the Arizona Department of Health Services as well as other agencies.

Family centered system of care. Children, youth and their families are more able to meet their needs when they're supported within a system of care built on parent and professional partnerships and community based approaches. Many of our grants involve Tsunami parents and youth currently. We're working on a champions grant we received in January to develop a parent and youth institute curriculum and training. All of the -- we have 11 parents and four youth that are currently writing and reviewing that curriculum and we plan to have our first training in August. That curriculum includes leadership, strategic planning, community development, mentoring, communication and administrative responsibilities. Other examples of past, present and future Tsunami work are community development and assessments. Physician resident training program related to medical home and transition, youth leadership, curriculum and document development and training for providers.

And last but not least is the contact information if anyone has more in depth questions for me. This is a very quick overview of the Tsunami program because it really -- I want everyone to be able to see an example of some of the work that we are able to put out there and actually Turner is going to present in a little bit and I would like to preface her presentation. Her presentation is an example of some of the things that our office can advocate for or help youths to advocate for. Ashleigh's presentation has a very personal

meaning for her she advocates personal connection but also an example of how she has been able to transition into many of the obstacles that she has faced when trying to transition, so her presentation is an example of the barriers and the changes that occur because of her life and this will be explained better than I can ever hope to do in just a moment.

TRINA ANGLIN: Thank you so much, Todd. Could you please formally introduce our next speaker, Ms. Ashleigh Turner?

TOD LEWIS: Our next speaker the Ashleigh Turner. Ashleigh is 17 years old and recently graduated from high school here in Phoenix and she'll be attending Arizona state university in the fall. She is a long time member of the Tsunami program, almost two years now. And she advocates for us out in the public on different issues. She's a member of the governor's council on chronic illness and disability issues. And here she is.

ASHLEIGH TURNER: Good morning, good afternoon, everybody. I hope I don't have too much of a radio announcers voice. I am actually 18 years old. I had a birthday. My name is Ashleigh Turner, like I said, and I'll be talking to you guys about new driver's safety initiative. Something very close to me and something that you will obviously see that has a very profound meaning. For many people, for ages 15 and over a written test is all it takes to get a drivers permits. No experience is illegal to get a driver's permit. And responsible driver is required to be in the passenger seat. However, on times where the new learner panics, it's often difficult to control the car to reach over and take over. For many teenagers and inexperienced drivers in general they do not get the proper training

for the various driving conditions. And the motor vehicle association, MVA, has done some studies on this and has found that motor vehicle accidents are the leading cause of death for 15 to 20-year-olds.

In 2002, 3,827 young drivers were killed in motor vehicle accidents that occurred and an additional 324,000 were injured. And the fatalities for this age group actually rose 21% in the past decade. And police report crashes for its age group costs taxpayers \$40.8 billion in one year. These problems are links to inexperience, risk taking behavior and often immaturity. And I had an opportunity to speak with an administrative specialist at the high school district that I attend about driver's ed. She said it used to exist but since it was very costly and the school district doesn't get as much funding as it probably should for this kind of program, it was discontinued. And she said that they really didn't bring it back because they haven't -- they haven't really pursued it in many years. And the reason this is so important to me is because I was in a car accident when I was 15 years old. I had just gotten my permit. And I was driving with my family to Houston and on our way back from the fourth of July vacation we got into a car accident and how the accident happened is I was driving and I was passing up a diesel and I somehow lost control of the car. I don't really remember how. I know I did. It is suspected that inexperience had something to play with that. As a result of my panic and inexperience, I lost control of the car and the car rolled twice and when that happens you can see the picture, it's not very pretty, the roof caved in and caused a compression fracture to my neck. As a result I am now a C6-7 quadriplegic.

Ever since then I had to learn how to do everything differently. I now had to deal with insurance companies that I never had to deal with before and I had to -- I had to pay more attention to my medical situations, and I also had to become an advocate for myself. And through the Tsunami group I was able to learn how to speak effectively to people to convey my needs and wants. And help others to become their own advocates because you don't really have a manual to deal with spinal cord injuries or any other disabilities. It is like an individual thing that only a person with experience can understand. As a solution to this problem that I underwent for the lack of driving experience, I proposed that we -- that the high schools reintroduce driver's education for high school students wishing to get a driver's license. I believe the class should be mandatory, not something that kids can pass away like just blow off. I believe it is something that would be really important.

These classes will include how to control a car in different conditions. The effects of driving while fatigued or under the influence of drugs or alcohol or anything else that may influence driving and a virtual reality off-campus behind the wheel driving and presentations by Department of Transportation officials. I believe this is really important because it will actually add relevancy to the class, not just something that the kids have to go to. And the process that I believe we should take is before being granted a driver's license, students are required to take and pass, not just like I said blow it off, a full semester of driver's education including behind the wheel training. And the Arizona Department of Transportation or any Department of Transportation participating in this class will form a curriculum if one does not already exist, consisting of lessons essential to operating a vehicle safely including road hazards, weather conditions and other situations

that may be catalysts for disaster. And for students, it offers a great understanding of motor vehicles and they get a class credit so any class credit is great. Lower insurance rates with less accidents insurance companies will trust their drivers more and therefore give them lower insurance rates and they'll be less likely to be injured or killed in avoidable accidents and they will essentially bring back better drivers. And incentives for the public are less traffic jams due to the accidents caused by youth. There are quit a bit of them as my statistics showed.

There will be a lower risk of car wrecks and lower insurance rates because they don't have the worry about a little kid hitting them -- I mean a teenager or inexperienced driver, I should say. Less innocent fatalities and less taxpayer money spent to clean up wrecks. In 2002 \$40.8 billion was spent from taxpayer's money to clean up these accidents. And like I also said in the long run better drivers. And certain issues to examine. This is something that may, you know, be a problem. Is the high school districts and whatever state need to work together to teach the classes and the Department of Transportation -- they need to grant those people who pass the class a license. They need to work together with the state. And Arizona or any state works with insurance companies to give good drivers rate discounts and also funding for these programs. That's been a big problem.

And also getting students into this. They may think it's corny or stupid or whatever but they really need to understand the importance of participating in stuff like this so they don't end up, you know, like a quadriplegic or dead or anything like that. And I have actually

been given inputs from many people, including an officer of the Phoenix police department and numerous instructors from north high school, that's in the Phoenix union high school district and our senior English class at north high school also and also I have gotten statistics from the national highway safety administration, the national Center for statistics and analysis. And what has really helped me to get to where I am to be such -- I don't know if I'm an effective speaker, but be able to do things like this, to participate in programs like these where I'm allowed to and able to be an advocate has been through the Tsunami group.

I have just become independent. I have been able to take classes from Office for Children with Special Health Care Needs and the Tsunami group and activities through SWI and ASU to become an advocate. I use that word a lot, but I will. And through those programs they've allowed me to do -- to become a better person. So that's my presentation and I thank you guys very, very much.

TRINA ANGLIN: Ashleigh, thank you very much. We're moving onto our third panelist. Dr. KATHY BLOMQUIST who serves as co-director of the healthy and ready to work national center. She has a broad background in nursing that includes public health nursing, school nursing, as well as teaching nursing as a member of the faculty in conducting both research and program evaluation. Kathy has held several positions with the State of Kentucky, the focus on transition for youth with special healthcare needs. Kathy's presentation will discuss healthy and ready to work data, what do we know and

what can we do? Remember that you can type in questions at any time during her presentation. Kathy.

KATHY BLOMQUIST: Thank you, Trina, hello, everyone. What I would like to do today is look at data about children and youth with special healthcare needs and then use the Kentucky healthy and ready to work project data and activities as an example of what we can do to work with families and youth to improve outcomes. On slide 2 we see information about children and youth with special healthcare needs. Todd gave us a definition of who children with special healthcare needs are. We see from the national survey of children with special healthcare needs there are about 10 million children and youth under 18, 13% of the population. We see from other groups that anywhere from 6% to 30% of young people are considered children with special needs depending on the criteria used. 1 1/4 million children are served by agencies and many are S.S.I. recipients and another 700,000 between 18 and 29 that transitioning age who are on S.S.I. We do want to remember that life on S.S.I. is life in poverty.

On slide 3 we see some sources of data for youth with disabilities but let's look again on slide 4 and see the gateway to the data, the healthy and ready to work national center website. This website has sections on systems and services, youth involvement, healthcare and tools and solutions. And each section has a data to know section where you can find information about youth with disabilities. On slide 5 we'll look at the desired outcomes related to transition. The MCHB Division of Services with children with special healthcare needs have grants including screening, family involvement, medical home, insurance and community organizations. And the sixth is transition to adulthood. Topics

for data collection under this block grant performance measure include the systems development for healthy and ready to work. Youth participation in decision making. Accessible and affordable health insurance, medical home and transition from pediatric to adult healthcare and then education, employment, recreation and independent living. It's what we call having a life.

On slide 6 you see some ways we can use data. It's a good idea to plan for the data that you're going to be using before you collect it so you collect it in a form that you can use. Look at the status of your particular population in your state. You might want to look at youth over time. Different groups of youth cross sectionally or one group of youth over time. Pre-and post intervention outcomes or data and might want to compare results or status among populations or age groups to look at gaps and changes over time. On slide 7 let's look at a healthy and ready to work project. The Kentucky project. Kentucky teach. It was funded by MCHB from 1999 to 2003. Each of those years we did a survey of all of the graduates of the Kentucky commission and Shriners' hospital for children when they were discharged when they were 18 to 21 years old. It was a mail survey sent 6 to 18 months after discharge. The survey form is 10 pages long with fairly large print and mostly check boxes.

We sent personal letters to each young person and for those who did not respond to the first mailing we sent a second complete mailing and for each of these mailings we offered McDonald's coupon as an incentive to sent the surveys back. We did a two-year follow up for the first two years of the survey. The young people that returned the surveys two us, a

four-page follow-up. What did we learn? In terms of our survey of graduates this was the December 2002 results I'll present and give you some comparisons across time or with the two year follow-up. Our response rate was about 50%. It varied from 45 to 52% across the years. Gender was always more highly female than male. Mainly females return surveys for often than males. Race was 90% white which is close to what Kentucky is. Age was 21. 61% reported being independent in their A.D.L.'s and it was a variety of diagnosis, 21% quite severe. 23% with vision problems. 19% hearing impaired and a variety of cardiac, cystic fibrosis and a variety of other conditions. Most of our families and young people were poor in that our Title V agency has an income cap and many of the families that go to Shriner's are poor also.

What did they learn about healthcare access in youth? 86% of our responders have a family doctor compared to 75% of 18 to 24-year-olds in the Kentucky from the behavioral risk factors survey. This is good. We found a 28% have a specialist. This was of concern to us. All of these young people were discharged from specialty services. 22% had not visited a physician in the previous year which is the same as 18 to 19-year-olds in the national health interviews survey. 40% had been to the emergency room in the past year compared with 25% of 18 to 24-year-olds nationally. This is of great concern in how they're using it. In terms of reasons for going to the emergency room, 25% went for trauma and some of those were car wrecks, as Ashleigh described. 25% were pregnancy and miscarriage issues. 25% were acute issues. And 25% related to their actual diagnosis. The question is did their physician send them to the emergency room? Under health insurance status, we found that 25% of our young people have no health insurance

but this is the same as 18 to 20 year olds in Kentucky. 45% were on Medicaid and 7% had insurance through their own work and 23% through their family insurance. So that 30% was family based as compared to 53% of American youth.

Our two year follow up showed some improvement. 18% now had insurance through their own work. So that was a great improvement over the years. Over the two years. On slide 11 some general population statistics related to insurance and young people. The percentage of young people with no health insurance the first year after graduation is 40% for college graduates and 50% for high school graduates who don't go on to school. 40% of young people between the ages of 19 and 29 will be uninsured during a year which is double the rate of adults 30 to 64. And this is due to young people with part-time work, entry level jobs and possibly waiting periods in their jobs. My son worked for the Arizona game and fish and he did not have health insurance for the first six months that he worked with them.

On slide 12, healthcare access, what should we do? Graduates have doctors but they go to the emergency room at double the rates of young people nationally. What can we do? We want to teach early detection so crisis don't occur. We want to teach and practice contact with their physicians. The concept of a medical home. Having a doctor who knows you and that you know and can contact when you need help. Teaching young people how to use insurance responsibly and planning ahead for healthcare and insurance changes that will happen around the age of 18. Health perceptions, what did we find about health perceptions? We found that 43% of our young respondents say their

health is excellent or very good compared with 51% of Kentucky youth. We found that 23% say that their health is fair or poor compared with only 7% of U.S. and Kentucky youth that are 18 to 24. And this was about the same in our two year follow-up.

Those health perceptions did not change much as the young people got a little older. We found that 41% said they were sad, lonely, depressed a lot or sometimes compared with about 20% of the general population of young people. In relation to risk factors, we found that 45% of our young people are taking medications. We found that 23% smoke as compared to 35% of young Kentuckians. 13% drink alcohol compared to 18% of high school students. 18% have children and 47% of those mothers are not married compared with 30% of pregnancies in Kentucky. Kentucky has a high unwed mother rate. We talk to teach about medications, health related to smoking, drinking and drugs and teach about sexuality and promote mental health. There could be a collaboration among school programs, public health programs, among mental health programs. Children and youth with special healthcare needs programs.

Volunteer work, social interaction and community involvement with great meaning. Our children and youth with special healthcare needs need to be included in all of these kinds of programs to reduce risk factors and promote mental health. What about education and work? We found that in 2002 18% of our young people with special needs had dropped out of high school but this was an improvement over the four years of the grant when it started at 25%. 44% of our respondents are working. And this was maintained about the same across the four years of the grant which was very disappointing to us. However, the

unemployment rate in Kentucky went from 3.5% to 6% over that same time period so we actually maintained our employment during that time. The news was good as far as follow-up. The two-year follow-up. 49% were working but half were working full time. What is disappointing is that 40% of the young people are not working and not in school.

A few of these young people are parenting, are home parenting but there are an awful lot of young people not engaging in meaningful activity. 36% of our youth were on S.S.I. and 18% of those people on S.S.I. were working and we found that 28% of our young people had been or were currently clients of V.R. Vocational rehabilitation and 54% of those young people were working when they returned the survey. We found that of those not working, those 50 some% that were not working. 67% of those young people do want to work. We need to find ways to help them get to that goal. What can we do related to education and work? We can encourage expectations for families, for home chores of young people, young children with special healthcare needs. Treat them as normally as possible and have the same expectations as they do for their typical children.

We want to encourage expectations for work and pacey white has found there is a critical age of 11 to 13 where young people get excited about the prospects of working and if they can get some training and have high expectations at that point they will go on and work. We want to support youth aspirations for the kinds of things they want to do. We want to plan for driving and transportation and we want to resolve toilet issues. These are the T and T issues. Transportation and toileting which help people do well in education and work settings and social situations. We want to find opportunities for participation in work

in the community. We want to refer to vocational rehabilitation and we want to teach about S.S.I. work incentives. Since the A.D.A. was passed in 1990 people with disabilities are not working more and some of that is because of the S.S.I. disincentives and lack of safety nets.

There are work incentives in place that young people should know about. What about independent skills? We found that 77% of our young people use computers which is very positive. 57% use the internet. 55% drive compared with 65% with youth with disabilities in other studies and 90% in the general population. 44% of those who would like to work says they need transportation. Transportation is a big issue in independence with our young people. More information on independence. 59% of our respondents live with their parents. It isn't as bad as it sound. 56% of men and 43% of women live with their parents. The current age for moving out of the house is about 26. We also are very aware that this is a cultural issue and an issue of poverty. 16% were married or ex compared to 10% of men and 18% of women in the U.S. census. We talked about the unwed pregnancies. As an example. 72% go grocery shopping compared with 55% of those with disabilities and 83% of Americans without disabilities from the national organization of disability Harris poll in 2000.

What can we do to promote independence? Help these young people develop computer skills. We want to plan for transportation. We want to help young people practice housekeeping skills for independence. Practice social skills. Practice self-care skills related to their health issues. Practice community involvement. Help young people get

involved in the community early on. And practice that throughout their teen years. Then we want to help improve the socio-economic levels of families with education, work and healthcare because if opportunities are improved for the youth if the family economic situation is improved. It is our belief that health affects everything. If you're not healthy you cannot work, you cannot be independent and cannot be involved in the community. Conversely be involved in the community promotes health. So we encourage that tremendously.

I would like to talk a little bit now about how Kentucky integrated transition into its system. We were lucky enough to have grant funding for about eight years to do transition integration and these are some of the things that we did. We changed the philosophy and mission of the commission. We have an executive staff focuses very much on transition and on parent and youth advisers and the actual commission, the advisory group has a parent and youth member. We had one of the first negotiated performance measures related to transition and this forced us to report on what we were doing related to transition activities. We built transition into the care coordination program that was going on and we were develop a web-based data and information system and patient record system at the same time we were doing the transition programming.

Currently this web-based system includes a checklist which helps staff focus as they work with the families and youth on the transition building blocks. The transition checklist has issues starting at age 2. Other changes. Our expectations for the staff. We built it into quality review of records. We have regional managers who are resources and every one

of our offices has a transition liaison who is our point person for any transition issues. And these people meet together on a regular basis. We've done lots of staff development and we have a professional parent on the staff. We also have had youth working with us off and on in our project and in some of the district offices and they work with newsletter and data entry and working with families. We've found that we as nurses and social workers have a lot of disempowering activities and we've learned to stop some of those and raise our expectations for what young people with disabilities can do. We raise the expectation. We started early and developed what we call life maps which are screening questionnaires starting with the parents filling these out for young children and then the youth filling them out for themselves.

These are what have become our transition checklist. We focus on many transitions including the early intervention to school transition which is so important. Helping families learn to negotiate systems as they move through the different systems so that when transition to adulthood comes it's not as confusing and scary. We've developed work camp and independence building workshops and experiences and worked closely with our centers for independent living which I encourage you to work with. We've been involved in disability mentoring day. In October we've had 100 youth working in families -- factories and offices and with a mentor and this has been an incredible school collaboration for us. These people are out of school as they do this and build their experience into their school portfolios. We developed a Girl Scout troop.

Every meeting has a health component. Our collaborations with the community. We've worked more closely with physicians in the community and all of our regional staff have visited most of the physicians in their areas offering them resources and telling them what we can do to help with specialty care. We've had articles in the local medical society newsletters. We've worked with independent living centers and employment people. We worked with the schools and we're working with them more all the time. We're involved in health education planning with curriculums. We're involved with special education co-ops. We're involved with the family resource and youth service centers. The children are in school and that's where they can learn the transition skills that they need. We try to see that health is built into every individual graduation plan that young people with special needs have.

Involving health promotion and the transition for all is our idea. We have parent groups. We work with family voices and P.T.I.'s in our state with leadership development. We have developed a summary of services which is a four-page listing of services with phones and websites in categories of health, education, work and independent living and we have a website listed on the slide and many of these things which I've talked about the transition checklist, life maps and four page listing of services are on that website and we encourage you to look at that. Many other health-related handouts and things you might find helpful with transition. Some nuggets to take away.

Transition is a new focus. It isn't new programming that necessarily costs very much it's including and focusing differently on building blocks for transition. It takes a dedicated

staff. Our transition liaisons in each of our regional offices are people who volunteered to do this who were interested in outcomes for the young people and wanted to know more about the resource. We suggest you infuse health into already existing groups. Don't try to develop new groups to work with, particularly education groups. We encourage interagency collaboration and it works best when there were specific programs to work for. We did the pediatrics medical home training which involved 30 agencies. The next year we did a family professional camp weekend where the same groups got together to do the planning and we've been involved in health curriculum development for the schools.

Lastly, we encourage you to start early. Transition takes lots of time for families and youth. We need to have high expectations for what is possible and to help young people follow their dreams. On the website there is available for you -- there are available for you two documents. One is called 15 things Title V programs can do and the other is building transition into the performance measures. We encourage you to look at those for specific ideas on other things you might do. At the end of the Power Point that is on the website are also some other resources for you to look at. Some web resources. In conclusion. We want you to look at the outcome. Quality of life. On healthcare access in youth. On health insurance and informed decision making by youth. Also on meaningful activities through education, recreation, independent living and work. And the last slide shows you our health and ready to work team and our contact information. Patti will talk more about the national transition initiatives. Thank you very much.

TRINA ANGLIN: Thank you, Kathy. Our fourth panelist is Patti Hackett who serves as the lead and co-director of the healthy and ready to work national center which is headquartered at the academy for educational development in Washington, D.C. She telecommutes from Florida. She provides technical assistance to the Maternal and Child Health Bureau, state Title V programs and family and youth leadership organizations. Patti credits her son, Glen, who was technology dependent, with providing her with insight and stimulating her creative vision. For example, Patti coins the phrase healthy and ready to work. She'll conclude the formal presentation section of our panel by discussing, "What's Health Got To Do With It?" everything. Remember you can type in questions at any time during Patti's presentation. Patti.

PATTI HACKETT: Hi, everyone. Glad to be with you today. As the title of the presentation is "What's Health Got To Do With It?" It's everything. If you aren't healthy you can't participate. I'm Patti Hackett and I'm with the healthy ready to work center. In this presentation I'm going to do a short overview of the federal mandates. Although you may be aware of them I think it's important to remind others in our partnerships who might not be. We do things for a reason. We'll talk about the healthy ready to work initiative and how it can be helpful to you in your national performance measures. Then the last part will be six case scenarios of youth who have or do not have insurance and perhaps opportunities we can be more helpful. In the federal mandates there were two that are critical into what we do today. The first one was the over 89 which talked about community based systems and like which is which we all know and live and dream and

breathe by is the 2010 objective 1623 which talks about delivering quality healthcare to children and youth to special healthcare needs.

In full integration, slide three, the Supreme Court decision set a series of events to really start for the first time in our country civil rights on healthcare services and community integration and that was the Supreme Court decision. That then incurred -- made the president's new initiative come up. This was under President Bush in the second year of office. He encouraged a convening of all the agencies that provide services and PWD on 5-4 means people with disability. In that report he targets solutions and barriers that HRSA, MCHB will be responsible for. Item 4 is transition to services to adulthood. National performance measure 6 is transition to adulthood. It's adult healthcare and independence and quality of life. I really would like to see a generation of taxpayers instead of tax recipients.

Slide 6, there are five elements Kathy referred to. If these pieces are in place transitions has the possibility of being successful. Systems development. Youth to be informed decision makers. There needs to be access to quality care and insurance. There needs to be a place for medical home and the handoff to adult healthcare and all other education, employment, independent living and recreation. You need a full life. Not one just about medical issues. Health and ready to work center is a virtual center and our team is located in several spots. The lead is Dr. Fountain with headquarters in Maryland. Two women at the center of education and development. Some of you may know that agency. In Minnesota C.C. Chaplain whose expertise is family and youth involvement.

KATHY BLOMQUIST is from Title V in the State of Kentucky and evaluation, care coordination, medical home and just a great resource and solutions for Title V. Betty Presser some may know. My expertise areas would be national initiatives, inclusive education and health insurance. Phase 1 and 2 for healthy ready to work projects are indicated in colors. The blue is phase one. Red phase two. Kentucky and Iowa having had both phase one and two. In the current grants each have a skill area that they have an expertise area. Arizona project is medical home. Iowa employment, Maine is interagency partnership. They were the first Title V agency that had a paid youth advisory council. Mississippi is independent living. Wisconsin does a wonderful job with regional care and community base issues. Youth for surveys in many places different times by the pacer center and by the new national youth leadership network and they are saying to us here are four issues that mean something to them on health. What are they going to do in the case of emergency? How do they get healthcare insurance?

What can happen if the condition gets worse? Learning how to stay healthy. All those are targeted to youth of special healthcare needs or kids who don't have a diagnosis at this time. Transition and screening. We think of screening several times, it should be going on along all along to make sure we're optimizing the performance level of kids and youth. The screen for life and health transition needs. Is he can temporary disabilities. Our kids will age differently because their bodies are used differently. We want to make sure they don't age out of issues. Transition and family involvement. We talked about family centered care but now youth involvement. They need to be -- services need to be

delivered not only just for what families wish but are we listening to the youth who are the recipient of the services. Youth leadership we need to encourage opportunities that have development on a leadership level. Aging without jeopardy.

So often we've done a great job under the age of 21 but fearful of what happens after 21. A lot has been said on this. I'll talk about three issues that we need to think things more comprehensive. It is not just about the special healthcare needs it's about all the things that make life meaningful and allow you to have full participation. Hygiene. You can't smell bad if you're going to go to work. Nutrition, you need stamina. Exercise and sexuality issues. Having sex and being safe. Mental health, aging issues, assistive technology. Have we had the hard discussions with our youth? Who do they want to be their spokesperson if they can't be their own spokesperson during a health crisis and advanced directives. I would suggest doing this for a family plan. What does the family think for each other.

In 2001 MCHB funded a consensus building group in a document that came out that was endorsed by the professional groups noted above on this slide 16. Talk about a call to physicians. They looked at transition. If you go to 17 the key points of these to remember that an individualized healthcare transition plan should begin at 14. They line it up at 14 with the I.E.P. but it could be done at a much earlier age. Preventive and primary care guidelines and needed to always take a look at transition coordination. They recognized it needed a health funding component. It's a hard thing when you've been with a

pediatrician for 18 years who has saved your life to let go and think about a physician who may or may not want you and put your life in their hands.

We hope this will make it more of a seamless, painless system. The last part is transition and community based services. A picture of this woman is Dr. Linda Mona. She used a pass plan to pay for her van that allowed her to go to work. She is married and now has a young son. The lessons learned in community based system that we heard from phase one, coordination is essential. Having a transition coordinator if you can fund it, do it. Collaboration, it's not a solo act. It has to be among all the other partners who provide services. School nurses. I wish we had more. When they're there they do it right and make kids have the opportunity to be in school and not be absent. Education, our kids are in the education environment much longer than with their parents. We need to partner more to recognize health is a direct relationship to performance. 21, the aspirations and expectations.

We talk about expectations for providers. What we learn from the healthy ready to work project in Maine it was supporting the aspirations of youth. No matter what they want in life they should be supported. It could always change but they should have an opportunity to try. Youth centered. Too many times adults are making decision and youth who have been in the system a long time are quite savvy. We need to listen to what they're saying and involve them early and have them co-sign procedures at an early age. At age 10 or 11. Those who are unable to sign think about creating a signature stamp and they can direct what services and when the stamp could be used. Self-determination goes back to

supporting aspirations. The person is an individual and their needs and wishes should be honored and respected. The part that usually stumps everyone, we have kids getting healthier, kids living longer but the big problem is can they keep insurance?

Who is going to pay for the heavy ticket items without insurance? It's not impossible to maintain health insurance. On the next series of slides are six case studies of real people with real issues. Some are working and some aren't. I'm not going to read each slide but I'll share a little bit about each person. The first person, Jim, is from Indiana and from a very early age he wanted to be a pilot. Having a diagnosis of cystic fibrosis and low altitude low oxygen isn't compatible but made it work. A physician said early after a devastating diagnosis what do you want to do in 20 years. Here it is at age 24 he's married, works as an air traffic controller and he does have a pilot's license and able to match his dreams. Travis lives in New Mexico. His issues were progressive. He had a hearing impairment early on. The family and he were informed it would get worse. He learned signing early. He currently has a job at home depot and his insurance is through his employer. Eden does not have insurance because somewhere along the line people forgot to mention to families about maintaining private healthcare when they could.

When families become unemployed paying for Cobra is very expensive and you don't have portability when you have a lap of insurance in 63 days. Maya is now 22. I call her my Helen Keller gal in a walker. She is deaf, blind and has cerebral palsy. The State of Illinois paid \$45,000 to have her go to the Helen Keller institute to learn independent skills. She came back to the state and the state had no capacity to provide any services to her

for after that. However, agencies currently are collecting money to provide services but they don't have community capacity. So Maya sits home and she's not a happy camper. Her insurance issues are through Medicaid. Mac happened to be -- this is his fiancé. Mac works part-time. He does have a support coach on the job. He has Medicaid.

The last slide happens to be my son. He's the person as Trina mentioned earlier who inspired the healthy ready to work. I brought him up early if his mind was going to work his butt was going to be earning money. He was able to use voice activated computer. For those listening today if you had heard Glen. You can see he's quite complex. Would you have supported the idea he wanted to be a professional horse racing handicapper? He ended up fulfilling his dream. He's one of six people in the country to do this and he worked until the day he died. He paid taxes. He had too many winning tickets for us. After we heard the diagnosis he said live the life you would have just realize you'll have more equipment. Our team is a team. Kathy identified our players. If you can't remember our names the easy way is our website. WWW. HRTW.org. Use the search engine. If you can't find what you want. Email us. Thank you for your time today and look forward to your questions.

TRINA ANGLIN: Patti, thank you so very much. We've had four really outstanding presentations and now it's time to move to our discussion period and some of you have been writing in questions as you heard each presenter. Please continue to do that so we can include your questions in our discussion period. Panelists, feel free to ask each other questions, too. I'm sure you've heard new ideas from each other. Our first question is

directed to Todd. In is a real concrete one. Todd, how many youth are in the Tsunami program and what are their ages and what are some of the examples of their special healthcare needs? This question came from Maine.

TOD LEWIS: OK. At last count I believe we had 24 youth all over the state. That doesn't include -- we have a telemedicine, telehealth grant projects and they're recruiting youth to work with them in their various activities. Right now in our office it would be 27 parent leaders is an additional 25 to 30. So we're at about 50 to 60 total parents and youth Tsunami advocates. There is a huge range of disabilities.

Spina Bifida, cerebral palsy, a few with asthma for our asthma program. Metabolic disorders, TBI, we have one gentleman with autism. Spinal cord injury. Sickle cell and a few others but off the top of my head that's about it. That pretty much covers the main group.

TRINA ANGLIN: What types of challenges has the program faced?

TOD LEWIS: The biggest challenge that we face is figuring out how to -- we have a lot of travel involved because our state is so diverse geographically we have Tsunami families in the four corners. Paying for travel is a huge issue because of the way our state is and like many states, they have to pay for travel up front and then be reimbursed. As families they don't necessarily have the resources to do that for extended stays and they can't necessarily with other family obligations that type of financial burden really isn't fair so we've really had to push the limits of bureaucracy within state government to try and get

some kind of minimal turn around. The shortest we've been able to do it is seven days which apparently is really good thing. I think seven days is about six days too long. But that's one of the major problems. Also including X amount of dollars in our yearly fiscal budget, it varies from year to year and we have to defend it vigorously each year. Our Tsunami funds from last year to this year are drastically different so we'll have to go out and look for more grant funds to supply money for that, for those activities.

TRINA ANGLIN: Thank you, Todd. I was wondering whether any of the other speakers have some questions for Todd and the Tsunami program?

>> I have a question, Patti for Ashleigh. As you receive skill care on becoming more independent now that you're quadriplegic what are the things you find helpful tips you would like to share with others that you wish you knew beforehand?

ASHLEIGH TURNER: I would just -- one thing that I have really learned is that in order to get help you have to look for it. It is not just going to come to you. And I have had to really ask people and become sort of a pain in my physician's back side to get information and to really become a part of the disabled community, not just somebody who is disabled, you know, to actually get out there and do -- participate, just be a person who is in it, not just someone who has to deal with a disability.

TRINA ANGLIN: Having connections to the community to represent your needs is helpful and access to information?

ASHLEIGH TURNER: Definitely. Definitely. Networking and helping out new injuries is a very good thing, too. Sorry.

TRINA ANGLIN: I think you did a nice overview. I think so many times providers are worried they should give more information or let some time pass but I think you tell us they want their life now. They want most of it back. I think what you said was right.

ASHLEIGH TURNER: Yeah, but sometimes it gets kind of overwhelming because we don't really know what we need at the -- sometimes we know what we need but we don't know the whole picture. We're still learning and we're still dealing with the new situation. So finding the balance between -- between information given and information absorbed and needed at the time I think -- it's trial and error, but I think so far it's finding that balance.

TRINA ANGLIN: Thank you.

ASHLEIGH TURNER: No problem.

TRINA ANGLIN: Ashleigh, a kind of similar question. What kinds of things that adults do or did have been helpful to you as you've been developing your safe driver initiative and conversely, what kinds of things that adults have done were not very helpful to you?

ASHLEIGH TURNER: One thing that adults have done that have been really helpful to me to get input and support on the subject and to really develop it is to have their input -- or to let me in on what they think and how like say when they were in high school, if they had a driver's ed. program or not, how well it helped. And they have turned me onto some sources I was able to get information from and one thing that is kind of been a hindrance, I guess, is they always question me about funding. Well, where are you going to get the money from? Where are you going to -- who is going to be teaching the program? That's just another class that the state has to fund and has to provide resources for. But for the most part people have been very supportive towards it. They have seen many car accidents, the traffic out here is getting horrible because people are terrible drivers. They go and they don't really have much training. All they have to do is, like I said, take a written test and that doesn't make up for the actual experience needed.

TRINA ANGLIN: OK. Right now it seems like we're focusing on questions for Todd and Ashleigh but I thought it might be a good way to organize our questions so there are plenty of questions for Patti and Kathy as well. Here is another question for you, Ashleigh. It's kind of a personal one. That is, how did your motor vehicle crash and what happened to you and your family change your view or perspective on people who have disabilities?

ASHLEIGH TURNER: Oh my gosh, that is -- that's a 180. I completely changed. Before I was a normal high school student. I was obnoxious, loud, I was a freshman. I was somebody -- I used to see people with disabilities and I didn't really -- I wasn't one of those people that insulted them or made fun of them. But I thought of them as kind of weird and

different and I didn't hang out with anybody who was disabled because I couldn't really relate. My family really were much the same as I was. They didn't interact with them but they didn't reject them. But as soon as the accident happened, it seemed like the whole disabled community opened up and we had to learn to accept the disability and now it's -- when I meet somebody who is disabled I look for the person, I look for the full -- the -- not the disability, the actual person, who they are. And I didn't really do that before. And people don't -- haven't really done that with me until they really know who I am until they talk to me. And realize I'm a real person, not just somebody who is disabled.

TRINA ANGLIN: Thank you so much, Ashleigh. Todd, here is a specific question for the Tsunami program from a physician in Rochester, New York who would like you to explain how your program is able to bring about being able to work with physician resident training programs. How did you get their buy-in to be eager to work with you and the youngsters in the Tsunami program? At the same time that physician residency programs have a lot of other requirements.

TOD LEWIS: We worked through an organization called raising special kids. It's charged with -- part of a program here through the University of Arizona, that's the only medical school that we have in Arizona, and they have a satellite school here in Phoenix. And part of their curriculum is to go and do site visits and some other home health activities, and in order to do fulfill that requirement, the residency program, those that developed the program went to raising special kids and to us and worked with raising special kids to develop that program. And we are able to provide some Tsunami youth and families that

are part of the C.R.S. family and the Office for Children with Special Health Care Needs family. It's kind of a round about way of getting there but -- it's the raising special kids has a good job of making it get down and dirty realizing there are severe time constraints but understanding as part of -- it's one of their requirements and we've gotten a lot of positive feedback from that program and from our support of that program.

TRINA ANGLIN: Here is a general comment and a question that goes along with it. That one member of our audience feels that driver licensure should not be issued before the age of 18 and all following a period of intensive training such as what Ashleigh has suggested. And informed us that in Europe this is what happens in many countries, that driver training. I assume this is behind the wheel, takes place for a period of a good eight to 12 weeks and the testing for licensure takes place in high and low density traffic areas to see how the student driver is able to handle those situations. Someone wanted to know if Arizona has a graduated drivers license program because it has proven to be effective in reducing motor vehicle crashes.

TOD LEWIS: We have a graduated drivers license program just instituted a little less than two years ago. 18 you get your adult drivers license. There are -- you're allowed many fewer points in terms of for tickets, for accidents or speeding. And you can also be required to take additional education. But the education requirements for that graduated license are no different now than they were before they instituted the graduated driver's license.

TRINA ANGLIN: Here is a real specific question for Kathy. When you collected the information, did you find out what types of work or employment the youths in your survey had obtained?

KATHY BLOMQUIST: Yes, we did. It varied tremendously. It varied from Wal-Mart, which is a big employer out in the rural communities, to computer website managers, developers, things like that. In the two-year follow-up we found that we had a number of young people who had graduated and were teachers and nurses and going into business activities and that kind of thing so the range of jobs and occupations was really much, much wider than I had anticipated.

TRINA ANGLIN: Here is kind of a general comment that I think would be great if each of our panelists addressed if you have thoughts about it. And that is, the observation by a member of our audience that it seems unfair that we expect, quote, regular peers, youngsters who don't have major healthcare needs or disability to continue with school and training as to way to be able to increase their adult productivity but that in general we don't offer these opportunities to youth who have disabilities. What suggestions do you have to remedy this?

>> Well, I think, number one is we do expect youth with disabilities to continue with their schooling and training and many, many do. That's one way especially that with computers and that kind of thing that they can develop the skills that they need to work. Patti.

PATTI HACKETT: Well, 10% of the population that does graduate with a high school diploma will go on to college. Problem is maintaining the attendance sometimes because of health issues and insurance coverage is a problem. But kids perhaps won't be college bound but have great ability to have skill levels. Community colleges for over 25 years now offer transition programs that are funded by the Department of Transportation. One of the leading ones was IBM whose computer program and then they had an offshoot of one computer designed for the disabled. There are some technical training plus post secondary experiences with degrees.

TRINA ANGLIN: In your experience, are these programs more likely to be available to young people who live in urban areas or what about youngsters who live in rural areas or even frontier areas in our country?

PATTI HACKETT: There is a couple of thoughts. Usually the community college bases will appear in your all areas. Frontier folks may have to use telecommunications and website-based instructions. We live in a one-click world. Attending school is important. It doesn't have to be limited to on-site presentations. When you take a look at the State of Maine who provides laptops to all their 7th and 8th grade students they make sure they have access to online learning. There are lots of possibilities out there.

>> I agree. In our rural areas in Kentucky. The community colleges really do offer a lot of web base is becoming more important.

TRINA ANGLIN: Ashleigh, from your personal experiences because you are actually going to be a college freshman this fall. What types of expectations do you think might have been helpful from your family and from your school?

ASHLEIGH TURNER: I think the thing that helped me best is not to really treat me like I'm any different. I mean, I do have some combinations that I need. I also received a brain injury from this but it was minor, just affected my memory. But basically treat me like I'm a normal student. Give me the same expectations as they would normally do. But maybe make allowances for time and since I don't really have a mental disability, it's mainly just physical, and with fatigue and everything played into it, that's it. But I imagine it would be different for someone with a mental disability. But one thing that has really helped me, like I said, is to just treat me like I'm a normal student. Understand that I want to be as successful as the next person and I am more than willing to put the effort into it.

TRINA ANGLIN: Thanks, Ashleigh. We just got a really helpful comment in from a member of the audience. That relates to Patti's observation that for young people who, because of medical reasons might need to miss a certain amount of school, that it can be helpful to encourage youth with special healthcare needs to attend school on a part-time basis or to take a reduced course load or somehow to make arrangements so that the school itself has a good understanding of what those needs are. And as Patti also said that web-based instruction is available. Here is a real specific question for you, Kathy. That is, is your transition checklist available on the Internet?

PATTI HACKETT: Yes, it's on our website. The website that is listed on the slide there. The commission kids. It's [HTTP.CHS.Kentucky.gov/commission kids](http://CHS.Kentucky.gov/commissionkids).

TRINA ANGLIN: Patti, here is a specific question for you. That is the name of the person who said to you about your son, Glen, for him to be able to live his life and it sounded to me it was said to you as a baby?

PATTI HACKETT: The second day after diagnosis at nine months.

PATTI HACKETT: Live your life the way that you would have and remember that you'll just need more equipment.

PATTI HACKETT: That was the brace man, the orthotics. You never know. Some of the things we say to people when they're half listening, what sticks. And that really just helped create a different path and a different vision for us. We thought we had lost the dream and we put it back on the burner. Having grown up in Boston I thought my son should be in the Boston red Sox so I kept my optimism and we switched gears and he became a sports manager and later statistician.

TRINA ANGLIN: Here are a couple of questions that have to do with health insurance. One is as kind of a general one. How can we increase the number of people who have disabilities to actually obtain and to be able to maintain health insurance?

>> On a general one, again I'll direct you to the handout. It's insurance options for youth because there is quite a variety. If a youth who is prior to age 19 is on their parents' family plan, they can continue their healthcare coverage if they are a student or if they are what's qualified as adult disabled dependent child. It usually means they don't work. My suggestion is for anyone who has family health plans to declare adult disabled dependent. This one would assure continuity. In over 40 states there is a state statute that mandates all insurance coverage within those states have to have the provision. The student status one gets tricky. Many of the insurance companies want a full-time load and different seasons make things difficult to do full-time load. Two options is to get an override through the disabled student services to verified you're a disabled students and they accept part-time classes or my son's favorite approach was take some easy courses and get a soft C and do really well in the courses you do great in and get an A. There are several Medicaid blends. A lot of people aren't aware of the extended healthcare for private insurance. For Medicaid for kids who are currently on S.S.I. in all the ten states are the S.S.I. Medicaid are linked together, 11 states, there is a unique law called section 301 which allows a young person to continue S.S.I. and Medicaid if they're hooked into a vocational employment plan. Kids vulnerable may determine it at age 18 get them connected and keep the S.S.I. benefit but their Medicaid benefit until their employment training is completed. Hardly known, hardly used but it is in statute and you need to download it and bring to an S.S.I. office.

TRINA ANGLIN: OK. Here is a question from a pediatrician. That is, what tips do any of you have to help young people and their families with disabilities to transition from

pediatric to adult care? And the observation was given is that health insurance doesn't even pay for a consultation visit from the adult provider.

ASHLEIGH TURNER: Can I answer that question? This is Ashleigh.

TRINA ANGLIN: Absolutely.

ASHLEIGH TURNER: I find that mentors are one of the best resources forgetting the foot in the door and learning how to transition. I found that I actually had some mentors through an organization here in Arizona and they were very, very helpful in helping me to transition from being just a high school student to being a functional member of society, I guess. Mentors help a lot.

TRINA ANGLIN: And what would our speaker say to the adult healthcare system or to adult healthcare providers so that they themselves can be better able to accommodate young adults with special healthcare needs in their practices?

PATTI HACKETT: This is Patti. The pediatric and other providers under age 18 need to do a better job of making sure that their patient is very well informed and has been able to direct their own care for many years and can order supplies. They can call in their prescription. They take charge as much as they can. For the adult physician, they get overwhelmed by the thick files that pediatricians and hospitals love because it means a long life but a complex kid. A lot of the body systems affected by our youth are the same

ones experienced by the elderly. When we would present Glen I would say he had an age appropriate mind. He had a pediatric body. He only weighed 80 pounds but his health issues were all geriatric. When he hit the floor going from Children's Hospital to an adult care facility it took a little bit of learning but because he was well versed in patient directed care and had practiced the consent they respected what this little person on a ventilator was directing his care. Some of it is attitude. Some of it is civil rights. Other ones it's easy. It would be nice if pediatricians went to some adult healthcare meetings or join office buildings together and had an already established relationship.

TRINA ANGLIN: Our last set of questions has to do with issues for states. And Kathy, because you've had a lot of experience in Kentucky, what advice would you give or would Kentucky give to a state just beginning to develop transition programming and might not have extra money to do so.

KATHY BLOMQUIST : I think one of the first things that I would recommend is to have some sort of program. Disability mentoring day that they could be involved with which would start collaboration among more local agencies and have some success with some young people experiencing some transition kinds of things. The other thing that I think I would suggest is most states have a care coordination program of some sort and I would encourage integration of transition and transition building blocks into the care coordination program that they develop and that they already have in place. Some of the resources that we have on our healthy and ready to work website and some of the resources on the website with this webcast would be helpful in that way. I think those two things. One

specific thing where you could get your staff and young people that you serve involved in some transition activities and then another integrating of transition into whatever you already have going on.

TRINA ANGLIN: OK. And for any of our speakers, could you perhaps summarize what benefits a state might see if they actually were able to enact and then evaluate a comprehensive transition program? Have states been able to document any of these benefits?

KATHY BLOMQUIST: I think we're very early in having any sort of actual transition programs. I think some of our healthy and ready to work projects, which are involved with states, have some documentation. But in terms of costs and benefits I don't think we have the data we need yet. Patti.

PATTI HACKETT: I think the return on investment is what we're talking about. The amount of money we pay in clinics and services. Did it make a difference with kids? What we can tell you is the average length of time a young person, an adult is on S.S.I. is 30 years. If you think of living in poverty for 30 years drawing down a check no more than \$750, that's a cheap -- in over 30 years? I don't know, Kathy, I think ages ago—

KATHY BLOMQUIST: We figured if we had eight people go to work that wouldn't be gone to work without our program we more than paid for their S.S.I. and Medicaid for 30 years. Our project. The funding was more than covered.

PATTI HACKETT: I think that's the way we need to keep selling it. The alternative is nursing home care which starts at \$45,000 a year plus the S.S.I. benefit.

TRINA ANGLIN: And one last question before we wrap up our webcast. In addition to children with special healthcare needs programs in states, who are other potential allies. What other agencies and states would become powerful partners and good stakeholders?

>> The Department of education, schools, mental health programs, Department of Labor, the one-stops have an initiative for youth. They'll need health provider assistance to make sure kids can become employed. Department of Transportation. We find out a lot of the kids have all the places together but they don't have the wheels to get there.

TRINA ANGLIN: What about like state healthcare financing agencies?

>> Absolutely.

>> Some are being very clever with their home-based and community waivers but I think they need to have more input. As kids live longer and some may become more technology dependent the rules need to be a little looser. The homebound rule on people on ventilators need to ease up. Currently they can go to funerals and birthday parties a couple times a year.

>> We work close with the state to align ourselves with them when we're working on, you know, figuring out how to pay for care coordination and whatnot. With one of our focuses being medical home and transition together that has taken on more of a priority.

TRINA ANGLIN: Thank you so much to our really outstanding panel. Todd Lewis, Ashleigh Turner, Patti Hackett and Kathy Blomquist. We hope you enjoyed it and found it to be a good learning experience. We appreciate the technical support at the University of Illinois at Chicago and thank our audience members and generation of discussion points. Please register for the second remember cast of the series, searching for a path through bureaucratic systems scheduled for a week from today on Wednesday, June 30. Again you can register for it at www.mchcom.com. A link will appear automatically after the broadcast ends. Your responses will help us plan future broadcasts and improve our technical support. The archive of this webcast will be available for viewing within several days at the website www.mchcom.com and in addition to being able to access our speakers' presentations you'll be able to download the reference tips and tools that the healthy and ready to work program has so graciously provided to us. This concludes our webcast, "What's Health Got To Do With It?" Thanks again for your participation.