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Transcript of Conference Call Presentation

What's Health Got to Do With Transition? Insightful and Innovative Programs

presented by:

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Ms. Edelman: Good afternoon, everyone. My name is Andi Edelman, and I am with the Academy for Educational Development in Washington, D.C. I would like to welcome you all to our monthly teleconference. It's sponsored by the National Transition Alliance and the National Center on Secondary Education and Transition. Today's program is entitled, "What's Health Got to Do With Transition? Insightful and Innovative Programs" and it's going to focus on transition of youth with special health care needs and the Maternal and Child Health Bureau's Healthy and Ready To Work (HRTW) Initiative.

Today we have a panel of three speakers. Each one has extensive experience in this area. I know you will find their presentations insightful and informative. Dr. Patience White is the Executive Director of the Adolescent Employment Readiness Center at Children's Hospital in Washington, D.C., and she will begin the dialogue. Following Dr. White will be Tom Gloss, who is the Director of the HRTW Federal Initiative at the Maternal and Child Health Bureau (MCHB). After Tom, we will hear from Patti Hackett, who is the MCHB HRTW Consultant and the project coordinator at the MCHB for the Academy for Educational Development.

Each presenter will have about 15 minutes to speak, and we will save the last 10-15 minutes for questions. Our presenters have volunteered and have done a wonderful job preparing a PowerPoint presentation to accompany their presentation. If you would like to follow along, you can access it on your computer. I am going to give you the Web site. You have to type in www.dssc.org/NTA. When

the NTA screen comes up, if you click on the word "continue" at the bottom of that screen, it will take you to the announcement for today's teleconference and the PowerPoint presentation. I understand that it takes a few minutes to download, so don't give up. I would like to invite you, the audience, to ask questions of presenters after the last speaker has presented. We would appreciate it if you would press the mute button if you are on a speakerphone so everyone can hear.

I want to go ahead and get started with Dr. White. You are on.

Dr. White: Great. Well, good afternoon. I appreciate being asked to join you all as a physician. My job here is to start by focusing on a program to see how I, as a medical person, am dealing with transition and then give you some of the lessons I have learned from my perspective. Those of you that are following the PowerPoint, I am going to turn to the slide that starts a little bit to tell you about the program that I run at the Children's Hospital. It's called the Adolescent Employment Readiness Center. This is a program that's been going on now for about 10-15 years that was graciously started by the help of the MCHB. We target a population that is really identified by no other system. Now, what do I mean by that? Well, I think many of you are familiar with youth that are in special education programs or in 504. The majority of the youth that we are dealing with aren't in either of the systems, probably for two reasons. One is they don't know about it. Many of them didn't know that anything is available to them. Or, secondly, they don't want to be a part of

it. There are some families that say they don't want their child to be a part of those programs for fear of some kind of—who knows why, but many of them do not want to participate in either 504 or IDEA.

We are talking about a whole different group that tends to have chronic illnesses and some disabilities. The program itself is really a pre-vocational program beginning around the age of 12. We will see young adults up to age 26. We are focusing really between the 12- and 18-year-old.

We really focus on developmental stages as well as the age of the youth and are looking at the disease stage as well. Let me give me an example. You see a youth that is HIV positive who feels totally healthy, but we have to get them ready for that time in the future where they will become ill related to their illness. What we try to do with this youth is improve their career readiness skills. We secondarily do all the other areas of transition. We do this by bringing together a whole group of people that really help me, including business at the local area, the medical people that are dealing with these youth, the educational people that are so important in these young people's lives like yourself, parents, and many of the disability community and groups. That's the group that we bring together to help us really run this program.

On the next slide, if you are following, that says we started in 1984. We have served about 2,000 adolescents but have many health care professionals and other professionals that have come through the program as well. We have a number of services including adolescent services and parent services. We do a lot with transition training. We have educational programs such as college bound and youth leadership, and I will talk about that in a little bit.

To give you an example of how it all fits together, we currently have this on the next slide, Social Security contract, where we are in an agreement with the District of Columbia managed care for youth with special health care needs. Now, in the District of Columbia, all those youth are on SSI, and they all have significant disabilities because they have met the criteria and could be on SSI. What we are offering to the 11- to 21-year-olds is this kind of wrap-around service. We try to assist them with other transition aspects than the medical piece, which they do extremely well with case managers, since there are about 1,000 of those youth. We will

be working with these case managers to give this kind of intensive program to a percentage of the youth that are going to be going on in transition.

I look at transition from a medical standpoint, not in a vacuum. I really look at it in a broad sense, but obviously I am most attuned to the medical issues. I think all of us know that transition includes home and independence, school-to-work, or postsecondary education. I am often focused on the pediatric to adult health care.

What I want to focus on is a series of questions that are on the next slide, a little about what I learned about what youth want and what medical transition is from the perspective of the people who are involved, who need this medical transition and why do it anyway, which is what families often ask. Then, what are some of the medical issues that affect school attendance and some of the learning environments.

Now, in general what I have learned in lots of surveys that have been done, when you ask youth who have special health care needs and say, well, what do you want in transition, they don't say what I often wish they would say, which is, "Boy, I would like to find an adult provider and move on in my life." No, they have the goals that I think every other youth do, which is they would like to make some money and be independent. More recently they say they would like to own the stock market in some format. I don't know if that's changed in the past couple of days. In any case, they are like every other youth who want jobs.

In that sense, I learned way back when I was developing medical transition, I would have this nice medical transition where there were adult providers and pediatric providers, and nobody came. None of the youth were interested in this. That's when I started a program like the Adolescent Employment Readiness Center, which offers what kids really are interested in, which is finding a job, finding out how they can make money. This program helps them realize that leading a healthy life is very important to attain the original goal that they walked through the door with. I have learned that you have to start with doing whatever they want first. The different groups of youth that we have had participate in our program certainly have had a variety of things that they want us to handle first. Some, it's they are homeless and want a roof over their heads, or child care, if

they are a teenage mother, getting a driver's license, whatever it is, they usually walk through the door with that focus. We work with that and then turn around to begin to ask the questions, well, to be successful at whatever they want to do in a particular job or wherever their vision is they need to begin to manage their health and the other aspects of transition. We are looking at trying to improve their function towards the direction of where they want to go and try to not focus on the disability.

There are some general definitions of medical transition that people have been talking about. It sounds like in most definitions, medical transition is a planned movement of youth with special health care needs/disability from child-centered to adult-centered care. Obviously, the goal is to provide health care that is uninterrupted, coordinated and comprehensive, developmentally appropriate, and psychologically sound. Well, that sounds terrific. As you know, that the health care system is quite fragmented, and it's very hard to keep that continuity of care, which is so important for youth with special health care needs. That's a goal that we are trying to achieve as we help them transition.

There is a slide in my group and a slide in Tom Gloss's group that points out who needs this medical transition. There are many different definitions for how you would define someone with a special health care need. If you take the most broad definition, which is the way we look at it, it runs about 21% of the 15.3 million youth in the United States. As I mentioned before, many are not in special education or do not have 504 plans. They tend to have these kind of visible and invisible disability chronic illnesses. For example, they may have arthritis or diabetes. As you know, asthma is the number one chronic illness out there now as well.

I am often asked, "Why rock the boat?" by the family. "You are looking at a youth who is in their pre-teen or teen years, why change?" I turn to them and first ask: "Are *you* still seeing your pediatrician?" They will laugh and say, "No." I think that is very helpful to give expectations to the youth that they are going to move on. They are going to do what every adult does and move into the adult health care system and find an adult provider. It makes them feel like everybody else. I think it gives them a vision that we think they are going to survive and

go about their business like everybody else. I believe that adult providers by the nature of their training are focusing more on wellness and prevention. It's just the nature of whom they care for. It's helpful to get them into an adult system at a time where they aren't acutely ill. I can't tell you how difficult it is for me as both the pediatrician and internist to suddenly have transferred to me a very complicated youth with lots of medical problems when they are ill. It's much better to plan these things when they are well.

Finally, if you don't do it, they don't transition. I think you send a subtle message which reinforces dependence and difference—that they are very different from all other youth and that they are not capable. I think that's really a tough, tough message for them to hear in a subtle way when they don't make that transition. You really have to work very closely with families as well as with the youth, because they are also worried about this transition going into the unknown and finding a new person.

I will finish up with my final slide, which is some of the medical issues that I think both us in the educational system and in the medical system can work together on. You can ask some of these questions as I am asking lots of questions about their school setting. I think there are many skills that you can teach so well if you put them in the context of some of the medical issues that are going on in their lives would be very helpful for them as they are trying to navigate this difficult road.

First of all, I always ask a youth, you know, are they seeing their physician by themselves. By the time they are moving into their mid-teens, it's time for them to have developed a relationship in some form with their health care provider that's one-on-one. It turns out that many pediatricians are used to talking to the parents, and you have to begin to make this shift because certainly the adult provider is going to talk to the youth. It is always a bumpy transition. I do take care of a lot of youth as they move into the college setting at The George Washington University. I receive these absolutely irate calls after the youth has seen me from the family saying, "You have to tell me what went on." I will say, I will if the youth will allow me. Certainly there are things that are privacy issues around somebody as unless the youth has said, fine, or there is some agreement for him. That's something we are trying

to get—a collaborative relationship.

Obviously, helping them understand their diagnosis and its implications, how it has affected them in the school setting, have they had to take medicines at a particular time, have they had to leave class because they had to handle some other issues with regard to their health. Certainly with regard to this diagnosis and implications what they really need is to be well and participate fully in their educational experience; in other words, what kind of medical team. As they are beginning to look to hopefully go on to some kind of post high school experience whether it's a technical school or a college or whatever, what kind of medical team do they need to put together? Do they have medicines that are hard to get; for instance, youth who have arthritis are getting some of these new drugs that are not available everywhere in the country, those kinds of things. Finally, anything to help manage their skills to manage their health when you all are talking about maybe filling out forms, talking about filling out insurance forms. These youth are going to have to manage very complex finances, learn and think about how they are going to take care of their chronic illness in the future. They need to think about how they are going to pay for it, how to schedule their appointments and obtain their medication.

Anyway physicians can help you as you are working with youth in the educational setting, but you have to coax physicians. They are not as familiar with the issues that you are talking about, but calling them, I am sure they would be willing to assist you. I certainly depend a lot on my educational colleagues to help me as we formulated this program sitting in the middle of the health care setting.

That summarizes the program I am involved in and some of the issues and lessons I have learned over the years. Now I will turn it over to Tom.

Mr. Gloss: Thank you, Dr. White. Great presentation as always. We appreciate your expertise and being here with us. I am grateful to be on this call today and appreciate Patti Hackett and Andi Edelman for getting the PowerPoint put together. I hope that this is helping you. We thought it would be a little more interesting than just hearing—you know, not even talking heads because you can't see our heads. I realize we neglected to put our pictures up here for you. To help you—I won't speak for my

lovely co-presenters—but for myself just so you have a visual, when you hear my voice, just think Brad Pitt. I look just like him. You will acquaint me—

Dr. White: Go, Tom.

Mr. Gloss: All right. I direct the HRTW Initiative for the MCHB. I previously worked the Social Security Administration in disability policy areas. The first slide in my presentation gives you a little background on what MCHB and the Title Five programs are all about. Title Five goes back to 1935 when the Social Security Act was put together. There was a realization that women and children historically didn't fare so well in society and that there were those with special needs who needed attention and that there needed to be a concerted federal effort to promote the health and well-being of these populations. Over the years Title Five of the Social Security Act was amended and now it works as a block grant. The Federal government gives money to 59 states and territories to run programs. The law requires that a minimum of 30% of the federal block grant money be used for programs for children and youth with special health care needs. In addition we also spend money on special projects of regional/national significance which are demonstration projects primarily, and that's what the HRTW project is.

The next slide is the definition of children with special health care needs that is used by the Health Resources Services Administration and the MCHB. It is that there are children who have or who are at risk for having chronic physical, developmental, behavioral, or emotional conditions and require health and related services of a type or amount beyond that required by children and youth generally. This is a very broad definition of disability, if you will, that goes way beyond what Social Security uses for their Supplemental Security Income, the SSI program or the Social Security Disability Insurance program. It's a much broader definition than many private insurance plans would have or other federal qualifying programs would have. This is a pretty broad definition.

We have a count of over 12 million children and youth nationally who meet that definition, and it represents about 18% of the U.S. population. About 6% are without a source of health care, about 11% are uninsured. This population would have three times as many school absences and bed

days as kids without any kind of special health needs. Those data are from 1998.

Next slide, this is a really good representation—this graphic. The green line shows the employment rate for all adults with disabilities, and the orange line going up the top is the survival rate for children and youth with spina bifida. You can see from 1966-1996, during that 30-year period, the survival rate for young people with spina bifida has gone from approximately 30% to 80% or more. The employment rate for people with disabilities has stayed relatively flat. You know, less than 30% or right around 30% of people with disabilities who are working age are reported as working. Although medical science and health care and all have improved tremendously so that, for example, people with spina bifida and other young people who, you know, a long time ago wouldn't have lived to adulthood are now living to adulthood, but the employment outcome is the same as it was before.

The next slide gives the Web sites for how to get more information about the MCHB, specifically about the state program. Each state and territory has a Title Five program. There is a directory that's been put together that explains the eligibility criteria and the scope of services that each program runs. I won't read those all off, but they are there on the PowerPoint presentation for you.

The next slide is a graphic of something we are calling the Healthy People 2010 agenda for children with special health care needs (see <http://www.healthypeople.gov/>). You all are probably aware that the Surgeon General created a Healthy People 2000 Plan that Surgeon General Coop helped put together. There were specific goals that were set and some of those were met and some of those weren't. Healthy People 2010 is the next iteration of that. Our Director, Dr. Meryl McPherson here at the Division of Services for Children with Special Health Care Needs, really wanted to ensure this time that these goals were met and that there was no excuse for us not being able to accomplish them by 2000. We certainly have to get them done in this decade.

There are six outcomes that we are setting as goals to accomplish in the next 10-year period for children with special health care needs, and these are all specifically outcome oriented. It's not research. It's what can be accomplished.

1. The first one is regarding medical homes which is the American Academy of Pediatrics' definition of medical home, and we are saying that by 2010 all children/youth will receive regular ongoing comprehensive care within a medical home, which is a concept of care, not a place of bricks and stone.
2. Secondly, health insurance: All families of children/youth with special health care needs will have adequate public and/or private insurance to pay for the services they need.
3. Third, screening: All children will be screened early and continuously for special health care needs. We realize that this often doesn't happen and kids fall through the cracks. We recognize that these problems aren't identified until much later in life when they're harder to deal with.
4. Fourth, integrated services and that those systems at the community level are inclusive of children with special health care needs and their families.
5. Fifth, that families of children with special health care needs will participate in decision-making at all levels and will be satisfied with the services they receive.
6. Finally, the topic that I am most concerned with and most involved with is transition. All youth with special health care needs will receive the services necessary to make transition at all aspects of adult life.

Our work group was formed in each of these fixed areas and our team for the transition HRTW came up with five action steps:

1. The first step is that the states' Title Five MCHB Programs should be the people facilitating this HRTW transition system. That's not to take anything away from the education community. We understand that education has responsibilities under IDEA, 504, and others. The health component is our responsibility and we should be more involved. We want to be involved with education, with Social Security, the Department of Labor, and with all other agencies that assist in disability services. We want to carry the responsibility and ensure that the health needs are met and that we are there at the table to assist in these plans and transition actions.

2. Next, that youth would be decision-makers and partners both in policy and in the issues that concern them. The youth should be directing their own health care as they become old enough to do that. We hear stories all the time from kids who are adults who will say, "Yeah, when I was eight and nine I understood everything they were saying about me. They were talking over my head and thought I didn't know but I understood it all." The youth want to be directly involved in their health care.
3. Health insurance needs to be accessible and affordable. It doesn't mean having a Medicaid card. There are many parts of the country where you can have a Medicaid card and theoretically should be getting the finest care available in the country under EPSDT. This doesn't happen because there aren't providers who will accept new patients, patients with a Medicaid card, or the appropriate kind of specialist or care is not available in that particular area.
4. Next, the medical homes should be responsive to the childrens'/youths' needs, and age appropriate. That transition to an adult provider. Adults with disabilities tell us there is a really organized comprehensive system out there for kids. The problem arises when they become an adult, they fall into a black hole and none of that exists. How do we get Title Five in those state programs looking at what's there when the kids transition and developing the adult providers across the country? They need to be ready and able to accept these youth who are becoming adults.
5. Then life, recreational, social, and employment.

It's not a simple problem and the answer isn't simple either. It's comprehensive and it goes across all these various systems.

The next slide shows a map of the country and talks about the HRTW initiative, which are specific projects that have been funded for the last five years. They are in their last year of operation, and so we expect to have final reports coming out later this year. The projects are running in Oregon, California, Minnesota, Iowa, Louisiana, Ohio, Kentucky, Maine, and Massachusetts. The University of Florida's Institute for Child Health Policy (<http://www.ichp.ufl.edu>) has served as a national center for us.

These projects are varied. They are not doing the same things. Most of them, however, do look at systems change as opposed to direct client services. Many of them are focusing on youth from minority populations. One project focuses on working with employers. Several of them focus on working with the medical community and the education community in trying to get doctors to the table in terms of the IEP and transition planning.

On the next slide, you will see some outcome measures. These aren't specific—this isn't an evaluation tool to look at specific project success but rather a way to talk about what these eight or nine varied projects have been doing and what are some specific outcomes that have happened. You can see about 16,000 providers and educators have been trained in transition issues. We have projects that have developed curricula if you wanted to talk to health care professionals or talk to educators about health impact on transition and specific transition issues. There are curricula that have been developed and are available. We have more than 12,000 families who have been trained and had skill-building sessions on transition issues. More than 16,000 youth have gone through skill-building and self-determination and leadership in transition issues. About 14,050 youth have been referred to the medical home setting for comprehensive and community-based quality care. Finally, over 200 kids have had some sort of work experience through their involvement with our projects.

What's next? Right now we have a grant announcement that closed February 23. We received 20 applications from state Title Five programs or their designees. This grant will be used for a project that will start this summer and run for four years. The grant will cover \$300,000 per project per year, so \$1.2 million for each project over the life of the grant. That money will aid in developing state models for how the state Title Five programs can incorporate transition into their programs.

The Kentucky TEACH project (http://www.hrtw.org/about_us/proj_files/hrtw_ky.html) that's running right now, that one is not in the same cycle as the other HRTW projects but it's been running for about two years and developing a model. They have changed the way their Title Five program does business. Transition is now a focus of every aspect of what

they do, from the time a family becomes known to them as first interviewed with an intake interview and their child has gotten a diagnosis of some chronic health need. The nurses, staff, and intake workers are talking about transition and talking about age and developmentally appropriate milestones for children in terms of getting ready for transition. When the time comes, as Patience was saying, the change from a pediatric base to an adult-based provider is a natural and expected transition. The transition is done in an orderly process. Everyone is expecting it so the person isn't 40 years old and still seeing the pediatrician because no one ever planned for it.

The next slide shows a graphic of our policy papers that we have developed to support both our HRTW projects and our state Title Five programs (see <http://cshcnleaders.ichp.edu/policypapers.htm>). There are five papers here, including one on Section 504 and one on transition in general which is an excellent primer. If you wanted to give someone a lesson about transition or help a family understand in general terms about transition milestones, that middle one, the blue one on transition, is excellent.

The most recent one is the insurance paper. That talks about HIPAA, the Health Insurance Portability and Accountability Act; and COBRA. These are different ways to help a young person who is becoming an adult who has special health care needs to keep some sort of health insurance coverage. It talks about Medicaid and the changes with the Supplemental Security Income (SSI) program, and entitlement to Medicaid is part of that. Kids are coming on at 18 when they are considered an adult under SSI, versus kids leaving, those who have been on SSI as a child and then turn 18 and the welfare reform changes require that Social Security review that individual's medical case using the adult standards, and some kids are coming off the program. It talks about all those issues in there.

One paper focuses on sexuality. It's a paper on sexuality because the youth told us that adults tend to look at them as being asexual, that sex is not a part of their lives. Any adult who believes that, I will sell them some property in Florida where Perry lives. Sex is part of everyone's life and kids with disabilities need to have those needs addressed.

Finally, the yellow one is on Title Five—what the Title Five MCHB programs are and what their

responsibilities are in terms of transition. Then the material product list brings together all the materials, the videotapes, the CD-ROMS, the course curriculum materials, the journal articles, everything the HRTW projects have been doing over the last four or five years and lists them, summarizes them, and tells you who the intended audience is, what the product is, how it can be used, and how to obtain it. We tried to be accountable for this expenditure of federal dollars and say, here's what our project has done so that anyone else coming along behind wouldn't have to reinvent the wheel.

The next slide is a graphic of our Web site (<http://www.hrtw.org/>), where you can get all of this information. If you click "HRTW Projects," it takes you to a page that shows all of the HRTW projects along with their abstract for the project and a link to their Web page so you can get more information on that specific project or contact them with specific questions.

We have streaming video (see <http://video.ichp.ufl.edu/>). Videos have been made on the Social Security work incentives, SSI work incentives on PASS, and the "Ticket To Work," the brand new one. The videotapes are meant to be motivational for the kids more than instructional. They wouldn't tell you exactly how to do a PASS plan, but they show kids and how a PASS plan helped them and why it might be good for someone you are working with in an upbeat and positive way.

What's next? In addition to this Healthy People 2010 plan, we are trying very hard to work with the Title Five programs, and this next grant opportunity is part of that, to push them along. Like I said, we have 20 applications. We think we can only award five or six because of the limited budget. There are many states that are interested in working to improve transition for kids with special health care needs. I encourage you if you don't know your Title Five people to find out who they are and talk to them. Even if they are not funded, I think that families out there need to press their service systems to be meeting their needs. The Federal HRTW Interagency Council, which is part of the President's Task Force on Employment for Adults with Disabilities, has formed a full committee.

We are working with the key stakeholders. We have a meeting coming up later this year that

will be with physicians to get pediatricians, family practitioners, internal medicine doctors, and their professional organizations to help them come to consensus on transition. We would like them to issue a statement that would be released to the public saying, we support this and here's our recommendation for how this should happen. Then we have a follow-up meeting, which would be a larger summit, a HRTW summit where health issues for youth and transition are the focus, and that would be with a broader audience. Then there will be a larger meeting, which is the rollout of the entire Healthy People 2010 agenda that has all of the other five outcome issues in addition to transition.

That's it. Thank you so much for being here, and just remember—Brad Pitt. Thank you. Patti, on to you.

Ms. Hackett: Hi. I will try not to laugh too hard as Tom is my project officer.

Well, greetings from sunny, breezy Florida. At this point, we have heard from a physician and we have also heard from our federal project officer about the initiatives that are out there. What do you do as a teacher, whether you are in an elementary, secondary, or postsecondary setting? What can you do to help families and youth move along to make sure that the goals are met? For me, I look at transition as exceeding expectations.

When we look at expectations, we need to think beyond the diagnosis and whether the diagnosis is a special education issue or a chronic disability or its impact on health status. We need to take a look at what that is but not get stuck there.

For the first time ever, our population that we are talking about today is able to live to adulthood. Never before in any other generation do we have a group of kids who now can vote, who could drink a beer, and even get a license. They finally became of age. Preparing for the long haul, I don't think many of us who had children recognize that with all the good care and good education that they would become 18. Although we have a generation of survivors, we also have a generation that didn't realize they were going to get there. The message I have is, when we talk to younger families, let's start talking about saving energy for over the long haul and include some opportunities. I think we have heard the word "inclusion" a lot lately, but I go back to the

other "I" word that we heard in the fifties. It's more of an integration. Our people belong in society, as they are a part of the community.

Matching dreams and opportunities. Again, after the diagnosis, many families will need to reinvent the dream. I have always worked with families. My son is pictured in this slide. I was a teacher for 10 years. Then I moved into health policy. Later on in my slides I am going to weave in these stories.

When I would teach my kids in middle school, I would ask them what they wanted in the next five years. I needed to know the skills that they wanted by the end of the five years, not just what we could accomplish in the first year. Families and youth are informed decision-makers. If you don't give them the ball, they will never learn how to run with it. It takes practice over time. I think as a teacher we get to be that conduit to the dream, because we are the ones that have these families, these kids for the longest period of time. Physicians will see children over a period of 18 years, but not a lot unless there are a lot of hospitalizations, they won't see their patient quality time or quantity time. For educators day in and day out, nine months a year, we have our kids.

Adaptive. Look at what can we do to make services nonintrusive. My son who is currently the racing editor for a daily publication here in Ocala, FL, has a lot of physical needs. I can tell you his strengths. He has two jobs and he went to school as a 504 student back in the late '70s. If I share with you about his medical issues, you might be a little overwhelmed. He has a gastrostomy tube. Some people choose to do that in the daytime to be able to feed kids through this tube. We chose a nighttime setting so it wouldn't be intrusive for school. There are different suggestions and options out there to make sure this kid becomes a kid first.

Reducing barriers. Sometimes that means reducing them, sometimes it means eliminating them. We take a look what's out there, recognizing what can be solved and attacking it. There are some issues with stamina. A lot of the kids in my classroom became fatigued. No one ever talked to them about how to conserve their energy and especially in a high school setting with the new larger campuses. This is really important.

Medical partners. Now, this is a dual conversation. I have a wish list for my medical partners

and also ideas that could help them. When they have our kids in their clinics, I hope they talk about maintaining and sustaining wellness. For my son, he would miss 60-70 days a year, which is a considerable chunk of time. When we focused more on him staying well, we could make sure the time he spent in the classroom was quality.

Facilitate self-determination and choice. It's important that these youth hear the message, not only from the medical people, but also from educators, that they understand that this is a part of life. We probably should emphasize that a little bit more forcefully with this population. It's good practice and it should be across the board. All should mean all.

Informed and proactive. It's very important, as Dr. White mentioned—our kids need to know what their disability is. Not the sole persona, but be aware of it, and be aware of the health implications. One of our projects in HRTW had a youth with asthma. When he received his first job placement, which was at a gas station, no one could understand why he couldn't make it through the day. Well, nobody had looked at the environmental issues with his health. Anybody in their right mind would never put a kid who had breathing problems by gas all day. Those are the kinds of considerations that need to be addressed.

Assent to consent. When I taught fourth grade, any time we had an IEP meeting, all my students would attend the meeting at the summary part and they would sign off after their parents signed off. They needed to know that nothing would ever happen to them without a permission signature. The way that they could run this was through practice. Fourth grade is a great time to start.

Flexible appointments. This is one of my biggest issues with the medical people. I always told my students, when you are well, have your medical appointments after school because when you are sick you may be out of class more time than other students. If physicians had more flexible hours after school, I would be a happy camper. I couldn't teach the kids if they weren't in class.

Now, take a look at the education partners. I noticed when a lot of my students who were in typical classes—I had an assistive technology inclusion class in middle school and then experiences with my son as a 504 student, many teachers had never seen kids with different types of disabilities

and chronic illnesses. It was an unusual experience. I tried to avoid getting stuck at the diagnosis.

“Terminal” doesn't always mean tomorrow. Many times when people do have what's called a “terminal disease,” they get the big message of living for today and they live fully. It's a good message that the rest of us can take to heart.

We in education need to teach functional life skills, as Dr. White mentioned. When we are teaching kids about different kinds of forms, why not put in a medical information needs form, how to read a prescription bottle.

Taking charge of IEPs, 504, and career. Kids need to know about the laws. As a matter of fact, when our principal needed to take a look at the compliance of our building with ADA, he gave it to our class and we did all the measurements. That was the most effective way we all learned that law.

Family and youth as partners. Whose life is it anyway? I think we see many times when we have our kids in our class, they are “our kids” and physicians feel the same way. But this is really their life.

Integration and age parity experiences. I looked at what would be an integrator for any of my kids. Sometimes it was music. Sometimes it was art. Sometimes it was sports. But they needed to be where the other folks were. For Glenn, it was sports. He couldn't play them because he never walked or moved; he has one finger that moves ten centimeters. He chose sports and did it with a statistician.

Mentoring our mentors. Now, there has been a lot of discussion about pairing people off with the same disability with an older person, but I would like you to take a look at not only that but looking at people who are action-oriented, who are positive message givers. For families it's sometimes helpful to pair them up with somebody who has gone the distance and learned the ropes. They may want to pair up with an adult who has a disability. Don't get hooked on it. Just have able-bodied or disabled people. Find the people who are able to solve the problems.

Experience and skill-building. Sometimes school districts pay for families to be able to attend conferences with their education partners. It's helpful when you do cross-training. Once you have that golden gem of a family leader and you start using their expertise, consider paying them.

I will now talk briefly about some resources that you may or may not be aware of:

- The Family Village Web site (<http://www.familyvillage.wisc.edu/index.htmlx>) happens to be one of my favorite sites of all time. When I ask families about their kids' disabilities and about the needs for the future or recreation, many of them don't know where to go. They need to recognize this new generation coming at us. They will most likely be online, be Web ready. Family Village is a very inviting kind of site, not only for families, but also for people who provide services.
- The counterpart with the parent training information centers that look at health is called Family Voices (<http://www.familyvoices.org/>). It's a young organization, although they are led by very seasoned leaders. The organization started in 1992; they are state coordinators in almost every state and currently have pilot funding to look at health information centers, which are active now in six states. They have an extensive national network. They are known to people who help shape policy at the national level.
- The American Academy of Pediatrics. The APP medical home: As Tom and Dr. White mentioned, it is important that kids receive services from somebody who is consistent and in the community. AAP, through an MCHB grant, offers communities training on how to set up a medical home. This curriculum now has a transition component in which they are bringing in pediatricians to learn how to provide these services in the communities. Often, at these trainings, questions about education come up. If you are interested and like to know when there is a training in your state, contact Bob Moore. He certainly would welcome your participation.

Reciprocal roles and responsibilities. When you are a teacher, one of the first things you find out is how good your classroom can run without you on substitute days. The same thing happens with a family member, with a leader. If the child can do what he is supposed to do without you, then the lesson has been learned. I think we need to encourage families to take a look at longevity and productivity. If they get the information about how to keep their

child alive, they also need to think about the long haul. Coaching attitude, providing opportunities to learn, to grow, to try—it's a gift teachers can give to families and families then can give to youth. The idea is to keep moving on and to keep improving.

Inclusion. Encourage trial and error and transfer decision-making. It's important to learn from all of our mistakes. We can't learn if we don't have a few. And for youth, responsibility is life sustaining. For example, it could mean something as simple as directing the caregiver to charge the wheelchair. With Glenn, we never charged his chair unless he directed us to. Now, that meant if the battery went out, there was a 300 pound chair that we had to push. Glenn would hear it from all of us or his friends. He was in second grade when we started that. He recognized if he wanted to move the next day and not have a bunch of people griping, he had to be in charge. Age eight was certainly not too early to get those kinds of skills going.

Again, ongoing skill building, goal orientation, and it's not goals that are the kids' career goals, it's like Dr. White said, it's money. These kids want what other kids have and they have to figure out how to get there.

Needs vs. wants. You need to make sure that you can't have it all but you have to get your priorities.

Fears that get in the way. Trust—there are broken promises. We all have experienced families that have a little bit of an attitude or resistant behavior. We really didn't create the problem, we inherited it. Have we ever stopped and asked why and what can we do to perhaps resolve it?

Insurance. Often there is a big fear. A lot of our kids definitely need their insurance to stay well and to stay alive. The rules change at age 18 and 25. Again, I direct you to the policy paper that Tom mentioned that gives bits and insights of some opportunities and obstacles.

Income gain and loss. How many times have our kids on SSI been told if they go out and get a job, the SSI income would be affected. What's also not known is sometimes a sibling of these kids who are on SSI, if they go to work and the kid is under age 18 they may lose their sibling's SSI benefits.

We talk about employment and we need to take a look at what else is going on in the family

and offer support—link to resources.

Failure as a learning curve. The idea is, yeah, they are going to fail sometimes. What about it? What can we do to do something different in the plan?

Transition also means letting go. Here I have included a variety of people: the educators, the providers, the community, family, and youth. The bottom line is, we need to recognize that these kids probably will do it with us or without us. It would be nice if we gave it our best shot. Many times when we talk about terminal, we talk about our kids, but we forget that some of us tend to have these fears too. Sometimes we may not be around for the long haul either. The physician that diagnosed Glenn died when he was ten. In his last year of life, we talked about the irony that he had prepared us for losing Glenn, and here he needed to prepare for his death. He worked very hard that last year to make sure all the medical issues that he wanted to transfer to us were in place.

The last slide is a picture of my son looking at what we have down here in Florida. We have cable TV that has horse racing 24 hours a day. Florida by the way is second to Kentucky in raising thoroughbreds, so horse racing is a big deal here. In our audience today, who would have ever supported his dream? When you take a look at passion and look at ability, you need to look at opportunities and think with technology today anything is possible.

I leave you with the idea of engaging families, of sharing accountability, and of networking resources and people who are doers. Andi?

Ms. Edelman: Thank you, Patti. Thank you all for your presentations. I think it was wonderful. We have about seven minutes left. I am going to go ahead and open it up for questions. All I ask is that when you have a question, state your name and the state that you are from. Thank you. Go ahead. Does anybody have a question?

Mr. Gloss: No one is asking me for a date?

Ms. Schoeller: Tom, I will ask you. It's Kris from Minnesota.

Mr. Gloss: Hi, Kris.

Ms. Schoeller: Hi. I have one question. One of the issues that's come up for me in working with families and kids is not necessarily primary diagnosis of the chronic illness or disability, but some of

the secondary mental health or emotional health pieces that come in during adolescence as the kids are trying to make this transition. It's so often unidentified or not even acknowledged. I wondered if that's a component that's being put into the multiple programs.

Mr. Gloss: I will say first that, yes, we are looking at that in terms of the Title Five in HRTW models that we are trying to develop. If the Title Five agency doesn't deal with it, then they need to be tightly linked with the mental health agency in their state to ensure that these issues aren't falling through the cracks. Patience, would you like to add something?

Dr. White: Well, no, but I think it's a really important question. It's a general question for adolescence overall.

Ms. Schoeller: Right.

Dr. White: We have a hard time identifying depression. As you know, suicide rates are high, and there are a lot of issues. Some of it is hard to separate out. Is this an adolescent issue or an issue that's related to the disability? Many times I find it's an adolescent issue.

Ms. Schoeller: Right.

Dr. White: Life is hard. I think it's particularly hard for teenagers today. I think families tend to come in and say: My child is depressed because they have X. I end up finding out they are depressed because they are like many teenagers that are depressed, and sometimes learning that is a positive thing. They are like everybody else. There are many studies that show teenagers are depressed as a group.

Ms. Schoeller: Thank you.

Ms. Edelman: Are there any other questions? (No response). Wow, you guys were very comprehensive. I do have one question. I was wondering if any of you can address the idea of what we can instill in the youth that we work with to get them to be more proactive in bringing the health issue into their transition planning with whomever it is they might be working with, whether it's a community-based organization or their teacher or a state agency. How can they be more proactive and bring their health issues in and identify what their needs might be in terms of their transition planning and achieving their goals?

Dr. White: Nobody is going to answer? Patti?

Ms. Hackett: Go ahead, Patience. I will follow you.

Dr. White: Well, you know, I think it's extremely hard. I have two teenagers and I know others do. To get them to think that they are potentially not invincible is extremely difficult. I think part of it is, as Patti aptly pointed out, they have to find out that health becomes a problem that prevents them from doing something that they want to do and then they learn that way. Many of the lessons that I try to work with youth on when they say, well, "Why can't I do that?" You think it through with them and they realize that and then they begin to ask about those questions. I have not found personally that sitting down and saying, "You have to think about health" does anything at all until they begin to say, "Ah-ha—for me to get what I want I have to keep my asthma under control" or "I have to power up my wheelchair," whatever it is, so they begin to have them thinking around health. But it never happens until they realize it's not there. My son never did anything about his health until he really fractured something and then he began to worry about breaking things. You know, he took a lot of risks jumping off his bike and doing all sorts of crazy things with his different vehicles that he would run around in. Until he did something, he didn't really think about it. I think that's very human. I think it's an adult problem too, by the way. Patti, if you want to add.

Ms. Hackett: I'd like to take a look at that solution a little differently with the youth. We have two sets of kids, kids whose disabilities or chronic illnesses are obvious, you could see it, and then ones who are invisible. Then I think overall, people tend to want to be quiet about it. If this country took a look at wellness like we do with sports meds as improving function, I think health would be a very quiet partner there and kids would feel more comfortable. If we took a look at that energy and endurance that's needed in the high school area, if they went to a sports meds concept and said I am having some fatigue, they might get some nutritional support and might get some options for how to get to classes faster or other kinds of strategies. These kids are going to be quiet because they want to fit in.

Ms. Edelman: Right.

Ms. Hackett: We go back to the wellness. As long as they stay well, health is not going to be that

big a deal.

Ms. Edelman: Well, I want to thank everybody for participating today. I think it was a really informative and insightful presentation. I want to alert you to some things that are upcoming. The next teleconference is going to take place on April 26, at the same time, 1:00-2:00 p.m. Central. It's going to focus on comprehensive school improvement for all students in Iowa. The discussion will cover change strategies for communities, present the state and local perspective on comprehensive school improvement, and highlight interesting projects and programs including an e-mentoring program.

Again, thank all of you for participating. I think it was wonderful.

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