

**2011 AMCHP and Family Voices National Conference: Got Transition?
Opening Doors to a Healthy Future for Youth and Young Adults with
(and without) Special Health Care Needs**

02/14/2011 Omni Shoreham, Washington, D.C.

LIBRADA ESTRADA: Welcome, Good afternoon, my name is Librada Estrada, and I'm Associate Director for Workforce and Family Involvement within AMCHP. I'd like to introduce today's speakers.

This presentation is entitled: Got Transition: Opening Doors to a Healthy Future for Youth and Young Adults With and Without Special Healthcare Needs. It is Session ITG8, which is a workshop. AMCHP Family Voices shared session.

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Be sure to keep track of the session you attend throughout the conference as you will be required to enter this information on the online system. A tracking sheet has been provided in your conference bag and further information may be found on Page 10 of the AMCHP Conference Program. A Conference Evaluation Survey will be posted online immediately following the conference and a link to the survey will be emailed to all attendees. AMCHP will use this **** to plan next year's conference, so please be sure to take the time to let us know what you thought of this year's conference.

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And finally, please turn cell phones to silent mode. And now I'm going to turn it over to Carl.

W. CARL COOLEY: Welcome everybody, this is an intimate room, I hope that all of you can kind of survive in this environment. We're each going to briefly introduce ourselves and then kind of launch into our presentation. And three of us at the table and one at the door at the back and walls represent the Concord, New Hampshire based staff of the new National Center on Healthcare Transition and we're excited to begin doing this work this year. Eileen Florenza at the table is a member of our cabinet. We have a kind of governing group that meet by conference call every two weeks to try to continue to move our work forward. And they'll each introduce themselves.

I'm a Developmental Pediatrician clinically. I work as the Chief Medical Officer at a fairly large rehabilitation hospital in New Hampshire around issues there with kids with special healthcare needs, traumatic brain injury and other conditions. Along with Jean, Jean McAllister and I have been working for quite a number of years around the transformation of primary care in the Medical Home model; the Center for Medical Home Improvement where we have based the National Center has been active in this area for quite some time. I know I've worked with a number of you in the audience in your states or your areas around Medical Home.

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We think health care transition is part and parcel of Medical Home that the two are very closely connected and we look forward to using some of the skills we've learned around Medical Home to try to bring Healthcare transition practices to life in more places around the country.

Jeannie, do you want to... we'll pass this down...

JEANNIE MCALLISTER: Hi, I know some of you, my name is Jeannie McAllister and I Direct the Center for Medical Home Improvement and I'm co-Director of this center and I work, as Carl said, has been around supporting practices for many years, helping them to form teams with parents, with staff, with coordinators and with clinicians to improve their Medical Homes. This is an important part of being a Medical Home.

I also happen to have three children who are now in their 20's, one actually 31. And so I think about this a lot as well.

MALLORY CYR: Hi, I'm Mallory Cyr, some of you may already know me from my work with Healthy and Ready to Work, which was the former Healthcare Transitions Center. I'm super excited to be with the new **** Transition National Center with Carl and Jeannie and our amazing advisory cabinet and Ann with Great Leadership. And I play the role of representing youth through the transition process whether it be provider or just having that relationship in the healthcare world.

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EILEEN FLORENZA: Wooo! I'm celebrating all of you for coming, thank you. My name's Eileen Florenza, I'm a parent of a 21-year-old currently going through the transition process. I am representing the parent perspective on the national cabinet with Carl and Jeannie and a host of other wonderful experts. And I also am directing the Medical Home Initiative for the state of Colorado and I'm a member of the AMCHP Board and representing the family perspective on behalf of board members. So thanks for being here.

W. CARL COOLEY: and one other brief caveat, we originally submitted two workshop proposals for this meeting and one of them by Eileen Mallory and one from the rest of us and were asked by the staff at AMCHP if we wouldn't mind combining them into one. So I feel a little as though they also combined the rooms into one to have us all fit in here, but this is very related material, material that we really generally would not want to pull apart, but we thought at first that there was enough of it for you know, the time involved in two workshops rather than one. So we will have done our best to kind of compress this.

And one of the things that is different about what you're going to hear today is that one of the elements of our original proposal, the one that Jeannie and I had submitted included actually one of our first products. And Catherine Rogers is... is she here? Yeah. good. There you are. Is here from the

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National Alliance for the Advancement of Adolescent Health here in Washington and is one of our partners. And they have completed a report based on the National Survey data, looking a little bit deeper into how states are doing with regard to healthcare transition and how that relates to issues like Medical Home, insurance, gender, race and ethnicity. So we don't have enough copies to hand this out to everybody and not everybody wants to carry paper home in their bags, so this is available for download at our website at:

www.GotTransition.org. The website, as you'll see is a sort of preliminary model, but it does have the capacity for us to provide you some materials like PDF files and this report can be downloaded, so I'll commend that you your...

Audience member: What is the title of the...

W. CARL COOLEY: The title of the report Healthcare Transition for Youth of Special Healthcare Needs, and Analysis of National and State Performance. And it will appear in a more interactive format on our website before too long.

So we're going to talk a little bit first about the focus of the National Center and kind of why this is important now and it's really about health care transition, we recognize all of the other important aspects of the health of transition that aren't necessarily purely healthcare. We also recognize that all of these issues are in inextricably intertwined for youth and

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families, but our focus is really on the healthcare system. And as a pediatrician on our sort of collective, I think chagrin, that the healthcare system hasn't taken up this issue more effectively. In our business, one of our primary orders of business as a national Center, agile here in a minute, is really the implementation of transition best practices. We sort of all know what they ought to be, but we also would've no that they're not happening. And we know this by surveying people and pediatricians.

So less than half of the US Youth for Special Healthcare Needs got the transition support they need, not to mention all the other youth who also don't get the transition support that they need. Positive transitions begin with prepared youth and families and for plan and successful healthcare transitions, pediatricians and adult primary care providers and specialists need tools and concrete methods to address barriers and improve care.

And we kind of feel that the tools are actually around, what they need is a methodology for implementation. They need a way to say, we're going to do this differently next week. Maybe with only a few people at a time, and again that's the kind of work that we've, I think larger do fairly well around Medical Home and looking forward to applying it to this.

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So help is on the way with this issue. I'm going to talk a little bit about some new professional practice standards that are about to emerge. And that National Healthcare reform efforts, should they survive, affect youth and young adults in important ways, as most of you know. But healthcare transition remains one of the six performance priorities for the National Child Maternal and Child Health policy. It also, as you probably know, has been one of the lagging elements of those priorities and one that we all want to see advanced.

And finally, is to introduce you today to the new international Center. Over the past several years, I have had the privilege of co-sharing a group at the American Academy of Pediatrics that has been charged with writing a new clinical report on healthcare transition. Many of you might be familiar with the 2002 report that was a joint statement on issues around healthcare transition. I think of it as a sort of the 30,000 foot view of things for the most part and it's almost 10 years since 2002. So the sense is that it's time to get down to the ground level and talk in a very granular and specific way about what needs to be done.

The American Academy of Pediatrics began looking at this as an agenda of the organization. It was identified as a top 10 priority in 2007, a national survey of American Academy of Pediatrics members on healthcare transition issues in 2008 revealed the serious need that they all had for more

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information, more support, more guidance about what to do and how far they all were admitting they were from what we consider to be standards. Over half of the pediatricians polled thought that the transition process could begin around age 18, most of us don't agree with that. And there are other things to accomplish with my fellow professionals.

In 2008, a Transition Advisory Committee was convened at the Academy and crafted a four-part agenda and felt that this clinical report, which is about to be published, was sort of the foundation piece for the rest of the agenda. The report is about implementation in practice, but it also creates a foundation for policy development around reimbursement and financing, development and training of medical education resources and the advancement of health care transition research. And one of the things that I have sort of come to realize is that looked into the research base is around healthcare transition, is that again it is about the pediatrics under the bridge. We don't know too much about what happens or what fails to happen on the other side of that bridge. I think those of you who are parents and family members may understand much of that first hand, but as far as outcomes or concern that are sometimes needed to justify new ways of doing things, we don't have a lot of material yet to point to.

This first item on the agenda, The Healthcare Transition Clinical Report, is in its final stages Of Preparation. It has been

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approved by the Board of the American Academy of Pediatrics, just last week, it was endorsed by the Board of Regents Of the American College of Physicians, which is the internal medicine, internist's national organization and it's in the hands of the board of the American Academy of Family Physicians. So when it is... appears in print, it will be jointly endorsed by these three organizations.

And the importance of that is that documents of this sort represents these organization's statement to their membership about best practice. And it really I think pressures another ship to be really looking at these issues seriously, looking at their own practices and we expect this to appear in the *Journal of Pediatrics* and probably late spring of this year, I'm thinking realistically. And there will be simultaneous reports or commentary in the journals of those other organizations.

In this report targets all youth, it's certainly about children with special health-care needs, but it's intended to say, this is really the kind of care we think all youth and young adult should receive. It's an algorithm based on logical framework for healthcare transition in office settings. In other words, it's exactly what elements do you need to be at a 12-year visit, had a 14-year visit, at a 16-year visit when in a space of time between 18 and 22 or so do you think about transfers of care. By the way, with relatively uncommon exceptions, in other words individuals who have some kind of guardianship

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arrangement, all individuals should have an adult model of care at age 18 whether it's in the pediatrician's office, the family physicians office or the internal medicine office. And what does that look like exactly?

We know there is some guidelines around confidentiality and who gets to hear about what went on in the office and so on at age 18, that all settings need to make that transition whether there is any transfer of care or not. It outlines concrete elements of practice structure and processes. This is really about the nitty-gritty of how do you fit this into a busy office setting. And in our view, from our past experience with trying to change office systems in healthcare, it's really about how do you get something on the ground that can help them start next Tuesday doing things in a different way. And if you don't provide that level of kind of detail, then it's very difficult for change to occur at all.

This extends through the transfer of care to an adult Medical Home and adult specialist. It talks about age 12 making youth and family aware of a practice's healthcare transition and transfer policy. By the way, how many primary care practices do you think have a written transition policy? It's not very many.

Question: ****.

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W. CARL COOLEY: Yeah, yeah. I don't have any data about it, but I know from talking with practices and doctors, they don't. I was talking to a pediatrician in Ohio just the other day who was interested in this subject. Twenty-two pediatrician practices in southern Ohio, he says his 19-year-old daughter has type I diabetes and works in the office. And she works as kind of an office assistant at recently her task was to stuff the envelopes that go up three months before the 19th birthday to say, by the way, our policy is that at age 19 it is the limit. So it's time to start looking for another doctor. And that is part and parcel of their transition policy and transition practice. And he was very candid about why he was calling us to say, can we get on board with what we're up to. But I think it represents what goes on in a lot of settings.

Age 14 health transition plan is initiated, age 16 youth and parental expectations and preferences are explored regarding adult care. Age 18, as I mentioned, the transition to an adult model of care and all settings as appropriate in terms of guardianship arrangements and so on, but I would say that regardless of that, and adult model of care is an appropriate approach at age 18. And it's not the same as a pediatric model of care.

And somewhere in the range of 18 to 22, because practices vary and they probably need to, the transfer of care would take place. And so I feel that should happen after the college years

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are after whatever, but there needs to be some flexibility probably around that.

The content of this report, and as I say, it gets very specific about when to use tools, what tools to use, about transition assessment, transition planning, about having a portable medical summary about the things that adult providers say they need. They need that portable medical summary; they don't want 20 one years worth of medical records sort of arriving in a bundle across the Internet in their office. And they want information. They want facts about this individual's condition if it's a one of childhood onset that they're not terribly familiar with area and they would like to have a twenty-something who's prepared for this new model of care that they're embarking on.

And we have condensed what we think are the three main primary care practice elements; preparation, ensuring that young adults are ready to manage their own health care as independently as possible and families are ready to support this. And by the way, pediatric providers need to be ready to support this, sometimes letting go is hard for many. Planning, assuring that healthcare transition needs are anticipated and responsibilities clear about who will do what and when. We use the word "explicit" a lot in our work, things need to be very, very clear, who's going to be responsible for what. And

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implementation. Assuring a smooth and seamless transition and transfer from pediatric to adult model of care.

So we're basing a lot of our work around practice interventions on the content of this clinical report. I've had the advantage of being involved with its preparation, so I sort of know what's there. The report itself has remained embargoed by the professional organizations until he can go through this process. Believe me, it's a little bit of a delicate undertaking to get all three of these organizations to agree without having to rewrite the report every time it makes the rounds of their review. And some of you may have seen it, it was out for some public comment. We got some wonderful comments from families from Title V people in a lot of states from other organizations as well as professionals. And I was involved in the incorporation of those comments into the final version and I would say that most of them were really, really useful. There was a lot of common comments and I think we've managed to probably embrace most of them as a result.

So that's some of the... that's I think an important thing for you as families and as policy makers that know is on the immediate horizon because if you're planning to work with professionals in your state around healthcare transition, healthcare professionals, this document can truly be your guide and you can turn to it and say to your colleagues, this is the way you ought to be doing things, we're here to help you figure out how.

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And to hear more about that, I'm going to turn things over to Jeannie to talk about our national center's goals. Thank you.

JEAN MCALLISTER: So I'm going to walk us through a little bit of the goals and a little bit of how we're going to get granular, as Carl said. But before I do that, we'd like a little bit of information of who's in the room. So how many MCH Directors are in here? MCH staff? Okay. How many Title V Program Directors, program staff, if it's identified as differently? And then Family Leaders? Okay. And then do we have some program specific people in here that have special programs that you're interested in investing. How many people took advantage of some of the supports from Healthy Ready to Work? A lot. Okay.

So we have this interesting transition, if you will, for ourselves in what I've been calling, "narrow the aperture." And I actually really like it because they want us to focus on healthcare transition. So were not going to be the people providing the technical assistance for everything related to transition. There was a really good session this morning on education transition and healthcare transition, but we are supposed to focus on stimulating some activity around healthcare transition and that's what we'll talk about a bit today.

So the Surveillance and Needs Assessment is in the report as Carl suggested and you can download that, and that is our first goal. The second is right where we are right now, and that is

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stimulating some best practice development, really working and learning collaboratives in some different cities which we'll tell you a little bit about. The third is to stimulate that youth and family leadership and we've got some treats for you along those lines. And we are all learning from each other and then cross-fertilizing in our team and then figuring out the best ways to get that out.

From the first three we're really going to inform the fourth related to policy and then have new information and figure out the best ways to leverage the available opportunities for information.

So this is how we're going to bring it to life. We're going to take a look at what we're learning, what we're learning from the report, we're going to be identifying innovative approaches and building evidenced-based informed practices. We're looking to stimulate activity across different programs, help them learn from one another and continually find out what's needed. And our work helping primary care practices around Medical Home typically teaches us that they need a lot and certainly with this arena, we need a lot and we'll talk about that a little bit.

We've been using the question, why this, why now? Got transition. Lots of questions. Trying to stimulate some answers. And we have some information, but we need more

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and better information. I was wondering this morning why our life's work seems to be the two lowest ranking healthcare outcomes, Medical Home and healthcare transition. It's like, okay, here we go again. But what is really exciting is some of the medical homework began with very little experiments and I think we're going to have the opportunity to do that again. Transition ranks the lowest, less than half of U.S. youth get the support they need. In a Rhode Island study, only 13% of the practices there responded that they had a written policy. And as we might expect, a good degree of pediatricians and internists say that it will be very difficult to identify adult medical homes for youth, particularly youth with chronic conditions.

What are families saying? What do we know, when we learned has been going into this? There's certainly a lack of really clear guidance. Package of information, map, pathway, if you will, people that have been educated to walk that path with them. And then do they want... the families want the same thing the youth want? I've been saying lately that in addition to calling home for money, my kids call home for health coaching all the time. Navigating the system, what to do, how to make an appointment, how to get them to communicate. So what to do in an emergency, how to find an adult doctor, what do I do if I get sick? These are some of the things that youth are suggesting through the surveys and data that we have. And

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then the ever present navigating are very fragmented system, which I think we've talked a lot about at this meeting already.

Professionals. As you begin to think about what Carl said about the algorithm in some of the steps, do they have the resources and the supports and the tools for the steps? Not really. Healthcare transition policies, a package of reliable information, education and nursing and medicine to prepare you for this, it's not really there. Clarity of rules around the transfer of care, that is something that "who's upon first?" Who's going to do that clarity? Who's going to help everyone be explicit about those roles? So that it helps everyone.

And then the development of care coordination. Certainly we've made headways with care coordination and practice, but we really now reads stronger and advanced Medical Homes to be doing healthcare transition. And we need advanced care coordination functions to really help with these activities.

So I think of this as, oh my goodness, we've got a lot to do and we cannot do it by ourselves and working hard was great experts, we have a cabinet, we have some advisors we'll pull together tomorrow, and we also have you. And so that you're not listening to us this whole session, we have like a three-minute activity we want you to do. So I'd like you to take 30 seconds and just write down one word or one phrase about why you think it is so important in February, on Valentine's

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Day, 2011, to focus on healthcare transition. And just shot a word or phrase down. And once you've done that, I want you to just turn to the person next to you, sort of like church on Sunday, and shake their hand and share your word or phrase. And then maybe a few of you will be willing to share with the rest of us. We've got about two minutes to do this. Why is it important to focus on healthcare transition, now, Valentine's Day, 2011?

[AUDIENCE TALKING]

Okay, Happy Valentine's Day! Times up! Singing a song, what can I do here. Okay. That is the definition of a buzz group. You guys, you took about three to four seconds for a roar to come forth. We wanted to tape record your roar. Okay, we've got time for maybe three or four answers. And by answers, I mean a word or a phrase. Yes. Real loud.

Question: Since it's Valentine's Day and we love our children and our youth, we have to provide them with **** to move on to adulthood.

JEAN MCALLISTER: Okay, moving on. To help them move on, we love them. Way in the back with the black top on I think.

Question: Empowerment.

JEAN MCALLISTER: Empowerment, thank you.

Question: Wellness.

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JEAN MCALLISTER: Wellness. Well you guys are so good that we're going to take more than three. Go ahead.

Question: Monica is 16.

JEAN MCALLISTER: Very good. Way in the back.

Question: It's coming.

JEAN MCALLISTER: It's coming.

Question: **** she turns 18 next month, so that's **** so.

JEAN MCALLISTER: It's coming. Yes.

Question: They need to know it before they leave my house.

JEAN MCALLISTER: Okay. And that's coming too. Anybody else have one that just has to get on the air?

Question: **** Anxiety.

JEAN MCALLISTER: For...

Question: We focused on the parent.

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JEAN MCALLISTER: Okay, okay.

Question: Well, and the kids sometimes have that sense of omnipotence. So there could be denial, they really can get hurt... or not.

JEAN MCALLISTER: Okay, one more. Yes.

Question: The older that young adults who have special healthcare needs... the more adult they achieve in years the less equipped pediatricians are to handle those **** and pediatricians cannot take care of chronic adult diseases. [Inaudible]

JEAN MCALLISTER: Okay. So we need to focus on healthcare transition now. It's here today, Valentine's Day. Okay. One of the things that we're doing, and it relates to our goal number two, which is creating those best practices as we have the opportunity to now go from the algorithm that Carl describe and create a learning collaborative to help people actually test the ideas that are being recommended in that algorithm.

So, we're going to be doing this in D.C. and in Denver and in Boston with pairing up of pediatric and adult medicine groups, some specialty clinics. We actually had our first learning collaborative last week or two weeks ago now, right down here in D.C. and it was, again, very exciting because it was a very small group and they were beginning to have conversations. And as I'll show you, the breakthrough series, and when the

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physicians that seem to look "they're having breakthroughs!
They're having breakthroughs!" In the breakthrough was that
they were talking together and planning together, and that was
a breakthrough.

So I'm going to skip through some of this area that how many
people have been involved in a true learning collaborative.
There's so many of them out there now. Okay, so maybe a
quarter of the room. Basically you pick a topic and develop a
charter, very clear what practices are signing on, you develop
measures, we've developed what in our... and for Medical
Home, we've developed the Medical Home index for this.
We've put together some healthcare transition indices are
under 18 age and over. So if you're caring for youth younger
than 18, some of the clinical people are filling both out. We've
created a planning guide to help these identified sites set up
and run a learning collaborative with our help, and then we'll
be doing that breakthrough series, learning collaborative and
doing some measures and harvesting of those best practices.

So your mini class in improvement for today, the model for
improvement says, what are we trying to accomplish and we
say, we're trying to accomplish prepared plan, successful
healthcare transition because Valentine's Day, we need to do it
from now going forward. How will we know that it changes
improvement? Well use the Healthcare Transition Indices and
some other measures. What change can we make that will

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result in an improvement? What we're doing is taking the algorithm and overlaying it with what we're calling the six core elements of healthcare transition improvement and working with these learning collaborative teams who have youth and families on them to test those changes simply with two youth the next week. Not to put a healthcare transition program in place the next week, but to begin to test some of those changes.

This is a busy slide and I won't take the time to go all through it, but I would focus on the three boxes in the center because our national center is doing a lot of the pre-work and packaging and identifications and tools, but those three cities, the teams there will go together. Learning session one and action period, learning session two and action period, learning sessions three and then hopefully will harvest some really good ideas, some really good experience and as you know when practices come together to learn something new, they want to hear some other practices that are doing it and we haven't had that. So hopefully we'll have that.

And so during those times, they'll be learning and going back during action periods and trying things and sharing those on conference calls and webinars with us. I mentioned the six core elements of healthcare transition improvement and this what we've put together so far for the pediatric and adult healthcare setting with tools developed for each of those six steps and those will be overlaid over the algorithm. More

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simply, it looks like this, that we've created examples. What do you mean by a healthcare transition policy? Well here's three examples, take a look at it, cross out some words, put some new words in, make it your own, own it, and use it.

A registry begin to identify youth that they're following with a variety of things. Some of those preparation things and there we're having them test readiness assessments and develop transition action plans together. And then we will move on in learning session two and three with really testing out transfers of care, more transition to an adult healthcare model and looking at and following up so that the cliff is not what we're always talking about, the drop off the cliff, but we actually can document some success and what it took explicitly across those different points in the healthcare continuum.

So to sum up this section when we did a session on Saturday that was all about the relationship between public health and primary care and what folks charges and what they're sort of intent is. And I see a lot of parallels today and for you all in your rolls. What is your outreach and how are you creating partnerships with primary care. What are you doing around family engagement because primary care need a lot of explicit, if you will, examples on how to engage families and then what about care coordination. A lot more care coordination is being developed in practices, but they need to know what's going on

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outside the practices so they can link up and have communication out and communication in.

So that is what we're up to and we're just embarking on it, so stayed tuned. So we'll have a lot to share, I believe.

And I'm going to pass it off to Mel and Eileen.

EILEEN FLORENZA: So, like Carl said, when we first submitted our Abstract, Mal and I had you know a presentation planned and these guys did. So this is a little bit of a shift right now. But what we wanted to do was really bring it down to real stories and real people and real families and real experiences. And so when you think about all of the work that's going into the dataset, the development of the national center, what we want to do along the entire process is assure that we have the family and youth perspective.

And one of the things that we're looking at is to kind of level set so that we are understanding. In the adult model we know we talk about patient-centered care. In Geriatric and pediatric we talk about family-centered care and what we want to talk about is just the return on investment on our work and that we know that when we engage the end-user, if you will, in the services that we are developing that the quality is so much better. And that's the role that Mallory and I will be providing with the national center.

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We did handout at the very beginning this goal that indicates, just you have it in front of you, around goal three of the national center is, again, to assure that the voice of youth and families is strongly embedded in the development of the national center.

So what we wanted to talk about is looking at what Mallory and I have been experiencing, like from the parent role and from the youth role is this really interesting game of deficit-based language and strength-based language. And we call it a “game” because we felt like we were really, you know, having to maneuver. So what we were talking about was, you know, in the pediatric, in the children’s system because a lot of it is based in education and because of the way things work in children’s systems, it’s really about entitlement and when you’re a parent of a child that’s served on an IEP and through the other children’s services, it’s really about you are entitled to certain services just because.

But then when you move into the adult system, it’s all about eligibility. And it’s all about proving what you need. And so what we found is, all those years, what I’ve found as a parent, of all those years of really talking up all the great things about my daughter and all the things that she can do and what I’m so proud of her and all the things she can do. You know what? Wrong idea.

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So in accessing adult services and now I have new case managers and all this new kind of language, I had to say. Oh no, she can't do that. No she can't do that. No, no... NO! She can't do that. And I learned that as hard as that is for someone like me who's totally an optimist and always looking at the bright side, it was difficult. And then in talking with my dear friend Mallory, guess what. She was experiencing the same thing. So.

MALLORY CYR: So, what we want to do is, again, because we have all been sitting for the past, however many days you've been here, we want to get you really involved in this and kind of feeling and thinking about what we're talking about because it's really something you have to experience. So what we're gonna do is, do an interactive activity and for two minutes, you're going to turn to the person next to you and describe your loved one or someone that, you know, has brought you into this world of children with special health needs and NCH, or just someone you care about and take two minutes and describe them using strength-based language and then two minutes describing them in what we call "deficits-based" language. And then we're gonna take a couple of minutes to talk about how that was.

So, ready and break.

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[AUDIENCE TALKING]

EILEEN FLORENZA: So, we'll work through this and do you want to say, do you want to share your story first. Because I listed you first and then me.

MALLORY CYR: Okay.

EILEEN FLORENZA: Okay.

MALLORY CYR: And like I said, just, I mean if I babble, just cut me off.

EILEEN FLORENZA: Well, some of the points I'll tell you that really touched me when you shared it with me was even as far as you had to hide your iPod. You didn't want to wear makeup, you wanted to look as destitute and how that made you feel.

MALLORY CYR: And how afterward it was like, what do I have to do to get **** and who I actually am, right.

EILEEN FLORENZA: Which will then lead us to this piece about, amazing how I'm having to go through that, made you even just start feeling like, you know, like you said, I worked my whole life to feel positive about who I am and then...

MALLORY CYR: And that's like what gets us through day-to-day.

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EILEEN FLORENZA: So, cool. I don't see Cathy in the room, do you?

MALLORY CYR: She's in the very, very back. I saw her for a split second.

EILEEN FLORENZA: So I wonder who this young woman is talking to Emily, do you remember?

MALLORY CYR: She's Heather from Kansas. I'm actually going out there the end of March to work with them. So, she's fantastic. And she's...

EILEEN FLORENZA: Oh, I just remembered. Right, I met her in October.

MALLORY CYR: She's doing their youth retreat that weekend and she wants me to come in for the family retreat before then, so.

EILEEN FLORENZA: Yeah, I remember when she was hired. Their new Director was excited because she was young and that she was bringing in new **** of energy.

MALLORY CYR: Very cool. I'm gonna give them like one more minute. We have a little clock. You have about one more minute to finish your conversations.

EILEEN FLORENZA: Maybe we could ask a probing question, how many of you say talking in strength-based **** was easier just to try to get some **** in the room. Okay, should we bring them back now.

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MALLORY CYR: Yeah. All right. And we're done.

EILEEN FLORENZA: Just keep talking.

MALLORY CYR: All right and we're going to get... Hello. Reflection time. Everybody. Silence starter. And we're almost there. Heather and Emily down in front, thank you. Cool. Hey that's what you get for sitting at the front of the class. And when I can see everybody. Okay. So who would say that speaking about your loved one in strength-based language was easier and was more fun?

So then, let's shout out some other emotions when you were talking in strength-based language. It was fun... it was... what else?

Question: Empowering.

MALLORY CYR: Empowering.

Question: Positive.

MALLORY CYR: Positive.

Question: Uplifting.

MALLORY CYR: Uplifting.

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Question: Hopeful.

MALLORY CYR: Hopeful. Cool. Sorry?

Question: Energetic.

MALLORY CYR: Energetic. Nice.

Question: Happy.

MALLORY CYR: Happy.

Question: Interesting.

MALLORY CYR: Interesting.

Question: Joy.

MALLORY CYR: Oh, joy.

Question: I think it's ****.

MALLORY CYR: Yep. Great. Okay, so then when we switched and had you talk using
not so positive language. How did people feel?

Question: Bummers

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MALLORY CYR: Anxious, bummer.

Question: Mute.

MALLORY CYR: Mute.

Question: Sad.

MALLORY CYR: Sad.

Question: Angry.

MALLORY CYR: Angry.

Question: Guilty.

MALLORY CYR: Guilty. That's a good one.

Question: Clinical.

MALLORY CYR: Clinical. Okay. Cool, so that's kind of a little, a look into how that process feels for families and eventually young people who are going through that process.

So, Eileen and I had a conversation this summer, and I don't even remember what kind of prompted it, but we had both had experiences with proving eligibility in the system. And we just

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kind of got to talking about how weird that was for us and how it was sort of this language that you had to switch it out and it just was this weird feeling like you all said. And for me, it was an interesting experience because it was the first time that I had had to do that on my own. And I had always kind of been present for my eligibility interviews with my parents, but this was the first time that I was really doing it by myself.

And for me, when I get up in the morning, I do my hair, do my makeup, go on my laptop, I have you now, my cell phone, my Blackberry, all this stuff and when I got up the morning for my eligibility interview, I was like, okay. I have to look sick. They don't want to see this Mal. So I like get out of bed and I'm like, okay, I'm not gonna wash my face, I'm not gonna... like what is it... like we work so hard on not stereotyping, what it looks like to have a disability. And I'm like, okay. I don't know. But I was really aware all of a sudden of everything I was bringing to the table. And so then when the woman got there, she asked really invasive questions and I was very conscious about all the words that were coming out of my mouth. And every time you know, I would say, well, yes, I can do that. I would think for a second and I would be like, but it could lead to this and I have to do this to prevent this secondary issue that could happen, that could be expensive. So, no, I can't do that. Just kidding, don't check that box.

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And so, you really second guess everything you say and it's kind of like you're on a game show or "Survivor" or something, you know, you're like, oh my god, don't take away my services. I have to say the right answer.

And so when she left, I had talked about all the things I couldn't do and how my living situation was really hard because it was an interview to get in home support because at the time I was trying to live on my own. And it ended with, "Well congratulations! You qualify for nursing home level of care. But I know you choose home." Well yeah. I choose home and you know, my family and my friends and school and my job and a lot of things that normal young adults would choose over that. So, but it was, even in the way she said it like, you won the game. Yes! But when she left I was left feeling like, oh, my life really is kind of hard and scary and there's a lot I can't do and now I'm kind of bummed out. And I really had to kind of shift my mindset after that. And I actually wrote an essay about the whole process because I just really like burned me. And I was like, ah that's not fair.

So after that, I really had to process it and take time to you know, go up and take a long shower and straighten my hair and put my makeup on and go, okay, you're well now again. So it's... and I had realized how sheltered I had been from that whole process with my parents doing it. But at the same time, I had learned the rules of the game, which I realized was so

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crucial and that's a skill set that isn't prepared for that young person, then it's way too easy to say all the good things that they don't want to hear. So it was very... it was an interesting process for me to go through and to see how to play the game, win the game and then bounce back from it. Whereas, most times the victory is something you feel good after.

Eileen, do you want to talk about your experience?

EILEEN FLORENZA: Sure. Thanks Mallory. So interestingly, as a parent, I have been preparing, best, I thought, for you know, since she was 14, got her on the list in the Developmental Disability system and all of that. And I think one of the best supports that I was able to access were my mentors in my life, one of which is in the audience today, Christie Blakely, who is the Executive Director for Family Voices in Colorado. And without Family Voices and without Christie's guidance, I would have been still floundering.

And so even as we were moving into transition and my daughter's non-verbal, so unlike Mallory's situation, I do feel this extra set of responsibility 'cause I have to be her voice exponentially. And yet when it happened... when it happened, the transition after 18 and then 21, I was shocked at how hard it was. And how hard it is. And it all kind of came to a head when we... she was being re... having a reassessment meeting and the case worker came out and spent about 20 minutes in

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our home. And this is a long-term care case worker for Medicaid. And... or the agency that's doing the Medicaid work.

And within 20 minutes did this assessment and then went back to her office and did the report and came out with a report that did not truly reflect my daughter's needs. And indicated just things that were not true. And while I was so afraid of what that meant, I wanted to believe it too. Like even though her report said, she can dress herself, she can't. And even though report said, she can go to the grocery store and shop for herself, she can't. And it was like, I wish that she would know how hard that was for me to see, in your eyes and in black and white paper and was far as the Medicaid system was concerned, my daughter could do all of that, she can't.

And so it's that fight of saying, thanks for believing her and first of all, I don't even know what kid you were looking at because that's so not even close. And so one of my nursing friends... anyway, I called Christie White right away because five days later, we got the letter from Medicaid that Holly's allocation, here benefits package was cut almost in half. All because of a 20-minute intervention with a case worker who had never worked with a non-verbal person before and all of the other things.

And again, called Christie right away and said, what do I do? And she, you know, you've got to file and appeal, you've got a

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couple of days to do it. We're actually on our way to another trip here in D.C. and we're doing it in our hotel room on our laptops and she's walking me through it the whole way. And I am an English-speaking systems person. And I just can't imagine what that would feel like for a family who don't even have these kids of supports.

And so we went through the process, did the appeal and even preparing for the court hearing. And I just... it was like having to speak at all of the things that Holly cannot do. This is Holly, but the way, all of the things that she can't do, and it's just like... it was like, why do I have to... why, why. Why do I have to go through this again? Why do I have to say, "No she can't." Can she wipe herself? "No." Can she comb her hair? "No." Can she tell you if her stomach hurts? "No." Can she catch herself when she fall in a seizure? "No." So it's like for me, bringing back up all of the stuff that for years, I'm like Holly is the delight of my life. She's the teacher that I've always wanted. She's the joy of my heart and blah, blah, blah.

So it's just so interesting that Mallory and I was going through this at the same time. And I am the parent of a child and she was the youth trying to like speak it out. And it just so happened that the AMCHP Abstracts **** were like, "We need to write this down."

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MALLORY CYR: Bada Bing! Put this in a Power Point quick before we forget. So, we have to use this. So this... yes.

Question: Sorry to interrupt. I'm a dad, I'm the dad of that little girl, I'm Eileen's husband. And dad's go through the same stuff. And I made the mistake in that interview saying that Holly made her way downstairs and ate some meat through the plastic. And they wrote down that she was ambulatory, that she could walk and that she could feed herself.

And I'm a CNA, I'm an advocate, and this isn't about me, but I would hate to forget that dads are going through this same stuff and a lot of times, it's from a whole different perspective and seeing them a lot less and not getting stuff. And so...

EILEEN FLORENZA: Thank you for the reminder.

MALLORY CYR: So when Eileen and I were going over our Power Point, she goes, there's this one slide with this cartoon on it and I don't get it. Did you do that? And I was like, yes Eileen, that's the pink elephant in the room. And she goes, "Oh, because..." Because what nobody really talks about until we come along is the fact that doing those eligibility interviews and going through that negative, heart-wrenching, tortuous process every year for some things, it takes an emotional toll on you. And so I really saw that as something that, well, duh. But it doesn't really get discussed and so I think this is a great opportunity and sharing

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our experience is something that we recognize that that process takes you through various steps. It introduces the grief cycle, and when you're stuck in that place of, wow! You know I really feel defeated, my child really can't do a lot of things. When you're thinking in that way and you're in your dark place, that makes transition planning really hard because you're not forward thinking. You're stuck in that place.

EILEEN FLORENZA: All I would really want to add to that is that as a parent going through the transition year starting at age 14, and then 16, 18, there are other milestones that are not achieved typically. Holly doesn't, you know, our kiddos don't get their driver's license, they don't get asked to prom, they don't participate in graduation. So it's like... it's enough already that we have to go through this transition with the documentation and do all of that and then to be able to move to the adult system and speak professionally and have the kind of presence and poise and savvy in the system that... because we want to be partners on our Medical Home team and we really want to be wise healthcare consumers. And we have to be real, but we have to play the game.

And it was just something that, not... this is not an effort because I work in the state system and this is not a way to say... I'm not here to say that the people in the system are bad people because we all do this work because we care and we love the population that we work with. Sometimes it's just this

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“System” of work and the eligibility criteria that we have to go through. So please don’t misread the comments of being down on the people within the system, ‘cause I’m one of those people. So you know it is. And many of you are as well.

MALLORY CYR: Do you have a comment?

Question: Along the same lines, I just want to say, I’m a Parent Navigator and I also have four children who experience special needs and like I tell all my families, I said, it’s all about networking because it’s so different when you do that for your own child versus when you’re helping another family. And it just makes it so clear to me how we all need each other and if you’re... it’s not that you don’t know what you’re doing when it’s your child, but it’s so emotionally charged. But that’s what gives you the power to help other families.

MALLORY CYR: Thank you. Okay. So as a result of coming up with this presentation, we’re think of what could be some takeaway points and things that we wanted to send with parents and youth that would make them feel stronger in various aspects of this as someone... how to be advocates when going through that process. So we came up with a top five list of strategies for healthcare transition as a whole and there’s one for parents and one for youth and those are handouts that we’re going to be passing out. So, and I won’t go over them.

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EILEEN FLORENZA: Since we're short on time, maybe we could just say, these are the handouts and we'll give them out and then we can open it up now for questions, how about that?

MALLORY CYR: Okay, perfect. I love questions. So. We'll hand them out and you can look at them kind of on your own time and we'll jump to questions. Yes.

Question: I actually have a comment. When I talk with families about this process and they said, well why do I have to do this, why is this so hard. And you know, it's the rules, it's the game. I want to **** the fact that we have to do this really hard process and be very truthful because there are people out there who commit fraud. So the process has to be hard. It has to be difficult because there are people who fraudulently present themselves as having disabilities or present their children as having disabilities. So we have to be very upfront with what our kids can do, what they can't do in a truthful manner and that it's not the system getting us... It's the system looking to be very strict on finding those people who are fraudulent.

EILEEN FLORENZA: I agree. And my comment to that... thank you. And my comment to that would be simply an awareness that for the non-fraudulent folks going through the cycle, just to be aware of the... have that family-centered approach, the cultural responsive approach to understanding the emotional piece that goes along with it and you made a great point. Thank you.

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MALLORY CYR: Thanks. Joy.

Question: You know, in listening Eileen's story, you know we're all encouraged to make sure our kids are part of all of these meetings and then I spent my daughter's whole life telling her all the wonderful things she can do, every time she says, but I can't do this or I can't do that, you know, I turned around, but you can do this and you can do that, and look at all you can do. And then to watch these kids sit in this meeting where everyone is only talking about negatives for her. She ended the meeting the first time, she had to go through her review and looked at the woman and said, just find me some place for my mother to give me away then. Why does that woman have the right to come into anyone's life and make her feel that way.

MALLORY CYR: And that's such a huge point, and something that I wanted to touch on too was that, when you're in this world and as a young person with a disability and challenges and as parents, that's how we get through the day-to-day is reminding ourselves of the positive, of the things that keep us going, that we're good at. Why we get up in the morning. And then to be you know, put back in that box of all the things you can't do, that's why it's so important to recognize that process and have... be able to bounce back and remember those positive things. And it is such an unfair process. And that is truly how it affects people.
Peg.

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Question: I really think we have to figure out a way to address this from a policy perspective. Because I understand what you're saying about fraud, but there are bank robbers, I don't have to be frisked every time I go into a bank. You know, and it's just not fair. As a way to implement. We could... this is great, but this is the Band-Aid part, meanwhile, put a tourniquet on a bleeding artery. You know, how?

MALLORY CYR: Exactly. And that's huge... Well good, let's do that. Right that down Carl.

Question: ****. I'm sorry, but what about like take a page from like, you know, well not that it's the best system but special education where you talk about the deficit and the accommodations, I don't know there's something about it that makes me want to say, well, "No, she can't do this, but this is the way we get around that." I don't know. I know that's not necessarily going to get you the support that you want, but you know, I guess ideally you want to change that so you can be on **** like we expect our educators to be and we want that in the health system. That's...

MALLORY CYR: Exactly. Yep.

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Question: Yeah, just the point I'd make. I totally agree, talking in strength-based is what you want to do, but when you are **** talking to the system and trying to get needed benefits, I go negative.

MALLORY CYR: Right, exactly.

Question: It's not a problem with that because that's just how the system wants to hear the negative and that's the time to talk about the negative. At home, friends, family, it's all about positive. But there's a time and place to stress negative. And that eligibility meeting is definitely the time.

MALLORY CYR: Exactly. Exactly.

Jeanne McAlister: I was gonna say, we have seven minutes remaining so if there's questions also about the first part of the presentation...

MALLORY CYR: Beth.

Question: Well, this was more about the first part, but thank you.

MALLORY CYR: That's fine, jump in.

Question: I know that families need support for transition and primary care for pediatric **** needed, what's going to happen to support the receiving end on the adult side?

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W. CARL COOLEY: Yeah, that's, I mean that's the big issue in a lot of people's minds, that it creates the belief that there's no one out there. It creates the belief that the adult providers aren't interested...

Question: I'm not saying they're not interested, I'm just saying they... I think they need support too.

W. CARL COOLEY: They do. They do. And I think part of it has to do with developing for them, a model of care for 20-somethings coming into their practice. I mean, what's the difference between a new patient who is a 55-year-old with hypertension and diabetes or a new patient who is a 24-year-old who has a very complex childhood onset condition that they have very little experience with. We're trying to get planning to try to get that side of the bridge some of the tools they need to redesign in their practices to accept a new patient who is a 20-something, well actually whether or not they have any special healthcare needs. It's different than somebody that's a veteran of the adult healthcare system if you're 60 or whatever.

So, we're working on that. It hasn't been addressed for as long as the pediatric side of the bridge has been **** a mountain of materials for this.

MALLORY CYR: Yeah and...

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Question: What's to keep the pediatrician and the adult provider from talking to each other? Also so they get that background.

[OVER TALKING]

MALLORY CYR: All right, all right... Jerry Springer... Okay. Bring it back. We just have a couple of minutes left, we're just going to take a couple of questions. In the back.

Question: My question is, what has been the observation, the experience with youth who have mental health challenges and mental health disabilities in ****, what have you seen, what have you observed, what are the concerns?

W. CARL COOLEY: Well, I guess the simple answer to that is that we've observed that no youths seem to have this handled very well. That... whether they have mental health issues or mental healthcare needs, or none of those issues. Everybody... almost everybody just kinds of drifts away from some time they stop going to the pediatrician and maybe they find someone else. Many of our children our young adults as children are not going to be outside the healthcare system for very long 'cause something is going to happen. A lot of you still regard themselves as needing healthcare until they're 55, so they have to work on that mentality.

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I think for mental health issues, and that's a broad topic. One of the things that we've seen in New Hampshire is that many adults with complex mental health issues are getting all of their care, such as it is, in their mental health center, it's not the health care... they're not going anywhere else, but they're not getting their health care needs met. So to some degree, that's a medical ****, where is the medical for those individuals and maybe find ways to integrate and certainly intending to pay attention to that.

Question: And I would just add to that that the learning collaboratives, there is so much emphasis in healthcare right now on value. So if there's investment in families and in youth and in pediatric practices and those providing pediatric care, there needs to now be support so that we don't lose the value of that and it is passed off and transitioned and transferred so adults learn from it, learn that history, learn that content. So all that value and all that investment is not lost. That needs to be invested in future success of that young person.

MALLORY CYR: We have time for one more question, that gentleman right there.

Question: Thank you for a great presentation. One of the things that I've observed is that kids or young adults being recycled to adult medicine back into pediatrics. I mean, that's a big recurring problem in that they... they're send with best intention. Do you think that this, what you just presented here could be a contributor to

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that? I mean, and then as pediatricians then we take them back and we wait a year or two and then it happens again. I mean, do you have any sense of why or how to deal with this recycling of youth... you know what I'm talking about, right.

****: Is this the kid's decision or because of a practitioner's decision?

Question: Both often. But I'm wondering if the deficit conversation contributes to them saying, gee, I'm going to go back to Dr. Coolig because he really understands...

MALLORY CYR: I personally haven't actually heard of that happening, honestly, so I can't speak to that. Carl, or Jeannie, can...

W. CARL COOLEY: I think it's... it's to be it represents the fact and why we're all here is that we haven't solved all of... I mean there are many challenges buried in this health... why this hasn't happened. And it's nobody's fault. Everybody would like to provide good care if they're a healthcare provider, every... all of us would like to have good care. It's kind of a systemic issue, but it includes people's education, it includes the financing system for healthcare, it includes a lot of factors, I think. **** that kind of solution where, you know, the transfer is attempted and it bounces back and it doesn't work. You know, the elements aren't built-in, you know. We're going to be working a lot on that conversation. We think that there's a period... if there's going to be a transfer of care to new providers, there's a period

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where they both need to be involved. There's actually a model where the pediatrician can change from being the primary care provider to being a consultant. And you know, the primary care is transferred; the pediatrician continues to have a consulting role. There's a billing mechanism for that, there's a way to make a business model around that. So, I mean,...

MALLORY CYR: Excellent. As Carl said, "Help is on the way!" So we are putting... we are passing the handouts around and we are just out of time. So thank you so much for coming, everyone have a great evening.