

AMCHP 2008 ANNUAL CONFERENCE

WE ARE MAKING A DIFFERENCE:

LEADERSHIP, INNOVATION AND INVESTMENT IN MATERNAL AND CHILD HEALTH

Making a Positive Impact for Children with Special Health Care Needs Through Cross Systems Care Coordination

March 1st to 5th, 2008

MARY KAY HOLLERAN: Hey. Good afternoon. Thank you all for coming. In an effort to try to stay on time, we're going to try to get started now. And hopefully if people keep filtering in, there's plenty of room yet. I just want to make sure you're all in the right place, that this is where you want to be. This is a little presentation about our caring program, Care Coordination for Children of Healthcare Needs. And what we'd like to share with you today is making a positive impact for children with special healthcare needs through cross systems care coordination.

We have an hour and a half. And probably Amy and I will be speaking at the speed of sound so--you can't hear me. Thank you. We're going to say it sounds like we're screaming, so please let us know if you can't hear us. That we're certainly going to have time at the end, though, for questions, as well.

So I'd like to first introduce myself. My name is Mary Kay Holleran. I'm the director of caring program. This is a program through the Caring Foundation at

Highmark. It's part of Highmark Blue Cross Blue Shield, but it's actually the Caring Foundation that we're through. I'm a registered nurse, and also very dangerously also have a degree in Business Administration. I've been working this program for the last four years, so we've been very blessed to be able to implement this program through the caring foundation.

My background has been in performance measures which probably led me to this place, is to try to do a program like this and yet put some evaluation criteria around it. I also sit on a couple of panels with NCQA, the Women's Health Measurement Advisory Panel. I was actually fortunate to be sitting a prenatal panel that was done in conjunction with the CDC and many different organizations through NCQA, as well, sat on the (inaudible) panel that helped develop the auditor's exams for that and have been very fortunate to have co-author a couple of articles, as well.

So with that, I'm going to turn the podium over to Amy Shannon and let her introduce herself and then to get you really started into the presentation.

AMY SHANNON: Now, dancing is not in my background. But you're going to see us doing this little dance up here at the podium all afternoon here. I want to first thank you, as Mary Kay did as well, thank you for being here today. We're really excited to share with you information that we believe has made a positive impact on children with special healthcare needs.

Again, my name is Amy Shannon. I'm a licensed social worker in Pennsylvania. And I've been with the Caring program for the past four years through the development and implementation. A little bit of my background prior to coming to the Caring program, I have worked in the child welfare system investigating child abuse as well as working with children who were--or are dependent on mechanical ventilation and reside in their communities throughout Pennsylvania and supporting them in the cross-systems coordination in their care in the community. And really working within those systems is what led me to come to the Caring program, looking at a very bigger, broader picture and how to make some systems change.

So with that, we want to tell you a little bit about what the program is going to be about. Where we're going to go with this presentation is we're going to what the caring program is, where it resides, how we're funded, the children that we work with, the population specifically within children with special healthcare needs, looking at what support and services we provide these children and families, how we work with them, and as well, how we work with the graduate school of public health through the University of Pittsburgh to evaluate the program by both on a social measure as well as on a cost and utilization impact, as having care coordination.

So if there's anything else that you're thinking that you were hoping to get out of this, please feel free to say so now, and I'll let you know if it's in there. And if not, we'll add and answer your questions. Also, it's an open dialogue throughout this. Please feel free, as Mary Kay said, to ask questions while we're going along. But we also plan to leave a few minutes at the end for additional questions.

I wanted to start with where the Caring program is at and how we came to be within a foundation. I know many folks who are here today are funded through government funding, both Federal, state and local funding. We actually at the Caring program are funded through the Highmark Caring Foundation. And just to kind of back up a little bit and give you a little bit of history about the Caring Foundation.

We are physically located in Western Pennsylvania. And for anybody whose familiar with Pennsylvania, it used to be a very big steel town, lots of mills along all the rivers that we have. We're the city of bridges. And in the early '80s, the majority of those mills started to shut down. And when that happened, community members came to Highmark and said, "Listen, we have a problem. It's one thing for us to be unemployed as adults and uninsured as adults, but our children are uninsured, and that is very concerning to us."

And the community said to Highmark, "How can we work together?" And what happened--and that's why you see the two top boxes of Highmark and the

community. They came together because Highmark agreed that we needed to do something. Children weren't playing. Children weren't being seen medically. Children weren't getting the regular checkups, let alone emergency care checkup.

And so Highmark worked with the community to implement a program, which was called the Caring Program, to really look at an insurance product to support these families. And that was a model that was used to help develop what we know today as SCHIP, the State Children's Health Insurance Program. And for up until about three years ago, that CHIP, the Caring Program, and then, CHIP, as we know it today, was administered under the Caring Foundation. A few years back, we just did some realignment, and now, CHIP is under Highmark Proper, as we refer to it.

As that began to develop, as CHIP and that model of insurance began to develop, the foundation working on its, you know, from its foundation being the social mission of supporting children and families who are at risk and underserved, looked at children with special healthcare needs and heard from the community again that needs weren't being met. Children didn't have coordinated care. Families didn't know how to access community resources. And at that time the foundation applied for a SPRANS grant and implemented a care coordination program over the four years of the grant and identified that there was a need for coordination of care even then, bringing specialists and primary

care physicians together with educators, connecting families to financial resources and community agencies.

When that funding ran out for that grant, unfortunately, the foundation was not in a position to continue to fund that program. And they were really working diligently on implementing CHIP, working with the state legislatures. And so that program, in essence, was time-limited to that grant and did not move forward after that. But the issues didn't go away, as all of you know, working with children with special healthcare needs. But in the meantime, the foundation did begin to develop what we now refer to as the Highmark Caring Place, which is a program for grieving children and families. Because again, the community came back to Highmark and said, "We have another issue that's affecting many, many of our community members where children are losing loved ones."

And based on that need, Highmark supported the Caring Foundation in developing what we call the Caring Place. It's a peer support program for grieving children and families where they come for support through a volunteer program run by our volunteers trained by our clinical staff. But again, as I mentioned, over time the issue of children's special healthcare needs didn't go away. It continued to resonate, and the community continued to talk with the foundation to say, we still need help around this issue.

And so in 2004, our executive director went back to the board of the Caring Foundation and said, "We really need to revisit this issue." We implemented a program in 1989 with the SPRANS grant to provide care coordination, provided the up-to-date issues and statistics in the research. We also did focus groups with our members through Highmark and really demonstrated to the board that there was a need for care coordination across our region--the Highmark region. And the board agreed, and the board has supported us now for four years. They are our full funding source at this time. We don't have any external source of funding.

Any donation that's made to the Caring Foundation is a dollar for dollar match. So if the community donates ten dollars, Highmark also gives us ten dollars. So that helps maintain our funding. But, you know, with anybody, we're always looking for additional funding resources to continue to build our program and expand it.

To give you a sense of the territory that we cover, Highmark covers all of this blue territory, which is 49 counties of Pennsylvania. And that is where we have been able to implement the Caring Program for children with special healthcare needs. It's a pretty huge area, obviously. And for those of you not familiar with Pennsylvania, we have, you know, some really densely populated cities within Alleghany County. We don't cover the Philadelphia area. That stops right there. But your Lancaster, Dauphin County and that area. That's your Harrisburg area,

much more populated. And Erie is pretty densely populated. And then, all those surrounding counties are pretty rural. So we've got, you know, some discrepancies in what resources are available between rural and urban areas that we provide supports to.

And in trying to cover all those areas and thinking about our program, how do we identify the kids we're going to work with and get that distributed to our staff, Mary Kay is going to explain that process.

MARY KAY HOLLERAN: Thanks, Amy. I also want to share with you--we're referring to the organization as Highmark. It was initially Blue Cross of Western Pennsylvania in the Western side of our state and Blue Shield on the other side. So we are a Blues--Highmark is a Blues plan. So I wanted to make sure everyone recognize that. So we're really coming at this probably in a much different direction, as Amy said, than many of you are funded--that we're actually coming through an insurer.

So in the next piece of this, we wanted to share with you how we identify populations. Many of you--if you're working through Title V programs--those children and families are fed to you a very specific way through state and Federal agencies. We actually now, because we are based in an insurance company, have multiple ways in which we identify these kids. They've been a very rich resource for us.

If these children have been enrolled for any length of time, we can actually use claim data. We use identifiers--the same identifiers the ICD-9 codes--that through NCQA's CAP survey for children with chronic conditions--same ICD-9 codes. So what we wanted to do was look for a standardized set of codes, which really isn't very easy to do at this point.

So besides that, the only thing that we thought was very important to add to that, that those CCC ICD-9 codes don't have, were major organ transplants. So that's the only caveat of not using that really strict claims identification method. We also stratify those claims, and I'll probably go into that in just a little bit more detail later. But we try to ensure that we're letting the care coordinators know whether these children that have special healthcare needs should be severe, moderate or low--are our three classifications.

And there are some diagnosis--cerebral palsy, spinal bifida, epilepsy, diabetes--become automatic severes for them. So there's no question that they don't have to look for additional stratification. But for example, a child with asthma--even though according to the CAP survey, that should be a child that has chronic, persistent asthma, but it's not always coded appropriately. You know what they say--garbage in; garbage out. So if we get some code that comes up and it turns out to be a child that has allergies but has had one identified asthmatic

intervention or episode through an emergency room, we don't want the nurses going out and making undue calls to those families.

So we also look at--in stratifying these children--how many times they've been to the emergency room, inpatient admissions, prescriptions per member per month, the number of specialists they see. So all of those different things help us stratify these children into severe, moderate or low.

We also use the CAMI, which--do I have that here? I just wanted to give credit where credit was due. Is that over there, Amy? So if anyone in the room is from Oregon and was part of the implementation of this, I wanted to definitely give that credit. This is actually down, I believe--I think in the Commonwealth Funds, they had a whole section in there--booth down there--that had all of this information in it with the national survey information.

CAMI is a nationally recognized non-profit initiative that was developed to facilitate the implementation of a comprehensive set of consumer-centered quality measurement tool. The CAMI is based out of Oregon Health and Science University's Department of Pediatrics and was established in 1997 at FACT the Foundation for Accountability. It's funded through grants from the Maternal and Child Health Bureau, the Commonwealth Fund and other funding organizations, as well as via contracts for consulting and technical assistance.

The CAMI basically is a non-categorical survey. And it basically says, "Does your child use medications for at least 12 months that is greater than other children, seeing specialists in that amount?" It's a copyrighted survey, so there was nothing that we could do on the front of it. That was very valuable information. But we knew if the parents were going to return that to us, they might be willing to be more specific. So we actually put a page on--a second page of that, that actually had, like, in school, the Scantrons that fill in the bubbles, and they could identify their child had chromosomal abnormalities. They had diabetes, asthma, epilepsy--you know, any of a certainly subset of chronic conditions that we would know automatically would be a trigger for us to want to go and intervene with those children.

We're also fortunate because these children in our program are in the state's Children's Health Insurance Program. And so we actually get a stream of information in that is on the medical assistance and CHIP application where the parents can self-identify a special healthcare need. Those aren't always specific enough and makes them necessarily eligible for our program, but it's another great identifier. And it's a great way when the nurses go to call these families, they can say, "You noted on your application that Susie had X." So it's a nice way to go in and be able to introduce ourselves to the families that we're calling.

Also within Highmark, we have a care and case management area called Health Management Services. When they get a case and they recognize it's beyond just

an authorization or a referral to a rehab hospital or something along those lines to see a specialist, we actually have monthly meetings and monthly feeds of information from them to our program. That is another--just a wonderful source of information for children who really could use the specific services that we're able to offer.

And lastly, there's the community. When we first started doing this and would be an advocate for families and we went to physician's offices with families to be their medical eyes and ears and interpreters, some physicians--to be honest with you--were kind of perplexed and were wondering exactly why were we there? We're with Blue Cross. Were we going to be doing something for credentialing or was this part of a site visit that we were trying to throw in there? And they were a little bit suspicious of what we were going to do.

Once those physicians got to know us and know what we were doing there, that they actually became a great ally to us. They're actually referring families to us that we really cannot necessarily have this higher level of care coordination and go with these families to visits and do home visits. But as Amy noted, we're part of the Highmark Caring Foundation. And because the Caring Foundation can really service anyone, we definitely can provide information and resources to those physicians.

We never leave a physician's office that we go and visit without giving them a copy of our resource and information guide. There's a copy of that on the back table that I think Amy will be talking about a little later on. And some of them are services specific to the state of Pennsylvania and possibly even to Allegheny County, but others are national resources. So, you know, feel free--we want everyone to be informed and to know where they can get services for children with special healthcare needs.

Our care coordinators also go out to schools. And they attend IEP and 504 meetings with the families, and school counselors are there. The school counselors now have been another wonderful community referral to us, that if they know that these children are enrolled in CHIP through Highmark, we can enroll them in that manner as well. So it's a kind of very rich set of data, but again, I just want to share with you that--that you're aware that our program right now is specifically targeted for children enrolled in CHIP through Highmark as a pilot project. And with working with the graduate school of public health at the University of Pittsburgh in putting together some evaluation criteria, so that hopefully we could have and be able to show return on investments and that programs like this do make sense for these children and families. It's not only the right thing to do; it makes financial sense, as well.

Our data management and distribution system is what we finally refer to as Wes, fondly on a good day--not always, though. It is an intranet-based application. We

went obviously--when you first start out--a paper process. But with the resources that we were provided, we were able to begin to make this a paperless process. We're two years into this, and I can't tell you it's completely finished, but it's about 95% there.

By utilizing this system, we are able develop--or to identify the zip codes that our care coordinators are in. And as Amy noted to you, we're in the 49 counties of Pennsylvania. And our care coordinators are actually regionally-based. They actually are telecommuters. They work out of their homes. And the idea of that is so that if you work in an area--if you live in an area that you would, you may know the resources that are around the corner or in the next community that aren't necessarily written down on paper. So we have found that to be very valuable.

So at this point, we have ten community-based medically-trained care coordinators. They are primarily nurses. One is a licensed practical nurse, but also a licensed social worker. So that was a gift from heaven. We have Amy in our main offices as a licensed social worker. And the pairing of that was so important. We found out in doing this, it's great to be able to provide these families and children with the medical and educational needs that they have to try to address those things. But so often, like anyone, it's the hierarchy of needs.

We've had children who have had very rare liver abnormalities. And they're supposed to be getting MRIs every six months. And we see from looking back once we enrolled them in the program, that they haven't had any of these services. So we're kind of scratching our head, and we're calling the families and trying to engage them. Well, the reason they're not going for their MRIs is we found out that the next Tuesday they were going to be evicted from their home. They don't have any food--just a horrible situation. So, you know, obviously, we need to address their primary physical need sometimes before you can get them engaged to be calling their doctor to get the MRI. So the value of being able to go to their home and have them trust you and see what really is going on has been sometimes a curse and sometimes a blessing. But in those cases where we're able to identify those needs, that's something that we believe that typically we don't hear over the phone when we're talking to some of the other families.

The curse side of that is that sometimes of these families are very reticent to let the care coordinators come to their home. And I do believe part of that is because they're afraid--and they've shared with us before--they're afraid we are going to report them to Children and Youth. They live--obviously this is a financially tough--

UNKNOWN SPEAKER: Depressed.

MARY KAY HOLLERAN: Depressed. Thank you. Population to begin with. And they're doing the best they can. You know, they might in trailers, but they're clean trailers. You know, there isn't always carpeting on the floor. There have been times that we've had to discuss whether it was an issue that might have to be referred to Children and Youth. But primarily, these people are really afraid. They need help, but they're afraid to have someone come into their home.

And the other thing I wanted to share with you, the nurses, licensed social workers--and we have one lovely person who is actually a physician in Bosnia. And her medical credentials were not transferable to the United States. And her primary job in Bosnia was that she was dealing with children somewhat like a rheumatologist, is the way she explains it to us. So she's a great asset.

And as I heard in a presentation this morning that was talking about care coordination, the value of having these ten regionally-based care coordinators is they have something like 20-plus years of experience. And it's so broad a spectrum. We have nurses who have been worked in the school. We have nurses who have worked in doctor's office. We have nurses who have--nurse practitioners--neonatal nurse practitioners. Some of the nurses have worked in behavior health field. And we do get them together even though they're telecommuters. We do get them together every three weeks. But they've gotten to know one another. So they're a rich, rich resource for one another when they come up against a problem that isn't necessarily their area of expertise.

I shared with you what--that we use this system we call WES, which just stands for Web-enabled System. I want to share with you a couple of screen prints from that to be able to have you visualize what it is that the nurses get and what they're able to do in an electronic format that started in paper.

What I have up there for you now is the eligibility screen. And this basically shares with you how--I was talking to you about how we got disability data in it. There's claims data in it, the CAMI piece of it. And Amy--we were hoping to be able to go over and show that to you, but we're hooked up so that we really can't do that. But the disability data that comes from state is populated in the area that Amy is pointing to right now. The CAMI data--the non-categorical part of the survey where the families can answer yes or no to those questions about has your--does your child use medication at a greater degree than other children is--

AMY SHANNON: This is why I'm not allowed up here. (Inaudible). It has to be yes or nos. And then, it's really hard to see, and I apologize for that. But this is the second page Mary Kay was referencing where they've checked off (inaudible) heart condition, Chron's, and this is asthma. So those automatically populate prior to coming to the coordinators.

MARY KAY HOLLERAN: And we actually have a second--the screen goes down a little bit further. Well, actually in the next part of that, it shows the claims

stratification. And I mentioned to you--I'll give you the next screen that will show you that in a little bit more detail. But the child that you see there has a severity of low, and that was based on the utilization criteria that I share with you.

This next screen is actually the bottom of that same screen. This one is actually showing you a severity level of severe. It's showing you the top three frequently diagnosed--diagnosis from our claims area is over on the side there. And also showing us of interest--you know that this is a frequent flier--that this is child who probably needs some help or the family does. They have had 19 specialist visits, four emergency department visits, fortunately no inpatient hospital visits, no DME costs. But their average prescription per member per month is \$14.75. So if you knew nothing else, you know that something is going on with that child, and it makes it definitely worth a call.

The area right below that is the call status, so the nurses can actually go in and say what level they want to enroll them in. There are drop down screens where they can edit, and they can enroll them in level one or level two of the program, populate the date. And then on the next section over, it speaks to the date of a home visit. Did they have consent signed to participate, copy on file, research authorization?

We live in this HIPAA environment right now. So obviously to work with these children and to do an evaluation, this had to go through an internal research

board through the University of Pittsburgh. And we actually had to have families sign consents to participate and that their data could be shared with the University of Pittsburgh to be able to do the evaluation. So those are very important components of that.

If we need to go to the school, they have to sign authorizations for us to do so. It's a lot of paperwork, but actually gets just put in one central place, which is a phenomenal opportunity for us.

AMY SHANNON: (Inaudible).

MARY KAY HOLLERAN: Thanks, Amy. In that claims data that I shared with you on a monthly basis our own--it's called our informatics department--actually identifies children in CHIP does that stratification process and drops it down into this application for us. Similarly, the disability data from the state comes like that. And our CAMI information drops in the same way. That's sent out, by the way, to every family about two weeks after they're enrolled. We know that they--you know, as soon as you register or enroll with any insurance plan, you get a packet that's about this thick. And we recognize putting this information in that packet probably wasn't--well, potentially probably wouldn't have gotten read.

So about two weeks after they enroll, they get a letter from us explaining what the program is with one of our brochures. And it give them information about how

to call into the program. And we have a toll-free line. And by the way, this brochure--we have it in Spanish, as well, because we recognize in looking at the diversity part of our population that we have some areas within the state of Pennsylvania that have a high Hispanic population.

This next slide shows you what we call our roster for the nurses. This is what all that has fed into. So obviously we've blanked out where the families names and telephone numbers are. But this is listed so the nurses can look at it alphabetically. But as you can see on the very bottom of the slide, this is one of 12 children, but it's a 491 potential enrollees in this instance. And the care coordinators go down through this. They review each one, and it's really easy. Right next to this black here if they click on anyone of those arrows, and it drops them into information related to that child's eligibility.

If I can take you back to that other slide for just a moment--two slides back actually. You'll see at the very top of this--I'm sure it's hard for you to see, but there are little tabs like in Excel, and it has demographics--the eligibility one is the one that's opened right now--case history, care plan goals, non-medical information, the next tab is medical and the family structure. So all those have tabs--have information in them that are added (inaudible) and that the care coordinators use to document the information on the family and when they do a home visit.

And then, when they go to do the calls to the families, we have first and second attempt calls. So it lets them note all this information in a very electronic-savvy format. And then, they have a roster on here, as well, that it's just the children they've enrolled in what we call Level Two. Amy will share a little bit more information about the different levels of care coordination. But these are the kids that the care coordinators actually gone out and, you know, met with the families, met with the children, and have enrolled them in this higher level of care coordination that we can go to medical appointments and school appointments with them. So they have a separate roster of those children and families alone.

Okay. We're going to go to the enrollment piece now. And we're going to have Amy share with you a little bit about how the families get enrolled, and we'll move on from there.

AMY SHANNON: Thanks. As Mary Kay was explaining to you and showing you all of the roster detail in WES, it's kind of, I know, hard to conceptualize. But what happens when--as Mary Kay was saying--that once those kids--as we populate monthly that CAMI, that disability and those claims, they pop onto that potential roster. And where we showed you those arrows, they click over to get to that individual child's information, including phone number, parents' name, county that they live in, what level of CHIP they're in and all the diagnoses. And that's when the coordinator--they see that potential list based on their zip code territory.

Coordinators cover anywhere from two to five counties based on the geographic need, based on population that we know from pulling the data and looking at that, is how that determination was made. And so they get these children on their individual rosters. They can't see each other's rosters. It's strictly, you know, if it's my roster, I can only see the kids that are eligible to me to talk with to potentially enroll and provide supports to. So at that point, they can work on making those outbound outreach phone calls to potentially eligible families.

And what we know from keeping the statistics over the past few years is it takes about four calls on average to reach one family, because everybody has got different schedules. You know what yours is like. You know you're all here today, and your families are probably doing many other things. And our coordinators are really trying to reach these families at home. And so, you know, sometimes that works to call them during the day, but very often, they have to make some evening calls and weekend calls, because these are families that are working too. So they really have, you know, by technicality, our work day is 8:30 to 4:45, but I can assure you that our coordinators are working much longer hours than that. They do a lot of evening to make those phone calls to do home visits when the families are home and on weekends, at times, when it's needed if that's what's going to best meet that family's needs. That's when they schedule those visits.

But even before they get to the point of making a home visit, they do that telephonic call, and they make an assessment. And it's not just a medical assessment, as Mary Kay mentioned kind of the hierarchy of needs. They really talk with the family not only about the identified child and their special healthcare needs and what's working and what's not and are the needs. But they also talk about what are the psychosocial issues in the family. What are the stressors that the family is facing? Is it the extreme, as Mary Kay mentioned, where, you know, there's a housing issue where they're going to be homeless in the next few weeks? Is it a food issue? Transportation--is that why they can't get to the visits--to the specialist visits? Or are there school issues? The child is not receiving the supports that they need in school.

And they do talk about that with the family over the phone to help determine and to offer to the family what's going to be the best level of support, whether it be Level One or Level Two. One of the handouts that we shared with you is the psychosocial factors, the complexity of condition index. And really this is just used as a guide for the coordinators when they--they know what the medical assessment is, and they're trying to determine does the psychosocial need really roll up to being, you know, significant, that we need to be out there as well.

And we look at things like language, financial difficulties, insurance, community and family supports. What agencies are they working with? Has there been history of drug and alcohol, transportation needs, school-related issues. And you

can see when you look at this form. This is a pretty high complexity form for people when they roll up and score at the high complexity. But this is used as a guide, and we've taken multiple sources and adapted them to create that guide, but we found it to be helpful in many instances.

The program itself is voluntary. As we make all of these outreach phone calls to families, they're offer what we call supports of Level One or Level Two. And as I mentioned, in those phone calls we do the assessment around all of these issues about the--because it's cross systems. We look at the medical, the transition, education, transportation, community agencies and social support. So we do--we look at all of those features, and the coordinators speak with the families about how--what resources are available and how they might be able to help, whether it be letting them know they can go to the school meeting, whether they can go to the physician visit or connect them with the community resources or apply for financial funding for them and offer to the family the supports that might benefit them.

As I mentioned, the supports come as Level One or Level Two. Those are available across all of the 49-county region that we service through Highmark--so that whole blue coverage area of the map. Again, both levels of support are for children enrolled in CHIP through Highmark.

Level One, some folks will refer to as the softer touch. It's the primarily telephonic or email or correspondence with families. When we talk with them, and we talk with them over the phone about all those systems and what they need help with, these families to our nurses that, "You know what? I just need some information about a IEP. I need some information about what I need to talk to my endocrinologist about or what I don't understand about, you know, PCS or my diabetes or what equipment might be available for my child with cerebral palsy. And so they can do a lot of that over the phone. And they send out resources and whatever fashion best meets the families' needs. Because many of the families don't have email, so we mail a lot of things. And what will happen is that dialogue continues with those families in Level One. They call back, "You know what, Amy? I got that information. Thank you. But I need more about this." Or, "I don't understand this." And they spend the time and they talk them through it. Let me know how it worked out. Were you able to access the equipment that you needed? I know you needed to get an updated wheelchair. This is who you call. This is how you access it, those pieces.

And so although it's sometimes referred to as that softer touch, sometimes it's a lot more than a softer touch. It's an ongoing relationship with this families, simply the coordinator hasn't met with them in the home and doesn't go to the community visits with them, but it has great value. And as Mary Kay, mentioned earlier, you know there's a trust level of, you know, families are hearing this program being offered to them free of charge, and you'll come to my home, and

this it a little too good to be true sometimes. And they'll kind of back up and say, "Thanks, but no thanks. You can send me whatever you want, you know." And we have had many, many families move from Level One to Level Two at a later time after those multiple phone calls. And you build that relationship with those families, and they begin to trust you, that you said you would send me the information. You've explained it to me. You followed through. And it builds that relationship to a point where now they're comfortable to say, "Okay. I really could use you. Come to my house. Let's talk about the issues, and then, maybe we can go to the specialist appointment." And that really has helped out a lot of families along the way.

For families who, you know, are ready for the support of a more intensive level support, that's what we refer to as Level Two. Again, available in all those areas, but this is the Level Two where we do the home visit. We do a home visit, at a minimum, once a year. There's the initial visit, but I can tell you--and you'll see in a slide a little bit later--the multiple visits that the coordinators do that they see the families, probably on average, anywhere from five to six times a year based on specialists and community visits that they're doing with the families.

In addition to doing the visits, they maintain also, at a minimal, quarterly telephone calls. And what they do, as Mary Kay referenced on those tabs at the top of that Web-enabled system, is when they meet with the families, they talk about what supports and services are currently available to them. And they also

talk about what are the unmet needs? What are the challenges that they are facing? And together, they compile all of that data into a care plan that they, in turn, establish issues and goals and whose going to be responsible to work on action steps that the family creates with the care coordinator?

And this is the family's plan. This family--the family sets the goals. The family says, "This is my priority. I need to get this whatever--equipment. Or I need a new endocrinologist." You know, and the coordinator might have a different concept of what the priority might have been, but this is the family's plan. And so we start with where the family is, and we work with them towards making sure that the child is getting all the supports and services that they need.

That individualized care plan is provided to every parent that enrolls in Level Two. And when the children are 14 or older, we give them a copy as well, because they need to know the information about their health. They need to start to take--we support them through the transition process and beginning to take ownership for my health, my medication, my physicians, my decisions and begin planting those seeds so that when they transition out of CHIP and hopefully one day into independence, that they have a greater knowledge and a greater understanding of what they can do to take care and maintain their own stability and health.

In those Level Twos, we--the coordinators facilitate training, not only for the families, giving them education about whether it be the diagnoses or the available resources in the schools and the community. But oftentimes when we are in the schools, we find out that the schools--they're there to educate and to teach the children. They don't necessarily know about the rare genetic disease that this child has or how it's impacting their day to day functioning in the classroom. And the teachers are saying, "I don't have time to research this information."

And what we do is our coordinators work with the local community agencies, hospitals, practitioners' offices, to bring someone in that school for a teachers and service day to teach them. They're nurses, they're teachers. Oftentimes we have the principles in there. Whomever has the time and the interest and the dedication, in essence, the willingness to learn it--we bring them in, and we provide them with that education and support that process so that child can be better supported when they're in the education environment.

As we mentioned before, we provide the referrals to community supports, and then, we also assist in the transition planning. And we really--transition planning--and I'm sure all of you are aware of that. It's kind of like preaching to the choir here. But we look at transition holistically in the fact that it's medical transition taking them out of the pediatric world into the adult provider world, looking at transportation, independence, education, career--all of those pieces and really

working with what are the targeted areas that these young adults are trying to advance towards, and working towards that with them and with their families.

When we talk about the community visits--just to give you a sense of how frequently the coordinators are out in the community. In 2007, they did over 216 visits that were community visits external of any of the home visits that they did. Medical specialist clearly is the biggest one followed secondary to school primary care physician visits. The 23 other falls into a lot of community support visits that they're doing, just depending on the area, whether it be visiting--supporting them in getting their child enrolled in a recreation program for after school and supporting them in the process and helping educate whether it be the local YMCA that has a program for basketball and trying to engage this child to be more active in recreation and making sure that this community agency is comfortable in knowing what the special healthcare need is coming in if the parents choose to self-identify that information. And this is, again, some of the information that we've touched on.

MARY KAY HOLLERAN: Thanks. And basically in a little bit of follow up from what Amy has said, what we hear so often--yes?

UNKNOWN SPEAKER: I have a quick question. The 216 visits over a 12-month period--do you now how many patients that represented?

MARY KAY HOLLERAN: A little bit over 400.

UNKNOWN SPEAKER: (Inaudible) patients. Okay. There were 216 visits over a 12-month period--

MARY KAY HOLLERAN: It didn't necessarily mean each one of them--the patients had two visits. Sometimes if it was a really complex family--

UNKNOWN SPEAKER: So that's what I'm asking. So were there five patients who had (inaudible) visits each (inaudible)?

MARY KAY HOLLERAN: Oh, I see. Do we know exactly how many families those 216--

AMY SHANNON: Duplicating that? I couldn't tell you that without going back and looking. But I could--if you want to leave me your name and contact information, I could get that for you.

UNKNOWN SPEAKER: Thank you.

MARY KAY HOLLERAN: What's interesting though with these children and family in being an advocate, you know the old adage, we want to teach them to fish, not feed them the fish. So many of them will say to us that when we with

them as an advocate whether it's to a practitioner or it's to the school with a counselor, saying, you know, "Thank you so much for being here. This is the first time anyone took my concern seriously." And didn't necessarily mean that every time that child had a IEP or 504 meeting or it was with the specialist, that that care coordinator had to be there. We just established a level of trust and credibility.

And we're not always in there with everything the family wants at those visits, because sometimes you have to reel them in, as well. Some of their expectations are not realistic. And that's how we've gained trust with both the practitioners in the schools. If the parent wants an aide for their child because they have severe allergies, for example, they're expecting the school to have an aide in there, you know, every day the child is there. We have to help them recognize it. We could put some things in place to try to insure that that child's--whatever their trigger is--if it's peanut butter or whatever it is--that there's something in place that the cafeteria knows that. The other parents know that. But they don't really need an aide in there every day when the child is in school.

So it's been a very collaborative approach with the schools. And I think that that's raised the credibility of the school for the parents and our part in that as well.

Then, as Amy said, the data collection and management--these are some of the things when I showed you the WES system before and those different tabs, that we put diagnosis in there. We try to identify on there a start date with that where

they were diagnosed. And oftentimes in putting this, then, into the care plan, it's what the family really uses to go to multiple practitioners that keeps them all on the same page.

The treating physician--sometimes the parents will say, "Oh, you know, I saw a pediatric rheumatologist two years ago. He was out in, you know, Beaver County. I don't remember the name." And so by having all that information there, it's been a blessing--I can tell you--many times that the parents and care coordinators have been grateful that they've had that there.

The hospitalizations--when they were and for what length of time--the diagnosis, the medications we try to keep as accurately as possible, even those--especially we keep a history of those if the child had been allergic to a medication.

Obviously if you kept every medication a child was on a period of--if they were enrolled in this system and program from birth to age 19--by the way is what the CHIP age range is--it would be a entire, like, three sheets of probably information just related to medication. So we try to keep the most current medications on that. Immuniza--yes?

UNKNOWN SPEAKER: (Inaudible).

MARY KAY HOLLERAN: To a certain extent. And we actually work with the Pennsylvania chapter in Epic that we attend those meetings. And this is very

much like the medical home, but rather than being a specific nurse embedded in a practice, the nurses are--their scope is much more broad than that one practice. But the resource and information guide--some of that information--that is always available to them. And if the child is in a practice that is a medical home, the care plan, then. The parents own that, and we highly encourage them to bring that to their appointments with them, whether it be a medical practice or not, especially to new specialists visits, those sorts of things.

Obviously, immunization allergies--problems--if there's been anything identified in the educational arena. As Amy said, transition plans--we work very hard with these families. If they are transitioning out at age 19, we encourage them to do the MA applications. And as I heard this morning, sometimes it's very frustrating. The parents don't follow through on what you're asking them to do, but we can encourage them. And by being in this higher level of care coordination, we found out with one family fairly recently the reason they weren't filling out the MA application is the mother was not literate. And she's actually learning with her first grader how to read. So we help them work through that process, as well.

As Amy noted, support services--anything that the child has needed and where they obtained that if it's a durable medical equipment, it's listed in there, as well. Family impacts--referrals wherever they were given and the care plan. Our goal is to make this care plan actually just pull out of the application as a stand alone. Specific, the nurse can actually say if this is for school, they might not need all

the elements of it. If it's a doctor's visit that they're going to see a specialist, all of the medical components need to be there, but maybe some of the extra referral to recreation might not need to be there. So we try to make it as specific as possible.

Our ultimate goal is to make this intranet system Internet. So if this child would end up unconscious in the Emergency Room, that the doctors would be able to access this component of their medical history by gaining permission from the parents with a password to do that. But to be honest with you, we're probably a couple of years away from that. There's a lot of HIPAA and other legal implications into trying to do that.

This is one of the screens that I just mentioned before that we showed you at the top piece, is the part of the medical component of this plan. It has allergies on this part--the diagnosis specific, and then, again, health problems that may be related to their attendance at schools, behavioral issues and just some of the system components of this.

This screen actually shows us the practitioners that are involved in this child's care. As you can see, this one is saying--and by the way, these are all made up so that we're not sharing any PHI with you at this point. Pediatric, endocrinology, the address of the provider, the date of the visit, the reason for the visit, and then, again, for just the child's pediatrician.

This next screen actually shares with you a component for inpatient hospitalizations. Again, what the hospitalization was for, whether it was planned or unplanned, whether there are ER visits and why, the admit date, the discharge date, the facility and provides them with a little bit of free text to write some comments in there.

The next piece is the educational display. This one asks whether this child is enrolled in cyber school, home-schooled. And we're finding out that--and again, as Amy said, we're kind of preaching to the choir here--that so many of you know that children with special healthcare needs end up kind of getting pushed out of the public school system because it's just so onerous for the school to try to accommodate what these parents are asking for. So we're trying to look at what the percentage of those children are and whether they were really advantaged or disadvantaged because of that.

School information is there. And, you know, if they're in special ed or anything--special programs such as that. And whether a IEP or 504 plan has been put in place for the child. And the care coordinators do help in doing. We often say, these parents--they don't know what they don't know. They don't know that there are things out there such as a IEP that can help a child who has educational issues or a 504 plan to help a child that's somewhat medically compromised be able to succeed very well in this public school system or night school system, for

that matter. And so we educate them on what that is about the Health Log Project--whatever it is that it takes to get that completed for them.

At this point, we'd like to take a little bit of a break from the hard statistics with this. We often say, you know, these are the statistics with tears. These are--we have two examples for you of some children that we've facilitated who have been in our Level Two program that we facilitated some care coordination for. Amy is going to share with you Buddy's story.