

2011 AMCHP and Family Voices National Conference: MCHB Title V Block Grant Update and Rethinking MCH: Life Course as an Organizing Framework

02/12/2011 Omni Shoreham, Washington, D.C.

BARBARA POPPER: We'll start in one minute, on time. There should still be handouts on the back table; otherwise we have some in the front. I hear the gong out there, so it must be time to begin.

I'm Barbara Popper and I want to welcome you to our session on Bright Futures. If there are not handouts in the back, we have a few up here and it's such a long room, I'll encourage people to move up if you can. There's some spots up closer to the front.

I have with me on this panel, Beth *****, from Mass Family Voices, Mercedes Rosa, from Spand, New Jersey, and Dr. Paula Duncan, who is actually going to start speaking for us from AAP on Bright futures.

We'll each do a section of this. I'll tell you a lot about the materials, ask for some discussion from you about how you might be using Bright Futures or what you would like to see us incorporate into some future materials. This is a joint project with... working with our Impact Project and working with AAP's Bright Futures, doing Bright Futures for Families materials.

I'd like to just get a show of hands. How many are with Family voices here as parents? Okay. And how many are with health departments? Great. And are there other? And what's the other? Academics. Okay, great. Good, well welcome. And I'm going to let Dr. Duncan start.

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When you do collaborative work, you might find that your outline in the slides have been rearranged, so... so Paula, in just a minute, I'll turn it over to you. I'm sorry. It's my misunderstanding. The Impact Project is funded by MCHB and it's just been refunded. And Betsy Anderson is here and is the Project Director, and we've been working on Bright Futures as part of that project for several years. It was, as you can see up there, established in 1995 and we've been working on the Bright Futures materials based on the Big Bright Futures.

We have been providing families, including children with special healthcare needs with family information and materials from that time. And we did have a first Bright Futures for Families Pocket Guide that we are now working on a second one, a second version. And we participate in Title V, MCH in Children with Special Healthcare Needs Initiatives through Family Voices. We've done surveys of family's knowledge and beliefs about health for all children, including children with special healthcare needs. And we do public outreach, building a network of people... other interested people.

We have worked with a network of family organizations that we've met with a couple of times, finding all the other parent organizations, there's a group of them listed there, who are looking at health for their membership in very different ways from the PTI... PTA's to La Leche League, Latin-American Health Institute, people who have similar interests and concerns and are interested in the Bright Future's materials that we have developed.

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We... are we doing this? No, okay.

Among the materials that are out in the back that you might be interested in are the Family Matters Electronic Newsletter. And I know, how many of you are already on that subscription list? Not so many as could be. And it's very easy for you to send on to other groups and memberships and lots of people do forward it and give it out to families. And there's a sign-up sheet and we'll just take your name and add you to the list.

The Bright Futures Family Pocket Guide is the one we are almost done updating and that will be ready soon. And we have a website: www.BrightFuturesforFamilies.com. And now I see Dr. Duncan's slides.

PAULA DUNCAN: This friend and colleague is being very gracious because I didn't get my slides in. I thought I had them in, and so I went to just check my email because when she said, I don't have your slides yet, Paula. I said, oh my gosh, 'cause I know I sent them a week ago. I didn't send them. So the reason things are messed up is because of me. I'm really sorry. I did have the slides done, but I didn't send them. So thank you, even... here she is taking the blame, that's okay. Ayy-yi-yi. I'll move over here a bit because I can't quite see the whole slide.

I'm just going to stand here for just one more second. How many of you would already say you're a Bright Futures champion?

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Okay, you know, what, I can't see the whole slide on this. So let's... maybe I can stand. I know what I can do, I can stand over here I guess. I just want to stand in a place where I can see it. Yeah.

How many Bright Futures champions do I have? Okay, great. Because I'm hoping that each one of you at the end of this talk will raise your hand if I ask how many Bright Futures champions there are because this is one of the things, just one of the ways that I think we're really going to be able to change things for kids and for families. And I think that the second thing is that we really understand that with the new Bright Futures especially, but with all the editions of Bright Futures, that we totally... everybody totally gets it. Which is why we're doing this sessions, which is why Betsy has been with us on the Steering Committee and the leadership of this Bright Futures initiative since the beginning, why so many of you have worked on it because if we don't really get that partnership going or with Bright Futures, with families, we're not really ever going to ever make the kind of changes we need to.

So I wanted to just remind you of the different guidelines that used to be there. AMA, the middle one is the AEP, and over here we have Bright Futures, Second Edition. So what happened then is that all of them got combined into one guideline. So is that a good thing? Yeah, probably. Because to some people that makes a lot of difference, 'cause once there's two guidelines, people could just say, "Well I'm not going to do this because it says this..." and that, so now at least we've got just one guideline. Here it is, the Bright

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Futures Guidelines. I'm really echoing, so I'm going to try this without this.

And here's the **periodisti[ph]** schedule. That's the... what physician, nurse practitioners, physician assistants, people that are seeing kids for well child visits need to make sure they do. I realize you can't see that, but I'm showing it to you because it's exactly like it says, at two months, you're supposed to do these things, at four months, you're supposed to do these things. And we used to think that this was merely a communication for healthcare professionals and public health professionals to make sure that things got done in a certain way. But we also see now that it's a communication tool for parents. Maybe not this exact piece of paper, but the idea of, what should we be doing together. If parents come to a visit, understanding what's going to happen at that visit, what we're looking for as physicians, nurse practitioners, when we see a kid that's four months old or nine months old, that's really been part of the collaboration that we're really going for and that we need your help to take to the next steps.

I was working in Oregon with some parents and this wonderful woman, who's got two kids, was on the Parent Advisory Committee for one of the practices. And she said, after working... and she was reviewing all the Bright Futures materials for incorporation into their practice, and she said, "I used to think that what I was supposed to do was take my baby, put my baby on the table, and then you were going to do everything else. And then I was going to pick my baby up at the end and comfort her after she

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got her shots.” And she said, “Now I realize that I need to really be involved because you probably want to know what’s on my mind. You really want to know what my questions are because otherwise I’m not going to have really... it’s not going to be the best visit it could possibly be.”

So I thought that was such... I didn’t even meet this woman before and she so got it. But that’s exactly what Bright Futures is about; it’s all of us working together on an individual patient level.

So, let’s just put this in the right context of the Medical Home. We think Bright Futures is just part of the Medical Home. I know the Medical Home isn’t a building, but sometimes in my mind I think of it that way, and I think that the Bright Futures is the disease prevention, health promotion wing of the medical Home. There’s other things that happen in the Medical Home, right. Kids with chronic conditions get taken care of really well, we deal with emergencies, but there is this huge part. And I won’t say it’s bigger than half, I’ll just say it’s this big, that we really want to focus on prevention and health promotion. Not just prevention of disease, actually health promotion. Thriving.

Some of the things that people have been talking about for the last two days; how do we measure thriving and do we really see that kids are doing really well and families are doing really well? That’s where we’re at. So here’s the 10 themes that are in the Bright Futures book. This has been a really good thing in public health. A lot of public health departments, Wisconsin, some other

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folks have taken these 10 themes and actually put some educational modules around them, they do webinars with their public health folks about these things and I think that if you wanted to know about one of these topics, like oral health. Maybe you might be like me and say, I don't know too much about oral health because I thought that was for the dentists. Turns out it's for the healthcare professionals that take care of kids in primary care because it's such an important issue. And these guidelines have included oral health right in there. You can go and read that oral health chapter, it's only about 17 pages long and you'd be up-to-date with oral health.

Then... so I think that these themes really match up with a lot of the ways that we think about things in public health and the way that we think about things as families and as parents sometimes.

So we have health professionals; Bright Futures is for families, Bright Futures is for public health and schools. So let's just think about what we're really trying to do. We want to make sure that parent's informational needs are met, their strengths are identified and their concerns are addressed. Does that sound like the care that we've all received when our kids are little if we have kids or neighbors? Sometimes. If we've got somebody really good. If we got a Medical Home going.

So the new Bright Futures says these things are really important. They're just not add-ons, oh you got to get your shots, and then oh if you want to you can ask about parent's informational needs.

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Make sure their strengths are identified and their concerns are addressed. No, no, no. This edition of Bright Futures says, this is what you got to do. This is what... this is what the guidelines say are really important. All children, including those with special healthcare needs will receive preventive and developmental service emphasizing the Bright Futures visit anticipatory guidance priorities. Families receiving information about community resources and help with links to needed services. And that are really engaged as partners in promoting the health and well-being of their children.

So now you can see, these are the real four things. This is why I'm inviting everybody in the room in to be a Bright Futures champion, 'cause I think we can all get behind this, right? And we know that it's going to take a little bit to move things in that direction. But it's what... don't we all believe it's what we really need to do? "Cause it will really change things if we do it this way. So let's just come onboard, we need you all desperately to see how we're going to make this really a reality.

We have a Bright Futures toolkit for practices that can... people in Medical Homes can use, health departments can use, WIC people have liked some of the... professionals have liked some of the materials in here. There's pre-visit questionnaires and patient and parent handouts.

So let me just show you this one thing because I think it really, personifies what we're really trying to do. So if you have a pre-

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visit questionnaire and it's only one page long, why would you have to have a pre-visit questionnaire? One reason is to save time so that you can get all the things, you know, you can find out beforehand what the parent wants to talk about. Another is to make sure you don't miss anything, and also it's to elicit the parent's concern.

So if I, as I said, there's five priorities for each visit, literature what's important to talk about a 18 months old, with an 18-month-old... parent of an 18-month-old. But then we're saying that at each visit there's actually six priorities. Guess what the sixth is? Whatever's on the parent's mind. So, whatever question or concern the parent has, that goes to the top of the list and then you do the other five priorities if you have time.

And this, use of this questionnaire really, as I said, personifies that. 'Cause it says at the top, I know you can't see this, but I wanted you to see what I'm doing. "For us to provide you and your baby with the best possible healthcare, we'd like to know how things are going, please answer all of the questions, thank you. If you have any concerns, questions or problems that you would like to discuss today." So if that's the very first thing that is asked, and we only have a one-page questionnaire, so a lot of things aren't asked. That just says what we're really trying to do here.

Then there's the priorities for the visit that I told you about. They are listed there so parents can say what they'd like to talk about from the five priorities. So they're kind of like prompts 'cause not

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every parent knows what is usually talked about at an 18-month-old visit, right. So this is one way.

What if the parent checks every single box? Fine. Then the nurse, medical assistant person can say, which are the two or three most important to you today? I see that you have a lot of stuff that you want to talk about and we're thrilled. But we want to make sure we address your most important concerns today and maybe you and I as the nurse could set up another visit at another time to go over some of these things or maybe I could call you on the phone, but tell me what are the most important things to you?

So we're really trying to walk our talk with that and link up the priorities. This is the... I just wanted to show you an example of the handout. Well why would you do a handout if you could talk about all these things? Because you probably don't have time to talk about all those things, right. So this way, in case you did miss something that the parent did want to talk about, here's a list of things. Some practitioners say that what they do is they circle the things that were the most important during the visit or circle the things that they want the parent to focus on because this is what we talked about and I wanted to just remind you that... because sometimes you hear too many things and so if somebody circles something, that may be a help.

And the final things that's been really exciting is what to expect at you're next visit. So a lot of parents say, I just look at that. I keep these in my baby book and I then I just look at that before I go to

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the next visit so I know what we might be talking about or what will be on that pre-visit questionnaire to ask about. This just shows you that the priorities are there as well.

And this is the final thing from this part of it that I wanted to show you in terms of walking the talk about parents being really important.

So now, for the first time, we have some measures. How can we tell if a practitioner really does a Bright Futures visit? How can we tell if they've really done things because the measurement that we usually use is, did you have a visit with somebody at 18 months, two years, and that... we don't go into the depth of that visit, but sometimes we got into the depth about immunizations and measure that, but what we're trying to do is really focus on the real heart of Bright Futures.

And so we have a couple of measures in here that I think really reflect the heart about the partnership with parents. Developmental Screening, which is mostly a parent-filled out tool. Autism Screening or the MCHAT is filled out by the parent. Maternal Depression Screen is another screen that gets filled out by the parent. Did you actually ask about parent's concerns and did you actually identify parent's strengths? We'll be looking for those things in the chart to see if they're actually there. This isn't just a nice list; these are the things we're going to be measuring Medical Home's practices on to see if they incorporated the principles and the themes of Bright Futures.

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And look at that last little puppy there. Shared Decision-Making. It's just one line, but it's a huge deal, right. Huge deal for us to figure out how to do on both sides; parent's side as well as the practitioner's side, for WIC people to figure out how to do. How do we really approach behavior changes that might need to be made? About physical activity, nutrition or any kind of decision-making in a shared way so that we really do this in a way that makes sense to parents.

As you know, healthcare reform, fortunately those guidelines are included so that all of these services and the things that we've talked about will be available with new insurance, when people... with companies that do new insurance companies and then they come on with their new guidelines, they have to pay for this with no co-pays. I also... we're going to be hearing more about the family resources, but I just wanted to put some of them on a slide and mention again, **** for babies. We think that's going to be a great potential in addition to the things that Barbara already talked about.

We do have a Bright Futures Activity Book. I don't think that was on your list, Barbara. It's a coloring book. We have some in the back. We have... we're also developing... right now, it's a little bit adjacent to Bright Futures, but I just wanted to mention it to you. We're developing messages for parents of kids, birth to five, about healthy living and healthy weight. And one of the things we did in that direction was to get the parents together first, so we didn't get

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a group of experts about healthy weight together, profession... academics. We decided to get parents together first. Do focus groups with parents; get the messages they would like to hear. And then we took those messages back to the experts from academia and said, what do you think about these parent messages? So it's a little bit flip, but we're getting it. We understand that we've got to have new strategies as we move forward.

In public health, Virginia has done a wonderful job of having little short videos with topics from Bright Futures for parents on their website. And we're really thinking too about this... wanting to make sure that we're really going in the direction of strength-based approaches. Are we really looking at families and really identifying their strengths, not just their problems. So some of you who were in our session the other day heard about this 17-year-old mom and her 18-month-old child. They were in a homeless shelter and she had moved out of her parent's home about four months ago. Anybody worried about this young lady and her baby? A lot of us right. She's got a lot... you can imagine the troubles that this person has right this second.

Using the Bright Futures questionnaire, you can see that when asked, she said she was worried about additional shots because her boyfriend's mother has a child with autism. We also found out by using the Bright Futures questionnaire that she's in a homeless shelter with a family from Laos and the child has been playing with their children, so she needs a TB test. So you can see that the

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pre-visit questionnaire has really given us what's on this mother mind mostly, and then what's something that we didn't want to miss because we were so concerned about all the other thing that were going on for her.

Then we go on a search for strengths and we find out some other things about this woman. She finished high school, she has had a job. She's trying to ensure a safe place for her child away from smoke and yelling because her mother was yelling all the time and smoking all the time. She has a boyfriend and she has... and she's close with him. He is not the father of this baby, but they are very close. And so she organized a clean-up of the playground behind the homeless shelter and got it all straightened out so the kids could at least run around a little bit. Give you a different picture of her? Search for strengths. Different way that we might interact with her if we were the WIC nurse... the WIC person... the physician, nurse practitioner.

So Bright Futures would say, even though you don't have a lot of time, please go on an absolutely safari for strengths because it's really gonna help us to partner with families in a different way, partner with youth in a different way too.

So I think that the major thing I wanted to say was just that we think that we totally as a team, we really get it about the partnership. We're trying to figure out how to do it in very practical, substantial ways and we need your help, which is one of the reasons I was thrilled to be invited to this sessions today

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because I'm going to learn so much. I've got to sit in the corner so I can take notes. And I think in terms of children with special healthcare need, in particular. Let's just finish on that note. One of the things that I heard was that we were going to do a special Bright Futures for children with special healthcare needs. And we decided not to because with a lot of consultation from, maybe many of you in the room. Kids are kids first, teenagers are teenagers first, they happen to have a chronic condition second, and so let's make sure that they get their preventive services, that they get their prevention and they get their strengths identified. Right?

A pediatrician from Utah emailed me after he heard me talk about this, it was awhile ago now, a couple of years ago. And he said, "Paula," he said, "When you're talking to physicians and nurse practitioners, PA's about this, make sure you say, 'if you're only going to search for strengths or safari for strengths with only one group of kids, make sure you do the children with special healthcare needs or the youth with special healthcare needs. Because,'" he said, "I just saw a kid and I've known her since birth, she's 14 now, and I really... we're very close, you know, it's a great relationship and I realized that what I mostly do is talk about OT/PT and all the other things and I think I do a great job of coordinating her care. But I haven't gone on a..." He didn't call it a search for strengths, but he... that's what he said, "I haven't really identified her strengths before. And we spent 10 minutes going over all the wonderful things about her and strengths that she's gonna use to start high school next week." Because this was

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in August. And he said so, “I usually don’t write emails to people,” he said, “But I’m passing this along that Bright Futures is a wonderful thing and we should really make sure that we’re using that particular aspect of it with children and youth with special healthcare need.”

So are you on with me? How many Bright Futures champions have we got any? All right! Thank you.

[Inaudible]

BARBARA POPPER: And now Beth Dworetzky.

BETH DWORETZKY: So good afternoon, thanks for coming. My name is Beth Dworetzky and I’m the parent of a young adult with some complex health needs. And I help staff the Massachusetts Family to Family Health Information Center, but I also help contribute a bit to writing some of the materials for the Impact Project. And so I was going to talk to you about some of those.

And so, the family materials that are companion to the Bright Futures for... to the Bright Futures AAP materials are built on the concept that what families do at home every day matters. And I’d always heard this quote that you as the parent are your child’s first and best teacher, that it’s an awesome responsibility, but one that brings immeasurable rewards. I never knew who said that. A Google search showed that it was by a woman named Jackie McTaggart, who was a career school teacher. And she did, she

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spoke as a career school teacher. And I was thinking that our role as parents involves... you know, we try and teach our kids to you know, the different colors and how to count and how to play nice with others and share. But our teaching role also includes helping them develop healthy habits. Hopefully habits that... and to create healthy routines that will give them a sense of security and help them grow up to be... special needs or not special needs to, you know, grow up to be healthy and hopefully to develop habits that they're carry with them into adulthood so that they can you know, maintain their own health, build their own relationships with health providers and take responsibility for managing their own health.

But I also know that we can't do it all and that we're inundated with health messages, just a few, like eat five servings of fruits and vegetables, get, you know, 30 min... you know, get one hour of physical activity... be physically active at least one hour a day, limit screen time for our kids. So, you know, it's one thing to say, "Eat your vegetables," but how do you actually make that happen? I mean, I'm not kidding, and I've said this before, so I apologize for those that have heard me say it, but in my house, my kid didn't eat until he was three-years-old. A blueberry Pop Tart is still a serving of fruit in our house. So, I'm not really proud of that, but it's progress. All right?

So anyways, these materials were built to sort of support families in how you actually make that happen. And so, the materials... and I'll go into some of the... I'll go into the materials a little more in-depth, but the materials provide strategies families can use to

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promote these healthy habits based on the 10 Bright Futures themes and they include ideas to help children take responsibility for their own health and wellness as they get older. And these materials were created by families, for families with lots of input from families and with the network of professional... the National Network of Professional Partners that Barbara showed you on the previous slide.

So the first thing that I'm going to talk about is Bright Futures, Family Matters, which is an electronic newsletter. It is sent out over the list serve. Actually I have no control of that piece and have no idea how it works, but anyway, can receive it for free. We do really encourage people. It's not one of those kinds piece... it's not one of those emails that you get that says, you know, do not forward on. We do encourage people to forward it on, print and in fact, some Health Departments actually print it and send it out in their materials, post it to websites, sharing it... share them at meetings and we do have some samples that if you have not seen the materials, we have printed hardcopy that you are welcome to take. We share at meetings, workshops, conferences and other events.

So how many of you have used these materials? ****. Do you want to give a quick... do you want to give an example of how you use them please? This is Nina Baker from Nebraska.

NINA BAKER: Specifically around the Family Matters newsletter that come out periodically, I've immediately **** off of the email that I receive

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and I send it out on list serve to Nebraska and send it to 845 families, almost immediately. Now, whether they look at it or not because in list serve I don't have control over that, but they're getting the information. I also try to print off a few of these and take them with me to every workshop that I do so that it's **** available and I know it's up-to-date information. Like the ones on oral health, I **** our Oral Health Family Focus Groups and so even if parents are here to talk about oral health and how they were trying to access oral health or unable to access oral health in their community, they had new up-to-date information **** **** about oral health. So it's been real helpful.

BETH DWORETZKY: So recent issues have... so Nina mentioned the oral health one, but we also... a recent issue is about health literacy and child development and each one starts with a quote and sort of an introduction of the overall topic that's being addressed. There are information and resources broken down by age stage. There are always resources for other, like websites where you can find information in other languages. There are always resources for families who are raising children and youth with special health needs. There is a research piece... there's a research piece sort of like something like the importance of naps or something about, you know, bullying prevention or something, but some research-based piece in there. Family Resources, Tidbits and then there's always an invitation to share with others. And we also profile a partner organization, which would be, again, one of the members of that national... on the list of the national network.

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So this just an example. And again, we have printed hardcopies. I know you can't possibly read that, I just wanted to sort of show you what the layout is like. And so this was about child development. There's a little introduction and then you can see at least the early childhood... the breakout for the early childhood and the middle childhood sections. And this is what the back looks like with the partner... the profile of the partnership organization, the research piece, the family resources corner and the sort of tidbits for the month. And this is where... I don't know how many people actually share their news, but we do and every single one asks for people so share their news and that we will be very happy to sort of profile it in an upcoming issue.

And Paula mentioned the 10 themes for... the 10 themes that the Bright Future's Guidelines are written around and again, just to remind you, it would be like promoting family support, promoting child development, promoting healthy mental health, healthy weight, healthy nutrition, physical activity, oral health, healthy sexual development and sexuality, safety and injury prevention and community relationships and resources. Did I leave family support off the list? Nope, promoting family support. That's what I said first.

But anyway, so for each one of those themes, the Impact Team worked to create a... worked to create a theme sheet about each one that was family friendly, we reviewed it for healthy literacy. It introduces each thing... theme again. It breaks it down by some information by age, state, sort of companion to what you can

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expect part of the parent pre-visit questionnaires that Paula showed and then it has a section on what families can do to promote a child's overall development or to promote a particular theme as part of a family... because again, it's one thing to say, "Eat five servings of fruits and vegetables a day," it's another to actually give families concrete strategies that they can use to help promote the theme. And I'm hoping that we picked, like, you know, just because there's a bunch of strategies doesn't mean you actually have to do everything. I'm actually a big fan of lists and I like things that I can pick and choose to do. Again, as I mentioned my own son did not eat for the first... he didn't eat food orally for the first three years and it was a bit decision to transition him to oral feeds. And I had all these people sort of telling me what I had to do to make that happen and none of it was comfortable. And I finally met up with a dietician who said, "Listen, these are the things I'm gonna suggest. Just pick any one on the list, do one thing, go in baby steps, and then see if you can move on to something else." And that's exactly with I did and he did learn to eat. You know, orally. So that was huge for us. And I think that that's something that a lot of families probably struggle with. It's really hard to make a big change like that. Obviously, I'm talking about a kid with some complex health needs, but regardless, if you have to like implement some sort of change. Change is hard. You can't work on everything at once and sometimes when you feel successful in having done one thing that was your choice to pick, you can move onto another thing.

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So this is an example of the theme sheet that was created as a companion piece, again to the Bright Futures AAP material. On this one was about promoting physical activity. Again, this was done... these were created with input from lots of groups, particularly family focus groups and Mercedes is going to talk about how that actually happened for the mental health... for the Healthy Mental Health one. And I will say that we really did struggle with the health literacy piece of this only because so many of these words... like if you use the words... a lot of times, health literacy is computed using the number of syllables in a word and it can be really hard to talk about things like healthy nutrition without totally raising the reading level of stuff.

So a lot of times, we left the word in there because that's the vocabulary that people need to use to sort of share a common ground and to have a discussion. But we did really work hard to figure out healthy food and eating. So we used the big word and then we sort of also broke it down into hopefully more understandable concept.

This is just an example of what the flip side looks like, and again, Betsy has printed out some sample theme sheets and those are up here that you can take a look at.

And then Barbara mentioned that we have a Bright... that there is a Bright... there will be a Bright Futures Family Pocket Guide again, a companion piece. It is coming soon. It will have age... it will have family-friendly information by age, stage and theme to

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correspond with the Bright Futures AAP materials. Again, it helps identify the priorities that will happen at each visit so it piggybacks and is a companion to the pre-visit questionnaire that Paula talked about. It will help families know what to expect at each visit and if they know something to expect and it was not covered, hopefully it will give them, you know, hopefully... and it's something they do want to cover they can say, "Oh, what about..." and move the conversation forward. 'Cause I do think that sometimes families have to drive the conversation.

There is an emphasis on family/provider relationships because we know that that's the key thing to family-centered care 'cause without that it just doesn't happen. And again, many, many resources. And again, if anyone was at the Family Voices ***** this morning and heard Dr. Tate and she mentioned how Bright Futures is a part of... is specifically mentioned in health reform as... or in the health reform legislation as the recommended guidelines for health visits and supervision and as Paula echoed this afternoon, because I believe that was her slide that she used. It's very exciting that it... that these are now incorporated into health reform and that Bright Futures is specifically mentioned because Bright Futures are integral to and dovetail with... so, let me see, so the... so now the Bright Futures are recommended are now part of healthcare reform and the Family to Family health information centers, which were funded through the Maternal and Child Bureau, the additional funding for the continued operation of the Family to Family Health Information Centers is part of the Patient Protection and Affordable Care Act.

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So for those of you that might not be familiar, the Family to Family Health Information Centers are family-run centers that provide assistance to families raising children and youth with special healthcare needs and others, around six national performance measures, which include: access to Medical Home, early and periodic screening, navigating community resources, health... issues of healthcare financing, partnering in decision-making and transition to adult systems of service.

So, really, all of these... all of the impact materials that I talked about, and the Bright Futures Family Matters Electronic Newsletters, the theme sheets and the Family Pocket Guide, when it comes out, they all contain information, which is helpful to families raising children... for all families, but there is a lot of information for families with children and youth with special health needs. And in a way, this will help advance the work of the Family to Family Health Information Centers because clearly, promoting health and wellness is a piece... it overlays with all of these performance measures.

And also, as already been stated, Family Voices was recently refunded for the Impact Project and it will develop strategies to expand the capacity and infrastructure of family organizations to address child health prevention that can be used by families and families organizations. The Family to Family Health Organization Information Centers, some of them already track this, but we collect a lot of data and so we can also now ask people specific...

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ask the Family to Family Health Information Centers specifically how they might be using the Bright Futures materials with families. And it's particularly import... let me think...

And the reason why this is... we're making such a push for this is because children and youth with special health needs are subject to the same secondary conditions that can happen to any child, like unhealthy weight or Type II Diabetes. And so family... any family could use these strategies, you know, we need to focus... we spend so much time focusing on the complex needs and the underlying diagnosis of our children that sometimes the health and wellness piece sort of falls... sort of gets to the end of the "To-Do list" and you know, drops off the bottom of the list and it just cannot be a priority. And especially now that regular preventative visits, like well child visits, again through the Affordable Care Act, because there will be no co-payment for that particular visit, hopefully that will... you know, because co-payments like nickel and dime us to death with all the other specialty stuff going on, hopefully that this will be something that children... and also because our children spend so much time seeing doctors anyway, hopefully this will make it easier for families to do that and clearly more affordable. And also, actually we won't talk about that... okay.

So anyway, let me so. So there are some exciting new partnership opportunities because of this funding and Family to Family, in addition to collecting the data as part of a pilot within the new grant funding, some Family to Family Health Information Centers will be... at least two in the first year, will be selected to work in

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partnership with the Impact Project specifically on health and wellness promotion for children and youth with special healthcare needs and their families.

BARBARA POPPER:

I think one of the exciting things for us working with Bright Futures is, for those of us who go way back and the difficult conversations or relationships that had to be built over the years for ourselves and the providers, it is such a joy to be working on Bright Futures where it really is based on a partnership and it's something that's held as a common belief. There's no arguing about it, it's really how to get more families to understand it and participate. And I think Mercedes will talk a little bit about that, about parents not even knowing that they're supposed to come in with any questions. That they're going to be asked about anything, that they just take their kid to the doctor. And as Paula said, you know, "I pulled the kid on the table." This is a huge change for a lot of us that we have seen and have been able to work with partners. And we know in a lot of places, there aren't pediatricians, but there are people who are building this in places where it's family practice that they might be using or people who only see a nurse practitioner in a clinic.

But the guidelines are there and they're going to become more generalizeable so that people will really begin to know what they are. And doing family materials that parallel them so that we can say, yes they're asking all those things and here in a simple version is why and what it means to you. And so families are sort of

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prepared. They've got like a cliff notes version of what's this all about. We do have the earlier one and we haven't said much about the website, but all the materials are on the website, the earlier Pocket Guide is there and it's there in Spanish as well.

I'm gonna just say one thing about the Family Orgs Group because that was exciting for us. We've had two meetings with all of those... I think it was 10; I won't even go find the slide again, national organizations. We went looking for national parent organizations that were not really professionals serving families, but were run by families and for families. And they were so excited to be invited to meetings about health because one of the things we've found was what their cross-interests were, there were military families there, there were families of multiples. Well, military families have twins, and families of multiples serve in the Armed Forces and some of them are Latino families and some are Native American. And so when they all got together and realized that many of them were talking about the same concerns and the same issues, when we were showing the materials and asking their input, they were just very excited to know more about Bright Futures, to know more about how to build the partnerships and how to work with their membership. And certain PTA also ahs always had an interest in health. Not just school health, but in helping families make the most of medical care for their kids.

I just wanted to mention something we did on CDC funding at one time, but also a Bright Futures... using Bright Futures to promote health and wellness. This Family Matters booklet was for families

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with kids with special healthcare needs. A lot of it came out of focus groups, survey of parents, and a lot of parent tips. And this is also on the FamilyVoices.org website.

I'm going to ask Mercedes to give you some real life examples of how she's worked with families and what it means within a family to family. Are there any people here from the state health departments who work with your Family Voices or Family to Family? Okay, and we'll give you some more ideas on how to extend those relationships. And for those who are not doing it yet, we'll encourage you to think about that.

MERCEDES ROSA: Thank you so much. I'll figure out how this works. I am a parent of two children with autism and I can say Bright Futures rocks! I wish these tools and resources were available for me as a parent when I was struggling with my daughter who had developmental delays. I wish I had a tool or resources that could have guided me, and when I express concern to my Pediatrician, it was, "Wait and see, wait and see, wait and see." And I did waste a lot of time and eventually she was diagnosed with autism. So I'm very passionate about empowering families with tools that really work and where their voices can be heard and I had the opportunity to do a focus group with mostly immigrant families, with and without special healthcare needs. We had 10 families and they were pretty excited. We sent out an invitation in both Spanish and English, we recruited families through list serves, through Facebook, parents that receive our Span Blast, an e-newsletter that we send out monthly. And the response was positive. Families were eager to

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participate. They were curious what we were going to talk about and we really, really want to include them. And what about mental health. So it was really exciting. We got them together in a local venue, in a library, and the \$20 gift card is always an incentive. So if you're doing focus groups for families, you know, that little incentive does bring them out, and we had to you know, stop at a certain number so that it could be really interactive and more meaningful.

What we learned from the families, we asked a series of questions around schedules, mental health, and we found that families with children with and without special healthcare needs really shared the same concerns. I was so pleased that there wasn't two separate booklets that the families had to use and it was the same. So the families of children with special healthcare needs, they sat next to each other and they realized how much we have in common, the same struggles, the same resistance from our children around all of these topics.

So parents... what we learned is that parents are having struggles, just balancing emotional and social wellness with their children, technology, internet, children are becoming more savvy than their parents. I mean, they can... I know my son can dance around me as far as he... he helps me create Power Points, but the children are so much more advanced and trying to keep up. And is that a good thing that the children spend so much time online and they see it as a tool of empowerment. You know, they're learning and the teachers are giving homework. So families felt like they're not

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really in control or they don't know what's best. And working with, you know, mostly Latino families, we learned that they don't really feel like they have a voice, or a choice. Everything that the doctor tells them is a good thing. And they assume that's right.

And around diet, some of the things that I learned through diet, what they feed their children, you know, it was rice and beans is not a breakfast. You don't wrap it and put it in a burrito and that's not really good. And so we touched on a lot of different things and they shared about sexuality. Very concerned. The parents of children without special healthcare needs were concerned that the children are learning too much. Using the internet, they're exposed to too much information while the parents of children with special healthcare needs, you know, they want their children to learn a little bit more and they want to know where can their children be taught that and is that part of a IHP and IEP or where are they going to expose their children so that they develop, you know, healthy sexual you know relationships, to the extent possible. So that was a real concern for them.

And families felt that there needed to be collaboration with other systems, especially around mental health. And that was a whole question mark, what is mental health? Anxiety, you know, children that did have diagnosis; there was one family that had a child that was, you know with bipolar and it was very stigmatizing within the Latino culture. Mental health is a big... there are a lot of stigmas associated with that and around just accepting that you

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have a child with a mental health condition and that it's okay. So the fact that there was an integrated group, they really bounced off of each other and compared to what some of the other families are going through they said, oh, it's nothing, it's great.

And parents realized that they are role models, you know, for their children. That no matter what, they should be the one to provide structure, to teach within a safe environment, and to set boundaries, healthy boundaries around everything that the children do, around the internet, around learning, around sexuality and to monitor the information as best as they know. Many were challenged to take computer classes to learn because the children should not be more advanced than the parents to the extent possible. We should learn some things. And it's good to learn from your kids, but it's also good to monitor you know, what they're doing. There are real dangers around that so. It was a really interactive time and the families really enjoyed being together.

They went through the tools and I'll share one story where there was... when we put the booklet, what do you call it... do you have it? The Pocket Guide. We put the Pocket Guide on the table and all of the resources just to see the initial response. What the families would think. Many of them had never seen Bright Future's tools and one mom got very quiet and she just looked... and on the other one, there's a rainbow, so she just kind of looked at the rainbow and we had a bathroom break. So I went to the restroom and she said, "You know, my son's not gay." And I said,

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what do you mean? I said, we're going to talk about a range of topics. And she says, "No, no, no, you know, that rainbow." And we had a good... and we came back and we had a good laugh because it's a very inclusive tool. I don't know if that was intentional, but we were able to talk about and just to kind of diffuse it to say that, you know, if you are concerned about your child's you know, sexual development, that's okay. That's a valid question that you could talk about and it's okay. To be accepting. And so I think that's an additional plug. You know, for the resources that it is all inclusive.

So some of the ways that we use the Bright Futures tool is, sharing information with families. We use it at workshops that we do, we are... we connect families with resources throughout the community. And we share this booklet because, one, it empowers families in all the ages and stages. To work with their doctors, to really believe that they can partner and ask questions about development, prepare for the next visit. Most of them go in and they don't even know, you know. They're giving my child a shot and that's okay. And they don't know what shot. Many of them now... I know in New Jersey, we have many families that are anti-vaccines. It's a whole movement. And as a parent of two children with Autism, I let them know, do you know what some of these diseases look like that we were able to, you know, cure with vaccines. And many of them did not. So I took the opportunity to do a focus group and show them the gory visuals of some of these diseases because they don't have any idea what these look like. And misinformation spreads like wildfire on the internet. And if

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families are going to partner with their pediatricians, at least get information that matters or begin to ask questions.

So they carry the booklet around in their pocketbook, they are able to go in and ask questions and be empowered to advocate and to learn more around, you know, whatever topics that they want. We use it extensively doing outreach to underserved families. Why? Because there is a great need there. There's a lot of misinformation, there are a lot of barriers around language and it does come in Spanish. And the families really loved that they can know the vaccines. They used to provide these little cards, those of you that work for health departments. Remember those little... yeah, they don't do that anymore.

Well, we promote the electronic registry, but families like to have that information handy as well. We use it in our Medical Home pilots, which was really a hit with a lot of the interns and families that come there to receive treatment in the federally qualified health care centers, the school nurses really love sharing this tools with families. Faith-based organizations as we do blood drives and screenings, diabetes and other things. They really love the resources. I have a lot of resources and I'm promoting this because my table gets cleared. I take a lot of things back, but I never take anything back that's Bright Futures. So, families really... they're very, very family-friendly.

We have links on our Span website, we also have family resource specialists that work with our Title V in our case management unit

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and when we provide technical assistance to families in early intervention, families that have children that are newly diagnosed, I think it really empowers families to know, yes, things are going to be a little bit different, but primarily your child will develop and will go through all of these different stages. And the more normal we can feel, I think it's great you know as a parent.

Everything that we do to promote tools and resources for families, we, like I shared before, we focus on the strengths of what's going on within a family and what can a family learn and ensuring that its family centered. The families do have a voice and by including them in developing tools and materials in the no families had input. And these were your concerns, it really validates the voices of the family and the families use it to find solutions around the critical information that they really care about.

I believe is apparent that knowledge is power and the more that we empower families about things that matter, the development of their children, whether it's vaccines, whether it's mental health, whether it's early screening and getting a diagnosis, and if you do get a diagnosis, it's the beginning of a new journey and you can partner with professionals. And that's a hard thing. Parents don't believe that that can really happen. They don't believe that their stories are there concerns are really important.

And I'll share a story about one dad, and it's rare that we work with dad's, but we really make an effort to reach out to dads because there concerns are valid and we know when a child is having

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challenges in marriages struggle as soon as the child is diagnosed there is that communication breakdown. So we really do a lot of work to reach out to dads. And instead went through... he collected the resources and attended a training that I was doing and he saw the book look. And he began to read it, and he began to weep. And then I notice, he was in the back and I went up to him afterwards, and he says, "I learned so much today and I'm going to help my son." And I didn't really think much about it until after, when he contacted me, and he said, "My son was diagnosed with autism and I know what to do." And he contacted early intervention and we had talked about all of these things, but it wasn't the mom, it's always the mom... you always do a lot. But this was the dad. And he told his wife, it's good to be okay, there are a lot of resources, there's a lot of tools available and he is going to be okay. And the child went on to make progress, but that now is a parent leader because we validated his concerns, we listened, and the information was at the right place at the right time and critical in that child's life.

And so we empower parents with information in this tool, certainly and all of the resources do that, that we validate their concerns and we provide parents with the choices. You can share great tools and great resources and then it's really up to the parent to do what they need to do to really make sure that their children and their families develop healthy in every area. And I think that the more information that we expose families too, that is likely to happen.

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I know, in New Jersey around obesity in so many different things, it touches it. I mean all of the resources touches areas that families are really struggling with and it's a way to empower families that it's not so in-your-face, like you want to share, you want to give them something where they don't feel that you're pushing it on them that they can read and acknowledge on their terms. We include parents and decisions as partners so their choices in their information they share and focus groups, we use that. Enhancing their Medical Home. It's their Medical Home. If they don't feel that they have a voice, it's not a Medical Home. If they're not partners, it's not them Medical Home. So we really want to promote the Medical Home and ensure that parents are determined and that youth, the young adult with special health-care needs find their voice to advocate for themselves. You know, it will become their Medical Home. You know, the families will step back so learning to go to the doctor, learning to write the information down, what's next, that's very important to prepare our young adults. And if we prepare our children and youth with special health-care needs and we give them what they need today, it will lead to successful transitions in the future. And that's our goal, to really have young adults that are empowered and ready for the future. Thank you so much.

BARBARA POPPER:

We're really hoping to have some discussion with all of you about what you're thinking about, what makes you think you might be interested in or able to do, I will tell you, as a grandparent, that giving each of my kids one of the Pocket Guides, I know they are

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using them because one of the things we put in there is not what your child should be doing at this stage, but might be ready to do in a gentler way because there is that normal range, it doesn't mean there's anything wrong if your baby isn't walking at 12 months, but maybe he's getting ready to, but it allows you, as you were saying Mercedes, it was great that people can take it, absorb it, think about it, you're not pushing it on them and certainly as a mother, grandmother, and mother-in-law especially, it's so much easier to hand people material and say, you might like to use this, you might find this useful when you're going for a visit.

So, questions, comments, anybody would be able to answer for you? Yes. Go ahead.

Question: [Inaudible]

PAULA DUNCAN: Great. Let me tell you what we've got so far, but we're also trying to investigate ways to collect parent's view on this as well. It's hard enough to get into the charts and try to figure out actually what's happening, but that is what we are doing right now. We are using some of our precious funding, our Maternal and Child Health Bureau, Bright Futures funding, to work with 22 practices right now from across the country, community health centers, Indian health service, inner-city, in residency programs, to see if they can and should do all of the things that were on the list. Can they really do the five priorities, can they really ask about parent's concerns and document so that we can tell. And we're off and running with that. It started in January, they did collect data and

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we're going to look at it after we do monthly phone calls and that's one thing. We're really happy about that because we think that... we don't want parents to be going to a practice for their visit and have nobody there to do the stuff we're just talking about, right? So we're trying to work on them Medical Home side.

Betsy was in attendance at that session and then led a very important session, started out, we gave it the best place of the day, the first session of the day, how to involve families in your Medical Home, in the measurement of your Medical Home, and all kinds of ways. So that's one thing. And that's our first foray.

Obviously parent surveys. Paired focus groups, our parent advisory committees to the Medical Home are the second one. But I think you're more talking about what **** survey. So we could use the **** what happened at your visit survey perhaps in some practices. In Vermont we were actually doing that with practices. And they are very surprised when they get the results because many of them of course, that wanted to do this, think they're doing a very good job, and they are, but sometimes they realize that they're talking a lot about seatbelts and car seats and not enough about behavior and things like that. So we have no specific plan, if we certainly had more resources, may be partnering with Family Voices, something, maybe we can get something done in that direction in a pilot way, certainly in some places are doing pilot work.

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Let me just say that I think your questions are **** about the opportunity. The opportunity right now is that maintenance and certification, and this is for pediatricians. Remember, Bright Futures was written and is for everybody, not just pediatricians, but it just happens that right now, pediatricians when they recertified, instead of just taking a test, they have to do a quality improvement project. Mr. started in 2010, so if you haven't heard about it, that's why. And a lot of the pediatricians don't seem to know about it yet. But we're hoping that when they go to look and see, I wished I do my quality improvement project on, they're going to say, coheres the Bright Futures measures, let's do those. And because we're working it out with these practices, there's also an equipment module that pediatricians can get from the AAP to work through that way. So it's just another opportunity for us to work together.

Now we need another opportunity to add in the family voice. So Medical Home, the parent... Medical Home AAP Medical Home Index, the NCQA Medical Home, there are many pieces in there that talk about how are you really going to get feedback from families, from the people you're serving. And so I think there's an opportunity there I personally, we don't have as a complete part of Break Futures, but if anybody has ideas that would be a great public health activity.

BARBARA POPPER:

Yes, comment in the back. Go ahead... louder.

Question: [Inaudible]

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BARBARA POPPER:

Is there a what for that? A Spanish version. The Pocket Guide has a Spanish version. Jane **** is also Bright Futures just stood up in the back...

Question: [Inaudible]

BARBARA POPPER:

Can't hear. So your toolkit Jane. You're so far away; your toolkit is in Spanish?

Jane: The question was if ****.

BARBARA POPPER:

Oh, okay. And the question about Spanish, the theme sheets and our Family Matters Newsletter are English and Spanish on our website.

Question: [Inaudible]

BARBARA POPPER:

Keep shouting, it's far away. Do shout Jane.

Question: [Inaudible]

PAULA DUNCAN:

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So let me just say, those are the professional ones, right? So the
**** questionnaires and the handouts are in Spanish, the
documentation forms and some of the other things in the toolkit are
not all in Spanish. We just had the trans... we just got these
translations done and they are the things that parents would need
the most.

Question: [Inaudible]

BARBARA POPPER:

We'll let you guys do that one offline, which Spanish it is,
Mexican or... yeah. Our Spanish is online and it is done... what
did you want to say Betsy?

Betsy: [Inaudible]

BARBARA POPPER:

So, trying to standardize the Spanish so that through the translation
process and her advisors, it is the most useful to the most groups of
people. There are a couple of more questions. Do you want to ask
a question? For Paula, yeah. Paula, back you go.

Question: [Inaudible]

PAULA DUNCAN:

Sure. I'll end this up gotten from people in the field, in public
health, and in the states right now. We haven't done any national
collaboration yet about, although we would love to come to a WIC

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meeting, that would be awesome. Or develop a WIC partner that could go to the WIC meetings. So what we've heard is that folks that are doing WIC clinics love to have the guidelines, the **Paradicity[ph]** schedule, so that they know exactly cancer supposed to be going in. They love having one set of guidelines. They also love to know what questions are going to be asked that thing about, you know, so they can help people to prepare. But the thing I really like the best is the handouts. And so sometimes... the handouts are in the toolkit, the toolkit is purchased if you're in public health, but we'd like you to talk to Jane Basowitz because we're trying to get the toolkit out to all public health people that really would like to use it. And you can just download all of those handouts. You can have a stack if you're seeing, in all different ages. And then you could maybe, if there was a point that you wanted to make with a parent, something that you think they could really benefit from, you can pull out the handouts and say, I look, this is what all of the experts in the field have agreed on is really important and here's the thing we were just talking about. Right here.

So when you go to your healthcare appointment, I'll probably discuss this with you as well. Do you have any questions about that? Or just making it the same, because sometimes you know, sometimes between WIC clinics and the Medical Home, there is not always the same message. At least some people are worried about that, especially about weight. So they try to synchronize the message, trying to standardize the message. We actually, Judy Shaw, who is another... she's here at the AmCHP meeting, and she

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is co-author of the Guidelines, editor of the Guidelines with me. And what she has a student working on right now is designing a wall chart for WIC clinics because someone asked her, could you please make a bigger one of those Paradacy schedules more understandable, so it's not a million dots and everything, so she's got a student working on something that could go on a wall of a WIC clinic. I don't know if that could be helpful to you too, but she's trying to get it to the right level so that we can make it available to people in another tool. Jane?

Jane: [Inaudible]

PAULA DUNCAN:

At home visitors, yep. To help parents prepare.

Jane: [Inaudible]

PAULA DUNCAN:

Yes. That's what we need. Yes, no I know. I know. Right. Right. Exactly. And let us know what kind of materials you need. So I didn't really talk about how happy we are with all of the materials because I didn't want to steal anybody's thunder about what everybody's going to be talking about. They can imagine from my point of view of how it looks to see all of these materials that are just right for parents and to hear that Bright Futures rocks for parents. I mean, that's not because of us that's because of our partners here. And so thank very, very much for doing that with us. The family meeting with the organizations, different family

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organizations, was really awesome. We learned so much about how we should be speaking about this and how it works for different groups and people. It was really, really important.

BARBARA POPPER:

I also want to acknowledge Melissa Vickers who was one of the original infancy reviewers and helped bring a consumer viewpoint when Bright Futures was being written. Each one of the section groups that was doing the writing had parents who were participating and the different age groups, and you know, felt like they had points they were going to stick up for to the end, right Melissa?

And Melissa works with us on Impact as well.

PAULA DUNCAN:

There were only six experts on each panel, infancy panel, early childhood panel, and on each panel there was a parent. So of the six experts in the world that we could get on each of these panels, that was one of the experts that we got. So thank you.

BARBARA POPPER:

And working with people who consider parents expert is really terrific. And as I say, we all worked together a long time to make sure we could get to that point and be able to work together.

We want to thank you for coming. We want to send you to our FamilyVoices.org website for Bright Futures materials and Bright

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Futures for Families.org and we would love for you to sign up for the Family Matters, talk to us, email us, take copies of materials and we will be letting you go when the Pocket Guide is available.

Thank you for coming.