

AMCHP 2007 ANNUAL CONFERENCE

HEALTHY COMMUNITIES

March 3rd to 7th, 2007

Family Matters: Research Findings on Health and Wellness for Children with Disabilities

BARBARA POPPER: And those are the graphics for the materials Betsy was talking about. So, going on to our CDC project, and I lost myself here, great. What we've called this project funding, uh, funded by CDC is Family Matters using Bright Futures to promote health and wellness for children with special healthcare needs or disabilities. And when we started writing, as Betsy and I, with partners at Tufts University School of Medicine, Paula Minehan was not able to be here, Aviva Must is the other professor who's worked with us and is, um, well known in the nutrition world. Uh, but what we wanted to think about was, are these things that families are thinking about? Are they getting information about these topics? Or is this just one of those things that isn't thought to apply to children with special healthcare needs.

So, we looked for methods for supporting families of children. Um, we know, as parents who came up, uh, in the ranks through parent groups and support groups, uh, that there's a lot of value in having parents get information from each other, so that was a feature we decided that we would work into this, uh, research project.

We've done three phases, the first one took quite, longer than we thought, because we thought, we better know that the questions are, we better know what families are thinking about before we design an intervention, and we spent a year doing focus groups, and I'll talk a little bit about what we found out from there, some of it surprised even us, because we think we know a lot about what families are thinking. Uh, the second part is, and I have, um, as of only the last few days, the very early data from a broad-base, online survey. Um, I will tell you it's still online, probably for the next couple of weeks, it's a survey monkey survey. People have, uh, over a thousand people have responded. It's a 20 to 30 minute long survey and we've been very impressed with not only their willingness to take the time and go through the little short answers, but the lengthy notes that we have, we have about 30 pages of notes and comments that people have written, including ones like, thank you for even taking on this topic, and what are you gonna do with the results? So we'll talk about that too.

And the third part, which has really been happening all along, but I don't have data on yet, just very initial impressions, is our non-clinical intervention study where we have used mentor parents. So we'll talk about all of those.

The partnership, as I said, is with Tufts University School of Medicine and Family Voices. And Betsy and I in the Boston office have been working with them across the city. Uh, it expands the view of health from health services to the day to day

health behaviors, and Betsy always likes to say, those under the control of families. When you go to the pediatrician or the family practice person, you don't have a big discussion about, um, very often, what time do your kids eat breakfast and what do you feed them and where do they eat it and is the TV on? So those are the kinds of things families decide for themselves. They may get some guidance about good eating, but often, again, for kids with special healthcare needs, we didn't know how much that came up.

And we used as the basis the Bright Futures guidelines. That was vetted medical information and we, um, as families, took ideas from ourselves and others on practical ideas that people could use at home. And we found that people really were looking for very basic ideas.

Research was not something Family Voices was quite as used to, it was a new venture. And having funding from the CDC I think we're one of the first family organizations that they funded. We've used community participatory research design, families were involved. Um, families who are doing the mentor peer support are parent leaders, parents who've been involved. They're the kind of parent I describe as the parent in your town or your community that other parents go to. And they'll say, you probably can help me with this. And a lot of us have been asked things that are way beyond what we think we know, but we can brainstorm with people, we're used to doing that.

And so, we found in our state some pretty strong peer mentors to work on the project. Uh, as you see, Louisiana's, uh, one of the sites, and I'll tell you how things changed because of Katrina, but Massachusetts, where we are, uh, in New Jersey, and we did English and Spanish in New Jersey, Vermont and Washington state. What we also did for our advisory group is find some partners within those states, and some of you may have been involved, uh, either directly or indirectly, because we went to state Title V programs in those states and Bright Futures partners, in Vermont there's a very strong Bright Futures component and so we have involved Paula Duncan in Vermont and, of course, their health department too.

And we were looking for the widest variety, economically, ethnically and linguistically so that we knew that this was gonna apply to everybody. So because Family Voices, uh, has the project, families are the focus. We are leaders with partners. We are not a disability specific organization and so we wanted to be sure that we didn't, in any way, slant this towards any particular disability, we wanted families to participate with all kinds of backgrounds, and the activities are family centered, of course.

When we went out in 2005 to, uh, talk with different parents and we had about six different focus groups, we found out from parents that, yes, health and wellness was an important issue for parents and a source of frustration that it wasn't something that always came up in their visits. They saw the link, as Betsy said,

you don't want your kid with a disability to develop some other kind of problem, unnecessarily, because these things are not getting attention. So if you've got a kid with Spina Bifida, who then needs a lot of oral health work because nobody talked about flossing and brushing, that's just, you know, kind of an insult to injury, it's an extra burden on the family. As would be, um, excessive weight gain because of, for a child who is trying to use upper body strength. And in the same way if the child has asthma or diabetes or whatever, autism, you want to be able to find ways to keep it to a one disability challenge, as opposed to adding things that could've been prevented.

And parents wanted to be involved in this because everybody else is talking about these issues and they don't want to be left out and shunted to the side, this isn't about you, uh, seatbelts are about you and helmets are about you, and they wanted to feel that health and wellness also applied. So they wanted to become involved. We asked people at a workshop, if this were offered to you, would you participate? Everybody said, absolutely, I would want to be part of this kind of project.

And even the New Yorker tells us, everybody is thinking about some of these health and wellness issues, and the witches are saying, remember when we had to fatten the kids up first? Kind of a horrible cartoon but it kind of makes the point. You can't go anywhere without seeing, uh, comments out there about our, uh,

kids and what they're eating, junk food, weight gain, lack of activity, sitting there on their electronic devices.

So here are the themes that resonated, uh, healthy eating, definitely, we culled these from the taped focus groups and then pulled out what were the most relevant to parents. They wanted to know how to get their kids to eat balanced, nutritious meals, how to have them be active, not just sitting around watching TV, and again, for kids with special healthcare needs, that's added challenges for families. Um, if they're not local, places they can go if their kid isn't welcome to some of the activities that exist. So these were not just lightly discussed.

Family routines and rules. Do the same rules apply to all the children in the family? Are they separate or different or don't exist for a kid with special healthcare needs? Parents wanted help with that. Supervising screen content, what their kids were watching. And taking good care of teeth, oral health, um, and that's another whole issue, probably there's another workshop here about oral health for, uh, the availability and the accessibility, coverage, we have a real problem for families on public, uh, insurance getting any kind of dental care for their kids. So it's more important that their children have good oral health habits, because it's not so easy to find a dentist who enjoys taking care of some of the kids that come in with, um, special needs.

And then sedentary behavior limits versus screen time benefits were a little more complicated. Also, down at the bottom, avoiding the risks regarding alcohol, drugs, sex, people worried about there are kids out there in the world who might be more vulnerable, who might be more innocent, and how do we help protect those kids?

We brought up the well child visit schedule and, um, I know Merle's not in the room, but yes, people were not as concerned about that, partly because they, that was just routine, and also their kids saw other doctors.

Second hand smoke, um, that was gonna be a focus for us and we dropped it. We also found out that for some, uh, cultural groups, that is a topic that could be domestically not, um, discussable. If there are families where somebody is smoking, we, we've talked with families about, um, is there an area where people who smoke are not around the child, the child's bedroom, etcetera. But these families didn't feel they could take on having whoever else in the household smokes, stop. So, that was less on the radar screen. And we had many people who didn't smoke, never smoked, would not let anyone in their house who smoked and they didn't want to talk about it either, so we had both extremes.

Other issues that came up and, uh, we were not prepared to address directly, but they certainly, with the peer mentor, might discuss them, gun safety, lots of homes with guns versus, uh, a child visiting homes where there might be guns,

and that was a concern. Again, for kids with special needs too, because they might be more interested, less interested, less able to, um, make those determinations about the safety.

And teaching children self-advocacy skills. Uh, some of us have children who are, what we call, second generation advocates, we've modeled it, they have learned it from us, and, uh, a lot of parents were interested in that.

Self protection and non-traditional approaches. And Paula and Aviva have put in a paper to, uh, I think it's APHA for next year talking about complimentary health practices, whether people use complimentary forms of medicine, whether they discuss them with their doctor.

BETSY ANDERSON: It was really interesting to hear families' comments about screen time, because, even though, in some cases, families felt that their kids might be watching or using too much computer or television, in a lot of other cases, and this may be true for some of us in this room too, television was seen as a real, as a real aid, you know? A lot of families are working, families said, you know, gee, it's such a relief to have my kid be, do, be occupied. And for some kids with special needs, there were not safe places in their neighborhood, or the kids needed a lot of supervision, and that all is very time consuming. Other families felt that television provided educational resources or social models. So as, as Barbara said, there was a real mixed, kind of, feeling among families

about the benefits or, um, problems with television time, something for all of us to be thinking about.

BARBARA POPPER: So we asked them, where do you get your information on health and wellness? And, as you can see, the internet. We started before the internet, where you wrote letters and you sent for information and I think I've got some things from, uh, the U.S. government on raising children that I got back when I started many years ago with the first of my four children, but now people go to the internet. You can do it in the middle of the night, you can find resources, you can find support for everything. The media does get the message out.

People do see things about obesity and, um, kids with high cholesterol and the need for exercise. Other parents, always a good resource, and the support networks that they're involved with. School nurses, we were, uh, very pleased to see school nurses, and for some families that was another reason they weren't interested in the smoking and drug issues, so much, because they said, boy, the schools got that handled, and they really, the kids bring home those messages, so that was a good reinforcement for people who are in charge of school nurse programs. Dentists and WIC, the dentists can say things to a child, the child will, uh, follow more than if the parent's the only one nagging. But, on the bottom, as you see, health providers, themselves, were not viewed by families of children, uh, of special health care needs, as the important source of health and wellness information. And as some parents told us, when they went for regular visits, I have a mike so don't worry I can be louder, uh, babies are always welcome, the,

uh, one of the things that they said was they use those visits, regular visits to the primary care person to update them on what the specialists were saying. So, you know, the families are often doing case management, and so they are the provider, they're the conduit for information, and that leaves, we know, how long a regular visit is down to, 15 minutes in some places, eight some other places. So, in that little visit, to squeeze everything in, health and wellness may not come up.

Uh, the challenges, we've talked about time, energy, money. If a child has a particular condition that limits nutrition and activity options, kids who are on G-tubes, um, kids who have, um, brittle bone disease, who are not gonna be in the gym class, all kinds of things. We had such a wide range of disabilities. Drawing the line, parents who aren't as sure for their kid with special healthcare needs, where to set those rules and set the limits because you have to consider the disability and the child's ability to understand what you're doing.

And then people said, well, this year we're hearing, you know, lots of milk is good for you, and next year we'll hear, not too much dairy, and all the advice that changes. And, of course, the media's always got a little alert out there, news, you know, coffee's good, coffee's bad. Um, I now drink half decaf and figure that'll cover both halves of the story, and add green tea occasionally because that's probably better. So that's a, a conflict for families, and I think, uh, when we talk about our guidelines and our materials, we have to think about how often, uh,

things are gonna change and what do we say to people about being consistent when we're not.

But with, uh, common to all children, the challenges, um, are in the culture, and the parents are lifestyle. When parents say to you, I don't eat fruits and vegetables, how do I get my kid to eat it? That's the kind of thing they can work on with a mentor parent, because that's not easy.

So, then we went into the controlled, non-clinical intervention study, with the idea that, let's see if having a peer mentor, a buddy system, I come from the background of La Leche League, and I was a group leader and just knowing that a bunch of mother's together could help each other, I've always said, the woman who delivers can't remember a thing she read, she might remember the woman who sat next to her who said. And I think that's a piece of what we wanted to pull into this. And people who are disability support groups, whether it's autism or whatever, that's a really big source, it's someone who's walked in your shoes, knows what you're talking about, and we thought the mentors would do that.

We also found in the focus groups, although not in the intervention study, the focus group parents wanted to be sure it was a one to one direct match. That if they had a kid with autism who was five, they wanted a parent with a kid with autism who, maybe, was no older than seven. And so we thought that would be a problem. When it actually came down to the intervention and we said, well, in

Massachusetts the mentor parent will be Beth Dwordsky, and a lot of people go, oh, well that would be okay even though her kid has a cardiac issue, and not some of the other things. So, it started out as a worry for us and was not.

We tried to recruit 120 families of children six to eighteen, uh, for the intervention and the control group, and as you see our final numbers, a few people moved away, left the area, um, said they couldn't, didn't have the time or the energy for this and withdrew one more thing, and for parents of kids with special healthcare needs, that's a common refrain, it's one more thing. Uh, they were asked to select goals with the mentor parent from the, uh, Bright Futures, uh, goals, and we were measuring pre and post the study period what their attitudes and health behaviors were. There were written questionnaires, and we are just finishing up, we are weeks away from the last person, and then we will begin to have data, which, of course, family voices will put on its website and will share with all of you.

Uh, we had to define what the mentor parent role was and was not. And I, probably the italics there aren't so clear, but it's a parent of a child with special healthcare needs who has experience providing peer support to parents as an employee of a parent support organization. They all had to attend training sessions and complete, uh, human subject protection educational requirements of the IRB, this went through the Tufts University Institutional Review Board to be sure no one would be harmed. And part of what was funny when they asked

what were we promoting we said things like, make mealtime pleasant, which is not too risky a behavior, although I suppose some nights in some houses it could be dangerous. Uh, and they participated in ongoing scheduled supervision. We have regular calls not only with ourselves from Family Voices, uh, but with Tufts and also a pediatrician, um, at Tufts Medical School, in case any questions come up that we think need medical advice.

People the, our just initial impressions from, uh, the comments and the post-surveys that people do use, the parents are using the information and support to achieve goals they have selected and, a lot of the mentor parents said, they wanted five or six goals, I asked them to stick with one or two to start. So people thought they could do it all. Not so easy to change behavior for yourself and your family, so, having just one or two that they felt were important. And then we have picked up information from what the parents have done, and among the mentor parents on our calls, we share what are those ideas, how do you do this? Um, helping each other. And we will be trying, in some ways, to collect that information and publish it.

So you all know the, um, project goals for Bright Futures, these are the ones we use. We stuck to healthy eating, physical activity and screen time. And again, knowing for some families one or two of those might not apply because of the disability or might not be so negotiable within the family. If you're limiting the

child's TV time, you might be limiting that for everybody else in the family. There are homes where TVs are just on and so that might not be a goal for that family.

We are very proud and we speak proudly together, uh, of the fact that we have a very cohesive team. This is an unusual kind of arrangement for, uh, professionals in a family organization to be partners in this kind of research, working with mentor parents and our medical consultant, it works well. We have written another grant that we'll try and get funded at some point, we'd like to go forward on the next stages of this project. Uh, we've also, are just about at the end, as I said, of the intervention study, and we have done in-person interviews with 55 families in Louisiana, and I'll give you some data from those, and I will give you the early findings from over, I think it's been 11 hundred, of the online surveys.

Uh, Louisiana, we wanted to get diversity across the country, so we had Washington State, Louisiana, New Jersey, we're in Massachusetts so we allowed Massachusetts in, we think we're a diverse state, and Vermont. Um, but Hurricane Katrina forced us to make some changes in our plans, and what we decided was we certainly could not just drop them, although having the mentor parent though, uh, Phyllis Landry in Louisiana, in New Orleans, try and go out and recruit parents on health and wellness would just have been absurd. So what we, uh, came up with, with help from our CDC project director Don Lawler, was that we would do something different. And to meet our commitments to Louisiana, we converted the survey, and let me tell you this was not an easy

process, to an in-person interview. Uh, fortunately we knew somebody in our state, uh, who teaches or has taught interviewing skills at Brandeis and is, guess where she's from? Louisiana. So Dotty Robinson came in and helped us do that and helped us do the training. Linda Pippins from, uh, Louisiana state Department of Public Health, helped us immensely. She was so supportive. Uh, she helped us work with 11 other state health department parent liaisons whose staff there helped clinics throughout the state and are in direct contact with families. And she arranged to have them, as part of their job, conduct interviews. And what we did was come down and do the training for them. Each one agreed that they would do five, in-person, hour long interviews at the clinic sites. And don't forget, families come with their children to the clinic. And so, this was not so easy. And sometimes what they'd do is come to the clinic, agree to be interviewed and set up a separate time. And, of course, there were privacy, confidentiality issues. We really just went over this in such detail, it's not the same as go to a computer and respond. And because Louisiana had previously done emergency preparedness surveys the year before, we added some of their questions for comparison to that survey, so that data will all go to Louisiana.

And so the goal was to conduct the interview survey and gather information, again, healthy eating, physical activity, screen time, but the added piece was disaster preparedness. And the self-administered questionnaire, going to the interview, we had a sample design, uh, we developed a protocol, those 11 parents, when we went down, part of the training was the research ethics, and

again, they know these families, they see them on a regular basis. It was even more important that they, um, be aware of, of the IRB requirements and research ethics and not say, oh, are you sure you don't want to do this survey with me? Uh, the interviewers were just a wonderful group and we continued to have calls with them after so that there was supervision and support from our project and an evaluation.

So, the adaptations called for scripting, we actually had some cards with all of the answers because the parents weren't reading this, and so, if you said, what would your answer be? We showed cards. Uh, we had very specific, um, just like as though it were directing a play where you have directions for the actors, we had directions for the interviewer and we did some adaptations and other formatting changes. And we just used what other families were coming to the clinics, uh, we had probably, I think, eight out of, eight or nine of the 11 clinics, I think, or 11 out of 13, whatever it was, we got just about the whole state. We offered to the interviewers if some couldn't find that fourth or fifth or didn't have time, somebody else would do it for them. Uh, they were free to do that among themselves but it didn't actually turn out to be necessary.

And incentives to respondents, and this is always a, an IRB question, you can't give so much money that people can't say no, but we felt that we wanted to give something and something that would be useful and we were told Wal-Mart cards would be just the thing. So, that's what we did.

Uh, we wanted 50 to 60 interviews, we got 55 completed interviews, um, and so the collaborators included the Family Matters, uh, people, the parent liaison consultants and their statewide parent liaison trainer Angie Myers, who was just terrific.

And there we were in Hammond, Louisiana on a very hot day in July for our one day training. And there was great southern hospitality and a wonderful group of parents. And we brought, um, I was there and Aviva Much and we also had one of their, uh, graduate students who came down and Dottie Robinson. And having a southern accent is really helpful. So, and she, she came from a town that they all knew that I'd never heard of, but it was right nearby.

And the interview in a box is something we did with our focus groups as well. Every single thing the person might need, the tape recorders, the masking tape, everything got to them in a box, and we did the same thing with this. So we came in with our box of materials, we had everything that we needed.

We also have, um, another major part of our project is our toolkit for mentors, which is a huge volume, like the Manhattan phone book. Uh, what we would like, it's what the mentor parents have used when they needed information. We knew our mentor parents were support people but they weren't knowledgeable on every website in the world and everything about how, and some of them said, I'm

no expert on health and wellness myself, my family could be eating better. And so, uh, with Tufts we developed a huge book of resources, and the next trick is going to be how to turn that into something usable on the Family Voices website, perhaps another pocket guide, with some of the direct ideas and suggestions we've gotten from parents. And I have given you a very early sample page that we're working on to think, how would this work? Sort of a question, answer, um, how do I get my kid to the table without a, you know, a big fight and some suggestions and things parents have told us, parents of kids with special healthcare needs, and then some really popular websites that we have culled from it.

It skipped. Okay. Okay. Well, I may need, I may need technical help. Okay, there we go. Um, the process evaluation was that, after we left the training everybody did one survey and FedExed it to us, overnight, so that we could see how they were doing and if they needed any assistance and they could call and ask questions of how they had done it. And then, as I mentioned, the weekly calls.

The mean age of the respondents was 11.98 years. I've never before seen an even split like this, but it was 50-50, boys and girls. Ninety-six percent had some form of medical coverage and the mother's education is listed there, so there were a lot with high school and some college. And the ethnicity was varied, as one might expect, in Louisiana, and the household income, I would say, when you look back and look at the number of people with, um, college education,

probably the below 20k, um, 63% from 20 to 40, 31% might just speak to the fact that they were coming to the clinics for their care.

We asked people to rate their child's severity from, on a one to ten basis, and this was one of the things the CDC was interested in, that we work with families of children with severe disabilities. And on an eight to ten basis, uh, 30% rated their child's severity. And that does, as Betsy said, that doesn't mean their kids were sick all the time, but the severity of, uh, their disability.

We asked about emergency planning and 76% had an emergency plan. One of the comments the interviewers got was, I didn't have one until I got the survey last year, and then I figured I'd better have one. So, I think that's really good for Louisiana to know. And then for those who said yes, they did have one, did it include steps to evacuate the family and, boy, after Katrina, it sure did. But did you evacuate for the last hurricane? Forty-five percent, many of those people said, um, that they were not affected, that they were not in the path of the hurricane. But some of them also, um, told the interviewers that they didn't feel that the shelters were really a place for their kid with special needs, particularly some of the families who had kids with autism, they just felt it would be too overwhelming, and they rode out the storm in place.

And if there was a special need shelter in your town, would you go to it? Fifty-six percent said yes. So that's still a bunch who would not, but it's also, um, the idea

that they, they felt that the shelters would not be prepared to handle their kids with special needs. And a lot of these are families who've already negotiated these same issues within their school system, so they know, not everybody is prepared.

And, uh, for Louisiana they wanted to know if the families would be willing to register for emergency purposes so that, uh, and this is something that, um, I think probably Suzanne Gottlieb talked about yesterday if you went to her session, getting families and Family Voices talks about this, does the fire department know about your kid? If there were a 9-1-1 call, do they know? Uh, do you, are you dependent on electricity? And some of those are the kinds of things that families should be letting, um, first responders know about. And, in this survey, the, uh, 42% had children who were in a wheelchair.

So now we go to the online survey results, for the 11 hundred or so that we have. We talked about communication with providers, nutrition, physical activity, screen time. And I'll just give you the earliest data, and it's preliminary, it'll get cleaned up and added to. So, we didn't have 50-50 here, um, and I think I'm less surprised that it's not 50-50 for the online than, um, than I was surprised for Louisiana. So, it's, uh, two-thirds male, about the same mean age as it was for the other survey, and the severity is, uh, probably a little bit higher here, uh, at eight to ten, and families really who took the time to do this are probably that self selected group.

Uh, we've got, um, a much larger proportion here of white families who are responding and more with some college. So, I think that either speaks to the time it took or the fact that it was only on a computer. We did have people request that we send them surveys, uh, that they could administer in some other fashion, and we just couldn't do it, there'd be nobody to input the data, so we were not able to do that this round, but, who knows? We may do another version somehow.

We asked, uh, about the well child visits and other visits a child might have had, and so 79% had one or two well child visits in the past year, and lots of them had other visits, medical visits, either for illness or to a specialist. And that five times or more is 19%, so some of these families are seeing lots of providers. But, are they discussing healthy eating with the primary care provider? Uh, and we, what we don't know is how much is parent initiated, if you look at 14% were more than, oops, I should take that off, almost all of the, um, visit was spent on healthy eating and that might have been speaking to the child's disability or a concern at that time. But little or none was about a third.

And physical activity, little or none is over a third. It just didn't come up. And for some, again, it was a great deal or almost all. And we had to have a category for not applicable, and that's where some of the kids either, for the eating issues, um, where they're maybe tube fed, these are the parents, uh, decisions on how to respond to that. Was screen time discussed? And that number goes even

higher than a third, it's almost 60%, it just doesn't come up. Uh, except for some, and a great deal, and again, we don't know whether that's a particular provider who's discussing it or the family saying, this is the biggest issue in our house at the moment.

The 20-10 goals are two servings a day or more of fruit and three servings a day or more of vegetables, and the families were asked, um, on a weekday, uh, does your child have two or more servings? And then we asked about a weekend because we know people's schedules and lives are very complicated. Families said, I have no control over the school lunch, I have no control over what goes on some of the time, and other families said, we're more relaxed on the weekend, I have time to cook, I have time to make sure these things happened, and other families said, we let all the rules go by the board on the weekend because it's, we're trying to have harmony here and so we allow treats that we wouldn't. So those were some of the, the numbers on fruits and vegetables.

And physical activity, does your child participate in moderate or vigorous activity 20 minutes a day? Another 20-10 goal. And, uh, during the week, um, I'm sorry, the moderate was 4.4 days a week and we, again, we don't know, that may include some school programs, it could include physical therapy as well, for many kids. Vigorous was lower, only two and a half days.

Television time, um, 63% half an hour to two hours, and only three percent, five hours or more. We have a whole range of, of the primary data that goes up to, um, between two hours and, uh, five by, in half hour increments. And on the weekends the, um, five hours or more goes up, certainly, and half an hour to two hours, um, goes down. So, we had a whole wide range of, of results on what people do about TV.

We asked people, as we had in the focus group, what are your sources of information on health and wellness? And, in this group, 51% said their primary care provider was the source of information. Again, we don't know whether that's offered or only on request and it may depend on the family as well as the provider. But notice that 54% are getting health and wellness information from their other medical specialists, and that could be a broad array, not just subspecialty people but some of the other people who provide care to their child. The internet, 75% used the internet to get health and wellness information, 60% from advocacy groups, uh, 50% the more informal parent support networks and only 29% said TV and radio as media, that's a little different from, uh, our focus groups.

And this is what it popped to before with the, uh, the tools for family and our toolkit which I gave you a handout on. So what we are hoping is that the information that we're getting back from families in different ways and from the mentoring, we want to see, what our next result we want to find out will be

whether having a mentor parent, uh, during the intervention period, versus the control parents made any difference in the behavior changes. It may be that just knowing that they were in the control group and getting some of the Bright Futures information they all got through Family Matters may also enhance, uh, health and wellness. People know that. And because of the way Family Voices operates, what we decided to do with the intervention group is not just have intervention six months, control six months, but all of the control parents were then offered mentorship for the following six months, and many of them have said, yeah, I've been waiting six months, I've been thinking about my goals and yes, I do want to work with the parent mentor. So that part of the project will not formally end until about August when we have the last control parent who has had six months of training.

But from the research perspective, when the intervention and the control parents have done that first six month period, it was rolling admission, so it is, uh, ending in April, then we will have, uh, some data, again, admittedly a small sample, where we can see, does it make a difference to have another person who will help you find resources, who will talk you through some of what the difficulties are. Um, we hope that there is some, uh, benefit shown, because, scientifically, everybody wants evidence based, although we, who are parents and have been through this route know it's particularly helpful to talk it over with another parent. And if they have resources, things to mail, things to email, all the better. Uh, so, but that remains to be proven. So, um, we'd love to take your questions and also

ask you if you have experiences that we can learn about in terms of health and wellness. We do know that under the Family to Family Health Information Centers that Peter was talking about, we know, at least in Washington state and Rhode Island that the people who wrote a proposal for, uh, a Family to Family Health Information Center specifically put in that they wanted to include health and wellness information for the families who call. Families don't just call with one issue, they don't just call to find out how to get Medicaid or CHIP, they call and they say, and it's really important because I have a kid who's not eating and not eating enough of the right foods, or I have a kid who the doctor said is at risk for obesity. So having our toolkit and information available we think will be valuable for the health information centers. Did you want to say something?

BETSY ANDERSON: Well, um, I, I think one of the things that you will not be surprised to know is that the qualitative comments from families are just, you know, just really astounding. Um, and, and maybe I could just read, just a, just a two or three of them. Here, here's one parent who says, this was very thought provoking to complete. It made me realize that while I'm quite concerned about my child's diet and level of physical exercise, the demands of day to day life, getting him to school and me to work, finances, my, my son living in two households with different food and activity levels, his increasing desire for autonomy and making his own choices, make it tough to be more conscious and deliberate. And she goes on to say more. Um, and another parent said, I found this hard to, hard to answer because my child is underweight and has multiple

food intolerances. So foods that others consider junk food are important for him to eat in order to get adequate calories. And another parent says, TV, videos, DVDs, computer and video games, these are things my child can do independently. Any physical activity requires assistance by me or another adult. We live in a rural community, and she kind of goes on from there. So you see families kind of struggling with the issues, both with the interpretation of them as well as their own energy levels. Another parent says, fatigue, you've got to take into account our fatigue. Um, and I think we hear professionals, primary care professionals, talk about, um, the fact that they need, they, they know the overall messages and they need more specifics and that's what families are saying too, you know? They know healthy eating is important, and a lot of times our kids do too, um, that diet and exercise are important, but how do you actually, how do you actually make that happen? And I imagine anyone in the room here who's a parent has struggled with those issues too, and there are just some extra issues for families of kids with special needs.

So I think the idea of the toolkit and making resources available and making them ones, being very aware from the beginning that they're ones families are gonna adapt, and they may adapt them not only just for the kid with special needs, but to fit into their family's life, because this child is likely only one of, one of the family members. So, um...

BARBARA POPPER: Can we take questions or comments or find out, yup, thank you.

UNIDENTIFIED SPEAKER: I'm curious, did you address the issue of what, of kids that were transitioning at the transitioning age?

BARBARA POPPER: Which, which end of the transition age? Older end?

UNIDENTIFIED SPEAKER: The older end. So, when you're, when you're, um, talking to families about, for example, um, healthy eating, how do you teach that so that when the families aren't there, the kid is actually...

BARBARA POPPER: Right, and I put one of the quotes on, uh, the handout about modeling behavior, the family that's worried that if their kid ever got some place where there was a buffet. Um, and, you know, again, there, for some kids, that's an issue. So, um, for my husband, sometimes, that's an issue. But for a kid with special needs, to be offered everything, and then there's also a comment about putting food on the child's plate as opposed to food on the table. People were very, um, direct in the focus groups and, as Betsy said, we have pages and pages of comments we haven't even sorted, um, all of them through, but to look for the themes, but very concerned about having their kid take this on and become more independent with it. Um, and for some families, that is more of a pressing issue than for others. It's either coming up because we did have some

older teens, and we, actually we had families who said I'm outside of the age range but I'm gonna respond to this anyway because they felt so strongly that there needed to be data. When we first went looking for research studies, there was nothing on this topic around kids with special healthcare needs. And people are really hungry to find out how do you practice it? How do you model it? How do you get your kid to be able to say, that's not something I can have or that's not something I can eat? Certainly we know the preschools with the peanut allergies, there are kids who are two and a half who can barely talk or say, no peanuts, because that's crucial to them. And so we want to get messages across, uh, so that families can figure out how to do this.

I, I would say the, one of the issues that comes up, even when we've done the mentor parent calls about helping a family, is the inconsistencies, either having two parents who do things differently, two households as Betsy read, um, but also having practitioners who believe different things so that people kind of get caught between some conflicting goals, what's more important? We had a mentor parent working with a family where the child was losing weight, and we were looking for all, the most fattening things you could find for this child, dense calories, and, uh, if anybody remembers peanut butter balls? That was something I used to make for my kids, boy, that kid loved peanut butter balls and he could eat them, coconut and powdered milk in them and, um, that was great. But normally we're looking for, you know, not so much juice and finding some things that are, um, good substitutes for, um, what we call junk food, and we

always put it in quotes because pizza to one person is a nutritious meal if it gets you, um, you know, cheese and, and whole wheat and some other things, and to somebody else it's totally dismissed. So, we have to broaden some of our own attitudes. Someone else have a question or a comment? Anybody working in this area that has something they can share with the group? Yeah, Chris.

CHRIS: Um, based on [unintelligible] do you have any recommendations you can make on where we should go [unintelligible]

BARBARA POPPER: Well, I think like everything else it starts with awareness and, at both ends for families. I mean, families definitely said this was something they thought about and maybe thinking about how to get the whole public health community to think about it. I know Paula, uh, Minehan who worked with us talked about when she, uh, worked with adults with retardation, uh, cigarette smoking was an issue and a lot of the people who worked with that population said, oh, let them smoke. Well, the last thing they needed was lung cancer. But we have attitudes about kids with special healthcare needs and I think it's really the Bright Futures message that we want people to be as healthy as can be. If they have a disability that doesn't change that message, it often just makes it more imperative because then it becomes a second issue. So I think the public awareness, I think materials that go out on regular health and wellness need to either have some mention of the fact that these are all adaptable, that families

can think about these and how they apply to children with special healthcare needs. Betsy.

BETSY ANDERSON: And, um, a couple of other things, Chris, and I think I may have neglected to say this, but, um, but we are very, very pleased to, um, because it appears that children with special healthcare needs are very much infused in the new edition of the Bright Futures guidelines, which the Academy of Pediatrics will be publishing in the next year, I think that will be one way to make sure that kids with special needs get on the, on the radar screen. And even though people know, maybe, that these things should be part of a well child visit, they just, as Barbara said, they may not be gotten to all the time now, but I think this will increase the awareness of that. So I think, definitely, getting to primary care providers, I think we, as, for instance, Family Voices and family organizations, Parent to Parent, other kinds of family organizations, can do a lot too because we talk to families everyday. If, if we know these are important issues, even if the family doesn't bring them up directly, we can raise these issues with them, we can have material available and we can have items on our conference agendas and things like that, that address it. So just like, you know, 10, 20 years ago, 20 years ago we didn't have healthcare financing on our, you know, it wasn't a typical thing to talk about, as you know. That's, that gets addressed all the time, so can health and wellness too. And I think having the concrete ideas, not just the overall eat healthy foods, but specific ideas and examples, and there are, as Barbara knows, a wealth of wonderful examples

both things that work for a variety of kids and that are adapted for kids with special needs, kids who, will only eat foods that are orange, you know, what, you know, we, we struggled with that on one call. Okay, you know? What are ideas, uh, that would work?

BARBARA POPPER: Carrot smoothies did it, yeah.

UNIDENTIFIED SPEAKER: [unintelligible]

BARBARA POPPER: Thank you. And having Family Voices be connected with Bright Futures really does help share both messages that way, that it is family centered. And again, we looked at the things that are under the control of families that are not typically medical topics to begin with. Uh, helping families take some responsibility for coming up with some of the solutions and using information and then being there to assist them as they tried it out. We had a couple of comments and, as I said, it's a very long survey so I don't have any data for some really important things, but we had some comments from parents who wanted to know, why do you want to know my height and weight? Because that will be a piece of what we come up with, uh, the child's height and weight, the parent's height and weight, to see whether some of these weight issues are really for the whole family, not just the child. Uh, we had a couple of fathers who complained on, uh, their comments that this looks like it's directed at mothers only, and there are a lot of fathers who are involved in doing things, and we just had, we do have

fathers in the intervention study in a couple of states, and that, that's wonderful, so that's terrific and we're gonna learn from that as well. So there's gonna be a lot more data coming out in the next few months and being analyzed, I just wanted to give you, as I said, about three day old data, because it's the first time that we have seen any of it ourselves.