

2011 AMCHP and Family Voices National Conference: Building a Statewide Family-Driven Navigator Network for Families of Children with Developmental Disabilities

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

DEBORAH WALDRON: Ready? Okay, great. Welcome everyone. I know that we have a few more people coming in, but with the wanting to be true to the schedule and trying to get you out of here by 4:00, we're going to go ahead and start.

So welcome everyone. And I'm glad that you're here instead of out in the nice sunny, warm weather that is out there because if you're from the Midwest, this is a nice breath of fresh air for you, so, but thank you for coming.

So, this presentation is entitled Building a Statewide Family-Driven Navigator Network for Families with Children with Developmental Disabilities and Special Healthcare Needs. And basically this presentation is being brought to you by the Iowa Title V Program for Children with Special Healthcare Needs. In Iowa, we're called Child Health Specialty Clinics. And I am the Medical Director. My name is Deborah Waldron, and I'm also the Title V Director for Children for Special Healthcare Needs in Iowa.

The rest of the presentation team, Barbara Call, Rochelle Swanson-Holme, and Erica Zito. And I'm just going to read their bios and actually, I'm supposed to tell you, actually I have to read this. This session is accredited for continuing education. Immediately following the conference, a link to the CDC Training and Continuing Education Online System will be posted on the AmCHP website. In order to receive continuing

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education, you must complete the online CDC Continuing Education Evaluation Form by Monday, March 21, 2011. Be sure to keep track of the sessions you attend throughout the conference as you will be required to enter this into the online system. A tracking sheet is provided in your conference bag. I think it's yellow or gold. Further information can be found on page 10 of your program.

Also, a Conference Evaluation Survey will be posted online immediately following the conference, a link to the survey will be emailed to all the attendees and AmCHP will use your feedback to help plan future conferences. Your input is very important and greatly appreciated. Now I'm supposed to ask you to turn your cell phones to a silent mode and I will introduce our speakers.

We have Barbara Call, directly to my left. She is the Program Consultant Director for the Division of Public Health for the University of Iowa Children's Hospital, Child Health Specialty Clinic. And she has had key roles on grants and special projects for the past 15 years? What is it? I thought it was 25. And served on several state advisory groups dedicated to early childhood and children with special healthcare needs. She presently serves as the Training Facilitator for Title V, the Leadership Education in Neuro-Developmental Disabilities Project, the LEND Project in Iowa, and also serves as the Project Director for the Iowa Family to Family Health

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Information Center, Family 360 Grant, as well as Iowa's Early Hearing Detection Intervention Program.

Barbara's major professional interests include: Title V Programs for Children with Special Healthcare Needs and Quality Improvement, Data Driven Principles, and Policy Develop in Public Health Programs.

Next is Rochelle Swanson-Holme, and she is the Project Director for our Family Support 360, Family to Family Iowa Project, and she's also a Parent Consultant for one of our child health specialty clinics in Fort Dodge Iowa. She has 12 years experience serving various populations in a clinical setting as a Therapeutic Recreation Specialist, and was chosen as the 2010 AmCHP Family Scholar in the 2010/2011 State of Iowa's Family Delegate. She currently serves on community strategic planning groups including the Drug Exposed Children's Task Force, Parent Partners in Webster County, Early Childhood Mental Health Workgroup, and Webster County Human Services Provider Group. She also co-facilitates the Northwest Iowa Parents Support Group for families with children who have developmental disabilities. She's the mother of three and is in that role that led her to strive to support and serve others who are raising children who have disabilities and special healthcare needs.

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And rounding out our team here, and Erica Zito, and she is the Project Director for our Iowa Family to Family Health Information Center, also at the Child Health Specialty Clinics in Iowa city. She has worked in the social services arena for more than 15 years; she has worked with adults and families who are homeless, teens and adults with developmental disabilities, and families impacted by the Midwest floods of 2008, which were pretty significant.

She provided post adoption support to families who adopted children from foster care and continues to support families as her service areas adoption champion. She also works with adults with chronic mental health issues and substance abuse issues, helping them to live independently in the community.

Erica and her husband have two children to be adopted and foster care. They've navigated the maze of services themselves as parents and Erica feels the best assistance a parent can receive is the support of another parent.

So, we are... Barb is going to start off the presentation, she's going to give a little bit of the background and the history and then we'll hear from our two Project Directors about their projects. So please welcome... join me in welcoming them.

BARBARA KHAL: Well, we're all delighted to be here and thanks for that nice introduction Deb. I'd like to say that I am privileged to work

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with two of the best parents in the state of Iowa. And I was humbled last night... Rochelle and Erica. I was humbled was night when I, well I was invited to serve on the Youth Leadership Development Subcommittee for AmCHP, and I was humbled last night when I went to that meeting and was able to relate to all the other parents from around the state and I know that I can learn as much from them as they can certainly learn from me. So, I'm really... I see many of them in the room today, so thanks for coming to this session.

So I'm going to get just a little bit of the background, I thought that if we could help set the context of the State of Iowa when we applied for the Family to Family Health Information Center Grant. Is anybody in this room a leader of an F2F, as we call them, in their state? Okay. That is fantastic. Iowa, just so you know, we were one of the last states to receive one of those Project grants. So, what are we about a year-and-a-half into it and we have about a year-and-a-half left. So we're learning as we go.

In addition, then after I set the context, what we're going to do is talk about a few of the tangible items that we've developed through the F2F, Iowa, we're going to speak to some of the challenges that we're going to run across in working with so many parent groups, some of the rewards, some of the challenges. And that we're going to talk about some of our next steps that we plan to do, a little bit, we have a year-and-a-half

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left, what are some of those things. And we're going to try something new with technology today, which for any of you who are techie in the room, it's not going to be a big deal to you, but we're trying video clips. And for someone who just turned 60 in June, this is high-tech for me. So I not only have a wireless mouse, they're going to show me how to start this video clips. So cross your fingers.

Question: Are you the one who just learned how to blog?

BARBARA KHAL: Absolutely. You must have been in my session.

Question: [Inaudible]

Question: New skills Barb.

BARBARA KHAL: Yesterday, I didn't... okay, somebody said, yeah, blog, Twitter, Tweet, and then ePub or something like that. And I made myself go to that session so I could learn things to try to apply to this project. And with the youth over here, I'm sure we will be able to do that. Okay, my first challenge, I have to advance the slide, so I'm just gonna do... oh, there we go.

So, what will be like about a year-and-a-half ago in Iowa? Well this is the Children with Special Healthcare Needs Survey from 2006 which, I'm sure you all have your results for your states. But even though Iowa was a leader on many of the elements,

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you can see that we still have a lot of work to do on some of them. For example, we still had a quarter of the people that didn't think they've received family centered care. Just like other states many of our people had financial problems. Families spent a lot of time actually coordinating the care for their children, many had to cut back. I was at a session this morning when they were talking about that, health care for their child. And these are the ones we really wanted to concentrate on to say, look at how many parents in Iowa, although we were one of the leaders in the nation, still didn't feel like they were partners in decision-making. So what could F2F And the F360 project do about that?

And was part of Deb's leadership, which you might hear about a little bit later, 43% that they didn't feel like they have a Medical Home. And then some of the transition issues, of course, at the bottom that teens felt they didn't have all needs they need to transition into adult on healthcare.

The summary is, there are a lot of families out there that felt they were inconsistent, they got inadequate and non-evidence-based information. So what were we going to do about it?

So, just to set the stage, we were the applicant for this and you might say to yourself, well how come you're not a 501(c)(3), you're not a nonprofit, why did Child or especially clinics get the Grant? It's because our intent is at the end of the three-

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year cycle we fully intend to turn the grant over to a 501(c)(3). We have the infrastructure building facilities at Child with Special Needs Clinics as a Title V entity that we can work with a 501(c)(3) to help them build the strengths at the time that the Grant gets turned over.

So the way we were set up, we have a long history in Child with Special Needs Clinics of providing family support. So this is, for those of you who don't have the silhouette of Iowa memorized, this is Iowa. So, this is where... this is our administrative offices, where we sit, Deb and I, Rochelle over here to my left, sits in the Fort Dodge office and Erika lives up in this part of the state in Cedar Rapids. But in all of these other places around the state, I think there is 13 of them, regional centers, we have staff that are paid parent consultants that work within our regional centers and each staff PC, the abbreviation for Parent Consultant, works anywhere from 10 to 20 hours a week. So counting all of the staff that we have here, we probably have between 30 and 40 paid Parent Consultants.

Now I'm going to show you, historically, the trend that we had with our agency. This shows you that from 1985, the moral of the story is we had one type of paid Parent Consultant in our centers, there was a certain type that served our regional centers. And then look through the years, we kept hiring on different types. So we had a specified group that did the Ill and Handicapped Waiver. Then we added Early Access Service

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Coordinators, they did a unique type of parent consultant work. Communities Circle of care does things for children with serious emotional disabilities. Guide by Your Side does specific tasks related to children with hearing loss. MCH, we had that contract for about five years, which works with well-child low socioeconomic children. We're doing special projects with children with Autism Spectrum Disorder. And the last project to be added for specific care coordination types of duties was the Family Navigator Project, which will talk about later.

So you can see, from 1985 until today, we've gone from having about nine Parent Consultants to a staff between 35 and 40.

Question: Are the **** Home federally funded?

BARBARA KHAL: These are funded, no. Well, they're funded from a variety of grants and contracts. So, like the Eddie, these are from a HRSA Grant, where's Eddie, right. They Guide by your Side, they're from an Early Hearing Detection Intervention Grant. These are from the MCH block grant you this is from a contract with the Department of Human Services, Department of Ed contract, SAMSA Contract, MCH contract with Iowa Department of Public Health. This is a special research project with autism. And then this is from the Department of Human Services this is the ACF. So we have a variety of funding sources.

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So I guess the key for me is saying that this is that partnerships are key for our agency. We couldn't have the parent consultant network that we have without partnerships.

Question: About what is that in terms of full times equivalence? How long do the parents work ****?

BARBARA KHAL: They work anywhere from 10 to... we have a few that are 20 hours a week. Most were under 20. And we designed it that way because many parents felt that they wanted to be flexible because of their family needs. If a parent consultant decides they want to be a permanent staff and work at least 20, then we're working on trying to have... we have about six staff that are now working that way.

So I brought this map up again, I'm just going to do a few clips. With all those types of parent consultants, you can well imagine that we had many discussions about, well, I do autism, you do early access, what do we all have that's common? How do we know what you're doing up in that part of the state versus what this parent consultant is doing for another project? So how do we keep that knowledge amongst all of us? So we had an internal communication knowledge challenge, as well as... (this **** high tech here) see all of these? These are all the external parent consultant groups that Iowa has worked with over the years, but there really wasn't anything kind of formalized. We would get together, we would see each other at

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meetings, and say hi how are you doing. We served similar populations. So the moral of the story for that is, we had to come up with ways relate to those other groups of parents in a more systematic way.

So these were the challenges that actually, when we started the projects, which I've just alluded to, we didn't have a statewide vision for what family support was. Like I said before, we lacked communication between not only our own groups at have medical Homes and other providers, we couldn't really say what his family support. I don't know if many of you are challenged with... we get in a room and we start talking about it to some people and we say we provide family support and they go, oh well, what is that? So that was one of our challenges. We have variation from area to area to state. What was the quality of what we provided? What's the information we can provide? We didn't have unified technology to communicate and guess what, we were putting a lot of money into this, but what data did we actually have to show that what we do actually makes the difference?

And the bottom line was, families didn't have any really easy way to access it, so with F2F, we thought how can we make that easier for them to get information? And then the conclusion was, many families were just not supported.

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So with that, I'm going to turn it over to Rochelle to tell you what we did about it. And we're going to play a clip, aren't we?

RACHELL SWANSON-HOLM: And we're gonna...

BARBARA KHAL: And we're gonna play a clip, aren't we. I'm gonna let you do it.

RACHELL SWANSON-HOLM: Well, we have a clip to share with you. One of our partners, and since we couldn't bring all our partners here, we brought a few of our partners to share with you throughout our presentation. So we're going to meet Ann.

[BEGIN VIDEO]

ANN RILEY: Okay, Hi, I'm Ann Riley and I work at the Center for Disabilities and Development, which is Iowa's University Center for Excellence on Developmental Disabilities. I have been a member of Iowa's Family to Family Governor's Council, as well as, I was actually involved in helping generate the grant application and formed the whole concept together of the Family to Family network in Iowa.

I've been asked to kind of explain the landscape of how families were getting support before the network was formed. And in Iowa, we have 99 counties and we have many people and organizations that help families navigate and understand how to access services and support or get peer, family support from

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mentoring and understanding different options or directions they can go.

But what we heard over the years and clearly all the way back in 2004 when we had a statewide conference with 300 people participating, the overriding message was, a lot of times the services or supports that I get depend on who I talk to. And we wanted to address that in this Family to Family network. We wanted to bring all of the existing navigators together to make sure that they were all trained and had access to the same information, as well as, they were aware of each other so that they could work together to support the family regardless of what their unique need was.

A perfect example was, we had a family member share with us that they had a young child with Down syndrome, and they had asked a person to help them find supports and services they needed. And they had said, well what about a home and community based waiver. Should I apply for that? When the child was four, was when they began to ask their questions.

What that person said, who was an expert in navigating other areas of Iowa systems, but not necessarily the health services and support. She shared that, well, perhaps it wasn't worth the effort to fill out the application because she heard it was very timely and it probably didn't help that much. So the family didn't. And 10 years later, they ran into another family with a

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child that had the same diagnosis and their child was really active and doing well and they asked, how they got all those supports that they needed to help their child be involved in community activities? And the family explained it was through the waivers. And this mom felt devastated because she had been told 10 years ago that it wasn't going to probably be worth her time.

So through the network now, we know that if a person doesn't know the health and human service area, that they can either go onto our network sites and locate a navigator that knows that information and work with the family to say, do you want me to refer you to this local navigator or do you want me to find you the information and bring it back to you? But they work together, collaboratively, and they can really help the family and know they're getting expert, familiar, important information to them without just having to guess because that's not their area that they've been trained in.

So, the network for Iowa, we're hoping really makes a big difference for meeting the families needs and giving the navigators the support they have so they're not out doing it on their own.

[END OF VIDEO]

RACHELL SWANSON-HOLM: Okay. Thank you for being patient with out technological problems. It doesn't matter how old you are, but

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I'm right close to Barb, actually, so I'm a little low on those skills too, but I'm working on it just as well.

But anyway, so, Family to Family, Iowa is a combination of two federal funding sources. (And I think we're at the wrong slide. Here we go Families **** 360). And that grant is a five-year grant, it was awarded, like Barb said, in October 2009, and the grant will proceed for five years. and we were really excited to acquire the grant and I came on in June of this last year and have been working really hard to start attaining some of the goals and objectives that others had kind of set the stage for us for the first several months of the grant.

And some of the things that of course we wanted to concentrate on to start enhancing the capacities of our navigators and they're known throughout other agencies as support staff in a variety of ways, they could be parent consultants, case workers, mentors, they've been called. A lot of you probably know other names that the parent support work **** have been called. But we've been trying to work to enhance the competencies of them. And to do this, we've decided that we would try to offer a comprehensive training program for them. We wanted to provide them with a lot of family-centered guidance and help our parents and our communities to be able to tap into resources and supports that were... that we could rely on and know that they were there

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and that the families could actually tap into those that we were recommending.

We also wanted to train our navigators to provide a variety of different types of services, etc. So we wanted to be able to provide comprehensive services which would include trying to help families meet multiple unmet needs and through that type of a process, we would want to be able to do a full family assessment because we want to serve the entire family, not just the child with the developmental disability or the special healthcare need.

We also wanted to provide families with casual assistance because some families would choose just to have casual assistance. They might have one or two needs and at that point in their journey they might not want to do a complete family assessment and also have a support plan and be followed for quite some time. So we definitely see that as something is important as well. And so we would want to work with them on a casual basis.

And then we also wanted to make sure we offered some participatory type activities to our families in the state and that would include such things as educational activities and sessions and that would include also that we could provide them the means to attend those types of things throughout the state or even you know, a national conference as well

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depending on... we'd set some guidelines etc. for stipends and child care mileage reimbursements and those types of things.

We definitely wanted to provide our navigators with the tools that they would need, the information and the supports that they would require and so we also recognized that our state, we would want to have a web-based center or some type of a web-based manner in which we could make sure that that information was up-to-date, current, accessible, so we're going to talk a little bit about that in detail later.

But of course, we want to definitely connect people to programs, supports and services. We wanted to provide them a real consistent level of support and then one of the main points too is we really want to encourage that there's no wrong door in our state. Whatever door they enter this journey to find their support and service, it wouldn't matter what agency, what individual they asked a question of, as far as like our navigators, etc., that that would be a good choice to go to.

ERICA ZITO: So how many of you here are familiar with the F2F HIC's? Pretty much everyone, right. So when Rochelle's going through the FS360, do you see how they match up? Does that sound familiar? A lot of the language sounds very, very consistent with what we're talking about here. Right? So it was a natural partnership, I think. So CHSC applied for the grant for the HIC to develop a statewide network of mentors to help families

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make informed choices about their healthcare and to partner together with primary care and primary care physicians and then together, (where's the next slide?). So we're, again, we're a combination of the two federal funding sources and we are Family to Family, Iowa. And we're guided then by a governance council of all of these organizations. So.

RACHELL SWANSON-HOLM: And as you can see, as you read through, I'm not going to read every organization here, but as you can see, that Iowa has many community and statewide based disability services and this governance council was originally formed to oversee the work of Health Information Center, but because we're combined now, they are our combined advisory board. We do meet monthly and we also meet face-to-face quarterly. Our monthly meetings are through go-to meetings or teleconferencing, etc. And of course, they guide our work.

We have several subcommittees, etc., working towards the goals of our combined grants and historically, we didn't really have a formal structure for assessing any of these agencies for our supports and services for our families, there was no necessarily one place to go or that type of thing. So all of them had some types of family support and most of these agencies all are family representatives. But through our work now, we are... and our training of these navigators, we are working towards, again, the whole concept of one stop, no wrong door.

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And so now, again, our advisory group helps us prioritize our activities, they help us survey families. We all know how much importance has been placed on collecting data, having family input into what we are doing so that we can sustain our programs. Again, oh, I just wanted to mention too that we welcome all agencies throughout the state that are... that offer some parent support and some of these agencies though tend to, like some of them are more mature than others, some of them have more mature systems in place than others. So like say, for instance, on data collection, we found that some agencies have never collected data, others have quite mature data collection systems in process.

And we're working towards having and helping everybody to be able to collect more data because we know that still very important, but we recognize that everybody has something to bring to the table and we would, you know, we welcome... everyone... this is growing and of course, each of these agencies then in turn, we hope, will be joining our network of navigators too by providing their support person to join our navigation teams too.

Question: How did you get buy-in from all of these organizations?

ERICA ZITO: We're going to talk a little bit about our challenges in a few minutes and how we're attempting to address all of those challenges too because that definitely is a challenge.

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Do we have time for... Okay. I'm going to introduce Deb from Iowa to you next.

[BEGIN VIDEO]

DEB SAMPSON: Hi, my name is Deb Sampson, and I'm glad to be able to talk to you today. I have had some personal experiences with navigating this world of both special education in the medical field with our own son who happens to be in his 40's right now. And because of that experience, currently I work at the Iowa Department of Education coordinating a program called the Parent and Educator Connection, which in our state hires a parent of a child with a disability, pairs them with an educator in each of our regional education units where we provide information and support to both families and educators on the subject of special education help them at IT meetings, find other information for them and because they're located close to where the families are, we do provide a lot of resource and referral to them on other topics other than education. But because of that, I know that we just really are thrilled to have the expertise from the Family to Family people who are working in the Health Information Center in Iowa as well.

So when we get on the less solid ground of medical issues, we can rely on the support from the Health Information Center. One of the really fun activities with the Health Information Center work and another grant that happened to come into Iowa called the Family 360 is bringing a whole group of

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organizations that work with families in different capacities. It could be a disability, a categorical disability organization; it could be they work real closely with our parent training and information centers.

So having everybody at one table talking about their wishes for families, the kinds of information and support they provide to families across the state has been just really a wonderful activity. And I think helps make the Iowa system stronger and better for the families and children we serve.

Have a wonderful conference. Thanks, bye.

[END OF VIDEO]

BARBARA KHAL:

We have professional video, can you tell?

ERICA ZITO:

the answer to your question is that the state was ready. I mean, people were tired of working in silos. People were tired of not knowing what was happening on the other side of the state. The western side of the state is very, very rural and, or in my opinion, and so... and people always say, they never get any services, they never get any help. And everything's in Des Moines and everything's in Iowa City. And so you always... you'd always hear that and this is one way for us to address that. The other thing is, what Barb said, I think people were just ready, they'd been tired... people had been talking about

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this for a year, this was just... the time was right. And people were ready to see the benefits.

I love how Rochelle says that some organizations were more mature than others. Some organizations have existing great intake paperwork and all that kind of stuff. Some scribble notes on Post-its and stick them next to their desk you know, while they're feeding a baby or something else at the same time in their own homes. Right? These are all of the organizations that we want. We don't just want the Arc of Iowa; we also want Prader Willi Group, which I think is one woman who was out of her home. And that's what the cool part is. It's not... and they have as much a voice as anybody else.

So these are the benefits to merging the two projects and the benefit to the network in general. We're trying to create a one-stop shop. That does not mean that all the calls have to come to the F2F HIC. We have an 800 number; we're using the 800 number. We're in the process of a website. We would love for that website to be the go to site and the go to place, but if families go to the Arc or go to the Epilepsy Foundation, that's fine too. But we want to make sure that all the families, no matter where they go, get the same information.

We can reach more families, we want to decrease the fragmentation that's been happening in the state and we're

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providing the same core training across the state for parents who do family support.

I did family support for four years, and the training I got... when I started, aside from just being a parent who had done it myself, the woman who trained me, I watched her make two phone calls. That was my training. So, I knew nothing about waivers, I knew nothing about SSI, I knew nothing about... I didn't know what an IEP or a 504, I'm being honest. I knew nothing. Because my kids were four, I think, three and four or four and five when I started, so I hadn't gone through any of that myself. So now we have this fantastic 40-hour training that steps our Family Navigators through that.

So we can also share resources and training dollars, our training manuals. We have an intake assessment so we don't have to use... an intake, excuse me, and assessments. So we don't have to use the Post It Notes. So that while the Arc or whoever, which ever organization, they continue to use their own intakes, we have a common intake paperwork that we can use.

And if one organization is having training, we're asking them to open it up to the entire network. So where normally it would be just for their staff or just for their family support people, this is supposed to be opened up to everyone. So we have more people at the table to share more ideas and... so

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communication is improving and we're collecting that impact data together, which is going to show, we hope, we think, and I believe it is, is showing the value of family support which nobody likes data, but we know that that's what's going to prove to people that there's actually some impact in what we do. So.

Question: Yes, can I ask a question?

ERICA ZITO:

Yes.

Question: About the data or the information. How, for instance, if I'm a, you know, maybe the Arc or one of those other organizations. If you're collecting data, how do they decipher and do they report all the data of family support that they do or is there a line between this is something related to Family to Family and this is not? Does that make sense, versus all...?

ERICA ZITO: Right. That's a good question. And I think that we're still kind of... that's still evolving. That's one of our challenges. Some of the organizations as we've gone forward have not reported data at all, some have reported some. Some only report what they consider their trained navigator data. So, we don't have that... we don't have all that ironed out yet. So.

Question: Is there any... are any of them getting any financial assistance for what they are doing or **** intake, or ****?

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BARBARA KHAL: Do you want me to take that?

ERICA ZITO: Yeah, please.

BARBARA KHAL: Those are two excellent questions because one of the discussion items was, if Iowa COMPASS existed for 20 years and then Family to Family, we call this F2F, Iowa, what portion does F2F, Iowa take credit for versus what COMPASS is doing as an entity without F2F, Iowa. So I don't know if you're from and F2F, Iowa or not, but on all the data that we report... I mean F2F...

Question: Yeah... **** collect all the data. And what we run in to in North Dakota is that we are trying to partner into other things that other agencies are saying, we have to provide this for our grant and that's not really the data that, you know, we can **** in two different grants or you know, so it's kind of...

BARBARA KHAL: Right. So what we do when we report the data for the F2F, Erica, is we put notes in there that... they report what they think is fair, but we also put a description in when we report it that this was another entity that existed. I mean, they have a good understanding at the federal level what... that our network is different and someone like... we used to have a place in Des Moines, which we still do, then one of our partners it's called, Ask Resource Center, which was more like, they had three or

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four people and that's primarily what they did. They didn't speak out and have a network concept.

So, and then your second question was related to resources. Somebody asked... do they get paid?

Question: Well I just wondered if there was any kind of financial incentive.

BARBARA KHAL: Right. Well...

Question: To make sure that you can collect that data or kind of ****.

BARBARA KHAL: Right now, there is not, we are going to issue subcontracts to anybody who might apply. We have some carry forward money from one of the grants from last year. We can issue some subcontracts to try to get Navigators. But as far as reporting the data and just those kinds of things, we do not provide financial incentive. But thanks for asking that.

Question: I have a question. ****, how did you come up with a common training ****?

BARBARA KHAL: That... I will let them talk about that, that is on their docket. Thanks for asking.

RACHELL SWANSON-HOLM: Yeah, we're gonna answer a lot of these questions. Why don't we go ahead and go and then we'll answer all the

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questions at the end. So, okay. I think we're gonna answer some of these as we go along. But Iowa COMPASS is our disability information and referral center in Iowa, and it's been in existence since 1986, and they do, as you can see, they do a lot of information and referrals, searches, product searches, they have a database that shows a lot of... what some assistive technology, a lending library of assistive devices. They do funding searches. It's a great website, great tool to use, but all these years, it's been very hard to navigate. And so they've partnered with us, they have just recently rolled out a new search tool. They have been training our Navigators on this tool. And so, we are really pleased because all of our Navigators have options to use this, our families are going to find it a lot more useful than they ever did in the past and it's just something that we can rely on. The information that we can gather here is... our Navigators, our family support people can just rely on this type of information and resources.

The training. When we decided to start building our network, we recognized that most of the family support individuals in Iowa had little or no training. Each agency sometimes provides a little bit of their own agency training, etc., and probably their support person had some maybe, some expertise in the area of whatever that disability agency really served. Like for instance, ARC of Iowa would have Down Syndrome support individuals. And so they were probably a parent of a Down Syndrome child and knew quite a little bit about that area. But

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if somebody else in their family or you know, or they needed to find out information outside of the Down Syndrome arena, a lot of times, they didn't know. So that's just one example perhaps of a family support individual.

In my own case, when I was hired by Child Health Specialty Clinic and I had some expertise as a parent, I did happen to have an education beyond high school, which probably helped me a great deal as well, but still, like Erica had mentioned, there were things that I was not familiar with in the disability world and so you know, I felt a little inept at times.

So now we have developed a comprehensive training. As you can see, we have developed a pre-requisite type curriculum and that would include their own organization orientation and training and then we have some group process training. And then the core curriculum trainings and they're all web-based, primarily. And then we also have some supplemental requirements.

All the trainings, like I said, are basically web-based. We do have a manual available for every Navigator to acquire and the whole process is outlined in the manual. We have two face-to-face trainings that go along with this and we are providing them at least twice a year, but we do want to offer them actually, and we have been offering them quarterly because we're just getting this rolling. And our goal is to have 70

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trained Navigators by the end of the five years. And as of this date, we have 14 that have completed all of their training.

Like Erica mentioned earlier, it is a 40-hours training, 40+ depending on... and we expect them to get CEUs eventually.

Some of the training includes quizzes, tests; we do have a final test. It is open book. We want everybody to just get the skills, get the knowledge, be able to know where to find the information, the resources, know how to fill out forms to access some Medicaid programs, etc. So we have this... it's actually just a wonderful training. Like I said, we have 14 individuals right now that have received their certificate and we have 20 that are in process of completing the modules. And then we're just on a roll to kind of keep that momentum going and encourage agencies to get their Navigators to start the training process.

ERICA ZITO: We have a... we use a Wiki. Are you guys familiar with the Wiki? Anyone? You can raise your hands. All right. I wasn't. I thought it was the Star Wars Wookie when I first started. I had no idea what it was. So they... this was developed before I came on board and this is for... this was... this was free and this was for... this is housed through the University. And we're just using this temporarily to kind of collect our thoughts, kind of. And kind of figure out how to compartmentalize things, kind of for our website, but also to share all those really awesome

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emails that we get and as a place for the Navigators and folks to communicate. Yep.

Question: Is that an internal only for Navigators or just anyone can access it?

ERICA ZITO: It's, all of the Governance Council has access to it and the Navigators. And so... and we can grant access to folks.

RACHELL SWANSON-HOLM: And I think a big key to it too is that, not only does it. We share a lot of resources here, but also all of our Navigator training logs are kept here so that anybody can see who in the state of Iowa is working on their training. It'll show who has completed training, has received certificates, etc. So it's trans... it's a transparent part of making sure everybody knows that our Navigators have been trained and certified.

ERICA ZITO: And this is our website. It's in development. We had hoped that we would have it up and going by the time we came today, but we don't, but it's in process.

Our Navigators have gone out to talk to folks and to physicians to occupational therapists to schools to other places to share about the network and about what we can do. And so this is just the front of our postcard and the back of our postcard, but we've been trying to do a lot of work with Medical Home and also... so that people are beginning to be aware of Family to Family, Iowa.

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So I want a minute about the challenges. I think one of the greatest challenges is... one of the greatest benefits is everybody's at the table. But that's also one of the greatest challenges is that everybody is at the table. So you have all these people who are really, really passionate about kids with special healthcare needs. So they have lots of opinions and they like to talk. And so sometimes meetings can get challenging, getting approval for things can get challenging. So that's been a challenge.

Another challenge that we face is our language. Some of you... "children with special healthcare needs," some people don't like that language. "Children with special needs" "children and youth with special needs," "children with developmental disabilities and special healthcare needs," you know, people are very, very opinionated. I believe language is very powerful and I respect that, but it's you know, it's challenging.

The Navigator training is fantastic, but it's time-consuming. So that's tough. That's tough for some of the... especially for the small agencies to be able to absorb that. The communication across the state is definitely improved, but we still have barriers with our communication. And I think confidentiality; we talked about this earlier in the week. And while folks are really good about releases, I think we're concerned about when Navigators maybe share, if they might share information

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through emails or if they're thinking about a share point or down the road, a Facebook page. We're... there's just a lot of... you get all these people. There's a lot of room for some concerns about confidentiality.

Our Governance Council is... in a training I heard earlier today, Female and pale, I think that that's a fair way to describe our Governance Council. We're primarily women, we're primarily Caucasian and so we need... we need a lot more representation from a lot of groups on our Governance Council.

Getting youth involved. It's really hard for me to sit through meetings, so why would a child or... excuse me, a young adult, or a teenager with a disability want to sit through out meetings. Seriously, come on. So we can pay them, we can train them to you know, sit on a board and how important that is, but they don't want to... they really don't want to do that. We can buy them pizza, but they don't want to do it. So we have to figure out... we're trying to figure out ways to get them involved, but in meaningful ways. And we haven't figured that out yet.

Marketing. Ninety-nine counties. I mean marketing... hello. That's a tough one. And collecting data. You touched on some of the issues, but nobody wants to collect it. And everybody collects it differently, so that's a challenge.

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And sustainability. We have a year-and-a-half left of the F2F
HIC Grant, the other grant is what, four...

RACHELL SWANSON-HOLM: It in the second year.

ERICA ZITO: Okay, so we have three more years of that. And we want to continue
with all of these organizations, still meeting and still going
forward, but how are we going to do that. So. Are there
questions? Yes.

Question: About the confidentiality you mentioned the one direction of
confidentiality, do you have any issues with the other direction
**** versus not finding that it's you know, they can talk because
of all of the confidentiality issues, like ****. I'm working with
this family that can't share that and obviously...

RACHELL SWANSON-HOLM: I'm sorry. Well, we definitely have you know, releases
and we expect everybody to follow those guidelines, I mean,
it's the law. And we work with our agencies. If they don't have
releases, we have all these forms on our Wiki site for their
disposal. So we cannot share you know, we actually have hired
three Navigators from our grant and, of course, we definitely
will have to follow that policy. We can't share information
without the releases and we really expect you know, all the
agencies because they're all aware... and part of our training is
HIPPA and FERPA and so... and we have a face-to-face

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confidentiality training as well. That's one of our major concerns, so.

Question: I was just curious if training, particularly with the families ****, do you use Skype and other assistive technologies and then put those kind of that maybe can't afford internet connections and stuff, how do you ****.

RACHELL SWANSON-HOLM: Yeah. We're really young yet. We just kind of started this whole process and social media is huge of course, for everyone. It's something that we're trying to address.

Right now we do some like go to meetings or webinar meetings and you know, those have been primarily to our parent support folks out there. But... and then our trainings for our families, when we've invited families to our like our big conferences or any type of training that we might have, we've offered stipends to help pay for childcare, mileage, hotel, etc. And then they can... part of Erica's grant provides for some training dollars if they want to go to a specific training, they can fill out an application and... but yes, those are things that we are thinking about and we need to really address because that would be a great way to meet the need.

Question: **** is another one. Apple, I just found out that Apple will be doing in D.C. in April is a techni-talk day. Yeah, Apple is bringing in iPads and stuff and we're going to be reaching... meeting the fams,

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they give them a **** goodie bags and they're full of t-shirts and other little things, but it's a day at our convention center which the Mayor donated for free and AmCHP comes out to find out what **** are available **** paying for it for free to be able... we partner with a lot of assistive technology like the hospital for sick children and stuff where they're going to bring their consultants to be able that families can come in and on the other side of the convention center there will be college students that are **** community service hours that are trained to... they'll take care of kids while the families are in the two-hour session. But check into Apple, check into ****, they are donating some of their ****.

RACHELL SWANSON-HOLM: Okay, thank you.

Question: Some of their things.

RACHELL SWANSON-HOLM: All right, did you have a question. I want to make sure I got to you since you had asked earlier.

Question: So, do you foresee most of your Navigators coming from the partners in the network that you've created and if they're not paid except by the organizations that they work for, so there's no additional funding going to these organizations to be a part of this network, so I'm kind of rolling back to incentive and **** and how do you... I mean I know **** everybody's ready to do something, but that's a difference from the practical ...

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RACHELL SWANSON-HOLM: Right. It's a real issue; however, I guess you know, I'm a real believer that it is saving each agency some funding. If they take the training and they have all these resources and they are a part of this network, it's going to take them far less time to find resources, find these supports, help these families. So to me, that's a big savings in the big picture.

I recall when I first started, if I got a question that I had no knowledge of whatsoever, how many hours did that take me to do all my research on my own and not know whether these sites were adequate or current? I just was, you know. So I really firmly believe in that respect, but are those dollars large enough to make a big difference in that agency? I don't know that answer, but I think it does.

They have those folks onboard anyway, so it just seems that in the big picture of things they're going to see so many benefits to it that I think as we continue, they're gonna do... reap some financial benefit and I think they're gonna be please with also, our families are gonna tell us, I think and our data is going to show that impact is great and maybe more federal dollars will trickle down because of that. That's our hope.

ERICA ZITO: Another... I wanted to mention... the training is free, yes. Another thing is, I mean, as a parent who has done this work, we're not taken seriously. We are not taken seriously. So when you have

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a 40-hour training and that it professionalizes family support. And that is really, really important. So we can say that there are all of these organizations that stand behind you and say that we respect and honor what you do. And this... and we believe in what you do. That makes a huge difference and you're not dangling out there by yourself. And I think that that alone is what really makes a difference.

Question: It sounds like it professionalizes, saves money, and also creates a sense of community.

ERICA ZITO: Absolutely.

Question: So for people who are being isolated, but my question has to do with the youth, getting youth involved in a meaningful way. Are these youth with special healthcare needs, or do you include siblings?

ERICA ZITO: One of the things that we've talked about is, you know, the grants specify youth... that we need to have some sort of youth involvement in the... on our council, Governance Council or things like that. And so, again, they don't... they don't want to sit through a meeting. So we're just trying to figure out other ways to get them involved. We want to hear what they have to say. Rochelle, she's with the Navigators, working with the Navigators. They're looking at the whole family; it's not just... so it's not just what does a child with a special healthcare need,

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need. What does mom need, besides a Margarita, it's... but it's what does dad need? What does grandma need because she's taking care of the kids after school? It's what do the brothers and sisters need as well. They're part of the support plan. So that is something that we're looking at.

Question: What can [inaudible]

RACHELL SWANSON-HOLM: Well, they just have to be a parent of a child with a special healthcare need and a developmental disability.

Question: My question is about that. If I am just a parent and wanted to go through this training and be a parent Navigator and then **** agency, is that... do you **** to your parents ****?

RACHELL SWANSON-HOLM: We have had some interest in that and we would welcome a parent to come and take the training and... yeah.

Question: My next question, even though there's a lot of agencies there and I know some of those agencies **** parents going through them, so who is their parent navigator? I mean, do they not have a Navigator employed in their agency?

RACHELL SWANSON-HOLM: Most all of our agencies do have either volunteers or a paid... some of them are volunteers. Right.

Question: So basically, they're volunteers. Okay.

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RACHELL SWANSON-HOLM: So some of our agencies just have volunteers.

BARBARA KHAL: Rochelle, can I just add one thing? I just wanted to add to what Rochelle said about we would welcome the expertise of any parent; they don't have to be affiliated with an agency, necessarily. The only caveat to that is, remember when they said we do casual type of support and we do participatory type, you know, attending educational events. And then we do the comprehensive. The comprehensive type of navigation, where you have to do a family assessment and follow the family on a long term basis. That has a lot more HIPAA, FERPA type requirements so in order to be a Navigator and maintain that ongoing paperwork and things, if you receive money from the project, we have to ask a certain level of like liability insurance coverage. And in order to do that we have to have proof that they have it. So many people, that's a limiting factor. It helps when their agency has it. So that's the only caveat.

Question: We have a parent navigator program in North Dakota, it's all volunteer parents in the communities. So **** on to it, so that's why I was wondering...

BARBARA KHAL: Okay, go ahead.

Question: I was wondering if there were any... if there were parent organizations where resistant to the network and what you might have done

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if there were, what you did to overcome that resistance or
were you ever able to or not able to.

RACHELL SWANSON-HOLM: To be honest, we had a lot of agencies come to the
table, you know, with a lot of desire to build this network. Now
that we're into it, etc., we are running against... there's always
like some underlying currents of, of

Questions: ****.

RACHELL SWANSON-HOLM: Yeah, yeah ****.

Questions: **** have some **** organizations who just don't get along all that well
together.

RACHELL SWANSON-HOLM: Or there's, I don't know, you know, I have been asking.
I ask outright, I've asked outright at our Governance Council
meetings, you know, are you onboard with this? You know,
because okay so we offer the trainings and we did have a lot of
people for our first kickoff training. We had, I think there were
40, at least 45 potential Navigators that came to our first face-
to-face training and it was kind of our kickoff for our training
component. And... but I heard some under currents from the
potential Navigators, like well, I'm not really going to be a
Navigator, I'm... somebody else is going to be the Navigator,
but I'm just here to take the training and you now. So I was
like, you know. So yeah, I was like, what's going on here?

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But anyway, those are kind of things that, you know a lot of those people that came, they have never taken another module yet. And so you know, that's what I'm trying to work through is... and that's part of the marketing efforts is to convince the agencies that it will benefit them in the long run. I work towards convincing the Navigators themselves that the training is going to be very worthwhile, there was, you know, that some of our Navigators are parent support individuals who are a little resistive to the training stuff. They felt like it took away from the, you know, the 40, 60 hours trainings were taking away from actual family support. And so we'd hear some comments like that. So, you know, it's so ****. We just got to continue to work towards figuring out what and having the agencies. We want the agencies to be open with us and tell us, like, their concerns about you know, why are they not having somebody come to the table as a navigator yet. So.

ERICA ZITO: And different agencies have different levels of participation as well. Some agencies don't have the ability to have trained Navigators. And so they just want to remain on the email list, maybe participate in the phone calls or whatever. We've had... and I don't remember exactly all the details, but the Department of Human Services wants Family to Family, Iowa to be the go to organization in the state for children with special needs and so if they want to distribute information, if they want to... if they want to talk to parents, they want to go

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through us because we don't have... we don't have a Family Voice... a strong Family Voices group in our state right now. We don't have... we don't have a unified voice... this is becoming the unified voice for families.

And so that alone I think is a reason just for those organizations to be a part. They don't necessarily have to have... I mean, the woman who's part of the Autism Society, she's a volunteer. She doesn't have the time. You know, she's got a full-time job. She doesn't have the time to take this training at this point in time in her life as well as being a parent. So.

RACHELL SWANSON-HOLM: And I did want to say, I brought two training manuals, so if you'd like to take a look at our training manuals to see what they're like, you're sure welcome to.

Question: After taking the training, how does it change what they do?

RACHELL SWANSON-HOLM: Well, we have some tools that they've never had before, like the assessments, impact data, a pre and post survey for comprehensive services, we have you know, other things that it helped or changes what they do is, it's given them a lot more confidence, a lot more tools, a lot more skills, they're much more equipped to provide the services and supports that our families are asking for. So I think it's changing them a great deal.

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Question: So **** result in parents... I mean parents being connected to other services that they might not have been, I mean...

RACHELL SWANSON-HOLM: Absolutely.

ERICA ZITO: Absolutely.

Question: **** way that you track that or, how do you?

RACHELL SWANSON-HOLM: We do have surveys in place, pre and post, conferences, and trainings, etc. And so those are things that would be good to include in some of those surveys. So yeah, good point. So I need to do that one. We have just a couple of minutes, so.

Question: Let me share with you, at least in Alaska, we can build... we could use this comprehensive mental health centers concept of HIPPA businesses associates and the business organization agreement to bypass this whole HIPPA, FERPA **** because we out stationed peer navigators in different areas and that's a way, so long as you maintain the approach that you're empowering a parent to make a decision. Then I have a lot of concerns about your saying you do a family assessment because... all depending on how you do it. If it flies in the face of **** parent empowerment...

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RACHELL SWANSON-HOLM: The think about the... I want to make clear, this is all family-driven, these are all family-driven, I mean the plans and the support... the support plan that we end up developing; it's all family-driven. So if they choose not to give us some information on our family assessment, etc., I mean, that's totally up to them. And you know, we're... so that's what we consider ours. I mean, we have a family assessment; we would like to complete the entire assessment so we can best serve the family and serve everybody in the family, but it's still family-driven, so we would only ask them to answer questions and complete that whole process to the....

Question: I have a quick question **** again, what's the basis of your education because **** I do the National Certification for parents of core providers and I would just like to know what you base the training on...

ERICA ZITO: The curriculum? The curriculum was developed with the Federation, the Federation for Families with Children with Mental Health, is that for Children's mental health, is that correct, Rochelle? **** and that was the... we use... it was the Federation's training curriculum and it was modified by a panel or I mean, by a group... a committee of parents.

Question: And actually, I **** from the Federation ****.

RACHELL SWANSON-HOLM: Well Magellan, Magellan.

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ERICA ZITO: I thought it was the Federations.

BARBARA KHAL: There's going to be another session ****.

DEBORAH WALDRON: Magellan was the **** who actually helped support us...
develop the Iowa specific family navigator training. The
training was actually developed in coordination with the
Federation for Families. It may not have been the standardized
curriculum that they had, but it is the curriculum that has been
adopted from them.

BARBARA KHAL **** more information. Actually our companion group and our
SAMSA Clinic project **** here, the family navigator... ****
family navigator actually helped develop the curriculum is
presenting at this conference, so if you want to learn more, I
can get you contact with her and she can get you the
information.

Question: Well, no, no we did. We do have the data nationally, and we've just **** it
so. Okay. But if you'd like to speak with me, we can make that
happen.

BARBARA KHAL: Thank you all for coming. ****