



U.S. Department of Health  
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Office of Family Assistance

# NRFC Technical Assistance Webinar



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“Working with Fathers of Special Needs Children”

**Moderator: Nigel Vann**, NRFC Director of Training and Technical Assistance

**Presenters:**

**Greg Schell**, Washington State Fathers Network (WSFN)

**W.C. Hoecke**, Family Information and Education, Family Connection of South Carolina

**Tuesday, September 23, 2008**

**Webinar Transcription (provided by Global Crossing)**

Operator: Ladies and gentlemen, thank you for standing by. Welcome to the National Responsible Fatherhood Clearinghouse Technical Assistance Webinar.

During the presentation, all participants will be in a listen-only mode. If at any time during the conference you need to reach an operator, please press the star followed by the zero.

As a reminder, this conference is being recorded Tuesday September 23, 2008. I would now like to turn the conference over to Mr. Nigel Vann, NRSC Director of Training and Technical Assistance. Please go ahead sir.

Nigel Vann: Well thank you very much and welcome to everybody. I'm actually I'm calling in here from one of the Grantee Roundtables that we're having in Minneapolis for the grantees that are working with incarcerated fathers. So unfortunately some of those folk aren't on the call today, but they will be able to access as anybody else of your staff who may not be on the call.

You know, you can always access these on PowerPoints on the Clearinghouse Web site. So that they'll be doing that. And I'm actually going to give them a bit of a rundown at the roundtable later.

*Take Time to Be a Dad Today*

So today we're focused on a very special topic. And I think it's going to be really useful and interesting and something that we may well want to follow-up on more in terms of working with fathers of special needs children.

Before I go ahead and introduce our presenters I'll pass it over to Jen McHenry just to go through some of the logistics.

Jen McHenry: Thanks Nigel. I just want to walk through with everyone, try to ask the question, if you did notice at the beginning, you will be on a listen-only line throughout the call which means you won't be able to voice your question and, you know, and shout it out in the middle of a slide. But you will be able to shout it out online to us.

So if at any point during today's presentation you have a question whether it be about a number or a concept or programmatic, you can send it to us electronically via Live Meeting. You'll receive a standard answer. And what that's going to do is that's going to free up your line to actually ask another question, if perhaps you have two at one time, want one - another later a couple slides in.

If you do not get your question answered at the end when we go over all the questions and answers, please email us or your federal project officer and we will work to get you an answer.

Now as to how you ask your question, what you do is you go to the top of your screen and you'll see a Q&A button. You scroll over, it will highlight for you. Click on that and a box will pop up for you. Type your question in the box and hit the Submit - submit it by hitting the Ask button.

It's very simple. It should work without too many glitches for everyone. And it will get your question to us and then we can ask it to both Greg and WC for today's presentation.

Just a couple other technical issues. You may feel like the presentation slides are a little bit too small. You may want them bigger to read something more clearly.

In order to do that you can hit the F5 button. That'll take the presentation full screen.

If you want to ask a question or you decided that you want the presentations to be smaller again, you can hit the F5 button a second time or the Escape key and that'll bring you back down to the original view.

If you have trouble hearing at any point, if there's something in the presentation that is unclear or the volume fluctuates too much, please send it - that concern to us as a question and answer sort of tool. And we will address that as best we can.

Also if you're interested in the slides and you did not receive them prior to the Webinar, please email us at [info.fatherhood](mailto:info.fatherhood) - the info to the [@fatherhood.gov](https://twitter.com/fatherhood.gov) and we will be able to send those to you.

Thank you and enjoy the Webinar. Nigel?

Nigel Vann:

Thank you very much Jen. You know, when I first started talking to a few people about the subject of this Webinar I heard from a few grantees, well, you know, how is this going to apply to everybody because isn't this just a special population?

I think one of the things we're going to learn today is that there's many, many fathers who are dealing with this situations with special needs children. And so as practitioners I think it's really important just to be sensitive to that and to be aware that, you know, I think we're probably all going to have fathers in our program who have some of the issues that Greg and WC are going to be talking about today.

So we're going to do something a little bit different with this Webinar. You know, normally we have two or three presenters and one goes first and then the other one goes.

Greg and WC have worked very closely together over the years. And they've actually come up with this PowerPoint presentation as a joint presentation. So they're going to be going back and forth with a shared PowerPoint.

So I'm just going to briefly introduce both of them to you. You should have all seen the brief bios that we send out. So I don't want to belabor this.

But Greg Shell is the Director of the Washington State Fathers Network. And he was actually involved with the founding of this 25, 30 years ago. It's been the premier, in fact, maybe the only organization in the country that's really focused on these issues over that period.

And Greg sort of was involved in the beginning of this and then went away and has come back now as the director of it but certainly brings as you see from his bio, a wide ranging experience of these issues.

And, you know, I was just asking Greg and WC as we were waiting for the call to start how they got involved in this work. And as with many issues, they both had special needs children of their own.

And so I think it's interesting how we get led to the work we do by our personal experiences and situations.

WC Hoecke, is that that correct pronunciation WC?

WC Hoecke: Hoecke, like a heck of a family, Hoecke.

Nigel Vann: Hoecke, Hoecke, yes.

WC Hoecke: Yes.

Nigel Vann: I mean he always has it on the bottom of his email. I should've learned that by now. WC Hoecke is the Director of Family Information and Education for the Family Connection of South Carolina and working with the South Carolina Father's and Families organization there which is one of our grantees with the OFA project here.

And as you again, as you see from the bio, WC has been involved in this work in numerous ways over the years. And with his wife he's doing all sorts of things in this area.

And I was just talking with William Wubbenhorst of Macro who's, you know, part of the TA team with us here at the clearinghouse. And they actually had a visit down to South Carolina recently and saw WC in action with some of the families. And I believe we have some of that captured on video.

So at some point as we move down the road here, we are capturing some video footage from quite a few of your programs. And we will be looking for avenues to share that. So hopefully you'll all get to see that at some point.

But so now I'm going to pass you over to Greg and WC and we're going to have a lively presentation here to walk us through these issues. And so please send your questions in at the end.

Greg Schell: This is Greg. And I'm leading off today. I'm just going to tell a brief story of how I got here.

Thirty-one years ago exactly to this day my daughter was born and she had Downs Syndrome. And at that time the resources weren't as extensive as they are today. And we were really in a quandary as to what we were going to do and how we can maximize her development and tend to our own major issues of how did this happen and what are we going to do?

Fortunately at the University of Washington they had a major program doing research on Downs Syndrome. And they suggested that I get involved in founding a program for dads.

So to make a long story short, we started off with five dads. We met on a Saturday morning. They brought their kids. We had a great time with the kids. We played, we learned how to interact with our kids and how to have fun as dads and men. And it's grown to be a network of about 4000 dads in the state of Washington. And we're very, very pleased to be still a major role player in fathers and families lives.

So I left the program after about seven years. And (James May) took it over and did a great job for about 20 years. He retired. And then I came back three years ago to become director.

And I just have a great day every day because I get to work with wonderful dads, dads that are having a little difficulty across the board, but just wonderful people trying to maximize their work with their families, their spouses, their kids and really try to understand part of the voyage themselves as to where they fit in and how they can make a big impact. That's my story.

WC Hoecke: Well for me it was only 13 years ago. This is WC. My wife and I were expecting our first born and just thrilled that we were having a child that was coming along. And midwives allowed me to deliver all three of my kids which has been kind of fun.

And I delivered this kid and I looked down at him and he looked funny and passed him off to the midwife and continued to work with my wife.

And I think all of us as dads in the back of our brains have these ideas and these visions and these expectations of what our children are going to be and do.

And I wanted an educator. I have an education degree and my wife has an education degree. We're going to pour ourselves into these kids and they were just going to step out and really change the world in front of them. You know, that's what our hopes and our dreams were.

And a few minutes later the midwife wrapped the baby up and brought him over and laid him in Catherine's arms. And she stated that it was her strongest suspicion that Carl had Downs Syndrome.

And she knew I was a pastor and she asked me to pray. And that's a great thing for a person's strength-based model. If it's faith that's what I needed at that moment. And I dedicated Carl and then the midwife prayed.

And she said God, WC's been asking for a teacher. And you decided to give him - that he was going to become a teacher but his son was going to be the educator and WC was going to be the student.

And it really has been the most prophetic word I've ever received. Carl a you can see in the - oh, we need to go to the next slide I think.

Carl as you can see in the photograph is the guy in the middle. But he has been an incredible educator for me and has taught me more about slowing down, enjoying life and taking it as what it really is, a chance to pour yourself into your children.

And within six hours there was a knock on the hospital door and in came in a mom who had a seven-year-old with Downs Syndrome. And we found about this wonderful organization called Family Connection of South Carolina.

And what Family Connection does is it connects a parent of a child with special needs to another parent of a child with special needs.

And we found this wonderful network of parents. But Greg and I both will kind of chuckle about it. But the reality is we call it parent to parent support, but 98% of it is mom to mom support.

And I very, very quickly found out I was the only one going to any kind of a group and that there was really no network for fathers, began to work with Sisters of Charity in South Carolina looking at the fatherhood initiative. And since that point they have received funding. The Center for Fathers and Families has received funding. And they've actually contracted with me to come in and help them work with a group of - where our fathers or all fathers of any child with a disability across the state of South Carolina, there's really is the focus around low income non-custodial dads.

So I've been doing work with them for almost a year now - two years now so and let's go on to the next slide.

Next slide.

WC Hoecke: Yes. First of all we want to just kind of step back and give you guys a picture of what we're talking about. When we say children with special healthcare needs -- and you'll see those initials -- CSHCN -- a lot. And that's a very, very broad definition.

Maternal and Child Health Bureau has come up with that. And basically they're saying any child that has any physical, developmental or behavioral issues that needs some type of assistance.

So, you know, somebody will say well my child just has ADHD. Well if they're needing assistance in the public school system, we're going to qualify them as a child with special needs.

So whether it be Downs Syndrome or ADHD or autism, it's a very, very broad definition.

When we look at that broad definition if we go to the next slide, we're looking at about 21.8% of households having a child with special needs. We're talking about 1/5.

And if we look at those children we're going to say every one of those kids has got a dad somewhere. Some of them are connected, some of them are not.

But it is a very large population that's really kind of under the radar. Most people don't think well I'm doing a fatherhood program, you know, I don't have any fathers with kids with special needs.

Yes we found even with the program here in South Carolina when we asked them, many of the interventionists working with these dads said I never knew that this father had a child with special needs. I've been working with him for six months and never knew that he had a child with special needs. So a lot of times the question is not even being asked.

Greg Schell: So if you look at the 21.8% that's about 1/5 of the population could have some kind of disability to one degree or another. And some of these are significant, others are less significant but do impact the learning and the lives of families and individuals.

So if you look at that, we have a population in Washington of about 6 million. We're talking about, you know, hundreds of thousands, maybe a million people being involved or more. So it is very substantial.

And I think that's one of the things that we really wanted to emphasize today was this isn't just about a few people that have special needs. There are a large number of people out there being effected in their lives and the way they operate, the way they go to school, the way they receive services of any kind. And it's a big group of people.

WC Hoecke: Next slide please.

Go ahead Greg.

Greg Schell: Yes, this is an interesting slide because it breaks down the kinds of special needs that are apparent in our population. And I guess the one thing that really strikes me with this slide is that the cost for some families are picked up by insurance.

I mean if you work at Boeing in our area or Microsoft or those kinds of things, they have wonderful benefits. But if you are unemployed or if you're poor, frequently you don't get services.

And then some families because they don't have services that are specialized services that their children really do need, they're not covered by insurance.

So I have some families that are connected to us that spend up to \$30,000 a year just in specialized therapies for their kids. That's a pretty big hit on most family budgets.

Not only do they have the stress of the economics, but they also have the stress of are we actually going to make progress with our child and make things better for his or her future?

WC Hoecke: Okay and the next slide. When we looked specifically at the numbers -- I just pulled them for South Carolina -- we're looking at 387,000 children with special healthcare needs.

So approximately 24% of South Carolina's children are going to be diagnosed with some type of a disability. So in some poorer populations like in South Carolina where

we have a much lower cost of - or income levels, you're seeing a higher number of disabilities.

Let's go to the next slide. And those disparities are even sharper when we're looking at African American families, low income families and when we're looking at minority populations.

So when we went down and actually get down to specific numbers, when we look at birth weight and early prematurely, we're 2.5 times more likely to have that within white families compared to minority populations in South Carolina. So...

Greg Schell:

In Washington the data is similar, but because our demographics are different, the largest population other than Caucasian is Hispanic. So this same kind of thing would apply to the Hispanic population.

Frequently underserved in significant ways not even on the radar. So it's just important to be really aware of the demographics of your area and then start looking and start supporting those dads in the areas that they really need.

And I'm just going to point out one thing for instance that we've done. We have several videos available that we've developed. And we're just about ready to conclude one that we've developed for about Hispanic dads.

And this is going to be in Spanish with English subtitles. So we wanted to respect the cultural and language differences there but in a way that would draw Hispanic men to actually look at this and a voice that was familiar to them.

So it's just trying to cater to some of the needs of your specific communities that I think you can really make a big difference.

WC Hoecke:

And when we look at South Carolina and going back to what we've done here with the Center for Fathers and Families, we basically pulled out - began targeting low income non-custodial dads. And in that population what we saw from the beginning of a presentation to the end of a presentation, 17% of the dads were identifying that their child had special needs.

And what happens is at the end of that time, an additional 7% were saying they needed follow-up or they needed more information to identify if their child was. So that's a total of 24%. So it's pretty much right what we're seeing, about 1/4 of the dads.

The next slide in the presentation, I actually have incorrect numbers on that. So I'm just giving you the correct information. So we'll go on to this slide after that one. But we will correct that for you in what you'll have in your PDFs when you can download that.

Greg Schell: There are two tasks for families that have a new diagnosis. And this is by Bill Dougherty. One, you must make a place for disability in your family. And you must put the disability in its place.

And I look at this quotation as kind of the rational response to almost an irrational kind of situation. Because many, many families that we work with have kids that are very medically fragile and they talk about the number of emergency calls to the hospital that they have even within a week, two or three. And you're going where in the world will that medically fragile child not overwhelm the family? It's just not possible that everybody is calm, deliberate and has put things in their place.

So it really is just as WC's talked about, sitting on the tetter-totter or standing on the tetter-totter, looking for that balance. And it's really hard to do because just as soon as you get it balanced almost one way, it tends to go the other way. And that really is the roller coaster that families are on.

Even when the disability is minor -- and I mentioned this because there was some research back in the 80s that said -- families that have children with minor disabilities frequently have the highest level of stress because they're almost there but they never get there. And it's in that almost that parents have stress generated and never are quite satisfied that their children will make it or get there.

So it really is - you would think that maybe it's for - the stress would be higher for families that have tremendous disabilities -- and that's sometimes true -- but it also works the other way also.

WC Hoecke: And just speaking personally, you know, I love my son Carl, I hate Downs Syndrome. Carl is Downs Syndrome. How does a parent begin to sort that out in their heads? They love their child but this disability that's kind of moved into their home and really has forced its way. You know, an unwelcome guest has moved in, you know.

And it is an emotional thing they're constantly trying to figure out. How do I make a place for that disability? But then how do I stop my wife from doing seven therapies a week because she feels like she can do more with this kid?

And I have to say what about me? I'm a husband. What about the rest of the family? What about the children, you know, the other siblings? So it's constantly this struggle of trying to balance it out. So let's go to the next slide.

Greg Schell: This describing the issues that fathers face, this fix-it mentality, there's a little story. We were doing a training in Indianapolis a few years ago. And they had a nice group of guys. They're about 15. And things are going right along pretty well.

And this one dad when we came to him, he was able to introduce himself and talk a little bit about his son who happened to have Downs Syndrome. And he said well, does anybody in the group here have a solution for my problem? And that is curing my son of Downs Syndrome?

And everybody kind of looked a little bit quizzically and maybe a little bit shocked like don't you know there's no cure for this?

So anyway, as dad's kind of just shrugged their shoulders and said no, we don't have a cure, he said well what the hell good is this group right here? It doesn't do me any good. And he stormed out.

But it really shows the depth at which sometimes men get stuck in I really need to fix it. I love my wife, I love my kid and I'm for my own self, I need to be able to manage this. And when that doesn't happen, the issues become pretty significant.

WC Hoecke: And I'm going to jump a little bit into service delivery. We're going to get to that in a few seconds here in this slide.

But I've also seen how to use that fix-it mentality as quite often as a drawing tool to bring dads in.

I was called by a hospital to come over for a referral for a new family with Downs Syndrome, sat down and started speaking with the family. Then the nurse came over and said oh sorry, you're with the wrong family who has a child with - it's the next cubical over you need to be speaking with. But go ahead and finish with this family. So I got two referrals in one day.

But I sat down and I asked these parents. And we'd come in we'd say to a mom, what's your biggest concern? And she gave me a whole list of all of her concerns and all of her questions. And we'd begin to empower that parent to find the answers for themselves.

And I finished and I turned to the dad I said well is there any questions you have? And he says no, I'm doing fine, you know. Well you know a dad, brand new diagnosis. He's not doing fine.

And I kind of said hey, tell me about your insurance, you know. And this guy jumps forward in his chair and his eyes get big and he says well I've got a - you know, this 80% that I've got a - that the insurance is covering, but there's a 20% that I've got to pick up. And, you know, he's been in the hospital for - well I said do you know about (Zefra) which in our state is a Medicaid form but typically a child with Downs Syndrome will qualify for.

And within 30 seconds this guy was crying. And he realized there was a solution for his medical expenses of his child. Well I finished with that family, I walk into the next cubical, sit down with the next family, could have just checked off the same list that

the lady had, concerns that she had for her child. I turned to the dad. Do you have any concerns? Oh I'm doing fine, you know.

Well I'm stupid but I'm not that stupid. And I kind of thought well it worked with the last guy. So I said, well tell me about your insurance situation, you know? And within 30 seconds here's the next father just breaking down realizing that there is a solution and a answer for him.

So quite often if we can give fathers information that is helping them, well I'm not going to fix Downs Syndrome. But I am maybe able to fix the insurance situation. I may be able to send them towards a resource. I may be able to give them some kind of an outcome. You'll see dads quickly respond to that.

The next bullet here is the Saint Syndrome. It's quite interesting that my wife within just a few months after walking through incredible amounts of grief became an expert in Downs Syndrome.

She knew everything. About every new vitamin supplement, about all renew therapy. And she becomes what our dads qualify the super saint. She knows everything there is about services. So I come home from work and she's like let me teach you about this.

Well I've got to be honest gentlemen, I am not a great student of my wife. When she starts teaching and educating me everything inside of me just balks.

And I don't ask for directions to the gas station around the corner. You know, I want to find my own answers. And all of a sudden all of the service delivery and the majority of the information that's given to families of children with special needs is given to the mother and the primary caregiver.

She brings the information home and now dad has to learn from mom. And we really are putting quite often couples and families into conflicts with that type of a model. And we've got to figure out how to give information and give information to dads that they can receive it in a way that it's not something that's having to come directly through their significant other.

Because I just ask how many of you individuals would want your significant other to teach you how to drive? It just probably wouldn't be a good experience for most of us.

So figuring out how to get information to dads is very, very, very important.

Greg Schell: One other thing...

WC Hoecke: Thanks a lot. Greg, you've got anything?

Greg Schell: Yes, just I wanted to add, one of the things that we've done as an organization is try to hit on topics that we know dads are really interested in. So for instance, trusts, wills, guardianships, legal questions, insurance questions, sometimes even political questions where things just have to be fixed on a bigger scale.

Dads tend to flock to those because they're a little bit distant. They're not as emotionally laden. And they can become experts of their own in that regard and contribute to the family welfare as well.

So sometimes just finding the issues that are important for your group of guys or the men that you're working with, that's pretty important.

WC Hoecke: Yes. Next slide please. Going on and just describing issues that we've seen with fathers and that fathers face, it was very interesting. We did a focus group in South Carolina. We were trying to come up with a training tool to mentor fathers and to have a father mentor a new father, a diagnosis.

And one of the issues was stress. So I brought a social worker in and we brought a focus group of dads together. And I wanted to kind of step back and just be a dad in the group and not have to be a facilitator.

So she came in and she must have asked the question at least six different ways. And she kept asking, what is it as - about being a father that causes stress for you as a dad? And what is it about your child that creates stress in your life?

Well every time she would ask that question the dads would come back and they'd say, you know, this child has been the best things that's happened to me. The stress is dealing with the mother of the child.

And it kept coming back again and again and again. And she kept asking the question a different way. And one of the fathers said, you know, what do I do when she literally goes and gets into the bathtub and cries for two hours straight? And there's nothing I can do to fix it.

And what fathers continually share and - well I came back after - they ask this question time and time again. And yes, an IEP, that's the Individual Education Plan in the public school system can be very stressful to try to get the right services for your child.

Yet overall, the number one thing that we see is usually it's conflict and struggle within the context of the relationship of the couple themselves or the mother of the child.

So it really is quite important to look at healthy marriage initiatives and those components that are there for you.

We've actually created a workshop specifically for couples of children with special needs to empower them and use the prep curriculum to do that.

We're finding some really powerful ways that you've got to give an opportunity for this - because they're having to talk about things that are much deeper than most people need to discuss about their child, what therapies, what resources are going to be allotted for what things, you know.

And Greg said earlier, you know, my family would pay \$15,000 a year out of pocket for private therapy that the school district and federal government doesn't pay for. So that puts a huge strain on families especially if you work for a non-profit. It makes it very, very, very difficult.

Greg Schell: Well the perspectives that I think most dads carry, although they frequently won't talk about this, but they do aspire to this. Whether they're good at it or not, they aspire towards it.

They want to love their spouse. They want to show that they are highly competent. They - and eventually confident about being a dad.

They want their children to be loved and successful. They want their family to be perceived as successful.

And of course when all of those issues are challenged by having a child with a disability, not only does the stress level get amped up, but the emotions of the dad frequently get tamped down. And it's very difficult to respond effectively under those conditions.

So just really focusing on what are some ways that we can distress this whole thing. And we have some ideas up head here that will answer some of that.

WC Hoecke: Okay, next slide please. When we look at fathers and fathers really trying to help their children tackle life, I'm not trying to stereotype, the research has shown this pretty clearly that moms tend to see the rest of the world in relationship to their children. And dads tend to see their children relationship to the rest of the world.

So mom's really trying to protect this child from those mean terrible things out there. And dad's wanting to prepare this child, moving this child out into this world.

So the way it looked in relationship with Catherine and I -- and I want to be very transparent so you guys really get a picture of it -- is I was a Pastor of a small church. I loved my wife. I was committed to her. Six months into having Carl we were in significant crisis.

My wife and I could not talk about our son without us ending up in a big explosion. We were arguing about issues continually. We were committed to each other. We won't allow the D word to be mentioned in our home. So divorce was not an option for us. But we were seriously in crisis.

And what it was was Catherine was saying okay, let's make believe he doesn't have Downs Syndrome. We won't tell anybody. We'll keep it secret. We'll get the surgery. We'll remove the flaps on the eyes so he doesn't look like he has it. We'll treat him like he's normal. If we treat him like he's normal everybody else will treat him like he's normal and he'll come up to a higher standard.

If everybody has a lower standard of him and just says he's another one of those kids, he'll never achieve.

Well I'm on the opposite end of the fence. I graduated from high school with fourth grade spelling ability and sixth grade reading ability. I know what it was like to have a significant disability.

And I was put in third grade into a remedial reading class with six other kids who had mental retardation.

So I was grazed and called in by third grade on the retard reader. I knew what it was like to be labeled.

So I'm over there saying we've got to prepare this kid. We've go to get him ready for this mean cruel world out there. We've got to blaze the trail, you know. And she's like, you're using that word. You're using - I'm - she's in denial.

Greg Schell: Yes.

WC Hoecke: And we just could not communicate. And I'll forget, we were sitting in Atlanta and we were sitting on my father-in-law's blue couch and it clicked. Catherine was trying to protect (Carl) and I was trying to prepare (Carl).

And as a couple you will never be one-minded on how you view your child. Now that's whether you have a child with special needs or any child. But for a child with special needs it's even higher. It's heightened.

But I realized that we would never be one-minded. She was going to try to always be there to protect him. And I was going to be thinking long term planning. And she's focused in on short term.

And sometimes these roles are reversed. But very rare do you find a couple on the same page on these issues.

And it really was enlightening for us to begin to say wait a minute, we bring balance to this crazy world that we're in and that she was going to always be thinking about protecting him and getting him ready and what are the things that we're focusing it on.

And I'm thinking about long term planning, assisted living and those kind of components and that we could bring a balance into healthy child development.

So that was my personal experience. But I hope that kind of puts a light on some of the stresses and some of the things that are going on with families.

Greg Schell: WC, I help teach a class here at (Kinderine). It's called Unexpected Journey. And it's for families that have a new diagnosis of disability with their kiddos.

And the same experiences that you describe happen with so many other couples so often. And there is a component that we didn't talk about there. But it really is talking about how grief works with parents and how people adjust to that grief.

And sometimes moms and dads, I would say most often moms and dads are on very different parts of that spectrum. And it's hard to communicate effectively because of that. It's trying to draw them together in the awareness of that. And then this idea that oh yes, protect and prepare. That might be the joiner there that helps bring them together so they can at least talk about it.

WC Hoecke: Yes. Because when my wife would go into fits of crying I had to be strong for her. That was my mentality. I wasn't probably correct, but I had...

Greg Schell: That's a guy thing.

WC Hoecke: You know? And I had - and she could go and she'd go off, you know, to the back yard and she'd be crying and she'd want to be left alone. I had 5 minutes to grieve. Then I had to suck it up and I had to have dry eyes and be strong for her when she came back. And then she wondered why I was never grieving, you know. Well I wanted to be there to support her.

So it gets so confusing and so - such a struggle within the context of that relationship. So...

Greg Schell: Next slide kind of shows the whole idea here that we have an incident that creates some grief. And most of you have lost somebody that you've loved, a family member or close friend. And you realize how significant that can hit you.

And sometimes just totally out of the blue it's like wow, I never prepared for something like this. But over time things tend to recover and you bounce back a little bit until there's a reminder of a camping trip or a wedding or whatever it was that was significant in that relationship happens. And then you have a little blip where you kind of go into a little valley there again. But basically you come back and you stabilize.

However, frequently parents with special needs children have this cyclical kind of thing where they have the incident, they have the grief, they recover. They seem to be stable.

And then all of a sudden they have a big reminder that this isn't going to go away, that it's still consequential whether it be a recurrence of an illness, a hospital visit, a refusal by the insurance company to pay a premium, IEP issues at school.

So you get caught up in this cycle. And there frequently is not a lot of stability. It's just you're cycling through this.

And moms and dads sometimes cycle through this differently. Moms tend to have a lot more emotions. Dads over time tend not to quite have so much emotion. They sometimes have a lot of anger against systems whether it be the insurance company,

the school -- that kind of thing. So we talk about ways to channel that and make that effective.

But again, it's caught up in a long term cycle that has constant triggers to it that makes it different than other forms of grief. It's just unique.

WC Hoecke: Let's go on to the - well let me just make one point there too on that. And it's for me it's kind of like a lighthouse. I find myself in exact same place. Hopefully I'm a story higher than I was the last time.

But it's a cycle that never truly ends. You know, when does this end for me? It ends the day that (Carl) dies or I die, you know. I'm going to never know when it's going to sneak up on me. And I get an evaluation back and I'm so excited about where I think my child's back and I get the word back that he's three years behind. And it's like getting stabbed all over again.

And I can't stay down here so I focus in on reading. And we get better. And then the next thing I know is I'm doing better and I'm clicking along and something else will come along. So it truly is cyclical. Let's go on...

Greg Schell: I have just one - I have one little story about this...

WC Hoecke: Sure, yes.

Greg Schell: ...that really quite well describes the issue. I have a dad that has been with the program for a long time. And his daughter has seizure disorder. And up until she was about 14 they really didn't know if they were going to be able to keep her alive because the seizures were so significant and frequent that keeping her alive was the big challenge.

So things really subsided after she went through puberty and almost no seizures.

Well all of a sudden when she was 19 these seizures started happening again. And I got a frantic phone call and (Jack) is saying you know what? This just irritates the hell out of me because here I am. I'm a 60 year old guy and my daughter's nearly 20 and

I feel like the day that she was born and we found out about seizures, totally helpless, totally unable to make things better. And I'm in my own crisis again. And I just...

WC Hoecke: Right.

Greg Schell: ...never really anticipated that that would happen. But it does and it really is significant.

WC Hoecke: And every incident that you have that reminds you of the back, it's kind of like a reflection of the past and all of those same feelings and emotions can come floating right back in to that same situation again.

You know, when I hear someone use the word retarded and not use it as a medical term, you know, it's like those same emotions just come flooding back again. So...

Greg Schell: Well and then he had to go work and lead a life and have all the stress of a regular life. So things just get amped up...

WC Hoecke: Sure.

Greg Schell: ...to a significant level with families having all of these issues going on pretty regularly.

WC Hoecke: And all the other guys at work are talking about their kids playing soccer and I'm thrilled that my kid's out of a pull-up. You know, it's just a totally different - and that's what so neat to get together with a bunch of other dads who are thinking the same way and talking about the same issues because all of a sudden you're no longer that fox - you're in a fox hole with a bunch of other guys. And I thought I was out there all by myself so - okay, next slide please.

We're going to talk just a little bit here because we want to give you just some of the issues that these fathers are facing. And that's the whole issue of abuse and neglect -- very little research that's out there. Let's go to the next slide. It was done in 2001 was the last time that (somebody) was pulled together.

And there's two major pieces of research that were done by (Cross & Sullivan). (Cross) found 1.7 times more likely for children with disabilities to be - have some type of maltreatment or neglect. But they acknowledge that their numbers were way underreported.

(Sullivan) went back to Omaha, Nebraska, took the codes for children receiving services and all the children who were diagnosed and cross those two numbers with abuse and neglect numbers. And they came up with 3.4 times more likely for abuse to occur. Next slide please.

So those numbers were way up. When we look at it, three studies found that males with disabilities were more likely to be maltreated than females. But we do need to note that there are more male children with disabilities, the XY chromosome kind of messes up genetically. And we'll see much higher numbers of ADHD, autism...

Greg Schell: Autism.

WC Hoecke: ...yes. And a lot of different disorders you're going to see much higher. So you are seeing more males with it. And that's why we see more males are more likely to have some form of abuse and neglect. Next slide please.

Among all family members, mothers are most frequently the perpetrators. Now please understand that this is not a mean cruel mom who's out there that's wanting to beat her child.

This is the mom who's primary care-giver taking care of this child 24/7 and who is overwhelmed has a child with behavior issues or mental health issues along with a disability. And she's at the end of her rope and there are no other resources.

This is why it's so vital, if you've never heard the word respite before you need to learn about it if you're going to work with families with disabilities. And that's just giving a family a temporary break, relief from the ongoing caregiver responsibilities.

It's essential that these families get a chance to step back from their child and get a breather themselves.

And Greg and I have different statistics on this next one here. Sexual abuse according to this federal report show that it was more highly - typically sexual abuse is by someone who's a family member that's committing or the perpetrator of sexual abuse.

What this research showed that it was much higher among males not related to the victims. So basically - you know, basically pedophiles are out there targeting our children because they believe that these children will not be able to report.

So it is a huge fear for us dads, you know, how do I protect my little girl? How do I protect my little boy when we know that they are literally being targeted?

Greg Schell:

Theresa Fears who's associated with the Arc of Spokane did some research in 2006 for the state of Washington. And she found that most often the abuse, sexual abuse was by someone well known to the family or a relative and that if you have a disability in the state of Washington there is about a 65% chance that by the age of 18 you will have been abused to 1 degree or another there.

So we know the abuse is significant and that it is perpetrated by different people in different places. But it's just something to be very, very aware of.

And I think for dads there's a little bit of a guilt by association because most of the abuse does happen by males. Dads are a little bit leery about talking about it because they don't want to be associated with that.

So I think as program directors, program people, it's really important that this issue be brought up and be discussed because it's a huge issue for the community that has disabilities. And the only way we're every going to change that is by being more transparent about it...

WC Hoecke:

Sure.

Greg Schell: ...and talking up and making things better.

WC Hoecke: And we've got an actual presentation which we've taken a curriculum and kind of retooled it for families with kids with special needs and what are the practical things that you can do.

And I've got that PowerPoint if anybody wants it. They're welcome to it. And it's just 20 different things that you can walk through. But very, very good response from fathers. They will be there for that one if there's something that can help them to protect their child from sexual abuse. So next slide please.

When we look at neglect and that category of abuse, it's most common form of maltreatment that there is. Again I don't think it is the mean, cruel parent. It does occur. But in most cases it's the parent of a child who's not able to communicate, not able to share their needs, having a meltdown inside a Wal-Mart.

It's the parent of a child who 24/7, that single mom is taking care of a child with autism who's at the end of her rope. And we really believe that the majority of that, I'm not saying that they're not culpable for their actions, but what I am saying is you need to understand that because of the stresses that are going on within this family, you're going to have to see and meet some of those needs. Next slide please unless you've got anything there Greg on that one.

Greg Schell: Well just one thing about that. We've done some research as to the effectiveness of our program. And one of the things that we were surprised about the first time we did the research was that moms were the biggest cheerleaders for our program. And going back and asking them why it was because they got some respite every week from having to take care of the child with a disability because we provided childcare, especially trained childcare staff that helped give mom the respite and the dad a chance to meet other dads and get a - learn about information and meet some other dads. So that is a huge thing.

WC Hoecke: Yes respite. You cannot under stress respite. So...

Greg Schell: Yes. If you want to do something really popular just have a respite care night and nothing else. You'll be very popular.

WC Hoecke: Yes, you will. So - and we've got a faith based model here at Family Connection if anybody wants information on that too.

So next slide here, we're still looking at service delivery to fathers. We're beginning to shift gears here and talk about if you're going to service fathers, what are some of the things you need to be doing?

And again, very little research. When we look back on what has been done for fatherhood as a whole, we know the feds have just put in the 150 million to begin to look at this.

But when you look at fathers of kids with special needs, we're talking zippo that's been done -- very, very little.

So (Vicky Turby Bill) did a piece. Back in 2001 it was published, basically did us a survey of 318 fathers. About 1/4 of those fathers had children with special needs. And they were in six states that they did it. And it was a pretty good - it was culturally diverse enough that it really (melts) the 1990 stats. So next slide please.

What she found as she was beginning to work with these - ask these fathers what they were looking for, activities in which fathers could participate with their whole families especially an initiation was very, very important.

Most of us dads don't want to do something just for ourselves. But something that my whole family can take advantage of, we'll show up.

So if you're going to think oh, we're just going to pull these guys together and have a think tank, you know, my guys don't want to come if it's going to be us sitting in a circle singing Kumbaya.

If it's going to have something very, very practical, if it's going to have something for me to do with my family and my children, they will show up.

So family events really are a great calling card to pull dads in at the beginning.

Greg Schell: And the thing we found in our program is that this is very, very applicable. You need something to draw dads in initially that is low key that's informal. And if you can involve other members of the family, they know they're not going to be the center of attention. Dads hate to be the center of attention especially early on.

As they become more comfortable with - and trusting of what's going on with the program, they may very well want more personal outcomes like oh I do have some stuff that I really need some answers for.

How do you deal with your spouse when she just won't give up on an issue and you don't have any income to address this issues? I mean those are common kinds of things that a lot of dads experience. But they're not going to be talking about that the first meeting. And they probably won't be doing that for some time afterwards until they know that they can trust what's going on with the organization and that they're getting the information and they're feeling more confident and competent as a dad.

WC Hoecke: So we look at outcomes - yes. When we look at the outcomes, it's really important too for these dads to kind of in the beginning to know exactly what they're getting themselves into.

If you just say we're going to have a group meeting for fathers it ain't going to fly. But if you're going to say we're getting together to really look at the insurance issues or Medicaid issues or we're going to do a workshop on wills and trusts, they want to know what it's going to be about. And that will be - it's pretty important for them to really see that they're going to get something out of this workshop or this information. So...

Greg Schell: We do a - our program in the state of Washington we do three conferences a year in different parts of the state, two of them regional conferences. Then we call one a state conference.

But we collect service delivery people that have expertise from insurance to the legislature to schools and that kind of thing, usually 18 to 20 presenters. And we have a conference.

And we keep the tuition low. But we have 100 dads show up for those kinds of conferences because they get to select which sessions they want to go to. They get a whole day of learning about all kinds of things with dads, only dads.

And it ends up being a very energizing kind of experience. So that's something to consider too is just putting some experts together and inviting a bunch of dads. And it ends up being pretty powerful.

WC Hoecke: Next slide please. When we look at (Vicky)'s research, these are the statistics of what fathers said that they had participated in okay? So these were activities that they've actually participated in.

And when you look at Part B and Part C, anything in Part B is ages three to five is their children who haven't diagnosed with some type of disability. Part C would be birth to 3.

But that will give you an idea of some of the things that dads are looking for and how excited they are.

What we believe both Greg and I, is that when you look there at the bottom it says support groups, you know, boy the numbers are really low. We don't know what the quality -- and I went back and talked to (Vicky) about this -- what the programs that were being provided and how were they being provided. We believe those numbers would come up significantly if a father came in through a family activity like you see on the top and then worked their way down into being into a small group that those percentages numbers would go up. Wouldn't you say Greg?

Greg Schell: Oh big time, big time.

WC Hoecke: Yes.

Greg Schell: Because yes, where dads do chose to come to our program and if they come a second time they start changing as men and as dads and they usually open up more dramatically on what's going on with them personally and it does make a big difference in how they are associated with a group then too.

WC Hoecke: And then one other piece of research. I had a student who was a genetic student here at USC. And I asked her to do a piece for us. And she actually did her final thesis. The next slide please.

(Deborah Lane) did a really small sample group. And I'm kind of even embarrassed to give you guys this because it was such a small group. But it was three focus groups from across South Carolina.

The - her focus was just fathers of children with Downs Syndrome as a representation of all disabilities because you'll have physical and cognitive with children with Downs Syndrome.

And - but she also - it was very, very hard for her to get any diversity into that group because you were just asking fathers to come to a focus group. So when we looked at the numbers it was mainly white middleclass dads.

But it does again give you another little snapshot of some of the information. Next slide please.

When we look at it, she asked guys and just surveyed them on a scale from 1 to 5, written materials was very, very high. Guys want stuff that they can take, take a look at and get information.

And then attending a group with fathers, it was 3.8. Talking with somebody it was 3.8. So it was interesting. It was the same level on those two receiving information through the Internet. Again with (higher) we have to realize these were middleclass dads who probably had that kind of access.

So...

Greg Schell: Yes I think...

WC Hoecke: ...next slide. Go ahead.

Greg Schell: ...that written material thing is really important because they don't have to divulge anything. They don't have to really participate but they can get information that's highly useful.

We try to make current information available to dads at every meeting just so that they have something they can walk away with and maybe read later that would apply to their situation.

WC Hoecke: And in South Carolina here at Family Connection we've created a parent's resource guide which has every listing of state agencies, how you access what they are all about in one parent's guide.

Well the initial development of it was a father's resources guide. Well the father - the mom's loved it so much they wanted it.

But I have capped where the first six sheets says Father's Resource Guide. The material in the back is the same whether it's the parent's resource guide or the father's resource guide.

Put two of them on a table and a dad sees something specifically for him. And it's so rare that somebody gives him somebody for - specifically for him. He will pick up the Father's Resource Guide immediately.

So some of it is just how we're marketing our materials and making sure that it's being targeted, the dads know it's for them. So next slide please.

Interesting. When they were sitting down and talking and the ways that they wanted to receive information whether it was a male professional or a female professional is the same level. It didn't make any difference to them if it was a lady giving them information or if it was a man.

But you see that the number jumps when it's another parent of a child with Downs Syndrome. And the number goes up even higher when it's a couple.

Again it's a little less threatening for a man to go and receive information when he's getting it from another couple rather than just him sitting down or his wife receiving the information and she's passing it on to him. So...

Greg Schell: And I had one perspective and I don't have research to back this up. But after 30 years of a program there's a little bit of intuition on this.

And that is that I think as dads go on they may appreciate the male whether it be a parent or professional actually interacting with them because they feel much safer in opening with a colleague that has again, very low stakes in this.

I've seen moms and dads in groups where the moms do all the talking and the dads do very little talking. And that's just because the vulnerability. If they open their mouths they show their weaknesses and they really don't want to do that.

WC Hoecke: Yes.

Greg Schell: So male professional and dads become an important source especially I think for older, I mean if they've had a child from some time and...

WC Hoecke: Longer period.

Greg Schell: ...the issues may get sticky -- that kind of thing. So...

WC Hoecke: Good. And...

Greg Schell: Okay, next...

WC Hoecke: Next slide yes.

Greg Schell: Next slide. Well I have the honor of going through some resources here. And I have a couple that I'll add at the end that aren't on this list. And it was just a brain skip on my part.

But we hope that you'll use some of these resources to help support your work because there's a lot of information out there that is really, really valuable.

And I'm just going to highlight our program, the father's network. We are the longest running and we believe one of the most vibrant programs in the US and even beyond because we've done training in several foreign countries that...

WC Hoecke: And I say here here to that. They were the ones that helped us get started in Columbia so...

Greg Schell: That served dads and families with disabilities and special healthcare needs.

You can take a look at our Website. We have books and videos and that kind of thing for sale. That's how we support our work. But you can spend some time and see if anything is useful there.

Our newsletter just came out. It's posted there also. And it's a special issue on seizures and epilepsy. We just did a special on that because we have a small grant that our state is supporting and we wanted to help get the word out about that.

National Fatherhood Initiative. Next slide there please. This is really a wonderful site to take a look at because of the - just the information. It's really quite extensive. And I think you'll find the materials quite valuable. Next slide please.

This is one of my favorite Web sites. It just has so much information, written information that you can copy off. But it's one of those Websites that I'd just like to learn from because they have so much information about all kinds of dads in different situations.

So take a look at that. I think you'll find that very, very helpful. This - excuse me. Next slide. National Center on Fathers and Families. It's a University of Pennsylvania

Associated Web site. And they are a little bit more academic about things. But again, a lot of useful information. And they get into some of the national policy discussions that help shape policy around dads.

So it depends on what you're interested in. But that's a pretty hefty and worthy Web site to take a look at, especially on some of the more difficult things like what kind of policy we should have in our country around dads.

Next slide please.

National Center for Fathering, quite informational, has a lot of general information about dads and some interactive information there that you could participate in. And then they have a lot of items that promote dads which I thought was kind of unique too.

Center - excuse me. Next slide please. The Center for Family and policy practice. This is really a pretty heavily weighted domestic violence Web site working against domestic violence. So if you have some of those issues, this is a good place to start taking a look at that and also useful information to get from the Web site.

Next slide please.

The Arc of US is an organization. It's a national organization although it's not in every state. And depending on the state it's vibrant or maybe not so vibrant.

In the state of Washington it's a landmark very cornerstone kind of program for us. They operate the parent to parent program for our state.

They have a lot of training. They do a lot of parent advocacy work with our legislature -- those kinds of things.

But in your state it may be somebody different. It may be the early intervention program. It may be family voices which is on the next slide that I can talk about.

But these kinds of program are important because they provide a lot of services that are already operational that you can just broker with dads and families and make your program a lot more successful I think.

And then family voices, they are a very unique organization that has become very prominent in the last few years -- probably over the last ten or 15 years. But it's another national network. And they really are focused on the special healthcare needs of children and they want that to work well for families.

And they have all kinds of ways of making things work for families that don't have resources but have all of the issues around a fragile child. So that's a nice Web site to take a visit and get to know about.

WC Hoecke: And they would be very, very disability specific and really targeting what resources are available in each state. So if you can find your family - and most states have a family voices chapter in it. And they've also broken up into regions. So you'll have some very, very strong regions and a lot of great collaboration going on among those groups. So...

Greg Schell: Yes. Next slide please. And then the national initiative of Children's Healthcare Quality. This is a relatively new organization. I think it's been in existence about eight years.

But they do education and research dedicated solely to trying to improve the healthcare provided children in the United States.

And it came about because we spend more resources on healthcare than any other country in the world. And we have about the poorest showing of 40 industrial countries in the world.

So a group of doctors actually started this. And they are trying to change things in the way that healthcare is delivered, trying to make it family friendly as well as effective.

And some of their research in different states, different locations is very, very encouraging. They do a national conference each year and they're going to be a major player, an influence for a long time to come I believe.

WC Hoecke: Yes. And they've also if you're looking for specifics on what a disability is, they've got probably some of the best dictionaries with the most up-to-date information on what's happening and what's going on.

So if you've got a question what in the world is autism or CP or spina bifida, their little fact sheets are superb and they're more up to date and it's a whole lot better stuff than you're going to get off of Wikipedia. So...

Greg Schell: Then I left two off and it was just an oversight on my part. The exceptional parent magazine. And if you - the email address on that or the Web site is eparent.com.

They have a annual resource guide that is extensive and very, very helpful. In other words lots of information in one place. So exceptional parent magazine. Their annual resource guide is just a great resource.

And then of course you're all familiar with Fatherhood.gov. So I didn't put that on here probably because you already know so much about it. So that's it for the resources there.

WC Hoecke: Sure. Can you go to the next slide? And I've just thrown this one out for you guys. My wife and I have started doing what we've - we've taken the prep curriculum and we kind of retooled it specifically for families with children with special healthcare needs. So and we'll go out and do another training here in Oklahoma who those are the folks that have the national dollars for healthy marriage and technical assistance.

But it really is - we do a lot of neat things here at the organization I work for, Family Connection. But I've seen more things happen through getting a couple to sit down and communicate and healthier outcomes for children than probably anything else that I've seen.

So if you guys can get your couples or get your individuals into some kind of a healthy communication component it can be significant for these families.

So and then also I work for Family Connection in South Carolina, but I'm contracting. And that's how I got involved in this Webinar with the Centers for Fathers and Families and (Pat), (Little John) and that whole gang out there in - running I believe it's 16 fatherhood programs across South Carolina.

And we've been really looking at low income fathers and targeting that population. And really they're in a lot of ways leading out in how do we make an outreach to that population. So they're doing some wonderful, wonderful work. Give us a little bit more time and we're going to have even more for you so...

Greg Schell: Some of you may be wanting to start groups for dads or understand how to do some of that. And we have a nice handbook on how to do that. It's called Circles of Care and Understanding.

And we do sell that on our Web site. But it applies to some groups. It may not apply to others. So you can take a look at our Web site and see if that would fit your needs. But that may be something that would be useful for groups that are retooling or ramping up -- that kind of thing.

WC Hoecke: And that concludes what we've got. Yes.

Greg Schell: Yes.

Nigel Vann: Well thank you very much guys. It was really good. I really appreciate all the information and the personal stories to really put a face on this and all those resources too.

I do have a number of questions here. I don't know that we'll have time for all of them. I did first of all, I actually had meant to add some resources on there too.

I've been talking with a few of the other grantees who also doing this kind of work. And I just wanted to briefly mention that for folk.

But the Parents as Teachers organization in St. Louis, (Jan Watson) there had sent me an email if you go to their Web site which is Parentsasteachers.org. They have a new guide for working with special needs children.

And Parents as Teachers also is working with the (Meld) curricula now for those of you who are familiar with that. And they are updating the (Meld) curricula that works around these special needs.

And then a couple other grantees have given me a bit of input into their story. I just wanted to mention (Seter) in Chicago. (Chris Frederick) there has been giving me some good ideas.

And also Oakland Family Services in Pontiac, Michigan. They have a specific focus on this kind of work. And you can get in touch with (Natalie Marchioni) there for more information on that.

And we'll continue to make all this kind of information available to you. But I did just want to make that point while I was thinking about it.

Just one set of general questions for you Greg and WC. In terms of the - you know, the work that the grantees are doing, there are a few like Open Family Services that do have a specific focus on the special needs children.

But for most of our grantees, you know, this is just - it's not the main focus. It would be tangential. But as you've pointed out, they should expect to have fathers in their program who have special needs children.

So I've got - sort a couple of questions along that lines. And one really is how can they sort of identify those fathers? How can they pull those fathers out? You know, what do you think it sort of takes to be aware of that?

Because I'm thinking that there's probably some fathers out there in these programs but no one's actually aware that they've got these special needs situations.

So that's - the first part of the question is how do you identify that? And then the second part of the question is to what extent can you help the fathers with the special needs children as part of a general parenting group? Or to what extent do you think they really do need to be in a group with other fathers of special needs children or even with other fathers of the same special needs children?

So if you've got an autistic child or a Downs Syndrome child, do you need to be in a group with guys of the same problem?

So that's a three or four barrel question. I hope that makes sense if you could address that for us.

WC Hoecke: Sure it does.

Greg Schell: WC, do you want to go on to identify dads?

WC Hoecke: Yes, let me tackle that one. When we look - when the Center for Fathers and Families began and they had written into their grant that they wanted to try to do a piece of identifying these dads but we really weren't quite sure what would be the best model.

So what we have done is they have a 24 week curriculum that they take their fathers through. Again, these are low income non-custodial dads. And what we've done is we've taken one of those weeks of curriculum and we've created a workshop specifically talking about fathers of children with special needs.

Now implicit in the curriculum is how important it is for a father to empower a child, how not to have prerequisites and preplans of what you think your child should do but to find out what your child wants to do and how to empower that child.

So they're getting a whole lot of parenting and other components in it. But in the midst of it very, very clearly we're saying, you know, what is a disability. And we're really trying to get them past this concept of being afraid of it in saying okay, if your child had a special - if you're child had special skills what would you do?



Well you would empower them. You'd help them do the Olympics. You'd help them be a great sports athlete.

Well what if your child had special needs? Would your heart be any different towards that? And we do bring out the discrimination that we all have about disabilities and not quite sure what to do in new situations.

And through a wonderful little process of walking through these fathers about the importance, we begin to say it's not a terrible world and that there are things you can do to help your child's outcomes.

So just simply through one presentation where we're walking them through in that curriculum, giving them a lot of other stuff on parenting but also looking at child development, what should a child be able to do at what age level and what is appropriate for that child.

We're beginning to bring up the issue so that when the interventionists who are working with these dads one on one sits down with them, they can go back and say, you know, WC talked about this, you know?

And a dad will turn around and say yes, my child had asthma. I never really thought of it as a disability. But yes, there are things I need to learn about in the management of my child's asthma.

And the interventionists are very, very surprised and have very been taken back by the number of fathers that they have been working with for a long period of time but had no idea.

And again it's - we're constantly looking for subsets within our groups of fathers that we're working with that we can hook them or get them engaged in. This is just one more of those topics that you can say special needs. And then you'd pull those fathers out.

Now the second question -- and Greg probably you need to jump in on this one -- but the second question is do you need to have disability specific? I think anytime

you can do that, it's great. But we are in such a rural state in South Carolina, we've never been able to do that in our support groups.

We will have multiple disabilities meeting together on multiple different issues. So we try to figure a topic that would be important to all of those groups of dads once we've identified them. And then those are the topics of the workshops that we're presenting on or the groups that we're having for those fathers. Would you say the same thing Greg or...

Greg Schell:

Yes. Well our experience has been similar to that. Because in Eastern Washington it's quite remote in some places and dads are very isolated. And so you can't have a or get to a support group at certain times of the year because the snow is too deep or the wind's blowing or the fog's too thick or whatever it is.

But the issue that we've tried to promote is that where there are groups whether it be a religious organization that offers support for dads or if it's a communication organization that the leaders of those groups have to have a part of their heart open to the fact that there are going to be some dads in their group that are going to be quite different.

And they may be different because of what's going on in their family. They may be looking at the world different because of the kind of child that they have.

And that whole idea of where there's a will and there's a way -- and there are lots of different ways -- but you have to have the will to be able to connect with dads.

And it is the personal connection that in the end is the biggest part of it whether it's in a support group for special needs for dads that have kids with special needs or whether it's a typical dads group.

You just have to have that willingness to go out on a limb, maybe ask some awkward questions originally or that kind of thing. But once people know that you really are interested in them and want them to be successful, supported and that kind of thing in a challenging life, they open up and then they help guide the way as to what you need to do.

Nigel Vann: Yes.

WC Hoecke: And a very non-threatening way might be just simply to do a survey, you know, where you're not having to ask guys have long have you guys had a kid with special needs in the group? And they may not want to share that, you know.

And so you survey those dads and you kind of get a feel from them where are they at. And then you've got at least - you know who those folks are. The only thing is you have to really clearly define what you mean by disabilities. Because some guys are thinking disabilities and the only thing they're thinking about is that child in a wheelchair that has cerebral palsy.

They're not thinking of ADHD. They're not thinking of a learning disability in the school system. But when you get those guys together it is amazing.

One of my dads just said, he says, you know, it's not that my child's any easier or harder than your child, it's just different. The same emotions and the same issues are there when I as a father feel inadequate and not able to give my child everything that they truly, truly need, you know. That's a pretty vulnerable spot for a dad.

Nigel Vann: Yes. No, I mean I think you really sort of hit it on the mark here because you, you know, you sort of show that in working with fathers this is just part of the overall work. The - you know, if you're a fatherhood worker, you need to be sensitive to this. You need ways to bring this up and help dads identify this.

But then once you've done that, you need ways to help them deal with whatever the issues are. You need to help them surface the issues, you know, like the insurance issue, how do you manage the relationship with your partner so that you don't let this get in-between you. How do you manage this relationship with the other children so they still feel special?

WC Hoecke: And siblings could be a whole other workshop.

Nigel Vann: Absolutely, yes. And I had questions for you on that, but we really are just about out of time.

I do just want to ask you one more quick question if you could just sort of take a minute to respond to this because we need to go to the survey so that folk can have some feedback on this.

But, you know, once you do identify some of these needs to fathers, what advice would you have for people in terms of where do you find community partners, resources in the community?

For instance, if you want the respite care, how do you get a hold of that? You know, what do you do if you identify issues with asthma? How do you find places to connect to in the community? If you could just both sort of take 30 seconds or so to answer that.

Greg Schell: Go ahead WC and then I'll...

WC Hoecke: I would launch right off with the (Exceptional Parent Magazine) and go to that resource guide that they put out every year. And you can look up by state to see what partners you have working in your state.

I'd also go to your - if you state has an early intervention program and look at that. See the problem is the services that are delivered for special needs across the nation are varied from county to county, not state to state.

So it's - what services I might get in one school district might be very, very different than I'll get somewhere else. So it is such a fragmented area.

Hopefully your state has one or two non-profits or somebody who's really looking at the big picture. In South Carolina it would be Family Connections, South Carolina because we'd look at resources as a whole.

But you will find a very quick group of people who will say I want to partner with you. Because with limited resources of what we have we are constantly looking for those

types of collaborations and trying to find out how do we take what you're doing with your program, supplement it with a small component of what we've got as a resource and really make a difference for your dads at the same time meeting an (unneed) - met population.

When we said we had 387,000 kids in South Carolina with special needs, Family Connection only has 16,000 parents on its database. And we're huge for most disability organizations. That means I'm reaching less than 1/3 of 1% of the state. The needs out there are just enormous in this population so...

Nigel Vann: Great. I'm going to ask Greg if you could just take a brief moment to respond as well.

Greg Schell: Yes. One of the things that we've done that is really helpful and brings in a broader aspect of the community is to actually work with community groups like Eagles or Kiwanis or groups like that that have - that are willing to help fund some things so that we have a respite care night four times a year so that dads and moms can bring their kids in and then they can go out and have a night, come back three hours later, pick their kids up. The kids have had a good time, mom and dad have had a good time and everybody wins.

But that doesn't happen without a community partner there.

Nigel Vann: Yes.

Greg Schell: So it's recruiting community partners to make that happen.

Nigel Vann: Sure.

Greg Schell: Frequently faith-based is another way to do that. But yes, that's another way.

Nigel Vann: Yes, okay great. Well...

WC Hoecke: And if you're looking at faith-based on respite too, we have a whole manual on how to get - help a faith-based organization start respite cooperatives. And that's a free download too off of the Family Connection Web sites.

So feel free to take that one, walk to a faith community and say would you take this on as a ministry. And basically they create a respite option. And it's a gold mine for everybody involved. So...

**Nigel Vann:** Great. Well I'm really glad we started this conversation. It really just feels to me like a conversation that we've started. So we will continue to work to get this information informed that we can get out to all the grantees.

So with that, let me pass it quickly to (Jane) to do the survey. And then I'll come back and say farewell.

**Jen McHenry:** Great. Thanks Nigel. We're just going to walk through four questions to see kind of what everyone's thought about this Webinar so we can work on some follow-up and how to serve you best.

So here's the first question. I have a better understanding of some of the issues and challenges facing fathers of special needs children. And if you just answer to these left of the color block your choices are strongly agree, agree, unsure, disagree, strongly disagree, or if you chose you can not vote at the bottom.

And the poll question is I have a better understanding of some of the issues and challenges facing fathers of special needs children. (Take) just another quick second.

Okay, we're going to move on to Questions Number 2. And that is I have a better understanding of the resources available to me to work with fathers of special needs children. And again, you can answer to the left of the color block.

And your choices are strongly agree, agree, unsure, disagree and strongly disagree.

And question (one) more time. I have a better understanding of the resources available to me to work with fathers of special needs children. Just take a couple more seconds to respond.

Okay, we're going to move on to Question Number 3. Question Number 3 is I have a more complete understanding of ideas and approaches that I can use in my program to work with fathers of special needs children.

And your choices are going to be the same, you answer to the left of the color block, strongly agree, agree, unsure, disagree, and strongly disagree.

And that question one more time is I have a more complete understanding of ideas and approaches that I can use in my program to work with fathers of special needs children.

All right. Now we'll move on to our last question. That is the advice and suggestions regarding working with fathers of special needs children and the Responsible Fatherhood Program were helpful to me. These answers are a little bit different. Same concept applies in the left of the color block.

The advice and suggestions were very helpful, helpful, unsure, of little help, of no help at all. I want to take just a couple more second with this one.

Thank you. And we'll turn it back over to Nigel.

Nigel Vann: Okay well Jen thank you very much. And I just again want to thank Greg and WC for taking the time to really share their expertise. And it really does feel like a lifetime of work here that you've shared those guys. So very much appreciate that.

And if the two of you will just stay on the line with me and Jen afterwards we'll just sort of regroup a little bit.

And for everybody else I'd just like to say thank you very much, hope you found this useful. We will be holding the next Webinar again on the third Tuesday of the month. So that'll be November Tuesday that 18th.

As of yet we haven't finalized the topic for that. But we'll be sending it out to you pretty soon. And I also look forward to seeing those grantees that are coming to the next couple of roundtables. We're in the middle of our third one now as I told you. So

by mid-November we should have gotten to a point where you've all been to a roundtable. And then we'll - we hope to do some more of that. So thank you very much and everybody have a great rest of the day.

Operator: Ladies and gentlemen, that does conclude our conference call for today. We thank you for your participation and ask that you now please disconnect your lines.

END