

March 2015 FSRTC Webinar Recording
“Virtual Town Hall: What Family Support Researchers Should Know”

>> ROBIN: This is Robin Shaffert. I'm the senior executive officer for individual and family support at The Arc of the United States. I want to welcome you to our virtual town hall on what family support researchers should know. This event is sponsored by the Family Support Research and Training Center at the University of Illinois at Chicago.

We are delighted to have with us two thought leaders to lead this virtual town hall. The first is Sandy Magaña, a professor of disability and human development at the University of Illinois at Chicago where she researches the cultural context of families that cares for persons with disabilities. Sandy is joined by Brian Grossman, an assistant professor of disability and human development at the University of Illinois, Chicago, and Brian is leading an effort to engage communities to identify family support research topics to be addressed by researchers. His own research focuses on aging and disability as categories of exclusion in social policies, and opportunities for re integration.

There are more detailed bios on the announcement for this webinar if you are interested, but without further ado I would like to turn things over to Sandy and Brian, who will lead us on the virtual town hall.

>> SANDY MAGAÑA: Okay, sounds good. Pass the ball to me. There we go.

Alright, I don't know if you are going to introduce your team also or --

>> Thank you Sandy, I'm Robin Shaffert, I'm joined by Jennifer Sladen, program manager national initiatives at The Arc, and Caitlin Davis program assistant for program innovations. And we are proud to be a partner on the family support and research training center. We are going back to Sandy.

>> SANDY MAGAÑA: I want to introduce the Easter Seals team that is working with us on this particular project, which is the Need to Know Campaign. They've been working with us on developing the online dialogue, which we will explain, really thinking through the different aspects of the project to get stakeholder input. Rachel Beyerle and Lisa Peters-Beumer.

One of the nice things about this campaign and a lot of things we are doing in the research center is really trying to make sure we have an academic and community-based partnership, working with community based organizations like The Arc is really important. We have other projects that we're going to be - you'll be hearing from The Arc taking the lead on the family support center, another example of the partnership and really trying to reach families and communities.

So, we are going to talk today about why family support is important and I think many of you on the call already know that so we will talk briefly about that. And why is research important in family support. Then we'll talk a little bit about what is the FS-RTC, which is the family support research and training center, we call it that for short, and what does the FS need to know, the family support need to know campaign that we are talking about today. Who should participate, what does participation and tail, and how you can participate, which is really important. We are at the end of the campaign. We really want to get you guys engaged right away.

And what we'll do with the information that we gather and how you can help us promote the campaign. So, just in terms of family support, we know that family members and family can be anyway that people want to define it. The person with disability, how they define the family members. Family members provide care and services and support for many people cross the lifespan, could be for older adults, children and adults with disabilities, children and adults with mental illness, and children and adults with the developmental/ intellectual disabilities and I know -- The Arc focuses on that. But there's a lot of people that go across these different categories as well.

So families enhance the opportunities for people to remain at home, and avoid institutionalization. Some families are paid through different Medicaid programs. Most are unpaid, you probably know. Another term that is used in terms of family support is caregivers. That is often more used in the aging field. Really family support means supporting .

And the research, one of the things that we're going to be doing is a strategic research plan to learn what the questions are the need to be answered at this point. There's a good deal of research that has been done on family support but there's missing research that we want to be able to prioritize and figure out what the missing research is.

Some of the things that we think there is limited knowledge about is the social, emotional, financial and spiritual experiences of family members that provide care. On this topic there's a lot of research on emotional needs of care givers. And probably some on the other categories as well but not across the disability spectrum.

What supports the family caregivers need? That can vary by different types of disabilities. We know little about the people of color. There's a little bit of information on that topic, minority families. And whether interventions need to be adapted culturally. And the connection between family caregiving and policy is really important. So how can we make sure that social policy is more effective to address the needs of families?

And another area of research can be helpful on is developing evidence-based practices, and one of the things we are finding our world of grant funding, and The Arc and other organizations find this as well, you have to use evidence-based

intervention so research can be very helpful in that regard. And we will definitely be looking at promising practices out there and what practices have evidence-based. and we will also try through the center to make sure that the interventions that we have developed are also being used and disseminated for example, The Future is Now is one that has been developed out of our center. And Parents Taking Action is another project that we are engaged in helping with Latino families with children with autism, to advocate for services and understand strategies that can help their children development. So those are examples of how research can really be helpful towards family support.

We also want to know more about the cultural context of families so different racial and ethnic groups have different needs, different ways they considered families and these are some examples where the idea of familism in Latino families is prevalent and a similar concept is familial piety in Asian-Americans families but there are some distinct differences. Social support in gay and lesbian communities, different types of caregiving across disability, really important in research.

And then -- let's see -- we want to make sure that research and then forming policy and advocacy, that's one of the other things why research is important in family support. And then also in terms of person directed services research can really help inform in some of these areas.

This is a slide that is kind of busy, it's just to give you an overview of the whole center and the different project that we are doing in the center. So we have six research projects. The center is funded by what is now known as NIDRR, National Institute on Disability and Rehabilitation Research, and that is being merged with the administration on community living. So now they're incorporating the community living aspect in their name, so I don't know exactly what the acronym stands for NIDRRRL, but they're funding this project, it's a five-year grant starting October 1st.

We also have a number of technical assistance and dissemination activities and I don't want necessarily to go into describing each of the research projects but we're happy if you're interested in learning more about any of these. I think you will have a copy of the slides and you will see the different projects and feel free to e-mail us if you want to know more about a specific project.

We are collaborating on this with a number of universities and also organizations. So The Arc is obviously is one of the main collaborators, Easter Seals, Sibling Leadership Network, National Alliance for Caregiving, Institute on Community Integration at UMN, and The Association of University Centers on Disabilities. Our research partners include Boston College, Brandeis University, the National Council on Aging, so you can see that we have a lot of national organizations and universities that are part of this and are either going to be engaged in the research project or in the technical assistance and dissemination project and you can see that there's a few of those projects listed. One of the ones I should point out that we are going to be doing with The Arc is trying to see where that project is -- sponsoring state family support

coalition, you will hear more about that from The Arc. They are gearing up for the project now. The idea is to get people within each state, try to pull together people from these different worlds, like aging, developmental disabilities, mental health services and trying to get them together on the same page about family support. So that's good to be an exciting project.

Brian, were you going to talk about this? I forget where you were going to pick up.

>> BRIAN GROSSMAN: Yes, I was going to start here Sandy.

>> SANDY MAGAÑA: I'll throw the ball to you.

>> BRIAN GROSSMAN: Good afternoon everybody and thank you Sandy for that wonderful introduction to the Family Support, Research and Training Center, which is where this particular project, this campaign as we sometimes call it, is housed. This project is called Family Support - tell us what we need to know, for shot FS need to know. It's available in Spanish, so you may also hear AF Díganos, which is the Spanish version.

In terms of the overview of the project, this is a nationwide project to elicit participation and information about what research topics and questions should be the focus of family support research here in the United States going forward. So it is a forward thinking planning project if you will, and the idea is to have a very wide funnel where lots of people from lots of different positions, like family members or users of family support, people who are policymakers, people who are researchers, service providers or direct care providers, can all provide varying ideas about what topics and questions need to be addressed and answered through research.

I want to be clear that this is the first step in a larger process. I will show you in just a minute a visual of what this larger process looks like, but if you can imagine a funnel, what is going into the funnel are these ideas and these research questions and what will come out of the end is a strategic planning document that will have analyzed all the data that we have collected from a variety of different groups and a variety of different people to try and create a meaningful and logical plan for what is going to be the focus of family support research in the United States going forward. And we want to be clear and explicit that our values include collaboration, input and diversity and we try to build that not only into the structure of how we collect data but also the structure in terms of how we are working with different partners including in this case The Arc.

So here's the visual that I referenced earlier. It's supposed to look a little bit like you are combining this magenta color with this teal color and winding up with this purple color. I apologize if not quite red and blue make purple. At the top is the stakeholders, a fancy word to refer to people who have an interest in family support. And again, I said who those folks might be earlier, to provide research topics and questions. And this is by IdeaScale, and I will explain that later on, by phone -- we

have a call-in line -- and through pen and paper which we'll show you in just a little bit.

And on the researcher side, the RRTC staff activity, the Family Support Research and Training Center staff will be working on producing literature reviews, and that will help us create a narrow focus for preliminary research topics. And on the basis of that we will create a narrow field of topics and questions that we will then send out to some other folks for some input and that will be used to create a larger document that will explain initial research priorities in this field, in family support, and that will help us produce this eventual document so as you can see we are early in this process and our arms are open wide to get information from as many people in as many perspectives as possible.

So the project goals are sort of broken down to short-term goal and long-term goal and I believe I already said this but again we want to be explicit that the short term goal is to gather input about family support as Sandy said earlier. Some people refer to this as care-giving. But really, even though it says family support, this is about supporting family. So this is not just the fact that families do indeed provide long-term services and support or care to individuals who have functional and other needs for assistance. But this about supporting those families in understanding their experiences, their financial, spiritual and other experiences and seeing how policy and or community can be responsive to the needs that they have which may be currently unmet.

In the longer term, our goal is to develop a national family support research agenda, again trying to clearly and logically have a way to ask questions, find answers to those questions, and have those answers be meaningful for policy change or for interventions or for ways to help families support other families or to have ways to help service providers support families in the work that is happening to provide home and community-based services for a wide variety of people across the life course.

This is just sort of the visual that gives you an idea of the diversity of people that we would like to hear from so family members again, sometimes referred to as caregivers, aging, disability, family support researchers, or people who research an inner section of those.

The third bubble on the left is people with disabilities or older adults who really on or use family support. And people with disabilities, disabilities is broad there. It includes intellectual disabilities, psychiatric disabilities or what might be referred to as mental illness, and includes physical disabilities and certainly includes people who have more than one part of those categories. It includes an older adult with mental illness; it includes a young adult transitioning into college as a person with an intellectual disability who may also have a sensory disability. We make these categories is broad as possible and recognize that the overlap.

And then we are also interested in talking to employees and volunteers from social service, health and advocacy organizations and for many of you on this call you may fit into that last bubble as well as other bubbles that are also here. As Sandy said earlier, we recognize people often wear multiple hats and we want to hear from the false wear multiple hats as well as those who find themselves securely in only one of these bubbles.

So you may be wondering at this point in the presentation, what do you really want to know? We know who you want to speak to. We know there are multiple ways that you're going to speak to us that you don't really know what you are looking to know.

The way that we have worded this question -- and with this with a lot of input from our national advisory committee and our technical assistance committee -- includes leaders in organizations at the national and state-level from a variety of different groups that we mentioned earlier, around older adults and also people with disabilities across a wide swath of disabilities, is this question here. Describe at least one topic that you think family support researchers should explore further. I want to be clear that this is about directing researchers. This is about saying we don't know enough about this topic. We need to ask more questions. We need to gather more stories. We need to have better data about this because that's going to help us as we move forward.

And then we are also asking people to explain why they think the topic is important. We have given people a little bit of guidance, which is something to think about as they respond and we have included practical issues, providing support to family members need assistance.

Physical, financial, spiritual and emotional aspects of providing family support and information that people may wish national and local decision-makers, or healthcare or service providers to know about family support.

So people can participate in any of three ways. Online via a series of software called IdeaScale, and this is available in English and Spanish. There is also a call in line, which people can reach in English or in Spanish, and it's a toll-free number. The number is right there. And they can respond via pen and paper, and we will offer printed PDF copies -- we will offer printed PDF copies -- one more time -- PDF copy to all of you who are in the call and you are free to print that out for folks that you have access to. And that can be other parents in your network. That can be people who come to the programs that you offer or day services that you offer. We'll gather the responses. The response can be sent to us by snail mail, by U.S. postal service, they can be scanned and e-mailed and will be then type them into this larger database that we're collecting.

I'm going now to talk a little bit about what the online dialogues are. I am not sure how many are familiar with the online dialogue. Can you maybe raise your hand using the button if you're familiar with online dialogues?

I see two hands. Bill Truebenbach. I see a few hands. I see five of you. Please indulge while I just explain briefly what an on-line dialogue is for the rest of the folks. This is a way to gather input from a variety of people using an online platform that is a mix between maybe Facebook and a blog. The way that it works is that people can respond to the questions and then other people can vote up or down on that response and they can also comment on that response. We'll show you a picture of what that looks like in just a moment.

So IdeaScale is user-friendly, mostly accessible web-based software and in order to participate, participants complete a five-question registration. That information is also duplicated in the pen and paper and phone versions. And that information will help us to begin to analyze the ideas.

For example we may be wanting to figure out whether or not family members, even if they identify also as researchers or also as users; if family members who provide support provide different research topics or different research questions than let's say policymakers, this is going to help us understand who is providing the information that also from what perspective and how we might use that to understand and move forward with our national strategic plan. Anybody can read comments, but only the registrants or people who filed this registration can pose, comment and vote and I want to be clear that there are way more users than there are ideas.

We will talk more about how many actual users there are but at the moment there are 124 on the national online dialogue, but there are close to 40 ideas. But each of those ideas has a large number of votes, somewhere between 5-30 votes. People can vote on as many ideas as they would like. And you can vote even if you haven't offered an idea.

So here is a picture of what this looks like. We have two separate websites, one is FSNeedtoKnow. IdeaScale dot com, the other is AFDíganos IdeaScale dot com. And they look very similar. There are currently way more comments on FSNeedtoKnow, IdeaScale dot com than on AFDíganos IdeaScale. com, which is the Spanish version but you can see on the screenshot that it is a family support dialogue and it says, tell us what we need to know. Because that's really the piece that we are trying to get information about.

So here is the story so far. We had intended to keep the online dialogue open until March 30th, about 21 days, and I provided data since last night but there wasn't increases yesterday, 32 unique ideas, we have 124 users, and over 250 votes and about 32 comments as of today. Or the last time that I looked. But this is only one of the three ways that we are gathering data for this project so I will talk more about the ultimate ways that we will collect data but first I want to give you an idea of what the idea scale looks like.

>> SANDY MAGAÑA: May I interject? I want to give more numbers Brian. The pen and paper version we actually have collected 33 Spanish versions and 22 English. We also have eight additional online for Spanish so 132 total on the IdeaScale. So we really have 187 different participants who have participated so far. Just wanted to give that update.

>> BRIAN GROSSMAN: Thank you Sandy. The other bit that I wanted to show folks, I am advancing to slide 25 then I will go back to 24. Slide 25 gives you a visual of what is going on, and you can see that there's a bolded piece which actually gives you what participants wrote and then underneath there is an explanation of why and to the right there is a number, you may see an 11 with an up and down like an elevator; that is how many votes that particular idea got.

Now jumping back to slide 24, to give you an idea of what the most popular ideas -- and these are only ideas on the IdeaScale, the digital national online dialogue. We have not analyzed the pen and paper version although we have flipped through it. But the five most popular ideas based on the number of votes that they received is the cost benefit analysis of family caregiver support programs, identifying ways to assess cost-effectiveness of respite for family caregivers, providing tax credit for family caregivers, concerns about people with disabilities who become parents -- how do we understand that experience and what support parents with disabilities need in raising children and then creating a database of backup or what I might call emergency caregivers. How is it that families are able to be less worried about someone who is a service user because they are aware that there are backup systems in place so that if one caregiver doesn't show up, that there are emergencies who are on-call. Or if something happens where a family who is providing services is unable to provide care or services because they are ill and what are the backup systems in place and where are those located and how are those sort of operating.

Just a reminder that the whole point of this project is to develop a national support research agenda and I probably said that three times now, but I want folks to know where we are going and why we want access to this information. We'll use all of the input that we receive through all three mechanisms, online, those provided by phone and those provided through pen and paper for analysis. We'll figure out what are the most frequent we suggested research topics, what are the most unique research topics, how research topics and questions can connect to one another, perhaps maybe outlining a larger project that might address multiple questions and also speaking about what is interesting and unique and maybe how that could inform the strategic plan.

And then we will take the results from this first piece in use this with the second stage, which will look something like a survey. We are still developing that and the analysis really will dictate what form that takes.

So, you may be wondering or at least I hope you're wondering, how can you help?

We hope that we convinced you that this is a worthwhile project and this is something that you would like to participate and you would like to encourage others to participate in. One of the things that you can do which is really a low level participation, low hanging fruit but really very helpful for us, is if you on this particular call would log into either the English or Spanish, the URLs are provided here. Log into the dialogue, provide your information, read the comments, provide some ideas, and participate.

Additionally it will be helpful if you would let your network know about the dialogue on social media and we have some pre-made materials to help you out. We recognize that today is the 25th, and is only open until the 30th, although if we see a bumper participation we might consider extending that and we will talk about that in the open question piece. Also if you'd like to put your articles on the website we have the materials to help you do that.

On this next slide you can see -- and I apologize it's a little bit small -- we have reproduced the question itself with brief primer information on the left, this is a double-sided piece of paper, pen and paper data collection instrument. In the box it says, in the space below, describe at least one topic that you think family support researchers should explore further, explain why this topic is important. That's in the bolded box on the left-hand side. And it doesn't look like it but there's actually about three inches of space where people can write. But we can also find more space if that's not helpful.

>> SANDY MAGAÑA: I want to add something when you're done with that.

>> BRIAN GROSSMAN: Sure. On the right is the five-registration question. On the bottom right it says on behalf of the FSRTC, thank you so much and it gives people three different ways that they might be willing to respond. I see that three hands went up. A look in chat -- Jenny just wrote, if you have any questions please remember that you can type them here. If you want to type them in chat I will split my eyes, for Bridget, Debbie and Joanna.

>> SANDY MAGAÑA: I wanted to say because our time is limited, as Brian said, it will be great if you or anybody that you talk to in the next couple of days go and do the online dialogue, and add to that. One of the things we really want to do is we want to reach underrepresented families and caregivers. And that can often be a challenge if you're working with an organization. You may have people from Latino, African-American or other communities that are involved in your organization and we want to hear from these families. One of the ways here in Chicago that we have been able to tap into, at least with Latino families, is we have attended a lot of meetings, groups or workshops where there are Spanish speaking families and then we pass out the page that Brian is showing now, and we ask them to fill it out on the spot and that works great.

So this part of the project is going to go on, we are thinking about extending this part to the end of April, so you can have the whole next month for any meetings that are scheduled to actually take that, print it out, take it and get it filled out on the spot. I also attended the National Alliance for Caregiving Conference yesterday, and they handed out that sheet to everybody in the conference and we got a bunch of them back in, turned into me that day. We're also going to The Arc in Chicago, they are having a family support seminar. We're going to go and do the same thing. So if you have opportunities to do those things in the next month with a pen and paper version that's a really good way to reach underrepresented families who may not have access to the Internet and may not be able to get an online dialogue. That's all I have there.

>> BRIAN GROSSMAN: Thank you. Nobody has type in a question or at least that I can see. I'm going to give forward. We are nearing the end anyway and soon we'll have an open dialogue where we can take your questions and hear some of what you are thinking. Again, I mentioned that we have some materials that we can send to you. And those will include a press release -- I did get a question now. I'd like to respond to it. From Patricia, we will work with Jenny to send the slides to you and get you a copy of the paper survey in English and in Spanish. The paper surveys I not do by March 30th. They were due by April 10th, but Sandy was saying that we might extend that to April thirtieth and we might have to do a quick update on whatever it says in the instrument itself Sandy we can talk about that afterwards but we will send you a version. In terms of promoting this we have a press release, a website text which we can send you focus primarily on the online dialogue. That does close at the moment on March thirtieth but if we got 20 participants in the next two days we might consider keeping that open an extra week as well.

I did want to briefly talk about alternative ways to participate in terms of the online dialogue. We have spoken a little bit about IdeaScale, but there are other ways to participate in this slide gives you may be four ideas and hopefully they are helpful. Patricia, this sounds like this is something that is going to be possible in your world, and the work that you are doing. Patricia said that their agency is going to outreach events in rural towns, so if you have events on your calendar, think about adding this need to know as part of the regular schedule meeting. if you have a group that regularly meets and unique programming or you are able to add programming on the fly, add a coffee and cookies that is focused on this family support, and maybe you have conversations with you try to encourage people to come up with ideas and then they fill out the form separately so you are sort of priming the pump with a brainstorming session if that is something that you are able to do in terms of space, time and staff which we know are challenges that you might face. Another is the idea that you might be able to find ways to have staff make FS-Need to Know a downtime activity.

Maybe people are sitting around in the waiting room or preparing for an event that has yet to start or a speaker that you are bringing in but there's thirty minutes before. I'm big on coffee and cookies today, maybe you can convince people to pass out some pencils and a clipboard and having this set up so people could fill this out and you

would collect it and scan it, or snail mail back to us. The last thing is that throughout all of these things, all three of these previous ideas is to encourage staff to offer assistance to people who may need help and this might include -- this is not exclusive to but will include users of family support, maybe users of family support are going to want to participate about things they feel need more attention.

They would like to participate but need help in terms of literacy, in terms of writing physically, in terms of thinking, there's lots of ways that users of family support need assistance but may be interested in sort of providing information with a little bit of assistance. and we gave a few examples here. Reading questions out loud. Writing or typing the responses. Helping people to use the phone to contact the FS Need to Know call in line. I got another question and let me try to address that. Mary from Pennsylvania. She says that families are asked to sign up at the local mental health and electoral disability offices and they sign-up, yes, sign-up your child but close the door because they are on a waiting list. In Pennsylvania there are 15,000 people waiting for services. This is one of my research areas. a look at Medicare home based services, one of the primary ways and there are states that have tremendous waiting lists, including Illinois.

There has been a variety of lawsuits that have attempted to get people access to services more quickly, an attempt to advocate for more dollars to go to the services so there are enough dollars so that the waiting list can go away. There is research on the use of the waiting list and why but less research on alternate waiting list, and less research about how being on the waiting list affects the family. so the question that you are asking would be a very welcome source of future research on family support. how do you best provide support the families of adult children who have been found to be eligible but they are put on the waiting list because there are more people who need services then there are services available. does that address your question, Mary?

>> SANDY MAGAÑA: One of the important things about the type of research that Brian is doing and others on the topic is, that is information that can be taken to policymakers so the research can be helpful in the advocacy process. If we had real data on these things.

>> BRIAN GROSSMAN: Absolutely Sandy, thank you. If you have any questions and you would like to e-mail us, my e-mail is the first one on the left column, Sandy's is the second. Karen and Miguel are fantastic research assistant working on this project. Lisa and Rachel's names are there for some of the work they have done on the digital side and the technological structure. I think this is -- before we go to the open questions we would like to acknowledge the Department of Education and NIDRR or NIDRRRL, for the grant they gave us. And Lisa and Rachel for their work on the IdeaScale campaign and helping us navigate through this powerful piece of software that is creating the sort of ongoing virtual Town hall for weeks at a time through IdeaScale. Mary has asked another question. I am just going to address this as well. Mary is asking, is a research on the benefits for individuals choosing a participant directed record

services under the waiver? The answer is a resounding yes. Kevin Mahoney is a national leader in this research and has probably published about 15 papers on this, looking at participant directed services. Looking at individuals with mobility limitations, sensory limitations, and have some positive results. His name is Kevin Mahoney.

>> SANDY MAGAÑA: I would like to add to that that were research is lacking in this area is on family so in our center we have two projects, one with Kevin Mahoney at Boston College, looking at how families impacted by consumer directed support -- so, is it benefiting families? The research done today has mostly been on people with disabilities and the outcomes for them but we want to know more about family outcomes. Also Brandeis University is doing a project on some are directed support in two states, with higher numbers of minorities so we want to know what his impact on families of these programs. There is not much research.

>> BRIAN GROSSMAN: Thank you for that Sandy. One of the things about Kevin's research is that it has built part of the argument so that states can't say that they are not interested in participant directed services, but one of the places for growth is what Sandy is talking about. Mary, I think I sent you a private chat with that information. Jenny, I just passed the ball back to you.

>> JENNY: Thank you Brian. Thank you to both Sandy and Brian for a great presentation. We are now ready to take any questions from you and get your thoughts on what else family support researchers should be thinking about. Please feel free as you have been doing to post any questions or thoughts in the chat box on the right-hand side of your screen. Or you can raise your hand and we will call on you. If you don't have questions now, but you think you want to participate later it will be sending the slides and the PowerPoint that Sandy mentioned following this webinar. So on to questions and thoughts.

>> This is Robin again. While we're waiting for you to type your questions let me take a minute to describe some of the other work The Arc is doing as part of this project. The research and training center is designed to reach out to the committee in a variety of different ways that you saw in that complicated slide to investigate and explore family support topics. And one of the things that we have been asked to do is to work with three of our chapters to organize meetings in three states to explore the family support systems and those states, across disability organizations, seniors, to look at the support system in a specific state, and explore what is working and is in working and what are the challenges in the states. so we are looking forward to doing that, this year and the next two years of the project and for those of you who are either members of chapters of The Arc or staff you should know that there is an RA, and request for proposal out the chapters now and if you think your chapters would be interested in participating in that in the first year please let us know if you need another copy of that RFP. We will be pleased to share it with you and we are looking forward to learning from this IdeaScale, some of the issues that may be appropriate to

explore in some of those state conneetings, and those will feed into other parts of the project that we'll work on the next years of the project.

>> We did have more questions. One was asking if there was a website or materials to promote the FS promote project, and will send a copy of the slides, so you can find out more about FS Need to Know. We also received a question on the chat box about sibling caregivers after the parents have passed away and the effects on siblings.

>> That's a really good search topic. I know there is research on siblings; a lot of the research I have seen on siblings has been about their own well-being outcome. And understanding the impact that being a sibling has. The question about future and siblings is really important. We have been working with our future is now project, which involves siblings in the process but it is not something with a lot of research on. I don't know about you Brian.

>> BRIAN GROSSMAN: That is an interesting question, timely. I am putting together a proposal for next year to specifically look at the role of siblings in the lives of adults with intellectual and developmental disabilities upon parental that is one of the things that I have been finding anecdotally, is that when parents die there is a physical and geographic dislocation into the geographic sphere of the siblings. They might move to new towns or to a new state. The states are not necessarily prepared to support the adults with intellectual disabilities they are not prepared to support the siblings is enough to maneuver in a state policy environment where they have never had to be an advocate before.

>> SANDY MAGAÑA: I wanted to add if the person asking the question would go to the online dialogue and enter that question. It's something that we want to include in our coming up with research topics, or send the pen and paper version.

>> -- also they would raise their hand as a volunteer as a sibling who is gone for that in their own life. We also have another question about have you considered youthful family caregivers as an undeserved population, and there is an organization for this group.

>> SANDY MAGAÑA: Let me understand this correctly. Youth who are the family caregivers? That is an important area, a topic that came up yesterday at the national alliance of caregiving conference, a large number of people that are youth or children even taking care of their parents. Again it's an important topic so post that or send in the pen and paper version.

>> Another question was, somebody asking about research related to rethinking or alternatives to sheltered workshops. Research on how to do this in a way that is fair and helps people understand their alternatives.

>> BRIAN GROSSMAN: Sandy is it all right if I respond to this? There is a variety of research and it's not my work. I do work on community integration and community

living policy but there is a lot of research on employment alternatives. And here in Illinois there's a big focus on customized and supported employment, but there's also a big focus on social entrepreneurship. Again, what Sandy and I would say is that most of this is focused on the experience of the individual with a disability as if they are not in the context of the family and I don't know that there is good research, sort of the family outcomes related to employment alternatives because I think there is some research on family outcomes for some of the forms of employment which we might now find less than preferable if not directly objectionable. That will be a great question to ask about what is the connection between employment alternatives and familial experiences.

>> We have another question. Has there been any research on how caregiving impacted caregiver's health, especially those on Medicaid and or Medicare.

>> SANDY MAGAÑA: Say the question again Jenny.

>> Has there been any research on how caregiving impacted caregiver's health, especially those on Medicare and/or Medicaid.

>> SANDY MAGAÑA: That is my area. There's a lot of research on caregiver sort of emotional well-being, not so much in health.

(Webinar continued past the hour but captioner had to log off).