

FAMILY SUPPORT RESEARCH: WHAT YOU TOLD US TO STUDY TRANSCRIPT

>> Max: Great. I am Max Daniel, a program associate here at The Arc of the U.S. I want to talk a bit about housekeeping rules for WebEx. Everyone is actually in listenonly mode, so if anyone has any questions or comments, please type them into the chat box. It should be at the lower righthand corner of your screen.

We also are going to be captioning this webinar, so if you need captioning service, I've actually provided the link in the chat box, so just go ahead and click on that link.

We are actually going to be recording this webinar, so just make sure that you're aware of that. And that's it. I'm going to hand it over to Robin Shaffert, The Arc's Senior Officer of Individual Family and Support, to get started.

>> Hello this is Robin Shaffert. I'm the Senior Executive Officer of Individual and Family Support at The Arc. Thank you for joining us today to hear our presenters on family support research. Today's webinar is sponsored by the Family Support Research and Training Center and the center aims to learn more about families' needs and supporting members with all disabilities across the lifespan as well as about promising family support practices around the country.

We are honored to have with us today, three presenters. Sandy Magana, Professor of Disability and Human Development at the University of Illinois in Chicago. She researches the cultural context of families who care for persons with disabilities and mental illness and the experience of parents who have disabilities. Second we have Brian Grossman, Assistant Professor of Disability and Human Development at the University of Illinois of Chicago.

Brian is leading this effort to engage communities to identify family support research topics to be addressed by researchers. His research is focused on aging and disabilities as categories of exclusion in social policies.

Last but certainly not least, we have Katie Arnold who is both the Executive Director of the Sibling Leadership Network and the Director of Community Education at the Institute on Disability and Human Development at the University of Illinois in Chicago.

Before I turn things over to our panelists, I want to remind attendees that you can ask questions at any time in the chat box. If you're asking us a logistical question, we'll respond through the chat box, but if it's substantive for our presenters, we'll hold those until the end of the presentation so each panelist can first discuss their experiences and their research. And we'll ask the questions of them at the end. Without further ado, I'll hand things over to our presenters.

>> Sandy: OK. Great. This is Sandy Magana, and welcome everybody. I'm excited to present with you some of our preliminary results for the study that you helped us with. You know, we asked for stakeholders to give us information about what would be important research topics, and we got a really good response. So we'll talk about what response we got and what kinds of information and how we're thinking about that.

The first slide right now also mentions some of our students and staff that

helped us analyze the data. So Karen Lukaszewski, Jessica Guzman, and Miguel Morales. And this is our acknowledgment of our funder, which is basically ACL, the Administration for Community Living. So what we're going to talk about in this first presentation we'll have two presentations, obviously. One on the Need to Know Campaign and one on the Sibling Leadership Network. So the first presentation we're going to talk about, a little bit about the context of developing the national research plan, the data collection we did, what kind of methods we're looking at in terms of analyzing that data, and then our findings, limitations and implications.

So first of all, our campaign was called Tell Us What We Need to Know. Some of you might remember because you got participants to help us respond to this.

And it's part of this overall goal to develop a strategic research plan. Our shortterm goal was to gather input about family support research topics. We really wanted to make sure we heard from people you know, different stakeholders that we have, and I'll define who the stakeholders are. We also got racial and ethnic diversity in those voices, and we also wanted to hear from caregivers and people with disabilities.

So in this slide, we have the term users and consumers. And also family, broadly defined. Broadly defined meaning whoever is defined as family by a person with a disability. Our longterm goal was to develop a strategic research plan, which we're still working on. This is a really fun slide that I'm probably not going to go through every bit of. But in this topleft corner is basically where we are right now and the project that you helped us with, engaging stakeholders to help provide research topics.

So that is what we're going to talk about today. These other steps are sort of this iterative process we're going to go through to end up with an actual research strategic plan that we can then use, ask funders to use and also use ourselves.

So for recruitment for this Need to Know Campaign to get stakeholder input, we had a large coalition of organizations. We have an extensive advisory committee including The Arc. The organizations represent different disability groups, different family groups, and also we're trying to make sure that our coalition also has racial/ethnic diversity and sexual minority diversity.

Then we have multiple modes of data collection in this process. We did this data collection going from March of this year to June of this year.

You might be familiar, those of you who helped participate, that this is basically what we asked people. We said, describe at least one topic that you think family support researchers should explore further is and explain why you think this topic is important. And then we gave them some things to think about, like practical issues providing support to family members that need assistance, physical, financial, emotional and spiritual aspects of providing support.

Information you wish national and local decisionmakers know about family health support.

So we have these different modes of data collection. One was the IdeaScale. So we had very good participation in that. This is more like an online dialogue, so we put that question out there that people could respond to, but they could also dial back and forth and vote on ideas. Out of 152 people, 33 gave distinct ideas on that

mode. We had a callin line as well because some people prefer to talk on the phone. We had three or four people who called in that way and gave us distinct ideas. And then we had a pen and paper version. We actually extended the time for this, and this was a really important piece of the data collection, to reach people who aren't traditionally going to go online. And to make sure we're getting underserved populations.

So we asked organizations like The Arc and Easter Seals and others, could they reach out to their affiliates and try to get out to different organizations particularly that represent minority populations and underrepresented groups.

We got a really good response on that. We actually had 345 people send in their demographic information and 201 gave distinct topics. So we had a total of 501 people who responded and 238 distinct topics.

This is sort of the racial and ethnic background of the people who did respond. So you can see that more than half of the respondents were nonwhite. So that was good. We were really happy with getting more diverse representation.

The largest underrepresented group was Latino/Hispanic in this data collection. But we did get a few Asian Americans, a few Arab Americans by reaching out to specific support groups and people who could actually talk to folks in those communities.

So that was our racial/ethnic background. And this is the different types of stakeholders that responded. So you can see we had family support providers. So that would be the caregiver. People want to call themselves different things, but people who support the person with the disability in the home, the family. So at least 50% of the family support providers were also people of color, but 258 people total were family support providers. And then the family support consumers.

That's the person with disability. We had about 190 people there and a hyperrepresentation of people of color in that population. Then 57 social service professionals. It was important to hear from that stakeholder as well because they provide direct support services.

And then we had home and communitybased service providers, healthcare professionals, researchers and policymakers. So you can see the numbers of those groups.

I mean I think they're decent to hear their voices. Obviously the representation of people of color is lower as you get into the professional area, but they're still relatively decent in terms of getting those diverse opinions.

So then we go to methods Brian's going to take over from here.
>> Brian: Hi, everybody. This is Brian Grossman. As a universe of data the responses were analyzed using what we called grounded theory methods. They were iterative, inductive and we used a teambased approach to make sure we had intercoder consensus. That means we agreed across all three researchers in order to create the codes or the themes. Some of the responses we received, we could generate a theme directly from the answer itself. Others we had to think directly of the context of the response.

Some was collected in Chinese or Spanish and that was translated. We're going to develop themes from the codes related to directly who is speaking or what we're

calling identity.

There are two key findings we're going to talk about. First is related to voice. Respondents differed in voice through which they offered topics or ideas. Some were unique to certain respondent types, but some were diverse.

In terms of voice parents and other family members who provided support tended to respond as if it were a needs assessment. First person language is used. Older adults who rely on family members for support offered a similar voice that they were more direct in responding as a form of advocacy, clarifying that their needs were requests to address unmet needs. For example we have this example of a Latina woman who is a family support provider. And she says I think there's a lack of support for persons like myself that in my case, I'm a single mother and it's not easy to find a job that provides adequate child care. When we look at people with disabilities, we have more money to help out with things like hearing aids and glasses and also selfdirection, better use. These are clients who want better access to services or more ability to direct their own services.

By comparison, researchers and service professionals unsurprisingly spoke from a voice of professional authority. They tended to emphasize the bigger picture with researchers addressing outcomes at the national level and service professionals focused on more local systems and program enhancement.

So we have a white male researcher who says, more research is needed to demonstrate the cost benefits of family caregiver support programs. Supporting family caregivers can reduce undesirable placements in institutional settings, prevent avoidable hospitalizations, improve care coordination, and enhance the overall health and wellbeing of individuals with disabilities.

The service professional or Latina woman who provides home or community based services says, we all know caregiving is difficult and requires a team. There are many resources available to caregivers but caregivers have challenges reaching out and asking for help. Building a care team and developing a care plan can avoid some caregiver health challenges, how do we make it okay to ask for help?

When we talk about topics specific to respondent type, there were two that stood out clearly. Those who provided support to family members that were specific to them. Access to linguistically/culturally appropriate services. These respondents tended to be very focused on siblings. Siblings were seen as a source of support and those who needed support. Additionally parents of younger teenage children tended to worry about what would happen to their children if they aged out of school or other programs. And even what social activities were available to them after school was over. These respondents clearly addressed the challenges of working while providing family support and had ideas for how to better support family caregivers.

It didn't really come up at all for white Americans, but this came up in terms of both faith as a source of support and the role of faith based organizations and communities.

>> Sandy: I just want to add one other thing. They also talk a lot about future planning, right? And that might be pretty relevant for The Arc because future planning for adult intellectual disabilities is something that I think is talked about.

>> Brian: Future planning was spoken about by those who provide support to family

members but also some of the professionals. We'll talk about that in just a minute. Those who use support from family members their primary unique topic was they were really interested in addressing shortfalls for services. Hearing aids and glasses support, greater consumer direction or someone saying, I could really use more hours. In terms of the share topics, there were five general categories they fit in. Aging, systems navigation, financial support, respite, and direct care workforce.

Within aging there are multiple subthemes. So one of them was about aging with a limited social network. This was not a frequent response but an evocative one. It was one in which it was clear people who fit in this particular situation were really looking for assistance and help. There are many of us baby boomers who live alone and either have no children or whose children cannot or will not provide support for an aging parent. Some families of children or siblings who have been rallied to provide support, but not everyone has this support.

The second theme is aging caregivers. The impact on parents and spouses was mentioned. In both examples there are mental health outcomes, stress and depression. The first addresses caregivers as they age, and the second for when one is not able to provide the same support. So the white woman who provides support, the top quote, what happens when the persons with disabilities can no longer live at home? This gives me much stress thinking what will happen to my family.

This degree of uncertainty was fairly common for parents, and common for parents when their children were maybe 18 or 19 and also when they were older like 40 or 50 and the caregivers were aging. You see in the second example, caregivers are often elderly and taking care of a spouse can be difficult physically. Aging caregivers leads us into a discussion of future planning.

Reflected throughout all there age related responses is a connection to the future. How would things be in the future and how does one prepare. Figuring out their own death or having means for other support systems they have advocated for. Or for children who are now adults and have their support system they advocated for their children who are now adults to remain in place. So you see the issue of the man saying, how can my daughter support myself and become independent? And then a healthcare professional says, planning for the future for parents who have children with disabilities, how can we help parents know their children will be cared for when they're gone?

This is identified by multiple groups as something in which we need more resources, people need more information and we really need to address some of the mental and emotional outcomes of this so people feel more confident moving forward. Systems navigation was a consistent theme in direct and indirect ways. All expressed frustration, confusion, need for information, need for training, resources and desire for social workers or other case or care managers to help them walk through "red tape." Many addressed the time investment needed to arrange services, access, and there should be designated point people who help. One said it should be like college, you should have access to a guidance counselor. Creating an easier way for immigrants with little English knowledge. It is difficult to navigate due to the language barrier. A white woman over 65: I found Medicare Medicaid Social Security systems daunting to deal with. Perhaps these areas would be a good topic for more

research.

Financial support was tricky. Some respondents were poor but others felt policy mandated they remain poor so they continue to receive benefits. But many self-describe themselves as having enough money so they didn't qualify for programs like SSI or Medicaid but not enough so they didn't need help.

Another issue around qualifying has to do with documentation status, particularly for immigrants. You see in the middle, the Latina social service professional says, Social Security benefits options for those who do not qualify for SSI and Medicaid. The provider support to family members also identifies as a user says, lack of income to help with needs.

Additionally for financial support, we saw that there's a connection to a penalty. So this white woman who is a provider of support to families says it is a shame that the child's check is cut when mom works even a parttime job. So there's tension between programs that provide assistance and programs that affect household income and household employment.

This African American transgender individual says even families who are not financially stressed still need financial support for a disabled child. This is important too because it highlights it may not be about income directly, but it's actually about the social situation of having a child with a disability. That means there needs to be financial counseling and/or programs in place that people are interested in knowing what's available to them and how to get support.

The last person, this is the not poor, but on a budget?

Respite care. Family members spoke about the utility and necessity of respite. Many spoke of the needs for daily care. I use respite to be quite broad so it's not necessarily capital R respite, but all forms of services and supports that allow family members the space to either go back to work or have social lives. You see on the bottom, the most important thing for caregivers and the family members that we/they care for is an occasional break so we can have social interaction outside the home. To take a break we need backup assistance from time to time that we can count on. There were discussions of emergencies, backup assistance, the needs for couples to have couple time and need for families to have social time that was pretty consistent across all groups.

There were a lot of issues around the direct care workforce, when I say that I mean things like personal attendants. This was raised as a topic for further study by almost all stakeholders. Users of longterm services and support wanted to know how to pay more and improve the quality. Providers wanted to know how to support families who are having trouble locating workers because they're in nonurban areas or emergencies again, backup needed.

You can see there are differences of what's going on. At the top, no providers and workers. Provider of family support is asking for a database of skilled caring caregivers.

The implications of this work. You might be wondering what's next for us. First we're going to connect the topic analysis to a separate literature review that's been happening. We've had researchers and experts in the field look at what we currently know and see how that connects to what people want to know more about.

It's possible we actually know a fair bit in the literature and we're just not communicating it well, it's also possible we're not asking the right questions. So we're trying to figure out the way to bridge these two data collection activities. Next we're going to share the analysis we've come up with, both through some papers and certainly presentations like this. And also to figure out how to come up with identifiable themes or topics that we're going to again build out and connect back to the literature.

For example, if we're looking at respite care, what do we know, and what do we want to know more about? We might know that people need and benefit from respite, but we might not know what the best models of respite are. What do you do in rural communities or if you're in a place where you need emergency respite or emergency or backup services.

The significance of this work is about recognizing the shared concerns across the different voices and the identification of key areas in which families as a distinct group would like concrete supports and information. This is necessary for a lot of different ways to generate research. For example we might do surveys, focus groups, we might look at individual interviews. To explain cost and benefits associated with these supports and to identify model programs that address these concerns so we can support these and have them proliferate so there's greater access to the support that the family needs.

>> Sandy: That's all we have on the Need to Know Campaign. Should we move on to the Sibling Network and take the questions at the end?

>> Max: I think that's exactly what we should do.

>> Katie: Hi, everyone. My name is Katie Arnold, and I'm going to talk a bit about a project that the Sibling Leadership Network did as part of this Family Support Research and Training Center. A little bit about me. I'm the second oldest of five and I have four siblings with disabilities. In this photo I am wearing the orange scarf for anyone who hasn't met me and doesn't know what I look like.

Growing up, my siblings changed my world view and changed my career path. I work at the Institute on Disability and Human Development at the University of Illinois in Chicago and I'm also a cofounder of the Sibling Leadership Network, or SLN for short. I became the first parttime Executive Director of SLN in 2012.

I'm going to share a brief overview of the SLN with you and then share about the National Sibling Survey we conducted. I will conclude with a short video created with selfadvocates sharing their perspectives on what they wish their family knew to support them better.

The SLN was created in 2007 by seeing a need to bring together the work regarding siblings of people with disabilities that was happening across the country. The purpose was really to provide a stronger collective voice, to build awareness of the sibling awareness and perspective. The mission of the SLN is to provide siblings of people with disabilities the support, information and tools to advocate with their brothers and sisters and to promote the issues important to them and their entire families.

We welcome siblings of people of any disability but we tend to draw the most people with intellectual and developmental disabilities. Also sibling supporters are

an important part of our network and participate in the work we do. Sibling supporters include parents, people with disabilities, and professionals. Really anyone who thinks it's important to support siblings. I want to encourage each of you to join the network online whether you're a sibling or Sibling supporter.

You sign up at sibingleadership.org. You can help strengthen our voice and effect more change together. Currently we have sibling chapters in 20 states and we continue to nurture the growth of additional chapters with the vision that eventually every single state will have a Sibling chapter. The chapters are really the grassroots of the Sibling Leadership Network and where the more personal contact happens. And each chapter has its own feel and flavor. There are three areas I want to mention. Support and information is the first one. We do things like hold a national conference and cosponsor an online peer support sibling group called SibNet. The second area is policy and advocacy. We do things like educate siblings on ways to engage in policy and advocacy. One of the best examples is the Family and Medical Leave Act which doesn't specifically include siblings.

One exciting development is we've had some meetings with the Department of Labor recently, and really tried to educate them about the importance of including siblings. And just recently they have updated their fact sheets to provide clearer guidance that some siblings actually may be covered under FMLA in certain circumstances, such as when they are called what's called "acting like a parent," so that guidance was updated on Department of Labor so that employers can use that for the specific situations where siblings are acting like a parent.

While this is really exciting in a lot of ways for the SLN, we're still really working on a larger legislative change that would more broadly include siblings to take leave under FMLA.

The third area that we focus on is research. We're working to get more and better research on siblings, and we're trying to share the information about sibling research in a way that's useful to siblings and their families so that they can advocate for their need.

Our most recent endeavor related to research is that we conducted a National Sibling Survey. Meghan Burke is the chair of research for SLN and she and I are working together on this survey.

It's made possible by a few funders, including the Family Support Research and Training Center, as well as the Pennsylvania Developmental Disabilities Council through a Sibs project we have in their state and also the North Carolina Developmental Disabilities Council through a Sibling Support Grant we have in their state working with First Care Families of North Carolina.

The current research on siblings of people with disabilities is limited. Gaps in the research show there's a need for more diverse samples in a few areas including racially ethnically and racially diverse siblings. Also most of the research on adult siblings focusing on the sibling who does the caregiving, and we need to look at the siblings in their noncaregiving but supportive roles as well.

Additionally the sibling research often looks at the research of one sibling in the family. Often the sibling with the greatest caregiving role who tends to usually be the oldest girl in the family.

And we need to learn more about the experiences of the additional siblings as well as when families have more than one person with disabilities. Most of the adult sibling research respondents tend to be women so we need to get a better picture of the experience of brothers. What are they thinking? What is their role?

Also we need more research that includes the perspective of people with disabilities to learn about their view of their sibling experience. This should really be across different types of disabilities.

Finally, we need more longitudinal research to examine how the sibling relationship changes over time and across the lifespan.

So for the National Adult Sibling Survey we conducted, we did not address all these gaps but we did try to take some of these into account to really help try to contribute to the literature. Since we're still in the midst of analyzing the results, I'm not going to be sharing this with you today.

I'm going to give you a brief overview of the survey and discuss some of the lessons we learned. The purpose of the National Sibling Survey we conducted is to address the current needs and necessary supports for siblings and their families. We created four versions of the survey to capture the perspective of siblings of people with disabilities, parents, professionals, as well as individuals with disabilities.

And these multiple perspectives are really unique to this survey. We think we will really learn a lot from asking the person with a disability what they think about their sibling relationship. And also we're interested in seeing the differences in support needs between parents and siblings because we ask a number of questions about certain supports such as different educational resources and peer support groups. We also ask if parents or siblings utilize the support and how important people think those types of supports are for siblings.

And additionally, the professional views of siblings, especially adult siblings, is not very present in the research literature. And this will be important to learn from.

We got input along the way from our partners from the different projects, such as from Pennsylvania, the Pennsylvania Civil Support Network and the Institute on Disability in North Carolina as well as families in North Carolina, as well as our Sibling Network research. Questions were included for people who have multiple siblings with disabilities since most of the current surveys out there assume and ask about one.

So that was kind of unique to our survey. We created a Spanish version of the survey to attempt to get a more diverse sample. We have the potential for a followup in three years by including a question asking people if they were OK with us following up.

We also used specific scales including a future planning scale, a maladaptive behavior scale and an advocacy scale. We based the survey off the current literature as well as some previous sibling surveys such as the Wisconsin longitudinal survey and the national adult sibling survey. And the survey was primarily online through Qualtrics and we also provided paper copies to those who requested it. The advantage of using an electronic version, it could be shortened depending on the response to someone's question. We recruited using multiple partners. We distributed through a number of national networks including the Sibling Leadership

Network, we have over 5,000 members, the family research is support and training center training network which includes the national disability councils, The Arc, selfadvocates becoming empowers, parent to parent and more.

We had partners in states, especially in Pennsylvania and North Carolina who were funders of the survey to do more specific outreach at the state and local level. We tried to incorporate creative advertising outside the traditional venues to ensure we were reaching people who may not already be connected to the traditional disability networks. And specifically we used social media and general electronic community boards that were not disability specific, as well as colleges and community centers.

Our response rate was larger than we anticipated. We were actually hoping to get about 1,000 respondents and we over doubled this with 2,628 respondents. The breakdown of the respondents shows that most were siblings with 39% of the sample. We also had a lot of parents complete the survey which accounts for 31%. And 17% of the respondents were professionals who work with people with disabilities and their families. We also had almost 7% of our sample as people with disabilities.

We learned a number of things in doing the survey. Mostly we realized that there were a bunch of things that we did not ask. It's one of those things where you try really hard and you spend a lot of time kind of trying to get the survey "perfect," and there's always something that you just realize after the fact that you leave out and wish you had put in or maybe phrased a little differently. And that's just part of the learning process.

So here are some of the things we wish we had asked. What about younger siblings who are less than 18 years old. We created the survey to be completed by adults 18 and over and it doesn't include the perspective of younger people. We would really need to think about how to adapt the current survey for younger siblings to complete. We didn't have an option for people who have a sibling who's passed away. And actually we did think of this while we were designing the survey, and somehow it actually got lost in all of the other things we were trying to do while developing the survey. Because it was such a big undertaking.

We went through a lot of different versions and I can't believe our final version didn't include this. The reason I think this would have been useful is because we've seen that within the Sibling Leadership Network, we actually have a number of people who are part of the network, whose sibling with disability has passed away. Some people's Sibs passed away long ago and got in contact because once a SIB, always a SIB. While they may not have a sibling who is still living they feel they have been impacted by their sibling relationship, which is interesting and important. What about other family members such as SIB in laws and grandparents. It was like doing four surveys in one, while doing this, trying to gather multiple perspectives, which is a lot. However we would have still loved to know about other family perspectives. So maybe in future versions of this survey, we can try to ask some of these things.

Also, we still struggled with getting the diversity and response that we were hoping for. While we created a Spanish version, we only received 20 responses in Spanish. While we tried to do outreach to numerous Latino and Hispanic organizations, we really need to build a relationship in this area to have a greater

impact in the future. I feel we're in the beginning stages of fostering these networks and it takes time. Also we realized having a paper copy, especially of the Spanish version was useful, especially for parent groups. And we had some of our partners that held inperson gatherings where they had the surveys available, which was great. Beyond the Spanish version, we also want to have a representative sample related to race. So we will need to look at this as we analyze the results. The hard copy of the survey looked really long because the skip logic that we used with the online version was not really apparent in the paper version.

So that was kind of a challenge and may have limited some people from completing the hard copy version. While we did get a nice response from people with disabilities that we were really excited to analyze, it was less than 7%, and we could also do better at getting an even greater response in this area. We really need to think about using different methods that are more accessible to different types of people with disabilities in order to gain their perspective.

Since we do have 182 survey responses from people with disabilities, I'm really excited to find out what they say and what we can learn from them that we can build on for future research.

And in acknowledging that the voice of people with disabilities is not often included in research on families and family support, the Sibling Leadership Network has created a video that highlights the perspective of selfadvocates. I was actually able to get this footage when I attended the Self Advocates Becoming Empowered conference along with my sister. Selfadvocates share their thoughts about what they wish family members knew to support them better. I'm going to show the video now. It's called Improving Family Support: Ideas from People with Disabilities.

It's about five minutes long, so give me a moment while I cue up the video. After the video we'll be going to questions so you can start thinking of questions you might want to ask.

>> Sandy: I wanted to ask you when do you think you guys will have some results from the survey just so we can tell our audience.

>> Katie: Great question. So we're cleaning the survey now, and it's a really big data set that has been a lot more work to clean than we initially anticipated. So we're running kind of our initial first frequencies just to get a sense of the preliminary data by the end of this month, and then we're hoping that by November we will have some more meat to the analysis. And we're going to be getting input from our stakeholders around which analyses they might want to see us do as we go along to really make sure that the information that we're looking at is relevant to the stakeholders.

Great question. So here's the video. Again, it's about five minutes and then we'll go to questions.

[Captioned video playing]

>> Katie: OK. So that was the video. We're now trying to get back to the presentation. That video is on the website. Both the Family Support Research and Training Center website as well as the Sibling Leadership Network website. And I encourage you all to use it in the work you do, in any way you could find that relevant. I've got to say just personally, I'll mention before we open it up for questions, that for me, attending I mean a lot of what the selfadvocates were saying

were for families to get involved and go to meetings. I found that myself.

I was able to attend the Self Advocates Becoming Empowered conference with my sister with a disability, and it was so beneficial to me to be around all of these other selfadvocates, to learn from them. And I really feel like it helped me learn how to be a better sister in many ways. So I'll just share that, and now I think we can go into questions.

>> Thank you. Our first couple questions relate to the need to know survey, how it was done. Can you talk a little bit about how age was considered as a demographic, and in particular, aging siblings of people with IDD who are now serving as primary caregivers and how research was done for underserved areas?

>> Brian: Sure. I can respond to both of those. In terms of aging and siblings and rural transitions, that came up both for parents and for siblings who identified themselves as siblings, but we didn't necessarily recruit specifically for that. That just came up in the responses that people provided. There were also some providers who were aware of that role transition and spoke about that in the context of future planning. That is something that I think we know we know a little bit about but we know we need to know more about.

I think that will be part of our plan, and it came up in a few different ways. The second piece about recruiting, specifically in terms of rural, there were a few different strategies that we used. And I can't quite say that they were successful. And we didn't really get folks from Appalachia as far as I know, although we did get some folks from rural Ohio, some folks from rural Louisiana and some folks from rural Florida. There were maybe some other folks but there were some clusters or groups.

We did that by working through people on our national advisory committee. So folks like Easter Seals, but there were other organizations as well. We also specifically tried to contact and partner with a number of organizations that had a wide variety of people of color in them.

So either specific groups, like there's a black coalition on aging or something like that. And those folks sometimes had access to people in rural areas.

We did ask about whether people identified as urban, suburban or rural in our demographics. So we do have that information. I didn't present the information in terms of that location, but definitely, there was more on aging and more on people lacking providers or lacking access to direct support workers in the rural folks.

>> Just add to that, we did also ask people what age sort of range they were in. So we can analyze it by older age or, you know, people who are more in the middle and so on, in our more refined analysis.

>> Thank you. And let's ask Katie a question now. We have a comment and a question. Great video. But these are all high functioning verbal Sibs what about Sibs who are lower functioning.

>> Katie: Great question. We actually don't know. We don't have a lot of information. When I was at the conference, this was just kind of a first attempt to try and get some voice and perspective from people with disabilities about what they think related to family support. And those were the folks that felt comfortable sharing on the video. It's a very limited sample of people, and we need to learn a lot more in that area.

>> Great. Brian and Sandy, we also have a comment and question combined. Amen, read the need for better support for system navigations. Can you provide more detail on this?

>> Brian: I could provide more detail, but we need about three hours.

[Laughter]

>> We could give you about three minutes. What can you do?

[Laughter]

>> Brian: Systems navigation was probably the most frequent complaint, for lack of a better word. It wasn't always provided as a topic, but it was one of the things that came up most frequently. I'll let you know, it was in every part of the process. It was in education, healthcare, it was in social services. And it was really actually people felt lonely. They felt confused, they felt overwhelmed, overwhelmed, they felt like systems were failing them. People spoke about just needing support to know that they had the right information.

So I think that will be a pretty large chunk of the strategic research plan, and we will work it with a broad category with a systematic focus on specific systems.

>> Sandy: Just to add to that, I thought it was interesting in the video, the gentleman talked about the red tape. So that's another, you know, he's talking about systems navigation, right? And this is a good example. This topic is a really good example of something that's really going to make it to the strategic research plan in terms of an area that needs research. This is sort of an emerging topic in the healthcare field with the Affordable Care Act, they actually talk about funding system navigators and so on. And there are more people starting to do research in this area, but not necessarily in the disability world.

So I bet we're going to find in our literature reviews, not a lot of research done yet, and this is going to be one of our big recommendations.

>> That's very helpful. We have one quick last question for Katie, which is whether a copy of the future planning scale is available.

>> Katie: Yeah. Just email me and I am happy to share that.

>> And just as a shameless plug, we also have information on future planning on The Arc's website, at futureplanning.thearc.org. We're at 4:28, so I want to thank our presenters very much for keeping us up to date on where this research is.

I predict we'll be on another webinar as we get more information on where the research is going. I hope all participants will join us for that. As a final last ask, after the webinar, we'll be sending out a few things, one of which is a short five-minute survey. We would appreciate it if you would complete that. It helps the presenters learn what worked and what we can improve on.

We'll also be making available the PowerPoint and the recording. It takes a couple days for us to work with the system to get that out, but that will be made available to all of you. Again, just one final thank you to Sandy, Brian, and Katie for both the work that they're doing and for joining us today on this webinar.

>> Sandy: Thank you. We really enjoyed it.

>> And we're giving you all back about 90 seconds of your time. Use it wisely.

[Laughter]

[Concluded at 4:29 p.m.]

