The Arc

Caring for Myself

September 14, 2016

>> FEMALE VOICE: Thank you for everyone who has joined us today. We are going to be starting in a few minutes.

>> FEMALE VOICE: Are you there?

>> FEMALE VOICE: Hi, Sandy. I'm here. It is now 2 o'clock. So I will go ahead and get started.

>> SANDY: Good afternoon, everybody on the phone, thank you so much for joining us for a webinar today. Before we begin the presentation, I would like to go over a few housekeeping rules. All participants are currently in a listen only mode, but there will be an opportunity to ask questions following the presentation. However, at any time during the presentation, if you need assistance, please post a question in the chat box on the right-hand side of the screen and we will be happy to help you.

We also want to let you know today that we are recording the webinar. The link and recording will be sent out to all attendees following this webinar. We are also captioning the webinar today, so if you are somebody who would like to see the captions, please feel free to use the web link that you see on your screen right now to access those captions.

We have one final request before we begin: you'll receive a session evaluation immediately following this webinar. Please take a few minutes to complete and submit this to us. It is very important for us to have a good understanding of what you have learned and how you plan to use this information. Once again, thank you so much for joining us today. I will now turn it over to Robin, the senior executive officer or individual family support to get started.

>> ROBIN: Hello, this is Robin Shepard, I’m the Arc Senior Executive Officer for individual and family support. Good afternoon and thank you for joining us today. The majority of children and adults with intellectual and or development disabilities, I/DD, live with their families. This is especially true for people with I/DD from Latino and other minority households.

The primary givers in these household who are usually mothers face challenges with their own emotional and physical health. Today, our speaker Sandy Magana, Miguel Morales, and Judith Rocha will give information they have used successfully, entitled Caring for Myself, I Can Care Better for My Family.

This program will promote healthy mothers by promoting well-being. Our speakers will discuss aspects of promotion promoting intervention. How to set up a similar project in your and how to adapt it to other cultural groups. I want to briefly introduce our speakers. Sandy Magana-- leader and investigating racial and ethnic disparities among children with autism and developmental disabilities and among the family caregivers. Sandy is also the director of the family support research and training center, which is supporting today's webinar.

Miguel Morales is the assistant director of research and training at the family support research and training center. He was previously the Northwest side community program coordinator for the consortium to lower-- Chicago children. Program manager and community organizing for obesity prevention. His community research efforts have included community-based participatory research and healthy behaviors related to nutrition and physical activity.

Judith Rocha is a licensed clinical social worker and a four-year PhD student at the University of Illinois at Chicago. As a Latino born in Chicago and raised in a little village neighborhood by a hard-working single mother and older siblings, all Mexican born, she has always been interested in helping Latino families negotiate the complexities of their transnational life successfully. Her research interests includes-- focus on family caregiving with older Latinos that have Alzheimer's is all timer’s disease and dementia. Without further ado, I will turn things over to Sandy to get started.

>> SANDY: Thank you for that great introduction, Robin. I'm going to present today about an intervention that we developed called By Caring For Myself, I Care Better For My Family, and talk about how some of the results of our findings and how we are using it. I'm trying to see a change of the slides. I'm not exactly sure. Maybe it's up here. I did it

Just to give background, a little more background on the issue as Robin mentioned, most adult with the disabilities live with their families, and that's even more true for Latinos and African-American families, and also immigrant families.

The other thing is that people of color in the United States do experience socioeconomic and cultural conditions that are often not shared by white families, and so it's really important to understand within each group what their situation is and what of the stressors, and what are the strains.

We do know that chronic exposure, there's chronic exposure to many stressors among many minority families that include not just taking care of the person with a disability, but also their living condition, discrimination, and other factors that may be part of the experience.

Then there could be language barriers as well. And often, there are health disparities among minority populations in general, so not even talking about caregivers, but there are health disparities and chronic health conditions, so that can be exacerbated by the caregiving situation.

I'm going to talk a little bit about previous research that my team has done using the national health interview survey. We actually look that within groups, comparing caregivers to non-caregivers on chronic health conditions, and I'm presenting to you the information on Latinos. We've also look at African-Americans in a similar way, but we can see that the light blue on the left, the bar are caregivers and the darker blue are non-caregivers. Clearly, caregivers are experiencing, with a Latino population of women 40 and over, experiencing more depressive symptoms. If you look at heart conditions and arthritis, live a similar finding that they are more likely to have some sort of heart problem, as well as more likely to have arthritis if they are a caregiver within the population, compared to non-caregivers.

That research really kind of led us to look at what can we do about that and how can we address it their intervention. Some of the factors that we have to take into account our language barriers, immigration status, especially for the Latino population. Whether they are living in poverty, facing discrimination, unfavorable working conditions, lack of familiarity with her toll system, and lack of social support. Those of the many factors that contribute to the disparity issue.

Within the field of disabilities, often there is a person, or an adult, there's very rarely services for the caregivers. It's typically the mother, I mean, often, their are other family members as well, maybe grandmothers or fathers, but those supportive services are just not in that silo of services.

This graph, we are showing how it's really important to provide service around health from others and that they need to be culturally appropriate services.

This slide is giving you an idea of the Promotora de Salud, from this we get community health service, that's the Spanish word for it, and we developed an intervention using that battle. Promotora and community health workers are used in--- large numbers of African Americans or Latinos, so widely used in the Southwest, as well as in Chicago, and the general health field to educate people about chronic health conditions and educate people about how to improve their health. We wanted to take that to the developmental disability caregiving world, and so one of the things that we did was require that the Promotora in our study would also be parents of children with intellectual disabilities. They would have that shared experience with the participants they are working with. You can see that the Promotora model is somewhere within that community, shares common identity with the participant and becomes a health educator, respected and invisible, and it would be bilingual and service a bridge that way, and really understand that community. Those are some of the components of Promotora’s program.

This study that we did were re-created intervention, and I will describe that a little more-- our theoretical framework was self-advocacy very, so the idea was that would engage in the program, and it would increase the confidence with self-advocacy of taking care of their own health kind that is the focus, their own health. That hopefully would lead to a change in health behaviors.

These are the research questions that we are presenting today. One is can't do the caregivers show increases in self-efficacy, compared to control group? So we did a randomized trial and we will buy more about that. Do they show greater improvements in health behaviors? And reduction in depressive symptoms? Do older caregivers have better or worse outcomes than younger caregivers in our study?

Just to give you an idea of what the curriculum involved, we developed a curriculum that was culturally based. We developed this several years ago by consulting with parents, as well as professionals that work with Latino populations, and families of children with I/DD.

The first session is really all about discussing what is taking care of yourself, because we find that with many of the Latino months, that conversation is so important, because it's not really clear that that's a priority in their lives. They sometimes feel selfish about taking care of themselves, and really try to put it in the context of, if you are going to take care of the rest of your family, which is a cultural priority, you have to take care of yourself.

Then we going to health care for the mom. Mom has been dealing with health care for years for their child with I/DD and other family members; going to appointments and navigating the system and all of that, but not for herself, because we really investigate with her with the Promotora’s help find ways to get the mom to take care of themselves.

Then we talk about well-being activities and nutrition, and all of these are in the context of having a child at home with I/DD. So how could you do these activities also with your child? if you're going to change her nutrition habits, that will affect the whole family, the person with I/DD. Exercise, the same thing. We talk about stress and depression, is that something in general, among caregivers of people with IBD, there are high rates of depressive symptoms, but even mode more so with Latino months.

Including others, have you not do everything yourself and helping them build their social support? And how do they sustain and grow after the intervention is over?

That's a program. This is an example of one of the adaptations that we needed to make. We started to develop intervention, there was a food pyramid, remember the FDA had a food pyramid, and they started with this, my plate graphic. The changed our manual to include my plate. One of the things about my plate as it is often presented as here's a piece of meat, here's a vegetable, here's bread and they are all in different quarters on the plate. That's not the way many Latino families eat.

In the context of how they do we, they may have a soup that has all those things in one dish or some kind of a dish where all of those things, there's more than one of those different elements in the dish to make it more culturally appropriate.

Another example, in terms of cultural elements in the program, is that when the Promotora has a conversation about nutrition with the participant, we start about talking about what they ate in the country of origin before you were an immigrant, or what did you eat in your family, and often times, the for the eight was quite healthy. For example, many of our participants are from Mexico, and if you think of a typical Mexican diet that's not big city fast food, which is also a trend in Latin American countries, but a typical diet might include healthy foods, like corn tortillas and avocados and a lot of fruit, not a lot of meat. A lot of dishes that put vegetables and meat together. That's a diet that's actually quite healthy. We talk about that and talk about, what are you eating now, and what can you do to go back to some of the previous practices?

When people moved to this country, there's fast food places on every corner, they have to work two jobs to make ends meet, they can't take the time that they use to take to cook meals. We try to explore that with them.

The same thing with exercise, a lot of times, they are an immigrant, as a family, they were everywhere in the country of origin and they got a lot of exercise, they come here and the neighborhoods are too dangerous to walk around, so they have to drive everywhere. They've lost some of that physical activity as a result.

The Promotora’s that we started working with, they educated us about things that were culturally helpful, like using a story or phrase that was based in Spanish language, and that something that we also included in our program.

In terms of recruitment for the study, I'm going to be turning it over to Miguel pretty soon, because he's going to talk about methods and results of actual study, but we did a randomized trial in Chicago, and we recruited 100 participants, and our criteria was that they were mothers that were 40 years or older, and their child was eight years or older. He wanted to do it for older caregivers, but it was really hard because Latinos tend to be a younger population, so we expanded the ages. They need to be Spanish-speaking in this case, so randomize them into either intervention groups or control group. It says intervention and treatment and that's not right.

The control group has a waiting list; they were offered intervention after receiving the food test. Now, I will turn it over to Miguel.

>> MIGUEL: Hello, everyone, I am ago, and I will be discussing methods and results. SND just explained, this was a randomized controlled trial. We had an intervention or a treatment group, those are interchangeable terms, and a control group. And then, of course, we had pre-and posttest measures that were taken for both groups.

The control group received the intervention manual and resources, but not the home visits or any delivery of intervention by the Promotora de Salud

Here's the methods we use. Self-efficacy for diet and exercise behaviors. Specifically, we asked them how confident they were doing the exercises in the program using a 10-point scale. This scale was not at all confident to totally confident.

And then we use a depression scale from the center of epidemiology studies Depression scale, which measures depressive symptoms using items that rates frequency over depressive symptoms over the last week, categories ranging from less than one day to 5 to 7 days. And a score of 16 or higher educated risk for depression.

It's not on here, but it's in the results, we also used a scale, a measure called caregiver burden, and it used eight items with such statements as, caring for my child hurts my job, or caring for my child leaves me a little time for myself, statements like that. There were four response categories ranging from disagree to strongly disagree.

And then also, we measured positive health behaviors related to diet, exercise, and healthcare. It was a 36 item scale, and they asked about how often participants did specific activities, such as setting goals to improve their own health and well-being, or also things like cooling soups to remove the layer of fat that rises to the top, working in the garden, things like that.

There were four response categories that range from never to always.

Let's get into the analysis itself. In the main analysis, we wanted to determine whether there were significant differences between the intervention and control group on pre-two posttest outcomes, the ones I just explained. Those outcomes again our health related self-efficacy, exercise, nutrition, and self-care behaviors, caregiver burden and depressive symptoms.

We use repeated measures analysis of covariance to adjust for demographic variables that were different between the two groups. We also conducted a qualitative analysis on focus group data, using an iterative process, two people generated themes that had to come to an agreement on them and their meaning.

This table here of course is the descriptive analysis and comparison of characteristics between the treatment or intervention and control groups. As you can see here, we take a look at age, in terms of a continuous variable, so we took a look at the mean age, proportion of participants who were 50 and older. Level of education. Income. Employment. Marriage status or partner status. Those who were foreign-born, ethnicity, particularly, whether they were of Mexican descent, and if the percentage of good or excellent health.

As you can see most of these are the same, and then were statistically different except for employment. We controlled for employment between the group analysis, that is the analysis comparing the results between intervention and control.

These are the child characteristics. We took a look at mean age, the percentage who are male, and then also, I believe primary diagnosis. Like I said, gender and developmental disability are all representative proportions. None are statistically significant.

Let's take a look at the results. Self-efficacy, you can see both the treatment and control groups. Self-efficacy is about the same baseline, around 74 points. The treatment group scores at 89, statistically significant increase in self-efficacy by about 15 points. So this is the posttest score.

In contrast, the control group realizes no increase in the self-efficacy score between baseline and follow-up. The difference between treatment and control scores results is also statistically significant, that is there is a statistically significant healthcare effect.

Taking a look at health behaviors, they showed statistically significant differences and exercises, from pretest to posttest. Although there were slight increases in the control group, these are not statistically significant France is between pre-and post-test.

The treatment control group was statistically significant for all measures. That's for the control group. In comparing the results, the differences between pre-and post-test, those for the treatment group are actually significant. So there was a real improvement and exercise, self-care, and nutrition behaviors for the treatment group.

Then we will take a look at the psychological outcomes. The treatment and control groups both solid significant decreases in depressive symptoms and caregiver burdens. The depressive symptoms decrease was slightly lower for the treatment group. Caregiver burden was also decreased more for the treatment group than for the control group. Nonetheless, the between group differences in the measures was not statistically significant. We believe the intervention group reported lower caregiver burden because the Pomodoro is discussed. They might've expressed a decrease in burden with them I have learned more about activities and strategies to care for their own children.

We also conducted an analysis controlling for caregivers, 50 years of age or older, and found that among caregivers 50 and older, depressive symptoms decrease more at follow-up for the treatment group than for the control group.

We're going to move on to the qualitative analysis. I will let Judith to take over from here.

>> JUDITH: Hello, everybody, this is Judith. Thanks so much for joining us today. In order to gain some qualitative knowledge about this project, focus groups were conducted with Promotora’s and also -- we were able to do it after the completion of sessions, eight week sessions. For the semi structured interviews, these were conducted six months’ post baseline.

The finding was very positive although there was limited depth to these findings, and the findings work Elementary of the quantitative results.

I will go ahead and read some of these comments that we received with regards to premature responses, as well as participant responses for the different areas. With regards to self-advocacy, there seem to be an increase. One participant said, “I learned that taking care of myself doesn't make me a selfish person. That something that wasn't in my mind before. Used to think that it was a selfish thing to think about myself."

One mentioned, “for my first participant, I saw the same pattern of change is seen in others. That thanks to the discussion of the manual, she started looking for medical assistance."

In terms of health behaviors, there seem to be in a program. One mentioned, “the participant had never in her life paid attention to labels and now she is already checking the labels, checking the content and nutritional value."

[reading text]

We do want to psychological distress and we saw a reduction with regard to the qualitative data, where a premature mention, I believe the most effective aspect of the program was to have someone to talk to about the problems they, the participants in this case are facing, someone who understands them and doesn't criticize them. The participant mentioned, “sometimes people forget about themselves in order to dedicate themselves to their children without sometimes concentrating on the fact that if we as mothers and fathers are not very well, we will not be able to take care of our children."

There are limitations to this study, all measures were self-report. The older adult sample was small. Despotism pens were midlife. We could have used a larger sample overall to examine the different subgroups and conditions. No measures were related to the child with I/DD.

Some of the conclusions that we came across, the program was found to be efficacious with the whole sample. We also found Fort to benefit mothers 50 and over. And program may be especially beneficial in providing social support and reducing the depressive symptoms among older adults, as we thought some of the quantitative results.

So currently, with this information, we have a goal of curing up for larger NIH study. In order to do this, we are piloting some new project, where we are integrating rigorous measures, 24-hour dietary recall and accelerometers to measure four levels of physical activity. Integrating text messaging to reinforce health habits and provide motivation. We are also going ahead and adding some child outcome measures. We are doing this with a pilot sample of 20 families with single arm pre-and post-test design.

The current accomplishments for this pilot study that was funded by the Royal Center, is that although we were two months into the study, we basically collected half of the sample. We have already 10 Latino mothers enrolled in the in the study. Some are engaging well in the current direction and complying with accelerometer use.

We have come across some challenges already. Some of the moms have found that the food recall seems a little cumbersome. They are not necessarily, I guess very willing to provide so much information about what they ate in the last 24 hours, where it seems somewhat difficult to measure at times.

The accelerometer is not the most discrete, we really had to make a case as to how this would be very beneficial for our project, so that the moms are cooperative and will be able to keep it on for a weeks’ worth of time, and we are doing this at the beginning of their participation in the study, so prior to the intervention, and then doing it once again once they are done with the intervention for a weeks’ worth of time.

Some of the feedback that we've gotten by the text messaging, is that some of the text messages seem to be long, and some months just don't seem to respond. Getting to know a little bit more as to what those issues are has been things that we've been touching upon as we are going along currently with the study.

As we look to the future, with regards to dissemination, there's been a few adaptations to date: one is an assessment and adaptation intervention the focus groups of caregivers and sequiturs. Selection and training of -- we will be implementing the intervention to the model with 74, community health workers. It will be pilot tested with 20 Latino caregivers in a group setting.

I headed back to Dr. Magana at this point.

>> SANDY: We're really excited. As one form of dissemination, really, or adaptation of the intervention for the populations that could then be disseminated more widely. Another thing that we have done in the past, we did some work too adaptive for the African-American community when I was in Madison Wisconsin. We did work with focus groups and there were very positive about the intervention overall. They like pretty much every aspect of it. There were some little tweaks that we needed to make.

We talked about exercise, and the word similar topics around hair, and not wanting to do a lot of exercise for that reason. Also, adapting the food recipes that we include in the manual to be more culturally relevant.

An interesting thing is that the Latino months, the name of the intervention is quite long. By caring for myself, I can care better for my family. They really need that last part of it, caring for my family, in order to be motivated, otherwise, they feel it selfish, as you heard from one of the moms.

With the African-American community, we initially called it, caring for myself and we were recruiting for the focus groups. We also they wanted to change the name and they could change it to anything, and they said they liked that name, caring for myself, because it reminded them that yes, they need to take care of themselves, so they embrace that first part of the name.

In terms of dissemination, we are developing a train to trainer program. We are open if there's any interested organization that wants to implement, we have implemented in group format, as well. We've done a study through home visits, and one of the things we found is at home visits, there's more retention, in other words, people are likely to stick with all of the curriculum, because you can reschedule when there's a cancellation and so on.

The group model, not all participants stick with the entire curriculum and that's the downside. The ones that do show good results. It is more economical to do a group format, so what you might do if you want to do it as an organization, as have to Promotora’s and two of them would leave each session. You are compensating them for their time, so you are compensating two of them, instead of a larger number for the home visit.

We are happy to provide technical assistance, and talking about doing train to trainer with you or train the trainer with you if you are interested in that.

I don't know if anybody has any questions or comments.

>> FEMALE VOICE: Thank you, Sandy, Miguel and Judith for this fascinating presentation of your work. It's really impressive how you can demonstrate change in these behaviors that are in so many ways difficult to change through the study.

We have a couple of questions coming in, one of which is, have you looked at single mothers and intervention with them as part of a group to target for the study?

>> SANDY: Yes, on some of the participants in our study, they were single mothers, so somewhere married and some were single. We did not exclude single mothers. In fact, the ones we recruited from the organization, they belong to a group of single mothers. Actually, the Promotora’s themselves were single mothers.

>> FEMALE VOICE: One of the things, Gil, you noted, it wasn't done in the study, was looking at the impact of the family member with I/DD, as well with these interventions. Do you have a plan to do that going forward or what would that look like if so?

City. And the current pilot study, we do have a measure of behavioral issues for the child. It's a parent report measure. However, I have a colleague who is here at USC, who has been doing a family health intervention where they all meet in groups into a number of activities. So we're talking about integrating the two interventions together, which will be really powerful. If we can have the home visits with the primary caregiver, and then maybe once a month or every two weeks, have this family gathering to integrate the entire family, and also measure child outcomes as a result.

I would think that even though we are focusing on the caregiver, the caregiver is responsible in many cases for the well-being of the entire family. She's going to pass that down to the person. We don't have any direct health outcome measures in the current pilot, but I think that would be important for the child.

>> FEMALE VOICE: Would also be interesting to look at whether the other family members not only are changing their own behavior, but are proceeding benefits from increased health on the part of the caregivers?

>> FEMALE VOICE: Exactly. I agree.

>> FEMALE VOICE: We had a question for Judith. With the adaptation of the curriculum for caregivers of people with Alzheimer's or dementia related disabilities, how did you make those adjustments to that curriculum, or what adaptations did you find most effective?

>> JUDITH: The project itself is in the works now. I'm actually waiting on approval currently, but the thought is that the focus groups, with the caregivers and stakeholders, I would be able to present the current manual, the current project as it is and be able to get their feedback to know, what should we keep, what should we change, what do we definitely need to be adding in.

Some of the thoughts I have based on the literature, I will definitely be adding in a session or part of a session about the condition itself, the Alzheimer's and the projector he of the condition. Trajectory of the condition. Definitely in the Latino community, it seems to be a concern that a lot of information is not readily available, maybe not in the appropriate line which. That a lot of times feeds into the issue of the caregiver burden. Those are just a preliminary thoughts based on the literature, but I will definitely take the feedback provided by the caregivers and stakeholders once I go through the focus groups.

>> FEMALE VOICE: Judith, we have just gotten another question related to that. In light of the high incidence of Alzheimer's disease and people with Down syndrome, and particularly early onset all levers, have you considered setting up a study combining I/DD and Alzheimer's disease?

>> JUDITH: Actually think that's a great suggestion. I would definitely be cut would welcome an opportunity to collaborate, maybe with Dr. Magana and formulate something like that, because I think it's very important and definitely something that's making the headlines and a lot of our areas. I appreciate that comment, thank you.

>> FEMALE VOICE: Again, for people listening, if you have questions, please do check type them into the chat box.

Let me just ask a question that came to my mind as I went through this. You are focusing the study first on Latino moms and then looking also at African-American families, and seeing some really significant support and changes in the families. As we get more data, I think we will want to move this broadly into the community. Do you think as we look towards more mainstream population, will it make sense to continue to do the studies and community groups, and would you look toward faith community, or how would you look at just expanding the work even more broadly?

>> JUDITH: That's a really good question. Those are really good ideas, actually. Maybe we should connect with you, Robin, about ideas to expand more broadly.

Faith community, and another thing might be online for families who do have that. The populations that we are serving, that really isn't a good mode for some of them, but when you get into middle class families who do have computers and they are available in their home or Internet is available in their home, online might be another way to disseminate the information and knowledge of the program.

>> ROBIN: I think it would be interesting to do that. I will show my bias, how much just the time focusing on the caregiver from the Promotora impacted and the willingness to make the changes. Whether online works is really an open question.

>> JUDITH: I was going to say, I think they are very good motivators and they really make a difference.

>> ROBIN: we have another question about whether you considered giving other primary caregivers, such as a single dads and grandparents in the study?

>> JUDITH: Absolutely, and I will answer a question about siblings. I definitely don't see what you would not include, especially if they are primary or secondary caregiver, dads, definitely. I think a lot of the health information we provide about what checkups you should have our focus on women. So there would have to be some adaptation to include that, in terms of what kind of checkups they should have. Other issues are going to be pretty similar. It's a good question of whether it should be like a couple or family at one time, or whether it should be a dead project, individually, I'm not sure.

>> FEMALE VOICE: Some of the participants that have been grandmothers or our grandmothers, they are definitely providing a key role in the child's life.

>> ROBIN: just as we can win grandparents day was already, AARP had an interesting book post the number of grandparents caring for grandchildren, and it wasn't I/DD focused, but my guess is that it is also, that there are a lot of families in which grandparents may have been carry so long for their children and grandchildren, refocusing on caring for themselves, they need the intervention to do that, if not just as much, just as much significantly more.

>> JUDITH: Absolutely.

>> ROBIN: we had another question, and it was kind of what you touched on, Sandy. The question is, siblings play a greater role in the lives of their family members with I/DD and parents age, and face there one physical decline and it's important to include them. There seems to be agreement on that. We know that you and your colleagues are very involved in research related to the sibling role.

>> JUDITH: Absolutely. I think when they've done it in a group, they would sometimes bring other family members to a group so a sibling or grandparent or aunt. Even when the home visits are done, all the members of the family could be present at that, at each visit. Sometimes, it works out better with just the mom because of scheduling. It's really hard to schedule the whole family at one time, but there's definitely no reason why other members of the family can't sit in on the intervention.

>> FEMALE VOICE: Sandy, I had a question. I know that you had mentioned that the mothers who participated in the trial, they were caregivers and their children had different types of disabilities. I know sometimes in the research, they talk about different stress levels for parents, based upon the disabilities they have. For example, the mothers of children with autism versus mothers of children with Down syndrome. Did you guys notice any differences in the stress or burden kind of change based on disability as well?

>> SANDY: We look at the baseline data and compared autism to other disabilities, and we did not find any differences in their baseline or change, in terms of parental outcome. That was interesting. It might be that this particular sample, it's not a representative study, because a lot of research does show higher stress. Actually with Latinos, I have a study where we found that autism might actually not be as high stress as regular I/DD, but that's really not a representative study, either, so it's hard to say. I think all mothers or all caregivers of children with I/DD face some sort of stress, and when there are behavioral challenges, it becomes more stressful, is one of a lot of the research shows.

>> ROBIN: we have another couple of comments that we want to share. First, there's a comment that there's material in Spanish available from the national Down Syndrome Society, aging and Down syndrome, and if anyone's interested, they can call the in DSS office in New York.

Another comment from a mother of a youth with learning disabilities, working with the community, says that she has a concert about doing online presentations, since more than 90% of the Latino population doesn't know how to navigate the Internet and may not have computers at home.

>> SANDY: Exacta, that's why we did not do it online and that's why we use Promotora. I was suggesting middle-class if we were going to do that.

>> ROBIN: he found that everyone had a cell phone broadly across Latino immunity?

>> SANDY: Yes, that was one of the things that we were trying to think, should we integrate technology in some way.

>> FEMALE VOICE: So far, we would not turn anyone away, so far, those that have cell phones and are willing to take part in the study.

>> SANDY: Not everyone has a smart phone, but we decided that they had a flip phone, if they agree to receive text, they can still participate that way.

>> ROBIN: that is such a fascinating development, that today, everybody texts.

>> SANDY: I went to the all text, some of them are familiar with texting, but I would say the all have a cell phone. The ones who have more difficulty, when you say maybe the ones who have not been familiar with texting.

>> FEMALE VOICE: Think that might be the concern, and I'm not sure if I mentioned this to Dr. Magana at one point as well, if age makes a difference. Maybe a generational difference as well? A generational gap as well. Maybe once it's done, we find those who are not responding to some of the questions that we surveyed with or just comments in general maybe the older side of the group, or if it's just going to be across the board, the people don't do it because they are busy or whatever the case may be.

>> ROBIN: I think that would be very interesting. I also wonder if we were doing the study over an extended period of time with older caregivers who are supporting spouses with Alzheimer's, if the caregiver who also is aging, obviously would be, over time, doing less technology and less texting.

>> SANDY: It seems like up to this point, it seems like the field is anticipated that a lot of the baby boomers would still be very connected to the technology piece, because it seems like it's been a part of their career to the lifespan, and maybe would still be interested in getting connected even if it was something like texting or emailing or groups online, that type of thing. We will definitely see what the development is when it's coming.

>> ROBIN: we have another question about other techniques like mindfulness have been included as far as physical wellness elements.

>> SANDY: We do not do a full meditation or anything like that, but we do show them how to breathe. The Promotora actually does a breathing exercise with them, so they often tell us, my participant fell asleep during that period, but we also do-- one of the interesting activities they do during the wellness session is doing a drawing activity, which sounds kind of silly at first, the people really get into it, and its kind of a way to reflect but also a mindfulness activity as well. We do stretching things like that.

>> ROBIN: I want to thank all of our presenters sharing the results of this and I want to thank all of the participants for joining us. As you will see on the screen now, we are acknowledging the funders and supporters of the studies, without whom this would not be possible. Sandy, Miguel, and Judith, unless you have any closing thoughts, we will thank our participants for joining us. Ask them again to please fill out the study that they will be getting, and to join us in the future for results of other research around family support.

>> SANDY: Great, a pre-shake-- everyone turning in. Thank you very much!