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FAMILY NAVIGATION TO REDUCE DISPARITIES IN ASD
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>> Maureen Johnson: Hello and welcome. We will begin in about 5 minutes.

Hello and welcome to the Family Navigation to Reduce Autism Spectrum Disorders webinar. Part of the Autism Acceptance Month series sponsored by AUCD's Autism special interest group. My name is Maureen Johnson, a program specialist at AUCD. We would like to thank you all for joining us today. Before we begin, I would like to address a few logistical details. Because of the number of participants, your audio lines will be muted during the presentation. However, we will unmute your audio lines one at a time during the Q and A portion at the end.

You can also submit any questions via the chatbox on your webinar console. You may send a chat to the whole audience, or to the presenters only. We will compile your questions throughout the webinar and address them at the end. Please note that we may not be able to address every question and may combine some questions. This webinar is being recorded and will be available on AUCD's webinar library. There will also be an evaluation survey at the close of the webinar. We invite you to provide feedback on the webinar and also to provide suggestions for future topics.

I will now introduce the presenters of the webinar. Today our presenters are Carolyn DiGuiseppi, PH, MPH, Ph.D., a professor of epidemiology at the Colorado School of Public health and professor of pediatrics in the School of Medicine

at the University of Colorado Medical Campus.

Jodi Litfin is the clinical child psychologist and the director of developmental a and behavioral health at Rocky Mountain Human Services, a non-profit in Denver, Colorado, that is contracted by the State of Colorado as the early intervention services broker for Denver County.

Guiterrez-Raghunath is a native of Costa Rica and joined Denver Health in 2009 as a senior research associate. She continues working with several programs assisting with all phases of implementations of bilingual Spanish/English studies. I will now turn the microphone over to Dr. DiGuiseppi. [no audio]

>> Dr. DiGuiseppi: That seems to be dominating every conversation. But I'm really pleased to have a chance to chat to you today about family navigation to reduce disparities in autism spectrum disorder. My goal today is to briefly define family navigation and explain its potential for addressing the disparities we see in early diagnosis of young children with autism spectrum disorder. And then I'll describe the results of our SaLSA trial, intended to evaluate navigation in a real world setting.

My colleagues today will reflect on the trial and navigation from their perspective in early intervention services and as one of the family navigators on the -- participating in the trial.

This is a collaboration among a number of different organizations. Including the Anschutz Medical Campus where I'm based. Denver Health, which is a comprehensive health care system located in Denver that is a safety net system for low income and uninsured families. Rocky Mountain Human Services, which provides part C early intervention services in Denver city and County. And has a specialized clinical team to provide diagnosis of children with autism spectrum disorder using standardize testing, parent report and observation.

And the fourth organization that collaborated on this project is El Grupo Vida, a network of Hispanic/Latino parents that provide support for people with disabilities and their families.

Just some brief background on screening for autism spectrum disorder. We know that young

children with ASD can benefit from early detection, treatment and services to reduce their symptoms. And because of that, national organizations like the American Academy of Pediatrics and others recommend screening for children 18 to 24 months to improve early recognition of ASD. Even when that screening is implemented, they are not always referred for evaluation or complete a diagnostic evaluation or engage in services and treatment.

And that's particularly true for minority, foreign born, less educated and low-income families who experience barriers to obtaining evaluation. Including the fact that they have less information about AS D and other aspects of child development. They report more difficulty accessing care due to financial, transportation, language, literacy, childcare issues and other problems. They more often report that they raise concerns to their provider, but the prouder dismissed the concerns or was perceived to have dismissed the concerns. They report less trust of the health care and educational systems in general. And about the ability of those systems to address their needs. And even when they do get into -- do receive an early intervention evaluation and engage in services, they report less satisfaction which could lead to dropping out.

So, for all these reasons, these families tend to receive referral diagnosis and services for ASD less office and at later ages of their children.

So, one possible way to address these might be patient or family navigation. Patient navigation was first developed to address disparities in cancer diagnosis and treatment. Navigators are trained to help patients who have a positive finding of some type, like a screening test, through and around system barriers in order to ensure that they obtain the diagnosis and treatment that they need in a timely manner.

And it has been shown to improve the management of cancer as well as other chronic conditions in adults and has been tested for improving delivery of preventive care in children.

So, we saw that there might be a potential role for a specialized Autism Family Navigator to help address disparities in early diagnosis and treatment of ASD. The navigator could potentially educate

families as well as providers about autism spectrum disorder, the different tests, why families needed referral, and about the system and services potentially available. They could help families to coordinate care across the health care and educational systems. They could coach families to advocate for themselves to obtain the care that they need.

And they could also offer psychosocial support to help families who are trying to address the needs of their children and assist with practical barriers potentially like transportation or insurance needs. So, we developed the SaLSA Trial to examine the effect of autism family navigation on referral, diagnostic evaluation for ASD and linkage to services in a largely minority, disadvantaged population under real-world conditions.

And we also aimed to see how autism family navigation was implemented in this setting and whether it could be successful. The setting of the Denver Community Health Services. A network of about 10 community health centers and 20 school-based health centers that are located throughout Denver county that provide primary care that is affordable for low income populations. The patient population is all low income and largely minority.

Denver Health has implemented routine ASD screening consistent with the guidelines of the American Academy of Pediatrics are screening at the 18 and 24-month well child visits in the primary care clinics. Denver Health uses the modified checklist with revised with follow-up which is a two-stage parent-report screening tool. It's to identify young people at risk for ASD and who require further evaluation to determine if they may have that diagnosis.

If a child scores in the high-risk range, they are referred for ASD evaluation. And if they score in the low-risk range, they don't require evaluation. Although if they're 18 months at that screen, it should still be repeated at 24 months to ensure that they are still negative.

The second step of the two-stage screening tool is the MCHAT-R follow-up which is implemented for children in the moderate risk range. Because some of these children are false positives. They

aren't actually at risk for ASD. And the follow-up questions aim to determine if the child really requires evaluation. And if that follow-up score is positive, then they are referred.

We included children who were between 16 and 30 months of age. So, the sort of range of ages when children might receive their 18 and 24-month well visits who were seen for a well visit at one of the Denver Health primary care clinics. They had to have a positive initial MCHAT-R screen of 3 or more, indicating moderate or high risk recorded in the Electronic Health Record. Obviously, we excluded those who already have a diagnosis since they don't require screening. And because we were collaborating with Rocky Mountain Human Services, we excluded non-Denver residents since they are not served by that agency.

As a real-world pragmatic trial, we were trying to enroll every single child that met the inclusion criteria irrespective of the family's characteristics, of their likely compliance with navigation, whether they were in foster care or any other potential issues.

So, this outlines the screening to services flow. And you can see that it's fairly complicated, which can explain why families might have difficulty navigating it. Starting with the positive initial screen, they still need to get the follow-up if it's indicated. They need to have a referral made by their provider for evaluation. If from there, they are evaluated through Child Find in the Denver Public Schools. If the referral for evaluation specifically states that the child needs or evaluated for ASD, they would then also receive the clinical evaluations from the clinical team at Rocky Mountain Human Services. And then depending on the results of the Child Find evaluation and the ASD evaluation, they get an individualized family service plan and link to early intervention services.

So, you can see that there's a lot of different places that barriers could act to impede this screening to services flow. Starting from obtaining the follow-up if indicated through to referral, evaluation and services.

Our intervention was implemented by two bilingual Latina staff members housed within Denver Health. They received standardized navigator training from the patient navigator training

collaborative which includes modeling, practice and feedback around communication and problem solving, care coordination, assisting caregivers and helping with patient resources.   We also gave them project-specific training around autism spectrum disorder.   How it presents in terms of symptoms. What the screening tests are and what they mean and how it's diagnosed and treatment and prognosis. And we oriented the navigators to part C early intervention, the types of services offered and to the agency that offers these in Denver.

This is fairly complicated-looking design so I'm gonna walk through it.   So, it was a randomized control trial.   So, the children who met the basic eligibility criteria were identified through electronic health records with a computer algorithm and then automatically randomized to intervention or control. So, this was a pre-consent randomization process. The control groups were not contacted.   They received their usual care.

For the intervention group, the navigator then reviewed the electronic Health records to see if these families actually needed navigation.   First, the orange box on the right that says referral needed.   If the electronic health records showed that the child definitely needed a referral, whether or not they had gotten one, because of their MCHAT scores, then she would try to contact the family and offer navigation.

We go over to the left.   If the score definitely indicated that no referral was needed for autism evaluation based object MCHAT, then the family was not contacted, and navigation was not offered.   Then there was a third box which was the sort of problematic group where they had a moderate risk score but never got a follow-up done.   The navigator would contact the family and try to help them to obtain a completed follow-up from the providers or staff.

If -- if the follow-up was then done and was 2 her more, she would then offer navigation.   Also, even if the follow-up was never done but the child had received a referral, she would offer them navigation as well.   And if the -- oops.   What am I -- one of my figures is gone.   There it is.   If the follow-up was less than 2, so, referral wasn't needed or they never got the MCHAT follow-up and received no referral, then navigation wasn't offered as well.   Because we didn't

really know whether they required referral or evaluation.

So, if a referral was made or needed, the navigator would contact the family, obtain consent for navigation and then interview them about barriers that they had encountered or anticipated encountering. In addition, if the referral was made and had not indicated a need for ASD evaluation, she would contact the provider and staff to ensure appropriate referral. Or coach the families to contact their provider and ask that the referral specify the need for ASD evaluation. And she would also try to work with providers to have a referral made if it hadn't been but should have been.

She provided families with a range of assistance, resources and education about ASD and early intervention. As a pragmatic trial, the navigators used a highly flexible navigation approach. That is, they offered as much or as little as the family needed or requested. There was no set minimum or maximum contacts or amount of assistance that would be provided. And then she also maintained ongoing communication and support for the families as they worked through the evaluation process.

So, our primary outcomes for aim 1 reflect all the places that we thought family navigation could have a positive impact. From obtaining the MCHAT-R follow-up, to completing referral, completing evaluations and completing an individualized family service plan.

We also examined barriers experienced by the families and how navigation was implemented in this setting. We had three primary data sources. For our primary outcomes, we used linked electronic health and early intervention services records. That is the electronic health record at Denver Health and the record at Rocky Mountain Human Services for the referral that they had received completion of the early evaluation and ASD evaluation. Barriers, the family at time of consent completed a standardized semi-structured interview over the phone describing barriers. And the navigator kept records of the contacts and activities with the family that they implemented.

Our primary outcomes were compared between the initially randomized groups based on

intention to treat to ensure that we maintain the benefits of randomization. We tabulated and summarized the barriers that families had experienced. And we also categorized and tabulated the navigation activities.

All right. So, what were our results? The first, we randomized a total of 275 children to intervention and control groups. And approximately equal numbers. The next few slides show characteristics of the intervention and control groups. And there are I think two things we can learn from these tables which is, first, that the randomization was successful. As you can see from this slide and the next several that the intervention and control children were similar in their demographic characteristics. You can also see from this slide that as we expected, the majority of children were of Hispanic ethnicity. Most of whom were White race. Most of the rest of the children were Black race, other, or multiple race.

Many of the families spoke languages other than English. And as you can also see from this slide, the large majority were low-income based on the child having Medicaid and the family living below the federal poverty level. We also looked at the MCHAT score distribution. About 10% in each group were high-risk. Nearly all the rest were moderate risk. Initially in the first few months of the trial, providers had an option to indicate fail or pass, that was similar in the two groups as well. Fail is 3 or higher.

So, what happened to the children randomization in the intervention group? Based on that diagram I showed you a little earlier with the blue and orange boxes? So, a little under half did not end up needing navigation. Either because the moderate risk force was followed by a negative follow-up, including after working with the navigator to make sure that the follow-up was done. Or in a few indications because the MCHAT had been mis-scored and they were actually low risk.

There were 15% from the MCHAT follow-up was never done. The navigator was not able to help them arrange that despite her efforts. A referral was never made. And so, these children did not -- were not offered navigation. And a few were found to be ineligible after randomization because they had

moved out of county.

So, there were about 50 children who were potentially eligible for navigation in the trial. Of these, about half consented to navigation. Very few who were successfully contacted actually refused. And almost all of those were children who were already in early intervention services and the family didn't feel they required any navigation assistance. One of these was also a foster -- a parent whose child was in foster care. A large portion, about a third, the family navigator was not able to contact despite a total of up to seven telephone calls including messages. At least one home visit, at least one letter. The family simply didn't respond to their efforts to reach the family.

And then a few more who were in foster care, the foster care coordinator refused contact with the family. So, there were 22 families who consented to navigation and who were interviewed about the type of barriers they perceived to obtaining ASD evaluation. And these fell into several broad categories. The first of these was pragmatic, which is the most common. And the largest portion of these barriers were around scheduling needs. Families encountered a lot of difficulty with making appointments with early intervention services and keeping those appointments. Also, important, although less so, were transportation and insurance needs. A lot of families have difficulty reaching the facilities where the evaluations were done.

We also had several families say they couldn't afford to have an evaluation because no one had told them that the Child Find and ASD evaluations were free for them. Medical needs and physical needs that were potential barriers were reported but were not very common.

The second broad category was informational needs. About half of families had information needs that covered the entire spectrum from the screening test itself to autism spectrum disorder, referral, evaluation, and early intervention. We found that informational needs were more commonly reported by native Spanish speakers. About two-thirds of those mothers had needs, versus only one in six of the native English speakers. Dissipate a fact that a large majority of the 22 families were native Spanish

speakers, very few reported that they perceived language needs as being a barrier to obtaining evaluation.

And finally, the category of beliefs and attitudes about health or about the health care system that were potential barriers to obtaining ASD evaluation. A number of the families who consented to navigation actually were not particularly concerned about their child. They felt that the child would improve on its own, the child's grandmother didn't think they were the problem. The pediatrician didn't seem concerned. That was a potential barrier to actually going through the process of obtaining evaluation. Some families thought autism wasn't treatable so there was no point to obtaining a diagnosis. And some didn't want a diagnosis for their child because they were concerned about the child being stigmatized.

And a few families also raised the concern because of their citizenship in particular that evaluation would not be adequate for their child.

There were other barriers that the navigator identified over the course of navigation. These are low income families. They have high mobility and often they -- they had changed phones, phones were disconnected, they moved in and out of the county. And, of course, all of those were major barriers to actually scheduling appointments. There were a lot of system barriers. The majority of families encountered at least one type of system barrier during the course of navigation. And these included ones I've already mentioned like the MCHAT follow-up not being administered. Not getting a referral from the child was positive. Or the referral not indicating that an ASD evaluation was needed. Some providers put a hold on the referrals. In orders, they asked the family to come back in 3 to 6 months and be re-evaluated before they got a -- before the provider made a referral.

The navigator would track these and try to help the -- help the family ensure that they got back in for reevaluation. But a lot of them did not. So, these families were sort of lost to the process. There were barriers also at the early intervention agency. For example, a lack of Spanish-speaking staff such that sometimes coordinators would leave messages in

English for a family who spoke only Spanish.   Which obviously impeded their ability to obtain an appointment.   Toward the end of the trial, there was also a month's long waiting list for ASD evaluations. That was at barrier encountered by some families.

In terms of the reported barriers that families reported, they reported a median of four different barriers.   But you can see the range is pretty wide. Some families really didn't perceive that that there was going to be any problem for them to obtain an evaluation.   And others just saw an endless and wide array of things that were going to keep them from obtaining an evaluation for their child.   Adding in the system barriers, about half of families experienced at least five different barriers to obtaining evaluation.

So, how did the navigator respond to the families?   The navigators together reported 54 different distinct types of activities that were implemented at least once to help a family. Our -- we had a team of investigators who categorized these distinct types of activity into eight general categories that activities implemented for -- for family navigation.

And these included care coordination, education, social support, and others listed here on the slide.   And I've given examples of each of these on the right.   For example, social and emotional support, the navigator attended a number of the evaluations with families.   Families would express concerns about these evaluations and asked her to come with them.   They said they would be more comfortable if she was there during the evaluation process.

This shows the proportions of families that received each type of navigator activity.   And you can see that nearly all received some type of care cancer. Which isn't surprising given that scheduling needs were the most important barriers that families had encountered.   And education was also important and provided to -- about two-thirds of all the families.

The next three most common types of activities for families were sort of the soft kinds of navigator support.   Like advocating for the family, coaching them to advocate for themselves, providing emotional support to them.   And around a third of families received each of these types of activities.   On the

other hand, the more practical tapes of support, like transportation or insurance resources, were actually not that commonly needed by the family.

The navigators also conducted some activities within the system that weren't directly related to the families including tracking and reminding after -- about repeat screens and after the holds that I mentioned earlier. The navigator provided training for staff and providers about the MCHAT to try to ensure that the children who were in the age group actually got the MCHAT as indicated and that they completed it. And that they obtained appropriate referrals. This is training for staff and providers about the process.

We also prepared and the navigators disseminated bulletins to the clinics about autism referral, the process and outcomes and early intervention services to try to just improve the capacity within the organizations to complete these processes. One of the navigators also attended several community events to try to raise awareness about autism spectrum disorders, screening and evaluation, early intervention services. In part this was to try to get the message out that the navigator was there to help and that families should respond when she contacted them by telephone or home visits to try to reach them.

These are the results of our primary outcomes. Remember, these are the ones that are obtained from the linked electronic records. And they're based on intention to treat. So, among all the children randomized. So, the first outcome was obtaining a completed MCHAT-R follow-up. Completing the two-step MCHAT with Fidelity. And you could see that the intervention group was more likely to have it, 70% in the intervention group, versus the 40% in the control group. On the other hand, it had little effect on referral for evaluation. Basically, providers referred if they wished to and didn't if they didn't.

In the intervention group, we saw somewhat more families completing the evaluation for eligibility, but that wasn't statistically significant. Once they were determined to be eligible, they were all uniformly referred and obtained an individualized family service plan. We did see significant differences in evaluations for ASD. And the numbers are shown

here.   Children in the intervention group were about three times as likely to receive a comprehensive ASD evaluation compared to controls.   And they were also about twice as likely to receive a diagnosis of ASD. Although that outcome was not statistically significant as the numbers were quite small at this point.

It's interesting to look at the families who actually received autism family navigation as opposed to the intention to treat analysis.   So, of the family -- the 22 families who consented to navigation, every one of them was eventually referred to early intervention for evaluation.   Remember, this was the group where referral was needed or indicated.   So, they were all referred.   The majority of them, 73%, did complete an early intervention evaluation.   So, this is substantially higher than the sample as a whole.   All but one of these children that completed that early intervention evaluation had completed the ASD evaluation or was scheduled or on a wait list by the time the trial ended.

Of those who completed the ASD evaluation, 80%, or about 36% of the entire group receiving navigation, was diagnosed with ASD.   And all of them had initiated early intervention services and were in ongoing services subsequently.

Just to compare this to another similar trial that was conducted by Feinberg et al. with 40 minority or disadvantaged children comparing navigation to no navigation.   They started a little later in the process. These were children who had already been referred for ASD evaluation.   A very large proportion of these families also reported multiple barriers to evaluation. And most commonly pragmatic and informational barriers.   Feinberg et al. also found that children receiving navigation were about three times as likely to complete a diagnostic assessment compared to controls.   And, again, like we did find, they were about twice as likely to be diagnosed with ASD.

So, in this community health center system, this serves primarily low income minority families, we found that families whose children who screen positive for ASD have multiple barriers to evaluation and services.   Including system barriers, pragmatic barriers, informational needs, and beliefs and attitudes that impede evaluation and treatment. There's an echo here.   We found that autism family

navigation to address these barriers is feasible. Navigators were able to provide a wide range of assistance. Particularly care coordination and education for the families.

Based on our trial we found that navigation is effective in increasing ASD evaluation, and also improving the quality of ASD screenings by ensuring the entire two-step MCHAT was completed. However, many families appeared to be hesitant to respond to offers of assistance from the navigators, reducing the potential impact of a family navigation-type program.

We speculate that program would be more effective if it was embedded within the clinical setting so that there were warm handoffs from the provider to the navigator who could introduce the navigator to families in person. And that might make them more receptive to navigation. Obviously, that's difficult in the current environment, but hopefully in the future that will be more effective. In order for that to work, clinicians have to be aware of the navigator role. What they can do and understand how they might help their patients.

The navigator also has to develop and maintain relationships with staff in the health care and educational systems. And be sure that they understand the objectives, protocols and processes at these systems so that they can work within those systems and not impede the processes that need to go on. And then finally, we do think it's helpful if navigators conduct community outreach and try to develop partnerships with community organizations. Both to address issues of awareness, to reduce stigma around autism, and also to try to enhance trust in the navigator program and in the health care and educational systems so that families are more receptive to participating in the process.

Before we move to our next speaker, I wanted to acknowledge our funders. Primary the Health Resources and Services Administration with some additional support from the NIH. And I wanted to acknowledge the rest of our study team. You can see that there's many others who were involved in this -- in this trial.

And the two names that are shown in bold are our next two speakers. And with that, I would like to

pass it on to Dr. Litfin who will address the trial from the perspective of early intervention services. Thank you very much.

>> Dr. Litfin: Hi. This is Jodi Litfin. We felt fortunate to be able to participate in this study. In addition to working with our partners, this has also helped us to think about what are some of the barriers that our families are experiencing and what can we do differently as an organization going forward outside of the trial. And the biggest take home lessons were really about radical collaboration. That we can't do this alone and that it's really important for us to collaborate with our community partners and also with the families.

The early intervention workflow, as Carolyn pointed out within is extremely complex. And it -- it's really important that we were working together to understand what does that look like from the health care provider perspective? What does it look like from the early intervention perspective and what does that look like from the family perspective? And to educate each other about that and then to really identify where are the places where we have the opportunity to make a difference? And how can we work together to intervene in those areas?

One of the things that has been interesting over the past several years is to see that, despite the fact that we developed our clinical intervention and assessment teams with the express purpose of making it easier for families to obtain diagnostic evaluations for their very young children in a system that they were already -- that already existed -- the early intervention system, that hopefully would be easy for families to really see that for many families, they're still not able to access these services. And to -- this study was helpful in our understanding what some of those barriers really -- really were. and are.

And some of that is really about the significant difficulty in the multiple handoffs and referrals. So, even in this study, even with family navigation, one of the biggest barriers was actually contacting the families who we were attempting to offer the navigation to. And that is certainly consistent with what we see when we are trying to contact families to schedule their EI evaluation. Or to schedule their autism diagnostic evaluation.

So, we certainly see that there are plenty of places where we're losing people to follow-up. Partially because of the way that our system is set up. So, what we have done at Rocky Mountain Human Services following this study, and some of the things that we've learned, is we have very recently hired an early intervention engagement specialist. And the focus of that position is to pilot some of the aspects of the autism family navigation for EI as a whole. So, focusing on autism, diagnostics, but also on engagement in the initial early intervention evaluation services.

And what our hope is, is to really pilot some different interventions and see what seems to have the bigger impact and then hopefully just gather those up. And some of the things that we're looking at are really, is there a way that we can embed our services, our evaluations and our intake better into community settings where the families already are? So, to have that warm handoff, as Carolyn talked about.

And is -- rather than having somebody refer and then have our people need to contact the family with a phone call and so on, is there a way to make that much more seamless from the family's perspective? So, we're looking at that in several different places with PCP clinics as well as with childcare organizations and other places that refer to us. And then we're also looking at what are some different ways that we can meet family's needs? Certainly, in this era, we are providing a lot of our services through telehealth. And, we hope that we'll learn which pieces of that are effective for which families. That we can continue even after this crisis period is over.

and really looking at making the appointments more accessible to our families. Whether that's in terms of location, type of service delivery, time of day, et cetera. Thinking about that. And then looking at, what is it about our system that we might be able to work with our state partners and figure out how to make it more accessible for our children and families? So, lots more to come on that. And now I would like to turn it over to Silvia Guiterrez-Raghunath who will speak about her experiences as one of the family navigators.

>> Silvia Guitierrez-Raghunath: Thank you.

This is a reminder of some of the barriers and activities that are summarized in this slide. And now, I want to tell you what was -- what there was -- what it was like for one family. The mother who I will call Juana, a 34-year-old speak we are two beautiful children. Her youngest children was 18 months. Astraya. In the well child visit was referred for a speech delay. So, at this time, the early intervention began speech therapy with her. At the 24-month well child visit, they administered the MCHAT ASD screening. The MCHAT was positive and the score was 3 to 7, moderate risk. Referred again to early intervention program because that is low progress. But it specified that Astraya needed an ASD evaluation. And then Astraya was randomly selected for intervention. The first thing in the intervention was reviewing the medical record.

So, I know that the follow-up intervention wasn't done. And no referral for ASD evaluation. So, I contacted the family. And Juana was concerned about Astraya lack of progress. She was happy to have a patient navigator like me helping her in the process. And asking me if I can come to the evaluation. So, after that, I make a three-way call with Juana and the early intervention manager to schedule an in-home early intervention for Astraya which I also attended.

At the home visit, I asked if early intervention could provide an ASD evaluation. So, early intervention case manager said, ASD evaluation was not planned for this visit because referral didn't indicate the need. However, the case manager informed the family that if the family is specifically referred to the ASD evaluation, the early intervention was provided. Because I talked to the family before and we had a conversation about the importance of the ASD evaluation, Juana requested the evaluation right away.

When Astraya turned 30 months old, after the early intervention evaluation, she had the ASD home visit. After the completion of the evaluation, the early intervention manager and the evaluator wanted to explain and the results and then the next steps. Early intervention arranged for the interpreter because Juana speaks only Spanish. However, the Spanish language interpreter arranged by the early

intervention case manager was 45 minutes late.   And Juana became anxious because he had to go to work in the afternoon.

So, I helped to interpret until the other interpreter arrived.   When we were talking about the next steps, early intervention case manager stated to Juana what services were available without explaining whether the services were needed.   So, then they were talking, but Juana was listening with a look of confusion and asking me to explain.   So, I was able to -- I was able to tell Juana that the services were for a purpose which Juana found very useful.   I also provided emotional support for Juana with regard to the ASD diagnosis.

I was in her house for half an hour after the early intervention team left.   After that, Astraya received in-home early intervention therapy including ASD-specific services and began to show very good progress.   At age of 3, Astraya became eligible for the public school services.   So, early intervention case manager set up a meeting with the public school preschool team.   And Juana received a taxi cab voucher to get to the meeting.

But then when Juana tried to call the cab company, they couldn't understand her because she didn't speak English.   And they reportedly became angry with her.   So, Juana called me.   And they had called the taxi cab company, gave them the voucher number and arranged for the taxi.   So, in order to help Juana with the trip home and to support her, I also attended the meeting with the DPS preschool team.

After the appointment, I call again to arrange for a cab -- a taxi cab and waiting until the cab came. So, I could explain where the cab needed to go because Juana didn't speak any English.   This was one of my roles in the program as a patient navigation.   Let me tell you that this is one of the programs where after the day I arrive in my house, before I enter, I have to stay in my car about 10 minutes to center myself.

Now, it's been around two years, three years program ends.   But this family is still in my heart. So, thank you.

>> I'm gonna start my web cam.   We have a couple questions hear which I think we may have

already somewhat addressed.   And maybe, Maureen, since there's only two, I'll just go ahead, and we can answer these.   The type of training that navigators usually receive.   I did talk about earlier and this question might have come before.   But they get standardized navigator training which has a lot to do with practice and skills and communication and coaching and problem solving and providing supports in education.   Also, around resources, carting care. Maybe Silvia, if you wanted to add anything to that about your experience with the training for navigation?   You're still Matted, Silvia.

>> Silvia Guitierrez-Raghunath: Sorry.   I didn't hear you, the last question.   The question.   You talk about the experience, right?

>> Dr. DiGuiseppi: Talk for a minute about your navigator training.   What you received in terms of navigator training?

>> Silvia Guitierrez-Raghunath: Yes.   This program was between the research piece and navigation.   The training is specific for the navigator was more -- I think it's the Colorado Health navigator. I think before it was public health, and now it's in the university.   The training is like the basic training for the patient navigation.   And now they have the medium and the advanced training.   So, I did that -- the basic I think almost 20 years ago.   And then with this program I did the medium and the advanced course.   So -- and we always have to be training ourselves like a patient in motivation interviews, for example.

They had different cores into the program. That during those three years I was doing those trainings to be able to talk to the families and giving the support.   And for sure, Rocky Mountain Human Services, they gave me a -- oh, Rocky Mountain Human Services, they gave me a beautiful training.   I think I shadowed one.   And in each evaluation, that they -- they provided me training where they was doing and why they was doing.   So, I was able to communicate that to the patient.

>> Dr. DiGuiseppi: Thanks very much, Silvia. Any analysis into whether cultural views impacted the willingness to participate in navigation.   Yes.   We don't have all the results of that.   After the trial we did some structured interviews with families who did and

did not agree to participate.   Shoot, that question disappeared.   And -- and we'd also had some of the barriers identified were on disability and particularly their perceptions around autism.   So, that will be forthcoming.   So, we'll have some more information on that.

The next question, are there any other recommendations you have for the larger early intervention, child find or primary care systems to help reduce barriers to families?   I think I'll give that one to Jodi.

>> Dr.   Litfin: I would say that overall, the more that we can make these processes seamless.   So, things like having early intervention embedded in primary care, for instance.   Having fewer agencies.   So, currently in Colorado we have a different state agency that leads the evaluations for EI versus the state agency that leads the services portion.   And so, that makes it more complicated.   So, again, just the more that we can streamline processes, the better.

>> Dr. DiGuiseppi: Next question, any place to acquire the templates?   I'm typing right now.   Finishing it now.   The project coordinator, Kristina Hightshoe -- did it pop in there?   Has copies of the interview that she can share.   We also created a picture guide for families about what they would encounter when they went to the early intervention -- or went to the evaluations.   Obviously, it could need to be adopted locally, but we could make that available as well.

Is there a coordination or referral to pediatrician for suspected medical or co-morbidities with autism such as genetic conditions?   We didn't do that with our trial.   I'm sure that's a factor with early intervention.   I don't know if you want to address that.

>> Dr.   Litfin: Yeah.   So, in the past, we actually used to have a developmental pediatrician who was part of our clinical assessment team.   And because of funding cuts, unfortunately, we could not continue that.   But we do -- with families permission, which we always request, we do share our results and recommendations of our diagnostic evaluations with the child's pediatrician.   And if there are recommendations for additional evaluation for medical comorbidities, then we follow-up with that.

>> Dr. DiGuiseppi: Another question is, did you

do media outreach to the general population?   What did that consistent of?   We did not.   That was a randomized trial and we didn't want too much exposure of the control children to the navigation program.   If I was doing this in the context of an implementation program, I might sort of put local media as part of that same raising community awareness.   Because I think it would be beneficial.   For example, local Spanish radio would have been very helpful for us.

Are there any other questions?   Media, I think that's the last question.   I don't see any others.   All right.   So, thank you all very much.   I'll pass it on to AUCD, to Maureen to close out.   But we really appreciated the opportunity to speak with all of you.   So, thank you for that.

>> Maureen Johnson: Yes, thank you all for attending the webinar.   The webinar has been recorded and will be archived in the webinar library at AUCD.org.   At the close of this webinar, a survey will appear.   Please take a few moments to complete the survey.   The final webinar of the Autism Acceptance Month series will be Wednesday at 1 p.m. eastern stand time.   Dr. Jeffrey Wood will present on the technique of cognitive behavioral therapy for people with autism spectrum disorders.   Again, thank you all for joining us and please complete the survey at the close of the webinar.