AUCD – Screening and Linkage to Services for Autism: Study of Patient Navigation for Low Income Families Tuesday, April 24, 2018 3:00 p.m. – 4:00 p.m. Remote CART Captioning

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>> Moderator: Hello and welcome to Screening and Linkage to Services for Autism (SaLSA): Study of Patient Navigation for Low Income Families. My name is Anna Costalas and I am the Resource and Dissemination Manager here at AUCD. We would like to thank all of you for joining us today!

Before we begin I would like to address a few logistical details. First, we will provide a brief introduction of our speaker. Following the speaker's presentations there will be time for questions.

Because of the number of participants, your telephone lines will be muted throughout the call. However, you can also submit questions at any point during the presentations via the chat box 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 entire webinar is being recorded and will be available on AUCD's website following this webinar. There will also be a short 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'll now pass the microphone over to our EIEC co-chair Corry Rosenberg who will introduce our presenter. Corry?

>> Corry: Thanks, Anna. Welcome, everyone, to this AUCD EI webinar. I have the privilege this afternoon of introducing our speaker, Dr. Carolyn DiGuiseppi, who is a professor of epidemiology in the Colorado School of Public Health and professor of pediatrics in the school of medicine at the University of Colorado Anschutz medical campus. She received her medical degree from the University of Virginia, a master's of public health from the University of Washington, and her Ph.D. from the University College of London. She is board certified in pediatrics and preventive medicine. Before joining the Anschutz faculty, she was a senior research fellow at University College London and prior to that served as a senior house policy analyst in the agency For Health Care research and quality and as science advisor and project director in the Office of Disease Prevention and Health Promotion. She has published more than a 150 journal articles, book chapters, and scholarly reviews. Since 2001, Dr. DiGuiseppi

has served as the epidemiologist, and since 2011 as co-principal investigator for the Colorado center For Autism. Dr. DiGuiseppi has led or coauthored numerous publications in national and international presentations from the SEED study. She has participated in the CDC disabilities monitoring network and collaborated on research using both Adam and autism network treatment data. She is the PI of the screening and linkage services for autism, the SaLSA study and the control trial investigating the effect of patient navigation on linkage services to autism among low-income Hispanic children, which we're going to hear about this afternoon.

With that, I'll turn it over to Carolyn.

>> Carolyn: Thank you very much, Corey, for the kind introduction. Thank you-all for inviting me to present about the SaLSA study. I'm going to be trying to forward these slides myself, so we'll see how those go. Didn't work. Do I have control, Anna? >> Yes. There you go.

>> Carolyn: There we go. Great. Thank you very much.

My plan today is I want to first just briefly introduce the study partners who are collaborating on this project and then spend some time describing the study, background, aims and design. The trial is actually still ongoing, so I will have some preliminary results to present regarding some of the aims.

So, the study is based at the University of Colorado Anschutz medical Campus, and it is a collaboration among School of Public Health, JFK Partners, and the schools of medical and nursing. A partner in this study is Denver Health, which is a comprehensive integrated health care system, including community health centers and school-based health clinics located throughout Denver. It is actually the largest provider of health care to Cade beneficiaries to the entire state, even though it is based in Denver. We're also partnering with Rocky Mountain Human Services, which is a nonprofit that provides Part C early intervention services for infants and toddlers. It provides services through identification and planning and provision and support for services. It also has a specialized clinical team that evaluates children for autism spectrum disorder using standardized testing. They provide a clinical diagnosis of ASD if they complete their evaluation and find that condition.

It's not going. Slides don't seem to be going. Anna?

>> Try again.

>> Carolyn: Okay. Maybe I should give it back to you because it doesn't seem to be consistently going.

>> I think there's a delay. That's what you're seeing, but I can advance them for you. >> Carolyn: Okay. We're also finally partnering with EI Grupo VIDA, which is a network of Hispanic and Latino parents that provides support for people with disabilities and their families.

Next slide, please. This is the study team. Most of the team involves a large number of people at these various organizations.

Next slide, please. Next, I'd like to describe the study background, aims, and design.

Next slide, please. As I'm sure many of you are aware, young children with ASD can benefit from earlier detection, treatment, and services, but most children with ASD are not diagnosed until after age 3 years and sometimes long after age 3 years. It's been shown that routine screening in primary care can improve early recognition. As a

consequence, organizations like the CDC recommend that all children be screened for ASD at the 18 and 24-month well visits. This doesn't entirely solve the problem of late diagnosis and treatment because even when children screen positive for ASD, many don't get referrals for evaluation. Many of those referred do not actually undergo evaluation, and many of those who are elevated don't engage in services and treatment.

Next slide, please. This is particularly a problem for minority foreign-born less educated and low-income populations. Research has shown that children in these populations tend to receive referral diagnosis and treatment less often. When they do receive them, they receive them at later ages. Those families also report that they are lacking information about how to obtain care. They have difficulties in accessing care in early intervention services. They have fewer support services to help them connect. When they do get connected, they report less satisfaction with early intervention services.

Next slide, please. One solution for this kind of problem is patient navigation. Patient navigation was actually first developed to address inequities in cancer diagnosis and treatment. Navigators are basically trained to address and overcome barriers to care. They work with patients who have positive findings. For example, a positive screening test to help them overcome barriers that might prevent them from obtaining a timely diagnosis and treatment. There's been a fair amount of research around patient navigation for management of chronic conditions like cancer, diabetes, cardiovascular disease in adults. It's been studied less in children, but has been shown, for example, to improve delivery of care, like immunizations in children.

Next slide, please. We designed the SaLSA study to examine this issue for autism using a randomized control design. We aimed to test the effect of autism patient navigation on referral, diagnostic evaluation, and linkage to services in a low-income population. We also wanted to examine the long-term maintenance of autism patient navigation in clinical settings like community health centers that serve minority disadvantaged populations.

Next slide, please. The setting for the SaLSA trial is Denver Community Health Services, which is part of Denver Health. It is a network of 25 community and school-based health centers located throughout Denver that provide primary care. Children are almost entirely Medicaid insured or Medicaid eligible. The vast majority are minority race or ethnicity. Mostly Hispanic. Within Denver Community Health Services, there were seven primary care clinics and two school-based health clinics that implemented ASD screening through the trial. Those are the ones from which we enrolled patients.

Next slide, please. At those clinics that have implemented ASD screening at the 18 and 24-month well visits, they use the modified checklist for autism in toddlers-revised with follow-up. When a child scores in the low risk range, they don't require further evaluation. But if they are at the 18-month visit when they are screened, they should have a repeat screen at 24 months. If they score in the moderate risk range -- some of these are false positives, so the follow-up interview is implemented. This that is positive, then they are referred for ASD evaluation. If they score in the high-risk range, they are referred directly for ASD evaluation without the follow-up interview.

Next slide, please. The screening to services flow in Denver -- whoops. Go

back one, please. Thank you.

The screening to services flow in Denver starts with the positive M chat. Those children are then referred for early intervention evaluation and ASD evaluation. The referral has to specify that an ASD evaluation is needed or it will not be done. The child then first undergoes evaluation for education eligibility. Then they undergo the clinical evaluation for ASD evaluation. Then the child receives services according to the results of those evaluations.

Next slide, please. Barriers to initiating services can operate at any of those stages, impeding referral and evaluation and initiation of services.

Next slide, please. What are the ways an autism patient navigator could potentially help? They could overcome system barriers. For example, working with providers to ensure that referrals are done, coordinating care with service providers. They can also help the families to overcome individual barriers that might prevent the family from, say, getting to the evaluation. They can provide education to families and also to providers about autism spectrum disorder, its tests and treatments, and they can provide support to the families in other ways.

Next slide. In order to be able to do these tasks, patient navigators undergo general patient navigator training, which involves modelling, practice, and feedback. It addresses a range of skills that are needed to provide navigation. For example, problem-solving skills, evaluating patient resources, providing coaching for caregivers and coordinating care. For our autism patient navigator training, we added training about ASD itself, how it presents, the screening tests, and how it works, diagnostic procedures, treatment, and prognosis. The navigator also is oriented to part C early intervention services in general and specifically to Rocky Mountain Human Services where the EI services are provided for Denver.

Next slide, please. Our study population was children aged 16 to 30 months. We put a slightly wider range because sometimes children have their well visits a few months before or after the usual age. We included children who were seen for well visits at Denver Health primary care or school-based clinics that provide primary care who had a positive M-CHAT R score. It was reported in the electronic health record at Denver Health. We have included children who already had a diagnosis since in theory they shouldn't have been screened in the first place and those who were residents of Denver County because we were collaborating with Rocky Mountain Human Services because they only serve Denver County.

This is the general design of the randomized control trial. Children were allocated to the intervention group or the control group. The control group received no specific intervention other than usual care and were not contacted by the navigator. For the intervention group, the navigator would first review the chart, the medical record, to see what their initial M-CHAT score was as well as the follow-up score. If the child had an initial score in the moderate range but the follow-up was negative, the navigator did not contact the family. However, she did track the family if the child was under 18 months to make sure that the child got the 24-month screening test. If that test was positive, that child then would become eligible for navigation. The remaining children were eligible for patient navigator contact. That included both children who definitely needed a referral based on their M-CHAT scores or it was unclear whether they needed a referral because the follow-up had not been done. Next slide, please. Thanks. The procedures that she then followed were as follows. If the indicated M-CHAT follow-up had not been done, when she contacted the family and the provider and staff to try to encourage the staff to implement the M-CHAT follow-up because otherwise it was unknown whether that child did or did not receive referral. Did not need referral, excuse me. If the M-CHAT indicated a need for referral and evaluation, then she contacted the family, obtained consent for navigation, and interviewed the family about potential barriers to obtaining an evaluation.

In some cases, the child had a score indicating a need for referral but had not gotten a referral. In that case, the navigator would contact the provider and staff to try to ensure that a referral was made. If it was made, that it specified the need for ASD evaluation. Then throughout the subsequent process, she assisted the family, provided resources, provided education, and maintained ongoing communication and support.

Next slide, please. Our primary outcomes include examining the effect of navigation on the occurrence age and timing of the M-CHAT follow-up interview, referral for evaluation, eligibility determination, ASD diagnosis, and initiation of early intervention services in the intervention group versus the control group to see if all the children received more of these often and earlier at a younger age. We also assessed barriers to referral, diagnostic evaluation, and initiation and engagement services in the early intervention group only.

We had secondary aims. These included looking at reach implementation and adoption and maintenance. We are examining the scope and volume of navigator activities and looking at staff provider and family attitude perceptions about autism patient navigation.

Next slide, please. We're using a range of data sources to address these different objectives. For the primary outcomes, we're looking at linked electronic health and early intervention services records. We look at the records to see who did and did not receive an evaluation and initiate services. We have the patient navigator implement standardized semi-structured interviews with parents in the intervention group to identify potential barriers to care at the time of consent as well as after the individualized family service plan or IFSP meeting. Patient navigator is recording additional barriers that she identifies during the course of navigation and also recording activities implemented to address these barriers. Then we've also conducted key informant interviews among parents of children who are allocated to receive patient navigator support including those who refused navigation, low users and high users, clinical and El providers and staff and members of the study team.

Next slide, please. This is the analysis plan. I have some preliminary data on those aspects that are bolded here on this slide. I don't have information on the ones that are not bolded. We are going to calculate descriptive statistics on participant characteristics. We have some preliminary data on that. Tabulation and summary of barriers experienced by families consenting to navigation. We have some preliminary data. We're still doing navigation for some of the randomized families, tabulation of navigation activities. Same thing, preliminary data. We're in the process of doing qualitative analysis to examine the feasibility and acceptability of navigation.

Next slide, please. As I said, I'm going to present some preliminary results basically based on part of the sample that has been included in the study.

Next slide, please. We have completed randomization, so these are the final numbers for the trial. We have randomized 275 children to intervention and control groups in approximately equal numbers, about half in each of these two groups.

Next slide, please. These data are based on a subset of those participants, but we can compare the intervention and control group to ensure -- to determine whether randomization was successful. You can see from this slide that in terms of the child's age, sex, race, and ethnicity the two groups are quite similar. As you would expect, it is mostly male. And as you would expect from the population seen at Denver Health, it is mostly minority ethnicity and race.

Next slide, please. The two groups are also similar in terms of language with about 1/3 of each group speaking a language other than English, and as expected, the vast majority of participants are Medicaid insured or eligible.

Next slide, please. We also looked at the M-CHAT score distribution by study group, and that also was allocated similarly in the intervention and control groups. About 10% scored at 8 or higher. About 80% in the moderate risk range. There's about 10% in each group where the initial M-CHAT score wasn't recorded, but the electronic health record had an option for a pass/fail. These were children whose record had indicated a fail.

Next slide, please. As I said, there were 142 children who were randomized to the intervention group. About half were eligible for navigator contact and about half did not require contact. Among the latter group, the vast majority were children who had a negative follow-up interview after a moderate risk M-CHAT. As I mentioned already, many of those were -- the navigator tracked them if they were less than 24 months of age. There was also some children who were no longer eligible by the time the navigator prepared to contact them because they had moved out of Denver, and then there were some where, when she reviewed the record, she determined the M-CHAT had been scored incorrectly. It is a screening test that can be somewhat difficult to score because both yeses and noes can mean risk. We did find some scoring errors as well. Among those who were eligible for navigator contact, about 2/3 needed referral and about 1/3 were missing the M-CHAT follow-up interview and needed assistance to attain that.

Next slide, please. Now we're looking just at the subset of children who needed referral. Close to half of those have consented to navigation, and there's about another 10% where contact is in progress. Nearly 40% the navigator was unable to obtain contact with the family. The process included up to seven telephone calls as well as a letter as well as in many cases a home visit, but there were still many that could not be contacted.

Next slide, please. An important reason for that, in about 1/3 of those cases, the child was in foster care and the navigator was not able to reach the foster care caseworker or in some cases she reached the caseworker, but the caseworker did not allow contact with the legal guardian. There were less than 10% who were reached by the navigator but who declined navigation.

One question we have is whether the families that do engage with the navigator differ in some important way from the other intervention group families who don't get the referral or who decline navigation or cannot be reached by the navigator.

Next slide, please. This is again based on preliminary data. This is looking at a

subset of children who consented to navigation versus a subset of other intervention families. And you can see that in terms of age, gender, and insurance the two groups were very similar. There was no evidence that consented families -- that those consenting differed from the other families.

Next slide, please. There was some suggestion of differences in terms of race, ethnicity, and language. The consented families were slightly more likely to be Hispanic and somewhat more likely to speak Spanish. This may in fact reflect the fact that both of our patient navigators were Latino women who were native Spanish language speakers. Those families may have felt more comfortable engaging with the navigator.

Next slide, please. When she consented the families, she asked the -- the navigator asked them specifically about what is their native language and in what language are they most comfortable receiving new information. Even though only about 1/3 of consented families had Spanish language indicated in the electronic health record of the child, more than half were native Spanish speakers, and the majority of those were most comfortable receiving new information in Spanish. They were able to communicate in English, but they actually preferred to communicate in Spanish.

Next slide, please. Referring to the information about barriers that the navigator collected directly from the family, families described an average of four to five different barriers to obtaining a diagnostic evaluation. A few families identified none and one family identifying 12. Families, once they were diagnosed with ASD, experienced somewhat fewer different barriers. On average three with a range fairly wide of 0 to 8 barriers.

What were some of the barriers that were identified by the families or in the course of navigation? Next slide, please. By far the most important was scheduling problems. This was experienced by more than 80% of the families. There was just a lot of difficulty actually scheduling the early intervention evaluation appointment, especially the first one for eligibility determination. In some cases, early intervention services only makes three attempts to reach the family. If they don't reach the family after three attempts, the family is dropped from the system and then has to go back to Denver Health to get a new referral to be considered for an evaluation. In some cases, an appointment was made, but then cancelled by early intervention services. Sometimes the family forgot or they didn't realize they had an appointment. Then there were families who had trouble making an appointment in the first place because most of the appointments were during weekdays and the families could not take off work or they were worried about losing their jobs if they did take off work. Interestingly, this was common across the board, but it was 80% overall but 100% of native Spanish speakers had scheduling problems.

The next most common barrier was informational needs, which were found in about 40% of families. I think this reflects to some extent a breakdown in the communication and the information they got from their primary care clinic. Families didn't understand why they even got the M-CHAT or what the results meant, didn't understand what autism was, didn't know why they were referred or how to obtain an evaluation. All those aspects normally would need to occur before they ever interacted with the early intervention services. They also didn't understand what early intervention is or what it does. There were lots of informational needs. Again, the native Spanish speakers, more than half had informational needs versus only 14% among English language speakers.

Next slide, please. Practical and logistical barriers also existed in about 1/4 or more of families. These included transportation, insurance, and medical needs. Many of these families had no access to private transportation and didn't necessarily have money for bus fare or for cabs or Uber. Again, a breakdown in communication from the primary care clinic is reflected in the fact that many of the families were worried about whether Medicaid would cover the evaluation because they had not been told that there would be no charge. Then in terms of medical needs some children or other family members had health concerns or health care needs that the family felt needed to be prioritized and taken care of before they could think about having their child undergo an ASD evaluation.

Next slide, please. Beliefs and attitudes about health or the health care system were less common but definitely existed. Some of those beliefs went in sort of opposite directions. There were some who thought there was no need for an evaluation because the child would improve on its own. They thought the pediatrician didn't seem that worried. Then there were others that understood that autism was a problem but were concerned that their child would be stigmatized or felt that there was no treatment that would help autism, so again they didn't want the child to be evaluated for ASD. Then the concern that they wouldn't get a good evaluation for their child because of their ethnicity or citizenship was also raised as a concern. Physical needs like the need for child care or housing were less common. Only a few actually expressed a need for interpretation or translation.

Next slide, please. Once the child had an ASD diagnosis, there were also barriers to initiating and engaging services. This is based on a small number of children, but really only two types of concerns were important in this group. Those were insurance and financial concerns. For example, around whether they were eligible for services because of their citizenship and then language and literacy needs. The families get quite a bit of written information about ASD and about services after their diagnosis, but these are written at too high a reading level for some families. In fact, some families can't read at all, so the materials are not useful to them.

Next slide, please. In the course of navigation, the navigator also identified a number of system barriers to screening, referral, and evaluation in the children in the intervention group. Some clinics didn't repeat the screen at 24 months, making the assumption if they were negative at 18 months, there was no point in screening again. You have already seen that many children don't get the M-CHAT follow-up interview, so they're left in limbo of maybe they have a problem or maybe they do not. Many providers would put holds after a positive screening result. They would, for example, say, well, your child is positive, but let's have them come back in six months and see if they're still positive. Sometimes no referral was made, but it didn't really say why. We weren't able to find that information, so the child screened positive and needed referral but just didn't get one. It was common for the referrals to be made without indicating the need for ASD evaluation so that the family then never got the ASD evaluation. Then I've already mentioned some of the barriers in the foster care system.

Next slide, please. The patient navigator implemented a wide range of activities. I'm not going to read all these out to you, but they were activities that she implemented to address the entire range of barriers that had been identified. I will say a majority of her time seemed to be spent on scheduling needs, on scheduling and rescheduling and going back to Denver Health to ask them to send referrals again and making reminder calls to the family and even attending the evaluations with the family to be sure they got there. She provided quite a bit of education, material support in terms of transportation and other physical needs, assistance around insurance, lots of education, and she did attend quite a few of the evaluations which addressed a range of different barriers. Then after diagnosis providing emotional support and helping to connect families to support groups was also important and also linking to services at 3 years of age.

Next slide, please. The navigator is also able to provide a range of assistance at the sort of system level to try to make the process work more smoothly. She provided a large number of training sessions mainly to staff but also to providers about ASD and about the M-CHAT and the need for referral. Providers had some questions about what happened after referral, feeling like it didn't seem like they ever heard back, so it was sort of a black box to them. They didn't know what happened afterwards, so providing information and education about that so that they felt more motivated to do referrals, working on the referrals themselves to make sure they specified ASD. Those are examples of activities within the health care system and then also establishing ongoing communication and relationships with the staff at rocky Mountain Health and Human Services.

Next slide, please. I thought it would be interesting to hear a case study. This was a family -- it was a 34-year-old Hispanic Spanish-speaking mother with two sons. The younger one was seen initially for an 18-month well child visit. I'm going to review what happened to this family over the course of a year. You'll see all of these barriers impeded the child getting an early diagnosis. When this child came in at the 18-month well child visit, he didn't get the M-CHAT screening even though it was indicated, but he did get an ages and stages questionnaire, which was positive. The child was referred to early intervention for speech delay, not for ASD. He was found to be eligible for speech therapy and initiated services. The mom brought the child back at 24 months for a well child visit and expressed some concern about the fact that he didn't seem to be making any progress. The child did have an M-CHAT screen which was positive in the moderate range, but the follow-up interview was not done. However, they referred him again to early intervention for another evaluation because of the lack of progress. That referral did not say anything about an ASD evaluation.

That was the point when the child was randomized to the SaLSA intervention group. The navigator reviewed the medical record, saw that no follow-up interview had been made and the referral didn't mention ASD. She contacted the family. She contacted the provider to try to ensure that the follow-up interview was done, but that didn't happen. However, the mom was concerned about the child's lack of progress, asked for the navigator's assistance, and so the navigator did consent the mom for navigation since the child did have a referral. The mom was having trouble scheduling the second evaluation because she had trouble taking off from work. She asked the navigator to help with scheduling the appointment, and she also asked her to come to the evaluation with her. They arranged an evaluation. At the home visit where that evaluation was being done the navigator asked if they were planning to provide an ASD evaluation. The case manager said no because the referral hadn't indicated the need, but the case manager did inform the family that if they requested an ASD evaluation, then early intervention would provide it.

The navigator encouraged the family to go ahead and request the ASD evaluation and they did so. Then the child was scheduled for the clinical services team evaluation which happened at 30 months of age, a year after the child first presented with delay, and at that time the child was diagnosed with ASD. The navigator also attended the clinical services team evaluation. At that visit, the case manager and evaluator wanted to explain the results or the next steps They arranged for an interpreter because mom spoke only Spanish, but the interpreter was late and mom became anxious because she had to leave for work, was worried about losing her job, so the navigator interpreted for her to learn the results of the evaluation. The case manager did provide mom with information about what services were available for the child but didn't explain why those services were needed and what they would consist of. The navigator was able to help mom understand what the services were and why they were recommended. The mom also needed a lot of emotional support at this point for the diagnosis of ASD.

The child then began in-home early intervention therapies, including ASD specific services and began to show good progress.

That's an example of a family -- this was an engaged mom who was concerned about her child and brought him in consistently for care and raised concerns throughout and just couldn't seem to get the assistance that she needed for a timely diagnosis and treatment.

Next slide, please. Just to sort of give an idea of where we are, among those children who were referred for evaluation, about 1/3 of those have completed an ASD evaluation. The majority of those, not all but most, were ASD positive. All of those children are engaged in early intervention services. Another 1/4 of those families who consented to navigation, they're in the process of scheduling and completing the evaluation. But even families who have successfully been referred and who are interested in having navigation don't necessarily proceed with that process. About 20% aged out before the evaluation could be scheduled. Those would be cases where there was a lot of difficulty scheduling the evaluation and the child eventually reached an age where they could no longer be eligible for Part C. Some families also moved away before they could obtain the ASD evaluation. Then there was a portion of families who were referred and were working with a navigator but decided not to proceed with the ASD evaluation. In some cases, they changed their mind or they had spoken with, for example, their husband or their mother who felt the child didn't have a problem. They didn't proceed with evaluation.

Next slide, please. Preliminary conclusions to date, low-income, minority families whose children screened positive for ASD experienced multiple different system and family barriers to accessing diagnostic evaluation and services. Autism patient navigators can successfully reach and engage at least some of these families and provide a wide range of assistance to them, helping to guide them through and around all the barriers that they encounter to timely diagnosis and treatment. They can also work to improve systems for ASD screening, referral, and evaluation by working within the system and across different agencies. However, as I said, even with navigation assistance, it still remains true that many children identified as being at risk for ASD

don't get the referral or linkage to services.

I wanted to acknowledge our funders -- Health Resources and Services Administration for their support for this study.

Next slide, please. Thank you. Any questions? >> Thanks. We do have a couple questions in the bank. Folks who do have questions, feel free to put it in the chat box. One question was, why have you used M-CHAT? Have you considered any other screening instruments?

>> Carolyn: So, the decision to implement the M-CHAT was made at Denver Health. That was not our decision. We built the study around the existing autism screening system that was in place or that was being in the process of being put in place at Denver Health. I will say that in one of the clinics they are doing a study to examine different screening instruments in a population that includes more than half of families who are immigrants. They are working on seeing whether other instruments might be more effective for them. But we, as I said, used the M-CHAT because that's what Denver Health had chosen.

>> What did the ASD eval consist of? Was it free?

>> Carolyn: The ASD evaluation was free, and it's conducted by clinical psychologists who've been trained to do standardized testing of ADOS and ADIR. It's implemented in the home. The evaluator comes to the home and conducts the evaluation. Then a team -- I don't know the details of the team, I'm afraid, but then a team then reviews the results and makes a diagnosis.

>> Did you only study Hispanic families or were there other ethnicities looked at? >> Carolyn: We did not only study Hispanic families. There's a slide about halfway back if you want to go back and look at it later. Among the families that were randomly allocated, about 60% were Hispanic. I don't have it right in front of me, but I think about 40% were African-American or other races. Almost none were non-Hispanic white. That was quite uncommon.

>> A lot of people are asking -- I'm just giving everyone an equal opportunity. Whoever has extra questions, I'll ask them. Are you worried that requiring M-CHAT is showing too many false positives?

>> Carolyn: Yeah, that's an interesting question. You're talking about at the very end, the 29% were negative for ASD and the 71% were positive? I assume that's what she's talking about. I think that is an issue. All of those families had some kind of developmental disability or disorder or delay and were eligible, even the ones who didn't have the positive ASD. It is a little difficult to make a lot of conclusion from that because the numbers are fairly small. We'll have hopefully more children, although it will still be fairly small numbers, and those percentages could shift quite a bit because, as I said, the numbers are quite small. I think that is potentially an issue. The M-CHAT does have a lot of false positives. That's one of the reasons the follow-up interview was developed, to reduce false positives at the initial stage. I think we need larger numbers to decide if it is a big problem here.

>> Were the ASD evaluations conducted in Spanish?

>> Carolyn: Not necessarily. They don't necessarily have -- I will say the team had turnover in staff. Some of the team were Spanish speakers and some were not and were done through interpretation. Not with a -- a navigator wouldn't have interpreted those. They would have brought the interpreter with them. That was the goal, but it

wasn't possible in all cases I don't think.

>> Can you provide a description of patient navigation process?

>> Carolyn: So, most of the navigation -- well, I think I understand beyond what I already outlined. Most of the navigation was actually provided over the telephone where the navigator would reach out to the family initially, would help with scheduling by contacting, say, Rocky Mountain Human Services or going back to the Denver Health to get new referrals. A lot of the information was provided over the telephone as well as the information about insurance. Resources would have been provided through Denver Health. In those cases, the mom might come in to obtain the resources or occasionally the navigator would make home visits. Then she attended a lot of the evaluations, so that was an opportunity to interact on a personal basis with the families. I'm not sure if that covers everything. I had already outlined the general kinds of things she did, but I think they're asking about the sort of process.

>> Can you give the contact information for the person doing the study with immigrant families and other screening tools?

>> Carolyn: Yeah, I can't do it off the top of my head, but I can send it to you later. I can't think of her name off the top of my head. I'll have to send it to you later.

>> Okay. Are there ABA treatment services available as part of the EI services? >> Carolyn: Corey, can you help with that? I think the answer is yes, but I'm not positive.

>> I'm going to unmute you, Corey. Give me one second. All right.

>> Yes. Early intervention Colorado Part C does support ABA services. There's not enough providers for what all families want, but it is available.

>> Carolyn: Thanks. Maybe you should keep her off mute in case she can add to anything. Corey knows that system better than I do.

>> Another question, is the APN a reimbursable service? What is your plan for sustainability beyond the grant?

>> Carolyn: Yeah, that is a great question. Denver Health does employ patient navigators in the pediatric clinics. Currently, the usual navigators are not trained in the autism aspects, but they have received all the other training. We have discussed whether we could just train the rest of their navigators who normally do other activities as well to also be able to effectively navigate for autism. We have definitely

established a plan going forward. We have improved capacity in the system generally in terms of lots and lots of education about autism and M-CHAT and what happens afterwards, but obviously, we would like it if it could be carried forward.

>> Do you have a ways -- is there a long wait for the families to get into the diagnostic clinic?

>> Carolyn: If you mean the normal process, if they were, say, referred to, say, JFK Partners or Children's, yes, those wait lists are quite long. The wait for referral through early intervention Services Part C is shorter.

Corey, you can disagree with that, but I think it is shorter in that case. >> Yeah, I think it is.

>> Also, are the navigators also parents of children with autism or developmental disabilities?

>> Carolyn: No. Neither of our navigators were. They were both research -- one was a research nurse and one had been a physician in Mexico. They are clinicians and

researchers but not parents of affected children. Some of the collaborators were, like Jeanette Cordova at El Grupa VIDA.

>> I don't know if you want to wrap things up.

>> Thank you so much for this very informative and very compelling webinar. I address my comments in somebody who works very similarly, but we have a population that is about 20% of what you have and had almost the exact same findings, which leads us to think broad-based with part C linkages how we close the disparities we see over and over again. I thank you so much for this webinar.

I'm going to close by saying stay tuned for our next webinar in May, fourth Tuesday, at 4:00. I ask you to please pull out the evaluations. That will pop up. Thank you.

>> Thank you.

>> Carolyn: Thank you. (Webinar Ends).