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Feasibility, Acceptability, and Clinical Utility of the EHCI Diagnostic Odyssey Interview for Spanish-speaking Latinx families of children with autism spectrum disorder

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Abstract

Feasibility, Acceptability, and Clinical Utility of the EHCI Diagnostic Odyssey Interview for Spanish-speaking Latinx families of children with autism spectrum disorder
By Adriana I. Mendez

Journeys towards an autism spectrum disorder (ASD) diagnosis can be longer and more complex for families of marginalized backgrounds, like Spanish-speaking Latinx families. Long journeys, or delays to diagnosis are consequential and risk sub-optimal outcomes in children with ASD who experience them. For Latinx families, disparities in access to ASD diagnostic services, a required eligibility criterion for ASD-specific intervention services in many US states, have been well-documented. However, these journeys have not yet been studied systematically. Here, we use a mixed-methods approach to examine the feasibility, acceptability, and clinical utility of a novel tool --a Diagnostic Odyssey Interview instrument modeled on the Event History Calendar Interview (EHCI) method-- that examines the journeys of Spanish-speaking Latinx parents systematically. Preliminary results indicate that this tool is acceptable to the Spanish-speaking Latinx community and feasible to implement in studies probing stakeholders' experiences in this domain. Results also open new lines of inquiry on specific factors likely to pose greater risk for longer diagnostic journeys. These include visits to 3 of more providers between the time parents first become concerned about their child's behavior and when the child is diagnosed, and encountering pediatricians who do not take parental concerns seriously. Together, these findings indicate that the Diagnostic Odyssey EHCI is a robust tool for the study of diagnostic journeys in this population.

Feasibility, Acceptability, and Clinical Utility of the EHCI Diagnostic Odyssey Interview for Spanish-speaking Latinx families of children with autism spectrum disorder

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For children with ASD, access to early and intensive intervention is associated with developmental gains immediately and later in life (Remington et al., 2007; Rogers et al., 2021, Volkmar, 2014). Early intervention is associated with gains in social communication, adaptive skills, IQ, and educational placement early on, subsequently supporting greater quality of life, vocational opportunities, and independence. Although general services provided by early intervention systems can support the developmental trajectories of young children with ASD before a diagnosis, obtaining an ASD diagnosis is necessary to access ASD-specific, evidence-based intervention optimizing treatment in core areas of disability, particularly language and social communication.

Unfortunately, access to early detection and intervention is not equitable. Families from structurally marginalized backgrounds face increased barriers to care based on race, ethnicity, socio-economic status, English-language fluency, and geographic location (Constantino et al., 2020; Bishop-Fitzpatrick & Kind, 2017; Zuckerman et al., 2014). The intersection of these factors is common and further exacerbates access to services. For example, families of a child with ASD who identify with more than one marginalized background (e.g., African American and low socioeconomic status, SES) are at even greater disadvantage in accessing care and at greater risk to experiencing poor outcomes. Crucially, autism service inequities have consequences. Families who face these barriers risk sub-optimal outcomes for their children and increased mental health issues for the parents (Bishop-Fitzpatrick & Kind, 2017; Gabra, et al., 2021).

Health disparities in Latinx families of children with ASD

The Latinx population in the U.S. the is the largest minority population and is fast growing, surpassing 60 million in 2020 (U.S. Census Bureau, 2020). Simultaneously, the

prevalence rate of ASD diagnoses has also increased over consecutive CDC surveillance cohorts growing from 16.8 per 1000 in the 2014 cohort, to 23 per 1000 in the 2018 cohort (Baio et al., 2018; Maenner et al., 2020; Maenner et al., 2021) thanks to improved community ascertainment. Despite this upward trend in ascertained prevalence for 8-year-old CDC cohorts, Latinx families experience significant inequities in early detection and intervention. Prevalence rates for ASD are often used to document disparities in identification, as the true incidence of ASD should not be mediated by sociodemographic factors like race, ethnicity, and SES given its strongly genetic base (Constantino et al., 2020). And yet, in the CDC eight-year-old cohorts, prevalence rates do vary by race and ethnicity. In Georgia, the CDC reports a prevalence rate of 11.4 per 1000 in Latinx children, 24 per 1000 in Black children, and 23.3 per 1000 in White children (Maenner et al., 2021). These prevalence rates suggest that current systems in Georgia fail to ascertain young Latinx children even during school-age years, thus being even more likely, than the national average, to miss early identification of children from this community. And yet, despite these stark differences in prevalence rates, factors accounting for these disparities are not fully known. For example, considering data from all CDC screening sites in the U.S., differences in prevalence rates do not differ by race or ethnicity (Maenner et al., 2021). Therefore, it is possible that while some efforts have improved health inequity in some areas or to some populations, sustained efforts are needed to do so in others.

Given this context, within-population differences are important areas for further investigation. As an example in regard to the Latinx community, research has documented how English-language proficiency can drastically affect the disparities that these families experience. A 2015 study reported a difference in the prevalence rate of ASD for Latinx families depending on their level of English proficiency: those who spoke English had an estimated prevalence of

14.1 per 1000 while the prevalence rate for those who spoke Spanish was 5.2 per 1000 (Jo et al., 2015). It is then likely that English proficiency status plays an important role in accessing diagnostic services. Moreover, Latinx families with limited-English proficiency face increase barriers to service utilization even when access is attained. For example, they are more likely to report low trust in providers and less knowledge about autism than those who are proficient in English (Zuckerman et al., 2017). Such distrust does not occur in a cultural vacuum and context to the primary care experience of the Latinx community may show potential differences in how pediatricians respond to developmental concerns in this population. Although the American Academy of Pediatrics (AAP) recommends both general developmental and ASD-specific screening to occur in pediatric care for all children, only 10% of pediatric primary care physicians offered such screeners in Spanish (Zuckerman et al., 2013). Also, in pediatric primary care, children who are non-English speakers are less likely to be referred to early intervention or an ASD evaluation despite meeting criteria for concerns on early screening compared to English-only speakers (Wallis et al., 2020).

In addition to barriers in obtaining an ASD diagnosis, once obtained, families from the Latinx community also experience barriers and disparities in treatment access. For example, families report difficulties in communicating with their providers, more unmet service needs, and fewer specialty services (Magaña et al., 2013). Disparities are also documented in service utilization within the school system, a federal mandate prescribed by the Individuals with Disabilities Education Act (IDEA), Part B services. Spanish-speaking Latinx families receive less hours of Part B special education services when compared to English-speaking families. For older children, individualized education plan (IEP) goals differ by population too. Spanish-

speaking children are less likely to have goals in social and communication skills goals listed in their IEPs (Amant et al., 2017).

Finally, the Spanish-speaking Latinx population also faces barriers to entry into research, with many research protocols excluding participants who do not speak English (Frayne et al., 1996). Under-representation in research signifies that these communities are then less likely to benefit from advances resulting from new scientific advances in the field. Researchers are not operating in isolation here, as IRBs are often unclear in their definition of, and protocols for inclusion of subjects who do not speak English (Resnik & Jones, 2006). In addition, there exists a lack of validated measures and tools for this population and limited bilingual research staff to support these families in participation. This litany of adverse conditions creates a circular problem: research that has improved these systems for early diagnosis and intervention for other groups is not designed to do so for Spanish-speaking Latinx families, and these families are then at risk to be abandoned by this system, further risking suboptimal outcomes for these children.

In summary, Latinx families of children with ASD face unique and exacerbated barriers to accessing diagnostic and intervention services, and these barriers constitute a crucial health inequity. Documenting such disparities in accessing an ASD diagnosis and early intervention should help clinicians and researchers to outline areas in need of improvement along this journey to diagnosis and treatment. Given the complexity of the systems that serve children with ASD and the structural barriers and apparent discrimination experienced by the Latinx community, diagnostic journeys are likely to be complex and non-linear. However, precise documentation and study of these diagnostic journeys have not been topics of systematic study. Many researchers rely on qualitative accounts of diagnostic journeys (Zuckerman et al., 2015), which, although useful in illuminating the rich individual variability in these experiences, have

limitations in analytical power and generalizability. Aggregation of data, collected systematically, from many families, and codified according to standardized and well-validated procedures, is likely to yield a deeper, more nuanced, and more easily operationalized understanding of different, actionable factors impacting the diagnostic journey experienced by families originating from different communities.

Present Study

The present study adds to the concerted efforts underway to understand the health disparities experienced by Spanish-speaking Latinx families by piloting the use of an interview that systematically documents their diagnostic journey. The EHCI Diagnostic Odyssey utilizes the event history calendar interview (EHCI) model to probe barriers to care and is designed to minimize caregiver misremembering (Abbacchi et al., 2017). This interview has been previously used to document delays to diagnosis in African American children with ASD (Constantino et al., 2020), but has not been used in Spanish-speaking populations to date.

To address this gap, a mixed-methods approach was used to examine the feasibility, acceptability, and utility of the EHCI Diagnostic Odyssey, which systematically documents the diagnostic journey of Spanish-speaking Latinx families of children with ASD. The goals of this study were to: 1) examine the acceptability and feasibility of asking Spanish-speaking Latinx families to complete an in-depth interview on the diagnostic journey their family underwent to attain a clinical diagnosis of ASD for their child; (2) quantify this community's diagnostic journey and evaluate factors that may pose a risk for more lengthy and difficult journeys – thus probing the utility of this novel instrument.

Methods

The present study was approved by the Children's Healthcare of Atlanta Institutional Review Board. Spanish-speaking Latinx families who were seen for a diagnostic evaluation at a large, university-affiliated ASD clinic were contacted for participation. Only those who made use of a Spanish-language interpreter during their visit were recruited. If families did not answer the initial call, they were called only one additional time. Enrollment data were gathered at this stage which included number of families called, spoken to, and ultimately enrolled. Those that expressed interest in participating underwent the EHCI Diagnostic Odyssey interview in Spanish and were later asked debriefing questions to assess the feasibility and acceptability of the interview. All interviews were conducted via phone call and interviews lasted 42 minutes on average. The final sample consisted of 20 Spanish-speaking Latinx mothers of children who were diagnosed with ASD. Lastly, data from the children's diagnostic evaluation were extracted from the electronic medical records. All participants were compensated for study participation. See Table 1 for summary of sample sociodemographic characteristics.

This study included qualitative and quantitative methods to evaluate the proposed aims. The qualitative methods focused on feasibility and acceptability of the interview. Proctor and colleagues (2011) previously defined these terms, and these definitions were used for the conceptualization of study design. Acceptability is defined as the perspective of the implementation stakeholders, or the participating families, and comprises how the interview is seen as agreeable, palatable, or satisfactory. On the other hand, feasibility includes the perspective of the implementer, and is defined as the extent to which the interview was successfully used in a given setting.

Measures

EHCI Diagnostic Odyssey. The EHCI Diagnostic Odyssey Interview (Abbacchi et al., 2017) is a semi-structured interview aimed at gathering detailed information about a family's diagnostic journey while also minimizing misremembering. Questions probe the domains of accessing quality services, delay in accessing services, perceived barriers to care, and service seeking experiences. The interview contains 9 pre-interview questions that may be filled out either prior to the interview or at the start. Additionally, there are several non-interview related questions that probe the participants' memory around the time of concern by asking about any child's birthday parties or other family events that may aid in remembering that period of time. Finally, the interview itself contains 63 questions with potential additions depending on certain responses. For example, if a child did not receive early intervention or special education services as their first line of services, the interview will ask parents to confirm this wasn't the case. Questions vary from multiple choice to free response. The interview protocol includes multiple check points that ask caregivers to confirm their answers and contains questions that ascertain the interviewer's confidence in the interviewee's accuracy and reliability. The EHCI interview was translated to Spanish and back-translated to English to ensure correct translation.

Feasibility and Acceptability. Feasibility and acceptability were assessed in two ways. First via enrollment and retention data (see Figure 1). Additionally, debriefing questions probed the participants' perspective on the interview questions, their comfort level answering questions, and the applicability of the questions to their experience. Specifically, the debriefing questions asked (1) whether the interview lacked any questions that tapped into their experience, (2) how the interviewee felt about sharing their information with the interviewer, and (3) how applicable were the questions to the interviewees experience.

Clinical Assessment Data. Diagnostic visits usually comprise three areas of inquiry: cognitive ability, adaptive ability, and level and severity of autism features. These data were extracted from each child's medical record. Cognitive ability was measured through the Differential Ability Scales – II (DAS-II) and the Mullen Scales of Early Learning (MSEL). Adaptive ability was measured through the Adaptive Behavior Systems – II (ABAS-II) and autistic features were measured through the Childhood Autism Rating Scales – 2nd Edition (CARS). These data were used to explore whether certain clinical features risk longer journeys than others.

Analytic Approach

Interview answers are coded on the interview protocol and the interviewer noted these during the calls. Additionally, a worksheet at the end of the interview protocol allows the interviewer to write the timeline of each family' journey. Interview and clinical assessment data were combined, and subsequent data analyses were run in R. An important variable, the concern-to-diagnosis gap, was calculated during data analysis to quantify the delay between the time parents first became concerned about their child's development and when they received a diagnostic evaluation for ASD. Age of first parental concern was subtracted from age of diagnosis. Both of these ages were reported by the parent and age of diagnosis was corroborated by cross-checking the answer with the medical record.

Results

Qualitative

Feasibility. Recruitment efforts were coded and analyzed to examine acceptability of this instrument in this population. Overall, of the eligible individuals who heard about the study, 51% completed the study procedure. Ten eligible participants were not interested in participating in

the study and reasons for declining participation included: resentment towards the research institution, child's diagnosis being too recent to talk about, lack of time for interview, being currently sick with COVID-19, being unsure about ability to answer questions, not wanting to share personal information, and a general disinterest in participating. Furthermore, an additional two individuals changed their minds and withdrew during the consent processes because they were not comfortable with the description of minimal risk (i.e., the minimal risk of breach of confidentiality was uncomfortable). See Figure 1 for flow chart depicting the recruitment efforts in detail. All interviews were conducted over the phone. Every interview was fully completed, and interview length ranged from 27 minutes to 68 minutes (*M*= 42 minutes*, SD*= 11.128*)*.

Acceptability. All 20 participants answered debriefing questions that asked whether they felt the interview lacked certain questions, how they felt about sharing the information with the study staff, and how applicable the questions were to their personal experiences. Five participants wished the interview asked questions about what happened to their family after the diagnosis. All other participants endorsed the fact that the interview questions were complete. All participants shared they felt comfortable sharing their experiences with the study staff and all felt the interview questions were applicable to their personal experiences.

Quantitative

Delays to Diagnosis. Interviewees indicated the age at which they first began to feel concerns about their child's development and reasons for concerns. Domains of concern included: speech, speech + diminished eye-contract, play, social withdrawal, social withdrawal + diminished eye-contact, general developmental regression, self-injurious behaviors, and motor delays. The concern-to-diagnosis gap illustrated the months that it took caregivers to acquire a diagnosis after they noticed concerns about their child's development. The concern-to-diagnosis

gap ranged from 5 months to 46 months (*M* =20.35, *SD*=10.90). The median age of diagnosis was 36 months and ranged from 24 months to 65 months. Although most mothers (65%) were first concerned about their child's speech, domain of concern was not associated with the concern-to-diagnosis gap or age of diagnosis. Lastly, most families (50%) reported needing to visit 3-5 providers before being referred to and attend a diagnostic evaluation. Those who reported needing to see 3 or more providers had a marginally longer concern-to-diagnosis gap (*M* = 22.55 months, *SD* = 9.616) than those who saw 0 – 2 providers (*M*=17.67 months, *SD* = 12.339) though a t-test did not reveal a statistically significant difference, t(14.97) = -0.970, *p* = .348.

Barriers to Diagnosis. Furthermore, various measures of barriers to diagnoses were gathered. Variables of interest that constituted barriers to accessing diagnosis included: difficulties with wait times, perceived language barriers, access to an evaluation in one's area, availability of transportation, needing to decrease work hours to satisfy child's needs, needing to stop working completely to satisfy child's needs, and perceived lack of knowledge about ASD. Overall, participants endorsed an average of 2.1 barriers with a maximum of 4 barriers. Additionally, 22% of participants endorsed that their pediatricians did not take their developmental concerns seriously. Although their concern-to-diagnosis gap was marginally higher (*M* = 22.72 months, *SD* = 11.628*)* than those who did not endorse this item *(M* = 17.44 months*, SD* = 9.812*),* a t-test did not reveal a statistically significant difference, t(17.96) = -1.10, *p* = 0.285. Additionally, when asked if there were providers who inspired less confidence than others, 45% of interviewees reported that their pediatrician inspired less confidence than did their clinical psychologist or therapist.

Clinical Assessment Data. Despite the small sample size, we ran Pearson correlations to examine the feasibility of examining associations between the concern-to-diagnosis gap and various assessment data. The MSEL results were excluded from analyses because scores were extremely limited in range. Additionally, one child's ABAS-II scores were excluded from analyses because the assessment clinician noted the parent-reported adaptive scores were not illustrative of the child at time of assessment. For the DAS-II and ABAS-II assessments, higher scores signify less impairment in the respective area. For the CARS assessment, higher scores signify more autistic features. There were negative correlations between concern-to-diagnosis gap and autistic features, cognitive ability, and adaptive ability though these were not statistically significant (r = -0.251, p = 0.287, r = -0.582, p = 0.096; r = -0.19, p = 0.473, respectively). See Figure 2 for correlation plots.

Discussion

The present study examined the diagnostic journeys of Spanish-speaking Latinx families of children with ASD using the EHCI Diagnostic Odyssey Interview. The feasibility, acceptability, and utility of this interview were probed using a mixed-methods approach. The EHCI Diagnostic Interview was deemed to be feasible by the implementers. Not only was time needed to administer relatively short, but the mode of implementation worked without any technical difficulties. Eligible community members were willing to participate and there was about a 2:1 ratio between eligible participants who declined participation versus those who were willing to. This is encouraging given that historically, this community has not been involved in research and that research in this population can be costly at times. Nonetheless, most participants understood the nature of a research study and were willing to participate despite minimal risk posed by participating. One participant declined participation because they felt

resentment towards the research institution. This participants had experienced a number of cancelled appointment from said institution and this led her to decline participation. This situation is not community-specific but worth discussing due to the possibility of it occurring in this type of research. Given that a couple families described their child's diagnosis being too recent to talk about, special consideration should be taken regarding the sensitive nature of these experiences and time it takes for them to be internalized and for families to be ready to discuss them. This tool was also deemed acceptable my the mothers who completed it. Mothers who enrolled were comfortable speaking about these experiences with the researchers and felt that the questions tapped into all aspects of their experience gaining a diagnosis.

We examined the ability for this interview to pick up on relationships between various characteristics and delays in diagnosis. Firstly, the delay from age of first concern and diagnosis was captured and was shown to be variable from family to family. Furthermore, a number of participants reported that their pediatricians – the first line of developmental screeners – did not take parental concern seriously. These parents experienced a marginally longer journey from concern to diagnosis than did parents that did not experience this, though this difference was not statistically significant. Additionally, almost half of participants found their pediatricians to inspire less confidence in them than other providers like therapists or clinical psychologists. These factors may play a role in the documented disparities in services provided by pediatricians for these communities. Prior work has shown that pediatricians are less likely to refer a non-English-speaking child to ASD diagnostic services (Wallis et al., 2020). These results may shed light on a possible mechanism by which this is occurring: pediatricians may not be seeing the developmental concerns parents are. The documented lack of available screeners for these families in pediatricians' offices may further exacerbate these issues (Zuckerman et al., 2013).

Pediatricians may be unable to corroborate parents' concerns about their child's development. These results may suggest that pediatricians' offices may be one area in which health disparities can be mitigated.

The present study also showed that this interview can capture barriers to diagnosis. Although prior work shows that language barriers are major areas of concern for non-English-speaking families, especially the Spanish-speaking-Latinx community, caregivers in this study did not report the same (Magaña et al., 2013). Only one participant indicated that language barriers were a problem during their diagnostic visit. However, all participants made use of a Spanish-language interpreter during their evaluation. It may be the case that Spanish-language interpreter limit language barriers that may be present in parents who do not speak English. Meanwhile, the most consistently reported problem in accessing diagnostic services was long wait times. Although all these parents did eventually receive the services, wait times were a significant problem. Limiting these wait times may be particularly beneficial to these families. Furthermore, increasing parent knowledge about autism may further help these families gain the knowledge they need to establish a course of action.

Examining factors that may be associated with delays to diagnosis in the assessment room are important, though this study was not specifically designed to do robustly this given the limited sample size. However, we were able to capture variability in the gap between concern-to-diagnosis and assessment scores in the areas of cognitive ability, adaptive ability, and autism features. Although the data trended towards the possibility that more impaired children are also experiencing longer delays to diagnosis, these results should be taken with a grain of salt. This sample was particularly impaired in cognitive and adaptive ability and all children did have an

ASD diagnosis; therefore, we may be experiencing a limited range in those domains which affect associations.

Limitations

Although this study had important findings and implications, various limitations were also present. Firstly, the sample size was small. Though the sample size is acceptable for studies of feasibility and acceptability, findings on the clinical utility of this interview should be interpreted with caution. Though intriguing results were found, the study was underpowered. Additionally, findings on cognitive ability and delays to diagnosis should be interpreted with extreme caution, as data from children who underwent the MSEL assessment were not included.

Furthermore, the study participants were all mothers of children who had eventually accessed a diagnostic evaluation at an autism-specific center in a large metropolitan city. Therefore, it is likely that the findings are not generalizable to the entire U.S. Spanish-speaking Latinx population who searches for ASD services. Especially those without access to autism-specific centers and those from more rural areas. All families also had an experienced interpreter present in their diagnostic evaluations. It is possible that not all instances of evaluations on Spanish-speaking children are benefitted with such specifically trained interpreters. It is also possible that this study suffered from bias on who ultimately participated. It is plausible that those who decided to participate were those who had a more positive experience.

Future Directions

Despite these limitations, interesting findings and multiple subsequent areas of inquiry have arisen from this study. Firstly, this study's results suggest that this instrument is feasible to administer and acceptable by the population it was administered to. However, future work may look to expand this type of inquiry to experiences that occur after a diagnosis is made. Secondly,

this study presents data on the barriers these families face, and factors that may be associated with longer delays in diagnosis – like certain pediatrician experiences. Future work should further examine these variables with a much larger sample, preferably increasingly heterogeneous in area (rural/urban) and state of residence. With a larger sample, further inquiry into factors like acculturation and utilization of state-dependent service systems would be possible. Strategies for recruitment and retention should include flexibility in contacting and scheduling as well as full transparency on study risks and benefits. Study contact person should ideally speak the language spoken by the participants, which limits need for interpreters and more direct communication between participant and study staff. Although this study only used one recruitment strategy, making phone calls to eligible participants, other strategies should be employed in the future to determine best practices. Additionally, further studying these journeys in those who had a child who did eventually receive a diagnosis and those whose child did not receive a diagnosis will allow for a broader investigation of these processes. Although additional studies are needed to further characterize the journeys of this population, our findings indicate good and robust prospects in this tool to do so.

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Table 1. Sociodemographic Data

	M(SD)	*p*
Gross household income	34023 (12024)	
Household size	4.70 (0.923)	
Maternal education level		
< 8th grade		0.15
>9th grade		0.35
Highschool Degree		0.25
College Degree or higher		0.25
Public health insurance		1

Table 2. Clinical Assessment Data

	M(SD)
Age of first concern (months)	21.10(12.199)
Age of diagnosis (months)	40.95(12.808)
General Adaptive Composite (ABAS)	67.28(16.481)
CARS Total	47.75(7.032)
General Cognitive Ability (DAS)	72.56(13.380)

Figure 1. Flow chat depicting recruitment efforts.

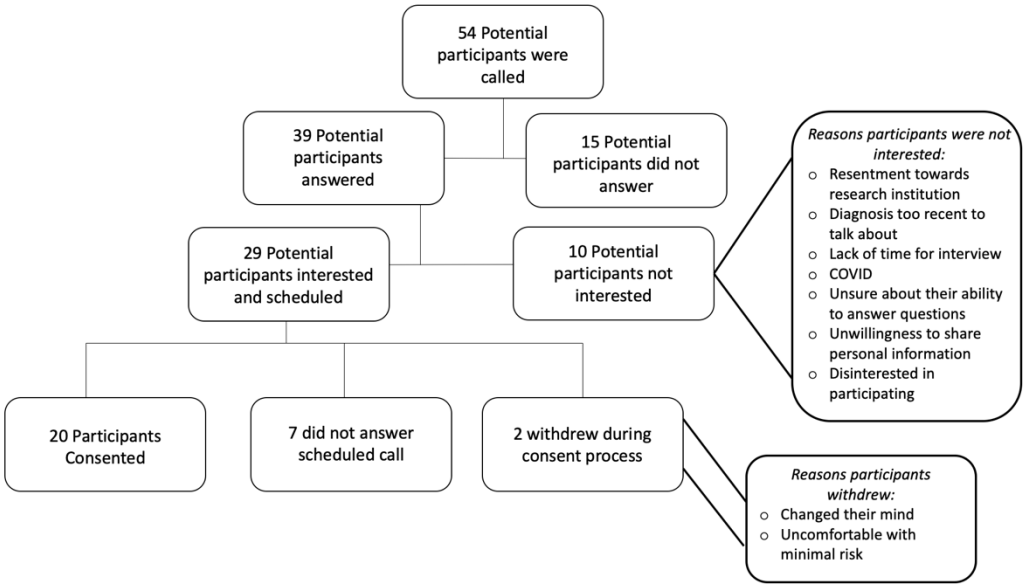
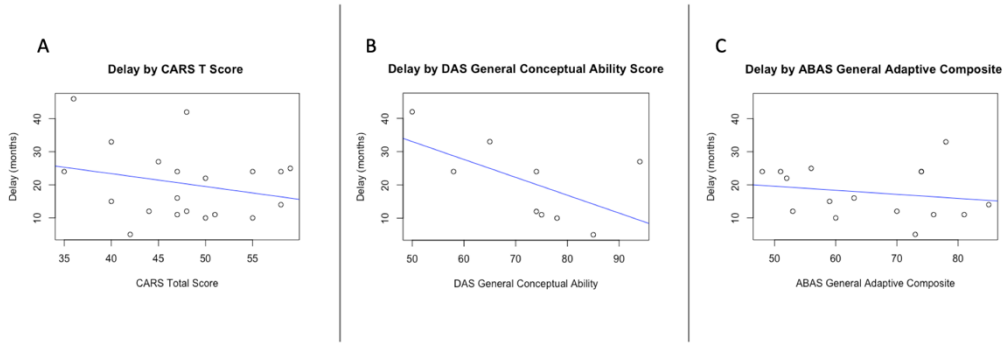


Figure 2. Correlation plots between delays in diagnosis after parental concern and various assessment measures.



(A) Pearson correlation between the concern-to-diagnosis gap (months) and autism assessment (CARS; r = -0.251, p = 0.287). (B) Pearson correlation between the concern-to-diagnosis gap (months) and cognitive assessment (DAS-II; r = -0.19, p = 0.473). (C) Pearson correlation between the concern-to-diagnosis gap (months) and adaptive behavior assessment (ABAS-II; r = -0.582, p = 0.096).