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Mohadeseh Solgi
Portland State University

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Parent Concerns Are Associated With Early Intervention Outcomes

Mohadeseh Solgi

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Thesis Adviser

Dr. Katharine Zuckerman

Portland State University

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Title: Parent Concerns Are Associated Early Intervention Evaluation and Eligibility Outcomes

Authors: Mohadeseh Solgi(1,7), Alicia Feryn MS(2), Alison E. Chavez MA(3), Laura Wilson BA(7), Margaret King MPH(4), Julie Scholz MBA(5), Eric Fombonne MD(6), Katharine E. Zuckerman MD MPH(7)

Affiliations: 1. Oregon Health & Science University - Portland State University School of Public Health, Portland, OR, USA 2. Biostatistics & Design Program, Oregon Health & Science University, Portland, OR, USA 3. Department of Psychology, University of Massachusetts Boston, Boston, MA, USA 4. Health Share of Oregon, USA 5. Oregon Pediatric Society, USA 6. Department of Psychiatry and Institute on Development and Disability, Oregon Health & Science University, Portland, OR, USA 7. Pediatrics, Div. General Pediatrics, Oregon Health & Science University, Portland, OR, USA

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Abstract:

Objective: To test the association of parents' concerns with Early Intervention (EI) developmental services outcomes including evaluation, eligibility, and enrollment in services.

Method: We collected survey data on parents' concerns and EI service use data from a sample of 428 children referred to EI in 2016-2018 from six Oregon primary care clinics serving lower income families as part of a developmental and autism spectrum disorder screening intervention. We assessed EI service use trajectories and associations of parent concern presence, age of child at time of parents' concerns, number of concerns, and type of provider concern, with EI evaluation, EI eligibility, and enrollment in EI services, using bivariate testing and multivariable logistic regression.

Results: Only 22.9% of children referred to EI were enrolled in services six months later. Children whose parents had developmental and/or behavioral concerns were more likely to receive an EI evaluation and were also more likely to be eligible for services, compared to children whose parents had no concerns. There was no association between age, number of concerns, or type of concern with EI evaluation, eligibility, or services enrollment.

Conclusion: Though only a minority of children referred to EI enroll in services, presence of parent concern is strongly associated with EI services evaluation and eligibility outcomes. Study results suggest that providers should assess the presence of parent concern when deciding on EI referrals, and provide more support to parents who are not concerned at all.

Introduction:

The early identification and treatment of developmental delays (DD) in early childhood is associated with improvement in child developmental outcomes¹. As diagnosed DDs and disabilities such as ASD (autism spectrum disorder) become increasingly prevalent², early identification becomes crucial to enabling optimal child development outcomes³. In the US, Part C Early Intervention (EI) of the Individuals with Disabilities Education Act (IDEA) provides developmental services to qualifying children up to age 3 through the educational system, free of charge to parents in most states⁴. While EI services and eligibility criteria vary by state⁵, EI has proven to be efficient in reducing the need for special education services in the future⁶. Yet, more than 37% of providers were still not using developmental screening tools in 2016 to refer children to EI services⁷.

Developmental screening is critical for diagnosis, but low referral rates and follow-up after screening also result in delayed eligibility determination and treatment⁸. Though specific estimates vary by state and local context, only a minority of children referred to EI are ever evaluated, and of those qualifying, many do not receive services^{9,10}. Despite the low rates of developmental screening and referrals, little is known about primary care level factors that influence the EI referral, evaluation and eligibility process. Patient and provider gender have been shown to correlate with provider referrals¹¹, including significant racial and ethnic disparities in ASD recognition¹². However, demographics are not the only factors that may influence EI outcomes: a 2014 survey concluded that pediatricians' EI referral behaviors were largely influenced by office processes, family preferences, and the parents' understanding of the developmental screening tool used¹³.

Parental level of concern may be an important predictor of later EI/ECSE service use. A survey of parents and providers further showed that parents may not follow up with receiving services because they may deny the existence of their child's DD, or they have little information on the benefits that EI can provide¹⁴. Among children ultimately diagnosed with ASD, parents' concerns about social communication and interaction skills have been predictive of later diagnosis¹⁵. Likewise, presence of parent ASD concern, the specific type of concern expressed by parents, and age of child when parents' concerns are expressed, can also predict EI outcomes¹⁶.

Though previous studies have addressed the relationship between parents' concerns and developmental screening¹⁷ and ASD diagnosis³, few have addressed outcomes in terms of EI eligibility and service enrollment, which are critical steps in advancing children's developmental skills. In addition, many studies that have addressed parent concerns as a factor in delayed child development, have specifically focused on ASD and/or only included children who are known to be either low-risk or high-risk¹⁸. Other studies have examined EI outcomes in terms of demographic characteristics¹⁹. To our knowledge, no studies have prospectively investigated parent developmental concerns in the primary care office setting, and their subsequent associations with EI outcomes.

The overarching goal of this project was to examine the associations of concerns with EI-related outcomes. We were interested in whether concerns (specifically the presence of a parental concern, age of child at time of parents' concerns, number and type of provider concerns), were associated with EI outcomes (evaluation, eligibility, and enrollment in services six months after referral) controlling for the effect of family socio-demographic characteristics.

Methods:

Study Design and Participants: Data for this study were collected as part of the REAL-START study²⁰. REAL-START was a quasi-experimental intervention aiming to increase PCP referrals to EI for children with ASD and DD risks by offering on-site training in developmental and ASD screening. The study lasted from 2016-2018 and was held in six Oregon primary care clinics serving many Latinx patients. Of these clinics, four were pediatric clinics and two were family medicine clinics. All clinic staff received four trainings on developmental and ASD screening, screening and referral issues for ethnically diverse and low-income families, ASD medical home, and disability services access. Primary outcomes of the larger study included rates of general developmental and ASD screening, rates of billing for screenings performed, and rates of referral to EI of children with high-risk screening results²⁰. Overall, REAL-START included 2,224 children (39% Latinx, 20% Spanish primary language) screened at well-child checks and 428 who were referred to EI.

The sample for this study included the 428 children enrolled in REAL-START who were referred to EI services by their provider. Their provider could refer them to EI for any reason, including screening test results or clinical concerns. The referral to EI was faxed by the provider to the local EI agency on a standard statewide referral form. A copy of the form was collected for study purposes. Per IDEA guidance, EI then had 45 days to contact and follow-up with parents for an evaluation {Updating}. The pathway to EI was similar for children who were referred for ASD or a DD. At the time of referral, the PCP asked the parent or caregiver (hereinafter “parent”) to complete a brief survey (see Appendix 1). This study excluded children >36 months

old, originally included within the REAL-START project, due to ineligibility for EI service use, and also excluded parents who could not complete study materials in either English or Spanish.

Ethical Approval: The study was approved by the Oregon Health and Science IRB. All parents received a study information sheet as a consent document and signed a release for their child's educational records.

Data sources:

Survey: The eleven item survey (Flesch-Kincaid reading level of 8.5) was completed by parents in the primary care clinic at the time of referral. Clinics were encouraged to provide the option of oral surveys for parents who requested one for reasons of disability, child care, or parental lower literacy. The survey contained two main sections: the first assessed parents' concerns about their child's development and the second section assessed child and family demographic characteristics. Overall parent concern at time of EI referral was assessed using an item adapted from the PEDS (Parents' Evaluation of Developmental Status) developmental screening tool: "Do you have any concerns about your child's learning, development, or behavior?" (yes/no) ²¹. If the parent was concerned, the *recency of concern* was measured by asking how old in years and months the child was at the time of first concern by the parent, or parents could choose "at birth". Subsequently, the instrument assessed *10 specific developmental concerns*, some ASD related and others non-ASD related, adapted from the 2011 Survey of Pathways to Diagnosis and Services²². Parents were asked whether they had any of the 10 concerns (e.g., "about how my child is talking or making speech sounds") and if so, the age of the child when they first had that concern (or if the concern was present since birth). The second part of the survey assessed child and parent demographic characteristics, which included the

parent's relationship to child, race and ethnicity of parent and child, parent English proficiency, and parent education²³.

Referral Form: The referral form, completed by providers, contained the following additional demographic information: child insurance type, clinic name, and the provider's reason for referral, which was classified as speech/language, gross motor, fine motor, adaptive/self-help, hearing, vision, cognitive/problem-solving, social/emotional or behavioral, or other. For sample size reasons, we collapsed these categories into "motor concerns" (including gross motor and fine motor), and "non-motor" (including adaptive/self-help, hearing, vision, cognitive/problem solving, socio-emotional or behavior, and other). In addition, the provider could specify if there was a concerning screen result. If "MCHAT [Modified Checklist for Autism in Toddlers]" was marked, then the referral was considered "positive autism screen" ²⁴.

Early Intervention Data: Through a data use agreement with the Oregon Department of Education, the study team then queried ecWeb, Oregon's online EI database, to assess the child's progress through EI²⁵. This database allowed for the tracking of outcomes starting from referral to enrollment status six months after referral date. It contains comprehensive information on all EI encounters from the moment new referral data is entered into ecWeb by EI staff until a child is discharged from EI. The study team was granted direct access to ecWeb records for all consented children and abstracted the following information from standard ecWeb data fields. A child was considered to be "evaluated by EI" if there was an evaluation date entered in ecWeb. A child was considered to be "eligible" by the placement of any EI eligibility code (e.g., DD, communication disorder) in the child case file. A child was considered to be "enrolled in services" if the child

was receiving services from the Oregon EI program six months after initial date of referral (defined by the date the referral was entered into ecWeb).

Data Analysis:

The statistical software package Stata 16²⁶ was used for all analyses. First, we merged child-level data from the survey, EI referral form, and ecWeb. Descriptive statistics assessed the proportion of EI-related outcomes (children who were evaluated, found eligible for services, and those enrolled in services 6 months after referral). A Sankey Diagram generator²⁷ was used to visually demonstrate EI-related outcomes (Figure 1). We then compared differences in the proportions of children evaluated, eligible and enrolled in services six months after referral according to child and family factors (i.e., age of child, child's sex, insurance type, race and ethnicity of child and parent, parent education, and survey respondent's relationship to the child). Associations between these child and family factors and (Table 1) EI outcomes were tested with Fisher's Exact test.

We then used multivariable logistic regression to test the association of child and family factors with EI outcomes. Models assessed the effects of child and family factors alone (Table 2). Model was adjusted for the site of data collection and study period within the REAL-START intervention.

Next we used descriptive statistics (proportions) to characterize the presence of parent concern, according to receipt of EI evaluation, eligibility, and enrollment in services six months after referral (Table 3).

To test specific parent concern characteristics, descriptive statistics (proportions) were used to characterize the child age at which the parent first became concerned, the number of

parents' concerns (from the list of 10 possible concerns), the type of provider concern (ASD or non-ASD), and the area of concern (motor, non-motor, both) (Table 4). We assessed these outcomes overall and according to receipt of EI evaluation, eligibility, and enrollment in services six months after referral (Table 4). We tested differences in proportions with Fisher's Exact test. Separate multivariable regression models were used to test the association of concern characteristics with EI outcomes.

Models (Table 3 and 4) were both adjusted for sex, clinic, adult race/English proficiency/ethnicity, child age and study period. A significance level of 0.05 was used.

Results:

Sample:

Of the 2,224 participants in the REAL-START study, this study included data from 428 children (mean age= 19.97 months [s.d. 8.43]; 63.1% boys) whose parents completed the survey. Most of the survey respondents were mothers (87.1%), who had an average education of 12th grade, and a plurality of parents identified as English speaking non-Latinx White (39.9%) (Table 1). Of the 428 children referred to EI, we excluded 16 subjects who did not have data about their EI evaluation and 167 who did not answer survey items about parents' concerns. Thus the analytic population of the parent and provider concern included 265 children with a complete survey and information about whether or not they were evaluated in EI.

EI service Enrollment:

Of the 428 children referred to EI, 238 (55.6%) were evaluated; of these, 123 (45.9%) were found eligible, and 98 (79.6% of eligible; 22.9% of all referrals) were enrolled in services

six months later. Figure 1 shows the stepwise attrition of children over time at each stage of the EI evaluation process.

Parents' concerns:

Among the 265 eligible children 93 (35.1%) did not have concerns and 172 (64.9%) did have concerns. Among those concerned, 54% of parents had more than one concern. The most frequent (54.4%) concern was "about how my child is talking or making speech sounds." Most common age of concern was between 13-24 months (50.3%). 87% of provider concerns were non-ASD related, and 77% had non-motor concerns.

Bivariate testing:

Bivariate associations were evaluated between child and family demographics and EI outcomes (Table 1). Results indicated that after the point of referral, more boys (72.8%) were evaluated than girls (72.8% vs 57.3%; $p = 0.003$; Table 1). There were no other significant associations between child and family factors with evaluation, eligibility, and enrollment in services. Next, bivariate models tested associations between presence of concern, number of concerns, age of concern, and type of concern with evaluation, eligibility, and service enrollment. In these models, children whose parents indicated developmental concerns were more likely to be evaluated in EI than children whose parents did not indicate concerns (66.9% versus 45.2%; $p=0.001$; Table 3). Likewise, of children evaluated, those whose parents were concerned were more likely to be eligible than those whose parents were not concerned (60% versus 33.3%; $p=0.004$; Table 3). There was no significant association between parent concern and enrollment in services, among children who were found eligible. Furthermore, no associations were found

between age of child at concern, number of concerns, type of provider concern and area of concern with any level of EI engagement.

Multivariable testing:

We further tested the associations between child and family demographics and EI outcomes, using multivariable logistic regression. The multivariable models adjusted for child/family demographics, site, and study period did not preserve the sex associations with EI evaluation: boys and girls were equally likely to be evaluated by EI after statistical adjustment (aOR 0.7, [CI 0.4-1.2]; Table 2). While the bivariate testing did not show any significant association between EI enrollment and child sex, the multivariable model showed a significant difference (aOR 0.1 [CI: 0.0-0.5]; Table 2). No significant associations were found between child's age and parent race and ethnicity with all levels of EI. One site was more likely to have eligibility for EI than other sites (aOR 4 [1.4-12.7]), and one site had more children evaluated in EI than others (aOR 16.5 [3.2-303.2]); however large confidence intervals suggest that these estimates were imprecise.

To understand the additional effects of parents' concerns on outcomes, we added parent concern factors to the multivariable models as a block. This multivariable model that also included concerns showed a similar pattern as the bivariate testing. This model, which included child and family socio-demographic and study period, revealed that presence of parent concern was strongly associated with evaluation (aOR 4.9 [CI: 2.4-10.6]) and eligibility (aOR 4.0 [CI: 1.6-10.9]), but not with service enrollment. However, the point estimate and the wide confidence interval for services enrollment (aOR 3.4; [CI: 0.4-44.8]) may indicate the existence of an effect which this study is insufficiently powered to detect (Table 3). The results did not support

associations between age of child at concern, number of concerns, type of provider concern and area of concern with any level of EI (Table 4).

Discussion:

In this study, we found that nearly half the children referred to EI from primary care are not evaluated, of those referred, an even smaller percentage become eligible, and even fewer are enrolled in services six months after referral. These findings corroborate previous studies⁹. There is a clear loss in the system, starting from referral to services use, suggesting that many children who potentially need services never receive them. Although this rate of attrition may seem high, it is similar to other state EI programs^{9,13}. Overall, our study extends previous research regarding parents' concerns and EI outcomes by following a child's path from referral to EI services use. While previous studies have expanded on the importance of parent concern in early diagnosis of DDs and ASD more specifically^{3,15-17}, very few have assessed how concerns may modify children's EI trajectories, from the point of referral to enrollment in services six months later.

Our study findings show that parent concern is highly predictive of whether a child will be evaluated and eligible for EI services. The mechanism by which parent concern leads to EI evaluation and enrollment in services deserves further examination. It is possible that parents who are more concerned have children who display more impairing or disruptive behaviors. It is also possible that parents who have had more exposure to EI (for example, due to another child) are more willing to share concerns with a PCP. Additionally, it is plausible that parents who are in agreement with providers regarding concerns, are more motivated to pursue services from EI. Previous studies have shown that children whose parents have concerns about their child's development tend to screen as at-risk more often²¹, but that the specific type of parent concern

did not matter; our study results suggest similar results. However, Zablotsky and colleagues found that specific types of parent concern have been associated with earlier diagnosis of ASD¹⁶. In particular, parents who are concerned about verbal communication received earlier ASD diagnosis than parents who did not have verbal parent concerns¹⁶. The study also found significant associations between timing of parent concern and outcomes: children who were younger had more parents' concerns and earlier service initiation¹⁶. We found no association between these factors and any level of EI engagement, which may reflect differences between the ASD population and children with developmental risks more broadly. The number of concerns presented by parents has also been identified as significant in association with whether a child develops mental health problems²⁸; however, our study did not identify the number of concerns as a significant association with EI outcomes. As the type of concern did not seem to be as important as presence of concern in our study, EI could consider assessing presence of parent concern as a severity marker on initial intake forms, upon intake calls with families, or creating a multi-stage screening system that takes parent concern into account, to address disparities in diagnosis¹⁹.

The study findings regarding sex and EI evaluations (on bivariate testing) and EI enrollment (on multivariable testing) are also intriguing. This result is consistent with studies done by Mesibov et al. in which parents of boys had more concerns than parents of girls, specifically regarding DDs, toileting and personality problems²⁹. It is possible that the lower rate of evaluation of girls found on bivariate testing could be related to differences in mean age at referral (girls were on average 5 months younger); however, this would not explain the multivariable differences we found in enrollment. It is also possible that girls who were referred

to EI differed in other unmeasured ways that were linked with factors in our models. For instance, some studies have shown that girls are less likely to have behaviors such as aggression than boys³⁰; perhaps sex differences in the disruptiveness of behaviors influence whether parents will seek out EI evaluation.

Our study results suggest that providers should assess the presence of parent concern and provide additional support to parents who are not concerned at all. If a parent is not concerned, providers may need to consider why parents do not share their concerns, as they may not be as motivated to follow up for their child's evaluation. For instance, parents may question the legitimacy of a provider's concern, think behavior is typical for age, think their child will catch up, lack information about expected milestones, or might share concerns but be hesitant or unable to act. These findings highlight the importance of shared decision making in conversations with parents. Similar to early identification of other issues in primary care, parents may make decisions based on motivational factors such as weighing costs and benefits, or other sociocultural considerations³¹. More research needs to be done regarding types of interventions that might be implemented when delivering developmental screening results. For instance, future studies could test different provider message types regarding EI services to understand which messages are most motivating and acceptable to diverse families. Providers may also need to be aware of sex differences in outcomes when having conversations around the development of girls.

Strengths and Limitations:

Due to the nature of the research, parents had to opt in to participate in the study. Parents who were more concerned after provider referral, may have felt more compelled to participate,

while those who had little to no concerns may not have enrolled. Likewise, all sites were participating in a developmental screening intervention and may have been particularly motivated to enroll children in EI services. As a result, our study may have overestimated the level of parent concern and subsequent service enrollment. Another limitation of this study is sample size, particularly for the services enrollment outcome, as it represented only 22.9% of the original referred sample, due to drop-off in EI participation. Similarly, not all parents (62%) responded to the “Do you have concerns about your child” portion of the survey, which limited the sample size. It is possible that studies with larger samples may have more power to detect weak associations; however, conducting such a study would be challenging since it would involve enrollment of a very large number of primary care clinics. While we measured some proxies of socio-economic status such as insurance type and parental education, we did not have any direct measures for socio-economic status which is another limitation to consider.

In addition, our survey had a relatively high reading level (8.5) which may have increased the difficulty of completion for some parents, however, most items regarding the child's developmental delays were adapted from previously validated items on nationally recognized surveys. Where possible, the survey used lower literacy levels. There may have been slightly different interpretations of the items on the Spanish version of the survey, but we did not notice any differences of EI outcomes for different racial/ethnic families. Other limitations included the site of referral. The REAL-START intervention took place in primary care clinics in Oregon; results may have varied if the sites differed in location or nature (e.g., WIC or Head Start). Even so, in Oregon and nationally, the majority of referrals to EI are initiated from health care providers, and due to the nature of the online Oregon EI system, we were able to attain

enrollment data directly from EI records. Likewise, outcomes might have varied in other states or localities where the relationship of EI with primary care, and with the school system, is different.

Conclusion:

In summary, many children referred from primary care to EI are never evaluated or enrolled in services. Our study found that parent concern was highly associated with EI evaluation and eligibility, however, it is important to note that these findings cannot be used as an indicator of developmental risk and do not have clinical implications. Findings do suggest that a deeper discussion of parents' concerns may help reduce attrition in the process between EI referral and enrollment in services.

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Table 1: Sample Characteristics and bivariate analysis; associations between child and family factors and EI outcomes.

English Proficiency (EP)

* P-value < 0.05

| | Evaluated Total (n) and (%) | P-value* | Eligible Total (n) and (%) | P-value* | Enrollment (n) and (%) | P-value* |
|--|------------------------------------|-----------------|-----------------------------------|-----------------|-------------------------------|-----------------|
| Participant (All) | 428 (55.6%) | | 238 (51.7%) | | 123 (79.7%) | |
| Age (months) | 358 | 0.09 | 238 | 0.14 | 123 | 0.82 |
| 0-12 | 91 (57.1%) | | 52 (40.4%) | | 21 (85.71%) | |
| 13-24 | 181 (69.1%) | | 125 (56.8%) | | 71 (78.9%) | |
| 25-36 | 86 (70.9%) | | 61 (50.8%) | | 31 (77.4%) | |
| Sex | 355 | 0.003* | 238 | 0.07 | 123 | 0.21 |
| Male | 224 (72.8%) | | 163 (55.8%) | | 91 (82.4%) | |
| Female | 131 (57.3%) | | 75 (42.7%) | | 32 (71.9%) | |
| Insurance Type | 357 | 0.40 | 230 | 0.80 | 120 | 0.40 |
| Public | 238 (67.2%) | | 160 (51.3%) | | 82 (75.6%) | |
| Private | 109 (58.7%) | | 64 (54.7%) | | 35 (86.7%) | |
| Uninsured | 8 (62.5%) | | 5 (60.0%) | | 3 (100.0%) | |
| Other | 2 (50.0%) | | 1 (0.0%) | | 0 (NA) | |
| Race & Ethnicity | 329 | 0.76 | 191 | 0.39 | 102 | 0.91 |
| Non-Latinx, White | 115 (59.1%) | | 68 (60.3%) | | 41 (80.5%) | |
| Latinx, Any Race | 179 (57.5%) | | 103 (48.5%) | | 50 (76.0%) | |
| Non-Latinx, Other Race | 30 (53.3%) | | 16 (50.0%) | | 8 (75.0%) | |
| Non-Latinx, Race not Specified | 5 (80.0%) | | 4 (75.0%) | | 3 (100.0%) | |
| Parental Education (years) | 318 | 0.52 | 183 | 0.68 | 98 | 0.97 |
| <12 | 90 (53.3%) | | 48 (60.4%) | | 29 (79.3%) | |
| 12-13 | 123 (56.1%) | | 69 (52.2%) | | 36 (80.6%) | |
| 14-15 | 39 (66.7%) | | 26 (46.2%) | | 12 (75.0%) | |
| >16 | 66 (60.6%) | | 40 (52.5%) | | 21 (81.0%) | |
| Relationship to Child | 341 | 0.87 | 197 | 0.53 | 104 | 0.28 |
| Mother | 297 (57.6%) | | 171 (46.2%) | | 92 (80.4%) | |
| Other | 44 (59.1%) | | 26 (53.8%) | | 12 (66.7%) | |
| Parent Race, Ethnicity, English Proficiency | 321 | 0.24 | 186 | 0.49 | 97 | 0.78 |
| Non-latinx, White, EP | 128 (59.4%) | | 76 (57.9%) | | 44 (81.8%) | |
| Latinx, Any Race, EP | 70 (55.7%) | | 39 (48.7%) | | 19 (84.2%) | |
| Latinx, Any Race, Limited | 102 (61.8%) | | 63 (46.0%) | | 29 (72.4%) | |
| Non-latinx, Other Race, EP | 21 (38.1%) | | 8 (62.5%) | | 5 (80.0%) | |

Table 2: Multivariable logistic regression; association of family factors with EI outcomes English Proficiency (EP), Odds Regression (OR), Confidence Interval (CI)

* p<0.05

Adjusted for site and study period

| | Evaluation OR (95% CI) (n=269) | Eligible OR (95% CI) (n=186) | Enrollment OR (95% CI) (n=97) |
|--|---------------------------------------|-------------------------------------|--------------------------------------|
| Child Age | | | |
| 0-12 months | ref | ref | ref |
| 13-24 months | 1.7 (0.9-3.4) | 2.3 (1-5.4) | 0.1* (0-0.7) |
| 25-36 months | 1.9 (0.8-4.6) | 1.8 (0.7-5.1) | 0.1* (0-0.7) |
| Child Sex | | | |
| Male | ref | ref | ref |
| Female | 0.7 (0.4-1.2) | 0.7 (0.3-1.4) | 0.1* (0-0.5) |
| Parent Race, Ethnicity, English Proficiency | | | |
| Non-latinx, White, EP | ref | ref | ref |
| Latinx, Any Race, EP | 1.3 (0.6-2.8) | 0.7 (0.3-1.6) | 1.5 (0.3-9.5) |
| Latinx, Any Race, Limited | 2 (0.9-4.2) | 0.5 (0.2-1.1) | 0.6 (0.1-3.2) |
| Non-latinx, Other Race, EP | 0.7 (0.2-2.3) | 2.7 (0.5-16.1) | 0.8 (0-32) |

Table 3: Associations of parent concern presence and EI outcomes
Odds Regression (OR), Confidence Interval (CI)

* p<0.05

Adjusted for sex, clinic, adult race/english proficiency/ethnicity, child age, study period

Subject numbers differed due to item level non-response

| Parent Concern | Evaluated Total (n) and (%) (n=265) | P-value* | Evaluation OR (95% CI) (n=211) | Eligible Total (n) and (%) n=157 | P-value* | Eligible OR (95% CI) (n=148) | Enrollment Total (n) and(%) n=83 | P-value* | Enrollment OR (95% CI) (n=79) |
|----------------|-------------------------------------|----------|--------------------------------|----------------------------------|----------|------------------------------|----------------------------------|----------|-------------------------------|
| | | 0.001 | | | 0.004 | | | 0.17 | |
| Yes | 172 (66.9%) | | ref | 115 (60.0%) | | ref | 69 (81.2%) | | ref |
| No | 93 (45.2%) | | 4.9* (2.4-10.6) | 42 (33.3%) | | 4.0* (1.6-10.9) | 14 (64.3%) | | 3.7(0.4-44.8) |

Table 4: Associations of EI outcomes with concern characteristics among parents who were concerned Modified Checklist for Autism in Toddlers(mCHAT), Gross Motor (GM), Fine Motor (FM)

* p-value <0.05

Adjusted for sex, clinic, adult race/english proficiency/ethnicity, child age, study period

Subject numbers differed due to item level non-response

| Among Concerned | Evaluated (n and (%)) n=172 | P-value* | Evaluation OR (95% CI) (n=114) | Eligible Total (n and (%)) (n=115) | P-value* | Eligible OR (95% CI)(n=93) | Enrollment Total (n and(%)) (n=69) | P-value* | Enrollment OR (95%) (n=54) |
|--------------------------------|--------------------------------|----------|--------------------------------|------------------------------------|----------|----------------------------|------------------------------------|----------|----------------------------|
| Age of Concern (months) | 153 | 0.12 | | 104 | 0.42 | | 62 | 0.84 | |
| 0-12 | 62 (72.6%) | | ref | 45 (60.0%) | | ref | 27 (77.8%) | | ref |
| 13-24 | 77 (68.8%) | | 0.8 (0.1-4.4) | 53 (62.3%) | | [0.5 (0.1-2.1)] | 33 (81.8%) | | [0.1 (0-7.6)] |
| 25-36 | 14 (42.9%) | | 0.3 (0-5) | 6 (33.3%) | | [0.4(0-4.4)] | 2 (100.0%) | | NA |
| Number of Concerns | 157 | 1.00 | | 107 | 0.08 | | 63 | 1.00 | |
| 1 | 72 (68.1%) | | ref | 49 (49.0%) | | ref | 24 (79.2%) | | ref |
| >1 | 85 (68.2%) | | 1.1 (0.4-3.7) | 58 (67.2%) | | [1.7 (0.6-4.9)] | 39 (82.1%) | | [20.5 (0.3-37203.9)] |
| Provider Concern | 147 | 0.56 | | 115 | 0.16 | | 69 | 1.00 | |
| Autism Related (mCHAT) | 19 (73.7%) | | ref | 14 (78.6%) | | ref | 11 (81.8%) | | ref |
| Not Autism Related | 128 (78.9%) | | 1.5 (0.2-11.1) | 101 (57.4%) | | [1.1 (0.2-8.1)] | 58 (81.0%) | | NA |
| Area of Concern | 130 | 0.59 | | 99 | 0.61 | | 59 | 0.43 | |
| Motor (GM or FM) | 12 (66.7%) | | | 8 (75.0%) | | | 6 (100.0%) | | |
| Non-Motor | 100 (78.0%) | | | 78 (59.0%) | | | 46 (80.4%) | | |
| Both | 18 (72.2%) | | | 13 (53.8%) | | | 7 (71.4%) | | |

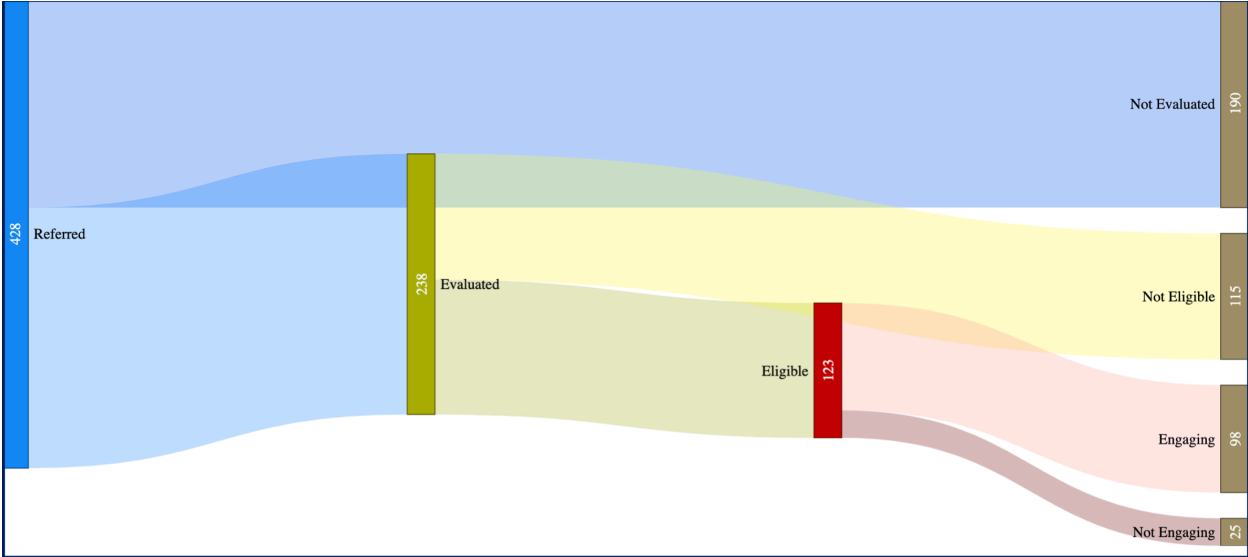


Figure 1: Sankey diagram showing the pipeline effect of Early Intervention from referral to enrollment in services

