

PROJECT TITLE: Autism Intervention Challenges for Low-Income Children

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I. INTRODUCTION

Autism Spectrum Disorder (ASD) describes a severe developmental disability characterized by early core deficits in social interaction and communication. Early diagnosis of ASD is important because behavioral and educational interventions can improve outcomes for children in cognitive, language and social domains (National Research Council, 2001). Professional guidelines state that young children with ASD should be identified early and connected with intervention services to ensure optimal health and developmental outcomes, but this may be difficult for disadvantaged or underserved children and families.

II. LITERATURE REVIEW

As more effective interventions have been developed for children with ASD, identifying these children as early as possible is a priority. Race/ethnicity and socioeconomic status may affect the timely diagnosis of ASD, and recent studies suggest possible disparities in the diagnosis of ASD in these populations. Mandell et al. (2002) found that for children with Medicaid insurance, white children first received the diagnosis of ASD at age 6.3 years, compared with 7.9 years for African-American children and 8.8 years for Latino children. Shattuck et al. (2009) in a study of timing of identification based on a population-based surveillance study found that there were significant differences for African-American and Latino children eventually diagnosed with ASD.

A recent study by Liptak (2008) examined the prevalence and severity of ASD based on parent report in the 2003 National Survey of Children's Health, a dataset of 102,000 children, and found that the prevalence of ASD for Latinos was half as much as that for non-Latinos. In addition, Latinos and poor families rated their child's ASD as more severe. The finding that Latino families are less likely to report symptoms of ASD—but that they report greater severity conditional on reporting any ASD symptoms—may suggest that an ascertainment bias exists that is associated with barriers in access to screening. Limited data on this topic suggest that this may be a problem. Because early detection and timely initiation of ASD therapy are essential components of

successful therapy, ethnic barriers to access to ASD services and interventions have potentially profound implications for the children and families involved.

It has been well-established that mothers of children with developmental disabilities are at risk for experiencing greater parental stress than mothers of typically developing children (Hodapp, Ricci, Ly & Fidler, 2003; Johnston et al., 2003), and additional studies suggest that mothers of children with ASD may experience higher levels of stress than mothers of children with other disabilities (Blacher & McIntyre, 2006; Kasari & Sigman, 1997). Given the challenges that are often associated with accessing services for ASD (e.g., obtaining an Individualized Education Plan through a school district, or accessing IDEA Part C services), level of parental stress is an important factor to consider when evaluating the extent to which underserved children with ASD are receiving the appropriate level of services.

Parent report of diagnosis and severity of ASD may yield an inaccurate representation of with the true extent of ASD, and accordingly of barriers in access to services. For children with limited access to mental health or developmental services, the diagnosis of ASD is often based on school assessments, which vary widely and have as their goal to determine eligibility for special education services. In addition, parent report of severity is based on the parents' perception of the impact the child's ASD has on them rather than a formal diagnosis of severity based on actual symptomatology.

These studies point to the concerning possibility that ASD is being under-treated at younger ages in traditionally underserved children, such as poor children and Latino children, and especially in those with less severe symptoms. Reasons why families whose children with ASD are not being treated early include the following: (1) parents in underserved settings may not have the resources necessary to access services; (2) parents in underserved settings may be too stressed to go through the necessary steps to access services; and (3) parents may not prioritize accessing services if their perception of their child's developmental level is not "too delayed." The finding that the lowest preschool prevalence of ASD occurred in children living in poverty who were younger than the age of six years is concerning because early identification is critical to comprehensive early intervention programs for optimizing developmental outcomes.

With these factors in mind, we sought to determine factors which contribute to the use of early intervention (EI) services in children with ASD from underserved families. We define underserved as low-income (i.e., receiving government assistance) or never having accessed services before.

III. STUDY DESIGN AND METHODS

Population

Children with an existing diagnosis of ASD were recruited from five study centers across the country: University of Washington, University of Michigan, Kennedy Krieger Institute, Florida State University and UCLA. IRB was obtained at all five sites. Inclusion criteria included children age between 2-5 years, diagnosis of ASD confirmed

with the ADOS, and reported lack of resources as defined by receiving government assistance such as Medicaid health insurance or never having previously accessed services for ASD. Recruitment occurred over 23 months (from August 2009 through July 2011), and data were collected on 119 subjects across the 5 sites.

Measures

Dependent Variable

Our outcome of interest in this analysis was the number of services or interventions the child was receiving prior to this study. The outcome variable was coded as “none”, “one service” or “two or more services.”

Covariates

Covariates of interest included child, parent, and family information, measures of parental stress, parent’s perception of child’s developmental level, and a measure of the adequacy of physical and human resources available to the family.

Child, parent, and family information

These covariates included child’s age, child’s gender, child’s ethnicity, language child hears most at home, mother’s education, mother’s employment status, and caregiver’s perception of child’s developmental level. Child’s age was calculated in months from date of birth to date of entry into the study. Child’s ethnic background was categorized as White, African American, Latino, and Other (Asian, Native American, and Pacific Islander were placed into the “other” category). Mother’s educational background was collapsed into high school diploma/GED or less versus some college/vocational school or higher. The language child hears most at home was coded as “English” or “not English.” Mother’s employment status was left as originally categorized: unemployed, part-time, and full-time. Caregiver’s perception of child’s developmental level was dichotomized as “behind age level” or “at age level or above”.

Child’s developmental status

The *Mullen Scales of Early Learning* (Mullen, 1995) was administered to obtain age-equivalent scores across the following four domains of cognitive functioning: Visual Reception, Fine Motor, Receptive Language, and Expressive Language. This scale is designed for young children, and allows the examiner to evaluate the child’s relative strengths and abilities. The age-equivalent developmental quotient (DQ) scores were used to determine the extent to which the caregiver’s perception of the child’s developmental level was accurate.

Measures of parental stress

Parental stress was measured with the Parenting Daily Hassles survey (Crnic and Greenberg, 1990). This is a 20-item measure of typical everyday events in parenting and parent-child interactions. For the Frequency Subscale, in response to each item, the caregiver rates the frequency of occurrence on a 5-point scale (never=0, rarely=1,

sometimes=2, a lot=3, constantly=4). A frequency scale score is calculated as the sum of the frequency ratings on all 20 items and treated as a continuous variable in the analysis. A frequency scale score of 37 (SD=7) is considered to be average. If less than a third of the items were missing, total scores were imputed using the Expectation Maximization (EM) algorithm.

Measure of available resources

This measure was acquired from the Family Resource Scale survey (Dunst and Leet, 1987). This scale is based on a needs hierarchy from basic physiologic needs (e.g., nutritional) to generativity or growth-oriented needs (e.g., planning for and contributing to the future). There are 30 items answered on a 5-point scale (or Not Applicable), ranging from not at all adequate (1) to almost always adequate (5). A total FRS score is calculated as the sum of ratings on all 30 items. A higher FRS score means more optimal with respect to adequacy of personal and family resources, and the average FRS for a family is 117 (SD=18). Similar to the PDH, if less than a third of the items were missing, total scores were imputed using the EM algorithm.

Data Analysis

All analyses were performed with SAS, version 9.2 (Cary, NC). No site differences were identified in our exploratory analyses; therefore, the data across all 5 sites were aggregated.

Because the categories for our outcome variable had a natural ordering, but may not be equally spaced, we fit a sequence of ordinal logistic regression models. To build our full ordinal logistic regression model, we first conducted simple ordinal logistic regressions between each potential predictor and the outcome. This initial bivariate analysis was used to assess statistical associations to determine candidate predictors for our ordinal logistic model. Correlations and tests of association were also conducted amongst each of the potential predictors. We wanted to control for child's age and gender in our final model, although they were not primary covariates of interest. The final model was built using forward selection and included the following covariates: child's gender, child's age, language child heard most at home, mother's education, mother's employment status, child's developmental level, and PDH frequency scale score. Preliminary analyses demonstrated that language heard most at home and ethnicity were highly correlated. From a theoretical standpoint, language could be a barrier for parents in initiating services for their children. Thus, this covariate was chosen as a candidate predictor in lieu of child's ethnicity.

IV. DETAILED FINDINGS

Descriptive Statistics

Of the 119 eligible participants, 27 were receiving no other services or interventions prior to entering the study, 33 were receiving one service/intervention, and 59 were

receiving two or more services. 47% of Latinos spoke a language other than English at home. In addition, 67% of Latina mothers had a high school diploma/GED or less.

Child's Developmental Level and Mullen Developmental Quotient

We were interested in whether a parent's perception of their child's developmental level was associated with the actual developmental level measured by a formal assessment. We used the child's Mullen DQ score as a measure of the actual developmental level. Parent's perception of their child's development was fairly accurate, with a mean Mullen DQ score of 85 (SD=26) for those that were perceived to be at or above child's developmental level and 56 (SD=23) for those perceived to be behind age level ($T=4.26$, $p<0.001$).

Bivariate Analysis

The odds that Latinos received more services was 0.2 (95% CI: 0.064, 0.620) compared to Whites ($p=0.005$). There was a trend toward receiving fewer services among those who heard another language at home compared to those who heard mostly English (OR=0.42; 95% CI: 0.161, 1.091; $p=0.071$). The odds that mothers who worked full-time received more services was 0.377 (95% CI: 0.133, 1.071) compared to mothers who worked part-time ($p=0.042$). Finally, parents who perceived their child's developmental level to be at or above age level were less likely to receive more services (OR=0.337; 95% CI=0.114, 0.990) than parents who perceived their child's developmental level to be behind age level ($p=0.052$).

Multivariate Analysis

Our final ordinal logistic regression model included the following predictors: child's gender, child's age, language child heard most at home, mother's education level, mother's employment status, parent's perception of child's developmental level, and PDH frequency scale score. Mothers whose education included some college/vocational school or higher had 2.4 greater odds of receiving more services than mothers who had a high school diploma or less (95%CI: 0.996, 5.796; $p=0.043$). Mothers who worked full-time had 0.3 (95% CI: 0.087, 0.850; $p=0.013$) times the odds of receiving a greater number of services compared with mothers who worked part-time. Furthermore, the odds associated with receiving a greater number of services among parents who perceived their children to be at or above age level were 0.2 (95% CI: 0.074, 0.762; $p=0.021$) times that of parents who perceived their children to be behind age level. While a one unit increase in PDH frequency scale score was associated with lower odds of receiving a greater number of services (OR=0.978; 95% CI=0.953, 1.005), this relationship was not statistically significant ($p=0.177$). Those who heard a language other than English most at home had 0.4 lower odds of receiving more services than those who heard English most at home (95%CI: 0.135, 1.086; $p=0.068$); this result was not quite statistically significant, however with greater power, we may be better able to discern this relationship. In addition, females had higher odds of receiving a greater number of services compared to males (OR=2.37; 95% CI: 0.795, 7.063; $p=0.119$) and each month increase in age was also associated with receiving more

services (OR=1.01; 95% CI: 0.973, 1.048; p=0.605), however, neither of these results were statistically significant.

V. DISCUSSION

To our knowledge, this is the first multi-site study of children with confirmed ASD diagnosis and their utilization of early intervention services. Previous population-based studies of ASD have included children with a diagnosis of ASD by parent report; the lack of confirmation of an ASD diagnosis by a gold standard measure leads to a heterogeneous study population that may include children with other developmental diagnoses.

In a reportedly underserved population of children with ASD, we found that more than 50% were receiving no or only one EI service (e.g., speech, behavioral, occupational). Given the known benefits of early intervention for the treatment of ASD, particularly in young children, this result is lower than expected. In our study, while the levels of parental stress appeared to be higher for parents of children with ASD than compared to national norms, stress did not appear to play a significant role in utilization of EI services.

Not surprisingly, socio-economic status (i.e., maternal education) was a significant predictor in whether children with ASD participated in EI services. In our model, maternal education was a proxy for socio-economic status with higher levels of maternal education strongly associated with higher household incomes. Interestingly, children of mothers who worked part-time were more likely to be in EI services than children of mothers who worked full-time, indicating the possibility that in addition to financial resources, time for the main caregiver (usually the mother) to participate in EI services could also be a significant factor for participation.

Parent perception of the impact ASD has on their child's developmental status also appeared to play a role in whether the child was in EI services, with children perceived as developmental delayed in more services. We found that parent perception of child's developmental status was fairly accurate with objective measures, and this has been substantiated in previous studies (ref. Glascoe). Our finding suggests that parents may be more motivated to seek out or participate in EI services if they perceive their child to be behind developmentally.

One limitation of our study was the difficulty standardizing "underserved" across all five sites where data were collected. Currently, "underserved" in autism services means families who have difficulty accessing any autism EI service, which may or may not be dependent on household income. As more studies examine access and utilization of autism services and interventions, further research should attempt to standardize the definition of underserved.

IMPLICATIONS

Our findings have implications for intervention research in ASD and suggest that programs should consider assessing parental “buy-in” and availability as part of enrollment. Future studies should delineate how these family factors may affect the depth and duration of involvement with intervention programs once families have been enrolled.

These findings are particularly relevant for traditionally underserved families of children with autism, recognizing that underserved mothers have higher levels of stress and lower self-perceived efficacy and more risk factors for mental health issues such as depression. While interventions for ASD in underserved settings have focused on language compatibility (i.e., being able to deliver the intervention in Spanish), existing interventions which are going to be modified for underserved populations may have to consider cultural issues as well as higher levels of maternal stress which could affect the ability of a family to “stick with” an intervention or even access the intervention in the first place.

VI. LIST OF PRODUCTS

Two manuscripts in progress:

Kuo AA, Gulsrud A, McCracken C, Karp E, Nimbale V and Kasari C. Early intervention service utilization among underserved children with autism. To be submitted to the *Journal of Developmental-Behavioral Pediatrics*.

Kuo AA, Gulsrud A, McCracken C, Karp E, Nimbale V and Kasari C. Factors contributing to disparities in attendance and completion of autism interventions. In preparation

A new autism services tool was developed to improve ease of data collection and entry. This tool will be used in future autism studies at the UCLA Center for Autism Research and Treatment. It incorporates a treatment history section adapted from a tool developed by Fischbach and Lord (2010).

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