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Parental Relationship Status and Age at Autism Spectrum Disorder Diagnosis of their Child

Luther G Kalb, PhD[1,2,3], **Calliope Holingue, PhD**[1,2,3], **Danika Pfeiffer, PhD**[1,4], **Rachel Reetzke, PhD**[1,4], **Emily Dillon, PhD**[1], **Gazi Azad, PhD**[5,6], **Brian Freedman, PhD**[7], **Rebecca Landa, PhD**[1,4]

[1]Center for Autism and Related Disorders, Kennedy Krieger Institute, Johns Hopkins University School of Medicine

[2]Department of Mental Health, Johns Hopkins Bloomberg School of Public Health, Johns Hopkins University School of Medicine

[3]Department of Neuropsychology, Kennedy Krieger Institute, Johns Hopkins University School of Medicine

[4]Department of Psychiatry and Behavioral Sciences, Johns Hopkins University School of Medicine

[5]Division of Child and Adolescent Psychiatry, Department of Psychiatry, New York State Psychiatric Institute and Columbia University Vagelos College of Physicians and Surgeons

[6]Center for Autism and the Developing Brain, New York Presbyterian Hospital

[7]University of Delaware Center for Disabilities Studies

Autism Spectrum Disorder (ASD) is a heterogeneous, life-long, neurodevelopmental condition that is defined by delays in social-communication and the presence of restricted and repetitive behaviors (American Psychiatric Association, 2013). The prevalence of ASD has risen over the last several decades. Today, the Center for Disease Control estimates that 1 in 54 (1.7%) children in the United States has ASD (Maenner, 2020). Although the prevalence of ASD continues to rise, there are still many barriers to receiving a timely diagnosis.

The American Academy of Pediatrics has issued recent guidelines on identifying, evaluating, and managing children with ASD (Hyman et al., 2020). Recommendations include standardized ASD screening for all children ages 18 to 24 months, followed by

Address correspondence to: Luther G. Kalb, PhD, Center for Autism and Related Disorders, 3901 Greenspring Avenue, Baltimore, MD 21204, kalb@kennedykrieger.org, 443-923-7602.

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continuous developmental monitoring by primary care providers (Hyman et al., 2020). This time period, between 12 and 24 months, is typically when parents begin to identify developmental abnormalities in their child (Ozonoff et al., 2009; Zuckerman et al., 2015). While reliable clinical ASD diagnosis can occur as early as 18 months (Ozonoff et al., 2015), there is often a gap of several years between first noticing developmental delays and diagnostic confirmation (Shattuck et al., 2009). At present, the national age at ASD diagnosis among children in US under 8 years of age, is 4.2 years (Maenner, 2020).

Much has been written about the numerous barriers to receiving an ASD diagnosis. The Andersen model for healthcare utilization can be used to organize these barriers into three components: 1) predisposing (sociodemographic and societal influences), 2) enabling (organization of healthcare infrastructures), and 3) need (clinical characteristics) factors (Andersen & Newman, 1973). For predisposing factors, later age at diagnosis is associated with non-white race and Hispanic ethnicity (Fountain et al., 2011; Levy et al., 2010), lower parental education and socioeconomic status (Emerson et al., 2016; Fountain et al., 2011), younger maternal and paternal age (Hrdlicka et al., 2016; Montiel-Nava et al., 2017), being a first-born child (Bickel et al., 2015), and rural geographic region (Coo et al., 2012; Fernell & Gillberg, 2010). For enabling factors, greater delays in diagnosis include no prior connection to the healthcare system (Kalkbrenner et al., 2011; Mandell et al., 2005) and greater distance to care (Antezana et al., 2017; Kalb et al., 2012). For need factors, higher IQ (Shattuck et al., 2009), lower ASD symptom severity (Daniels & Mandell, 2014), and the presence of co-occurring health or psychiatric conditions (Jo et al., 2015; Levy et al., 2010) have all been linked to later age at diagnosis. It is important to note that a recent systematic review found conflicting findings, in terms of the factors that influence age at diagnosis, across studies (Van ‘t Hof et al., 2020).

One area that has received surprisingly little attention is the extent to which the biological parents’ relationship status relates to a child’s age at ASD diagnosis. Parental discord, divorce, and/or separation likely make the diagnostic journey a greater challenge. The studies that have examined the biological parent’s relationship status among children with ASD have focused on divorce and separation, as well as the quality of the marital relationship (Freedman et al., 2012; Hartley et al., 2010). While the evidence is mixed in terms of whether parents of children with ASD are at increased risk for divorce or separation, it is clear that raising a child with ASD is associated with increased levels of stress, which, in turn, impacts the parental relationship (Chan & Leung, 2020; Huang et al., 2014; Lyons et al., 2010; Rao & Beidel, 2009; Wymbs et al., 2008; Yamada et al., 2007). To our knowledge, it is unknown if dissolution between a child’s biological parents - whether it’s separation, divorce, or never being together - affects the timing their ASD diagnosis.

The goal of this study was to fill this gap in the literature by examining whether the age of ASD diagnosis differs between children whose biological parents are married/together (hereafter ‘together’) and those who are separated, divorced, or were never married (hereafter ‘not together’). It was hypothesized that having biological parents that are together to monitor the child’s development and navigate the healthcare system would allow for earlier ASD diagnosis.

Methods

Participants

Data for this study were obtained from children referred to an urban, outpatient ASD specialty clinic located in the Mid-Atlantic region of the United States for an ASD evaluation between the year 2014 and 2020. This clinic provides medical, psychological, speech/language, occupational, and social work services. A primary goal of the clinic is to diagnose, monitor, and treat ASD. Most referrals to the clinic come from the state in which the clinic is located (86%), with the remaining originating from states within the region (12%) and only a few from long distances (2%). Within the state, 28% of referrals come from the city limits in which the clinic is located; the remaining come from the outlying counties.

The analytic sample consisted of children: a) whose caregivers reported no previous evaluation for, or diagnosis of, ASD; b) received an ASD diagnosis during their first clinical evaluation at the center; c) whose parents could be classified as together vs. not together; and d) whose caregivers gave written consent to join the IRB-approved research registry [Johns Hopkins Medicine Institutional Review Board, IRB #00010880] which allows for use of the medical records for research (80% consent rate; see Figure 1 for sample derivation and (Kalb et al., 2019) on the registry). The final analytic sample consisted of 561 children. After these exclusions were applied, children age ranged from 17 months to 15 years of age (M = 5.4, SD = 3.4). Most children were male (80%) and White (47%). See Table 1 for demographic characteristics of the sample.

Patient and Public Involvement—Registry participants were not involved in setting the research question or the outcome measures, nor were they involved in the design or implementation of the study. No participants were asked to advise on the interpretation or writing up of the results. At present, no dissemination methods are made available for the registry.

Measures

Numerous factors were included in this study that could be considered potential confounders of the relationship between parental relationships status and age at ASD diagnosis.

Demographics—Just prior to an appointment being scheduled, parents completed a custom Background and History Form to gain clinical information about the child and family. Relevant to the present study, this form captured information about parental education, whether the child has a sibling and if so, the number of siblings, whether the parent believes the child has ASD “regardless of clinical opinion”, referral source, and current receipt of any child intervention services (from a broad checklist of 6 services). Three demographic data points were gathered from the Electronic Medical Record (EMR). This included date of ASD evaluation, insurance-type and the child’s race. See Table 1 for details.

Parental Relationship Status—The independent variable of interest was current relationship status between the child's biological parents. This variable was captured in the Background and History form. The item asked, "What is the current marital status of the biological parents?" Response options included: a) married, b) never married, c) separated, d) divorced, e) living together but not married, f) other, and e) unknown. A dichotomous variable was derived from this item combining 'married' and 'living together but not married' as one category ('together') and 'separated,' 'divorced' and 'never married,' as another category ('not together'). The response options were combined into categories since the goal was to understand how dissolution of the parents' relationship, regardless of reason, was related to the child's age at ASD diagnosis. If the biological parents' marital status was reported as "Other" (n=10), widowed (n=3), or was unknown or missing (n=7), the child was removed (see Figure 1). This resulted in removal of all children who were either adopted or in foster care.

History of Evaluation and ASD Diagnosis—History of a developmental disability evaluation and ASD diagnosis was identified from the Medical and Background History form using two separate items. One item asked, "Is this the child's first evaluation concerning autism or any developmental concerns?" Children were removed from the analysis if their caregiver responded 'no' to this item. Previous ASD diagnosis was identified via a checklist, where parents could report if their child had been diagnosed with any of the following: a) Autism or Autistic Disorder, b) Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) or Pervasive Developmental Disorder (PDD), c) Asperger's Disorder, or d) ASD. Children were excluded from the analysis if the caregiver reported any of these previous diagnoses.

Clinical ASD Diagnosis—ASD diagnosis was determined by a licensed medical provider (e.g., psychiatrist, neurodevelopmental pediatrician) or licensed psychologist (clinical or neuro) based on the *Diagnostic and Statistical Manual of Mental Disorders*, Version 4-TR or 5. ASD diagnosis was informed by the Autism Diagnostic Observation Schedule, 2nd Edition (ADOS-2) (Lord et al., 2012), which is a gold standard, semi-structured observational assessment used to evaluate the presence or absence of ASD-related symptoms (Lord et al., 2012). There are five ADOS-2 modules (Toddler, Modules 1–4). Modules increase based on greater language ability and older chronological age. Module type was reported on for descriptive purposes only.

ASD Severity—ASD severity was measured using the ADOS-2 Calibrated Severity Score (CSS). The CSS score is a derived score to facilitate comparisons across modules. The CSS scores range from 1–10, with higher scores reflecting greater ASD symptom severity (Esler et al., 2015; Gotham et al., 2012).

Age at ASD Diagnosis—The outcome for this study was age (in years) at diagnosis. This was determined by the difference between the child's birth date and date of the child's first clinical ASD evaluation at the outpatient ASD clinic. This date of evaluation was identified using the child's EMR.

Child Mental Health—The Child Behavior Check List (CBCL; Achenbach & Ruffle, 2000) is a widely-known, psychometrically sound, parent-report instrument used in the current study to assess the child's mental health. The CBCL spans six categories: anxious/depressed, withdrawn, sleep problems, somatic problems, aggressive behavior, and destructive behavior. Norm referenced *T*-scores were used to characterize children's summative internalizing (e.g., depression and anxiety) and/or externalizing (e.g., attention and/or behavior) problems. A score of 66–70 is considered at-risk of clinical problems and > 70 represents the clinical range.

Parenting Stress—Parenting stress was measured by two instruments, the Parenting Stress Index-Short Form (PSI-SF; Abidin et al., 2006) and Autism Parenting Stress Index (APSI; Silva & Schalock, 2012). The PSI-SF was obtained between 2014 and 2017 (53% of the sample) and then the clinic switched to the APSI for the remaining time.

The PSI-SF is a 36-item, caregiver informant measure of stress that is generally related to parenting. It contains three subscales - *Parental Distress*, *Parent-Child Dysfunctional Interaction*, and *Difficult Child* – that are summed for a *Total Stress Scale*. The APSI is a 13-item, caregiver-informed screening instrument designed to evaluate parenting stress that is specific to raising a child with ASD. The items make up three subscales: *Core Social Disability*, *Difficult-to-Manage Behavior*, and *Physical Issues*.

The PSI and APSI total scores were combined to obtain a single composite score for parenting stress using a *T*-score transformation. *T*-scores have a $M = 50$ and $SD = 10$ based on the standardization sample (i.e., the present clinical sample). A ten-point difference in a *T*-score value is equivalent to a standard deviation difference between groups (i.e., a large effect size).

Data Analysis

The first step in the analysis was to examine the demographic and clinical differences across groups using a series of bivariate (*t*-test and χ^2) analyses. The second step was to impute any missing data on our covariates via multiple imputation by chained equations. Missingness was infrequent (<5%), except for insurance-type (6.5%) and parental education (17%). Predictive mean matching and polytomous logistic regression were used for continuous and categorical covariates, respectively, using the R package "mice" (version 3.8.0) (van Buuren & Groothuis-Oudshoorn, 2011).

The third step was to examine the association of parental relationship status and age at diagnosis while adjusting for all covariates using a doubly robust, inverse-probability of exposure weighted (IPEW) linear regression model. All demographic and clinical variables were included, except ADOS-2 Module (given it is based, in part, on the child's age). These covariates were included since they were considered to be risk factors for the outcome or both the exposure and outcome (i.e. confounders), based on existing literature and clinical experience (Myers et al, 2011; Austin and Stuart; 2015). The model has two parts. The first part includes the IPEWs, which are similar to propensity scores. Propensity scores represent a single numerical summary of information representing the probability of exposure (parental relationship status) conditional on the covariates. Weighting the inverse

of exposure creates a synthetic sample in which parental relationship status is independent of the covariates (Austin & Stuart, 2015). The second part of the model reflects the term "doubly robust," (Bang & Robins, 2005) meaning we employed the weights derived from IPEW and additionally adjusted for the covariates in our multivariable regression model. This combined or 'doubly-protected' method guards against misspecification of either the outcome or treatment model, though not both (Robins and Rotnitzky, 2001).

IPEWs are used in observational scenarios when an investigator aims to understand the association between a treatment or exposure and a predefined outcome. IPEWs are widely employed across a variety of fields. For instance, IPEWs have been used to evaluate food policies (Edwards et al. , 2016), pollution exposure (Higbee et al., 2020), home eviction (Tsai et al., 2020), and substance use (Abdollahpour et al., 2018). Like propensity scores, IPEWs seek to balance exposed and unexposed populations with the goal of "mimicking" experimental methods (Austin, 2011). In this study, that would be biological parents who are identical (in measured and unmeasured ways), outside of making the decision to separate. We chose IPEW over propensity scores since this "pseudo" population made sense.

The IPEW model was run on the natural log of age at diagnosis given its negatively skewed distribution. The R "MatchThem" package (version 0.9.2) was used to calculate the propensity score and carry out the IPEW model following imputation (Pishgar et al., 2020). From the imputed dataset, the "within" approach was carried out, in which the average treatment effect was pooled across imputations to produce a single estimate.

A final and critical step in the IPEW analysis was to assess whether the weighting procedure was effective in balancing observed group differences. This was achieved by ensuring the standardized differences in means are relatively small (e.g., <.1, or a 10% difference) after weighting. The "cobalt" package in R (version 4.0.0) was used to assess the performance of the weighting procedure (Greifer, 2020). All analyses were performed in R Studio (version 1.1.383) (RStudio, 2015) with R version 3.6. (R Development Core Team, 2019). Alpha was set at $p < .05$ for determining statistical significance. Data for this study are not made publicly available since it employs sensitive, protected health information.

Results

Bivariate Differences Between Biological Parents who are Together vs. Not Together

Overall, most children's biological parents were together (69%) vs. not together (31%). Among those who were together, most were married (91%), whereas most parents who were not together were reportedly never together (68%). Table 1 displays the bivariate demographic differences between groups. Those who were not together had lower parental education, differed in race, and were more likely to have public insurance (all $p < .001$). Table 1 displays the bivariate clinical and service-related differences between groups. Children of parents who were together had slightly higher ASD severity and were referred from different sources, whereas parents who were not together reported higher CBCL internalizing and externalizing scores (all $p < .01$).

Differences in Age at Diagnosis

Table 1 displays the unadjusted difference in age at ASD diagnosis across parental relationship status. On average, children of parents who were together were diagnosed 1.4 years (or 16.6 months) earlier than parents who were not together ($p < .001$). Figure 2a displays the unadjusted age at diagnosis between groups. For parents who were together, there was a clear bimodal distribution. A large peak in age at diagnosis occurred at 2.6 years of age, with a second peak in adolescence (12.2 years of age) (overall Median Age at Diagnosis = 3.8 years; Mean = 4.9; SD = 3.3). For parents who were not together, there was a trimodal age at diagnosis, with peaks at early childhood (3.7 years), middle childhood (8.8 years), and adolescence (13.4 years) (overall Median Age at Diagnosis = 5.4 years; Mean = 6.3; SD = 3.5). When the natural log of age at diagnosis was applied, separation between groups was further clarified (Figure 2b). To visualize the association between parental relationship status and age at diagnosis, survival curves were also employed (see Supplemental, Figure 1).

After adjusting for all covariates, using the doubly robust IPEW model, there was still a significant difference in age at diagnosis between groups. Parents not together, relative to those who are together, is associated with a delay of 1 year and 4 months (exp(.27) = 1.31; 131% of 1 year is 1 year and 3.7 months) in age at diagnosis ($\beta = .27$, 95%: CI .16, .37, $p < .001$).

After applying the weights, with one exception, all average covariate distances were within the 10% range. The propensity score had an average difference of 0.95 prior to weighting and 0.05 following weighting. This demonstrates balance was achieved, in covariates, across groups. See Supplemental, Figure 2 for details.

Discussion

The goal of this study was to examine differences in age at ASD diagnosis among children whose parents were together or not together. Despite several reviews on the topic of factors related to earlier age at ASD diagnosis, parental relationship status has received little, if any, attention (Daniels & Mandell, 2014; Fountain et al., 2011). Identifying barriers that lead to diagnostic disparities is critical since receiving an ASD diagnosis is a necessary first step towards receiving early intervention services.

Results from this study demonstrated a large disparity in age at diagnosis - about 1 year and 4 months - among children whose parents were not together, whether it was secondary to divorce, separation or never being together. After adjustment for numerous demographic, clinical, family and socioeconomic differences, this disparity remained. For children whose parents were together during the diagnostic journey, there was a clear urgency for evaluation around 3 years of age, with age at diagnosis precipitously decreasing thereafter. For parents of children who were not together, the first rise in age at diagnosis occurred closer to 4 years of age. This disparity was heavily driven by a large group of children whose parents were not together and were diagnosed around their ninth birthday, as seen in Figure 1. Despite this delay in the older children, disparities in age at diagnosis between groups was immediately apparent among very young children, as seen in Supplemental Figure 1.

The exact mechanism to explain the disparity in age at diagnosis is not clear from the present study. There are likely a multitude of factors at play. The later age at diagnosis could be due to the interference of relationship discord, either between partners or about the child's developmental status (Falk et al., 2014; Hartley et al., 2010; Huang et al., 2014). It also might be secondary to lower ASD symptoms (Daniels & Mandell, 2014) and greater mental health symptoms, which were evinced in this study and have been linked to later diagnosis in the literature (Jo et al., 2015; Levy et al., 2010). It could also arise from difficulties procuring and coordinating services, particularly for single parents, secondary to a lack of support with daily activities (Moh & Magiati, 2012). While further research is needed to identify these mechanisms, findings indicate the need for providing additional supports for these families.

The findings are relevant to both healthcare professionals and healthcare management organizations, since they are equally investing in providing timely access to care. Within this system of care, pediatricians play a particularly critical role in the diagnostic journey. They are present early in the child's life, watching their development unfold. This uniquely positions them to provide referrals as soon as screening or clinical observation warrants further evaluation. While pediatricians can provide a referral, it doesn't ensure the child will be scheduled for an evaluation or the family will attend if one is scheduled (Azad et al., 2019; Kalb et al., 2012; King et al., 2010). Additional supports may be needed to assist with coordination and follow-up of appointments. This reality reinforces the import of care coordination/family navigation services for families, particularly when the biological parents are not together, which has demonstrated value in the clinic in which this study was conducted (Singh et al., 2019).

As with any study, the present investigation has strengths and limitations. Limitations include cross-sectional design and inclusion of a single site. Limitations in measurement, notably changes in the measure of parenting stress and the lack of data on the quality of the biological parents' relationship or timing of divorce/separation, remain a concern. These findings require replication, especially using prospective designs. However, this study also has many strengths, including a sample that was large and heterogeneous from a clinical and demographic perspective, ASD diagnosis was confirmed by a licensed clinician using a gold standard measure, and age at diagnosis was identified through medical records, rather than parental recall. Our study also carefully attended to confounding variables, through robust measurement and modern statistical methods.

Conclusion

In sum, children of biological parents who were not together were diagnosed with ASD over a year later than children of parents who were together. These findings identify the need for systematic supports for parents who are not together and seeking an ASD diagnosis, given the prognostic implications associated with delays in ASD diagnosis. Future research is needed to replicate this finding, particularly through prospective designs and population-based samples. In addition, future research is needed to examine child, family, and geographical factors that moderate the association between parental relationship status and timing of ASD diagnosis. This includes dimensional measures of child ASD

severity, parental mental health status and health literacy, quality of the parental relationship, and access to the healthcare system. Use of cumulative risk models - that assess the interplay of risk factors at multiple socioecological levels – would be particularly valuable (Evans, Li, & Whipple, 2013; Spencer, 2007). This approach would provide a more holistic view of the relationship between parental separation and timing of ASD diagnosis than evaluating variable at a single level of measurement (e.g., solely child developmental characteristics). This study contributes to these models be identifying an important risk factor at the parental level.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Abbreviations:

ASD	Autism Spectrum Disorder
EMR	Electronic Medical Record
ADOS-2	Autism Diagnostic Observation Schedule-2
CSS	Calibrated Severity Score
CBCL	Child Behavior Check List
PSI-SF	Parenting Stress Index-Short Form
APSI	Autism Parenting Stress Index
IPEW	inverse-probability of exposure weighted

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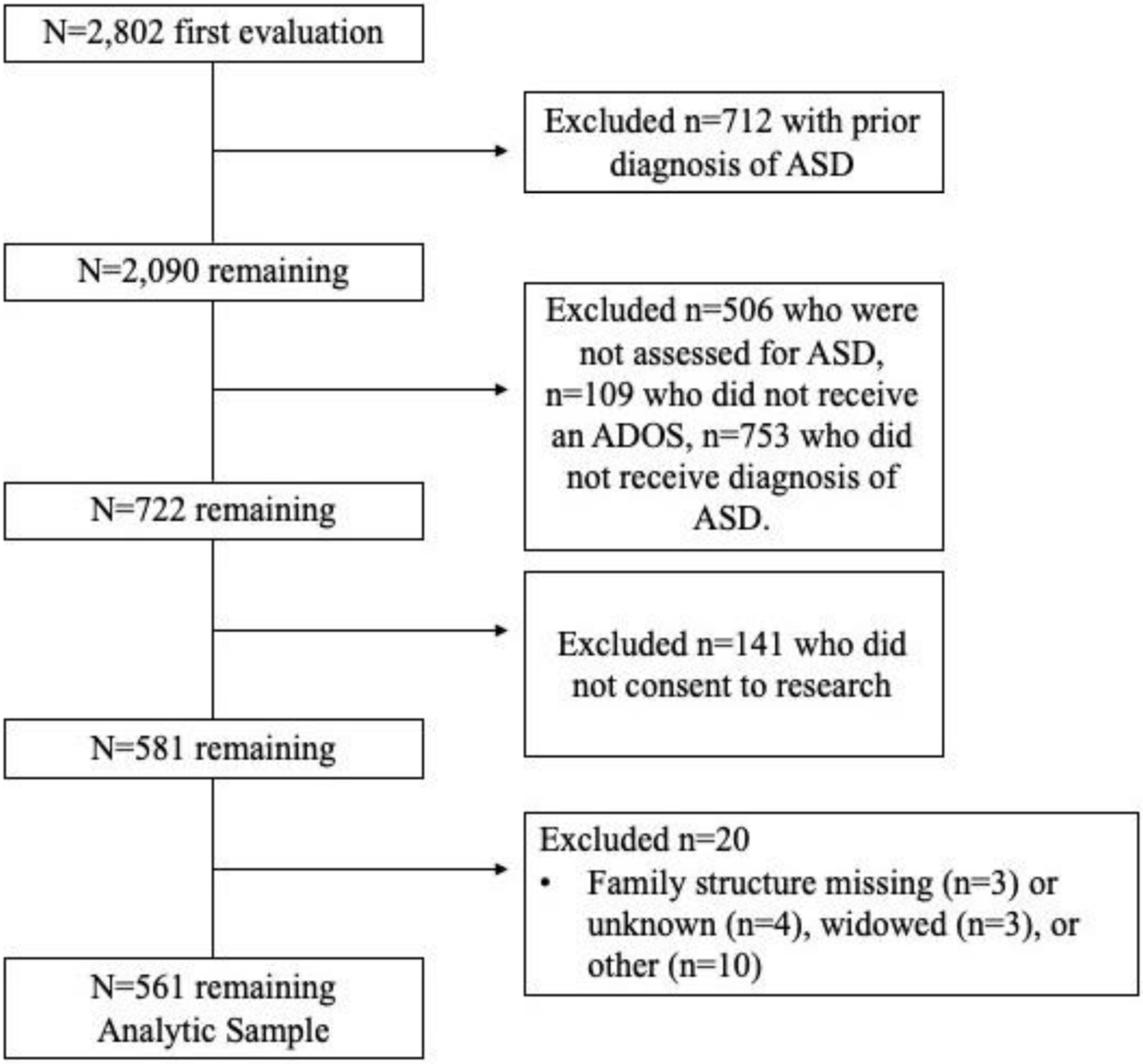

Figure 1.
Sample Derivation

Figure 2a and 2b.
Distribution of Age at Diagnosis, Stratified by Biological Parents Relationship Status

Table 1.

Participant demographic and clinical characteristics, stratified by relationship status

	Total (N=561)	Together (n=385)	Not Together (n=176)	P-value[a]
Marital Status, N (%)				
Married	350 (62.4)	350 (90.9)	---	N/A
Together, not married	35 (6.2)	35 (9.1)	---	
Never Married	119 (21.2)	---	119 (67.6)	
Separated	17 (3.0)	---	17 (9.7)	
Divorced	40 (7.1)	---	40 (22.7)	
Age at diagnosis (mos) (M, SD)	64.3 (40.8)	59.1 (39.2)	75.7 (42.1)	<0.001
Age (yrs) at diagnosis (M, SD)	5.4 (3.4)	4.9 (3.3)	6.3 (3.5)	<0.001
Ln Age at diagnosis (yrs) (M, SD)	1.5 (0.6)	1.4 (0.6)	1.7 (0.6)	<0.001
Child sex, N (%)				
Female	112 (20.0)	81 (21.0)	31 (17.6)	0.41
Male	449 (80.0)	304 (79.0)	145 (82.4)	
Child race, N (%)				
White	259 (46.6)	194 (50.8)	65 (37.4)	<0.001
Asian	61 (11.0)	49 (12.8)	12 (6.9)	
Black	136 (24.5)	70 (18.3)	66 (37.9)	
Other	100 (18.0)	69 (18.1)	31 (17.8)	
Parental Education, N (%)				
High school/below	167 (35.8)	97 (29.6)	70 (50.4)	<0.001
Trade/Associate	99 (21.2)	65 (19.8)	34 (24.5)	
Bachelor	115 (24.6)	90 (27.4)	25 (18.0)	
Graduate	86 (18.4)	76 (23.2)	10 (7.2)	
Insurance, N (%)				
Public	211 (40.3)	113 (31.4)	98 (59.8)	<0.001
Private	313 (59.7)	247 (68.6)	66 (40.2)	
Child has sibling, N (%)				
No	129 (23.0)	83 (21.6)	46 (26.3)	0.26
Yes	431 (77.0)	302 (78.4)	129 (73.7)	
Number of siblings (M, SD)	0.9 (0.7)	0.9 (0.6)	0.9 (0.7)	0.95
Year of diagnosis, N (%)				
2014	36 (6.9)	22 (6.1)	14 (8.5)	0.17
2015	95 (18.2)	62 (17.3)	33 (20.1)	
2016	100 (19.2)	74 (20.7)	26 (15.9)	
2017	145 (27.8)	109 (30.4)	36 (22.0)	
2018	76 (14.6)	49 (13.7)	27 (16.5)	
2019	68 (13.0)	40 (11.2)	28 (17.1)	

	Total (N=561)	Together (n=385)	Not Together (n=176)	P-value[a]
2020	2 (0.4)	2 (0.6)	0 (0)	
ADOS CSS (M, SD)	7.5 (1.9)	7.6 (1.8)	7.2 (2.1)	0.04
CBCL Internalizing (M, SD)	60.2 (10.9)	59.0 (10.9)	62.9 (10.4)	<0.001
CBCL Externalizing (M, SD)	55.9 (12.2)	54.9 (12.2)	58.2 (12.0)	0.01
Parenting Stress T-score (M, SD)	50.0 (10.0)	49.5 (10.2)	51.1 (9.6)	0.10
Parent believes child has ASD, N (%)				
No	153 (27.8)	110 (29.3)	43 (24.7)	0.32
Yes	397 (72.2)	266 (70.7)	131 (75.3)	
Referral Source, N (%)				
PCP/Pediatrics	239 (42.6)	158 (41.0)	81 (46.0)	0.01
Psychologist	28 (5.0)	18 (4.7)	10 (5.7)	
Other	124 (22.1)	76 (19.7)	48 (27.3)	
Not specified	170 (30.3)	133 (34.5)	37 (21.0)	
Received Services Prior to Evaluation, N (%)				
No	238 (42.8)	161 (42.4)	77 (43.8)	0.83
Yes	318 (57.2)	219 (57.6)	99 (56.3)	
ADOS-2 Module, N (%)				
Toddler	130 (23.2)	106 (27.5)	24 (13.6)	<0.001
Module 1	163 (29.1)	109 (28.3)	54 (30.7)	
Module 2	76 (13.5)	55 (14.3)	21 (11.9)	
Module 3	192 (34.2)	115 (29.9)	77 (43.8)	

[a]P-value for T-test of Chi-square test of association between participant characteristics and parent separated vs together.