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A Population-Based Examination of Maltreatment Referrals and Substantiation for Children with Autism Spectrum Disorder

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Abstract

Children with disabilities experience elevated rates of maltreatment but little is known about the interaction of children with autism spectrum disorder (ASD) with child protection systems. A population-based dataset of 24,306 children born in 2008 in Tennessee, which included 387 children with ASD identified through the Autism and Developmental Disabilities Monitoring network, was linked with state child protection records. Rates of maltreatment referrals, screening for further action, and substantiated maltreatment were examined for children with versus without ASD. Significantly more children with ASD (17.3%) than without (7.4%) were referred to the Child Abuse Hotline. Children with ASD were less likely than children without ASD to have referrals screened in for further action (62% vs. 91.6%, respectively), but substantiated maltreatment rates were similar across groups (3.9% vs. 3.4%, respectively). Girls versus boys with ASD were more likely to have substantiated maltreatment (13.6% vs. 1.9%, respectively). The high percentage of children with ASD referred for allegations of maltreatment, the differential pattern of screening referrals in for further action, and the high levels of substantiated maltreatment of girls with ASD highlights the need for enhanced training and knowledge of the complex issues faced by children with ASD, their families, and state welfare agencies.

Keywords

autism spectrum disorder; maltreatment; child protective services; child abuse

Population-based studies and national data reporting entities clearly indicate that children with disabilities experience elevated rates of maltreatment and encounters with child protection systems (Horner-Johnson & Drum, 2006; Maclean et al., 2017; Spencer et al.,

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2005; Sullivan & Knutson, 2000; Hall-Lande, Hewitt, Mishra, Piescher, & LaLiberte, 2015); however, specific disability status is not often adequately addressed and documented in the research or by child protection systems (Kendall-Tackett, Lyon, Taliaferro, & Little, 2005; Shannon & Agorastou, 2006). Children from different disability categories often vary substantially in their unique neurodevelopmental profiles and support needs (Helton & Bruhn, 2013). In order to develop systems of care that include maltreatment prevention, response, assessment, and intervention strategies, it is extremely important for states to know the proportion of children who interact with their child protection systems who have specific forms of disabilities (Helton & Bruhn, 2013; Kendall-Tackett et al., 2005; Lightfoot, Hill, & LaLiberte, 2011).

Many have hypothesized that children with Autism Spectrum Disorder (ASD) may be particularly vulnerable to maltreatment due to factors including (but not limited to) the presence of significant challenging behavior and potent and complex cognitive and language impairments among children with ASD, as well as increased caregiver stress, lower levels of family social support, higher rates of caregiver isolation, and higher rates of caregiver dependence (Mandell et al., 2005; Sullivan & Knutson, 2000). Despite these risk factors, existing attempts to catalogue maltreatment risk for children with ASD to date have suffered from specific ascertainment and other methodological challenges both within the child protection system and in previous research.

First, (a) there are few standardized definitions or criteria used by child protection workers across states for assessing or reporting disability status, (b) disability status is often only documented as a dichotomous variable (e.g., disability present or not present) (Helton & Bruhn, 2013; Shannon & Agorastou, 2006), and (c) child protection workers receive little training in identifying and supporting children with disabilities and their families (Lightfoot & LaLiberte, 2006; Lightfoot et al., 2011; Shannon & Agorastou, 2006). Second, previous research has (a) failed to adequately separate ASD from other disability categories; (b) dramatically under-identified individuals with ASD relative to the known prevalence of the disorder; or (c) examined of rates of maltreatment in clinically-referred samples and/or samples of convenience rather than population studies (Fisher et al., 2008).

In the current report, we attempted to overcome previous methodological limitations by linking children with ASD identified through the Autism and Developmental Disability Monitoring network (ADDM)- the specific methodology used by the Centers for Disease Control and Prevention (CDC) to estimate the prevalence of ASD in the U.S. (Rice et al., 2007)- to the entire record catalogue of a state-based child protection agency. We specifically examined the following questions within a population level cohort: 1) Are children with ASD in Tennessee (TN) more likely than those without ASD in TN to be referred to the TN Child Abuse Hotline? 2) After referral to the TN Child Abuse Hotline, are children with ASD in TN more likely than those without ASD in TN to be screened in for further action? 3) Are children with ASD in TN more likely than those without ASD in TN to have an allegation reported to the TN Child Abuse Hotline be substantiated? and 4) Are there gender or race differences within and between groups of children with substantiated maltreatment?

Methods

After obtaining approval from the Institutional Review Board, a single population-based dataset was created using deterministic linkage of common identifiers (e.g., name, address, and birthday) that included information from the (1) TN-ADDM network records, (2) TN Department of Health (TNDH) birth vital records, and (3) child protection system records from the TN Department of Children's Services (TNDCS).

Study Sample

The sample consisted of all 24,306 children born in 2006 from the 11-county TN-ADDM surveillance area. For context, the median household income for counties within the TN-ADDM surveillance area was $39,635 - $91,146, with 14.7% of households below the poverty line, and a majority of families with children (76%) in the surveillance area were White (TNDH, Division of PPA, 2018).

Of the 24,306 children born in 2006 from the TN-ADDM surveillance area, 387 children were classified via ADDM methodology as having an ASD ('ASD cases') and 23,919 were identified as not having an ASD ('control children'). ASD cases were more likely than control children to be male (82.7% vs. 50.7%, $X^2 = 66.9$, $p < .01$). The proportion of Caucasian to other races was not significantly different for ASD cases relative to control children (80.8% vs. 78.2%, $X^2 = 1.21$, *ns*). IQ data were available for 71% ($n = 274/387$) of the ASD cases (a classification rate common to the ADDM methodology), and 39% ($n = 106/274$) of these children with ASD had an IQ below 70 (e.g., intellectual disability). At the time of this data analysis, all children in included in the study were 10 years of age.

Data Sources

As part of the larger ADDM public health surveillance effort, ASD cases were identified from the TN-ADDM data for surveillance year 2014. Control children were all other 2006 births in the TN-ADDM surveillance area identified from TNDH birth vital statistics database. ADDM methods have been extensively described elsewhere (see Rice et al., 2007). In brief, educational and health records of all children born in 2006 (e.g., records up until the child was 8 years old were reviewed) were screened to identify potential ASD cases which were then confirmed (or not) as ASD cases by clinical review.

Records of all encounters from 2006 to 2016 with TN's child protection system were provided by TNDCS. Tennessee Code 37–1-403 (2017) sub-section (a) (1) states "any person who has knowledge of or is called upon to render aid to any child who is suffering from or has sustained any wound, injury, disability, or physical or mental condition shall report such harm immediately if the harm is of such a nature as to reasonably indicate that it has been caused by brutality, abuse or neglect or that, on the basis of available information, reasonably appears to have been caused by brutality, abuse or neglect." The language in the code is intentionally broad, so as to encourage child protection by casting a broad net. Accordingly, we use the general term "child maltreatment" in this paper to refer to all such reports. In TN, all such reports are routed through what is called the TN Child Abuse Hotline, which serves as a single point of referral for all such allegations.

Child protection professionals at the TN Child Abuse Hotline use a structured decision-making process to determine whether the referral should be screened out (e.g., no further action from TNDCS is required) or should be screened in for further action. If the referral is screened in for further action, then other child protection professionals begin looking into the details of the allegation(s) included in the referral and working with the family. This includes conducting interviews with the child, parent or caregiver, referent, and collateral contacts, observation of the child and home (if appropriate), and completion of all appropriate documentation including standardized screening tools (per TNDCS Administrative Policy and Procedure 14.14; TNDCS, 2017). After all interviews and other evidence is collected, the child protection worker uses the information to determine whether there is enough evidence to say the child was abused or neglected (substantiated) or there was not enough evidence to say that the child was abused or neglected (unsubstantiated) (TNDCS, 2014; TNDCS, 2016).

Child protection system records were used to examine: (1) all referrals to the child abuse hotline (hereafter referred to as 'referrals'); (2) screening for further action by the child abuse hotline (hereafter referred to as 'further action'); and (3) substantiation of maltreatment (hereafter referred to as 'substantiated maltreatment'). Because many children could be referred to the hotline multiple times or by multiple individuals for the same incident, we evaluated only initial TNDCS encounters.

Statistical Analysis

Group differences were tested with independent group proportion tests. The Benjamin and Yekutieli (Benjamini & Yekutieli, 2001) method was used to control the study-wide false discovery rates. R version 3.4.1 (R Core Team, 2017) was used for all data management and statistical analysis procedures.

Results

Results are shown in Table 1. Relative to the entire ASD and control populations, significantly more children with ASD (17.3%) than control children (7.4%) were referred to the TN Child Abuse Hotline (X^2=52.5, p<.001; odds ratio [OR], 2.63; 95% confidence interval [CI], 2.00 to 3.42). Relative to the total number of referrals to the TN Child Abuse Hotline, children with ASD were more likely than control children to be screened out rather than screened in for further action (X^2=59.9, p<.001; OR, 0.15; 95% CI, 0.09 to 0.26). Specifically, 62.7% (n=42/67) of ASD referrals were screened in for further action; whereas, 91.6% (n=1,618/1,766) of referrals for control children were screened in for further action. However, relative to the entire ASD and control populations, ASD referrals (10.6%; n=42/387) were more likely than control children (6.8%; n=1,618/23,921) to be screened in for further action (X^2=9.10, p=.003; OR, 1.68; 95% CI, 1.20 to 2.30). Finally, relative to the number of referrals screened in for further action, children with ASD (35.7%; n=15/42) were less likely than control children (50.5%; n=822/1,618) to have substantiated maltreatment (X^2=3.15, p=0.055; OR, 0.54; 95% CI, .28 to 1.01). However, relative to the entire ASD and control populations, children with ASD (3.9%; n=15/387) and control children (3.4%;

n=822/23,921) were equally likely to have substantiated maltreatment (X^2=0.1, *p*=0.62; OR, 1.15; 95% CI, 0.65 to 1.86).

Examining demographic differences for children with ASD, while the proportion of males with ASD is significantly larger than the proportion of females with ASD overall, the proportion of females with ASD with substantiated maltreatment (13.6%) was significantly larger than the proportion of males with ASD with substantiated maltreatment (1.9%; X^2=17.3, *p*<.001; OR, 0.12; 95% CI, 0.04 to 0.36). There were no significant race/ethnicity differences for children with ASD with substantiated maltreatment (50% other race vs. 50% Caucasian; X^2=2.6, *p*=.80; OR, 0.87; 95% CI, 0.30 to 2.52). Finally, there were no differences in substantiated maltreatment for children with ASD with IQ above versus IQ below 70 (X^2=0.68, *p*=0.98; OR, 1.01; 95% CI, 0.64 to 1.58). For control children, there were no gender or race differences for substantiated maltreatment.

Discussion

The current study addresses the methodological limitations of the existing literature by using a well-established methodology for identifying children with ASD and linking those records to referrals to TNDCS. The finding that children with ASD in the TN-ADDM surveillance area are more than two and one-half times more likely than control children to be referred to TNDCS is generally consistent with previous reports of high rates of child protection encounters for children with disabilities, including ASD (Hall-Lande et al., 2015; Mandell et al., 2005; Pfeffer, 2016).

Extending previous research, the current study provides a nuanced examination of the stages of encounters children have with the child protection system. While results of this linkage suggest overrepresentation of children with ASD in referrals to TNDCS- almost 1 in 5 children with ASD were referred to the TN Child Abuse Hotline- ultimate movement toward further action was different for children with ASD compared to control children. Far fewer referrals of children with ASD were screened in for further action, raising the question of whether children with ASD are over-referred to the TN Child Abuse Hotline or whether they are differentially screened out for further action.

There are several potential interpretations of this difference. First, it may be that children with ASD, by virtue of their multi-system involvement and involvement with professionals familiar with mandated reporting, have more opportunities for maltreatment to be noticed and/or suspected than do control children and are therefore more likely to be referred. Second, the increased number of referrals for children with ASD may be linked to the complex child and family factors co-occurring with ASD presentations. For example, behavioral challenges or self-injurious behaviors may appear as symptoms of abuse to those not familiar with ASD, thus leading to increased referrals for children with ASD that are ultimately screened out for further action (Westcott & Jones, 1999). Finally, it is also possible that those charged with triage and decision making from the TN Child Abuse Hotline make attributions about allegations or resource referrals differentially for children with ASD. Given existing research suggesting that child protection workers generally receive little training on recognizing and supporting children with disabilities (Fisher et al.,

2008; Helton & Bruhn, 2013; Lightfoot & LaLiberte, 2006; Shannon & Tappan, 2011), it may be that child protection workers could benefit from more specialized training in autism and other developmental disabilities. For example, the TNDCS staff in-service course catalog includes a one-hour, online course entitled “Autism Awareness,” that appears to be one of over 100 elective in-service options (Staff In-Service Catalog, n.d.)

Given that recommendations for further action were substantially lower for children with ASD, it is challenging to ultimately interpret the fairly comparable percentages of substantiated cases of maltreatment for those children with and without ASD. If there was a differential response to referrals, it may be that this difference represents a possible minimum or lower bound of maltreatment concerns within this population. Ultimately, it is vitally important for states to know the proportion of children within their child protection systems who have ASD in order to develop systems of care inclusive of effective maltreatment prevention, response, assessment, and intervention strategies (Kendall-Tackett et al., 2005).

An unexpected finding was that females with ASD were significantly more likely to have substantiated maltreatment compared to males with ASD. Not only does this disparity not reflect gender differences in our control population, but it also does not reflect gender differences reported in national maltreatment studies of children without disabilities (e.g., (U.S. Department of Health & Human Services, Administration for Children and Families, Administration on & Children, Youth and Families, Children’s Bureau, 2018) nor in other population studies of individuals with other disabilities (Maclean et al., 2017; Sullivan & Knutson, 2000). In their sample of individuals with ASD served in comprehensive community-based mental health settings, Mandell and colleagues (2005) found that compared to males with ASD females with ASD were more likely to experience sexual abuse but no gender differences were reported for physical abuse. It is possible that a similar pattern is evident in the current data; unfortunately, the dataset does not allow for an examination of the specific forms of substantiated maltreatment experienced by each child. Still, this finding highlights that females with ASD might be an extremely vulnerable population and future research should be conducted to better explain this finding.

Limitations of the current study must be addressed. First, the cohort was 10 year old at the time of identification and although all initial referrals up to this age were examined, this still only represents a portion of what a child’s experience with maltreatment and the child protection system may be (i.e. children and rates of maltreatment may vary dramatically past 10 years of age for children with versus without ASD). Second, while ASD was identified through a well-established methodology (Rice et al., 2007), other child characteristics were not well defined. Specifically, in addition to children without disabilities, the control group likely contains children with other disabilities who are at heightened risk of maltreatment (Hibbard & Desch, 2007). Similarly, given the heterogeneity of ASD, it is likely an oversimplification to discuss ASD diagnosis as a risk status in and of itself. There are likely complex specific child, family, and social factors overlaid with associated ASD characteristics that ultimately may drive risk for maltreatment. Third, the current dataset contained limited information, not allowing for the examination of who reported the abuse, the type of abuse reported, and the alleged/substantiated perpetrator. Despite these

limitations, the current linkage powerfully supports the need to examine and disentangle these additional factors for children with ASD.

Conclusion

Children with disabilities are often overrepresented within child protection systems, but population studies of the experiences of children with ASD have been limited. The current work examined referrals to the TN Child Abuse Hotline, screens for further action within the child protection system, and substantiation of maltreatment for a cohort of children rigorously reviewed for ASD. Results suggest high rates of both referrals and substantiated maltreatment for children with ASD. Further examination of the factors contributing to higher risk of maltreatment referrals and potentially to the experience of maltreatment is clearly warranted to disentangle the complex challenges facing this vulnerable population of children.

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References

Benjamini Y, & Yekutieli D (2001). The control of the false discovery rate in multiple testing under dependency. Ann. Statist, 29(4), 1165–1188. doi:10.1214/aos/1013699998

Fisher MH, Hodapp RM, & Dykens EM (2008). Child abuse among children with disabilities: What we know and what we need to know. In International Review of Research in Mental Retardation (Vol. 35, pp. 251–289). San Diego: Elsevier Science & Technology. doi:10.1016/S0074-7750(07)35007-6

Hall-Lande J, Hewitt A, Mishra S, Piescher K, & LaLiberte T (2015). Involvement of children with autism spectrum disorder (ASD) in the child protection system. Focus on Autism and Other Developmental Disabilities, 30(4), 237–248. doi:10.1177/1088357614539834

Helton JJ, & Bruhn CM (2013). Prevalence of disabilities and abilities in children investigated for abuse and neglect. Journal of Public Child Welfare, 7(5), 480–495. doi:10.1080/15548732.2013.843497

Hibbard RA, & Desch LW (2007). Maltreatment of children with disabilities. Pediatrics, 119(5), 1018. doi:10.1542/peds.2007-0565 [PubMed: 17473105]

Horner-Johnson W, & Drum CE (2006). Prevalence of maltreatment of people with intellectual disabilities: A review of recently published research. Mental Retardation and Developmental Disabilities Research Reviews, 12(1), 57–69. doi:10.1002/mrdd.20097 [PubMed: 16435331]

Kendall-Tackett K, Lyon T, Taliaferro G, & Little L (2005). Why child maltreatment researchers should include children's disability status in their maltreatment studies. Child Abuse & Neglect, 29(2), 147–151. doi:10.1016/j.chiabu.2004.09.002 [PubMed: 15734180]

Lightfoot EB, & LaLiberte TL (2006). Approaches to child protection case management for cases involving people with disabilities. Child Abuse & Neglect, 30(4), 381–391. doi:10.1016/j.chiabu.2005.10.013 [PubMed: 16603243]

Lightfoot E, Hill K, & LaLiberte T (2011). Prevalence of children with disabilities in the child welfare system and out of home placement: An examination of administrative records. Children and Youth Services Review, 33(11), 2069–2075. doi:10.1016/j.childyouth.2011.02.019

Maclean M, Sims S, Bower C, Leonard H, Stanley F, & O'Donnell M (2017). Maltreatment risk among children with disabilities. Pediatrics, 139(4), 1. doi:10.1542/peds.2016-1817

Mandell DS, Walrath CM, Manteuffel B, Sgro G, & Pinto-Martin JA (2005). The prevalence and correlates of abuse among children with autism served in comprehensive community-based mental health settings. Child Abuse & Neglect, 29(12), 1359–1372. doi:10.1016/j.chiabu.2005.06.006 [PubMed: 16293306]

Pfeffer RD (2016). Childhood victimization in a national sample of youth with autism spectrum disorders: Victimization and autism. Journal of Policy and Practice in Intellectual Disabilities, 13(4), 311–319. doi:10.1111/jppi.12203

R Core Team. (2017). R: A language and environment for statistical computing R Foundation for Statistical Computing.

Rice CE, Baio J, Van Naarden Braun K, Doernberg N, Meaney FJ, Kirby RS, & ADDM Network. (2007). A public health collaboration for the surveillance of autism spectrum disorders. Paediatric and Perinatal Epidemiology, 21(2), 179–190. doi:10.1111/j.1365-3016.2007.00801.x [PubMed: 17302648]

Shannon P, & Agorastou M (2006). Identifying children with developmental disabilities receiving child protection services: A national survey of child welfare administrators. Families in Society, 87(3), 351–357. doi:10.1606/1044-3894.3539

Shannon P, & Tappan C (2011). A qualitative analysis of child protective services practice with children with developmental disabilities. Children and Youth Services Review, 33(9), 1469–1475. doi:10.1016/j.childyouth.2010.11.014

Spencer N, Devereux E, Wallace A, Sundrum R, Shenoy M, Bacchus C, & Logan S (2005). Disabling conditions and registration for child abuse and neglect: A population-based study. Pediatrics, 116(3), 609–613. doi:10.1542/peds.2004-1882 [PubMed: 16140700]

Staff In-Service Catalog. (n.d.). Retrieved from https://www.tn.gov/dcs/program-areas/training/tpd/staff/dcs-is/staff-catalog.html

Sullivan PM, & Knutson JF (2000). Maltreatment and disabilities: a population-based epidemiological study. Child Abuse & Neglect, 24(10), 1257–1273. doi:10.1016/S0145-2134(00)00190-3 [PubMed: 11075694]

Tennessee Department of Children's Services. (2014). Classification and Review of Reports of Child Abuse/Neglect and Due Process for Release of Child Abuse/Neglect Records Retrieved from https://sharetngov.tnsosfiles.com/sos/rules/0250/0250-07/0250-07-09.20140116.pdf

Tennessee Department of Children's Services. (2016). Clients Right's Handbook Retrieved October 3, 2018, from https://www.tn.gov/dcs/program-areas/fca/foster-care/birth-parents/clients-rights.html

Tennessee Department of Children's Services. (2017). Policies & Procedures Retrieved October 3, 2018, from https://www.tn.gov/dcs/program-areas/qi/policies-reports-manuals/policiesprocedures.html

Tennessee Department of Health, Division of PPA. (2018). Based on interpolated data from the U.S. Census, Annual Estimates of the Resident Population: April 1, 2010 to July 1, 2016 Retrieved from https://www.tn.gov/content/dam/tn/health/documents/TN_Population_by_AgeGrp_Sex_Race_Ethnicity_-_2016.pdf

U.S. Department of Health & Human Services, Administration for Children and Families, Administration on, & Children, Youth and Families, Children's Bureau. (2018). Child maltreatment 2016 Retrieved from https://www.acf.hhs.gov/cb/research-data-technology/statistics-research/child-maltreatment.

Westcott HL, & Jones DPH (1999). Annotation: The abuse of disabled children. Journal of Child Psychology and Psychiatry, 40(4), 497–506. doi:10.1111/1469-7610.00468 [PubMed: 10357157]

Table 1.

Total Number and Percent of Children with ASD and Control Children to Receive Referrals to The TNDCS Hotline, to Be Screened In for Further Action, and to Have Substantiated Maltreatment.

Relative to TN-ADDM Population					
CPS system contact	ASD		Control		Odds Ratio
	N = 387		*N* = 23,921		
	n	*%*	*n*	%	ASD:Control
Referrals	67	17.3	1,766	7.4	2.63
Further action	42	10.6	1,629	6.8	1.68
Substantiated maltreatment	15	3.9	822	3.4	1.15
	Relative to total number of referrals to TNDCS hotline				
	n = 67		*n* = 1,766		
Further action	42	62.7	1,618	91.6	0.15
Substantiated maltreatment	15	35.7	822	50.8	0.54

Note: ASD = Autism Spectrum Disorders; TNDCS = Tennessee Department of Children's Services; CPS = children protective services; TN-ADDM = Tennessee Autism and Developmental Disabilities Monitoring