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# First-time maltreatment in children ages 2–10 with and without specific birth defects: A population–based study



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#### ABSTRACT

Children with disabilities are at an increased risk for maltreatment. However, little is known about the risk of maltreatment in children with specific types of birth defects. This study was conducted to determine whether the risk and predictors of maltreatment in children 2 to 10 years of age differ between those without and with specific birth defects: Down syndrome, cleft lip with/without cleft palate, and spina bifida. State administrative and United States Census data were linked to identify study groups, variables of interest, and outcome measures. Kaplan-Meier and multivariate Cox proportional hazard analyses were used to identify study groups and variables associated with an increased risk for maltreatment. The prevalence of substantiated maltreatment was consistently highest among children with cleft lip with/without cleft palate. After adjusting for birth-level factors, children with Down syndrome and cleft lip with/without cleft palate were 34% and 26% more likely to have been maltreated than those without birth defects, respectively. In all three birth defect groups, the risk of medical neglect was higher (relative risks ranged from 3 to 11) than in the unaffected group. The factors associated with increased risk for maltreatment were similar across all groups. Of note, parity, maternal education, and maternal Medicaid use at birth were all associated with greater than 2-fold increased risk for maltreatment. Our findings suggest that the families of children with birth defects may need support services throughout early childhood to help families cope with the needs of their children and reduce the risk of maltreatment.

#### 1. Introduction

Each year in the United States (U.S.), approximately 700,000 children are confirmed victims of maltreatment (U.S. Department of Health & Human Services, Administration on Children, Youth & Families, 2018). Children who have been maltreated are more likely to suffer from a range of adverse health and social issues that often impact them throughout their lives (Goldman, Salus, Wolcott, & Kennedy, 2003). Consequently, they use more public and private health and social services throughout their lives than do individuals who are not maltreated as children. It is estimated that in the U.S. the total economic burden of new child maltreatment cases that

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occur each year is \$124 billion (Fang, Brown, Florence, & Mercy, 2011).

Due to the impact of maltreatment on victims and society, identification and prevention have become a public health priority (Office of the Surgeon General (2005)). Multiple factors associated with an increased risk for maltreatment have been reported, including characteristics of the child (e.g. birth weight and birth defects (Putnam-Hornstein & Needell, 2011), family (e.g., parental education and family size; Dubowitz et al., 2011), and the neighborhood in which the child and family live (e.g., neighborhood disadvantage and stability (Coulton, Crampton, Irwin, Spilsbury, & Korbin, 2007). Conceptual models of the etiology of maltreatment (e.g. Belsky, 1980; Cicchetti & Carlson, 1989; Garbarino, 1977) have highlighted the importance of viewing maltreatment in a context that includes the individual, family, and community/society, with maltreatment resulting from a "toxic relational environment" (Cicchetti & Toth, 2005). As Ammerman, Hasselt, and Hersen (1988) explained, maltreatment occurs during problematic situations arising from child and caregiver responses to the given situation. Both individual and contextual factors act synergistically to produce the toxic relational environment in which maltreatment occurs. It follows that risk factors for maltreatment increase the overall likelihood of creating such environments but are neither necessary nor sufficient to cause maltreatment (Ammerman et al., 1988). This explanation provides insight into the challenges of creating risk factor checklists to aid child welfare workers in predicting the risk for maltreatment within a given family.

Over the past 20 years, maltreatment of children with disabilities has surfaced as an issue of particular concern as these children are particularly vulnerable and overrepresented in the maltreated population. Although only 8-20% of children under the age of 18 years in the U.S. have a disability, state agencies have reported up to 47% of the children served by their Child Protective Services have some form of disability (Brault, 2012; Bethell, Read, Blumberg, & Newacheck, 2008; U.S. Department of Health & Human Services, Administration on Children, Youth & Families, Administration on Children, Youth & Families, Children's Bureau, 2013). However, research in this area has lagged, in part because of state and agency differences in defining and identifying disabilities. Nevertheless, population-based studies have found a significantly higher prevalence of maltreatment in disabled children as compared to non-disabled children (Crosse, 1992; Spencer et al., 2005; Sullivan & Knutson, 2000). Additionally, among children with disabilities, the prevalence of different types of maltreatment (e.g. physical abuse, neglect) varies by age and disability category (e.g. speech/language delay, physical disability) (Sullivan & Knutson, 2000). Conceptually, these findings are consistent with the transactional model previously discussed; although the general stresses and challenges of having a child with a disability may be similar across disability categories and may exacerbate problem situations overall, the needs of the child and the interactions between the caregiver and the child vary by age and disability type. For example, a 5-year-old with profound developmental delays will need different support and will behave and interact with others quite differently than a physically disabled child of the same age. Similarly, the needs, behaviors, and interactions of the physically disabled 5-year-old are likely quite different than a 6-month old with the same disability.

As a group, birth defects are a leading cause of disability in the U.S. (McKenna, Michaud, Murray, & Marks, 2005). In addition, several studies have found affected children to be at an increased risk for maltreatment and out-of-home foster care placement compared to children without birth defects (Needell & Barth, 1998; Putnam-Hornstein & Needell, 2011). However, little is known about maltreatment in this population. In our previous study using the same 10 year birth cohorts, we examined maltreatment prior to age two in children with specific birth defects: Down syndrome, cleft lip with or without cleft palate (CL ± P), and spina bifida (author citation). These three conditions were selected because they are relatively common, generally easy to identify at birth, and differ from one another with respect to the types of disabilities that characterize affected individuals. Children with Down syndrome are characterized by developmental and cognitive delay, expressive language delay, and adaptive behavior problems (Chapman & Hesketh, 2000; Fidler, 2005; Korenberg et al., 1994). Children with CL ± P often require multiple surgeries, and many have additional challenges such as hearing loss, speech and language delays, feeding problems, dental problems, learning disabilities, and difficulties with social relationships (Broder, Richman, & Matheson, 1998; Centers for Disease Control & Prevention, National Center on Birth Defects & Developmental Disabilities, 2017c; Habel, Sell, & Mars, 1996). Children with spina bifida generally have varying degrees of lower limb paralysis and are at risk for motor delays and physical disabilities, bladder control/incontinence, skin problems, and specific learning disabilities (Centers for Disease Control & Prevention, National Center on Birth Defects & Developmental Disabilities, 2017a). Findings from this study were similar to those in the disability literature in that some but not all birth defects were associated with an increased risk of maltreatment, and the prevalence by age and types of maltreatment varied across the three birth defects examined. Specifically, in our previous study we found that children under the age of two with cleft lip with or without cleft palate and spina bifida were at an increased risk for maltreatment as compared to their unaffected peers. The risk of maltreatment was not significantly different between children with Down syndrome and children unaffected by birth defects. Across all groups, the risk of maltreatment differed by maltreatment type and age. Most notably, as compared to unaffected children, children with cleft lip with or without cleft palate and spina bifida were more likely to have a substantiated maltreatment report in the first month of life, and children with any of the three birth defects examined were more likely to have a substantiated report of medical

The present study was undertaken to further our understanding of maltreatment in children with these three specific birth defects. National reports have demonstrated that the prevalence of maltreatment is highest during the first few years of life (11–25/1,000) and decreases with age to a relatively steady rate of 6–7/1,000 during adolescence (U.S. Department of Health & Human Services, Administration on Children, Youth & Families, 2018). We aimed to determine whether the prevalence of maltreatment decreased with age in children with birth defects, similar to the patterns in the general population, and whether differences in maltreatment between birth defect groups remained as children aged. Additionally, we sought to identify factors at the child-, family-, and neighborhood-levels associated with an increased risk of maltreatment in children over age 2. These factors included gestational age, birth weight, gender, plurality, birth defects status, maternal race/ethnicity, parity, maternal age at birth, marital status at birth,

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