

Occurrence and Family Impact of Elopement in Children With Autism Spectrum Disorders

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KEY WORDS

autism spectrum disorders, elopement, wandering

ABBREVIATIONS

AD—autistic disorder

ASD—autism spectrum disorder

IAN—Interactive Autism Network

PDD—pervasive developmental disorder

SCQ—Social Communication Questionnaire

SRS—Social Responsiveness Scale

Drs P. Law and Anderson designed and implemented the survey instrument and were responsible for data collection; Drs Daniels, Anderson, and P. Law conducted statistical analyses; Drs Daniels and Anderson drafted the first manuscript; Drs Rice, Mandell, Hagopian, and K. Law made substantial contributions to interpretation of the data and critical review of the manuscript for key intellectual content; and all authors approved the final version to be published.

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

www.pediatrics.org/cgi/doi/10.1542/peds.2012-0762

doi:10.1542/peds.2012-0762

Accepted for publication Jun 20, 2012

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PEDIATRICS (ISSN Numbers: Print, 0031-4005; Online, 1098-4275).

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FINANCIAL DISCLOSURE: Dr Daniels was employed by Kennedy Krieger Institute through the submission of the manuscript. On February 26, she started a position with Autism Speaks. Autism Speaks is a financial supporter of the IAN Project, the study through which the elopement survey was implemented. The other authors have indicated they have no financial relationships relevant to this article to disclose.

FUNDING: Supported by the Autism Research Institute, the Autism Science Foundation, Autism Speaks, the Global Autism Collaboration, and the National Autism Association.



WHAT'S KNOWN ON THIS SUBJECT: Anecdotal accounts that suggest elopement behavior occurs in children with autism spectrum disorders (ASDs), that injuries and fatalities can result, and that associated family burden and stress are substantial. However, there has been little research characterizing the phenomenon or its frequency.



WHAT THIS STUDY ADDS: Nearly half of children with an ASD elope, and more than half of these “go missing.” Elopement is associated with autism severity, and is often goal-directed. Addressing elopement behavior is an important aspect of intervention for many individuals with ASDs.

abstract

OBJECTIVES: Anecdotal reports suggest that elopement behavior in children with autism spectrum disorders (ASDs) increases risk of injury or death and places a major burden on families. This study assessed parent-reported elopement occurrence and associated factors among children with ASDs.

METHODS: Information on elopement frequency, associated characteristics, and consequences was collected via an online questionnaire. The study sample included 1218 children with ASD and 1076 of their siblings without ASD. The association among family sociodemographic and child clinical characteristics and time to first elopement was estimated by using a Cox proportional hazards model.

RESULTS: Forty-nine percent ($n = 598$) of survey respondents reported their child with an ASD had attempted to elope at least once after age 4 years; 26% ($n = 316$) were missing long enough to cause concern. Of those who went missing, 24% were in danger of drowning and 65% were in danger of traffic injury. Elopement risk was associated with autism severity, increasing, on average, 9% for every 10-point increase in Social Responsiveness Scale T score (relative risk 1.09, 95% confidence interval: 1.02, 1.16). Unaffected siblings had significantly lower rates of elopement across all ages compared with children with ASD.

CONCLUSIONS: Nearly half of children with ASD were reported to engage in elopement behavior, with a substantial number at risk for bodily harm. These results highlight the urgent need to develop interventions to reduce the risk of elopement, to support families coping with this issue, and to train child care professionals, educators, and first responders who are often involved when elopements occur.

Pediatrics 2012;130:1–8

Autism spectrum disorders (ASDs) are neurodevelopmental disorders characterized by social-communication deficits and restrictive and repetitive behaviors¹ and are estimated to occur in 1 of every 88 children.² Families of children with ASD have reported that these children often place themselves in danger by “wandering” or “eloping.” In this article, elopement is defined as a dependent person exposing him or herself to potential danger by leaving a supervised, safe space or the care of a responsible person.

Elopement may be a significant contributor to mortality in individuals with ASD, which has been reported to be nearly twice that of the general population,³ especially mortality owing to accidents, such as suffocation and drowning.⁴ Despite reports of injuries, fatalities, and increased family burden, little research on elopement behavior in individuals with ASD has been conducted.⁵

Studies examining elopement among individuals with ASD have been very small, often focusing on a specific behavioral intervention used to address elopement in 1 or 2 individuals.^{6–8} Findings from the few studies assessing elopement frequency among larger groups of individuals with ASD suggest that it is fairly common. One study of challenging behaviors among 166 children with severe intellectual disability and/or autism found 23% and 16% experienced minor and marked wandering problems, respectively.⁹ Another study of 161 severely affected adults with ASD living in an institution found 34% of those with autistic disorder (AD) and 19% of those with pervasive developmental disorder (PDD) not otherwise specified exhibited elopement behavior.¹⁰ The objective of the current study was to provide a preliminary estimate of the reported occurrence and characteristics of elopement among children with ASD in

community settings and to document factors associated with elopement.

METHODS

Study Population

Study data came from the Interactive Autism Network (IAN), an online research database and autism registry. Families are eligible to participate if they have a child with a professionally diagnosed ASD and live in the United States. Research consent and, if appropriate, child assent are obtained upon registration. As of February 2012, more than 14 500 individuals with ASD were registered. This study was approved by the Johns Hopkins Medical Institutions Institutional Review Board (NA_00002750).

Sample

IAN families with an affected child between the ages of 4 and 17 ($n = 10\,634$) were eligible to take the elopement survey. To better estimate elopement occurrence, we sought to ensure the highest survey completion rate possible in a group of IAN's most active participants ($n = 1098$). These families received multiple communications and were entered into a prize drawing on survey completion. African Americans were oversampled in this group to compensate for their lower overall rate of participation in IAN. Because of the autism community's interest in elopement, all other qualifying IAN participants ($n = 9536$) were also invited to participate, although they received fewer communications and no incentive. All families were asked to participate, whether their child had ever eloped or not. As of November 8, 2011, 1367 families had completed the survey. Completion rates for the incentivized and nonincentivized groups were 60% and 7%, respectively.

There was no significant difference between respondents from the 2 groups

in maternal education level, child age, gender, or ethnicity. There was a slight difference in race ($P = .012$), with more than 7% of the incentivized group and only 4% of the nonincentivized group reporting African American race. Contrary to expectation, those in the incentivized group reported higher elopement rates than those in the nonincentivized group (52% vs 46%; $P = .044$). As overall differences were minor, the 2 groups were combined for analysis.

The Social Communication Questionnaire (SCQ) is an ASD screening instrument^{11–13} with scores ranging from 0 to 39; a cutoff of 12 is suggested for a child who is considered at risk for ASD.¹² IAN families complete an online version, and SCQ scores serve to confirm or refute parent-reported ASD diagnoses.^{14,15} A clinical validation study of 107 IAN children with online SCQ scores of 12 or above demonstrated that 99% are ASD positive according to the Autism Diagnostic Interview–Revised.¹⁴ Accordingly, 83 families with a child without an SCQ and 66 whose child had a score lower than 12 were dropped from analysis for a final sample of 1218, consisting of 620 incentivized and 598 nonincentivized families.

Measures

An elopement questionnaire was developed in early 2011 by a team of ASD researchers, clinicians, and parent advocates responding to the Interagency Autism Coordinating Committee's urgent call for data on this topic.^{5,16} The survey was launched online in March 2011.

Elopement

The primary outcome of interest was elopement status (modeled as “ever versus never” in the unadjusted analyses and “time to first elopement” in the adjusted analyses). Because a tendency to run from safe spaces and adult supervision is a typical toddler behavior, the observation start period

was set at age 4, after which elopement or wandering is increasingly non-normative.¹⁷ Age at first elopement was coded as the first year at or after age 4 that an affected child or typical sibling attempted to elope. “Missing” status (ever versus never) was a secondary dependent variable; a child who eloped and had gone missing long enough to cause concern was coded as missing, whereas those who had not were coded as non-missing. (Given that concepts like “a safe time or distance away” vary greatly depending on a child’s age, level of functioning, and the setting, concern for a child’s safety was determined by the parent who would take such factors into account.) If a child had gone missing, information was collected on resources mobilized, length of time missing, and dangers encountered.

Elopement Behavior

Parents were asked from what locations their child had eloped, and at what age elopement attempts were most frequent. They also had the opportunity to describe what they believed motivated their child’s elopement by “checking all that apply” from a list of descriptors (eg, “seems to elope completely at random,” “is trying to escape an anxious situation”) and to describe their child’s experience while eloping from a list including “anxious,” “playful,” “focused, with intent to go somewhere or do something,” and “confused or ‘in a fog.’”

Impact of Elopement on the Family

Parents were asked to rank stress caused by elopement in comparison with other stressors associated with caring for children with ASD, and to specify if elopement kept them from getting a good night’s sleep or attending or enjoying activities outside the home. They were also asked whether they had received guidance regarding elopement from others.

Clinical Characteristics

ASD Diagnosis and History of Skill Loss

Forty-eight percent ($n = 587$) of affected children had AD, 19% ($n = 227$) had Asperger disorder, and 33% ($n = 404$) had PDD not otherwise specified, PDD, or ASD, henceforth grouped under “other ASDs.” A history of skill loss (ie, regression) was reported in 40% of cases.

The Social Responsiveness Scale

The Social Responsiveness Scale (SRS) is a validated 65-item rating scale that measures the severity of ASD in children ages 4 through 18 with high inter-observer reliability.¹⁸ This study used the continuous T score measure of the SRS, with a higher score reflecting greater severity.¹⁹ A score of 65 to 75 is interpreted as the mild to moderate range, whereas a score of 76 or higher is considered to be in the severe range. The mean SRS T score for those with an SRS in our sample ($n = 1090$) ranged from 37 to 124, with a mean of 86.7 (SD 14.0).

Developmental Quotients

Parents were asked to estimate their child’s intellectual, social, and communication functioning. (“Intellectually, my child functions at the level of a person who is ___ years old.”) Developmental quotients for each of these domains were created by dividing the functional age reported by the child’s chronological age and multiplying by 100. A score of <100 indicates being developmentally behind, whereas a score of >100 indicates being ahead of expected functioning for current age. The frequency with which the child responded to his or her name when called and was able to communicate his or her name, address, or phone number by any means were also assessed.

Sociodemographic Characteristics

Participant sociodemographics, including child’s age, gender, race, ethnicity,

and mother’s education, were obtained from the IAN Research database.²⁰ Urbanicity, based on zip code, was analyzed by using the 6-level 2006 National Center for Health Statistics Urban-Rural Classification Scheme for Counties²¹ and collapsed into the following categories: large city, suburban, small/medium city, and rural.

Statistical Analysis

Means and proportions were calculated for each predictor variable as a function of a child’s elopement status (ever versus never), and differences were tested using t tests or χ^2 tests, as appropriate. The relative risk of elopement was estimated by using a Cox proportional hazards model, which is a survival model that compares the risk of elopement among children using time from age 4 until first elopement as the outcome variable.^{22,23} The Cox model accounts for differences in follow-up time across children and, specifically, the increased risk of elopement among children observed for longer periods of time (ie, older children). A covariate was included in the adjusted Cox model if it was statistically associated with ever eloping at $P \leq .2$ in the bivariate analysis.²⁴ Proportional hazards were assessed through global tests of the proportional hazards assumption, and collinearity was examined by using the variance inflation factor. Measures of central tendency and frequencies were used to describe elopement behavior, children who go missing, and the impact of elopement on family members. In addition, χ^2 tests were used to test differences in elopement behavior by ASD diagnosis, where appropriate. All analyses were performed using Stata Statistical Software version 11.0 (Stata Corp, College Station, TX).

RESULTS

Elopement Prevalence

Forty-nine percent ($n = 598$) of survey respondents reported that their child

had attempted to elope at least once after age 4. A total of 316 children, 26% of the entire sample or 53% of those who exhibited elopement behavior, went missing long enough to cause concern.

Comparison With Nonaffected Siblings

Thirteen percent of siblings of children with ASD had ever eloped at or after age 4 and children with ASD were more likely to elope than unaffected siblings at all ages (Fig 1). For example, from age 4 through 7, 46% of affected children eloped compared with 11% of unaffected siblings. Likewise, from age 8 through 11, 27% of affected children eloped compared with 1% of unaffected siblings.

Elopement Behavior

The most common locations from which children eloped were the child's own home or other home (74%), stores (40%), and classrooms or schools (29%). Elopement attempts peaked at age 5.4 years (SD 2.5). Of parents reporting on the "worst year ever" for elopement, 29% said that their child attempted to elope multiple times a day; an additional 35% reported that attempts occurred at least once per week.

Parents were asked to describe their child's reasons for and experiences

while eloping by choosing from multi-response checklists. The most frequently reported motivations were "simply enjoys running and/or exploring" (53%), "tries to reach a place he or she enjoys" (36%), "tries to escape an anxious situation" (34%), "tries to escape uncomfortable sensory stimuli" (30%), and "pursues his or her special topic" (30%). Children whose parents believed they eloped because they enjoyed running/exploring or were trying to reach a certain place they enjoyed were more likely to have AD or other ASD ($P < .001$ and $P = .011$, respectively), whereas parents of children with Asperger disorder were more likely to report the behavior was driven by the need to escape an anxious situation ($P < .001$). The most frequently reported child experiences during elopement were "focused, with intent to go somewhere or do something" (50%), "content or happy" (37%), "playful" (30%), "exhilarated" (27%), and "anxious" (17%). Children with AD or other ASD were more likely to be happy, playful, or exhilarated ($P < .001$) when eloping, whereas children with Asperger disorder were more likely to be anxious ($P = .001$) or "sad or confused" ($P = .002$).

Correlates of Ever Eloping or Ever Missing

Characteristics associated with elopement are presented in Table 1. Children

who ever eloped were older ($P = .012$) and more likely to have AD ($P = .037$) and score higher on the SRS ($P < .001$) than nonelopers. Elopement behavior was less likely in children who responded to their name ($P = .01$). Last, children who eloped were more likely to have lower intellectual ($P = .004$) and communication ($P = .019$) developmental quotients compared with nonelopers. After adjusting for other characteristics in the model, the risk of elopement increased an average of 9 percentage points for every 10-point increase in SRS score (relative risk 1.09, 95% confidence interval: 1.02, 1.16; $P = .013$).

Characteristics of children by missing status are presented in Table 2. Among children who eloped, children who went missing were older ($P < .001$), more likely to have experienced skill loss ($P = .018$), and less likely to respond to their name ($P = .001$). Missing children were also more likely to have lower intellectual ($P = .001$), social ($P = .017$), and communication ($P = .024$) developmental quotients than non-missing children. Children were missing for 41.5 (SD 52.4) minutes, on average. Parents choosing from a multi-response list reported that the most frequently mobilized resources after children went missing were neighbors (57%), police (35%), and school (30%) and store personnel (26%). The most frequently selected consequences of the missing period included "physical restraint" of the child (9%) and "emotional trauma" (7%). Close calls with traffic injury and drowning were reported for 65% and 24% of missing children, respectively.

Impact of Elopement on the Family

Among parents of elopers, 43% reported the issue had prevented family members from getting a good night's sleep, and 62% reported that elopement concerns had prevented their

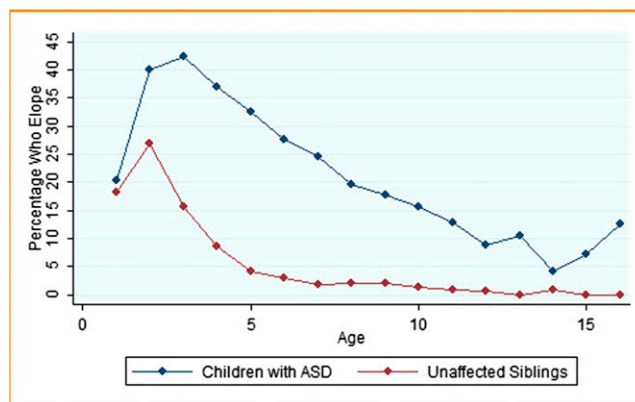


FIGURE 1 Reported rates of elopement at specific ages: a comparison of children with ASD and unaffected siblings. Children with ASD, $n = 901$; unaffected siblings, $n = 1076$.

TABLE 1 Characteristics of Children With ASDs by Reported Elopement Status

Characteristic	Total Sample (<i>n</i> = 1218)	Ever Eloper (<i>n</i> = 598)	Never Eloper (<i>n</i> = 620)	<i>P</i> Value
Sociodemographic characteristics				
Parent age, mean (SD)	41.2 (7.0)	41.3 (7.1)	41.2 (7.0)	.877
Parent gender: Female, <i>n</i> (%)	1152 (95)	565 (94)	587 (95)	.880
Child age, mean (SD)	9.7 (3.5)	10.0 (3.5)	9.5 (3.5)	.012
Child gender: Male, <i>n</i> (%)	1016 (83)	501 (84)	515 (83)	.737
Race, <i>n</i> (%)				
White	1093 (90)	526 (88)	567 (91)	.055
Black	70 (6)	44 (7)	26 (4)	
Other	55 (5)	28 (5)	27 (4)	
Hispanic, <i>n</i> (%)	94 (8)	48 (8)	46 (7)	.691
Maternal education level, <i>n</i> (%) (<i>n</i> = 1141)				
High school or less	111 (10)	53 (9)	58 (10)	.897
Some college	368 (32)	181 (32)	187 (32)	
Bachelor's or higher	662 (58)	331 (59)	331 (57)	
Urbanicity, <i>n</i> (%)				
Large city	294 (24)	147 (25)	147 (24)	.846
Suburban	388 (32)	195 (33)	193 (31)	
Small/medium city	387 (32)	183 (31)	204 (33)	
Rural	149 (12)	73 (12)	76 (12)	
Clinical characteristics				
Current ASD diagnosis, <i>n</i> (%)				
AD	587 (48)	310 (52)	277 (45)	.037
Asperger disorder	227 (19)	100 (17)	127 (20)	
Other ASD ^a	404 (33)	188 (31)	216 (35)	
Psychiatric comorbidities				
Depression (<i>n</i> = 1191)	71 (6)	36 (6)	35 (6)	.727
Anxiety (<i>n</i> = 1191)	207 (17)	106 (18)	101 (17)	.427
Attention-deficit/hyperactivity disorder (<i>n</i> = 1189)	329 (28)	161 (28)	168 (28)	.919
SRS <i>t</i> score, mean (SD) (<i>n</i> = 1090)	86.7 (14.0)	88.4 (13.3)	85.1 (14.5)	<.001
Skill loss, <i>n</i> (%) (<i>n</i> = 1199)	478 (40)	241 (41)	237 (39)	.359
Responds to name when called, <i>n</i> (%)	1095 (90)	524 (88)	571 (92)	.010
Able to communicate name/address, <i>n</i> (%) (<i>n</i> = 1217)	798 (66)	383 (64)	415 (67)	.271
Intellectual developmental quotient, mean (SD) (<i>n</i> = 1180)	77 (32)	75 (32)	80 (32)	.004
Social developmental quotient, mean (SD) (<i>n</i> = 1184)	54 (37)	53 (47)	56 (22)	.119
Communication developmental quotient, mean (SD) (<i>n</i> = 1188)	69 (74)	64 (57)	74 (88)	.019

^a PDD not otherwise specified, generic ASD, and generic PDD.

family from attending or enjoying activities outside the home. For 56%, elopement was one of the most stressful behaviors they had to cope with as caregivers of a child with ASD, and 50% reported receiving no guidance from anyone on preventing or addressing their child's elopement behavior.

DISCUSSION

Previous studies examining elopement among children with ASD have often grouped elopement under the larger category of "challenging behaviors,"

making it difficult to isolate elopement risk factors, examine potential consequences, and propose strategies for intervention.^{9,10} Findings from the current study confirm that reported elopement is common in community settings, that children who elope face many dangers, and that elopement adds to family stress.

Half of children with ASD in this study eloped and were far more likely than unaffected siblings to do so at every age. Greater autism severity was associated with increased elopement risk. Among elopers, half went missing long enough

to cause concern. Advocacy groups have reported that children with ASD are more difficult to keep safe because of their wandering behavior, and that parents fear being viewed as neglectful when these children succeed in escaping safe spaces.⁵ These data illustrate that unaffected siblings have much lower rates of elopement than children with ASD and it is doubtful that, as a group, these parents are remiss in keeping children safe.

Based on reports by parents whose children went missing, close calls with calamities like traffic injury or drowning are frequent, with police called in more than a third of cases. Many families lose sleep or give up enjoyable activities outside the home as a result of elopement concerns. The former could easily decrease a parent's ability to cope, whereas the latter could increase a family's isolation and diminish social supports.

The children's subjective experience while eloping, as described by parents, is more often anxious for children with Asperger disorder, but happy, playful, or exhilarated for children with autism and other ASDs. In either case, much of the behavior appears goal directed. Nearly half of parents reported their child's elopement was focused with intent to go somewhere or do something, whereas only a tenth reported their child was confused or in a fog or sad and lost. This finding is consistent with the behavioral assessment and treatment literature on elopement in ASD, which shows that elopement, like aggression and other disruptive behaviors sometimes seen in individuals with ASD, is usually goal oriented. The 7 previously published studies^{6–8,25–28} reporting collectively on 9 children with ASD found that elopement occurred to gain access to preferred items and activities, attention, escape, or to produce sensory stimulation. Commonly used functional assessment-based behavioral

TABLE 2 Characteristics of Children Who Go Missing (*n* = 598)

Characteristic	Ever Missing (<i>n</i> = 316)	Never Missing (<i>n</i> = 282)	<i>P</i> Value
Sociodemographic characteristics			
Parent age, mean (SD)	41.9 (7.4)	40.6 (6.7)	.021
Parent gender: Female, <i>n</i> (%)	297 (94)	268 (95)	.575
Child age, mean (SD)	10.5 (3.5)	9.4 (3.4)	<.001
Child gender: Male, <i>n</i> (%)	273 (86)	228 (81)	.067
Race, <i>n</i> (%)			
White	283 (90)	243 (86)	.174
Black	23 (7)	21 (7)	
Other	10 (3)	18 (6)	
Hispanic, <i>n</i> (%)	22 (7)	26 (9)	.310
Maternal education level, <i>n</i> (%) (<i>n</i> = 565)			
High school or less	31 (10)	22 (8)	.652
Some college	95 (32)	86 (32)	
Bachelor's or higher	171 (58)	160 (60)	
Urbanicity, <i>n</i> (%)			
Large city	78 (25)	69 (24)	.906
Suburban	106 (34)	89 (32)	
Small/medium city	96 (30)	87 (31)	
Rural	36 (11)	37 (13)	
Clinical characteristics			
Current ASD diagnosis, <i>n</i> (%)			
AD	172 (54)	138 (49)	.406
Asperger disorder	50 (16)	50 (18)	
Other ASD ^a	94 (30)	94 (33)	
Psychiatric comorbidities			
Depression (<i>n</i> = 580)	19 (6)	17 (6)	.964
Anxiety (<i>n</i> = 580)	54 (18)	52 (19)	.737
Attention-deficit/hyperactivity disorder (<i>n</i> = 579)	91 (30)	70 (25)	.230
SRS <i>t</i> score, mean (SD), (<i>n</i> = 538)	89.1 (13.2)	87.6 (13.3)	.188
Skill loss, <i>N</i> (%) (<i>n</i> = 585)	141 (46)	100 (36)	.018
Responds to name when called, <i>n</i> (%)	264 (84)	260 (92)	.001
Able to communicate name/address, <i>n</i> (%)	200 (63)	183 (65)	.684
Intellectual developmental quotient, mean (SD) (<i>n</i> = 577)	71 (32)	79 (32)	.001
Social developmental quotient, mean (SD) (<i>n</i> = 581)	48 (22)	58 (65)	.017
Communication developmental quotient, mean (SD) (<i>n</i> = 585)	59 (40)	70 (71)	.024

^a PDD not otherwise specified, generic ASD, and generic PDD.

interventions were found to be effective in reducing elopement in all 9 cases, suggesting that well-established behavioral assessment and treatment procedures for other problem behaviors associated with ASD are effective with elopement. One challenge will be to make these scalable and available to many more families.

Future research should elucidate whether there are different types of elopement, requiring different prevention strategies. Dementia researchers have begun to better characterize wandering behavior, proposing an empirically based typology with the aim of working toward

more effective interventions.²⁹ The current study provides preliminary findings that may serve as a foundation for similar work in ASDs. In addition, research should explore how best to support families coping with this extremely stressful behavior.

Some study limitations deserve mention. First, findings may not be generalizable to all children with ASD, as parents choosing to participate in the IAN Research registry are more likely to be white and highly educated compared with the general population. This is, however, the case for many other online

and clinic-based studies.^{30–32} Indeed, there is evidence that Web-based studies are more inclusive than center-based studies, and that the larger sample sizes made possible by these yield larger actual numbers of minority participants even when percentages are low.^{33,34}

Another potential limitation is selection bias among the IAN participants who chose to take the survey. Compared with the entire IAN Research population, respondents were more likely to be white, non-Hispanic, highly educated, and have younger affected children, but less likely to have children in the category of other ASD, or to report skill loss. As there were no to slight differences in elopement rates across relevant demographic groups, however, there is little evidence of associated bias. Selection bias was also possible because participants knew the survey would focus on elopement; however, nonincentivized respondents, who might have been more likely to participate because of an interest in elopement alone, actually reported a lower rate of elopement than the incentivized group.

In addition, we lacked measures of autism severity that may have been pertinent to elopement risk, such as level of rigidity or frequency of aggressive behaviors. Also, given the complexity of this question, it was beyond the scope of this article to evaluate shared child/sibling environmental factors, such as parent-related issues, culture, or locale, and hence within-family risk. Future studies should address such factors.

Last, because participation in this study required having a living child with ASD, families of children who lost their lives while eloping³⁵ were not included. It was therefore not possible to estimate the number of fatalities that occur due to elopement.

CONCLUSIONS

This study provides the first estimate of elopement occurrence in a US

community-based sample of more than 1200 children with ASD. Nearly half of families report that their child eloped at least once at or after age 4, with a substantial number going missing long enough to cause concern. Parents report high levels of stress and little support as they cope with elopement. Research

further characterizing the behavior and developing and refining interventions to address elopement is urgently needed. In the meantime, it is our hope that the results of this study will inform families, physicians, educators, and first responders who currently grapple with the consequences of elopement.

ACKNOWLEDGMENTS

We acknowledge and thank the organizations that helped to develop and fund the elopement questionnaire: the Autism Research Institute, the Autism Science Foundation, Autism Speaks, the Global Autism Collaboration, and the National Autism Association.

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Pediatrics; originally published online October 8, 2012;

DOI: 10.1542/peds.2012-0762

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