



Reported Wandering Behavior among Children with Autism Spectrum Disorder and/or Intellectual Disability

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Objective To characterize wandering, or elopement, among children with autism spectrum disorder (ASD) and intellectual disability.

Study design Questions on wandering in the previous year were asked of parents of children with ASD with and without intellectual disability and children with intellectual disability without ASD as part of the 2011 Survey of Pathways to Diagnosis and Services. The Pathways study sample was drawn from the much larger National Survey of Children with Special Health Care Needs conducted in 2009-2010.

Results For children with special healthcare needs diagnosed with either ASD, intellectual disability, or both, wandering or becoming lost during the previous year was reported for more than 1 in 4 children. Wandering was highest among children with ASD with intellectual disability (37.7%) followed by children with ASD without intellectual disability (32.7%), and then children with intellectual disability without ASD (23.7%), though the differences between these groups were not statistically significant.

Conclusions This study affirms that wandering among children with ASD, regardless of intellectual disability status, is relatively common. However, wandering or becoming lost in the past year was also reported for many children with intellectual disability, indicating the need to broaden our understanding of this safety issue to other developmental disabilities. (*J Pediatr* 2016;174:232-9).

Autism spectrum disorder (ASD) is a complex neurodevelopmental disorder characterized by a range of impairments in social communication and interaction as well as in restricted and repetitive behaviors and interests.¹ ASD can co-occur with other medical and developmental conditions (eg, epilepsy, intellectual disability) and with other symptoms, such as variable attention and limited verbal language, that pose potential challenges to everyday functioning.¹ Although little is known about the long-term health of people with ASD, higher than expected mortality rates have been documented in association with epilepsy, severe intellectual disability, and accidents, such as suffocation or drowning.²⁻⁴ Parents of children with ASD have worked to raise awareness of a tendency for these children to wander as a preventable source of accidents and untimely death.^{5,6} Wandering, also called elopement, occurs when someone leaves a safe area or a responsible caregiver and can result in potential injury or harm to that person; wandering is a behavior that goes beyond a brief period, such as when a typical toddler may run off from a caregiver.^{7,8} Challenges with communication, social interaction, attention, reasoning, unusual interests, and learning can potentially put some people with developmental disabilities, such as ASD or intellectual disability, at risk for becoming lost or injured because of wandering. Recently, parents shared stories of tragic accidents and deaths with the Interagency Autism Coordinating Committee and asked for more help understanding and preventing safety risks related to wandering.^{6,9}

Most research on the occurrence and prevention of wandering or elopement is based on elderly adults with dementia-associated cognitive impairments.¹⁰ Studies of wandering among individuals with ASD and intellectual disability have been based on limited samples^{7,11-14} or have focused on specific behavioral interventions used to address elopement in 1 or 2 individuals.¹⁵⁻²⁰ A larger study among children with severe ASD and/or intellectual disability reported wandering problems classified as “minor” among 23% of the sample and as “marked” among 16%.¹² Another study of 161 severely affected adults with ASD living in an institution found 34% of those with autistic disorder and 19% of those with pervasive developmental disorder-not otherwise specified were reported

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| ADHD | Attention-deficit hyperactivity disorder |
| ASD | Autism spectrum disorder |
| IAN | Interactive Autism Network |
| NCHS | National Center for Health Statistics |
| NS-CSHCN | National Survey of Children with Special Health Care Needs |

as leaving supervision without permission (elopement).¹³ Based on a recent survey of parents of children with autism enrolled in a large, online autism research registry, about one-half (49%) of children and youth with an ASD were ever reported to have wandered after the age of 4 years.⁷ Of those children, 26% were missing more than momentarily so that serious concern was reported. Among reported wanderers, they were most commonly reported in danger of drowning or traffic injury. Parents reported the child wandered off most often from the family's own home or another home (74%), stores (40%), and classrooms or schools (29%). The primary reasons reported for wandering included enjoyment of running or exploring, getting to a place or object he or she enjoys (eg, water or a road sign), and to escape a demand or situation (eg, loud noise).

Given the frequency of caregiver report of wandering as a major problem behavior and the potential for significant harm to the individual, it is important to understand more about the occurrence and characteristics of people with disabilities who wander. Currently, there are small interventional studies demonstrating the utility of individualized functional behavioral techniques in the treatment of wandering with people with ASD and/or intellectual disability.¹³⁻¹⁸ In addition, there are burgeoning efforts to raise awareness, develop strategies, and use technology for prevention and intervention, but with limited data to inform these efforts.^{5,21,22} This study describes the reported occurrence of wandering from a nationally representative sample of children with current ASD and/or intellectual disability and provides the frequency, location, characteristics of children, and prevention attempts across these diagnostic groups.

Methods

Data for this study are from the 2011 Survey of Pathways to Diagnosis and Services (also known as the "Pathways" study) conducted by the National Center for Health Statistics (NCHS).²³ The Pathways study sample was drawn from the much larger National Survey of Children with Special Health Care Needs (NS-CSHCN) conducted in 2009-2010 by NCHS and funded by the Maternal and Child Health Bureau.²⁴ The NS-CSHCN was a cross-sectional, population-based random-digit dial telephone survey in all 50 states and the District of Columbia among households with children age 18 years and younger, and was intended to assess the health, functional status, and service use of children with special healthcare needs. Participating parents/caregivers were asked a series of screening questions indicating special healthcare needs (responses indicating the child has a physical, emotional, developmental, or behavioral problem that is expected to last more than 12 months and requires medical, educational, or other therapeutic services).²⁵ If more than 1 child was eligible in a given household, one was randomly selected to be the subject of the caregiver survey. The data collection procedures were approved by both the NCHS Research Ethics Review Board and the institutional review

board at National Opinion Research Center at the University of Chicago.

As part of the NS-CSHCN, caregivers (almost always parents) were asked if "a doctor or health care provider had ever told them that their child had autism, Asperger disorder, pervasive developmental disorder, or other ASD?", "...any developmental delay that affects [his/her] ability to learn?", "...or an "intellectual disability or mental retardation?" Parents were also asked if the child currently had the condition. In addition, questions were asked about the presence of co-occurring psychiatric conditions, including "depression," "anxiety problems," "attention-deficit disorder or attention-deficit hyperactivity disorder (ADHD)," or "behavioral or conduct problems." These conditions were first identified in the NS-CSHCN and confirmed in Pathways.

The Pathways follow-up study was completed in 2011 on a sample of 4032 children ages 6-17 years whose parent or guardian completed the NS-CSHCN in 2009-2010 and reported they had once been told by a doctor or other health-care provider that the child had ASD, intellectual disability, or developmental delay. There were 2 components of the Pathways follow-up study, a telephone survey and a self-completed questionnaire. This analysis includes responses from both components. For this article, the analyses were restricted to children with a reported current diagnosis of ASD or intellectual disability at the time of the Pathways survey ($n = 2077$). Children were subdivided further into ASD only ($n = 1117$), ASD with intellectual disability ($n = 303$), and intellectual disability only ($n = 657$). Parents were asked to confirm the previous NS-CSHCN diagnosis from a doctor or healthcare provider and were also asked the follow-up question "to the best of your knowledge does (your child) currently have (autism or ASD) or (an intellectual disability)?" The completion rate for the Pathways telephone interview was 62%. (Of those parents with eligible CSHCN, 71% were successfully recontacted for Pathways and 87% of them agreed to participate in the telephone interview). Then, 75% of them returned the mailed questionnaire. More information about both Pathways and the NS-CSHCN, including the consent procedures, can be found at <http://www.cdc.gov/nchs/slaits.htm>.

Child demographics included child's age, sex, race, ethnicity, and current health insurance coverage. Household characteristics included age of mother at child's birth, highest education level in the household, family structure, number of children in the household, family income (recoded as a percentage of the federal poverty level based on the number of household members), housing status, and residence in metropolitan statistical area (federally defined core urban geographic areas). Demographic and socioeconomic characteristics of the child and family were obtained either at the time of the Pathways survey or were drawn from the NS-CSHCN.

Parents were asked if their child had wandered off or become lost from each of 4 locations (home; someone else's home; school, daycare, or camp; or from a store or other public place) in the past year (**Table I**; available at www.jpeds.com). In addition, parents were asked if they

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