A Survey of Family Response to Elopement Among Patients with Autism Spectrum Disorder

Allan M Andersen, MD1,2; J. Kiely Law, MD, MPH2,3,4; Paul H. Lipkin, MD2,3,4

1Department of Mental Health, Johns Hopkins Bloomberg School of Public Health; 2Kennedy Krieger Institute; 3Johns Hopkins University School of Medicine; 4Interactive Autism Network

Background

- Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by impairments in social engagement, communication, and restricted, repetitive, and stereotyped behavior, interests, and activities.
- Elopement (sometimes termed “running”, “wandering”, or “fleeing”) 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, and is a common behavior among children with ASD.
- Drowning, traffic accidents, suffocation, toxic ingestions and other injuries may occur in the setting of elopement, and have been reported as causes of early death among individuals with ASD, for whom mortality has been reported to be up to three times that of the general population.
- In response to the Interagency Autism Coordinating Committee’s (IACC) call for immediate study of the problem of elopement, Anderson and colleagues conducted the first large scale epidemiological study of elopement via the Interactive Autism Network (IAN) in 2011.

Methods

Survey respondents included parents of 1218 children ages 4 to 17, recruited via the Interactive Autism Network (IAN), an online interactive research ASD registry of over 20,000 individuals with ASD. The methods have been previously detailed in the report of Anderson and colleagues (2012).

Results

- **Intervention**
  - Alarms
  - Locks
  - Gates
  - Fence
  - Slept near child
  - Tracker/GPS
  - Tracking program
  - Service Dog
  - Notified school
  - Notified neighbors
  - Notified police
  - IEP changes
  - Removed from school
  - Swimming lessons
  - Social stories
  - Other

- **Estimated Cost ($)**

- **Effectiveness**

Conclusions

- Elopement among children with ASDs is a significant public health issue, with increased use of tracking devices anticipated.
- Understanding current approaches used by parents and their success is important in developing strategies to reduce this behavior and prevent injury and death and guiding resources.
- Further study of the effectiveness of specific interventions in community settings is warranted.

Future Directions

More detailed follow-up study of parental responses to elopement, their costs and comparative effectiveness has been funded through a grant from the Wendy Klag Center for Autism & Developmental Disabilities of the Johns Hopkins Bloomberg School of Public Health and will begin in mid-2015.

References

