



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

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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.

The results of the survey indicated that elopement is common:

- 49% of parents report elopement at least once after age 4.

Risk factors for elopement :

- Greater ASD symptom severity
- Loss of prior developmental skills, and
- Not responding when their name was called.

Of those missing,

- 24% were in danger of drowning and
- 65% were in danger of traffic injury.

Families also reported reduced ability to sleep soundly and attend or enjoy activities outside of the home.

A majority (56%) reported elopement was one of the most stressful aspects of caring for a child with ASD.

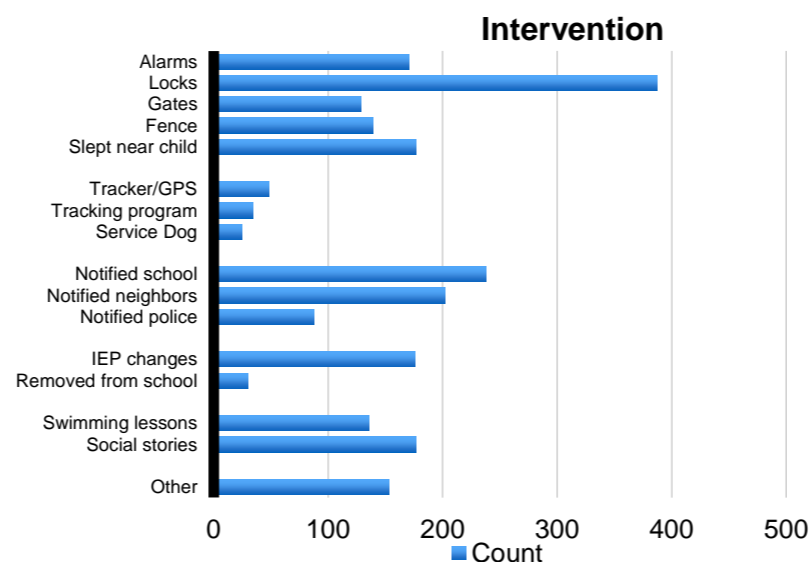
- Current knowledge of the comparative cost and effectiveness of interventions to reduce elopement is limited.

- Here, we report on new preliminary data from a large-scale epidemiologic survey of parental interventions for elopement, as well as their self-reported cost and effectiveness.

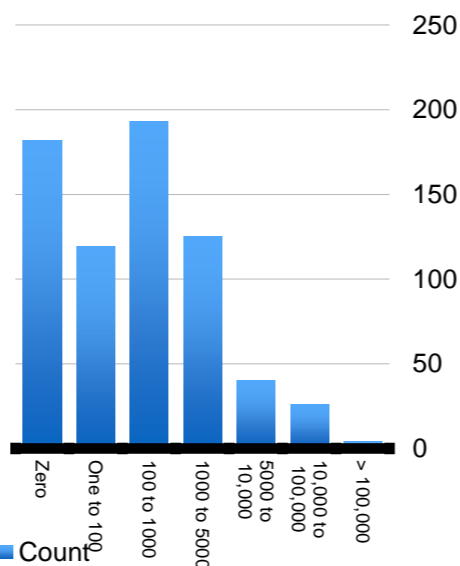
Methods

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).

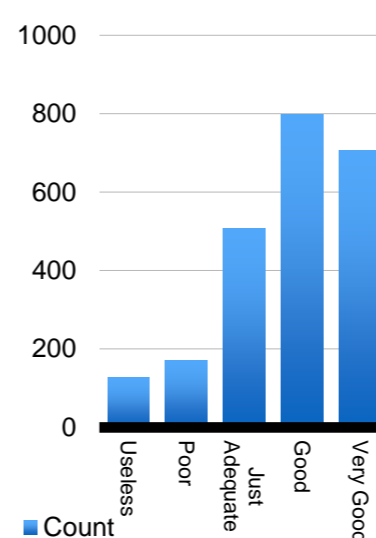
Results



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.



Participants in IAN Research:

- Complete online study questionnaires collecting important information about ASD diagnosis, treatments, services, and other related topics.
- Receive special notices about local, regional and national studies looking for families like theirs.



Families, researchers and anyone impacted by ASDs can take part in the **IAN Community** a comprehensive online library and meeting place focused solely on ASD research. Visitors can learn about the latest research, become more informed consumers of research, and join in a worldwide collaboration of people dedicated to finding answers.

References

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