

# *Injury prevention strategies for wandering in families of children with ASD*

**Paul H. Lipkin, M.D.**

Director, Interactive Autism Network  
Kennedy Krieger Institute

Associate Professor of Pediatrics,  
Johns Hopkins Medicine

# Wandering and Elopement

## A Journey in Online Autism Research



# Wandering and Elopement

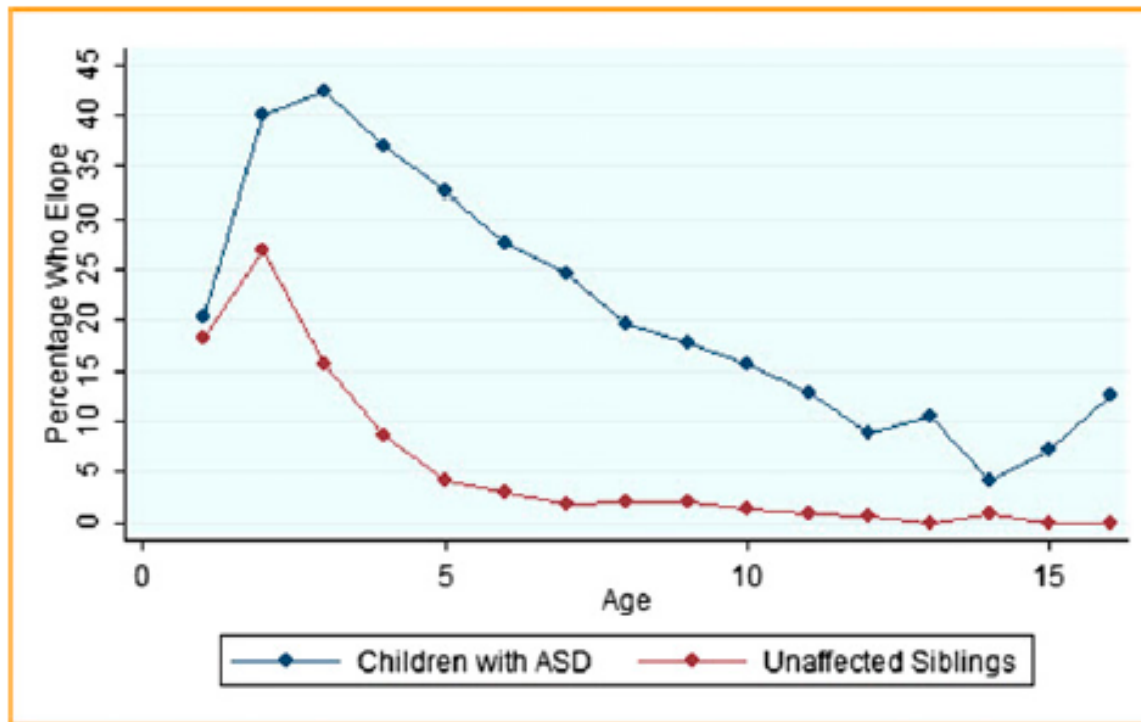
## *A Journey in Online Autism Research*

- All IAN Research families with a child between 4 and 17.9 years invited
- Online surveys completed by parents of 1218 children with ASD & 1076 siblings
  - All levels of functioning
  - The entire US
  - All ethnic and racial groups
  - Urban and rural

Anderson C, et.al, *Pediatrics*, Nov. 2012



# Overall wandering rate: 49%



**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,  $n = 1076$ .

Image source: Anderson et al. <sup>1</sup>

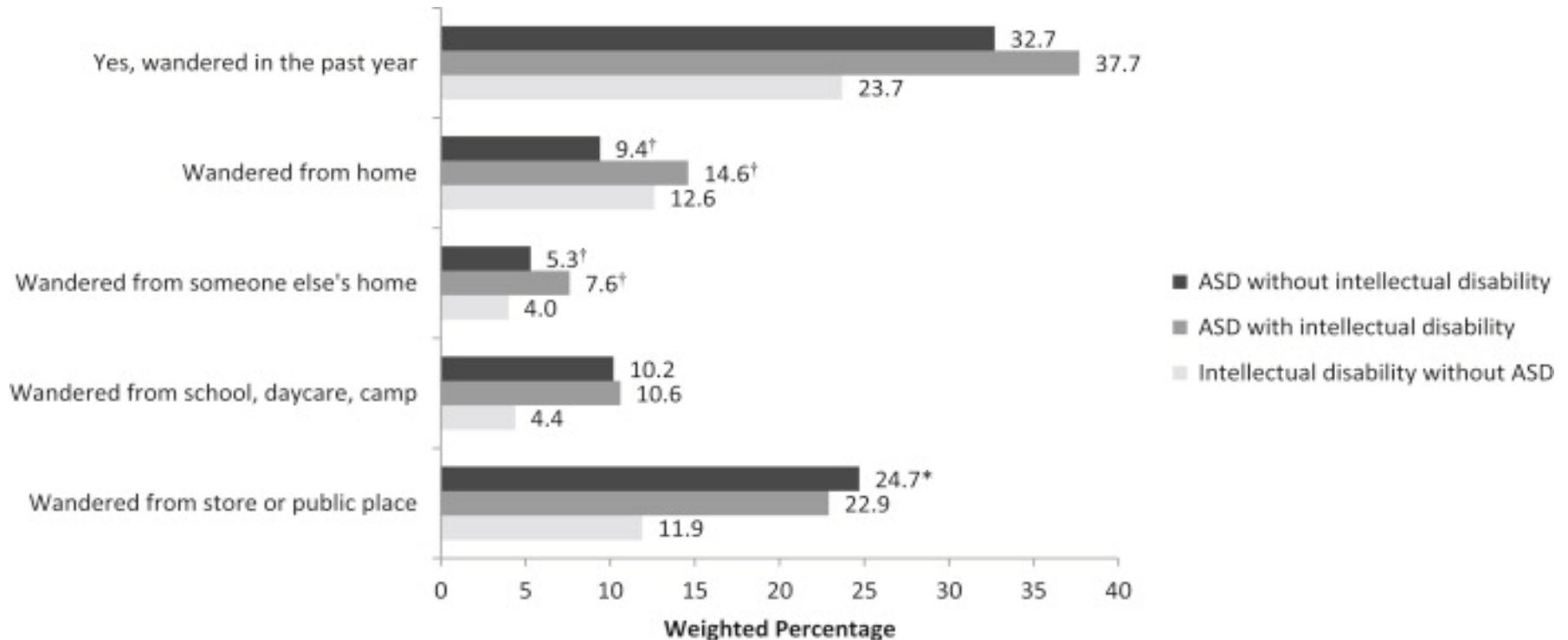
- Of all who attempted, 53% succeeded & missing long enough to cause concern about safety.
- Of those who went missing long enough for concern (26% of total)
  - Police called 31% of the time
  - 65% “close call” with traffic injury
  - 24% “close call” with drowning
- Motivations
  - Parents of children with Asperger’s: need to *escape an anxious situation*
  - Parents of children with autism/PDD-NOS: more likely to simply *run, explore, or head for a favorite place*

# Conclusions & Outcomes (2012)

- Wandering common & major concern for families
- Better supports needed
- ICD 9 code for autism wandering achieved
- Research needs:
  - Elucidate whether there are different types of elopement, requiring different prevention strategies.
  - Explore how best to support families
  - Research behavior characterization
  - Developing and refining interventions to address elopement is urgently needed

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

Rice CE, et. al. J Pediatr. 2016



Reported percent wandering among children with special healthcare needs, by current report of an ASD, with and without intellectual disability and intellectual disability without ASD. \*P < .05 for comparison of children with intellectual disability without ASD and children with ASD without intellectual disability. †Estimates have a relative SE 30% or greater and may be unreliable.

**Table 7. Preventive Measure Use by Condition Group.**

Condition Group	Physical Barriers (% ± SE)	Electronic Measures (% ± SE)	Any Prevention Strategy: Wanderers (% ± SE)	Any Prevention Strategy: Non-Wanderers (% ± SE)	OR (95% CI)
ASD-only	19.4 ± 3.4	2.7 ± 1.3	34.0 ± 7.3	12.8 ± 3.7	3.5 (1.4–8.8)*
ASD + ID/DD	36.9 ± 2.8	3.5 ± 0.8	54.7 ± 5.2	28.5 ± 3.3	3.0 (1.8–5.1)*
ID/DD-only	15.5 ± 2.0	1.5 ± 0.5	45.7 ± 5.9	8.0 ± 1.1	9.6 (5.6–16.6)*

**Notes:**

\*denotes significance. Logistic regression analyses were used to assess the association between elopement history and preventive measure use.

doi:10.1371/journal.pone.0148337.t007

Kiely B, Migdal TR, Vettam S, Adesman A (2016) Prevalence and Correlates of Elopement in a Nationally Representative Sample of Children with Developmental Disabilities in the United States. PLOS ONE 11(2): e0148337.

<https://doi.org/10.1371/journal.pone.0148337>

<http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0148337>



# Elopement Patterns & Caregiver Strategies

Allan M. Andersen <sup>\*</sup>, J. Kiely Law <sup>‡</sup>,  
Alison R. Marvin <sup>‡</sup>, & Paul H. Lipkin <sup>‡</sup>

<sup>\*</sup>Department of Psychiatry, University of Iowa, Iowa City, IA

<sup>‡</sup> Kennedy Krieger Institute, Johns Hopkins University, Baltimore, MD

# Elopement Prevention Study

- Aim: To report on strategies employed by caregivers of individuals with ASD to prevent elopement behavior, their perceived effectiveness, burden of use, and cost.
- Methods: “Elopement Patterns & Caregiver Strategies Survey”
  - Online survey of parents/caregivers of children with ASD registered in IAN; March - September 2016
  - Inclusion Criteria:
    - Ages 4 to 17+ years
    - Social Communication Quotient score  $\geq 12$
    - Clinician-confirmed ASD diagnosis
    - Social Responsiveness (SRS) scale completion

# Elopement Prevention Study: Definition and Survey Items

- Elopement Behavior (EB): “[Child] tries to leave safe spaces and/or the supervision of caregivers”
  - ASD and other diagnoses
  - Patterns of elopement- past and current
  - Consequences
  - Parental responses
  - Preventive interventions (including medications)
  - Perceived effectiveness
  - Burden of use/side effects
  - Estimated costs

# Elopement Prevention Study: Results

- 867 completed; **526** had ongoing preventive interventions and/or elopement behavior
  - Demographics (n = 526)
    - Mean age 10.9 years; Males 83%; White 88%, Non-Hispanic 88%
  - ASD Severity
    - Mean SRS T-score: 90.3
  - Co-occurring diagnoses
    - Intellectual Disability: 16%; Language Disorder: 31%
    - ADHD: 42%; Anxiety Disorder: 38%; Mood Disorder: 10%
  - Clinical Problems
    - Aggression: 20%; Self-Injury: 24%

# Elopement Prevention Study: Results

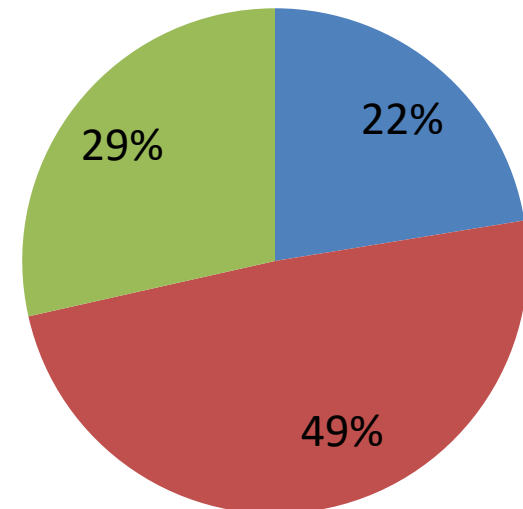
## Elopement Behavior (EB)

Frequency (n = 526)

- No attempts in last 2 years:  
118 (22%)
- Low (< 1 attempt/ week):  
258 (49%)
- High ( $\geq 1$  attempt/ week):  
150 (29%)

### Frequency

■ None ■ Low ■ High



# Elopement Prevention Study: Patterns

- **Locations:** Home (70%); Stores (47%); Classroom (41%); Transitions (28%)
- **Situations:**
  - **Avoidant/Anxious Situations**
    - Escape anxious situation (43%)
    - Stressful environment (39%)
    - Conflict-laden environment (24%)
  - **Sensory:** Noisy (38%); Uncomfortable sensory experience (34%)
  - **Goal-Directed:** Pursue special interest (27%); Reach play he/she enjoys (18%); Reach favorite food (11%)
  - **Impulsive:** Under-stimulated (27%); “Boring” environment (27%)

# Elopement Prevention Study: Environmental Interventions

- 96% use  $\geq 1$  intervention
  - Environmental (83%)
    - Dead bolts (51%); Latches (49%); Gates (36%)
  - Services/Behavioral (83%)
    - Behavioral psychologist (41%); Social Stories (40%); Aide (39%)
  - Devices:
    - GPS Trackers (19%)
      - Project Lifesaver bracelet (5%)
    - IDs (31%)
      - Bracelet or shoe tag, Medic Alert bracelet

# Elopement Prevention Study: Environmental Intervention Effectiveness

Overall effectiveness (“good” or “very good”): 75%

- None: 91%
- Low: 75%
- High: 61%

Mean # interventions tried: 6.1  
(± 3.9)

- None: 4.7 (± 3.0)
- Low: 5.9 (± 3.9)
- High: 7.4 (± 4.1)

Two-year Cost (median): <\$1000

- None: <\$500
- Low: <\$1000
- High: \$5000 or more

Burden (“high” or “very high”):  
68%

- None: 48%
- Low: 69%
- High: 81%



# Elopement Prevention Study: Cost & Burden

- **Good Cost Effectiveness**
  - **Window bars** - 57% effective, 14% burdensome, median cost <\$100
  - **Fencing** - 46% effective, 13% burdensome, median cost <\$500
  - **Project Lifesaver** - 48% effective, 15% burdensome, median cost <\$100
- **Limited Access**
  - **Home Behavioral Specialist** - 35% effective, 15% burdensome, cost \$0 (insurance)
  - **School Aide** - 49% effective, 16% burdensome, cost \$0 (school)
- **Effective But Burdensome/Expensive**
  - **Service Animal** - 53% effective, 33% burdensome, median cost <\$1000
- **Poor Cost Effectiveness**
  - **Security Cameras** - 26% effective, 3% burdensome, median cost <\$500
  - **GPS Trackers** - 15% effective, 29% burdensome, median cost <\$500

# Elopement Prevention Study: Medication

- Ever taken psychiatric medication: 48%
- Ever taken any medication for EB: 16%
  - Antipsychotic: 8%
  - ADHD medication: 5%
  - Antidepressant: 4%
  - Benzodiazepine: 2%
  - Mood Stabilizer: 1%
- Most effective (“good” or “very good”) for EB (n ≥10):
  - Lorazepam: 29%
  - Diazepam: 20%
  - Atomoxetine: 19%
  - Melatonin: 18%
  - Lisdexamfetamine: 16%
  - Amphetamine/dextroamphetamine: 16%
  - Escitalopram: 15%

# Elopement Prevention Study: Conclusions

- Simple environmental and behavioral interventions are generally rated by caregivers as cost effective and much more effective than medications in reducing elopement.
- Medications are generally perceived as ineffective, with have high rates of side effects

## Questions

- For interventions rated as highly effective but less used, what are obstacles to implementation?
  - Cost (e.g. fencing)
  - Availability (e.g. aides, behavioral specialists)
  - Burden/Hassle (e.g. door alarms)
- Do subtypes of elopement require different prevention strategies?

# Suicidality in Autism Spectrum Disorders

## A National Health Crisis?

# Suicidality and ASD Research

- UK: In adults with Asperger's, 66% contemplated suicide (vs. 17% general population; 35% planned or attempted (Cassidy 2014);
  - Greater risk in women, while opposite in general population
- Sweden: Higher mortality rates in ASD vs. general population (1987-2009); suicide leading cause of premature death (Hirvikoski 2016)
- US: “Assessment of Suicide Risk in Children & Adolescents with ASD Presenting to a Pediatric ED” (Vasa IMFAR 2017)
  - **31 of 104** with ASD screened positive suicide risk (ASQ)
  - 65% uniquely identified as experiencing suicidal ideation
  - 12 suicide attempts: stabbing/cutting (5), jumping from a height (2), choking/holding breath/hanging (3), overdose (1), firearms (1)

# *IAN Mental Health & Suicidal Behaviors Questionnaire*

- Aim: To establish a clearer understanding of the prevalence of suicidal behaviors and related factors in children and dependent adults with ASD
- Parent-report for:
  - Children ages 8-17
  - Dependent Adults
- Distributed online through the Interactive Autism Network (IAN)
  - 55,000 participants
  - 14,500 children; 7,500 adults
  - Data collected on this questionnaire can be linked to other IAN data

# Mental Health & Suicidal Behaviors Questionnaire Layout

1. Child/Dependent Adult Mental Health History
2. Child/Dependent Adult Life Events
3. Child/Dependent Adult Suicidal Behaviors
4. Sibling Mental Health History
5. Parent Mental Health History
6. Extended Family Mental Health History
7. Demographic Information

# Mental Health & Suicidal Behaviors Questionnaire

- Child/Dependent Adult Suicidal Behaviors
  - Verbal ability
  - Ideation
    - “Has |display name| ever expressed any thoughts or feelings about *wanting to die or not wanting to live anymore?*”
    - “Has |display name| ever expressed any thoughts or feelings about *wanting to end his/her life?*”
    - “Has |display name| ever indicated that he/she *had a plan* to end his/her life?”
  - Attempt
    - “Has |display name| ever *tried to end* his/her life?”
  - Follow-up questions:
    - Past 12 months
    - Age
    - Method
    - Treatment-seeking/Hospitalization
    - Satisfaction with treatment
    - Medication use six weeks prior



# QUESTIONS?

Linking the autism community and researchers



share. research. discover.