Injury prevention strategies for wandering in families of children with ASD

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Wandering and Elopement
A Journey in Online Autism Research

- Advocate concern at IACC
- IACC Safety Subcommittee
- IAN Study funded by Advocates
- IAN Survey Launched
- Results shared with Public
- Results published in *Pediatrics*
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

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. ¹
• 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 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.

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<thead>
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</thead>
<tbody>
<tr>
<td>ASD-only</td>
<td>19.4 ± 3.4</td>
<td>2.7 ± 1.3</td>
<td>34.0 ± 7.3</td>
<td>12.8 ± 3.7</td>
<td>3.5 (1.4–8.8)*</td>
</tr>
<tr>
<td>ASD + ID/DD</td>
<td>36.9 ± 2.8</td>
<td>3.5 ± 0.8</td>
<td>54.7 ± 5.2</td>
<td>28.5 ± 3.3</td>
<td>3.0 (1.8–5.1)*</td>
</tr>
<tr>
<td>ID/DD-only</td>
<td>15.5 ± 2.0</td>
<td>1.5 ± 0.5</td>
<td>45.7 ± 5.9</td>
<td>8.0 ± 1.1</td>
<td>9.6 (5.6–16.6)*</td>
</tr>
</tbody>
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Notes:
*denotes significance. Logistic regression analyses were used to assess the association between elopement history and preventive measure use.

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Elopement Patterns & Caregiver Strategies

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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 ≥ 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 (≥1 attempt/week): 150 (29%)
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 ≥ 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

<table>
<thead>
<tr>
<th>Category</th>
<th>Effectiveness</th>
<th>Cost Range</th>
<th>Burden</th>
</tr>
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<tbody>
<tr>
<td>Overall effectiveness</td>
<td>75%</td>
<td>&lt;$1000</td>
<td>68%</td>
</tr>
<tr>
<td>None</td>
<td>91%</td>
<td>&lt;$500</td>
<td>48%</td>
</tr>
<tr>
<td>Low</td>
<td>75%</td>
<td>&lt;$1000</td>
<td>69%</td>
</tr>
<tr>
<td>High</td>
<td>61%</td>
<td>$5000 or more</td>
<td>81%</td>
</tr>
</tbody>
</table>

Mean # interventions tried:

- 6.1 (± 3.9)
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