



# “Elopement and Wandering” Survey



Kennedy Krieger Institute

Linking the autism community and researchers



share. research. discover.

Sponsored by Autism Speaks, the Simons Foundation,  
and National Institute of Mental Health



**SIMONS  
FOUNDATION**

**NIMH**  
National Institute  
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### What is IAN Research?

Every day thousands of people from across the country are coming together through IAN Research, an innovative online initiative connecting researchers with individuals and families affected by autism spectrum disorders (ASD). The information being shared by those living with an ASD is already helping researchers discover new insights about the disorder and is assisting community leaders advocating for improved services. This dynamic exchange is the nation's largest online autism research study and is making remarkable strides to improve the lives of individuals and families affected by ASDs. This collaborative effort strives to accelerate important breakthroughs about causes, diagnosis, and treatments which may lead to the discovery of a possible cure.

### Why participate in IAN Research?

Each year, many important ASD studies are significantly delayed or not completed because researchers can not find enough qualified participants. As a result, valuable opportunities to learn about ASDs are lost. In the first year and a half, more than 25,000 people signed up to participate in IAN Research, and the results have been dramatic. During this same time period more than 100 research studies have been able to move forward using IAN Research.

By providing basic information on the diagnosis, family background, home environment, and services received, you can help researchers, educators, policy makers, and others better understand the impact of this puzzling group of disorders. It takes approximately one to two hours to complete the secure, online questionnaires, and you can do it as your schedule allows, without ever leaving home.

We all have questions. Together we'll find answers.

### Join the Nation's Largest Online Autism Research Effort

By sharing your experiences and knowledge, you'll help researchers and advocates as they fight to improve the lives of those with ASD.

**JOIN NOW**

### How do I join?

- Click on the "Join Now" button and follow the instructions to create your IAN ID and password.

OR

- If you are already a member of IAN community and have an IAN ID and password, enter them into the "returning members" sign-in at the top of this page. You will be asked to provide additional information about yourself and to complete the consent process. If you are enrolling a child (under the age of 18) or an adult under your guardianship, you will also need to provide information about this individual and complete the consent process.

### What Happens Next?

Once registration is completed, you will be able to add other eligible family members and complete your online research questions. It takes approximately one to two hours to provide this basic information. You may invite other eligible adult family

- **October 2010: Autism advocacy organizations report to IACC that elopement in ASDs leads to:**
  - Fatalities
  - Injuries
  - Family stress and burden
- **November 2010: IACC creates Safety Subcommittee with focus on elopement**

- IAN
  - Leverages Internet Mediated Research (IMR)
  - Two Diagnosis Validation studies for IAN diagnosis
  - In other fields IMR has been shown to be less biased than “center” based research overall

- Despite community knowledge and concern, virtually no research had been done on elopement in ASDs
  - Lowe et al, 2007, wandering common
  - Lang et al, 2008, treatment review for wandering in DDs
- IAN was uniquely positioned to quickly gather data on this issue

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- IAN partnered with concerned advocacy organizations



AUTISM RESEARCH INSTITUTE  
*Autism is Treatable*



AUTISM SPEAKS™  
It's time to listen.



etc...

- With input and funding from advocate-partners, IAN developed a national survey on elopement and wandering in ASD in 8 weeks.
- 41 item survey

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- Survey launched March 24, 2011
- Partners informed constituents
- >1,500 responses so far
- Results shared with public April 20, 2011
  - <30 days after launched
- Data already being shared with NDAR:



**NDAR** National Database  
for Autism Research  
*Serving the autism research community*

- Team of researchers working on peer reviewed publication



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- Results for today come from:
- 1,098 “pre-selected” children 4-17.5 years, 655 (or 60%) completed the survey. This group:
  - Were “active” IAN participants
  - Were incentivized (we held a drawing for an iPad)
  - African-Americans were oversampled
- An additional 900+ volunteered to take the survey.

- Key question:

“At what age(s) did your child attempt to leave safe spaces and/or a caregiver's supervision?”

- After a lot of prep to families (examples etc...)
- We purposely avoided terms such as wandering, elopement and running because of inconsistent use. (looked at NSCSCHN)

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“...a supervised, safe space”

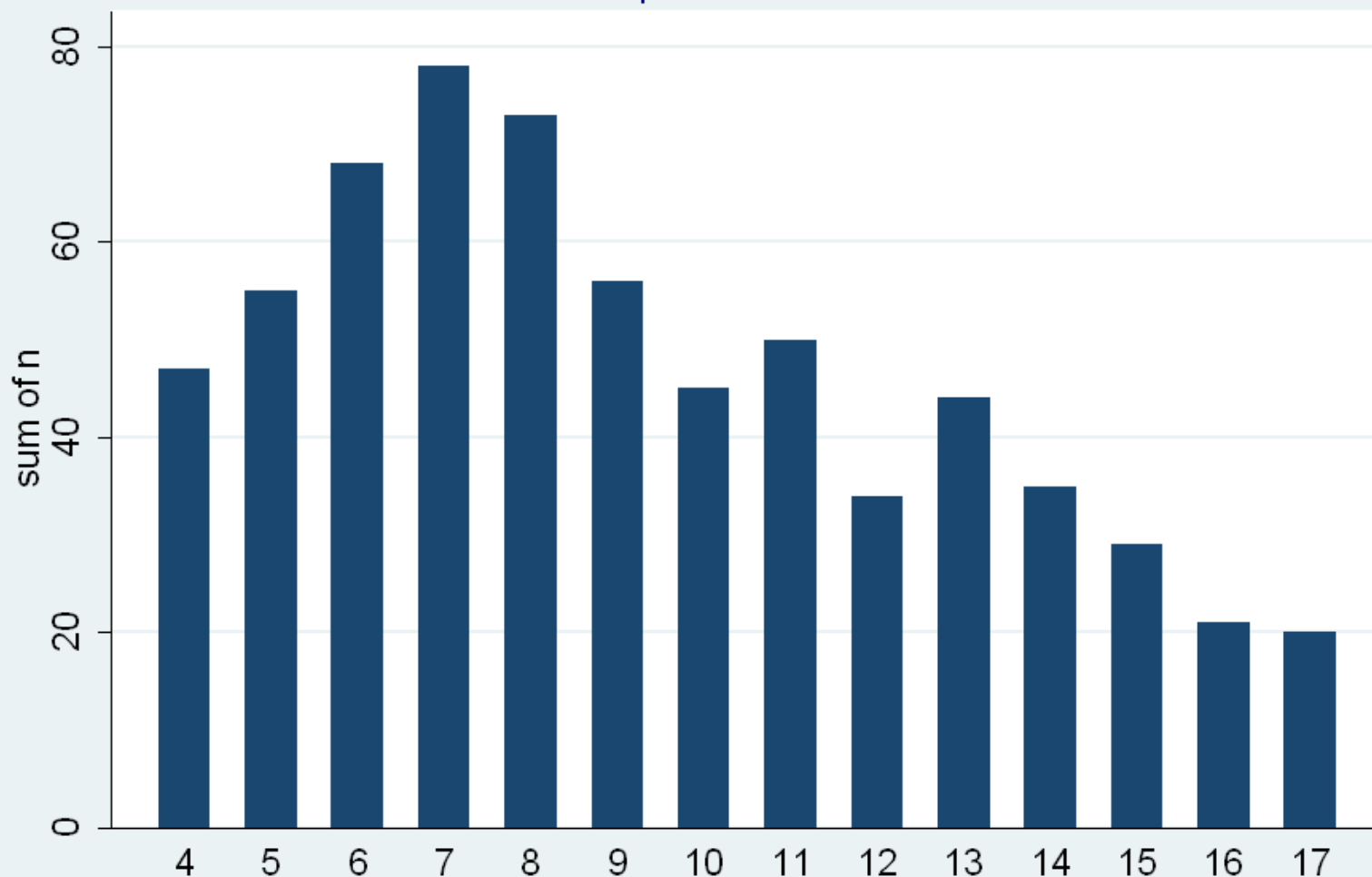


“...the care of a responsible person



## Age Distribution of Participants

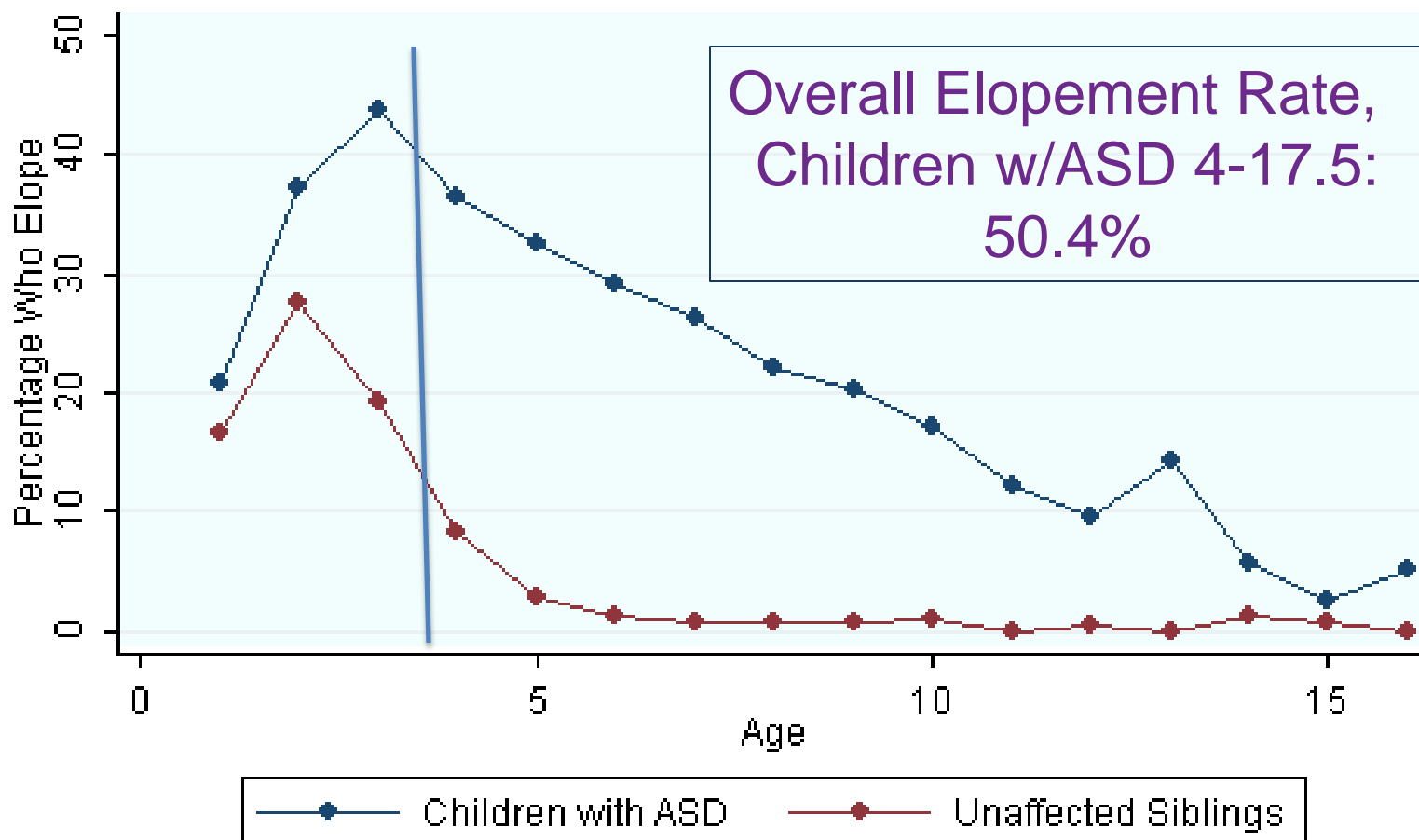
IAN data updated Jul 18 2011 N=655



## Rate of Elopement by Age and ASD Status

A Comparison of Children with ASD and their Unaffected Siblings

IAN data updated Jul 18 2011 N for ASD=655 - N for Sibs=662



- Of children age 4-10 – more than 53% attempted to elope.
- Of all who attempted, nearly half succeeded and were missing long enough to cause parents significant concern about their safety.

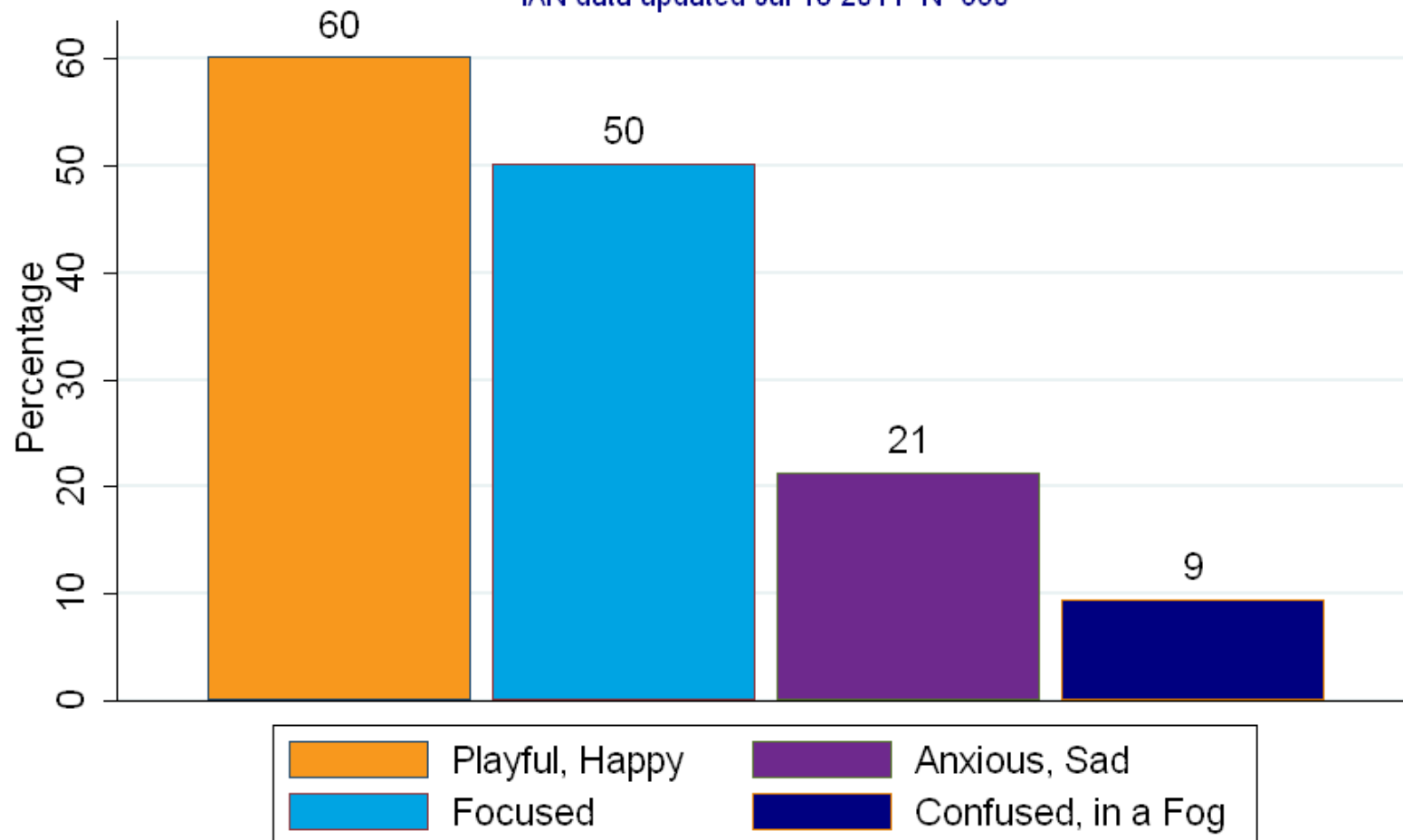
- Of children with ASD who went missing long enough for concern (25% of all kids with ASD)
  - Police were called 30% of the time. 8% of all children with ASD
  - Nearly two thirds reported their wandering child had a “close call” with traffic injury. 16% of all children with ASD
  - Nearly a third reported a “close call” with drowning. 8% of all children with ASD

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## Elopement and Children with ASD

State of Mind While 'Wandering'

IAN data updated Jul 18 2011 N=330





- IAN quickly able to collect data on important issues in ASDs
- Upcoming projects include:
  - Bullying and Children with ASDs
  - Sleep issues in Children with ASDs

- Immediate use of wandering for advocacy