



LINKING THE AUTISM COMMUNITY AND RESEARCHERS

# Auditory Sensitivity and Safety in Children with ASD

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Linking the autism community and researchers



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"Every child is different. And unless we as parents tell the researchers what is specific to our child, how will they know?"  
-IAN Participant

**Participate in ASD research. Join IAN.**

Autism spectrum disorders (ASD) are identified in 1 out of every 68 children in the United States. Other countries observe similar rates with an increasing number of children and adults living with the disorder worldwide.

Families and individuals with ASD play a critical role in helping researchers and clinicians better understand the disorder. IAN Research provides a secure online setting where those affected by autism are active participants in ASD research.

By participating in IAN Research, you can help make new discoveries and empower advocates to improve the lives of children and adults with ASD.

**Who can participate in IAN Research?**

Individuals with ASD and their family members are eligible to participate. The following ASD diagnoses are included in IAN Research:

- Autism Spectrum Disorder (ASD)
- Autism or Autistic Disorder
- Asperger Syndrome
- Childhood Disintegrative Disorder (CDD)
- Pervasive Developmental Disorder - Not otherwise Specified (PDD-NOS)
- Pervasive Developmental Disorder (PDD)

**Participate in the largest online autism research effort.**

**JOIN NOW**

**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.

explore **iancommunity**

Families, researchers and anyone impacted by ASDs can take part in the [iancommunity](#), 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.

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JHM IRB #: NA\_00002750

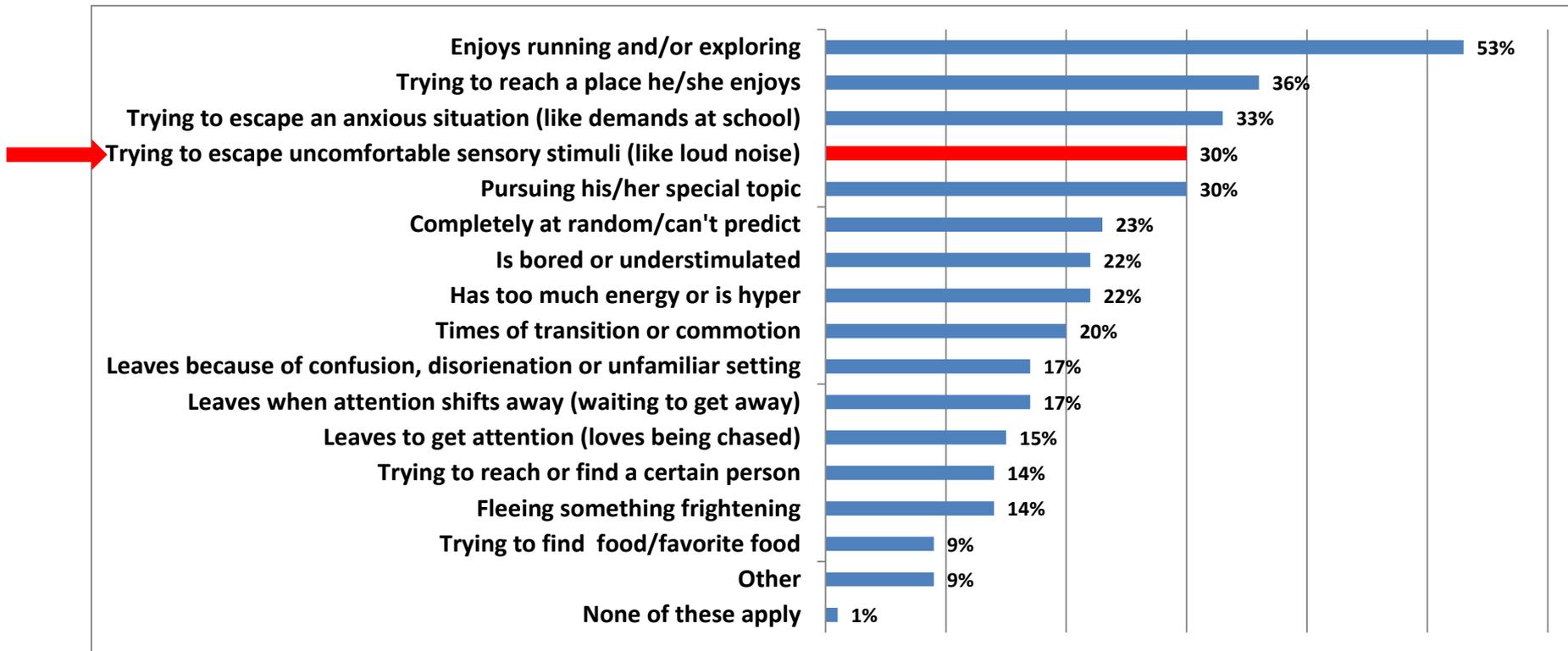
## 54,000 participants

- 15,000 children with ASD
- 5,000 adults with ASD
- 14,000 siblings
- 20,000 parents/guardians

# Background: IAN Elopement Study 2011

- Concern about elopement and child safety
- Possible link between elopement and auditory **hypersensitivity**

Question 10: If you are able, please tell us what you believe causes your child's elopement behavior. *Check all that apply.* (n=725)



# Auditory Sensitivity

- Abnormal sensory experiences common in ASD (40% - 100%)
  - Auditory **hypersensitivity** affects 30-50% children with ASD
  - Not related to auditory acuity
  - Parent concerns about **hypersensitivity**
    - Child in distress and/or pain
    - Increased unsafe behaviors
    - Difficult to manage
- 
- Safety concerns also related to **hyposensitivity**

# Auditory Sensitivity and Child Safety Study

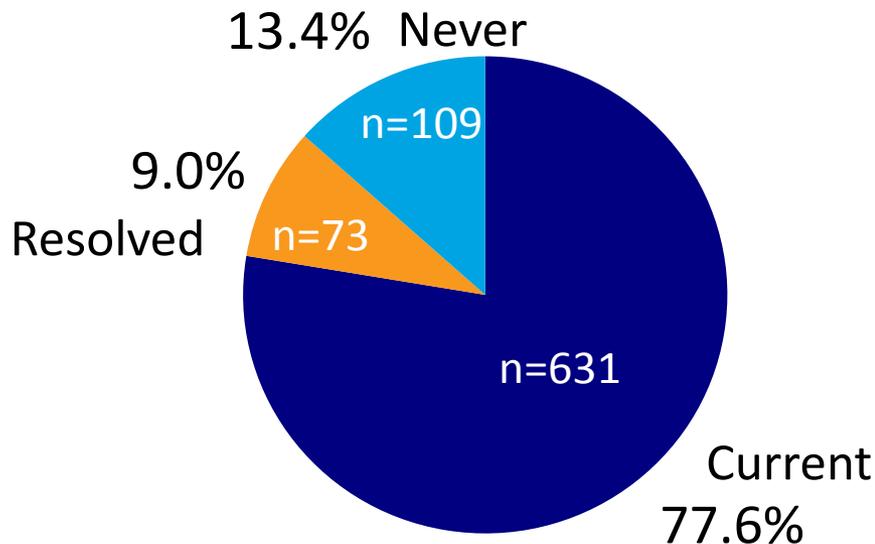
- Funded by National Autism Association
- Team included parents, ASD experts, audiologists, researchers
- Launched Spring 2014
- Aims:
  - Characterize auditory **hyper**- and **hypos**sensitivity in children with ASD
  - Determine relationship between auditory **hypers**sensitivity and potentially unsafe behaviors
  - Assess use and satisfaction of interventions for auditory **hypers**sensitivity

# Who participated?

- Survey of parents of children with ASD (n=814)
- Child Characteristics
  - 82.4% male
  - 87.5% non-Hispanic; 84.8% white
  - Median age: 10.3 years
  - ASD Diagnosis
    - ASD 28.1%
    - Autism 34.4%
    - PDD-NOS 21.0%
    - Asperger's Syndrome 13.9%
    - PDD 2.6%

# Hypersensitivity: Preliminary Results

- Reported Rates



- Median age

- Onset: 2.0 years
- Resolution: 7.5 years
- Worst symptoms: 4.5 years

- Child's Emotional State

(n=631 responses)

Stressed	77.7%
Irritable	61.3%
Scared	55.2%
Nervous	54.4%
Frustrated	43.9%
Annoyed	40.9%

- Child's Physical Response

(n=631 responses)

Covers ears	85.9%
Yells or screams	52.2%
Tries to run away	42.3%
Cries	36.3%
Tries to stop sound/noise	33.8%
Tries to hide	25.2%

# Hypersensitivity: Preliminary Results

- More Severe ASD symptoms
  - SRS raw score
    - 111.6 vs. 99.3 ( $p < 0.0004$ )
- More likely to have Epilepsy/Seizure Disorders
  - 11.3% vs. 7.3% ( $\chi^2 < 0.001$  FET)
- 18/60 (30%) seizure related to auditory triggers

# Hypersensitivity: Preliminary Results

- Impact: Always or frequently limits participation
  - 31.1% Family activities
  - 29.8% School activities
  - 38.5% Community activities
- Burden
  - 63.4% episodes weekly (26% daily)
  - 49.5% mod or extreme difficulty managing

# Hypersensitivity: Preliminary Results

- Safety Concerns

- 43.2% in an unsafe situation
  - 11.0% very unsafe
  - 10.7% moderately unsafe
  - 21.5% somewhat unsafe
- 18.2% Child physically injured or hurt
- 28.1% Others physically injured or hurt



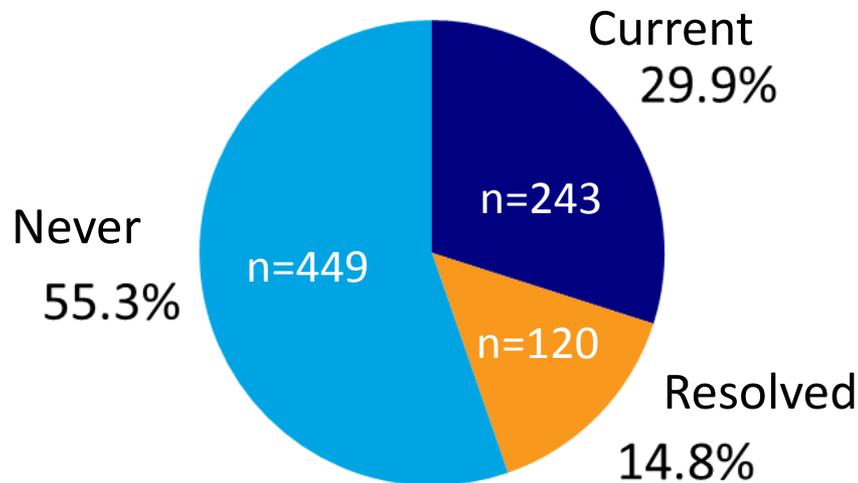
# Hypersensitivity: Preliminary Results

- Common Interventions

	USED BY	Very Satisfied	Somewhat Satisfied	Somewhat Unsatisfied	Very Unsatisfied
Warning/preparing child for trigger sounds	90.9%	13.5%	39.5%	9.3%	10.3%
Avoiding trigger sounds	89.8%	23.9%	34.1%	6.4%	4.2%
Taking quiet breaks	85.6%	31.0%	40.4%	4.1%	4.5%
Ear buds/standard headphones with music	57.6%	23.3%	31.1%	11.1%	12.2%
Ear muffs	50.3%	24.0%	27.4%	11.0%	19.2%
Ear plugs	44.8%	7.1%	17.4%	16.7%	45.0%

# Hyposensitivity: Preliminary Results

- Reported Rates



- Median age

- Onset: 1.5 years
- Resolution: 4.5 years
- Worst symptoms: 3.0 years

- Safety Concerns

(n=243 responses)

- 52.5% in unsafe situation
  - 16.1% very unsafe
  - 15.7% moderately unsafe
  - 20.7% somewhat unsafe
- 15.6% Child physically injured or hurt
- 10.0% Others physically injured or hurt

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- **IAN Families**

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