Wandering in Autism Spectrum Disorder:
Current Knowledge and Future Directions

David B. McAdam, Ph.D., BCBA-D, LBA
Associate Professor
University of Rochester

October 2014
Webinar

Learning Objectives

- Participants will increase knowledge of…
  - common reported reasons why children with ASD wander according to parents.
  - common reported reasons why children with ASD wander according to researchers.
  - evidence-based behavioral interventions for children with ASD.
  - technologies available to help locate children with ASD who wander successfully.

2

Definitions of Wandering

Leaving an area without supervision or caregiver permission

✓Classroom/School
✓Home
✓Community

3

Other Names for Wandering

- Elopement (term commonly used in Applied Behavior Analysis literature)
- Bolting
- Running away

What term do you think is best?

4

Problems Associated with Wandering

- School issues
  - Reduced instructional time
  - Lack of academic progress
  - Increased periods of time in which child is not supervised
- Dangerous behaviors
  - Running in front of cars
  - Contact with strangers
  - Getting lost
  - Accidental death

Wandering may result in placement in a more-restrictive setting (e.g., community based group home)

5

Problems Associated with Autism, cont.

- Researchers have found that the mortality risk for persons with ASD is twice as high as the general population (Gillberg, Billstedt, Sundh, & Gillberg, 2010)
- Researchers have found elevated deaths in persons with ASD and attributed it to several causes, including seizures and accidents such as drowning (Shavelle, Strauss, & Picket, 2001)
- In 2009, 2010, and 2011, accidental drowning associated with wandering accounted for 91% total U.S. deaths reported in children with an ASD ages 14 and younger
- More than one third of children with ASD who wander cannot communicate their name, address, or phone number

Sources: Interactive Autism Network Research Report: Elopement and Wandering (2011). National Autism Association, Lethal Outcomes in ASD Wandering (2012)

6

How often do Children with ASD wander?

- IAN, the Interactive Autism Network, was established in January 2006 at Kennedy Krieger Institute. IAN's goal is to facilitate research that will lead to advancements in understanding and treating autism spectrum disorders (ASDs). IAN is directed by Paul H. Lipkin, MD
- IAN is funded by Autism Speaks and the Simons Foundation..

7

How often do Children with ASD wander?

- Approximately 50% of children with ASD between 4 and 10 years of age display wandering. Four times the rate of their siblings without ASD
- Approximately 30% of children with ASD between 7 and 10 years of age display wandering. 8 times the rate of their siblings without ASD

Data suggests that wandering is associated with ASD not associated with parenting style

8

IAN data updated Apr 20 2011 N for ASD=856 - N for Sibs=928
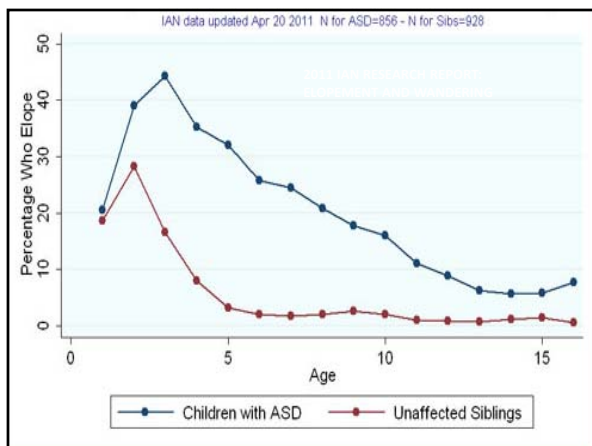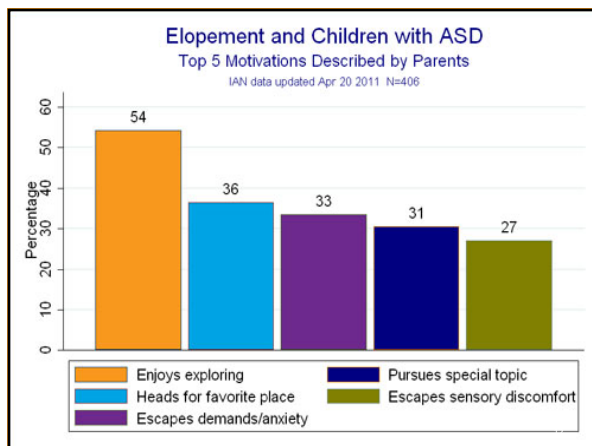
Safety and Wandering

- Approximately 50% of wandering attempts by children with ASD are successful
- Parents report often having to seek help from police (approximately 32% of the time)
- Many parents report that their child has experienced a close call with traffic injury or drowning
- 62% of families of children who wander reported that they avoided activities outside the home due to fear of wandering
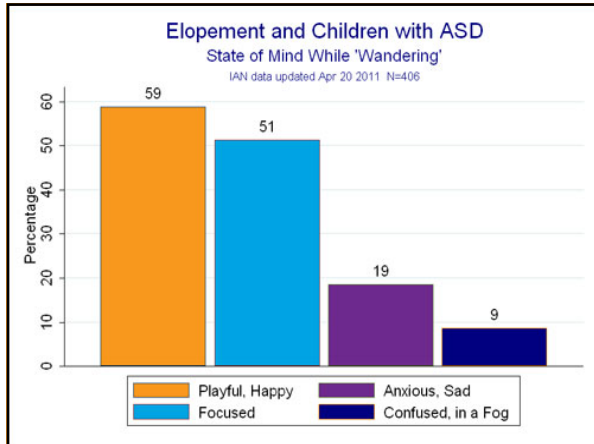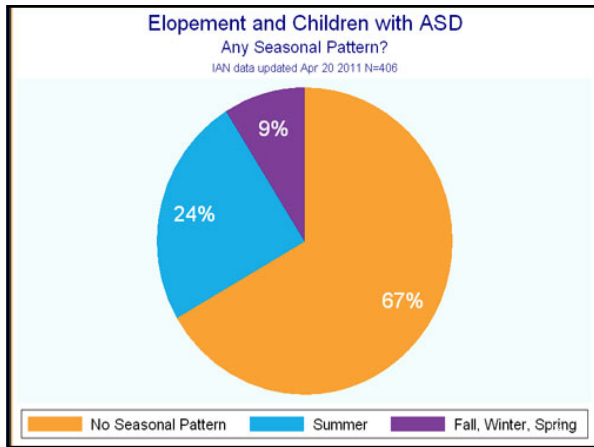- 40% of parents had suffered sleep disruption due to fear of elopement

10

Reasons reported by parents

- Simply enjoys running or exploring
- Is trying to reach a place he/she enjoys (such as the park)
- Is trying to escape an anxious situation (like demands at school)
- Is pursuing his/her special topic (as when a child fascinated by trains heads for the train tracks)
- Is trying to escape uncomfortable sensory stimuli (like loud noise)

11

Elopement and Children with ASD
Top 5 Motivations Described by Parents
IAN data updated Apr 20 2011 N=406

Motivation	Percentage
Enjoys exploring	54
Heads for favorite place	36
Escapes demands/anxiety	33
Pursues special topic	31
Escapes sensory discomfort	27

Elopement and Children with ASD
State of Mind While 'Wandering'
IAN data updated Apr 20 2011 N=406

- Playful, Happy
- Focused
- Anxious, Sad
- Confused, in a Fog

Elopement and Children with ASD
Any Seasonal Pattern?
IAN data updated Apr 20 2011 N=406

- No Seasonal Pattern — 67%
- Summer — 24%
- Fall, Winter, Spring — 9%

Elopement and Children with ASD
How Stressful Compared to Other ASD Behaviors?
IAN data updated Apr 20 2011 N=406

- Among MOST Stressful — 58%
- Stressful — 26%
- Not that stressful — 13%
- Not stressful at all — 3%

Who Do Parents Ask for Help?

- Most parents report not seeking help (51%)
- 19% of parents report seeking advice from a mental health professional (e.g., psychologist, counselor, social worker)
- 14% of parents report seeking advice from a medical professional

16

Current Treatment Studies

- Few studies compared to other challenging behaviors associated with ASD such as aggression or self-injury
- To date, all have been small N studies that used a single case experimental designs
- All studies have used intervention packages. All interventions components have been behavioral in nature (i.e., based on behavioral analytic components)
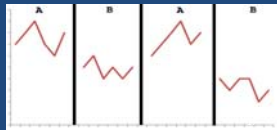
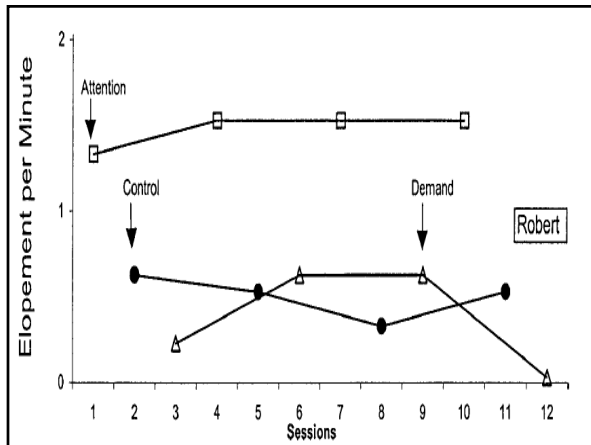## Additional Characteristics of Current Research

- Intervention evaluated for a brief period of time (e.g., 10 minute sessions)
- Research staff conducted the study and implemented the intervention
- In the majority of the studies, treatment/assessment setting is not the same as where the child typically engages in wandering (Two adjacent rooms in a research lab).
- Most studies produce reduction but not elimination of wandering . What is a clinically significant reduction?

18

Function (purpose) of Wandering

- Social attention from parents or other people
- Access to high preference item or activity
- Escape or avoidance of activity
- Sensory reinforcement (e.g., child often engages in self-stimulatory behavior)
- Goal directed

19

Typical Functional Analysis Conditions

- Negative Reinforcement (Demands)
- Positive Reinforcement (Tangible items or Social Attention)
- Automatic Reinforcement
- Control or Toy Play

21

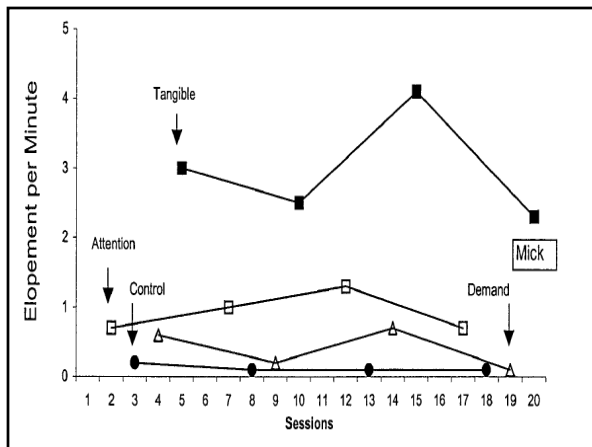## Additional Characteristics of Current Research

- Intervention evaluated for a brief period of time (e.g., 10 minute sessions)
- Research staff conducted the study and implemented the intervention
- In the majority of the studies, treatment/assessment setting is not the same as where the child typically engages in wandering (Two adjacent rooms in a research lab).
- Most studies produce reduction but not elimination of wandering
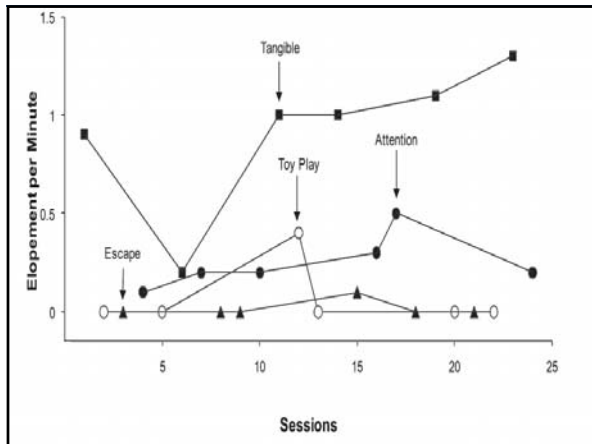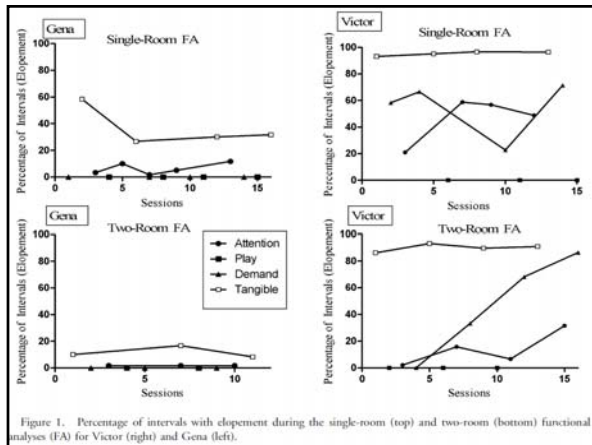
22

Experimental Design and Dependent Measure for Functional Analysis

- Experimental designs—alternating treatments, withdrawal or reversal
- Dependent Measures---rate (i.e., frequency per unit of time), frequency, percentage of intervals

23

Figure 1. Percentage of intervals with elopement during the single-room (top) and two-room (bottom) functional analyses (FA) for Victor (right) and Gena (left).

## Intervention approaches

- Differential Reinforcement -e.g., DRO
- Extinction (terminating what a child gets out of engaging in wandering)
- Non-contingent reinforcement (providing attention according to a predetermined schedule regardless of wandering)
- Response blocking (might increase other behaviors most likely aggression to other people)
- Functional communication training
- Scheduled exercise

27

Figure 1. Responses per minute (elopement) during the functional analysis (top) and DRO treatment evaluation (bottom) for Jimmy.

Figure 4. Responses per minute of elopement and communication for Geoff (top) and Mary (bottom) during baseline (BL) and treatment with functional communication training (FCT) and blocking.

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____
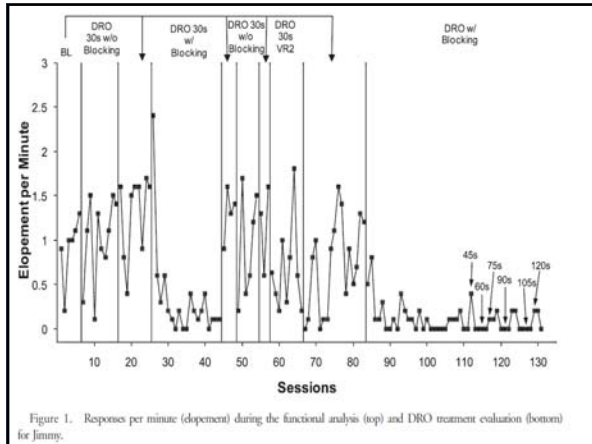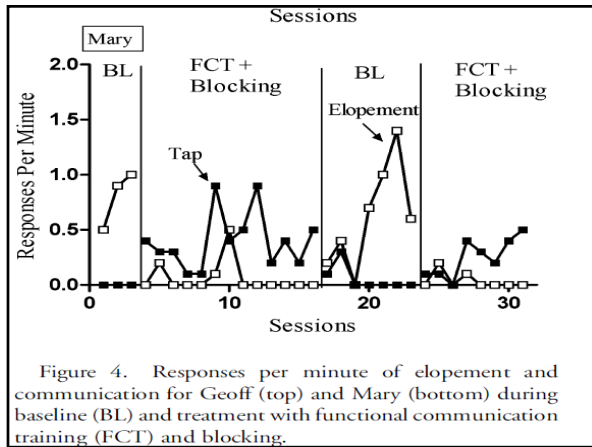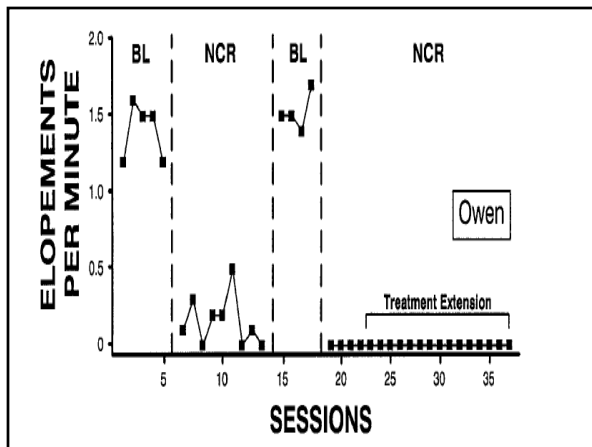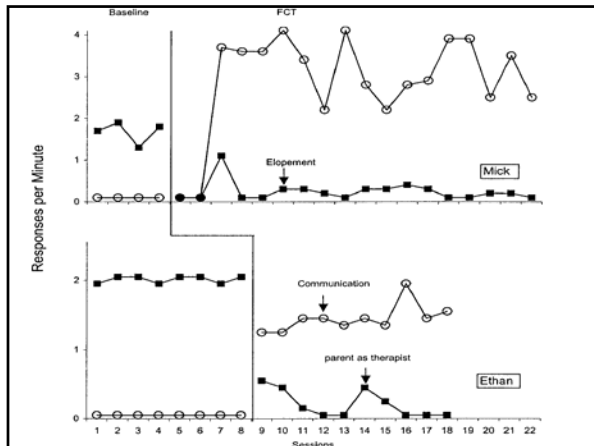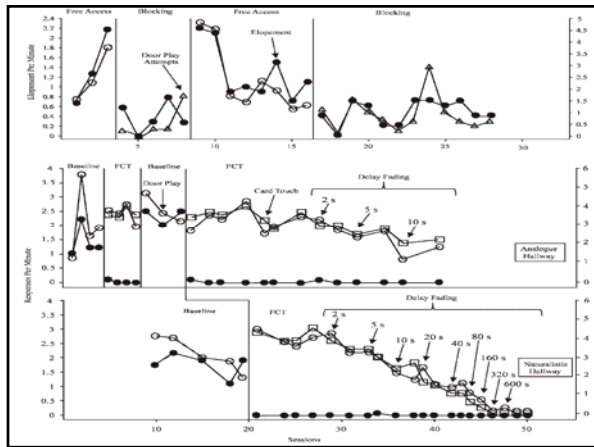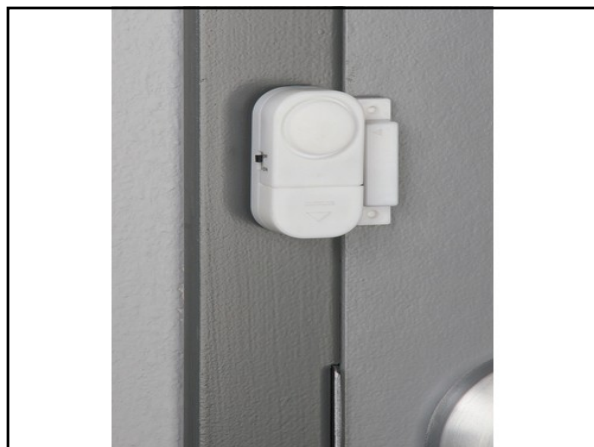
For additional information:

http://www.autismspeaks.org/family-services/autism-safety-project

37

Intervention Package

- Preventative strategies (alarms, door locks, fence)
- Behavioral interventions (e.g., NCR, FCT, DRO)
- Technology (GPS, safety bracelet)
- Community education (first responder training)

38

What is Interprofessional Collaboration?

- A process of developing and maintaining effective interpersonal working relationships with practitioners, clients, families and communities to enable optimal health

Canadian Interprofessional Health Collaborative (2010). A national interprofessional competency framework.

39

What is Interprofessional Collaboration?

- Characteristics of interprofessional collaboration
  - Respect
  - Trust
  - Shared decision making
  - Partnerships

- How do we get there
  - Integration of:
    - Role clarification
    - Team functioning
    - Collaborative leadership
    - Client/Community focused

40

Interprofessional Collaboration

"The whole is greater than the sum of Its parts"

-Aristotle

- The team shares the responsibility for making the ultimate decision about a patient's care
  - Opinions are equally valued
- The plan is developed by the whole team
- Assessment and care plan reflect the integration of expertise from individual disciplines

41

Interprofessional Team

- Youth & Families
- Nursing
  - Psychiatric and medical
- Medical
  - Primary care provider
  - Neurologist
  - Psychiatrist
- Behavioral services
  - Psychologist
  - Behavior analyst
  - Behavior specialist
- Service/Clinical Coordination

- Therapists
  - Social worker
  - Art therapist
- Education
  - Teachers
  - OT/PT
  - SLP
- Nutrition/Dietician
- Physical health services
- Administration/District Leaders

42

Current Work at the University of Rochester School of Medicine

History of Parent Training

Approach that has a long history in Applied Behavior Analysis/Behavior therapy:
- Gerald Patterson
- Alan Kazdin
- John Lutzer/ Brandon Greene

Parent training being evaluated with the parents of children with autism
- Johnson et al.
- Aman
- On-going trials being conducted at the University of Rochester in the Division of Neurodevelopmental and Behavioral Pediatrics

Also called Behavioral Skills Training by some people

44

Parenting Training

- Series of one-on-one sessions in which evidence-based behavioral topics are covered
- Home work is assigned (e.g., collecting information on the specifics of wandering)
- On-going problem solving (e.g., how to gradually increase instructional demands, how to promote generalization across people and situations)
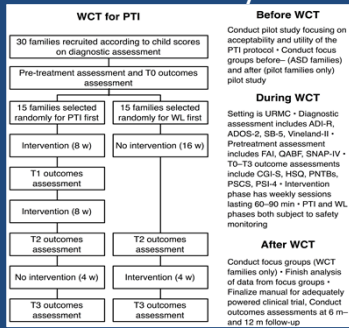
45

Study Sequence

- Focus groups/writing of parent training manual
- Initial test with 3 families (multiple baseline design across families)
- Revisions to manual
- Wait list control design evaluation
- Revisions to manual

46

Our Study

WCT for PTI

| 30 families recruited according to child scores on diagnostic assessment |
| Pre-treatment assessment and T0 outcomes assessment |

15 families selected randomly for PTI first	15 families selected randomly for WL first
Intervention (8 w)	No intervention (16 w)
T1 outcomes assessment	
Intervention (8 w)	
T2 outcomes assessment	T2 outcomes assessment
No intervention (4 w)	Intervention (4 w)
T3 outcomes assessment	T3 outcomes assessment

Before WCT

Conduct pilot study focusing on acceptability and utility of the PTI protocol • Conduct focus groups before– (ASD families) and after (pilot families only) pilot study

During WCT

Setting is URMC • Diagnostic assessment includes ADI-R, ADOS-2, SB-5, Vineland-II • Pretreatment assessment includes FAI, QABF, SNAP-IV • T0–T3 outcome assessments include CGI-S, HSQ, PNTBs, PSCS, PSI-4 • Intervention phase has weekly sessions lasting 60–90 min • PTI and WL phases both subject to safety monitoring

After WCT

Conduct focus groups (WCT families only) • Finish analysis of data from focus groups • Finalize manual for adequately powered clinical trial, Conduct outcomes assessments at 6 m– and 12 m follow-up

47

Contact Information

- David McAdam, Study Principal Investigator
  - E-mail: david_mcadam@urmc.rochester.edu
  - Tele: 585-273-2756

- Jill Aldrich, Study Coordinator
  - E-mail: jill_aldrich@urmc.rochester.edu
  - Tele: 585-275-7734

48

Resources

- **Rochester Regional Center for Autism Spectrum Disorder (RRCASD).**
  - On-line educational resources, webinars, Information & Referral services.
  - Contact information:
    - Website: www.golisano.urmc.edu/rrcasd-nyautism
    - E-mail: rrcasd@urmc.rochester.edu
    - Tele: 1-855-508-8485
- **Autism Speaks**: website: www.autismspeaks.org
    - This site contains various toolkits and guides for home, school, work, safety, health/medical, etc.

49

Question & Answer

A *Webinar Evaluation Survey* will be sent to your e-mail.
Please complete to receive a
Certificate of Attendance.

50