

Wandering Among Children with Special Healthcare Needs from the Pathways Survey

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Safety concern raised by autism parent community at the Interagency Autism Coordinating Committee (IACC) in 2010

October 28, 2011 3:54 PM

PRINT TEXT

Missing Va. autistic boy found alive after 6-day search

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By Casey Glynn Topics Daily Blotter, Missing



Robert Wood Jr. (Credit: WUSA)

(CBS/AP) DOSWELL, Va. - Police say the Hanover County autistic boy who was missing for six days has been found alive.

Police say 8-year-old Robert Wood Jr. was found Friday afternoon near the park where he was separated from his family.

At a press conference this afternoon, Hanover County Sheriff David Hines said the boy was found in a creek bed in the fetal position around 2 p.m. Fri with his family. Wood was in good condition at hospital.

The boy is in the emergency room being evaluated and treated, according to Adam Warman of the Faison School for Autism told WTVR that students at the school were overjoyed when the announcement that their classmate had been found was broadcast over a loudspeaker.

"They started yelling and cheering, and crying," said Warman.

The boy, who does not speak, was reportedly found by a citizen volunteer at a mile from North Anna Battlefield Park where he disappeared Sunday, Oct. 23. He had been hiking with his father, younger brother and his father's girlfriend.

Wood was the focus of an intense search involving thousands of volunteers a

When a Child With Autism Wanders, It's Crucial to Stay a Step Ahead

'Eye on the door': Life with autism wandering

This story started on CNN iReport By Elizabeth Landau CNN April 11, 2011 7:25 a.m. EDT



Michael Browne, who's almost 10 years old, has autism and has run away from supervision several times.

[Missing Autistic Child Spawns Virginia's Largest Manhunt | Survival ...](http://www.outsideonline.com/.../Catch-Me-If-You-Can-20120801.html?...)

Jul 12, 2012 – When Robert Wood Jr. disappeared in a densely forested Virginia park, searchers faced the challenge of a lifetime. The eight-year-old boy was ...

[Autistic Man Found Alive After Being Lost 3 Weeks in Utah Desert ...](http://abcnews.go.com/.../autistic-man-found-alive-after-being-lost-3-week...)

Jul 13, 2012 – (Courtesy LaFever family) An **autistic** man survived by eating frogs and roots as he wandered for weeks through the desolate Escalante Desert ...

[Another Child With Autism Lost to Wandering](http://nationalautismassociation.org/another-child-lost-to-wandering/)

Apr 9, 2012 – Another Child **Lost** to Wandering. We received heartbreaking news over the weekend that yet another child with **autism** has drowned following ...

[Lives Lost to Autism: Jeremiah Conn, Age 5, Wanders and Drowns](http://liveslosttoautism.blogspot.com/.../jeremiah-conn-age-5-wanders-and-...)

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Background

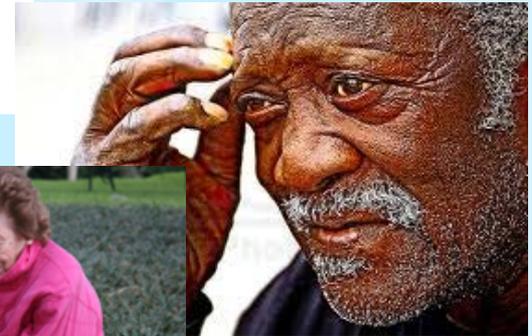
❑ Wandering / Elopement

- A dependent person exposing him or herself to potential danger by leaving a supervised, safe space or the care of a responsible person (Anderson et al., in press)
- Risk of stress, injury, and death



Background

- ❑ Most information on wandering focuses on older adults with dementia



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Background

- ❑ People with autism 2-3 increased mortality rate than general population (review by Woolfenden, 2012)
 - Associated with epilepsy or other medical conditions and accidents
- ❑ Anecdotal reports of wandering as a contributor to injuries and deaths
- ❑ Very little known about the occurrence of wandering among people with Autism Spectrum Disorders (ASD) or other developmental disabilities
 - 2 small studies estimate between 16-34% of people with autism and/or intellectual disability have problems with wandering
 - Recent parent survey of children with ASD in US (Interactive Autism Network, IAN)
 - 49% of parents report child with ASD wandering after the age of 4
 - Of these, 26% were missing long enough to cause concern

Objective and Methods

- ❑ Obtain estimates of the occurrence and characteristics of wandering among children with ASD, intellectual disability, and developmental delay
- ❑ 2011 Survey of Pathways to Diagnosis and Services
 - Telephone and survey follow-up from 2009-2010 National Survey of Children with Special Healthcare Needs (NS-CSHCN)
 - Caregivers of children ages 6-17 years – current condition

Groups of Children for this analysis	N = 3,518
ASD without Intellectual Disability (ID)	1,117
ASD with ID	303
ID (without ASD)	657
Developmental Delay (DD) Only	1,441

Methods

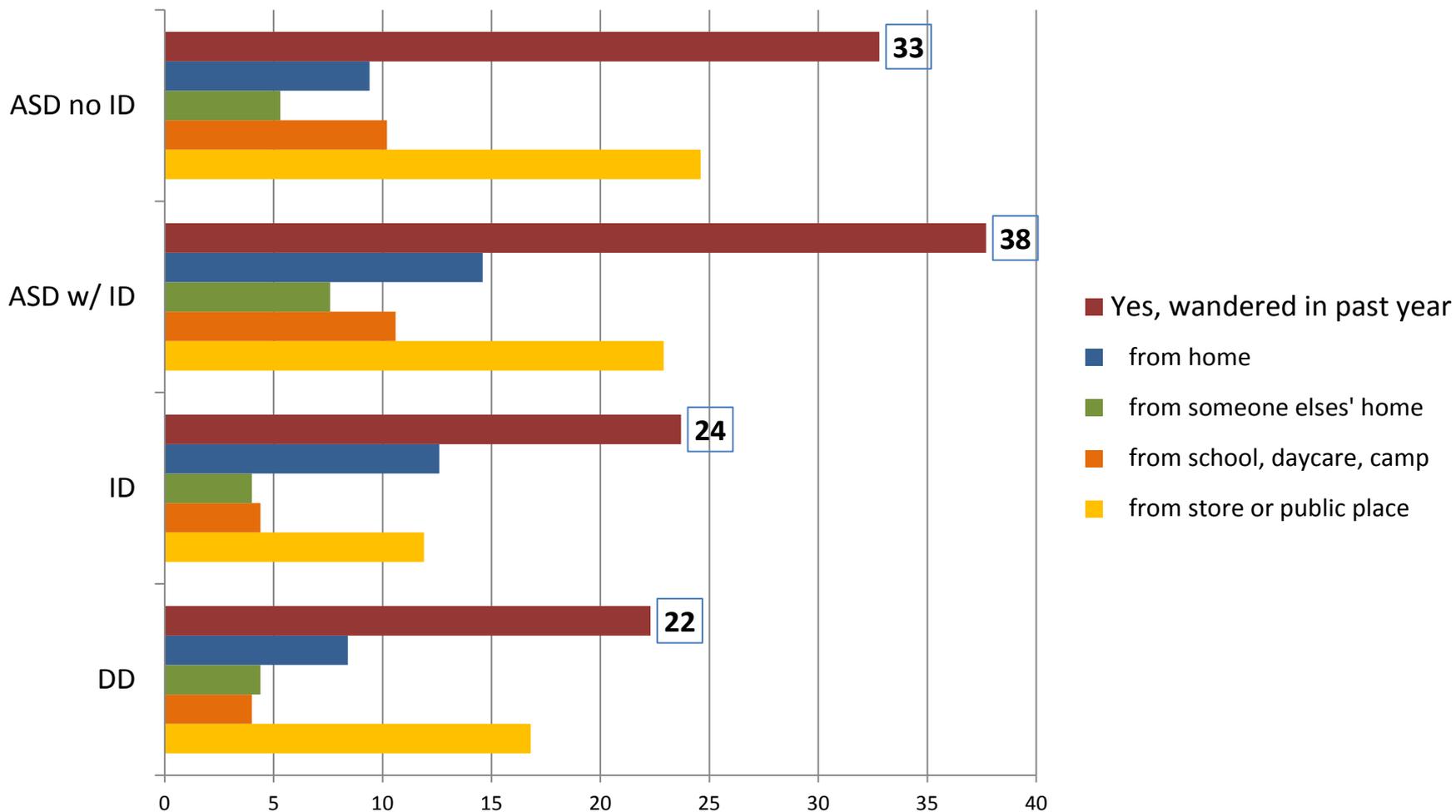
Some children with learning and developmental conditions are likely to wander off and become so lost that it is necessary to search for them. I am going to read a list of places. Please tell me if [SC] wandered off or became lost from any of these places within the past year, even if occurred just once.

1. **Within the past year, has [S.C.] wandered off or became lost from**
 - a. your home?
 - b. someone else's home such as a relative, friend, neighbor, or babysitter?
 - c. school, day care, or summer camp?
 - d. a store, restaurant, playground, campsite, or any other public place?
2. **Have you added fences, gates, locks, alarms, or other barriers to your home in an effort to prevent [S.C.] from wandering off or becoming lost?)**
3. **Within the past year, has [S.C.] worn a tracking device to help you find [him/her] if [he/she] wandered off?)**

Demographic Group Differences

	ASD no ID	ASD w/ ID	ID	DD	p-value
	Percent				
Age 6-11 (vs. 12-17)	56	49	42	50	.03
Male	83	81	51	67	<.01
Non-Hispanic White	69	56	58	60	.02
M aternal age (≤ 24 yrs)	26	21	32	37	.01
Ed > High School	79	69	68	61	<.01
2 Parent	72	66	56	59	.01
Children in home (≥ 3)	33	43	39	36	.15
Fam Inc (>200% FPL)	65	58	51	45	<.01
Own housing	67	72	59	55	.01
Metro Stat Area (yes)	80	85	78	82	.25
Health Ins (Private)	54	37	33	39	<.01

Percent Report of Wandering in Past Year



Multivariate analysis of wandering report

CSHCN who Wandered to those who did not Wander

Current Condition		OR	95% CI
	ASD without ID	1.7	(1.21-2.42)
	ASD with ID	2.2	(1.32-3.62)
	ID	1.1	(0.63-2.04)
	DD	1.0	.

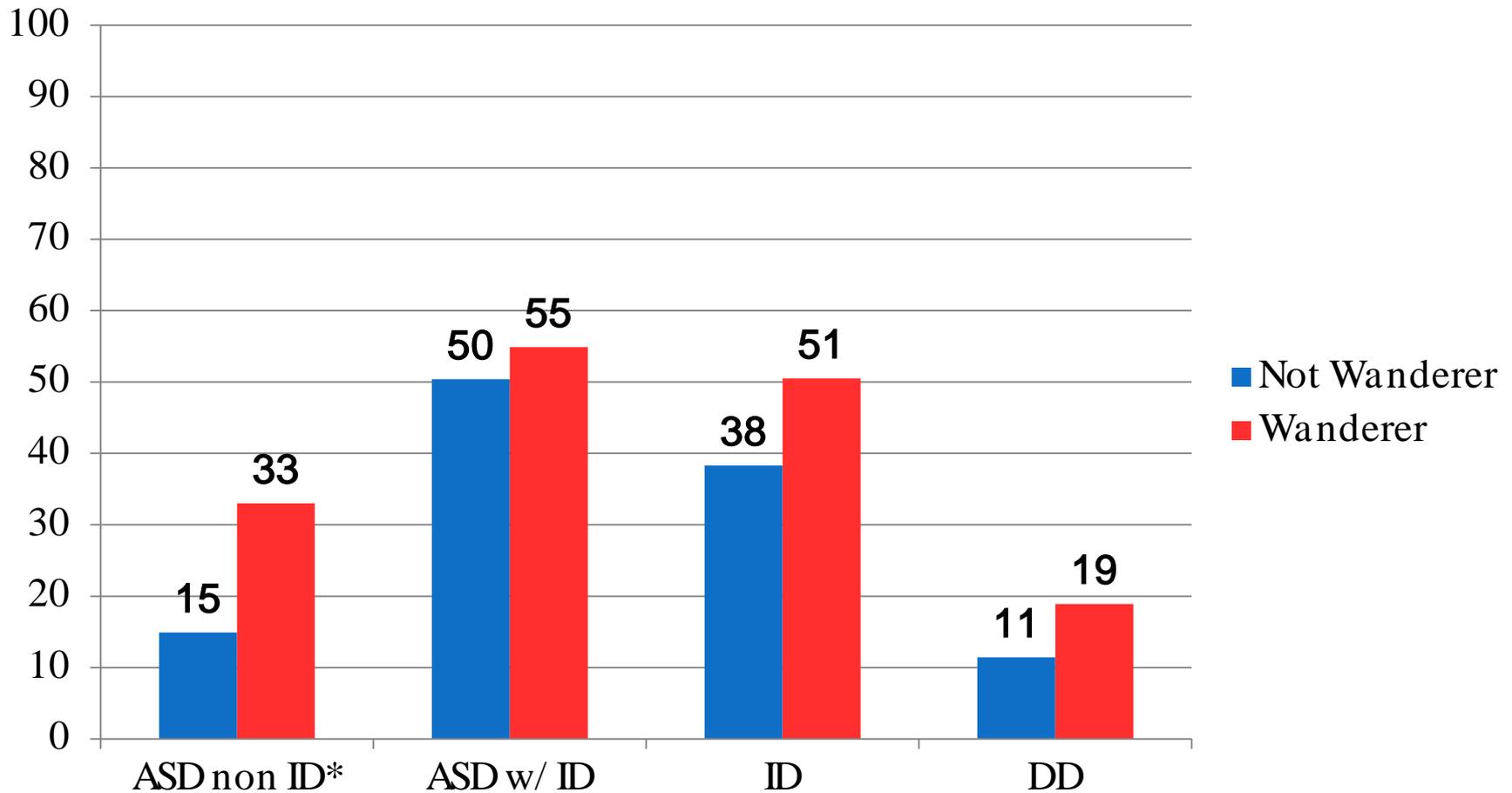
Note: Odds Ratios adjusted for age, sex, race/ethnicity, total kids in the household, and household income as percent of Federal Poverty Level.

Preliminary Multivariate Analysis: Demographics of Reported Wanders vs. Non-Wanders

	ASD no ID	ASD w/ ID	ID	DD
	OR (95% CI not shown)			
Age 12-17 (vs 6-11)	0.4	0.7	0.3	0.5
Male	1.1	2.3	1.2	0.6
Non-Hispanic White	1.1	1.7	0.9	0.8
Maternal age (≤ 24 yrs)	1.0	7.2	0.3	1.2
Maternal age (25-34 yrs)	0.8	6.0	0.4	1.5
Ed \leq High School	1.8	2.3	0.3	1.0
Other (vs 2 Parent)	1.2	0.8	1.7	1.1
Children in home (2 vs 1)	1.6	0.8	0.8	2.5
Children in home (≥ 3)	1.8	2.5	0.8	2.3
Fam Inc ($\leq 200\%$ FPL)	0.8	0.2	1.1	1.3
Rent housing (vs own)	1.2	0.5	1.7	1.1
Non Metro Stat Area	0.8	0.8	1.4	0.9
Health Ins (Public vs priv)	1.1	7.6	1.0	2.9

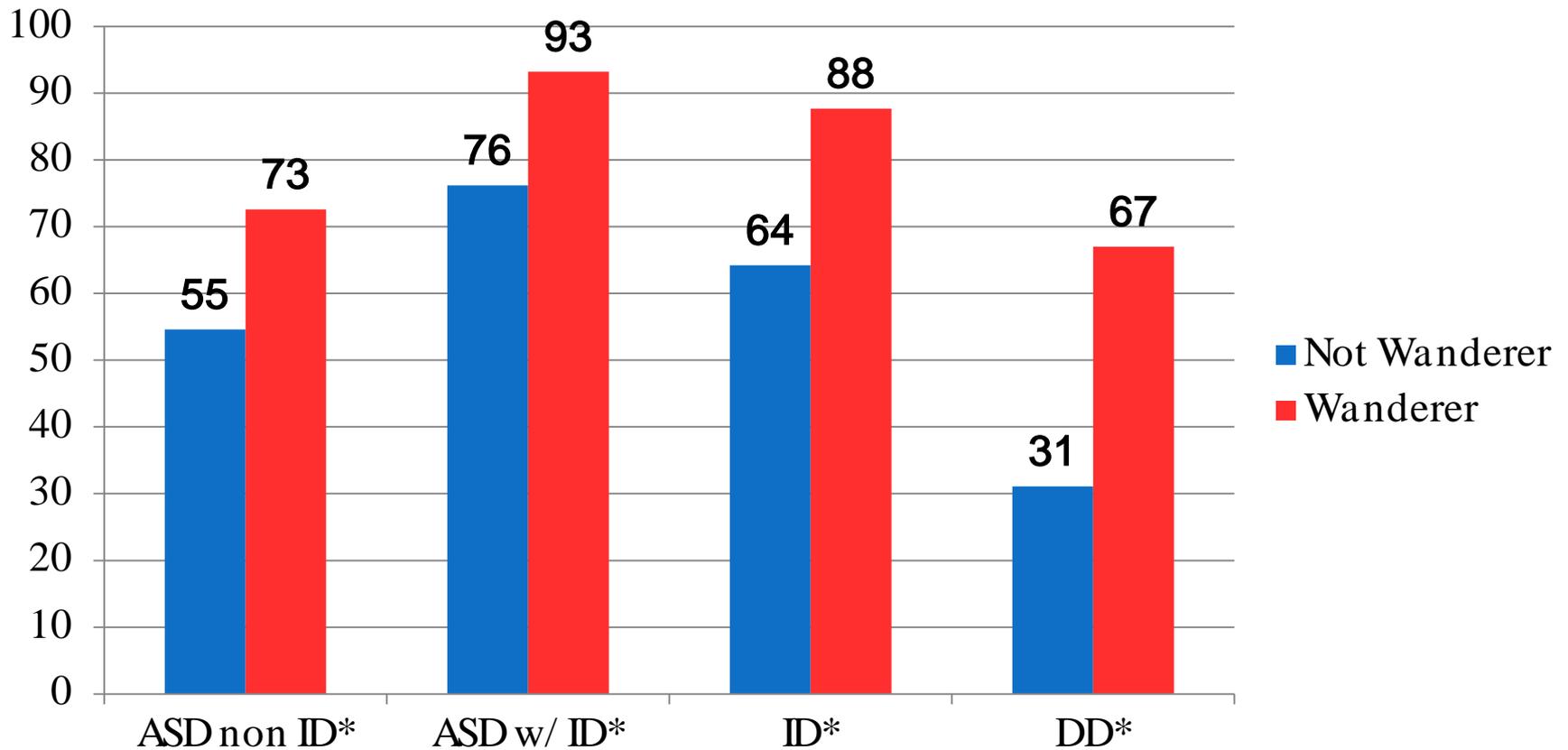
Self-Help Skills - % Not able to do one or more :

Go to the bathroom; Feed self; Dress self



*p<.001

Social Communication Skills - % Not able to do one or more: Ask for things he/she wants; Provide name, address, and phone number; Spend time with friends



*p≤.01

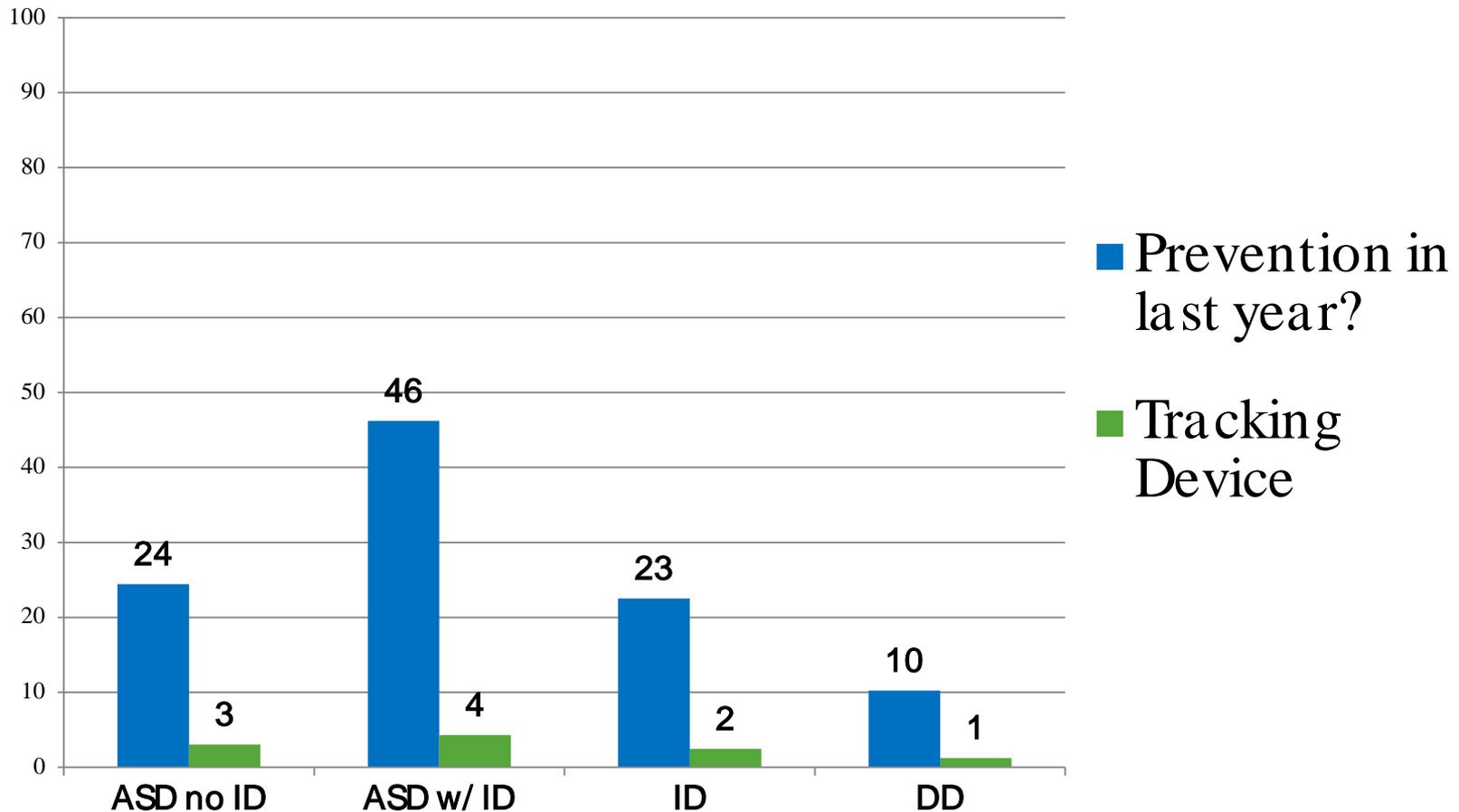
Preliminary Multivariate Analysis*: Function Indicators of Reported Wanders vs. Non-Wanders

	ASD no ID	ASD w/ ID	ID	DD
	OR (95% CI)			
Self-care Skills (No to 1 or more)	1.7 (1.0-3.0)	0.8 (0.3-2.0)	1.0 (0.4-2.2)	0.9 (0.4-1.8)
Social Communication Skills (no to 1 or more)	1.6 (0.9-2.9)	1.5 (0.4-5.6)	3.7 (1.4-10.0)	4.7 (2.7-8.2)
Brief Strengths and Difficulties Questionnaire** High Score vs Mod/Low	1.0 (0.6-1.7)	1.1 (0.4-3.0)	3.7 (1.4-10.1)	0.6 (0.3-1.2)

*Adjusted for demographic factors

** **Brief SDQ** based on 5 questions: well behaved, often worries; often unhappy, depressed or tearful; gets along better with adults than peers; has good attention span, finishes homework/chores

Percent report of prevention measures and use of tracking devices



Prevention and Tracking

CSHCN who Wandered to those who did not Wander

Current Condition	OR	95% CI
Prevention measures in home in past year?	5.4	(3.85-7.69)
Child wore tracking device	4.4	(2.22-8.88)

Note: Odds Ratios adjusted for age, sex, race/ethnicity, total kids in the household, and household income as percent of Federal Poverty Level.

Conclusions and Next Steps

- ❑ Survey of Pathways to Diagnosis and Services used to inform an important safety issue in the autism community
- ❑ Wandering reported to be a concern for 22-38% of the children in this survey
 - A particular challenge for children with ASD (with and without intellectual disability)
 - Younger age (6-11) most consistent demographic variable associated with wandering across groups
 - Limitations in social and communication skills also associated with wandering
- ❑ Next steps
 - Complete analyses and examine clinical characteristics
 - Data to inform prevention efforts
 - Future needs: Baseline population data on wandering by ages (toddler)

Acknowledgements

□ The parents and individuals with special healthcare needs

WORKING TO PREVENT WANDERING INCIDENTS AND DEATHS WITHIN THE AUTISM COMMUNITY

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Similar to wandering[®] behaviors in seniors with dementia or Alzheimer's, children and adults with an Autism Spectrum Disorder (ASD) are prone to wandering away from a safe environment. Typically they will leave to get to something of interest, such as water, the park, or train tracks -- or to get away from something, such as loud noises, commotion, or bright lights.

Dangers associated with wandering include drowning, getting struck by a vehicle, falling from a high place, dehydration, hyperthermia, abduction, victimization and assault.

Because children with autism are challenged in areas of language and cognitive function, it can be difficult to teach them about dangers and ways to stay safe.

"Wandering may also be referred to as elopement, running, bolting, fleeing. To learn more, [click here](#)."

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WHAT TO DO IF SOMEONE WANDERS

- Call 911
- Stay Calm

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Thank You!

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www.cdc.gov/autism

The findings and conclusions in this report are those of the author and do not necessarily represent the official position of the Centers for Disease Control and Prevention.