

DRAFT Safety / Wandering Questions to consider

Pg. 1 questions added to NSCSCHN Follow-up study (Pathways) for 2011 (rep sample of about 4,000 children diagnosed with ASD, ID, and/or DD).

I am going to read a list of activities that [SC] may be able to do independently, may be able to do with help, or may not be able to do. For each one, please tell me how capable (he/she) is when doing the following activities?

- e. Providing (his/her) name, address, and phone number if asked
 - (1) CAN DO INDEPENDENTLY
 - (2) CAN DO WITH HELP
 - (3) CANNOT DO
 - (4) NEVER TRIED

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 it occurred just once.

- a. From your home?
- b. From someone else's home such as a relative, friend, neighbor, or babysitter?
- c. From school, day care, or summer camp?
- d. From a store, restaurant, playground, campsite, or any other public place?

YES/NO/DK/RF

Have you added fences, gates, locks, alarms, or other barriers to your home in an effort to prevent [SC] from wandering off or becoming lost?

YES/NO/DK/RF

Within the past year, has [SC] worn a tracking device to help you find (him/her) if (he/she) wandered off?

YES/NO/DK/RF

ADDITIONAL DRAFT QUESTIONS

How often do concerns about your child's potential to wander affect your plans for how you manage your family's activities:

- a) Never or rarely
 - b) several times a year
 - c) several times a month
 - d) several times a week
 - e) several times a day
-

YES/NO/DK

Does [SC] need more supervision to keep him/her safe and uninjured than is usual for most children of the same age?

I am going to read several questions about related types of behaviors. For each one, please tell me if these behaviors were present during the past 6 months.

- a. Can't locate a safe authority figure to get help if lost
- b. Can't state full name, phone number, or address
- c. Walks about aimlessly*
- d. Gets lost*
- e. Walks away from caregivers in public places
- f. Runs off*
- g. Returned after leaving authorized area*
- h. Attempts to leave authorized area*
- i. Enters unauthorized areas*
- j. Gets up and walks during the night* ← This gets at most of the sleep/wake cycle issues but it may be interesting to add another element specifically targeted towards sleep patterns (because this could also imply sleep walking) ie: Doesn't sleep through the night or frequently sleeps during the day

In the past 6 months, have you been concerned about any of the following:

YES/NO/DK/RF

- a. He/she will do something on purpose to cause physical harm or injury to him or herself

- b. He/she will do something accidentally to cause physical harm or injury to him or herself
- c. He/she is likely to follow a stranger's directions, even if it may not be safe
- d. He/she is likely to wander off in a public or unsafe setting
- e. He/she is likely to become lost so that it would be necessary to search for [SC]

Has any of the following *ever* happened to [SC]?

YES/NO/DK/RF

- a. He/she has done something on purpose to cause physical harm or injury to him or herself
- b. He/she has done something accidentally to cause physical harm or injury to him or herself
- c. He/she has followed a stranger's directions, even if it may not be safe
- d. He/she has wandered off in a public or unsafe setting
- e. He/she has become lost so that it was necessary to search for [SC]

If yes to any of a-e, then ask for each:

What specifically happened? Describe briefly. [how to get at circumstances, unlocked door, opened lock, etc.]

When did this happen?

- a.....Within the last year
- b.More than a year ago
- c.....Both within the last year
more than a year ago

Was [SC] hurt or injured? Y/N

If yes, what type of injury

Were other people called to assist? If so, which people?

- a.....Other family
- b.....Teachers or school
personnel
- c.....Neighbors or other
community members
- d.....Store employees
- e.....Authorities such as police
or fire

If yes to d or e, then ask for each:

Did [SC] wander off or become lost from any of the following places

- a.....Home where [SC] lives
- b.Another home (relative, friend, sitter, residential home)
- c.....School
- d.Community (store, restaurant, park, etc.)
- e.....Other

Are any of the following reasons why [SC] wandered off or became lost?

- a.[SC] was trying to get away from something (noise, request to do something, etc.)
- b.[SC] was trying to get something (food, object, activity)
- c.Other reason, specify:
- d.Unsure

Children with learning and developmental conditions work with may have challenges with safety issues. Have you ever done any of the following as a precaution to keep (SC) safe from harm or injury?

- a. Sought professional assistance from health care providers, therapists, school professionals, or law enforcement regarding [SC]
- b. Added additional barriers in the home (gates, locks, alarms)
- c. Specifically taught safety skills to [SC]
- d. **Added monitoring and/or tracking systems to [SC's] person or personal space (bed occupancy detectors, baby monitors, GPS tracking devices)?**

For each of the above, have these measures been helpful in preventing future incidents?

Y/N

If no, why not?

*elopement items from

Donna L. Algase, Elizabeth R. A. Beattie, Erna-Lynne Bogue and Lan Yao

The Algase wandering scale: Initial psychometrics of a new caregiver reporting tool. *AM J ALZHEIMERS DIS OTHER DEMEN* 2001 16: 141

Also may be interesting to look into:

Lorna Wing

Language, Social and Cognitive Impairments in Autism and Severe Mental Retardation.

Journal of Autism and Developmental Disorders 1981 11:1 (36)

Characteristics for potential wandering risks:

- a. Aloof, Mobile, No Practical Skills
- b. Aloof, Mobile, with Some Skills
- c. Passive, Mobile, with Some Skills
- d. Active but Odd and One-Sided Social Approaches, Mobile, with Some Skills