Keeping Children with Autism Spectrum Disorders (ASD) Safe: Guidance for Pediatricians

April 3, 2013
Sponsored by: CT Department of Public Health and the Office for Community Child Health (OCCH) at Connecticut Children’s Medical Center
Presenters

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Disclosure

The speakers from the Connecticut Children's Medical Center have no disclosures to make, nor will they be discussing any off label, experimental, or investigational use of drugs or devices.
Learning Objectives

• Understand injury risks for children with ASD
• Identify common types of risks/injuries
  ▫ General injuries
  ▫ Elopement
  ▫ Drowning
  ▫ Motor vehicle
  ▫ Home
  ▫ Self-injurious behavior (out of purview/scope of this discussion)
• Be able to counsel parents/caregivers on preventive home safety measures
• Be able to explain the impact of stress related to risks/injuries on parents/caregivers
• Be able to offer helpful resources to parents/caregivers
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Who is at risk?

- Children with ASD are at higher risk for injuries due to challenges related to their environment
- Most common causes of death for children with ASD
  - Seizures, circulatory disease, congenital anomalies, cancer and nervous system disease have higher standard mortality rates (SMRs) than in general population
    - Mortality higher in males than females
  - Drowning and suffocation
Features of Autism Spectrum Disorders that Increase the Risk for Injury

- Poor communication skills
  - Can avoid communication with others
  - Often have difficulty asking for help
  - May not follow directions consistently
- Poor social motivation / skills
  - May have preference for being alone
- Poor perspective taking skills may lead to:
  - Limited motivation to comply with instructions
  - Limited understanding that they need to ask permission before leaving or engaging in an activity
- Poor future orientation
  - Difficulty understanding the consequences of their behavior
- Impulsivity
- Anxiety
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General Injuries

• Research by McDermott, Zhou and Mann demonstrated that:
  ▫ Compared to children who do not have ASD children with ASD or Pervasive Developmental Disorders (PDD) have:
    • A higher rate of head, face, and neck injuries (RR 1.47, 95% CI 1.13-1.90)
    • Lower rate of sprains and strains (RR 1.47, 95% CI 1.13-1.90)
    • 7.6 times more frequent treatment for poisoning
    • 7.6 times more frequent self inflicted injury
General Injuries (cont.)

- Compared to children who do not have ASD or PDD, children with ASD or PDD have:
  - 2.5 times the rate of treatment for upper limb injuries (RR 2.53, 95% CI 1.64-3.89)
  - 3 times the rate for fractures (RR 3.01, 95% CI 1.61-5.62)
  - Higher rates of treatment for injuries resulting from being cut or pierced (RR 2.59 95% CI 0.97-6.95)
  - Higher rates of poisoning (RR 8.57 95% CI 4.25-17.29)
ED and Inpatient Admissions

- Children with Autism have higher rates of emergency department (ED) and inpatient admissions compared to children without Autism
  - Children with ASD present to the ED with traumatic brain injury, other head, neck and face injuries, upper body and unspecified injuries, fractures, internal injuries and open wounds, contusions and burns
Occurrence and Family Impact of Elopement in children with ASD

- Anderson, Law, Daniels et al., Pediatrics 2012;130:870
- Despite anecdotal reports on elopement and increased risk of injury and death on children with ASD—there has been little research. This study looked at parent reported elopement occurrences (N=1200 children with ASD) and the subsequent burden on families
Elopement Behaviors

- **Elopement**: Nearly 50% of children with ASD engaged in elopement (wandering) behavior
  - ↑ risk for bodily harm
    - Suffocation
    - Drowning
    - Motor vehicle accidents

- **Most common location for elopement**:
  - Home (74%)
  - Stores (40%)
  - Classrooms/schools (29%)
Reasons for Elopement

• Depends on diagnosis
  ▫ Autism Disorder (AD)/Autism Spectrum Disorder (ASD)
    • Joy of running and exploring (53%)
    • Pleasant destination (36%)
  ▫ Asperger Disorder
    • Need to escape an anxious situation/stressful environment (17%)
Characteristics of Children Who Elope

- Older
- Dx Autism
- ↑ Scores on the Social Responsiveness Scale
- ↓ IQ and communication
- Lack impulse control
- Little understanding of danger
- Seek stimulation (vestibular)
- Altered sensory perception (high pain tolerance)

*elopement behavior less likely in children who responded to their name
Missing Children

Among children who elope and go missing
  ▫ Older
  ▫ Experienced a loss in skills
  ▫ Less likely to respond to their name
  ▫ ↓ IQ, communication, social

* On average: children missing for 41.5 minutes
Parental Response to Missing Child

• Most frequently mobilized resources:
  ▫ Neighbors (57%)
  ▫ Police (35%)
  ▫ School (30%)
  ▫ Store personnel (26%)
Consequences of Elopement

• During the Missing Period
  ▫ Physical restraint (9%)
  ▫ Emotional trauma (7%)

• “Close Calls”:
  ▫ Traffic injury (65%)
  ▫ Drowning (24%)
Elopement Impact on Families

- Elopement was one of the most stressful behaviors to cope with (56%)
- Poor sleep (43%)
  - ↓ ability to cope
- ↓ Participation in activities outside the home (62%)
  - ↑ isolation, ↓ social support
- Parents fear judgment from others
  - Viewed as neglectful if child succeeds in escaping
Elopement Impact on Families (cont.)

- Families and caregivers reported receiving no guidance on preventing or addressing elopement behaviors
- This signals the need for addressing these behaviors at the pediatrician’s office
Drowning

- Drowning is the #1 preventable injury for children with ASD
  - May have no fear of water
  - May be drawn to water
  - May not know how to swim

- Drowning statistics
  - Children drown without a sound
  - Drowning takes place in 1” of water
  - Nearly 9/10 deaths occurred with supervision
Motor Vehicle Safety

- 50% of parents worry about transporting their autistic children
- 75% of parents worry when their child is being transported by school bus/van (unfamiliar adults, unknown passengers)
Home Safety Risks

Curious behaviors can lead to:

- Putting items in appliances
- Flushing things
- Touching hot surfaces
- Turning hot faucets
- Inserting items into electric sockets
- Chewing on wires
- Crawling in the washing machine
- Playing with matches, lighters, or fire
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Guidance for Injury Prevention: Elopement

- Burrows, Adams, Spiers-Qualitative Health Research 18(12):1642-9, 2008 Dec
  - Examined the effects of integrating service dogs into 10 families with an autistic child
  - Themes:
    - The dog as a sentinel of safety
    - Gaining freedom through enhanced safety, facilitating public outings and family activities
    - Improving social recognition and status-presence of dog promotes awareness of autism and affected social interactions
Guidance for Injury Prevention
Elopement (cont.)

Safety Products

• Autism Speaks
  http://www.autismspeaks.org/family-services/resource-library/safety-products
  ▫ Tracking devices
  ▫ Harnesses
  ▫ ID bracelets www.IdentifyYourself.com
  ▫ Door alarms, locks
  ▫ Tent beds
  ▫ Service dogs and more
Guidance for Injury Prevention: Water Safety

- Consider extra layers of protection such as safety fences, safety covers and alarms on doors and windows leading to the pool.
- Have a 4-sided fence, rather than a 3-sided fence with an exterior house door that leads onto the pool deck.
- Remove chairs, toys or other items that children could use to climb over the fence.
- When using safety covers, fully remove before using the pool, replace them promptly after use and remove standing water after rains.
Guidance for Injury Prevention: Water Safety (cont)

- Active adult supervision
- Counsel parents to enclose pool and spa with a fence or wall. All gates should have a spring lock, self-closing and self-locking mechanism. The inside latch should be above the reach of toddlers and young children. Keep pool and spa areas locked to prevent unsupervised access.
Guidance for Injury Prevention: Motor Vehicle Safety

- Conventional seat should be first choice.
- Seats with 5-point harnesses now have higher weight limits, up to 80 lbs.
- A vest with back closure is also an option, vest is put on prior to entering vehicle and is secured with the seatbelt.
- A child who unbuckles their belt may need adult supervision when they ride.
Guidance for Injury Prevention: Home Safety

- **Around the house:**
  - Locking doors from the outside when a room is empty.
  - Use special latches on bathroom doors and a toilet lock, and ensuring no access to the garage or an attic/crawlspace.
  - Cabinet safety latches, no-pinch drawer closures, electrical outlet covers, window guards, picture frames made of plastic (not glass), attachment of dressers and tall furniture to the wall (to prevent tipping), working smoke detectors
Guidance for Injury Prevention: Home Safety (cont.)

- Be sure that furniture placement isn't allowing easy access to windows, door locks or other means for your child to escape.
- Install window locks (available at your local hardware or home improvement store). If your child breaks glass or pounds on the windows, replace the glass panes with Plexiglas to prevent injury and elopement.
Guidance for Injury Prevention: Home Safety (cont.)

- Place extra locks on doors that provide entry to or exit from the home. Having locks that are high and out of children's reach can prevent them from exiting the house unsupervised.
- A battery-operated doorbell chime (less expensive than an alarm system) is a good way to discern when a child has left the house.
- To minimize stress, families can use video baby monitor for day and night surveillance.
Guidance to All Families

• Encourage families and caregivers to speak with neighbors about child
• Notify local police and fire departments about child in case of potential emergencies
  ▫ Atypical behaviors that may attract attention
  ▫ Compulsive activities
  ▫ Favorite locations
  ▫ Likes and dislikes
  ▫ Approach and de-escalation techniques
  ▫ Method of communication
Guidance to All Families (cont.)

• Safety Skills
  ▫ The benefits of Virtual Reality (VR): Self et al.
    • Improved learning and transfer of safety skills
  ▫ Video modeling, graduated guidance and community based instruction: Akmanoglu and Tekin-Iflar
    • Effective in teaching children how to respond to lures of strangers
  ▫ Seeking help when lost: Bergstrom et al.
    • Treatment package (rules, role playing and praise) help seeking behaviors become generalized
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Resources

• CT Department of Public Health - CT Collaborative to Improve Autism Services
  http://www.ct.gov/dph/cwp/view.asp?a=3138&q=499610
• CT Department of Developmental Services - Division of Autism
• ASCCONN: Autism Society of CT http://www.asconn.org/
• ARSC: CT Autism Spectrum Resource Center
  http://www.ct-asrc.org/index.html
• CDC: http://www.cdc.gov/ncbddd/autism/index.html
  ▫ Learn the Signs. Act Early: http://www.cdc.gov/ncbddd/actearly/
Resources (cont)

- CT Department of Public Health-Medical Home Initiative
  - South West Region-Stamford Hospital
    1-866-239-3907
  - South Central Region – Family Centered Services of CT
    1-877-624-2601
  - Eastern Region- United community and Family Service, Inc– 1-866-923-8237
  - North Central Region- Connecticut Children’s Medical Center-1-877-835-5768
  - North West Region-ST Mary’s Hospital-1-866-517-4388
Resources (cont)

Education Materials available upon request from the Special Kids Support Center:

Contact us: 1-877-835-5768