

Safely Transporting Children With Autism Spectrum Disorder: Evaluation and Intervention

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MeSH TERMS

- child development disorders, pervasive
- child restraint systems
- motor vehicles
- safety
- transportation

OBJECTIVE. The purpose of this study was to investigate transportation practices of caregivers who transport children diagnosed with autism spectrum disorders (ASD).

METHOD. We reviewed documented transportation evaluations of children with ASD. The evaluations were conducted by pediatric occupational therapists at an outpatient center of a large children's hospital.

RESULTS. A review of 82 charts of patients diagnosed with ASD revealed that 74% of children with ASD were escaping their child safety restraint. More than 20% of parents reported that their child demonstrated aggressive or self-injurious behavior during travel, affecting not only their own safety but also that of others in the vehicle, including the driver.

CONCLUSION. Escaping from a child restraint can be a life-threatening problem among children with ASD. Parents, caregivers, and health care professionals should be aware of services available from trained therapists, certified child passenger safety technicians, or both to maximize safety during personal travel in the family vehicle.

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Motor vehicle injuries are the leading cause of death among children in the United States (National Center for Injury Prevention and Control, 2010). Many of these deaths could be prevented by placing children in age- and size-appropriate child restraints, thereby reducing serious and fatal injuries by more than half (National Center for Injury Prevention and Control, 2011). In addition, as many as 73% of standard car safety seats have at least one associated misuse with either installation or positioning the child within the safety harness or seatbelt, compromising the safety of the child in the restraint (National Highway Traffic Safety Administration [NHTSA], 2004).

The Centers for Disease Control and Prevention (2012) has reported that 1 in 88 children in the United States are diagnosed with autism spectrum disorder (ASD). Transporting children with ASD may be

complicated by behavioral problems, which frequently challenge parents to keep their child properly secured in a child restraint device (CRD) in the family vehicle. For example, children with ASD may demonstrate impaired receptive or expressive communication skills that may limit their understanding of the need to stay buckled up. Children with autism may also have sensory processing disorder, which affects their ability to tolerate harness systems. A child with ASD may not respond readily to commands or traditional behavior modification techniques, which may result in the child being unrestrained in the vehicle, causing risk of injury to themselves or other occupants by distracting or making physical contact with the driver.

When faced with these challenges, families may seek the advice of health care professionals. Families and health care

professionals who have not received adequate training in child passenger safety may be tempted to adapt CRDs or use aftermarket products that could compromise the safety of the seat (NHTSA, 2007). They may be unaware of resources, restraint options available, and best practice recommendations to address escaping from a CRD. For the purpose of this article, the terms *restraint* or *child restraint* refer to crash-tested systems that meet federal safety standards designed to provide crash protection for infants and children.

Research investigating how children with ASD are transported is limited. Falkmer, Anund, Sørensen, and Falkmer (2004) sent a questionnaire to families who were recruited from parent organizations for children with autism. The questionnaire assessed the transport mobility situation for children with autism. This study identified the primary concern of parents was that the child negatively affects the driver (54%) and the child moves the safety belt to an unsafe position (53%). This study was not based on direct observations of how children with ASD were being transported, nor were measures reported to eliminate escaping from a CRD.

Our study investigated transportation practices of caregivers who transport children diagnosed with ASD. Unlike the Falkmer et al. (2004) study, our study reviewed patient files that documented direct observation of transportation practices by occupational therapists employed by the National Center for the Safe Transportation of Children with Special Healthcare Needs, where we are employed. The occupational therapists are trained to complete transportation evaluations for children who are seen at an outpatient center of a large children's hospital.

Clients are referred to our program by physicians, therapists, and community programs to assess transportation safety. The center's therapists have more than 22 yr combined experience working in pediatrics, including direct treatment of children who have sensory and behavioral needs and securing adaptive equipment through funding sources. Having had the opportunity to directly observe how children with autism were being transported prompted the occupational therapists to

address the question "What are the transportation behaviors in family vehicles demonstrated by children with autism and the challenges reported by caregivers?"

Method

Research Design

This was a retrospective study of medical records of children diagnosed with ASD. This study was reviewed and approved as an exempt study by the Indiana University institutional review board. All data were deidentified, and analysis was based on aggregate data.

Participants

Documentation of all car seat referrals to the special needs car seat program from October 1, 2004, to July 31, 2009, was reviewed. The records of children with a primary diagnosis of ASD were selected for more in-depth analysis. All potential candidates without a diagnosis of ASD were excluded.

Instruments

The survey instrument was an evaluation form, the Child Safety Seat Evaluation and Delivery Form (Figure 1), developed by the first author (Yonkman) and reviewed by experts in the field of the safe transportation of children with special health care needs. This form was also approved for use by the Department of Rehabilitation Services as part of the medical record of a tertiary children's medical center. This form is part of a standard patient child safety seat evaluation report. Data were abstracted from this form, deidentified, and entered into an Excel (Microsoft Corporation, Redmond, WA) spreadsheet for analysis.

During the child safety seat evaluation, the therapist interviewed the caregiver to obtain information about how the child was being transported and the challenges the family experienced. Information was recorded on the Child Safety Seat Evaluation and Delivery Form, and the interview usually was completed within 1 hr. Patient charts were reviewed to learn how children with ASD were being trans-

ported at the time of their evaluation, if and how they were escaping, parent concerns, and the interventions provided to address escaping a CRD. For this study, *escaping a child restraint* was defined as any attempt by the child to interfere with proper restraint in the family vehicle.

The following variables were collected: age, weight, height, gender, primary diagnosis, current CRD, reported escaping from child restraint, misuse, and interventions provided. *Misuse* is described by Weber (2000) as a child restraint not "used to maximum advantage" (p. 14). Misuse occurs when a CRD is not used according to manufacturers' instructions. Some examples include harnesses that are not adjusted snugly enough and chest clips positioned too low or too high.

Data Collection

The data collectors were licensed occupational therapists with training as certified child passenger safety technicians and who are instructors for a 2-day enrichment course for the safe transportation of children with special health care needs.

Data Analysis

Descriptive statistics were used to describe the collected data. An Excel spreadsheet was developed to tally data collected from patient charts. The spreadsheet headings included diagnosis, reason for referral, sex, age, weight, height, CRD type, escaping behavior, misuse and type of misuse observed.

Results

During the study period, 637 patients aged 2 to 18 yr were referred to the special needs car seat program. Of those referrals, 82 had a primary diagnosis of ASD and were selected for this study. The mean age of the children was 5.5 yr (range = 2–13 yr), 65 (79%) were male, and the mean weight was 53 lb. Height was documented for 57 out of 82 children (mean height = 44 in.).

Type of Restraints

Children with ASD were being transported in a variety of CRDs, the types of which are described in Table 1.



OCCUPATIONAL THERAPY CHILD SAFETY SEAT EVALUATION & DELIVERY REPORT (Page 1 of 3)

PATIENT NAME: _____

MRN: _____

PHYSICIAN: _____

DOB: _____

Date: _____ Time In: _____ Time Out: _____

Diagnosis: _____

Referred By: _____

Pain: _____

Action Taken: _____

Height: _____ Weight: _____ Age: _____

Pertinent Medical History/Pressure Problems/Pertinent Info: _____

Present Child Restraint System: (per caregiver) _____

Seating Position of Child in Vehicle:
(PLACE X IN BOX WHERE CHILD IS LOCATED IN GRAPH AT RIGHT)

Number of children in CRD's or safety belts:
Ages: a) _____ b) _____ c) _____ d) _____ e) _____ f) _____
(mark letter of child in box at right)

FL	FC	FR
ML	MC	MR
RL	RC	RR

(Example: FL – Front Left,
MC – Middle Center, etc.)

Type of Vehicle: _____ Year: _____

Does your child attend school? Yes No Other: _____

BUS TRANSPORT TO SCHOOL – OR –

FAMILY TRANSPORT TO SCHOOL

Yes No

Does wheelchair have a transit option?	_____	_____
Is wheelchair tied down during transit?	_____	_____
Is tie down system on transit locations?	_____	_____
Is tie down system around frame?	_____	_____
Is child transported with lap tray?	_____	_____
Does child have a headrest?	_____	_____
Is child transported with headrest?	_____	_____
Does child have a harness for positioning?	_____	_____
Does the bus/family use a separate lap/shoulder belt around child?	_____	_____

OT CLINICAL ASSESSMENT

- A) Head Control: Good Fair Poor
- B) Sitting Balance: Good Fair Poor
- C) Trunk Tone: WFL Low High Athetoid
- D) UE Tone/Contractures: _____
- E) LE Function: _____
- F) LE Tone/Contractures: _____

Transfers: Indep Min Assist Mod Assist Max Assist Dependent

OT Assessment: _____



**CHILD SAFETY SEAT EVALUATION
& DELIVERY REPORT (Page 1 of 3)**

Q-14

Figure 1. Child safety seat evaluation and delivery form.

Table 1. Description of Child Restraint Devices

Type of Restraint	Position in Vehicle	Weight Limit	Harness Style
Convertible: “Converts” from rear facing for infants and smaller children to forward facing for older and larger children	Forward or rear facing	Typically 40 lb (forward facing)	5-point harness
Combination: CRD used with an internal harness system; harness can be removed and seat used as belt-positioning booster	Forward facing only	Typically 40 lb	<ul style="list-style-type: none"> • 5-point harness • Harness can be removed after certain weight and used as booster with lap–shoulder belt
Combination with harnesses to higher weights: CRD used with an internal harness system; harness can be removed and seat used as belt-positioning booster	Forward facing only	Typically >40 lb	<ul style="list-style-type: none"> • 5-point harness • Harness can be removed after certain weight and used as booster with lap–shoulder belt
Booster seats: Seat that raises child up so lap–shoulder belt fits properly; models can be high backed or backless	Forward facing only	Typically 80–100 lb	Vehicle lap–shoulder belt
Adaptive restraints: Designed specifically for children with special health care needs and not available at retail stores; can range from car beds for infants to large medical seats or vests for older children	Forward facing only	Greater than store-bought car seats; obtained via therapist or equipment vendor	<ul style="list-style-type: none"> • 5-point harness • Some have 5-point harness for positioning and use vehicle lap–shoulder belt

Note. CRD = child restraint device.

Figure 2 outlines the frequency of use of each restraint by children with ASD by age group. Booster seats were the most common type of CRD used, with 43% of children with ASD occupying this type of restraint. Another 41% of clients were transported in CRDs with 5-point harnesses, including convertible, combination, and combination with harnesses to higher weights. Fewer than 10% of clients used seat belts for occupant protection,

and 2 clients were transported in adaptive car seats. In four instances, children were transported in a CRD listed as “other,” because they failed to clearly fit in any other CRD category. For example, to keep his daughter seated in the van, one parent used a lap-only belt in conjunction with a child leash tied to the back of the vehicle seat.

Figure 2 reflects a total of 84 clients, rather than the 82 clients with ASD whose

charts were initially examined. Two clients were reported to use two different types of restraints at different times, depending on who was transporting the client and which restraint was available to the child.

Escaping Child Restraints

Of the 82 children, 61 (74%) were reported by caregivers to exhibit some form of escaping their CRD, the method of which varied from child to child. Some

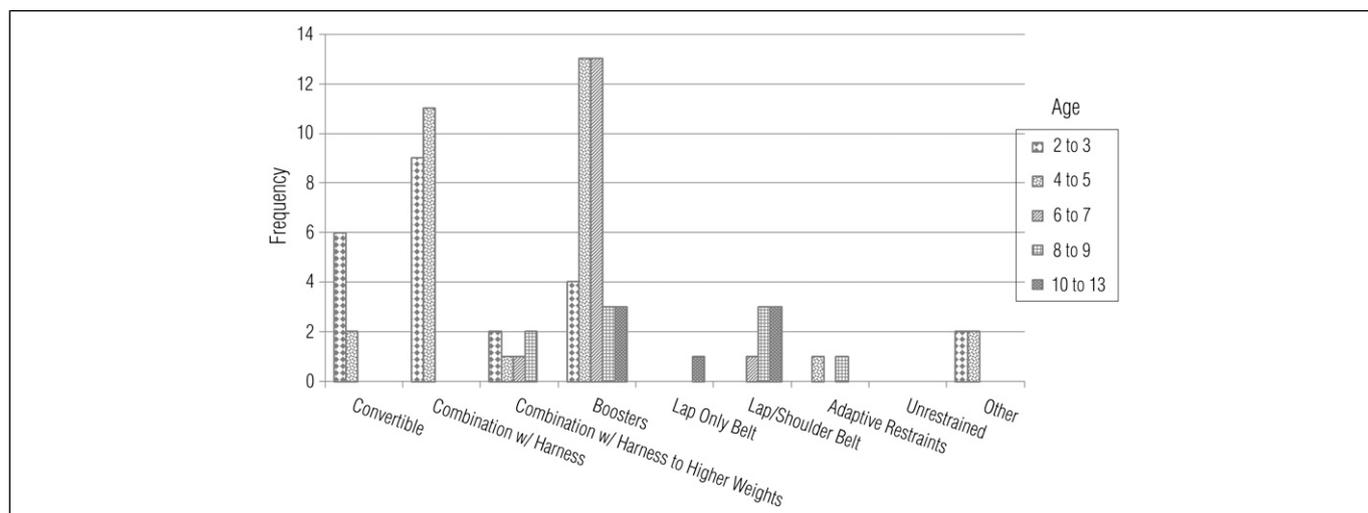


Figure 2. Restraint type by age.

children unbuckled the chest clip, some slid the chest clip down and removed their arms from the harness system, and others unbuckled the crotch buckle on the car seat or actually unbuckled the seat belt, thereby uninstalling the car seat from the vehicle. Those children restrained by a lap–shoulder belt unbuckled the belt, leaving them unrestrained. Generally, children restrained in booster seats or seat belts were reported to escape more often (84%) than those restrained in a child safety seat with a 5-point harness (58%; Figure 3), in part because of the less restrictive environment of the booster or seat belt, making escaping easier.

Misuse

Of the children who were demonstrating escaping behaviors, 44% also had documented misuse of the CRD by the caregiver. Misuses included errors with installation, adjustment of the harness, wrong selection for child size and weight, adaptations, and seats that were expired.

Disruptive Behaviors

In addition to escaping the car seat or seat belt, 17 (21%) parents reported that their child demonstrated aggressive, self-injurious, or disruptive behavior during travel. These behaviors were described as kicking the back of the vehicle seats, attacking the driver or other passengers, opening vehicle doors,

head banging, hitting self, holding breath, and rocking back and forth so forcefully that the harness straps made marks on the child’s body.

Intervention

Ninety-two percent of the children with ASD either received a new commercially available CRD at the time of evaluation or had a specialized CRD ordered for delivery on approval from insurance. Reasons for replacing CRDs documented by occupational therapists included the child exceeding weight or height limit for the current CRD, unknown history of child restraint, current CRD not offering adequate support or optimal for need, size and weight of child during transport (i.e., switching a child from a booster seat to a 5-point harness), and need for a specialized CRD. Some children did not receive a new CRD because of observed misuse of the CRD at the vehicle; these children had their current CRD adjusted for proper fit, installation errors corrected, or both.

Twenty-four (29%) families returned for a second evaluation for delivery of the specialized CRD that was ordered or because the child continued to escape and caregivers were seeking further assistance to explore additional child restraint options. Four returned for a third evaluation because of continued problems with

the child escaping the CRD. It was documented in 16 (20%) of the cases that the occupational therapist educated families on behavior strategies when riding in the car. Some behavior strategies recommended included positive reinforcement, ignoring bad behaviors that are not harmful to the child or caregiver, distraction strategies, social stories, and contacting a professional behaviorist.

Discussion

Children with ASD have the same needs for transportation safety as typical children, including the need to be transported to school, medical appointments, and other locations within the community. The study demonstrates that many children with ASD exhibit escaping behaviors while being transported in a CRD. This area of injury prevention is not addressed adequately by health care professionals, largely because of a lack of education regarding interventions to address the problem. This study is one of the first to report documented escaping from CRDs and seat belts among children with ASD. Our study differs from that of Falkmer et al. (2004) in that it involved documentation that caregivers actually experienced the child escaping from the CRD and were seeking help from health care professionals.

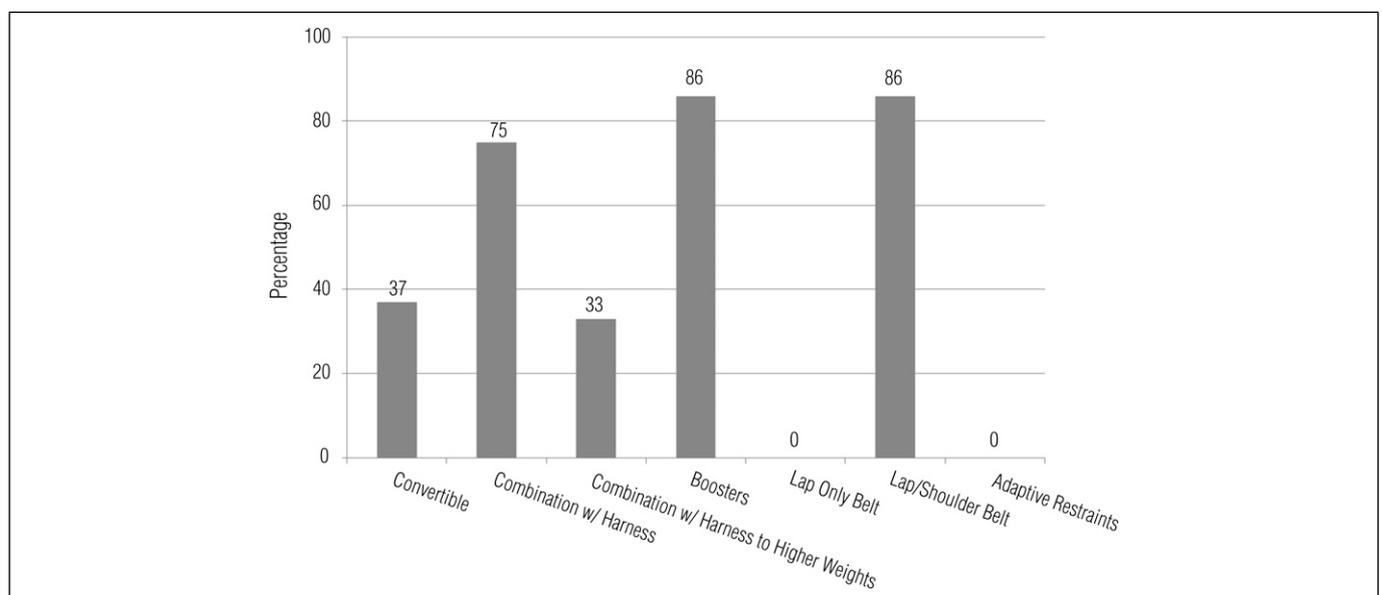


Figure 3. Percentage of escapism by restraint type.

Families may consult occupational therapists to obtain a specialized car seat for their child with special needs. These health care providers may be expected to make recommendations to families about their child with special needs, despite having little or no training in the field of child passenger safety. Such recommendations may lead to inappropriate selection or misuse of a CRD. For example, as a foundation to practice, occupational therapists are encouraged to adapt equipment or an environment to increase independence with functional activities. Adapting child restraints in an effort to address transportation challenges can affect how the CRD performs in a crash. We have observed clinicians' adaptations to car seats such as securing a baseball cap to a head rest to keep a child's head positioned or using a zip tie to prevent a child from pushing the chest clip down and removing the child's arms from the harness. Unfortunately, well-meaning adaptations such as these may prove detrimental in the event of a crash and put the occupant in jeopardy.

The safe transportation of children with special health care needs is an area of practice that is not widely known. To ensure that this population is being transported as safely as possible, we must raise awareness about the issues surrounding transporting children with ASD. To begin, it would be prudent for universities and colleges offering occupational therapy degrees to introduce the subject in curricula. Students would, therefore, have an awareness of potential issues among the population, develop problem-solving skills to use in clinical settings, and be conscious of available products and resources.

Occupational therapists are in a position to promote the safe transportation practices of children with special health care needs, working closely with the child's medical team and community child restraint resources. As the first rule of following best practice recommendations, occupational therapists not trained in child passenger safety should not exceed their area of expertise. However, when collaborating with community resources, pediatric occupational therapists are in a position to refer families to organizations that can assist their clients in finding solutions to transportation challenges.

Limitations and Future Research

A retrospective chart review study can be limited by incomplete documentation of patient treatment. However, medical records hold valuable information that will, if shared appropriately with other health care providers, increase the safety of transporting children diagnosed with ASD. A prospective study is implicated to continue to study this area of importance and ensure more accurate documentation and data gathering.

Implications for Occupational Therapy Practice

The results of this study have the following implications for occupational therapy practice:

- This study may help increase awareness of resources available to families with children with ASD experiencing behavior issues in vehicles.
- The subject of transportation safety in family vehicles should be added to the occupational therapy curriculum.

- Community-building partnerships can help ensure that families' child safety seat needs are being addressed. ▲

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