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Preface

This manual was developed as a supplemental resource for child passenger safety technicians who have taken Safe Travel for All Children: Transporting Children with Special Health Care Needs. Some of the information in this manual is not covered - or not covered in as much depth - in the training slides. We hope this manual helps you expand the knowledge you have acquired about transporting children with special health care needs.

“Children with special health care needs are those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who require health and services of a type or amount beyond that required by children generally.”

Merle McPherson, MD
Pediatrics, July 1998

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Chapter 1:
Reference Guide of Medical Conditions and Procedures
The purpose of this reference guide is to acquaint certified child passenger safety technicians (CPSTs) with medical conditions and procedures that may require special consideration during travel. This guide is based on cases with which the National Center for the Safe Transportation of Children with Special Health Care Needs has experience and is not all inclusive. It is arranged alphabetically for ease of use. Definitions of some of the terms contained within the guide can be found in the Glossary of Terms, which is in the Appendices. (The defined terms are underlined.)

The following medical conditions and procedures are addressed in this guide:

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ACHONDROPLASIA

Achondroplasia is a genetic disorder of bone growth. It is the most common form of dwarfism with disproportionate short stature, including a long torso with short extremities. A three-year-old child at the 50th percentile for height on the achondroplasia-specific growth chart is the height of a typically developing one-year-old at the 50th percentile. Children with achondroplasia have a head size that is usually near or above the 95th percentile. This measurement is followed closely in infants as hydrocephalus can develop during the first two years of life.

A few children with achondroplasia have upper airway obstruction and other breathing problems that may be affected by upright positioning. An additional problem for infants with achondroplasia with associated low muscle tone is angulation of the spine or thoracolumbar kyphosis. This problem can be minimized during infancy by keeping the back straight and avoiding a curled-up position (C-position). Unsupported sitting should be avoided, and parents are instructed to provide back support during the first year of life.

Infants with achondroplasia also have a relatively small foramen magnum (opening of the skull to the spine). Compression of the spinal cord is rare, but when symptoms occur, surgery is necessary.

Considerations for restraint selection

- Child safety seat selection should be determined by the size and positioning needs rather than age of the child.
- Use a rear-facing child safety seat for infants and young children as long as possible. A rear-facing seat will provide the best protection and positioning angle for a child with hypotonia; ligamentous laxity or loose ligaments; macrocephaly; and skeletal dysplasia. This positioning will also help prevent kyphosis. Families may benefit from suggestions for behavioral intervention to promote continuing the rear-facing position as long as possible.
- Then, use forward-facing child safety seats for older children.
- Transition to belt-positioning booster seat when the upper-most weight limit of harness is reached.
- Remain in booster seat until seat belt fits.
- Adolescent or adult drivers usually require a vehicle that is adapted with equipment, such as hand controls or pedal extenders to position the driver an appropriate distance from the air bag (10-12 inches). Families should work with a driver rehabilitation specialist (866-672-9466,
www.driver-ed.org) who is qualified to assess the driver’s transportation needs and who can provide them with a list of appropriate vehicle modifications. In rare instances, it may be necessary to get approval from the National Highway Traffic Safety Administration (NHTSA) for disabling an air bag.

- Refer to the Car Safety for Children with Achondroplasia fact sheet for more information.

ANGELMAN’S SYNDROME

Angelman’s syndrome is a genetic disorder that causes developmental delays and neurological problems. Children with Angelman’s syndrome are typically intellectually impaired, have problems speaking and walking, may exhibit jerky movements, and may develop seizures (usually between 2 to 3 years of age). They are often described as having excitable, happy personalities with frequent smiling and laughter.

Considerations for restraint selection

- Use a rear-facing child safety seat for as long as possible.
- Use a forward-facing child safety seat with higher-weight harness for as long as possible due to cognitive delays, physical disabilities and abnormal tone.
- May require an upright vest with back closure, large medical seat or adaptive booster seat, due to cognitive impairments, physical disabilities, behavioral challenges and abnormal tone.

APNEA

Apnea is the temporary interruption of breathing, whether normal or abnormal. Pathological apnea is a respiratory pause of more than 20 seconds or a shorter pause associated with cyanosis, marked pallor, hypotonia or bradycardia. There are different reasons why children experience apnea. One type of apnea, called positional apnea, is directly related to a child’s sitting position. Children who suffer from positional apnea may have increased symptoms or even stop breathing if their heads flop too far forward, and the airway becomes obstructed.
Considerations for restraint selection

- Conduct a period of observation of infants in their child safety seats prior to discharge from the hospital.
- If an infant with positional apnea requires a car bed, the infant should be monitored in the car bed prior to discharge. Infants discharged in car beds will need to be re-evaluated in a rear-facing child restraint before transitioning out of the car bed.
- Select a car seat that can be positioned at an angle, according to manufacturer’s instructions, that does not compromise the child’s respiratory status.
- Select a car seat with a forward-facing recline when child exceeds rear-facing limit.
- Travel with and secure prescribed medical equipment; have enough power for twice the length of the trip.

AUTISM SPECTRUM DISORDER

Autism is a developmental disorder that has occurred with increasing recognition and frequency in recent years. This condition is most commonly recognized in early childhood and has prevalence as high as 1 in 68 children. The symptoms may include delay in language acquisitions, impairment in social interaction, and narrow span of interests and occurrence of repetitive behaviors. The children often have a need for sameness and may require compulsive rituals. Repetitive mannerisms like hand or finger flapping and body rocking can be common. These children also may be very sensitive to certain textures and sounds.

Considerations for restraint selection

- With limited communication skills and a tendency to not respond to direct interaction, use of seats that provide five-point restraint as long as possible or use of a vest for older children is often necessary.
- If a child tends to “escape” his or her car seat, make sure the car seat type is appropriate and being used correctly before deciding to use another seat.
- Families may need to try a variety of seats to see from which one it is the most difficult to escape.
• A large medical seat with seat-specific accessories that deter escaping behaviors may be necessary.
• An upright vest with back closure and/or floor mount tether may be a good option to avoid escaping behaviors.
• Advise families not to modify restraints in attempts to deter escaping behaviors.
• If a child is in a child safety seat and unbolking the seat belt, try installing the child safety seat with LATCH (If the child is within the weight parameters and the vehicle is equipped with anchors.).
• If a child is bothered by light touch, make sure the harness or vest is snug, flat and not twisted. Also, make sure the harness is touching clothing, not the child’s skin. Tight-fitting underclothes or a compression vest may help prevent irritating light touch.
• If a child is bothered by loud noises, teach the child to cover her ears or wear headphones to block out loud sounds. Explain the reason for loud sounds to help the child understand.
• If a child chews on the harness or car seat cover, lightweight chew toys may help. You can purchase chew toys at stores that sell special needs products.
• Caregivers also need to be aware that children may have difficulty with transitions, including adapting to a new car seat, a substitute bus driver or a different route to school.
• If possible, have an adult sit in the back seat to supervise the child’s behavior.
• Behavioral management counseling may be beneficial and should be considered.
• Refer to the Car Safety for Your Child with Autism fact sheet for additional information.

BEHAVIORAL CHALLENGES

Children who exhibit behaviors, such as impulsiveness, distractibility and short attention span, which may be associated with conditions such as autism, attention deficit-hyperactivity disorder or cognitive impairment may resist consistent use of child safety restraints and prove to be serious distractions to drivers. Many parents need guidance with management of behavioral problems and may benefit from assistance from their family physician, pediatrician or a counselor. Children with severe behavioral challenges frequently do not readily respond to consistent limit setting and require specialized restraints in vehicles.
Considerations for restraint selection

- Check to see if the child’s car seat is appropriate and being used correctly before deciding to use another seat.
- Families may need to try a variety of seats to see from which one it is the most difficult to escape.
- Advise families not to modify restraints in attempts to deter escaping behaviors.
- A car seat with a higher-weight harness or large medical seat may provide securement for older children. Some large medical seats can be ordered with seat-specific accessories that deter escaping behaviors.
- An upright vest with back closure and/or floor mount tether may be a good option to avoid escaping behaviors.
- If possible, have an adult sit in the back seat to supervise the child’s behavior.
- Behavioral management counseling may be beneficial and should also be considered.
- If the child is in a child safety seat and unbuckling the seat belt, try installing the child safety seat with LATCH (If the child is within the weight parameters and the vehicle is equipped with anchors.).
- During school bus transportation, an upright travel vest or other school bus restraint system may be advised.
- Refer to the Car Safety for Your Child who Doesn’t Stay Buckled Up brochure for additional information.

CASTS

Casts are used to immobilize a part of the body. Casts are made from plaster or fiberglass and can be applied as primary treatment for a developmentally dislocated hip, postoperatively for a tendon release or after a trauma, such as a fracture. To immobilize the affected area, the cast will extend below and above this area. Some common casts are described below:

- **Body**  
  Cast placed on children who have spinal operations

- **Broomstick**  
  Cast with a bar placed between the legs to hold the legs in proper position
**Hip spica:** Cast formed above or below the hip to treat an injury, such as a fractured femur; or when a hip joint is unstable, such as in post-operative repair of hip dysplasia.

One or both legs may be casted and hip spica casts can be abducted or straight legged. Hip spica casts tend to present the greatest challenges to proper restraint use since they affect a child’s ability to sit up.

**Long leg:** Cast applied at or above the knee

**Short leg:** Cast applied for healing in the ankle

### Considerations for restraint selection

- Determine whether or not the type of cast applied affects the child’s ability to sit up.
- If a child has a cast and **can** sit up, a standard restraint will probably work. However, the following should be considered:
  - The wide spread of a broomstick cast may hit the sides of a standard convertible child safety seat. A child safety seat with low sides may be appropriate.
  - Leg support, in the form of pillows, should be provided.

- If a child has a cast and **cannot** sit up:
  - Alternative restraints appropriate for a child’s size (such as a car bed, Hippo convertible seat or modified E-Z-ON vest) should be considered.
  - In some instances, a child safety seat with low sides may accommodate a child.
  - Under no circumstances should a child with a cast be transported on a reclined vehicle seat. The seat belts will not contact the child’s body properly, and the child could submerge under the belt system.
  - Professional transportation may be required.
- Refer to the *Car Safety for Children in Hip or Leg Casts* brochure for more information.
CEREBRAL PALSY (CP)

Neuromuscular disorders are conditions involving muscle or muscle innervation. One of the most prevalent types of neuromuscular disorders is cerebral palsy (CP), with an occurrence rate of more than 4 per 1,000 live births.

Cerebral palsy is a group of movement and posture disorders due to a non-progressive defect or lesion of the brain. Damage can occur before or after birth (e.g. complication of prematurity, German measles, Rh incompatibility, head injury, illness such as meningitis, lead poisoning and trauma due to child abuse). Developmental delays in an infant or toddler are usually the first indicators of cerebral palsy. Symptoms range from slight speech impairment to total inability to control body movements.

Considerations for restraint selection

- Since children with CP may experience poor head and trunk control, they will benefit from riding rear facing to higher weights.
- Once a child travels forward facing, a seat that can be semi-reclined forward facing may help keep the head from flopping forward during normal driving.
- Rolled blankets can assist with centering the head and torso.
- A soft cervical collar can be used to help prevent the head from falling forward.
- Children with poor head and trunk control require the support of an adaptive restraint after they have outgrown a standard car seat. (Work with an OT or PT to determine and order the most appropriate restraint.)
- Forward-facing seats with harnesses to higher weights may serve as interim solutions while awaiting approval and delivery of an adaptive restraint.
- Application of casts after orthopedic surgery may necessitate use of a specialized restraint.
- If a child has pain or pressure areas on her skin in her car seat, work with the doctor or rehabilitation therapist to determine the cause. The child may need a different seat that fits better, a seat that offers more padding, or the child may need to be repositioned.
• Due to varying degrees of sensation loss, children may be unaware of problems caused by improper fit in their child safety seat. Monitor them closely for redness and skin break down.
• A wheelchair may be necessary for transport.
• Refer to the Car Safety for Children with Cerebral Palsy fact sheet for more information.

CONJOINED TWINS

Conjoined twins are identical twins developed from a single fertilized egg that does not completely separate after fertilization. Conjoined twins, who share skin and internal organs, occur once in about every 200,000 live births. Separations are often risky, and feasibility of surgery depends upon where the twins are joined.

Considerations for restraint selection

• Families should be made aware of the fact that there are no specific products designed or manufactured to transport conjoined twins.
• In some cases, professional transport may be the only option.
• Depending upon where a set of twins is joined, they may be able to use the Hope car bed with restraint bag.
• Families and institutions should work closely with child restraint manufacturers if modifications to child restraints are considered in order to accommodate conjoined twins.
• With any restraint option selected, there are unknown risks, and families should be required to sign a liability waver.

DEVELOPMENTAL DELAYS

As a child grows and matures, he or she acquires developmental skills, such as sitting up, walking and talking. Children who have developmental delays have slower than normal acquisition rates of developmental milestones or skills, including behavioral and motor skills. Developmental delays are associated with a number of medical conditions. These include, but are not limited to, prematurity, low birth weight and congenital anomalies. Some children experiencing developmental delays will eventually catch up with their peers. Other children will be limited in their abilities to acquire appropriate
developmental skills and will need the support of medical and rehabilitation services to function to the best of their abilities.

Considerations for restraint selection

- The restraint will depend on the specific problem associated with the developmental delay. For example, a child who has not developed head and neck support typical for her age will benefit from riding rear facing longer.
- Older children who have outgrown child safety seats with harnesses to 40 pounds may be developmentally immature and require a higher-weight harness or upright vest.
- Children who demonstrate cognitive deficits/intellectual disabilities/delays may need behavior plans to ensure they remain buckled up. (see Behavioral Challenges)
- Vests with back closures and floor mount tethers or large medical seats with seat-specific accessories designed to deter escaping behaviors may be indicated for some children.

DEVELOPMENTAL DYSPLASIA OF THE HIP (DDH)

This term is used to describe the hip bone slipping in and out of the hip socket. Heredity, gender, position in the mother’s uterus and birth order.

Although treatment varies depending upon the child’s age and the specific type of DDH, overall treatment goals are to place the head of the femur back into the socket to assure normal hip joint development. Treatment can include splinting, bracing, casting and/or surgery:

- Harnesses, such as the Pavlick, or splints are used to hold the child’s hip in place while the hip capsule tightens. These are generally used for infants.

- Spica casts are applied after a period of traction or postoperatively to help keep the hip in place. Hip spica casts start at the chest and extend to either the mid-thigh or to the foot of the dislocated hip.
- **Open reduction** of the hip is the surgical procedure required if splinting, bracing and traction are unsuccessful. After surgery, the child will be placed in a hip spica cast.

- **Hip abduction** braces are used for prolonged and continued treatment of DDH to keep hips in position.

**Considerations for Restraint Selection**

- In most instances, the child being treated for DDH will be unable to bend at the hip and maintain a sitting position required for use of a standard child safety seat.
- Alternative restraints, such as a car bed, Hippo or modified E-Z-ON may need to be considered.
- In some cases, a child safety seat with low sides will accommodate a cast.
- Some surgeons may appreciate input from CPSTs and other health professionals on hip angles necessary for child restraint use. By increasing their awareness of issues related to transporting children in hip abduction devices, they may be receptive to casting at an angle conducive to restraint use, as there may be leeway in hip angle.
- Refer to the *Car Safety for Children in Hip and Leg Casts* fact sheet for more information.

**DOWN SYNDROME**

Down syndrome, caused by the effects of having an extra portion of the 21st chromosome, is the most frequently occurring chromosome abnormality. It occurs in approximately 1 in 691 births. Children who have Down syndrome tend to be smaller than their typically developing peers and usually have developmental delays. Most affected children have moderate intellectual disabilities, but their intelligence can range from mild to severe impairment.

Nearly 50 percent of children who have Down syndrome have congenital heart defects and may require cardiac surgery. Additional structural defects can include tracheoesophageal fistula, bowel obstruction and other gastrointestinal abnormalities. Some may have a tracheostomy or gastrostomy tube. Skeletal abnormalities can include hip subluxation and atlantoaxial instability (instability of first and second cervical vertebrae). Children who have Down syndrome frequently have reduced muscle tone and loose ligaments resulting in
hyperextensible joints (often referred to as “double-jointed”). Children with Down syndrome have a tendency to become overweight as they grow older.

Considerations for restraint selection

- Conduct a period of observation of infants in his or her child safety seats prior to discharge due to hypotonia and possible associated apnea.
- If an infant with Down syndrome requires a car bed, the infant should be monitored in the car bed prior to discharge. Infants discharged in car beds will need to be re-evaluated in rear-facing child restraints before transitioning out of the car bed.
- Position rear facing as long as possible due to risk of hypotonia and atlantoaxial instability.
- Rear facing longer is especially feasible because children with Down syndrome tend to be smaller in size than their typically developing peers when they are younger.
- Restraints with higher-weight harnesses, large medical seats or upright travel vests may help prevent older children with loose ligaments and hyperextensible joints and/or behavioral issues from getting out of their restraints. (Refer to Behavioral Challenges.)
- Children with behavioral challenges may also benefit from behavior plans.
- After cardiac surgery, check with the surgeon about pressure on chest incision.
- An older child who is overweight may require a large medical seat to accommodate size.
- Hypotonicity of muscles coupled with hyperextensibility of joints can result in difficulty with positioning, which may be helped with the addition of lateral support rolls or a large medical seat with positioning accessories.
- During school bus transportation, an upright travel vest or other school bus restraint system may be advised.
- Refer to the Car Safety for Children with Down Syndrome fact sheet for more information.
FEEDING TUBES

Feeding tubes are necessary to provide or improve nutrition for children. A gastrostomy feeding tube is inserted directly through the abdominal wall into the stomach or a jejunostomy tube into the intestines. Another feeding tube called a nasogastric tube may be inserted through the nose into the stomach.

Considerations for restraint selection

- The type of feeding tube, location and protrusion above the skin will vary, which may affect harness fit.
- Select a car seat that does not rub against the feeding tube.
- Cover the opening with gauze if the tube comes out during travel.
- Families should have an emergency plan to replace the tube.

FRAGILE X SYNDROME

Fragile X syndrome is the most common inherited cause of intellectual disabilities and is due to an abnormality of a gene on the X chromosome. Children with fragile X syndrome exhibit developmental delays and mild to profound intellectual disabilities. In addition, the condition is associated with a variety of behavioral challenges. Poor eye contact, hand flapping and lack of awareness of social cues are commonly present and may be referred to as Social Communication Disorder or autistic behaviors. These characteristics and associated attention deficit hyperactivity disorder often require behavioral interventions, calming techniques and medication to help children cope with the demands of home and school. Children with fragile X syndrome may display aggressive behavior with violent temper outbursts, a short attention span and hyperactivity. These behaviors may lead to resistance or refusal to use restraint systems consistently.

Parents (usually mothers) who are affected may have less severe manifestations than their children, but their coping abilities may be limited. These individuals may benefit from repetition of structured, clear and simplified instructions.
Considerations for restraint selection

- A car seat with a higher weight harness or large medical seat may provide securement for older children. Some large medical seats can be ordered with seat-specific accessories that deter escaping behaviors.
- During school bus transportation, an upright travel vest or other school bus restraint system may be advised.
- Children with behavioral challenges may also benefit from behavior plans.
- Refer to considerations for restraint selection in the Behavioral Challenges section.

GASTROESOPHAGEAL REFLUX (GER)

Gastroesophageal reflux (GER) is characterized by vomiting or regurgitation of gastric contents into the esophagus as a result of relaxation or incompetence of the lower esophageal sphincter. Although GER is considered normal in newborns, continuation of severe reflux can produce symptoms such as weight loss and respiratory problems. GER is more common in infants born prematurely, children with neurological impairment and after esophageal surgery.

The angle of the back to the bottom of the car seat may increase intra-abdominal pressure, aggravate the reflux or make the reflux worse. Physicians may prescribe a specific position that will affect the choice of a child safety restraint (e.g. car bed).

Considerations for restraint selection

- Wait an hour after feeding before traveling.
- Explain the car seat angle and discuss positioning options with the physician.
- Use the car seat only for travel.
HALO TRACTION

Halo traction is a metal frame attached to the skull for the purpose of treating neck fractures, degenerative diseases of the cervical spine and stabilizing the cervical spine post-operatively. Research on the impact halo traction has on crash dynamics and on safe restraint use is minimal and inconclusive. To position a harness over a child’s shoulders, the harness must usually be routed through the frame of the halo instead of outside the frame.

Considerations for restraint selection

- Select a seat that provides adequate room for the halo.
- Select a seat with a harness that is easy to route over the shoulders and secure. Rear facing, select a seat with a harness that can be easily removed from a splitter plate and rerouted over the shoulders once the child is in the seat. Forward-facing seats with harnesses may need to be reinstalled every time the child is restrained unless the harness can be removed and rerouted from the front of the seat.
- Make sure that the child can be evacuated in an emergency.
- Consider a seat that can be tethered.
- Consider a modified E-Z-ON vest for older children who must lie down.
- Consider an adjustable upright vest for older children with shoulder straps that can be unthreaded, routed through the frame and over the child’s shoulders for ease of use.

HYDROCEPHALUS

The term hydrocephalus describes an abnormal increase in the amount of cerebrospinal fluid within the cranial cavity that, if untreated, is accompanied by expansion of the cerebral ventricles, enlargement of the skull and forehead, and atrophy of the brain. Increased fluid is diverted via a shunt into the peritoneal cavity, heart or gall bladder and re-absorbed into the blood stream.
Hydrocephalus can be caused by a number of different medical conditions, including congenital abnormality, prenatal and postnatal infection, tumors, trauma, and malignancy. It is commonly associated with myelomeningocele.

Considerations for restraint selection

- Children with disproportionate head size benefit from rear facing to higher weights.
- A large car bed may be indicated in some cases.
- Select seat with roomier head area.
- Forward-facing seats that can be semi-reclined can assist with comfort for older children.
- Additional considerations will be specific to related medical conditions.

LOW BIRTH WEIGHT AND INFANTS BORN PREMATURELY

Low birth weight infants are those born weighing less than 2500g. This classification includes infants born prematurely and some full-term infants. One of the leading causes of infant mortality, low birth weight is related to inadequate prenatal care, teenage pregnancy and multiple deliveries.

Infants born prematurely are those infants less than 37 weeks gestational age at birth. Improvements in medical care have increased the survival rate for infants born prematurely and contribute to the discharge of premature babies at lower weights. Some infants, especially low birth weight infants born full term, have been discharged at weights as low as three pounds.

According to the Clinical Report released by the American Academy of Pediatrics (AAP) in 2009 and reaffirmed in 2013, small infants and those born prematurely should be restrained in child safety seats that fit their smaller size. Rear-facing seats that have the shortest distance from the seat back to the crotch strap and that have the shortest distance from the harness slots to the seat bottom will provide the best fit.

In addition, the AAP recommends that infants born prematurely be observed for apnea, bradycardia and oxygen desaturation while positioned in a child safety seat. This period of observation or monitoring should take place before the infant is discharged from the hospital and should be conducted by appropriately trained staff. Significant documented events of apnea, bradycardia and oxygen desaturation warrant interventions such as supplemental oxygen, use of car bed, continued hospitalization or additional medical assessment.
Infants who experience documented events may also be at risk in other upright equipment (swings, slings, carriers etc.).

Considerations for restraint selection

- Select child safety seats with smaller harness dimensions, multiple harness slots and appropriate minimum weights.
- Do not add padding under or behind the infant to make the seat fit the baby.
- Center infant with rolled receiving blankets; position crotch roll if needed to prevent submarining.
- Prior to discharge, monitor according to AAP guidelines. Observe a minimum of 90-120 minutes or duration of travel (whichever is longest).
- Maintain appropriate recline angle during monitoring and in vehicle.
- Monitor infants in car beds prior to discharge if they are being released in a car bed.
- Infants discharged in car beds will need to be re-evaluated in a rear-facing child restraint before transitioning out of the car bed.
- Travel with and secure prescribed medical equipment.
- If possible, have an adult sit in the back seat and observe the baby.
- Use a child safety seat only for travel.

Many hospitals have followed the AAP’s recommendations to develop policies that include child safety seat evaluations in their discharge planning processes. Policy or protocol specifics will vary from hospital to hospital. When developing a hospital protocol for monitoring premature infants, it is important to:

✓ Define the population to be monitored.
✓ Identify appropriate staff and their roles.
✓ Determine parameters for monitoring.
✓ Determine length of monitoring.
✓ Determine when monitoring will occur.
✓ Develop documentation procedures and forms.
✓ Develop follow-up guidelines.
✓ Make provisions for alternative restraints.
✓ Provide appropriate training and information to all parties involved.
✓ Determine associated costs.
MYELOMENINGOCELE OR SPINA BIFIDA

Myelomeningocele or spina bifida is a birth defect of the spine resulting from abnormal closure of the neural tube during early formation of the central nervous system. At the location of the opening, nerve development is adversely affected and the formation of bone, muscle and skin around the spinal cord is affected. A sac, called a cele, is created at the opening. The cele can be covered by a thin layer of nerve tissue and sometimes by skin. It occurs in approximately 1 in every 2,858 live births.

The location of the cele determines the extent of nerve damage. In general, the higher the location of the cele, the more nerves are involved and the greater the damage. As a result of the nerve damage, children with myelomeningocele or spina bifida experience lack of bladder and bowel control, lack of sensation in the lower extremities, muscle weakness and imbalance or paralysis. Initial treatment of myelomeningocele is surgical repair of the cele. Children with spina bifida are at increased risk of the associated problem of hydrocephalus and frequently require treatment with a ventriculo-peritoneal shunt.

Considerations for restraint selection

- A car bed may be required during the post-operative period following myelomeningocele repair.
- Children with hypoventilation may require a car bed or car seat with adequate recline.
- Keep rear facing to higher weights due to smaller size, low tone and or/large head with hydrocephalus.
- The support provided by an adaptive car seat may be indicated for older children. Work with an occupational or physical therapist to determine the best option.
- A wheelchair may be necessary for mobility.
- Due to varying degrees of sensation loss, children may be unaware of problems caused by improper fit in their child safety seats. Monitor them closely for redness and skin break down.
OMPHALOCELE

An omphalocele is a congenital abnormality in which the abdominal contents are outside the abdomen in a sac due to a defect in the development of the muscles of the abdominal wall. It occurs in approximately 1 in every 5,386 live births. Approximately 25 - 40% of infants with an omphalocele have other birth defects, including genetic problems affecting the spine, heart and digestive system.

Typically, small omphaloceles are surgically repaired after birth. Large omphaloceles are surgically repaired over a period of time so that the child can grow, and the abdominal cavity can accommodate the organs.

Until repaired, care must be taken to protect the exposed organs from injury.

Considerations for restraint selection

- Consult with the child’s surgeon and evaluate seats with the surgeon to determine the best options. Pressure from the chest clip and buckle prongs could be a concern, and placement should be considered.
- Initially, an infant may require a car bed with restraint bag instead of a car seat with a harness.
- Before the child outgrows the car bed, consider feasible options with the surgeon.
- If the child can ride in a rear-facing seat, position rear facing as long as possible.
- The Jefferson rear-facing car seat designed specifically for children with omphaloeles may be necessary.

OSTEOGENESIS IMPERFECTA

Osteogenesis imperfecta, also known as brittle bone disease, is a genetic disorder of the skeletal system characterized by extreme brittleness of the long bones. There are several types of osteogenesis imperfecta, and symptoms and severity of symptoms can vary from type to type and from child to child. Characteristic features can include bones that fracture easily, short stature, skeletal deformities of limbs, chest, and skull, scoliosis, respiratory difficulties, and weak muscles.
Considerations for restraint selection

- Infants who have respiratory difficulties may benefit from travel in a car bed. Airway problems may be restrictive or obstructive.
- Car seats that allow rear facing to higher weights will allow children of short stature to remain rear facing longer, therefore protecting them more effectively from injury, especially to the spine.
- Look for a car seat with padding that helps the child ride comfortably.
- Children with leg fractures and casts will require restraints that will accommodate the type of cast applied.
- Older children who are severely affected may need to use a wheelchair.
- Work with an occupational or physical therapist.
- Refer to the Car Safety for Children with Osteogenesis Imperfecta fact sheet for more information.

OVERWEIGHT OR OBESITY

Overweight and obesity are both labels for ranges of weight that are greater than what is generally considered healthy for a given height. For children and adolescents (ages 2-19), overweight is defined as having a Body Mass Index (BMI) between the 85th and 95th percentiles for children of the same age and sex. Obese is defined as having a BMI above the 95th percentile.

Children who are obese frequently exceed the weight limits of a child safety seat before they are developmentally ready for the next step.

Considerations for restraint selection

- Rear-facing seats to higher weights then forward-facing seats to higher weights or booster seats to higher weights.
- Try before purchasing to make sure child fits hip and shoulder widths.
- May need a large medical seat or adaptive booster seat to higher weights.
- May need a travel vest (up to 168 lbs.).
- Refer to the Car Safety for Children Who Have Childhood Obesity or Are Overweight Fact Sheet for more information.
PIERRE ROBIN SEQUENCE

Pierre Robin Sequence is a congenital defect of the face characterized by abnormal smallness of the lower jaw and retro-positioning of the tongue with frequent obstruction of the airway. Cleft palate may also be present.

Treatment needs vary greatly depending on the severity of the baby’s problems. Some infants only require use of a monitor or oxygen; others may need to be positioned prone. Surgery to make the jaw bone grow longer (mandibular distraction osteogenesis) or a tracheostomy may be also be required to maintain a stable airway, in some cases.

Considerations for restraint selection

- Conduct a period of observation of an infant in his or her child safety seat prior to discharge.
- If an infant with Pierre Robin Sequence requires a car bed, the infant should be monitored in the car bed prior to discharge. Typically, they will be positioned prone in the car bed and will require close observation.
- For an infant positioned prone or on oxygen, follow-up sleep studies will be necessary to determine when the infant can travel semi-reclined.
- Travel with and secure prescribed medical equipment.

RETT SYNDROME

Rett syndrome is a genetic neurodevelopmental condition that primarily affects females. Children with Rett syndrome may exhibit some signs similar to Angelman’s syndrome, cerebral palsy and autism. They usually have typical development until 6-18 months, then start to regress. They may begin to exhibit signs of hypotonia and begin to lose purposeful hand movements, balance and coordination.

The clinical features include small hands and feet and a decreased rate of head growth (including microcephaly in some). Repetitive hand movements, such as wringing and/or repeatedly putting hands into the mouth, are also noted. People with Rett syndrome are prone to gastrointestinal disorders and up to 80% have seizures. They typically have no verbal skills, and about half are not ambulatory. Scoliosis, growth failure and constipation are very common and can be problematic.
Considerations for restraint selection

- Rear face as long as possible due to abnormal muscle tone.
- Use a forward-facing seat with higher-weight harness as long as possible, secondary to cognitive delays, language delays, writhing, rocking, hypotonia, problems with balance, and/or repetitive movements.
- Some children may require an adaptive restraint once they have outgrown a forward-facing seat.
- Some children may require a wheelchair.

SCOLIOSIS

Scoliosis is a term used to define curvature of the spine and its supporting structures. Scoliosis can be congenital and associated with conditions such as myelomeningocele or cerebral palsy. Severe scoliosis can lead to pulmonary complications.

In instances where surgery is necessary to correct the curvature, a body jacket or thoracolumbar sacral orthosis (TLSO) may be applied postoperatively.

- A car bed with a restraint bag may be necessary for an infant.
- Children with severe scoliosis may be unable to sit properly in child safety seats with their backs and bottoms flat against the seats and may require towel rolls along one side of the torso to accommodate the curvature.
- Consider adaptive restraints with optional positioning pads or positioning pads that can be customized to fill in the space the curvature creates.
- Consider an adaptive restraint that offers a scoliosis harness.
- Work with an occupational or physical therapist.
- If applicable, consult with the child’s medical team to determine if the TLSO is required during travel.
- A modified E-Z-ON vest may be necessary for children who must lie down or can be better positioned lying down.
- A wheelchair with customized insert may be necessary in some cases.
SEIZURE DISORDERS

Seizure disorders are a result of abnormal electrical activity in the brain. Seizures are associated with a number of conditions, including congenital disorders, brain injury, infection, high fevers and tumors. Symptoms can range from staring to uncontrollable muscle jerking and loss of consciousness (generalized tonic-clonic seizure). Seizures are usually controlled with medication, but may still occur intermittently.

Considerations for restraint selection

- For older children, a five-point harness to higher weights instead of a belt-positioning booster seat or adult seat belt will provide more support during a generalized tonic-clonic seizure and avoid secondary injuries from hitting the interior of the vehicle; or provide support if a child has decreased muscle tone post-seizure.
- During a seizure, pull vehicle to a safe location to attend to the needs of the child.

SPINAL MUSCULAR ATROPHY (SMA)

Spinal Muscular Atrophy is a motor neuron disease characterized by muscle wasting and motor impairment. The nerves do not conduct impulses to the muscles in a normal manner. Usually, the muscles closest to the trunk are most affected. Approximately 1 out of 6,000 babies are born with SMA. It is the most common genetic cause of infant death. Life expectancy is 2-3 years, although a child with Type III, a less severe form, may survive to early adulthood.

There are varying degrees of SMA severity. Children diagnosed with SMA may have severe hypotonia, respiratory problems and feeding issues. Intellect and sensation are not affected.

Considerations for restraint selection

- A car bed may be indicated in some cases.
- If an older child must lie down, a modified E-Z-ON vest may be necessary.
- Keep the child rear facing as long as possible.
- If an older child can tolerate forward facing, consider a forward-facing seat that can semi-recline and has a higher-weight harness.
• Some children may require an adaptive restraint with positioning accessories.
• Secure prescribed medical equipment.
• If possible, have an adult sit in the back seat and observe the child.
• If a child has a feeding tube, select a restraint that does not rub against the tube. (see Feeding Tubes)
• Some children may require a wheelchair.
• Work with a rehabilitation therapist to address positioning needs.

TRACHEOSTOMY

A tracheostomy is the surgical operation of cutting into the trachea through the neck to allow passage of air. A “trach” tube is inserted into the opening and attached to oxygen or humidity. Some children who have tracheostomies are “technology dependent” and require life-support equipment (such as ventilation) at all times.

Considerations for restraint selection

• A child safety seat that can be semi-reclined forward facing can help position a child’s head back and prevent the chin from covering the trach tube.
• Secure medical equipment.
• Any equipment that uses batteries should have enough power for at least double the length of the trip.
• Have an emergency plan to replace the tracheostomy if it comes out during travel.
Chapter 2:
Child Passenger Safety
Restraint Options for
Children with Special Health Care Needs
CHILD PASSENGER SAFETY RESTRAINT OPTIONS FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS

There are a number of factors to consider when transporting children with special health care needs. Discussions concerning transportation options should include participation by family members, health care professionals, certified child passenger safety technicians and other representatives from applicable health and educational services.

The following section describes some basic guidelines and issues relevant to providing appropriate child passenger safety restraints to children with special health care needs. In addition, it includes information on some restraint options available for use in passenger vehicles.

Basic Guidelines

- Use a conventional child restraint when possible. They tend to be easier to find, easier to use and less expensive than specialized restraints.

- Keep children with special health care needs rear facing as long as possible.

- When a child outgrows the rear facing limits of their child safety seat (CSS), use a CSS with a higher weight harness as long as possible.

- Avoid use of non-regulated products.

- Do not use child safety seats that have been structurally modified unless they have been crash tested with the modification and conform to Federal Motor Vehicle Safety Standard 213 (FMVSS213). What might seem like a minor structural modification can greatly compromise the performance of the restraint in a crash and place the occupant in jeopardy.

- Only use soft cervical collars during travel. A large child who has poor head and neck control will eventually have to be positioned forward facing in a vehicle. Although there are neck collars that provide supplemental neck support, their use during transport in vehicles is a concern. Recent crash tests with a variety of neck collars indicate that most models increase neck tension. The crash tests suggest that stiff and formed neck collars should be removed prior to transport and replaced with soft foam cervical collars during transit.
• Never secure a child’s head to a restraint in an attempt to prevent the head from falling forward. There is, however, an exception. One model of large medical seat offers a cap accessory that attaches to the restraint with Velcro. This product has been crash tested for use with the restraint.

• Only use child restraints for travel, unless they are designated as multi-positioning seats, such as the Special Tomato large medical car seat.

• If a child has complex positioning needs, involve a rehabilitation therapist and other members of the child’s medical team.

• Know your limits. Ask for help when you need it.

CONSIDERATIONS FOR CHILD PASSENGER SAFETY
RERAINT SELECTION

Child’s weight and height
Child passenger safety restraint systems are designed for specific sizes of children and must be used accordingly. Before considering a restraint, it is important to ask how much the child weighs and how tall the child is. Some children with special health care needs are of smaller stature and can fit in conventional child safety seats for a longer period of time. For example, a small toddler with poor head and neck control may be able to travel rear facing for a longer period of time.

Child’s age
A child’s age can influence restraint selection. For example, certain vests are designed for use by children two years and older and therefore would not be appropriate for use by a younger child. Age can also affect the type of transportation-related services that are available for a child with disabilities.

Child’s medical condition and procedures
The child’s medical condition and related procedures will influence the child’s ability to be positioned in a standard child safety seat according to manufacturer’s instructions.

Recommended position
When selecting a child restraint for a child with special health care needs, it is not always necessary to know the child’s specific medical diagnosis. It is imperative, however, to obtain information about the child’s required position.
during transport. Asking the following questions can help determine the best method of transportation:

1. Does the child need to travel flat and if so, does the child need to travel prone (lying face down) or supine (lying face up). Research has shown that a baby sleeping on his or her stomach is at greater risk of Sudden Infant Death Syndrome (SIDS).

2. Does the child need to travel on his or her side and if so, which side?

3. Can the child breathe satisfactorily when sitting up? Has the child’s breathing been evaluated in the sitting or flat position?

4. Can the child bend at the hips and be positioned in a sitting position?

5. Can the child sit unsupported?

6. Once the recommended position is identified, restraints that are capable of accommodating the child’s needs can be considered.

_Families or Caregivers_
Family members or caregivers are responsible for the proper restraint of their children on a daily basis. They should be included in decisions relevant to the occupant protection needs of their children and should be provided with instruction on proper use and installation of restraints. It is important to plan ahead and to allow enough time to instruct families. Instructions provided near the time of discharge may find families less receptive or less attentive. In addition, interpreters will need to be arranged for some families, such as those who are not fluent in English.

A family’s financial situation can influence restraint selection. If a family cannot afford a recommended restraint, alternative restraints may need to be considered or other means of funding pursued. The composition of the family and the ages of other children should also be taken into account when selecting a restraint to help ensure occupant protection of other family members is not compromised.

Families or caregivers may need assistance navigating transportation-related resources and networks. For example, families may need help locating dealers or manufacturers that install tethers or adapt vehicles.

_Medical equipment_
Children with special health care needs may require the support of medical equipment, such as apnea monitors, oxygen and ventilators during transport. Steps should be taken to minimize
the chance that equipment could be projectiles in a crash. To date, there are no products specifically available to restrain medical equipment. It is recommended that equipment be secured by seat belts not in use by other occupants of the vehicle or placed on the vehicle floor and surrounded with padding. Before wedging or placing equipment under a vehicle seat, it is important to check the vehicle owner’s manual to make sure placing items under the vehicle seat is permitted.

**Vehicle**

When selecting a child restraint, consideration must be given to the type of vehicle or vehicles in which the restraint will be secured. The transport vehicle must be equipped with seat belts that will accommodate proper securement of the restraint.

The vehicles also must have enough seating positions so that all occupants can ride appropriately restrained. In some cases, the size of a restraint or method of installation will limit the number of passengers that can be transported in the vehicle. In these situations, families may need to borrow or rent a different vehicle if all family members must travel together.

Many specialized restraints require mandatory tether installation, in addition to a seat belt. The vehicle must be capable of accommodating a tether, or an alternative restraint must be considered.

Front passenger-side air bags pose problems for restraint installation. The National Highway Traffic Safety Administration (NHTSA) recommends all children age 12 years and under ride in the **back seat**, generally considered the safest place in a vehicle. If possible, an adult should sit in the back seat observing the child.

In situations in which the only option is positioning a child in the front passenger seat, a parent or caregiver may need to have the air bag disconnected. They will need information on the process required to receive permission from NHTSA to disconnect the air bag. Since information on side-impact air bags is limited, vehicle and occupant restraint manufacturers should be contacted for specific recommendations on how to transport children in those seating positions.

Children who must travel in wheelchairs will require vehicles that are adapted so that the wheelchairs can be secured and the child restrained according to federal guidelines.
**Amount and length of travel**

Some children with special health care needs will require frequent visits to medical appointments. Use of an appropriate restraint can save money that might otherwise be spent on professional transport and provide for a more comfortable trip.

Depending on the child’s condition, it may be advisable to limit the amount of travel to that which is only medically necessary.

For long car trips, the caregiver should make frequent stops. Since a longer duration of positioning an infant in a safety seat can increase the risk of respiratory compromise, it is advisable to stop every 1 ½ - 2 hours with these infants. Older children should be removed from the seat every 2-3 hours. This will allow the child to stretch and be an opportune time to inspect the child’s skin for any redness or irritation.

Travel with a medical plan that addresses appropriate measures to follow in the event of an emergency.

Remember to have enough power for twice the length of the trip if a child is being transported with medical equipment.

**Funding sources**

Restraint selection or mode of transportation can be dependent on available funding. Hospital-based child safety seat programs may loan less frequently required restraints, such as car beds, for short-term or temporary use. However, restraints required for long-term use are typically not loaned.

The cost of child passenger safety-specialized restraints may be paid by third-party payers such as private insurance or Medicaid. Health care professionals can support families in efforts to obtain funding by providing letters of medical necessity to third-party payers. In some instances, organizations, such as early intervention programs, can provide funding. If professional transport is required, early planning is critical for families to acquire funding for these expensive services.

**CONVENTIONAL CHILD PASSENGER SAFETY RESTRAINTS AND CHILDREN WITH SPECIAL HEALTH CARE NEEDS**

Conventional child passenger safety restraints are appropriate for many children with special health care needs if the child is able to bend or flex at the hip in a seated position, breathe satisfactorily and maintain head control while
sitting in the seat. For purposes of this manual, conventional restraints are
defined as those restraints that meet Federal Motor Vehicle Safety Standard
213; can be purchased at retail stores; and are designed for typically
developing children. Examples include rear-facing and forward-facing seats,
and belt-positioning boosters. Seats with harnesses to higher rear-and forward-facing weight limits have increased the number of conventional restraint options available for children with special health care needs.

This section provides a brief description of conventional restraints and their applications to special needs transportation. A comprehensive discussion of conventional restraints is not included in this manual.

Rear-Facing Seats

Rear-facing seats, which include rear-facing only and convertible seats, provide appropriate protection for many children with medical conditions. Weight maximums as high as 35 to 40 pounds are not uncommon and allow some children with special health care needs to ride rear facing longer.

Many rear-facing seats come with head support systems that provide adequate lateral support for babies. Some support systems are designed specifically for use by premature or smaller babies.

Select seats with smaller internal dimensions for low birth weight and premature infants who do not experience cardio-respiratory events. If babies weigh less than five pounds, select a seat with a lower minimum weight limit. Maintain an appropriate semi-reclined angle during tolerance testing and vehicle installation.

According to current safety recommendations, children are best protected in a crash if they are seated facing the rear of the vehicle until they are about two years of age or have outgrown the rear-facing weight or height maximums for the restraint. Many convertible child safety seats can be used rear facing to weights as high as 30 to 40 pounds. These seats allow larger infants and toddlers with special health care needs to ride rear facing longer.

Forward-Facing Seats

Forward-facing seats, including convertible seats and combination child safety seats, with upper-harness limits as high as 65 to 80 pounds are increasing in availability, which provides some children with special health care needs the opportunity to benefit longer from the protection offered by a five-point harness.
Some features that may benefit children with special health care needs are as follows:

- Harnesses that can be used over 40 pounds provide extra restraint for children with behavioral challenges, positional issues or obesity.
- Seats with lower or more shallow sides may accommodate some children in long-leg broomstick or hip casts.
- Semi-reclined option in a forward-facing position may assist with positioning children with poor head and neck control and who have outgrown the rear-facing limits of their car safety seats.
- Seats with extra padding and positioning inserts can provide better positioning or comfort for children with neuromuscular or bone dysplasia conditions.

**Belt-Positioning Booster Seats**

In order to use a belt-positioning booster seat, a child with special health care needs must have good head, neck and trunk control. Boosters with higher-weight limits may be suitable for children who are overweight or obese. Extended booster use is recommended for children smaller than their typically developing peers, such as children with achondroplasia. High-back boosters with sides may provide adequate lateral support for some larger children who experience intermittent fluctuations with head, neck and trunk control. These seats may also assist with children with behavioral problems by improving their comfort by allowing their knees to bend and their legs to hang down. Compliance may also improve because the child is able to see out the window.

**SPECIALIZED OR ADAPTIVE CHILD PASSENGER SAFETY RESTRAINTS**

In general, specialized or adaptive child passenger safety restraints are designed specifically for children with special health care needs and are not available at retail stores. They are ordered through a local equipment vendor, or in some cases, directly from the manufacturer. Specialized restraints tend to be more expensive than conventional restraints and securing funding can be challenging. Special needs car seat loan programs are available through some hospitals, local Easter Seals affiliates, health departments and Safe Kids coalitions. Third-party payers, including Medicaid, may cover the cost of specialized restraints when sufficient documentation of medical necessity is provided.
The following section describes general information about categories of specialized restraints. It does not provide information about specific restraints. Details about products are included in the course slide presentations and handouts.

**Car Beds**

Car beds are designed for infants who must travel lying down. Car beds may be warranted for babies who have cardio-respiratory conditions, lower-extremity casts, omphaloceles and other midline chest or abdominal defects, or neuromuscular disorders. Use of car beds should be reserved for those babies who demonstrate a medical necessity. A baby discharged in a car bed should have a period of observation in the car bed prior to discharge to ensure placement in the car bed will not exacerbate any of the baby’s symptoms. Additionally, when the physician determines the baby may be able to ride semi-upright, a follow-up period of observation in a rear-facing child safety seat should be conducted to make sure the baby is ready to transition to a rear-facing position.

Although there are variations in design and weight limits, all of the beds must be used with the infant’s head facing the center of the vehicle, away from any door or side of the vehicle.

When positioning an infant in a car bed, it is important to clarify with medical staff if the baby should lie on his or her stomach, back or side. Since research has shown that a baby lying on his or her stomach is at greater risk of sudden infant syndrome (SIDS), a baby should **not** be positioned on his or her stomach unless medically necessary and prescribed by his or her physician. Side lying will not be possible in every car bed.

One car bed model offers the option of a restraint bag instead of a harness to secure a child. The restraint bag may accommodate babies for whom the pressure of a harness is contraindicated, such as a baby with an omphalocele.
Specialized Rear-Facing-Only Seat For Children With Omphaloceles

The Jefferson rear-facing car seat is the only car seat designed specifically for children with omphaloceles and who weigh 7.5 to 40 pounds. It has a yoke-harness design that routes the harness straps around the abdomen instead of over it and it does not have a chest clip.

Although adapted from a convertible child safety seat, it can only be used rear facing. The manufacturers have blocked the forward-facing belt path to deter forward-facing installation.

Because of its unique harness design, it may be useful for children with other medical conditions as well as omphaloceles.

Specialized Convertible Seat for Children In Hip Casts

To date, there is only one child safety seat designed specifically for children in hip casts. Adapted from a Britax convertible seat, the Hippo was modified and has lower sides and a shorter seat depth in order to accommodate children in hip abduction devices. Included with the child restraint is a wedge, which can be configured in different ways and used, if necessary, to better position a child. Since the restraint is a convertible child seat, it can be used rear facing and forward facing. Not all children in lower-extremity casts will fit in the Hippo, and alternate solutions such as a car bed, modified vest or professional transport may need to be considered.
Large Medical Seats

Large medical seats are designed for occupants who require supplemental positioning support from a car seat beyond that offered by a conventional restraint. Typically, upper weight ranges for large medical seats vary from 102 to 150 pounds.

It’s important for families to work with an occupational therapist (OT) or physical therapist (PT) who has experience working with pediatric patients and is a child passenger safety technician. OTs or PTs will be able to evaluate a child’s positioning needs and determine which restraint provides the best positioning options for the child.

Obtaining a large medical seat for a family can be a lengthy process, taking up to three to six months or longer. Typically, a physician will write an order for an OT or PT evaluation; a vendor is selected by the family after the evaluation and selection of a restraint; a letter of medical necessity (LMN) detailing why the child needs the restraint is written by the physician or therapist and provided to the vendor; the vendor submits the LMN to the family’s third-party payer for approval. If the restraint is approved, the vendor is able to order it and eventually deliver it to the family or institution. In some cases, interim restraints such as conventional forward-facing restraints with higher-weight harnesses will be necessary while awaiting delivery of the large medical seat.

Accessories for Large Medical Seats

Positioning accessories are meant to provide a child with a more custom fit in his or her adaptive restraint while riding in the vehicle. They are geared towards children who demonstrate abnormal muscle tone and need assistance sitting upright or demonstrate severe behavior issues and escape the car seat. Most are optional and cannot generally be found on conventional car seats.

Examples of accessories include head support pads, lateral pads, abductor wedges or pommels, and incontinence covers. A table that summarizes different accessories and when to use them is included in the Appendices.

Some accessories come standard with the seats, while others need to be itemized on the order form. Please check with the manufacturer for specific ordering instructions. It is also important to note that although one seat offers
several accessories, some of those accessories cannot be used in conjunction with the others.

Long- and Short-Belt Paths

The “long” or “serpentine” seat belt path is an installation option in some large medical seats. With the “long” belt path, the lap/shoulder belt or lap-only belt comes around the front of the restraint, then through seat belt slot or path, across the back of the restraint then back through the seat belt slot or path on the opposite side of the car seat, around the front of the car seat and is buckled. In some vehicles, the “long” belt path cannot be used because the seat belt is not long enough to be routed through the “long” belt path.

The “short” seat belt path is an alternative method of installing some large medical seats. With the “short” seat belt path, the seat belt comes through the slot from the back of the car seat to the front, then is routed between the foam and the plastic shell, and brought through the opposite slot to the back and buckled.

Tethering Large Medical Seats

Large medical seats call for use of mandatory tethering systems, which can vary in design and use. Some large medical seats require the use of two tether hooks attached to two different tether anchors in the vehicle. Manufacturers will specify the weights at which the two tethers are required.

A few large medical seats use the shoulder belt of a lap/shoulder belt as the equivalent of a top tether. This system requires that the restraint be installed with a lap/shoulder belt routed through the “long” or “serpentine” belt path (refer to Long- and Short-Belt Paths section above). This routing method allows the shoulder portion of the seat belt to lie across the upper part of one of the front sides of the restraint, serving as a “tether.” Manufacturers of these products also provide instructions for tethering the restraints in more traditional methods.
Some restraints offer heavy-duty tether hardware. This hardware is used in cases where the vehicle doesn’t have top tethers; the weight of the occupant exceeds the vehicle specifications for tethers; or the restraint manufacturer requires its use. Typically, the hardware is installed by a mobility specialist. There can be extra fees for the hardware and installation.

Temporarily tethering to a back seat’s vehicle safety belt is allowed by manufacturers of a few large medical seats.

**Lower Anchors and Large Medical Seats**

Large medical seats are typically installed using a seat belt and top-tethering system. In the past, large medical seats included lower anchors with top tethers as an installation option. Instructions for these large medical seats will indicate when and how to use lower anchors with top tethers.

Based on 2014 changes to FMVSS 213, large medical seats will no longer offer lower anchors as an installation option due to the combined weight of the occupant and seat exceeding 65 pounds in most cases.

The LATCH Manual published by *Safe Ride News* offers detailed information on using lower anchors and top tethers with large medical seats.

**Adaptive Belt-Positioning Booster Seats**

As with any conventional belt-positioning booster, adaptive booster seats rely on the vehicle’s shoulder/lap belt system to provide occupant protection. They differ in that they have positioning harnesses or devices, which provide supplemental support to a child with special health care needs. Depending on the booster seat, they may also have accessories that aid with positioning, such as abductor wedges, support pads, lap trays, foot props and turning bases. Upper weight ranges vary from 80 to 175 pounds. The evaluation and ordering process is similar to that for large medical seats.

Since they are not installed like a large medical seat, adaptive boosters may be options for families who have vehicles without top tethers or who frequently transfer their child from one vehicle to another.
Vests

There are a number of vests or harnesses designed for children with special health care needs to use in passenger vehicles. Some models are for children who can sit up, and one model is for children who must travel lying down. Upright vests usually fit children from 2 years of age and 20 pounds up to 168 pounds. They can be ordered with closure systems in the front or back. Models of the vest that adjust at the shoulders may be appropriate for older children in halo casts since the vest can be completely unbuckled and rethreaded at the adjustment mechanism. Typically, an upright vest will not provide adequate support for a child with poor head, neck and trunk support.

After the vest is put on the child, it is attached to the vehicle with a top tether and seat belt that runs through belt loops on the vest. One model of upright vest attaches to the vehicle with a floor-mount system, which eliminates the use of a seat belt. Combined with a back closure system, this attachment system makes it very difficult for children with behavioral issues to “escape” the vest.

One model of vest has been modified for children ages 1 to 12 years and 20 to 100 pounds and who must travel lying down. In order to use this product, the child must be able to fit lengthwise on a vehicle bench seat. This product is an option for older children in hip spica casts or other older children who are unable to sit up.
Chapter 3: The Role of the Rehabilitation Therapist
THE ROLE OF THE REHABILITATION THERAPIST

Rehabilitation therapists, including physical and occupational therapists, are responsible for assessing a child’s physical capabilities and determining ways to improve a child’s interaction with their environment. They are essential members of a child’s medical team and often work with children who have involved positioning needs. An occupational or physical therapist can offer individualized positioning guidelines if questions arise regarding how to position a child in a child safety seat.

Some hospital-based car seat programs utilize therapists who are certified child passenger safety technicians. Involvement by therapists allows a car seat program to offer more comprehensive services to a wider age range of children, in both inpatient and outpatient settings. Therapists may be able to bill third-party payers such as private insurance and Medicaid for their services.

Positioning In Child Restraints: Challenges and Techniques

A brief discussion of positioning challenges and techniques may benefit child passenger safety technicians interested in learning more about transporting children with disabilities in specialized restraints. Large medical seats and adaptive boosters also offer a variety of accessories that can aid with proper positioning.

Purpose of Positioning

Sitting is a dynamic action requiring balance and strength of the hips, trunk and neck. For children who have difficulty sitting, positioning should serve several purposes. It should protect the airway, provide support, promote posture, decrease tone (if needed), support functional positions and allow comfort. Any medical condition that alters normal functioning may affect proper positioning of a child in a restraint system.

Muscle Tone

One major reason children may need special consideration when positioned in a child restraint is muscle tone. Muscle tone refers to the firmness of muscle tissue and varies with each child. Some children will have low or high tone throughout the body. Children also can have fluctuating tone, which can cause abnormal movement. Tone can increase at certain times of the day, depending
on the child’s medication schedule and mood. Children often have both high and low tone. They may have increased tone in the arms and legs, but have decreased trunk and head control. Joints with abnormal tone can dislocate due to repeated abnormal positioning and decreased activity over time. This can lead to surgeries and procedures. The bones of children with increased or decreased tone may also be more fragile, and care with movement is necessary to prevent fracture. Most children with abnormal muscle tone should be positioned rear facing as long as possible.

- **High Tone**
  If muscle tone is high (hypertonia), the muscle is firing or contracting more than normal. This type of tone will feel like the child is pulling against you. For example, if a child has high flexor tone of the arm, the elbow will be bent when you straighten the arm, and it will feel as though the child is trying to keep it bent. High tone can eventually lead to contractures. A contracture at the elbow would mean that the elbow can no longer be completely extended or straightened because the tissue has shortened. For children with hypertonia, a therapist may be able to provide ways in which to “break up” the tone, allowing the child to be positioned in a child safety restraint, i.e., flexing the hip joints greater than 90 degrees to help the hip joints relax.

  **Examples of High Tone**
  Some children tend to have increased extensor tone, which causes them to push out of a sitting position. In this case, place small rolls underneath the knees outside of the harness system. This increases hip flexion, which can help to inhibit extensor tone. Another tip for positioning children with increased extensor tone is to place them in a flexed position before seating them in a child safety seat. This can decrease tone while they are being put into the seat and prevent a struggle with fastening the harness.

  Other children adduct or pull their hips together. In this case, place a foam block between the child’s knees or select a restraint with a pommel or abductor wedge. Hip adduction needs to be avoided because it can strain the hip joints and over time can cause dislocation and require surgery.

  Some children pull their shoulder girdle into retraction (or pulled back). This can prevent a child from getting the arms forward to reach or from being able to get the hands together. This can impair a child’s ability to
get the hands to midline (center of body) to develop fine motor skills. It is important that slumping forward be prevented, but also that extreme retraction be prevented to allow mobility and movement of the arms. Place nothing behind the child, but rolls placed along the sides of the child with arms forward can prevent retraction. This can promote good alignment at midline.

- **Low Tone**
  Low muscle tone (hypotonia) may also require adaptations for positioning. Muscles with low tone do not contract enough. They will feel floppy and weak. Low muscle tone decreases a child’s ability to move against gravity.

  **Examples of Low Tone**

  Children with special needs often have decreased head control. This can present a problem once a child begins to ride forward facing and more upright because the head will often fall forward or to the side. This can obstruct the airway and impair breathing. To help with head control, place blankets or towel rolls along the sides of the head and neck. This can help prevent side-to-side movement, but may not keep the head from falling forward. Another option is to use a forward-facing car seat with a built-in recline or recline feature. Check the car seat instructions to make sure a forward-facing recline option is available. This recline can help the child to keep the head up and the airway open. Reclining in the forward-facing position can be extremely helpful in preventing fatigue in a child who may have to expend large amounts of energy to breathe. Accessories, such as head support pads, may also be useful. In some instances, a soft cervical collar may provide additional head support.

Children with poor trunk control may also slump to the side or forward. Padding may be placed along the sides of the child. If a child slides forward in the seat, a small roll may be used between the child and the crotch strap. A full harness should also help prevent sliding forward. A large medical seat or adaptive booster seat with a pommel or abductor wedge may also assist with positioning.
Scoliosis can result from poor tone of the spine and trunk. To prevent this, avoid curved positions and keep the child well supported. If a child already has spinal curvature, more padding may be needed on one side of the child. In addition, large medical seats that offer a scoliosis harness or allow users to customize the seat with extra positioning pads may be useful.

Hips are another area that may need to be addressed with positioning. Some children tend to have abducted hips, which means their legs are apart. To prevent this, pad the sides of the child’s thighs with rolls to keep them closer together or use ace wrap or Velcro around the thighs, making sure they do not interfere with buckling of the harness. A restraint with deeper seat depth may also help.

The following table summarizes some positioning techniques or CSS accessories that can assist with positioning challenges.

<table>
<thead>
<tr>
<th>Positioning Challenge</th>
<th>Positioning Techniques</th>
<th>CSS Accessories or Features</th>
</tr>
</thead>
<tbody>
<tr>
<td>Decreased head control</td>
<td>Position rear facing as long as possible</td>
<td>CSS with semi-recline feature forward facing</td>
</tr>
<tr>
<td></td>
<td>Position head and neck in midline with lateral rolls</td>
<td>CSS with lateral head supports</td>
</tr>
<tr>
<td></td>
<td>Soft cervical collar if necessary</td>
<td>CSS with “EZ-Up” head-rest cap</td>
</tr>
<tr>
<td>Decreased trunk control</td>
<td>Position rear facing as long as possible</td>
<td>CSS that allows semi-recline when forward facing</td>
</tr>
<tr>
<td></td>
<td>Support trunk with lateral rolls</td>
<td>CSS with lateral supports</td>
</tr>
<tr>
<td>Scoliosis</td>
<td>May require more padding on one side than the other</td>
<td>CSS with scoliosis harness</td>
</tr>
<tr>
<td></td>
<td></td>
<td>CSS that allows addition of asymmetrical padding under cover</td>
</tr>
<tr>
<td>Slides down in CSS</td>
<td>Position cloth roll between crotch strap and child</td>
<td>CSS with pommel or abductor wedge</td>
</tr>
<tr>
<td>Increased extensor tone of trunk and hips</td>
<td>Use towel rolls under knees outside of harness to decrease tone</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Transfer into seat in flexed position (knees up)</td>
<td></td>
</tr>
<tr>
<td>Hips abducted (knees spread apart)</td>
<td>Pad outside of thighs to push together</td>
<td>CSS with deeper seat depth</td>
</tr>
<tr>
<td></td>
<td>Use ace wrap or Velcro around thighs (often referred to as hip wrap)</td>
<td></td>
</tr>
<tr>
<td>Hip adduction (knees close together)</td>
<td>Place foam block between knees</td>
<td>CSS with pommel or abductor wedge</td>
</tr>
<tr>
<td>Shoulder girdle into retraction (back)</td>
<td>Place rolls along sides of child with arms forward</td>
<td>CSS that allows placement of extra positioning pads over or</td>
</tr>
<tr>
<td>Condition</td>
<td>Type</td>
<td>Features</td>
</tr>
<tr>
<td>-----------------------</td>
<td>-----------------</td>
<td>--------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Transfer difficulties</td>
<td>Wheelchair</td>
<td>CSS with turning base, CSS with low sides</td>
</tr>
<tr>
<td>Growth</td>
<td></td>
<td>CSS with movable laterals, CSS with higher-weight limits, CSS that allows removal of padding under cover, CSS with seat extender</td>
</tr>
<tr>
<td>Incontinence</td>
<td></td>
<td>CSS with incontinence pad, CSS with non-cloth cover</td>
</tr>
</tbody>
</table>
Chapter 4: Occupant Protection in Wheelchairs
The authors would like to thank Miriam Manary, MSE, and the University of Michigan Transportation Research Institute for their contributions to this chapter.

This chapter covers the basic principles of wheelchair transportation safety for situations where the wheelchair is used as a seat in a motor vehicle. It includes a discussion of standards, tie-down systems, benefits of transit-option wheelchairs and other considerations to take into account when using a wheelchair as a transportation device.

A list of wheelchair transportation resources can be found in the Resources section of the Appendices.

**Wheelchairs: An Overview**

Some children with special health care needs may not be able to move themselves independently in or around their environment. Therefore, they may benefit from a mobility base (also known as a wheelchair) with a standard or customized seating system. Wheelchairs can be either manual or power. A manual wheelchair is designed so that a child can independently propel the wheelchair or be pushed. A power wheelchair has a motorized unit, which allows a child to independently maneuver the chair with a joystick or other type of control option. Wheelchairs are available from many different manufacturers. Styles, sizes and features are typically customized for each child. Features of wheelchairs must be carefully considered to meet the child’s medical needs and family’s needs.

A seating system is a custom support system that is placed onto the mobility base to facilitate postural control and to help normalize tone. A seating system typically consists of a custom seat, custom back and lateral supports for the trunk and pelvis. The goal of seating is to provide support, help normalize abnormal muscle tone, promote comfort, protect skin integrity and enhance or improve functional abilities. If a child is not well supported and positioned, it adversely affects his or her ability to use his or her upper extremities to operate a manual or a power wheelchair. There are many different seating systems available for children. These systems are typically custom ordered to meet the child’s medical needs and clinical picture.

Children with special health care needs may also use an adaptive stroller to meet their mobility and positioning needs. Strollers can be lightweight, have adjustable features and offer some growth potential to meet the needs of the child.
Convaid is one manufacturer that produces WC19-compliant strollers with a crash-tested five-point safety restraint harness. This harness allows children who weigh less than 65 pounds to be protected while traveling in their adaptive stroller.

Wheelchair Transportation Standards

Currently, there are no government regulations to address the safety needs of riders using a wheelchair as a transportation device. In response to the lack of legislation and standards, the Society of Automotive Engineers (SAE) and the Rehabilitation and Engineering Assistive Technology Society of North America (RESNA) have made efforts since the 1980’s to develop safety standards. These standards are voluntary and have established guidelines that wheelchair manufacturers can follow to improve the safety and usability of wheelchairs as transportation devices.

There are three voluntary standards that deal with the use of wheelchairs in vehicles, WC18, WC19, and WC20. WC18 deals with the systems that secure the wheelchair to the vehicle and restrain the rider in the wheelchair. WC19 deals with the wheelchair and seating, and WC20 deals with specialized seating used in the wheelchair.

A logo, introduced in December 2012, is on products that comply with the latest version of WC18, WC19 and WC20 standards to help consumers identify transit-safe equipment.
A more detailed description of each standard follows:

- **WC18-Compliant**
  - WC18 refers to the **Wheelchair Tie-down and Occupant Restraint Systems (WTORS)** used with a forward-facing wheelchair in a motor vehicle. This voluntary standard tests the strength of the WTORS and its ability to restrict forward motion of the wheelchair and rider using a dynamic crash test.
  - To secure a wheelchair in a motor vehicle, use a WTORS that has been crash tested according to the WC18 voluntary standard. For wheelchairs over 275 pounds (125 kg), additional rear tie-down straps may be needed.
  - To protect the rider in the wheelchair, use a WC18-compliant lap and shoulder belt system. Many people mistake the postural positioning belts attached to the wheelchair with a crashworthy belt that can protect riders in a crash.
  - Good fit of the belts to the rider is essential. The lap belt needs to contact the top of the thigh and the lower part of the abdomen. The shoulder belt should connect to the lap belt near the rider’s hip then cross their sternum and opposite clavicle.

- **WC 19-Compliant**
  - A WC19 compliant wheelchair means the manufacturer has designed the wheelchair (frame and seating) for use as a seat in a motor vehicle. This standard has features that make it easier to secure the chair with a four- point tie-down system (a person can do this with one hand) and passes a crash test with no structural damage in a 30 mph test.
  - Wheelchairs that meet this standard have four identifiable and crash-tested securement points.
  - Other features include: strong crashworthy frame, absence of sharp edges that could cause injury or damage webbing, improved battery retention, better occupant seat belt fit.
o Integrated lap belt option:
  ▪ In the field, most wheelchairs are secured, but many wheelchair riders are not provided with properly positioned seat belts. WC-19 requires wheelchair manufacturers to provide the option of a crash-tested lap belt. Attaching a protective lap belt to the wheelchair allows the belt to be fitted properly around the lower pelvis and upper thighs and reduces the chance that the belt fit will be compromised by wheelchair hardware. Most wheelchairs come with a postural support belt that is commonly mistaken for a belt designed to restrain the rider in a crash. If the lap belt is crashworthy, it will be labeled that it complies with WC19 and will allow connection to a vehicle mounted shoulder belt from a three-point restraint system. A revised version of WC19 will soon require compliant wheelchairs to offer a crashworthy five-point harness for children who weigh less than 50 pounds; some manufacturers are already offering this feature.

Many durable medical equipment vendors, physicians and rehabilitation therapists are not yet aware of the advantages of using certified transit chairs. It is important for physicians and therapists to educate their patients about transit chairs. If appropriate, physicians should write prescriptions for transit chairs and along with therapists, write letters of medical necessity to facilitate use of transit chairs

- WC20-Compliant
  o WC20 was developed to address a situation in which a person needs specialized seating that is not made by the same company that produces the wheelchair frame. Seating that complies with WC20 can be paired with any WC19-tested wheelchair frame to create a complete crashworthy wheelchair that can be used as a seat in a motor vehicle.
  
  o WC20 is a voluntary test of the wheelchair seating system in a 20g frontal-impact crash. The seating cannot break or collapse under the force.
  
  o WC20 requires that the seating system be tested on a wheelchair “surrogate” frame.
• The surrogate wheelchair was developed by analyzing data from WC19 wheelchair frames. The surrogate was then designed to absorb less crash energy than those researched. This means the seating system would need to absorb more crash energy, therefore making meeting WC20 tougher.

  o Other WC20 requirements:
    • WC20 seating must be used in combination with a WC19 wheelchair.
    • WC20 includes requirements for the attachment hardware that secures the seating system to the frame to ensure that the seating system is locked into the wheelchair base.

A list of commercial products that meet WC19 and WC20 can be found at: http://www.rercwts.org/RERC_WTS2_KT/RERC_WTS2_19_Chart.html.

Wheelchair Riders in Motor Vehicles

When traveling in a motor vehicle, it is generally safest to transfer to a vehicle seat and use an appropriate occupant restraint system that complies with federal safety standards. Once the rider transfers, the wheelchair and all other medical equipment should then be secured or stored.

If transferring is not possible, or if the rider requires the support of the wheelchair and seating system, you should secure the wheelchair to the vehicle and make sure to restrain the rider in the wheelchair with crash-tested belt restraints. When securing the rider, upper and lower torso (lap) restraints are required. Lap belt angles between 45 and 75 degrees to horizontal are recommended. Both the wheelchair and rider should face forward in the vehicle. If possible, tie-downs, restraint belts and wheelchairs that meet current standards should be used.

WC19 is a voluntary standard, and many wheelchairs do not yet comply. It is important for wheelchair users, parents, caregivers, clinicians, transportation providers and Individual Education Plan (IEP) members to advocate the use of products that meet the safety standard. However, noncompliance with this standard cannot be used as a reason to deny transport of an individual in a wheelchair. If it is not possible to use a WC19 wheelchair, the next best choice
is a wheelchair with an accessible metal frame to which tie-down straps can be attached at frame junctions.

**Securing Wheelchairs in Motor Vehicles**

When using wheelchairs as transportation devices, it is important to secure the wheelchair to a vehicle using an appropriate tie-down system. There are different types of tie-down systems, which are described below:

**Four-point tie-downs**

The most common, affordable and effective type of wheelchair securement is a four-point tie-down that uses four straps to secure the wheelchair to the vehicle. This is a universal tie-down that works with a wide range of wheelchairs and is commonly used in public and school transportation. This type of system requires someone to attach the straps for the person seated in the wheelchair. When using a four-point tie-down, it is best to position the wheelchair so that the floor anchor points for the rear tie-down straps are directly behind the securement points on the wheelchair. A rear tie-down angle of 30 to 45 degrees relative to horizontal is desirable, but the angle will depend primarily on the location of the proper securement locations on the wheelchair. If possible, attach the front tie-down straps to floor anchor points that are wider than the wheelchair to increase lateral stability during vehicle turns.

When using a four-point tie-down with a WC19 wheelchair, simply attach the straps to the securement points and tighten the straps to remove all slack.

To secure a non-WC19 wheelchair, the tie-downs should be hooked to structural securement points as high as possible but below the seat surface to provide greater wheelchair stability during travel. When securing a non-WC19 wheelchair with a tilt-in-space frame, all the straps should be attached to the base. Mixing wheelchair securement points between the seat and base can result in the tie-down straps becoming slack if the angle of the seat changes. Tie-down straps should never be attached to adjustable or removable parts of the wheelchair such as armrests, leg rests and wheels.

Wheelchairs with covered lower frames can be difficult to secure and may require modifications or the use of aftermarket hardware. A manual of
securement strategies and solutions for particular wheelchairs has been
developed by the Washtenaw Intermediate School District and the University of
Michigan Transportation Research Institute. Contact WISD
(www.wash.k12.mi.us or 734-994-8100) for details.

The tie-down manufacturer's instructions should always be read and followed.

Other types of tie-downs

- Wheelchair docking systems require special hardware on the
  wheelchair that will firmly attach to the docking station in the vehicle.
  This system is used mostly in private vehicles and may allow the
  wheelchair user to secure and release the wheelchair without
  assistance.

- Clamp-type tie-downs that attach to the wheelchair wheels or that
  push down on parts of the wheelchair frame are not recommended
  for wheelchair securement since they usually perform poorly in a
  crash.

Protecting the Occupant in the Wheelchair

In addition to securing the wheelchair, it is very important to restrain the
wheelchair user with a crash-tested lap and shoulder belt. Most postural
support belts and harnesses used to position a person in the wheelchair are not
strong enough to withstand the forces of a crash and are often not positioned
correctly to restrain the occupant safely.

Most crashworthy wheelchair occupant seat belt systems anchor to the vehicle
or the tied-down straps at three places to provide a lap and shoulder belt for the
rider. A few new wheelchairs feature an integrated

[Image: Lap belt fit]

crashworthy lap belt that anchors to the wheelchair
and has connector hardware to attach to a vehicle-mounted shoulder belt.

Good occupant restraint fit is often hard to achieve for
wheelchair riders. The lap belt should fit low over the
hips and should be angled between 45 and 75
degrees to the horizontal when viewed from the side.
Some wheelchair hardware, such as armrests, can
interfere with good lap belt fit by holding the belt away from the occupant. Try to
avoid routing the lap belt over the armrest, keeping in mind that it may be
necessary to carefully place the lap belt between the armrest and the rider to
achieve good fit. A shoulder belt should cross the collarbone and center of the chest and connect to the lap belt near the hip.

**Other Wheelchair Considerations**

- It is best for wheelchair riders to be in an upright, seated posture with the seatback reclined 30 degrees or less with respect to vertical. If a rider requires more recline angle, make sure that the shoulder portion of the seatbelt stays in contact with the rider’s shoulder.

- A headrest that is positioned close to the most rearward point of the back of the head may help protect the head and neck.

- Hard trays should be removed for travel and secured elsewhere in the vehicle. If a tray cannot be removed, consider using a soft foam tray or adding energy absorbing foam to the tray surface during travel.

- Postural supports should not be relied upon for occupant protection. They are used only for positioning the child in the wheelchair. Please see "Guidelines for Use of Secondary Postural Support Devices by Wheelchair Users during Travel in Motor Vehicles" for details about various postural support systems.


(Some illustrations were adapted from those in the *Ride Safer* brochure from www.travelsafer.org.)
Chapter 5: Transporting Children with Special Health Care Needs in Other Vehicles
Although *Safe Travel for All Children* focuses on transporting children with special health care needs in passenger vehicles, this chapter serves as an introduction to issues related to other vehicles, including school buses, adapted vehicles and ambulances. A list of school bus and ambulance transportation resources can be found in the *Resources* section of the *Appendices*.

**INDIVIDUALS WITH DISABILITIES EDUCATION IMPROVEMENT ACT**

When children with special health care needs are ready to enter early intervention or educational programs, their right to access equal services (including transportation) is mandated by federal regulations, including the Individuals with Disabilities Education Improvement Act (IDEIA). The IDEIA requires early intervention services for children from birth through age two, and special education services for children from three years of age through age 21. Issues relevant to the implementation of services must be documented in one of two plans. The plan should be developed by a committee comprised of parents or caregivers, agency or school representatives, medical or rehabilitation professionals, and others relevant to the provision of appropriate services. Brief summaries of the plans are as follows:

- **The Individualized Family Service Plan (IFSP)** is a written plan of strategies and activities for the provision of early intervention services for infants and toddlers with disabilities. The IFSP is a family-focused plan designed to provide services year round in “natural environments” such as the home or daycare. Not all children who qualify for early intervention services will require transportation.

- **The Individualized Education Program (IEP)** is a written plan of strategies and activities for the provision of educational services and programs for students with disabilities. The IEP is a student-focused plan designed to provide equal access to educational programs and related services for children between age three and age 21 during the school year. Transportation to and from school will be considered a related service if a child requires assistance, care or specialized equipment beyond that required by students without disabilities. If transportation is designated as a related service, a transportation representative should be a member of the IEP planning team.
### Transporting Children with Special Health Care Needs in School Buses

In most instances, children with disabilities will be transported to and from school on school buses. Each state has its own specifications for transporting children on school buses, and some states provide greater detail than others. School buses must comply with all applicable federal motor vehicle safety standards.

Considerations for safe travel on school buses differ from passenger vehicles due in part to differences in vehicular designs. School buses are statistically safer than passenger vehicles for a number of reasons. Large school buses (above 10,000 pounds) are heavier, experience less crash forces and distribute crash forces differently. School bus standards are more stringent than other vehicle types. School buses are painted a “school bus yellow” so that other drivers can easily see and recognize them. In addition, school buses travel during daylight hours and on familiar roadways, which may decrease the chances of a crash.

### Occupant Protection by School Bus Type

Certain federal motor vehicle safety standards require design features on buses to meet specific performance or occupant protection criteria. All school buses must meet compartmentalization requirements. Compartmentalization is a passive form of occupant protection. The combination of energy absorbing, flexible seatbacks and spacing requirements between bus seats creates a “compartment” to contain the passenger in the event of a crash. Vehicle seat backs on all school buses made after 2009 are higher (24 inches tall) and more energy absorbent.

Since buses 10,000 pounds and under experience crash forces similar to passenger vehicles, they are also required to have seat belts. As of 2011, new buses must be equipped with lap and shoulder belts not just lap belts. These buses are also required to have LATCH in at least two seating positions.

In the past, school buses 10,000 pounds and under were usually used for transporting children with special health care needs. With the advent of inclusion, however, children with special health care needs and typically developing children are often transported together in larger school buses.
Buses weighing more than 10,000 pounds provide occupant protection by compartmentalization. As of 2011, lap and shoulder belts are optional, not required, on large school buses.

Restraint Options
The selection of an appropriate child restraint for a child with special health care needs on a school bus should consider the following:

- The child’s age, weight and height.
- The child’s medical, physical and/or behavioral condition.
- The child’s positioning requirements.
- Supervision requirements.
- Allergies or physical sensitivities (e.g., problems with temperature regulation).
- Assistive devices and equipment requirements.

Conventional Child Safety Seats
For children who are smaller than 40 pounds and 40 inches tall should, whenever possible, use conventional child safety seats with harness systems that will accommodate their individual positioning requirements and medical procedures (e.g., g-tubes). Conventional restraints must be installed on reinforced bus seats (FMVSS 210) with seat belts that meet FMVSS 208 and 209. Conventional restraints should be installed next to a window to promote ease of evacuation and loading on and off the bus for other passengers.

Belt-positioning booster seats are generally considered unnecessary in school buses with lap and shoulder belts. This is because the shoulder portion of the belt is usually adjustable so that it can fit different sizes of children. If a booster seat is necessary, backless models are preferred since they allow the rider to be positioned as far back on the bus seat as possible. As in passenger vehicles, booster seats must be used with lap and shoulder belts, not lap-only belts.

Adaptive Car Seats
Medical or adaptive positioning seats may accommodate children who require more support than either conventional car seats or seat belts. Since many
specialized restraints must be tethered, both the restraint and school bus manufacturers should be consulted as to appropriate means of tethering in school buses.

Vests and Harnesses

Upright vests may be alternatives for some children with disabilities who require upper body restraint or who have behavioral conditions. The vests are usually secured to school bus seats by special tether systems called cam wraps or seat mounts. Manufacturer’s instructions should be followed for proper installation and usage of tether systems in school buses. Vests must have labels stating: “Warning! This restraint must only be used in school bus seats. Entire seat directly behind must be unoccupied or have restrained occupant.”

Other Restraint Systems Designed for Buses

Restraint systems specifically designed for use on school buses are available. These include integrated seating systems (These are built into the bus seat and cannot be removed.) and restraints that can be added onto school bus seats. Some manufacturers may offer children with special health care needs for use with integrated or add-on school bus restraints. Although the integrated seats are similar to those found in some passenger vehicles, the spacing between bus seats may hinder proper positioning of a child’s legs.

Additional occupant protection systems, such as add-on restraints and three-point seat belts specific to school buses are also available. Add-on restraints are secured to the school bus seat by means of a cam wrap system.
Wheelchairs

Under certain circumstances, it may be necessary to transport some children to and from school in wheelchairs or adaptive strollers. In general, the guidelines for transporting children in wheelchairs in passenger vehicles should be followed on the school bus. (Refer to Chapter 4, Wheelchair Occupant Protection.)

Installation Issues

- **Seat belts**
  In most instances, installation of restraints on buses will be dictated by the availability of seat belts that meet federal safety standards. If seat belts meet applicable standards, the seat belt webbing will have a tag indicating that the seat belt meets federal standards 208 and 209. If the non-adjustable end of the lap belt extends more than two inches from the seat bight, it could pose installation issues by bringing the seat belt too far into the belt path.

- **Reinforced bus seats**
  In order to tolerate attachment of seat belt anchors and hardware, school bus seats must be reinforced according to criteria established in FMVSS210. *School buses manufactured before April 1977 do not have reinforced seats and, therefore, should not be retrofitted with seat belts.*

- **Spacing**
  Other features can influence installation of restraints on school buses. Current guidelines recommend that child safety seats be installed on bus seats that are spaced apart the maximum distance of 24 inches from the seating reference point.

- **Tethers**
  Many adaptive restraints must be installed with tethers as well as seat belts. Often, the vehicle floors of buses are not adequately reinforced for tether attachment. Some tethers are attached to seat belts that are located in bus seats behind the restraints. This installation procedure can pose problems for school districts by limiting the number of available passenger positions in the buses. Another tethering system is called the cam wrap. The cam wrap attaches to the restraint, wraps around the back of the bus seat (through the vehicle seat crack) where it attaches to the restraint. Restraint and school bus manufacturers’ instructions should be consulted for specific or additional tethering methods.
• **LATCH**

   The advent of the LATCH system impacts restraint installation on school buses as well as passenger vehicles. Small buses (under 10,000 pounds) are required to comply with FMVSS 225 and be equipped with the LATCH system in at least two seating positions. Large buses have the option of installing the LATCH system in select seating positions.

**TRAINING CONSIDERATIONS**

The Individuals with Disabilities Act requires that all personnel serving students with disabilities be trained about the population they are serving. Training should be coordinated by the school district and provided to transportation drivers, including substitute drivers. Training on special needs transportation should include, but is not limited to the following:

- An overview of relevant medical conditions.
- Medical equipment securement and handling.
- Universal precautions, first aid, CPR and confidentiality.
- Do Not Resuscitate Order (DNR) and a plan for implementation.
- Emergency evacuation plans and procedures.
- Federal and state regulations regarding transportation and disability laws.
- Passenger loading and unloading, including wheelchair lift procedures.
- Required documentation.
- Use of extra equipment such as belt cutters, fire extinguishers and first aid kits.

**OTHER CONSIDERATIONS**

When transporting children with special health care needs on school buses, there are additional considerations that must be taken into account. It is important to ask the following questions when planning appropriate transportation options:

1) Are climate control features, such as tinted windows and/or white roofs available?

2) Are back-up power sources required for medical equipment?

3) Does the bus design allow young passengers to enter and exit safely (e.g. low steps, extra handrails)?
4) Will some children need to sit in specific positions such as closer to the driver and/or away from opening and closing doors?

5) Are extra assistants required?

6) Is the bus equipped with a two-way communication system in case of an emergency?

7) Is there an emergency information card that provides information on each child on the bus?

8) Will medically fragile children tolerate an extended route?

INFANTS, TODDLERS AND PRESCHOOLERS ON THE SCHOOL BUS

Although infants, toddlers and preschoolers do not necessarily meet the criteria of children with special health care needs, they are unique passengers who have specialized needs in the school bus environment and are thus worth mentioning here.

School districts now have guidelines issued by The National Highway Traffic Safety Administration (NHTSA) on safely transporting preschool-age children on school buses. These guidelines are referred to as “Guidelines for Transporting Preschool Age Children on School Buses” and were issued in February 1999. The guidelines state that any child of preschool age should be secured with an appropriate child safety restraint while riding on a school bus. A copy of the guidelines is available at www.nhtsa.dot.gov/people/injury/buses/children.htm.

ADAPTED VEHICLES

Some families may require use of adapted vehicles in order to meet the transportation needs of their children. The National Highway Traffic Safety Administration (NHTSA) publishes a brochure, “Adapting Motor Vehicles for People with Disabilities,” to assist families in navigating the process of securing adapted vehicles. In general, NHTSA recommends that families work with a driver rehabilitation specialist qualified to assess the family’s specific transportation needs and who can provide them with a list of appropriate vehicle modifications. Although driver rehabilitation specialists typically work with drivers with disabilities, they can also evaluate the vehicle needs of passengers with disabilities. Names of qualified evaluators can be obtained by contacting a
local rehabilitation center or the Association for Driver Rehabilitation Specialists at 866-672-9466 or www.driver-ed.org.

Once the vehicle modifications have been evaluated and discussed with the family, appropriate vehicle options can be explored. When choosing a vehicle, it is important for families to work with a reputable dealer of adaptive vehicles. The vehicle should be equipped with seat belts, vehicle seats and tether anchorage locations that meet all applicable federal safety standards. The seat belts should be capable of remaining locked during normal driving conditions if child safety seats are installed. If the vehicle is adapted to accommodate use of a wheelchair, it should provide adequate space for the wheelchair to face forward, a four-point tie-down system and a separate three-point seat belt for the wheelchair occupant. In addition, the vehicle should be equipped with appropriate restraint systems for all occupants.

New adapted vehicles can be expensive, ranging in price from $20,000 to $80,000. NHTSA suggests that families pursue both public and private avenues for funding the vehicles. For example, insurance companies may cover costs associated with evaluations and vehicle modifications. Adaptive vehicle manufacturers may offer rebates or reimbursement plans. Social service agencies may be able to help families explore applicable grants. A copy of the brochure is available at www.nhtsa.dot.gov/car/rules/adaptive.

AMBULANCES

Providing appropriate occupant protection for child passengers in ambulances presents multiple challenges to emergency service providers and child passenger safety technicians. Transport purpose and vehicle design vary greatly from passenger vehicles. Responding to the medical needs of the patient is the primary concern during transport. The ambulance is designed to transport, but not necessarily restrain the necessary personnel and equipment to meet these needs.

Although research is limited and preliminary, the special circumstances of ambulance transport have been recognized nationally and have resulted in the general consensus that all occupants and equipment should be restrained within the ambulance.

Automotive Safety Program Research

Specific guidelines given here for child occupants on cots are based on research conducted by the Automotive Safety Program, Riley Hospital for Children, and Indiana University School of Medicine at the University of Michigan Transportation Research Institute. This research is detailed in “Crash Protection
for Children in Ambulances” (Bull, et al 2001.) and is available at http://www.preventinjury.org/Research. These recommendations assume that the child restraints are secured to crashworthy cots and fastener systems but recognize that the method may also be effective when secured with less crashworthy systems.

It should be noted that the method in which the restraints are secured is not included in the directions provided by the child safety seat manufacturers. Specific manufacturers may be consulted concerning use of their products on an ambulance cot. Additionally, the recommendations provided here are most appropriate for planned transport, such as inter-hospital or home to hospital travel.

**Children who weigh up to 40 pounds and can tolerate sitting in a semi-upright position:**

- Select a convertible child safety seat with a five-point harness.
- Position the seat facing the foot end of the cot with the backrest fully elevated.
- Adjust the recline mechanism of the child safety seat so the back of the seat fits snugly against the backrest of the cot. The angle should not be more than 45 degrees from the vertical.
- Install the child safety seat using two sets of cot straps. Route one set through the rear-facing belt path and the other set through the forward-facing belt path. The set of cot straps that are installed through the forward-facing belt path should be attached to the cot backrest in a location that will not slide up or down. The set of cot straps that are installed through the rear-facing belt path should be attached rearward of the farthest side rail anchor.
- Fasten the five-point harness and snugly adjust it on the child. Ideally, the shoulder straps should be through the slots at or just below the child’s shoulders since the convertible child restraint will be oriented rear facing.
- For small infants, place rolled receiving blankets or towels on either side of the child to maintain a centered position in the restraint.
**Infants who cannot tolerate a semi-upright seated position or who, for other reasons, must lie flat:**

- Use only a car bed that can be secured with cot straps against rearward and forward motion.
- Position the car bed across the cot so that the child lies perpendicular to it and fully raise the backrest.
- Anchor the car bed to the cot with two pairs of cot straps attached to the cot as described above.
- Fasten the harness or other internal restraint and snugly adjust it on the infant.

**Ambulance-Specific Restraints**

Currently, there are no Federal Motor Vehicle Safety Standards to define performance criteria for child restraint use in ambulance patient compartments. Many ambulance-specific restraints may advertise they meet or exceed injury criteria measures such as FMVSS 213. Manufacturers should be contacted to obtain crash-test data and specific criteria used for testing their restraints on ambulance cots or in other seating positions inside the ambulance.

Products designed for pediatric use on ambulances are cot-mounted restraints and integrated restraints. Weight and height requirements for cot-mounted restraints vary by product, as well as the cot attachment systems and harness adjustment features.

Integrated restraints are typically built into an attendee’s vehicle seat. Similar to integrated seats in passenger vehicles and school buses, these products are usually designed for older children. There is one company, however, that manufacturers an infant-only car seat that is integrated into an attendee’s vehicle seat.

Emergency Medical Services (EMS) personnel should consider the following when selecting restraints specifically designed for ambulance use:
• Demographics of pediatric population served; typical height, weight and ages of children transported inside the ambulance for scheduled or non-scheduled transport.
• Ease of use during installation and harness procedures.
• Ease of cleaning and storage inside the ambulance.
Appendices
Glossary of Medical Terms

The terms defined in this abbreviated glossary are either mentioned in the *Reference Guide of Medical Conditions and Procedures* or are additional terms that may be used when discussing transportation issues related to children with special health care needs. This glossary is by no means all-inclusive.

4-channel cardiorespiratory recording
Computerized study that simultaneously records heart rate, SaO2, pulse rate and respiratory effort; can determine if there is an obstruction and if the oxygen supplementation provided to an infant is sufficient to maintain adequate oxygenation. In addition, it correlates the heart rate and pulse to determine that the values recorded are accurate. This equipment is generally accessed through a pulmonary department and the test conducted by a nurse or a respiratory therapist. The test is then downloaded and read at a center with a report generated for the ordering attending physician. If the equipment is available, this same method can be used to conduct follow-up evaluations at home or in the physician’s office.

A

**Airway obstruction**
Closing of airway, caused either by blockage from foreign object or anatomical position of head, neck and/or jaw; may be partial or complete

**Abduct**
To move a body part, such as a leg, away from the midline

**Abductor wedge**
Rigid or foam positioning device used to keep the pelvis from pushing forward or to help keep the legs from crossing in a wheelchair or adaptive car seat.

**Angulation of the lower spine**
*See lordosis*

**Apnea**
Transient cessation of respiration whether normal or abnormal

**Apnea monitor**
Equipment that measures the rate of respiration
Adduct  
To move a body part, such as a leg, toward the midline

Anomaly  
Deviation from typical, especially as a result of congenital or hereditary defects

Atlantoaxial instability  
Instability or increased movement of the first and second cervical vertebrae

Attention deficit hyperactivity disorder (ADHD)  
Brain disorder that results in problems with attention, hyperactivity and impulsivity

Atrophy  
Decreasing in size or wasting away of a part of the body or organ, such as a muscle

B  

Biox  
See pulse oximeter

Body jacket  
Back brace used in treatment of scoliosis or lordosis

Body mass index (BMI)  
Measure of body fat based on weight and height

Bradycardia  
Relatively slow rate of heart contractions whether physiological or pathological

C  

Cele  
Sac created in tissue; for example, from incomplete formation of spinal cord and nerves in myleomenigocele

Centimeter (cm)  
One hundredth of a meter; equivalent to .39 inch
To convert to inches, divide cm by 2.54 or multiply cm by .39.

Cerebral spinal fluid  
Fluid in and around the brain and spinal cord
**Cerebral ventricles**
Spaces in the brain filled with cerebral spinal fluid

**Cervical collar**
Neck collar

**Cervical spine**
Portion of the spine in the neck; the first seven vertebrae

**Chromosome**
A thread-like strand of DNA that carries genes

**Cleft palate**
The bones and/or muscles forming the roof of the mouth are absent or incompletely developed.

**Cognitive impairment**
Diminished intellectual activity

**Congenital**
Born with or present at birth

**Cranial cavity**
The space inside the skull, which houses the brain

**Craniofacial abnormalities**
Congenital deformities of the skull and face, frequently associated with genetically transmitted syndromes

**Cyanosis**
Bluish discoloration of the skin and mucous membranes due to decreased oxygen in the blood

**Degenerative diseases**
Diseases in which function deteriorates over time

**Durable Medical Equipment**
A broad term for equipment used to assist individuals with disabilities and their families gain independence with activities of daily living.
**E**

**Extend**
To straighten

**F**

**Femur**
Thigh bone

**Flex**
To bend; to move a joint in a direction to bring two parts together

**Fracture**
To break

**G**

**Gastrostomy tube “g-tube”**
A feeding tube inserted into the abdomen

**Genetic Disorder**
A condition caused by abnormalities in genes or chromosomes. A genetic condition is determined before birth but may not become apparent for months or years.

**Gibbus Deformity**
Extreme kyphosis, or protrusion, in the spine. Caused by abnormally formed or developed vertebral bodies, or the compression/deformation of the vertebral bodies.

**H**

**Hemi**
Half or one side

**Hemiplegia**
Paralysis of half of the body

**Hip subluxation**
Partial dislocation of the hip

**High tone/hypertonia**
High muscle tone; muscles contracting more than normal

**Hyperextensible joints**
Ability to be stretched more than normal; often referred to as “double-jointed”
Hypertonia/high tone
High muscle tone; muscles contracting more than normal

Hypotonia
Low muscle tone; muscle contracting less than normal

Hypoxia
Inadequate oxygen in body’s tissues

Infants born prematurely
Less than 37 weeks gestational age at birth

Inherited
Genetically passed through the mother and/or father to the child

Involuntary movement
Unintentional movement; independent of the will

Involved
Complicated

Jejunostomy tube “J-tube”
Feeding tube inserted into the jejunum, which is the part of the small intestine below the stomach

Kilogram (kg)
Equivalent to 2.2 pounds. To convert to pounds, multiply kg x 2.2. For example 1.8 kg x 2.2 lbs = 3.96 pounds

Kyphosis
Convex curvature of the spine; hump back

Low tone
See hypotonia.
**Lumbar spine**
Lower back; five lumbar vertebrae

**M**

**Microcephaly**
Small head; head smaller than two standard deviations below the mean

**Motor neuron disease**
A group of progressive disorders that destroys motor neurons responsible for voluntary muscle activity, including walking, talking and breathing. Spinal muscular atrophy is an example.

**Muscle innervation**
The process by which the nerves stimulate the muscles

**Muscle tone**
Refers to the amount of tension in muscle tissue

**N**

**Neurodevelopmental condition**
Condition characterized by problems with the growth and development of the brain or nervous system.

**Neurological impairment**
Conditions related to the central nervous system affecting speech, vision, memory, learning and motor skills. Includes cerebral palsy, epilepsy, brain injury and spina bifida

**Neuromuscular disorder**
Condition involving nerves and muscles

**O**

**Obstructive airway disease**
Common respiratory disease that results in reduced airflow during expiration; includes asthma, chronic bronchitis and cystic fibrosis

**Open reduction of the hip**
Surgical procedure used to position the head of the femur into the hip socket in cases of developmental dysplasia of the hip
**Orthopedics**
Related to the prevention or correction of skeletal deformities

**Oxypneumocardiogram (OPCG)**
Study that measures oxygen levels, heart rate, apnea

**P**

**Pallor**
Paleness of the skin

**Paresis**
Weakness

**Paralysis**
Complete or partial loss of function

**Paraparesis**
Weakness affecting lower extremities

**Paraplegia**
Paralysis of both lower extremities and generally, the lower trunk

**Peritoneal cavity**
Space between the abdominal wall and abdominal organs

**Polysomnogram**
A polysomnogram (PSG) is a sophisticated and observed computerized test, which is usually done in a sleep lab. It measures and records pulse, saturation, chest and abdominal wall movements, end-tidal CO2, airflow and utilizes EEG, EOG, and EMG for sleep staging. This is particularly helpful, for example, for infants who have Pierre Robin sequence or neuromuscular abnormalities where airway obstruction is frequently present.

**Prone**
Lying face down

**Pulse oximeter**
Device applied to extremity to measure O2 saturation

**Pulmonary**
Pertaining to the lungs
Q
Quadriplegia
Paralysis of all four limbs

R
Restrictive airway
Condition characterized by restricted lung expansion

Retro-positioning of the tongue
Positioning of the tongue backwards that causes the upper airway to be partially or intermittently blocked

Rigidity
Stiffness or inflexibility

S
SaO2/Oxygen saturation
Percent of oxygen saturating the blood

Shunt
Tube or opening that drains fluid from one cavity to another (e.g., shunt from brain to abdomen for hydrocephalus or opening between chambers of the heart)

Side-lying
Positioned on the side

Social (Pragmatic) Communication Disorder (SCD)
Disorder that exhibits ongoing problems with verbal and nonverbal communication that cannot be described by low cognitive ability. A new diagnosis in the 5th edition of the Diagnostic and Statistical Manual of Mental Disorders was developed to improve diagnosis and access of services for individuals with communication issues.

Spasticity
A state of increased muscular tone with exaggeration of the tendon reflexes

Supine
Lying face upward

T
**Thoracic spine**
Upper back; 12 thoracic vertebrae

**Tone**
See muscle tone

**Trachea**
Series of cartilaginous rings in the neck that comprise a tube that carries air to the lungs

**Tracheoesophageal fistula**
Birth defect in which the trachea is connected to the esophagus, which can result in fluids entering the lungs causing aspiration pneumonia and breathing problems.

**V**

**Ventriculoperitoneal shunt**
Device that diverts excess cerebral spinal fluid from the ventricles in the brain into the abdomen for absorption

**Voluntary movement**
Intentional movement; relating to will

**NOTES:**
## Accessories for Large Medical Seats and Adapted Boosters Seats

The following table lists common accessories (and their purposes) that may be available with a large medical seat or adaptive booster seats. Some come standard with the CSS, while others need to be itemized on the order form. Please check with the manufacturer for specific ordering instructions. It is also important to note that although one CSS offers several accessories, some cannot be used in conjunction with another (i.e., turning base AND wedge cannot be used together on Recaro Start 2.0 Plus).

<table>
<thead>
<tr>
<th>Name</th>
<th>Purpose</th>
<th>When to use?</th>
<th>Available on following CSS:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abductor (pommel)</td>
<td>Prevents scissoring of legs and keeps thighs positioned in neutral; assists in maintaining neutral pelvis and keeping hips back against seat</td>
<td>A child has high hip extensor tone (or straightens hips) when put into CSS; a child has high adductor tone (or scissors legs); can also be used for hypotonia</td>
<td>Roosevelt, Britax Traveller Plus EL, Columbia Products, Carrot, Churchill, Special Tomato, Carrie Car Seat, Recaro Monza, Snug Seat Pilot, Recaro Start 2.0 Plus</td>
</tr>
<tr>
<td>Seat extender</td>
<td>Keeps pelvis in neutral by adequately supporting thighs in sitting; ideally want ~1 inch between the end of CSS and back of child’s knees</td>
<td>More than 1 inch of space is between the back of the child’s knee and the end of the CSS</td>
<td>Roosevelt, Britax Traveller Plus EL, Columbia Products, Carrot, Recaro Monza, Snug Seat Pilot</td>
</tr>
<tr>
<td>Scoliosis harness</td>
<td>Allows for independent adjustment of harness over each shoulder</td>
<td>A scoliotic curve can make one shoulder higher than the other; therefore harness is tight on one side and loose on other</td>
<td>Roosevelt</td>
</tr>
<tr>
<td>Lateral supports (swing-away may be optional)</td>
<td>Provide more support in sitting</td>
<td>When child needs more support than is offered by base model of car seat</td>
<td>Columbia Spirit (swing-away), Recaro Start 2.0 Plus (swing-away optional), Carrot (not swing-away)</td>
</tr>
<tr>
<td>Wedge</td>
<td>Under child: increases hip flexion, Child has high hip extensor tone</td>
<td></td>
<td>Churchill, Recaro Start 2.0 Plus,</td>
</tr>
<tr>
<td>Feature</td>
<td>Description</td>
<td>Potential Uses</td>
<td>Suitable CSS Models</td>
</tr>
<tr>
<td>-------------------------------</td>
<td>-----------------------------------------------------------------------------</td>
<td>--------------------------------------------------------------------------------</td>
<td>--------------------------------------------</td>
</tr>
<tr>
<td>Head support system</td>
<td>Provide head support in sitting</td>
<td>When a child’s head falls forward or to the side</td>
<td>Roosevelt (Velcro cap optional), Churchill (Velcro cap optional), all other CSS</td>
</tr>
<tr>
<td>Footrest</td>
<td>Can assist with maintaining lower extremity circulation; helps keep pelvis in neutral by supporting lower extremities</td>
<td>Parent or child complains of legs falling asleep or needing lower extremity support in car</td>
<td>Carrie Car Seat, Carrot, Recaro Start 2.0 Plus</td>
</tr>
<tr>
<td>Tray</td>
<td>Allows for child to self-position in vehicle</td>
<td>Child would benefit from resting upper extremities or is able to position self</td>
<td>Carrot, Recaro Monza, Recaro Start 2.0 Plus</td>
</tr>
<tr>
<td>Turning base</td>
<td>Provides ease in transferring child in/out of CSS</td>
<td>Caregiver has difficulty transferring and/or positioning child in CSS</td>
<td>Recaro Start 2.0 Plus, Recaro Monza</td>
</tr>
<tr>
<td>Buckle cover</td>
<td>Prevents child from unbuckling crotch buckle</td>
<td>A child won’t stay buckled</td>
<td>Roosevelt, Britax Traveller Plus EL, Columbia Products</td>
</tr>
<tr>
<td>Chest clip guard</td>
<td>Prevents child from unbuckling chest clip or pushing chest clip down</td>
<td>A child won’t stay buckled</td>
<td>Roosevelt</td>
</tr>
<tr>
<td>Incontinence cover</td>
<td>Improves hygiene by wicking away moisture from child’s body; Allows CSS to remain installed while only taking cover off to clean; reduces misuse associated with re-installation and removes need to re-assemble harness and cover</td>
<td>Child has multiple incontinence episodes; is fed by G-tube (can spill)</td>
<td>Roosevelt and Columbia Spirit</td>
</tr>
</tbody>
</table>
RESOURCES

There are many individuals and organizations that provide resources and advocacy for children with special health care needs. Developing partnerships with them is an important component of promoting safe transportation issues for all children. This section lists and briefly describes some of the resources currently available. Child passenger safety technicians are encouraged to contact each organization and resource listed to learn more about them.

The authors of this Participant Manual acknowledge that these lists are not all-inclusive and inclusion does not imply endorsement.

ORGANIZATIONS

ALLIANCE National Parent Technical Assistance Center
PACER Center
8161 Normandale Blvd.
Minneapolis, MN 55437-1044
Phone: 888-248-0822
www.taalliance.org
The state centers provide training and information to parents and professionals involved in the care and education of children and young adults with special health care needs. A list of the centers can be obtained through the Alliance Coordinating Office.

American Academy of Pediatrics (AAP)
141 Northwest Point Blvd.
PO Box 747
Elk Grove Village, IL 60009-0747
Phone: 800-433-9016
www.aap.org
The professional organization of pediatricians addresses all aspects of childhood growth and development, including injury prevention issues. The AAP publishes transportation-related policy statements and offers car seat shopping guides for children who use conventional restraints, as well as special needs restraints.

The Arc of the United States
1660 L Street, NW, Suite 301
Washington, DC 20036
Phone: 800-433-5255
www.thearc.org
The national organization is devoted to promoting and improving support and services for people with intellectual disabilities and their families. The association also fosters
research and education regarding the prevention of mental retardation in infants and young children.

**Automotive Safety Program**
Fesler Hall, Room 207
1130 W. Michigan Street
Indianapolis, IN 46202
Phone: 317-274-2977
800-KID-N-CAR (Indiana only)
www.preventinjury.org
The injury prevention program is based at the Indiana University School of Medicine and funded through the Governor’s Council on Impaired and Dangerous Driving, Office of Traffic Safety. It provides education, training and resources on child passenger safety and transporting children with special health care needs.

**Children’s Hospitals Association**
401 Wythe St.
Alexandria, VA 22314
Phone: 703-684-1355
www.childrenshospitals.net
The national organization of children’s hospitals is involved in educational research, health promotion and advocacy. A number of member hospitals offer special needs car seat programs.

**Easter Seals, Inc.**
233 South Wacker Drive, Suite 2400
Chicago, IL 60606
Phone: 800-221-6827
www.easter-seals.org
The national organization with state affiliates provides resources and services to families and individuals with special health care needs. It supports child passenger safety programs for children with special health care needs.

**Emergency Medical Services for Children (EMSC)**
National Resource Center (NRC)
8737 Colesville Road, Suite 400
Silver Spring, MD 20910
Phone: 202-476-4927
www.childrensnational.org/emsc
The Emergency Medical Services for Children (EMSC) National Resource Center (NRC) provides support to the Federal EMSC Program. The NRC works primarily with state health departments, medical-based universities, and stakeholder organizations that receive EMSC Program funding (collectively known as EMSC grantees/contractors).
Exceptional Parent
65 East Route 4
River Edge, NJ 07661
Phone: 877-372-7368 (customer service/new orders)
www.eparent.com
Information and support for the special needs community. Monthly magazine devoted
to issues relevant to children and young adults with special health care needs and their
parents. Exception Parent publishes an annual resource guide of agencies, services,
parent groups, products and services.

National Association for Pupil Transportation
1840 Western Avenue
Albany, NY 12203-0647
Phone: 800-989-NAPT
www.napt.org
The national organization promotes safety and enhancing efficiency in pupil
transportation.

National Center for the Safe Transportation of Children
with Special Health Care Needs
Fesler Hall, Room 207
1130 W. Michigan Street
Indianapolis, IN 46202
Phone: 800-755-0912
www.preventinjury.org
Housed at the Automotive Safety Program (listed above) and established with funding
from NHTSA, the National Center provides education, training and resources on
special needs transportation issues.

National Highway Traffic Safety Administration (NHTSA)
1200 New Jersey Avenue, SE
West Building
Washington, DC 20590
Phone: 888-327-4236
Fax: 202-366-2106
www.nhtsa.gov
The federal agency sets national standards for occupant protection. It provides data,
technical assistance, and educational materials. There are regional NHTSA offices
throughout the country.
NHTSA Auto Safety Hotline  
Phone: 888-DASH-2-DOT  
The toll-free number receives consumer questions, reports on child restraint defects and recall information.

Safe Ride News (SRN) Publications  
PO Box 38  
Edmonds, WA 98020  
Phone: 425-640-5710/800-403-1424  
www.saferidenews.com  
Organization that addresses traffic safety issues, including special needs transportation. SRN publishes a newsletter, fact sheets, the LATCH Manual, the School Bus Safety Manual and other useful items for CPSTs.

School Transportation News  
P.O. Box 789  
Redondo Beach, CA 90277  
Phone: 310-792-2226  
www.stnonline.com  
The newspaper covers school transportation issues.

Pupil Transportation Safety Institute  
224 Harrison Street, Suite 300  
Syracuse, NY 13202  
Phone: 800 836-2210  
www.ptsi.org  
The organization provides school bus safety information and resources as well as training and grant work to school districts, governmental agencies, and school bus contractors.

Safe Kids Worldwide  
1301 Pennsylvania Ave. #1000  
Washington, DC 20004  
Phone: 202-662-0600  
www.usa.safekids.org  
The national organization is dedicated to preventing unintentional injuries to children ages birth through 14. It sponsors state and local child injury prevention programs and develops safety campaigns and materials.
SafetyBeltSafe, USA  
P.O. Box 553  
Altadena, CA 91003  
Phone: 800-745-SAFE  
www.carseat.org  
A long-standing child passenger safety program with national impact, SafetyBeltSafe USA provides child passenger safety training, advocacy, consulting and literature in both English and Spanish.

MANUFACTURERS OF SPECIALIZED RESTRAINTS

<table>
<thead>
<tr>
<th>Manufacturer</th>
<th>Restraint</th>
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<tbody>
<tr>
<td><strong>Adaptive Mall</strong></td>
<td>Special Tomato</td>
</tr>
<tr>
<td>Bergeron Health Care</td>
<td></td>
</tr>
<tr>
<td>15 S. Second Street</td>
<td></td>
</tr>
<tr>
<td>Dolgeville, NY 13329</td>
<td></td>
</tr>
<tr>
<td>800-371-2778</td>
<td></td>
</tr>
<tr>
<td><a href="http://www.adaptivemall.com">www.adaptivemall.com</a></td>
<td></td>
</tr>
</tbody>
</table>

| **Angel Guard**         | Angel Ride Car Bed         |
| 7001 Wooster Pike       |                            |
| Medina, OH 44256        |                            |
| 330-723-5928            |                            |
| www.angel-guard.com     |                            |
| Mercury Distributing    |                            |
| 800-815-6330            |                            |
| www.mercurydistributing.com |                        |

| **Besi Manufacturing**  | Besi Restraining Harness   |
| 9087 Sutton Place       | Proteck II and III         |
| Hamilton, OH 45011      |                            |
| 800-543-8222            |                            |
| www.besi-inc.com        |                            |

<p>| <strong>Britax Child Safety, Inc.</strong> | Hippo                         |
| 13501 S. Ridge Dr.       | Traveller Plus EL            |
| Charlotte, NC 28273      |                              |
| 704-409-1700              |                              |
| <a href="http://www.britaxusa.com">www.britaxusa.com</a>        |                              |</p>
<table>
<thead>
<tr>
<th>Company</th>
<th>Product</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Columbia Medical</strong></td>
<td>TheraPedic 2000</td>
</tr>
<tr>
<td>11724 Willake Street</td>
<td>TheraPedic 2500</td>
</tr>
<tr>
<td>Santa Fe Springs, CA 90670</td>
<td>2400 Spirit</td>
</tr>
<tr>
<td>562-282-0244</td>
<td></td>
</tr>
<tr>
<td><a href="http://www.columbiamedical.com">www.columbiamedical.com</a></td>
<td></td>
</tr>
<tr>
<td><strong>Convalid</strong></td>
<td>Carrot 3</td>
</tr>
<tr>
<td>2830 California Street</td>
<td></td>
</tr>
<tr>
<td>Torrance, CA 90503</td>
<td></td>
</tr>
<tr>
<td>888-266-8243</td>
<td></td>
</tr>
<tr>
<td><a href="http://www.convaid.com">www.convaid.com</a></td>
<td></td>
</tr>
<tr>
<td><strong>Dorel Juvenile Group</strong></td>
<td>Dream Ride SE Car Bed</td>
</tr>
<tr>
<td>P.O. Box 2609</td>
<td></td>
</tr>
<tr>
<td>Columbus, IN 47202</td>
<td></td>
</tr>
<tr>
<td>800-544-1108</td>
<td></td>
</tr>
<tr>
<td><a href="http://www.djgusa.com">www.djgusa.com</a></td>
<td></td>
</tr>
<tr>
<td><strong>ExoMotion (Thomashilfen North America)</strong></td>
<td>Recaro Monza</td>
</tr>
<tr>
<td>309 South Cloverdale St., Unit B 12</td>
<td>Adaptive Accessories for Recaro</td>
</tr>
<tr>
<td>Seattle, WA 98108</td>
<td>Pro-sport Reha</td>
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<td>866-870-2122</td>
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<td><a href="http://www.exomotion.com">www.exomotion.com</a></td>
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<tr>
<td><strong>E-Z-ON Products, Inc.</strong></td>
<td>E-Z-ON Vest</td>
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<tr>
<td>605 Commerce Way West</td>
<td>Modified E-Z-ON Vest</td>
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<tr>
<td>Jupiter, FL 33458</td>
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<tr>
<td>800-323-6598</td>
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<td><a href="http://www.ezonpro.com">www.ezonpro.com</a></td>
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<tr>
<td><strong>Merritt Manufacturing, Inc.</strong></td>
<td>The Roosevelt</td>
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<tr>
<td>2146 N Road 400 West</td>
<td>The Churchill</td>
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<tr>
<td>Bargersville, IN 46106</td>
<td>Hope Car Bed</td>
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<tr>
<td>317-409-0148</td>
<td>The Jefferson</td>
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<td><a href="http://www.eztether.com">www.eztether.com</a></td>
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<td><strong>Safeguard (IMMI)</strong></td>
<td>STAR</td>
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<td>18881 US 31 N</td>
<td>Safe Guard Transport</td>
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<td>Westfield, IN 46074</td>
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<td>877-447-2305</td>
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<td><a href="http://www.safeguardseat.com">www.safeguardseat.com</a></td>
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Q-Straint
5553 Ravenswood Rd., #110
Ft. Lauderdale, FL 33312
800-987-9987
www.qstraint.com

Q-Vest

Reha-Partner
225 Peachtree Road, NE
Suite 506
Atlanta, GA 30303
866-282-4558
www.reha-partner.com

Recaro Vendor
Recaro Start 2.0 Plus
Reha-KIT accessories for Recaro
Pro-sport Reha

Patterson Medical/Tumble Forms
1000 Remington Blvd., Suite 210
Bollingbrook, IL 60440-5117
800-323-5547
www.pattersonmedical.com

Carrie Car Seat

Snug Seat
P.O. Box 1739
Matthews, NC 28106
800-336-SNUG (7684)
www.snugseat.com

Hippo vendor
Traveller Plus EL vendor
Pilot vendor
WHEELCHAIR RESOURCES

*Ride Safe* Brochure - Information to help you ride more safely while seated in your wheelchair for travel in a van or bus.

- On the web at www.travelsafer.org
- For hard copies, contact:
  Email: umtridocs@umich.edu
  Phone: 734-764-2171
  FAX: 734-936-1081

Rehabilitation Engineering Research Center on Wheelchair Transportation Safety (RERC WTS) is a partnership between the University of Michigan Transportation Research Institute (UMTRI) and the Universities of Pittsburgh, Louisville and Colorado. [http://www.rercwts.org](http://www.rercwts.org)

A list of commercial products that meet WC19 and WC20 can be found at: [http://www.rercwts.org/RERC_WTS2_KT/RERC_WTS2_19_Chart.html](http://www.rercwts.org/RERC_WTS2_KT/RERC_WTS2_19_Chart.html).


University of Michigan Transportation Research Institute
[www.umtri.umich.edu](http://www.umtri.umich.edu)

University of Pittsburgh
[www.reercwts.pitt.edu](http://www.reercwts.pitt.edu)
[www.wheelchairnet.org](http://www.wheelchairnet.org)

Society of Automotive Engineers
[www.sae.org](http://www.sae.org)

RESNA Rehabilitation Engineering and Assistive Technology Society of North America
[www.resna.org](http://www.resna.org)

National Mobility Equipment Dealer’s Association
[www.nmeda.org](http://www.nmeda.org)
SCHOOL BUS RESOURCES

The following resources may be helpful for CPSTs interested in learning more about school bus transportation.


- The National Highway Traffic Safety Administration developed a one-day training that provides an overview on using child restraints on school buses. Although aimed at school transportation professionals, it can also be a useful training for CPSTs. Upcoming school bus trainings are listed at [www.saferidenews.com](http://www.saferidenews.com).

- *School Bus Fleet Magazine* is a magazine dedicated to school bus transportation issues. For information, visit [www.schoolbusfleet.com](http://www.schoolbusfleet.com).

School Bus Restraints

1. **The BESI Restraining Harness**
   The BESI Restraining Harness by BESI is designed for occupants weighing up to 164 pounds who have behavioral conditions or require trunk support. It is available in waist sizes from 22-44 inches. Unlike the E-Z-ON Vest, the BESI Restraining Harness is only for school bus use. A cam wrap and a lap belt are required for installation. [www.besi-inc.com](http://www.besi-inc.com)

2. **Proteck II and III**
   The BESI Protek II by BESI is designed for occupants weighing 20 to 65 pounds and up to 47 inches. The Protek III is designed for occupants weighing 20 to 90 pounds and up to 51 inches. It Proteck II and III fit all high-and low-back school bus seats and do not require the use of a lap belt or seat belt-ready seat. A harness system with six-point adjustability is used to support the occupant. This Proteks also have padded head and lumbar areas. [www.besi-inc.com](http://www.besi-inc.com)

3. **Cam Harness**
   The Cam Harness by E-Z-ON is designed for children 30 to 80 pounds for use on lap belt-equipped school buses only. The Cam Harness features pull adjusters and no fleece. [www.ezonpro.com](http://www.ezonpro.com)
4. **The E-Z-ON Vest**
The E-Z-ON Vest by E-Z-ON Products is designed for use by occupants two years and older and between 20 and 168 pounds. It comes in standard or adjustable models and with different closure systems, including a back zipper closure and front push-button closure. It is usually attached to the bus seat by means of a cam wrap, which attaches to the shoulder portion of the vest and two metal d-rings at the hip. www.ezonpro.com

5. **The Q-Vest**
The Q-Vest from Q'Straint is designed for occupant protection on school buses. It is available in two sizes with the smaller size accommodating children weighing 20 to 60 pounds and the larger size accommodating children 60 to 90 pounds. It has a three-point connection with push-button release instead of hooks, cams or zippers. A seat belt is not used with the Q-Vest. www.qstraint.com

6. **STAR**
STAR (Student Transportation Add-On Restraint) by IMMI is designed for school bus occupants 25 to 65 pounds and 47 inches or less. The STAR Plus is available for occupants who weigh 25 to 90 pounds and up to 47 inches. The adjustable five-point harness restraint attaches to the school bus seat by means of a cam wrap strap system. An optional chest strap is available to provide positioning support for children with poor trunk control. www.safeguardseat.com

**AMBULANCE TRANSPORTATION RESOURCES**

**NHTSA’S Working Group Recommendations**

Going beyond best practice recommendations for non-critical pediatric patients, NHTSA’s Working Group released a document in September 2012 outlining how best to transport both non-critical and critical pediatric patients in ground ambulances. Uniformity and consistency in protocols across the nation are severely limited, which in large part spurred the initiation of this project.

Beginning with “ideal” situations, hierarchical transportation solutions are provided in order of most desirable to least desirable, based on the child’s medical condition and availability of resources. These might include the number of children involved in the situation, their respective medical condition, types of child restraints available and set-up of the rear passenger compartment of the ambulance.
For more information on the recommendations established by the Working Group, please visit www.nhtsa.gov/staticfiles/nti/pdf/811677.pdf.

Training Curriculum for EMS Personnel

Based on the findings of the previously discussed research conducted by Bull, et al, in conjunction with UMTRI, the Automotive Safety Program offers a four-hour training curriculum on best practice recommendations for transporting non-critical pediatric patients in ground ambulances.

Targeted to EMS personnel who may or may not be certified child passenger safety technicians, the course covers basic crash dynamics, along with car seat and child passenger safety basics. In addition, both conventional child restraints and ambulance-specific restraints are covered, which includes hands-on exercises in the classroom.

In order to receive an application for instructorship or to learn more about transporting non-critical pediatric patients, please contact the National Center at 1-800-755-0912 or e-mail ajmcgove@iu.edu.

Ambulance Restraints Cot-mounted

**Pedi-Mate by Ferno**
- For infants and toddlers 10 to 40 pounds
- 3 straps attach to cot
- Five-point harness system
- Made of lightweight vinyl; rolls up for storage
- Call manufacturer for crash testing information on ambulance cot: www.fernoems.com; 1-877-733-0911

**EP-96 The Rescu-Air: Air Filled Child Transport Seat by Emergency Medical Products:**
- For children 20 to 40 pounds and less than 40" tall
- Cot-anchoring system consists of 3 color-coded straps
- Weighs approximately 12 pounds
- Five-point restraint system with pelvic adjustment
- Contact manufacturer for crash test data: www.epandr.com; 1-800-322-5725

**Safe Guard Transport by IMMI**
- For children over 1 year of age, from 22 to 100 pounds
- Color-coded installation system for ease of use
• Weighs 22 pounds, folded dimensions are 29.5" h x 17"w x 6.5"d for ease of storage in the ambulance
• Five-point harness system that features one-handed adjustment for harness height and tightness
• Not for use with potential spinal cord injuries
• Crash-test footage available on website http://www.safeguardseat.com/ems/index.htm
• 1-800-985-3974

Integrated Restraints

EVS 1880 Hi-Bac Child Safety Seat by E.V.S. Ltd.
• Designed for transportation of children who are not patients but must be transported in the ambulance with the patient
• Accommodates children 1 year and older and 20 to 50 pounds
• Five-point harness, folds down from seat back
• Contact manufacturer for crash test information, www.evsltd.com, 1-800-364-3218

Guardian Safety Seat by Serenity Safety Products
• 3-in-1 seat contains attendant seat with four-point restraint, infant-only seat with five-point harness and older child seat with five-point harness
• Integrated infant-only seat accommodates infants 5 to 22 pounds, faces the rear of the ambulance
• Integrated older child restraint accommodates children 23 to 85 pounds
• Contact manufacturer for crush-test information, www.serenitysafetyproducts.com, 1-800-536-0676.