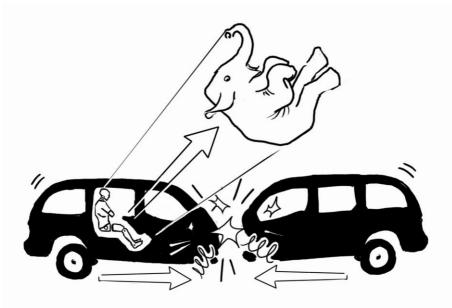
SAFE RIDE

Traffic safety for children with disabilities



A joint project between

The National Association for Disabled Children and Youths, RBU

The Swedish Road Administration

The Swedish Road and Transport Research Institute, vti

The Swedish Institute of Assistive Technology

RBU och VTI © 2010 Authors: Professor Torbjörn Falkmer and Karin Paulsson, PhD Lay out Ivan Li Graphic consultant: Louise Viotti Illustrations: Markus Thyberg © Translation: Norah M. Flodin

SAFE RIDE

How to fasten the seatbelt?

Which regulations are there?

How to adjust a child-seat?

What kind of demands can I make?

who is responsible?

by Torbjörn Falkmer and Karin Paulsson

"Those who travel will find something to tell"

Why do we need a handbook about traffic safety for children with disabilities?

Shouldn't it be a natural right for children with disabilities to travel in the same safe and comfortable manner as anyone else? Unfortunately, this is not the case in reality.

We, the authors of this book, know that parents of children and adolescences with disabilities for many years have expressed concern about the lack of safety in the way their children were transported with the Special Transportation System [STS]. We have often received questions like; "Which safety regulations and laws control school transportation and STS?", "What demands can be made towards the local municipality in charge of arranging STS?", "Who is responsible for our child's traffic safety?", "How do you adjust the family car to make it as safe as possible?"

Many parents have sought after an easy and comprehensible publication that describes all the medical, technical, ergonomic, legal, structural and psychological aspects that lies within the complex issue of traffic safety for children with disabilities.

This is why we made this handbook. Our purpose is to present a comprehensible image of traffic safety issues from the perspective of the children and the parents.

Even if the handbook is written primarily for parents, we know that many others who come into contact with these children in their day-to-day work are also seeking increased knowledge of the matter. These people include local government officials and politicians, STS and school transportation drivers, employees at the Technical Aids Centres and Paediatric Clinics, insurance companies as well as the assistants and teachers of the child.

In this handbook we will address general aspects of traffic safety for children as well as more specific aspects of traffic safety for children with disabilities.

"Safe Ride" is the result of a joint project between The Swedish Road and Transport Research Institute [vti], The National Association for Disabled Children and Youths [RBU], The Swedish Road Administration [SRA] and The Swedish Institute of Assistive Technology [HI].

We have also cooperated with The Swedish Association of the Visually Impaired (SRF), The Swedish Association of Hard of Hearing People (HRF), and The Swedish National Association for Deaf, Hearing-Impaired and Language-Impaired children [DHB], The National Society of Autism in Sweden [RFA] and The Swedish National Association for Persons with Intellectual Disability [FUB].

The main authors of this book are Karin Paulsson and Torbjörn Falkmer. Many other persons have contributed with their special skills and knowledge in many different areas;

- Jan Petzäll, PhD in Technology, SRA
- Nils Petter Gregersen, Professor, VTI
- Jan Wenäll, Research engineer, VTI
- Eva Sundsten, Former head of Disability Department of the County Council of Halland
- Pia Winnberg-Lindqvist, Physiotherapist, Haninnova
- Katarina Allbrink Oscarson, Physiotherapist, Astrid Lindgren's Children Hospital
- · Lars Wärnberg, Head of Department, HI
- Gunilla Hammarskiöld, Physiotherapist, HI
- Anna Anund, Researcher, VTI
- Gunilla Sörensen, Researcher, VTI

Thank You!

We who have worked in the project "Safe Ride" would like to sincerely thank all of the parents and other persons that have contributed in different ways to this handbook!

Special thanks to Swedish Inheritance Fund and Skyltfonden who funded this project.

Torbjörn Falkmer, PhD in Medicine Resercher, vti Karin Paulsson, PhD Research Director, RBU

Table of Contents

Why are children more fragile than adults?	10
Different body proportions	11
Not fully developed skeleton	12
How is the body protected in a collision?	13
How can children have a safe ride?	14
Preventive measures minimises the risks	15
Which seat is the safest?	15
Riding forwards or backwards?	15
Bware of the air-bag!	16
Safety belt is the most important thing	16
Postural comfort belts are not safety belts!	18
Exemptions from safety belt necessity	18
Great forces in movement	18
Child safety restraints offer protection	19
What if the child safety restraing does not fit the child?	21
How can children with disabilities have a safe ride?	21
Sometimes you need a little extra protection	23
Children with Cerebral Palsy	23
Children with Spina Bifida or other spinal cord injuries	24
Children with Osteogenesis Imperfecta (Skeletal fragility)	26
Children with muscular diseases	27
Children with rheumatism	28
Children with impaired hearing	28
Children with impaired vision	29
Children with autism and other neuronsychological disabilities	31

Can children have a safe ride in the wheelchair?	33
Sometimes you have to compromise	34
Some important guidelines about travelling with a wheelchair	35
A fastened wheelchair + a safely belted child = a safe ride	38
Getting in and out of the car – hazardous situation	39
Who is responsible if something happens?	40
Make demands!	42
How do you choose the car best suited for you?	44
Fincancial car support	45
Choose the right car and the right company	45
Think before you buy	46
Children have a right to special parking permits	49
What is stated in the law about children's rihgt to an independer	nt life and
traffic safety?	50
Children's right to development and an active life	51
Children's right to travel and accessible environments	52
Children's right to traffic safety	53
Don't forget the psychological aspects	58
A good trip is a safe trip	59
Where to direct you further questions	62
Addresses	63
Further reading	64

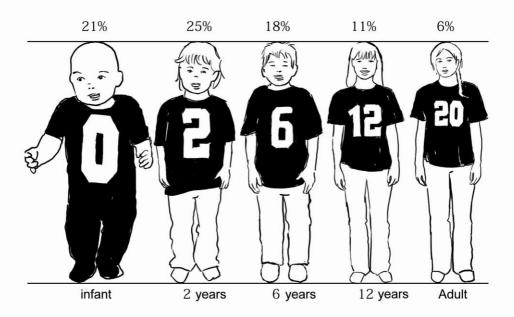
Why are children more fragile than adults?



Different body proportions

There are several reasons why children are more fragile than adults from a traffic safety perspective. One of the reasons is that the anatomy of children, in some aspects, is different from that of adults.

During childhood, the ratio between length and weight changes as the body of the child develops. It is especially the proportions between the head and the rest of the body that is important from a traffic safety point of view. The head of a newborn child makes up a fifth of the child's total body weight and a fourth of the total body length. In adults, the weight of the head only constitutes a 16th of the total body weight and a seventh of the total body length. The illustration shows the head's weight in relations to the total body weight at different ages.



The fact that the head of a child is proportionally larger and heavier means that the child's centre of gravity will be located higher up on the body, in comparison to the centre of gravity of an adult. This means that a child, during for instance a collision or a sudden stop, is very vulnerable to head injuries. Neck and head trauma is a lot more common in children than in adults, whereas injuries to the rest of the body are a lot more common in adults.

Not fully developed skeleton

The skeleton bones in the upper rib cage are not fully developed in children and because of this it has a lesser ability to absorb the impact of outer trauma. This means that, for a child, there is a larger risk that the heart, the lungs and other internal organs are injured in a collision. The spinal vertebrates are also not yet fully developed in children. This means that outer trauma puts a lot of stress on the discs that join the spinal vertebrates. The risk of spinal cord injuries in a collision that throws the body forwards is thus very high for children.

In younger children, the pelvis is not fully developed. With children under the age of 10, the upper frontal part of the pelvic bone lacks a special bone structure – spina iliaca anterior superior. This bone structure is crucial if a safety belt of the hip belt kind is to work properly.

In children, the abdomen is not as well covered and protected by the rib cage and the pelvis as it is in adults. This means that the risks of abdomen injuries are increased for children.

How is the body protected in a collision?

During a collision, three "speed decreasing factors" help to absorb the outer trauma and thus decrease the damages to those seated within the car:

- The car has its own deformation zones and stabilisation functions around the compartment that, in a collision, forms a sort of protective cage.
- Safety belts, rear-facing child safety restraints and, sometimes, air-bags slow down and capture the body's movement forward.
- The construction of the human body, through the skeleton and our internal organs, forms its own deformation zone.

A little more concretely it can be described like this:

- The first "speed deceasing factor" is the fact that the car's body structure helps absorb part of the force in a collision. The better the car is constructed, the lesser the personal injuries. In technical terms; "the deformation zones of the car contribute to an elongation of the vehicles retardation span, thus decreasing the momentum force".
- The second "speed decreasing factor" is how the movement of the body is slowed down and captured by safety belts, child safety restraints and air-bags (if installed). The better the safety equipment, the lesser the personal injuries.
- The third "speed decreasing factor" is inside our own bodies. Fragile organs are imbedded in soft tissue, muscles, fat and skin to cover and protect them. The skeleton of the head, the rib cage and the pelvis form a kind of protective cage with the same function as the deformation zones of the car. Thus, part of the force of the impact is absorbed by the skeleton

In conclusion, a good car construction and good safety equipment are essential to decrease the risk of injuries. Since the body of a child, and especially a child with disabilities, is so much more fragile than the body of an adult, the technical safety construction of the car becomes that much more important. In the next chapter we will describe more thoroughly how you can protect children in the car.

How can children have a safe ride?

-General rules and principles



Preventive measures minimises the risks

Travelling is an important part in people's lives. Everything from the everyday trips to school and the work place to fun trips ranging from spare time activities to exiting holidays require transportation. To travel is always associated with risks, but there is a lot that can be done to make travelling as safe as possible. In this chapter we will describe general rules and guidelines concerning traffic safety for children.

Which seat is the safest?

Is there a specific seat in the car that is the safest? Statistically, this is the seat in the middle of the back seat. This is because this seat is in the middle of the car and thus furthest away from all the impact surfaces in a collision. But, as we have already stated in the previous chapter, there are many other factor that play a far greater role in creating a safe seat for the child.

Riding forwards or backwards – or sideways?

As a rule, rear facing child safety restraints should be used whenever it is practically possible. The use of rear facing child safety restraint is the absolutely safest way of transporting a child that we know of to date. It decreases the risk of injuries with up to 90 percent. The use of front facing child safety restraints reduces the risk of injuries with 60 percent. However, this requires that the child safety restraint is installed properly in accordance with the manual it was accompanied by.



Some rear facing child safety restraints are approved to be used as front facing child safety restraints as well, but this requires that they are reinstalled and altered in accordance with the manual that accompanied the child safety restraint.

Please note: Riding sideways is absolutely inappropriate! The human body is not designed to absorb collisions from the side. This is especially true for children.

Beware of the air-bag!

Many parents who drive want to have their child next to them, to have contact with them and keep an eye on them. A rear facing child or baby safety restraint may *never* be installed and used in a seat that has an air-bag. If there is an air bag, it has to be de-connected by an authorised auto-shop or using the car key. After doing this, the car has to be equipped with a sticker or another display of information that clearly states that the air-bag no longer is in function (The Swedish Road Administration law, VVFS 1995:573)

Safety belt is the most important thing

The Swedish Traffic Law (SFS 1998:1276 chapter 4, paragraph 10) controls, amongst many other things, the usage of safety belts and the special safety equipment required for children in cars. According to this regulation, any person travelling in a car is required to use a safety belt, if a seat with one is available. In a bus, the regulations are less strict. There, you are required to use a safety belt only if seated in a seat equipped with a safety belt.

On the usage of special safety equipment for children, the law states that children, up to the age of six shall use a child safety restraint, a booster seat or other kind of special safety equipment for children instead of, or together with, the safety belt. If the child is travelling in a temporary vehicle that lacks special safety equipment, the child shall use the safety belt, if possible.

The law further states that the driver shall make sure that passenger under the age of 15 use the safety belt or other special safety equipment in accordance with the regulations.

Concerning school transportations, there are special regulations that differ from those concerning private cars, see page 53

In the Swedish Road Administration Law concerning the usage of safety belts, VVFS 1993:5, it is stated that:

• The safety belt should lay flat against the child's body and should be properly tightened. As a rule, you should be able to fit your thumb between the child's body and the safety belt, neither more nor less.

 A diagonal belt should be extended over the shoulder of one side of the child, across the frontal torso and reach the pelvis of the other side.

• The upper attachment of the three-point safety belt should be located at least four centimetres above and behind the shoulder of the passenger. If it is attached lower than at shoulder height it will, during a collision, form a downwards-facing force which will cause grave injuries to the spine.

How can you make the safety belt safer?

Safety belts are designed and tested for their intended

use, as it is stated in the manual accompanying the car.

Check to make sure that the belt is not twisted, turned or inserted into other than the intended parts of the vehicle. Also, avoid adding details to the safety belt, such as a comfort cushion. If the belt is chafing against the neck of the child, it is better to dress the child in a turtleneck or a scarf than to add protective covering directly to the safety belt

A safety belt that has been in a collision must immediately be replaced. The elasticity of the belt is lost after a collision.

Please note: The child should not have the safety belt under the arm, over the stomach or wear a groin belt between the legs. The armpit, the abdomen and the groin contains large unprotected blood vessels and fragile organs that can be severely injured in a collision.

Pstural comfort belts are not safety belts!

Some children with disabilities use postural comfort belts to support them and keep them in a comfortable position while they are seated in their wheel-chair. These belts may look like safety belts and are often referred to as safety vests.

However, postural comfort belts are not designed to absorb the extreme impact force that a safety belt can handle. In a collision, the postural comfort belt is designed to give way to the force of the collision, and thus letting the child be captured by the safety belt, designed for this purpose.

Postural

comfort

belts are not safety

Exemptions from safety belt necessity

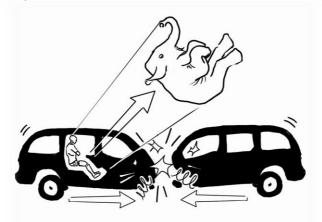
In extremely rare cases, the use of safety belts might be less appropriate. In those cases, there is a legal opportunity to let the child be exempted from the use of safety belts (VVF 2001:183). This requires a written assessment from a doctor, describing the medical reasons for why the child should not wear a safety belt or other special safety equipment. This written assessment has to have been issued before the child starts to travel without a safety belt.

Great forces in movement

In a frontal collision between two cars, the sheer force of the impact is extremely large. Even at a relatively low velocity (around 30 km/h) the safety belt has to be able to hold a passenger who, at the moment of impact, will weigh several times his or her actual body weight, when thrown forwards towards the safety belt. The picture on the next page will show you that a small child, at the moment of a collision, will have the body weight of a small elephant.

To decrease the effect of the impact on the child's body during a collision, you aim towards spreading the impact over as large a surface of the child's body as possible, to prevent each separate fragile point to take all of the pressure. Properly used, a three-point safety belt will do this. The pressure is

divided over the entire body much more efficiently than with the use of only a hip-belt or other such constructions. The three-point safety belt is also designed to let the body's skeleton absorb most of the impact, since the skeleton is the part of the body best designed for doing this. A rear facing child seat also contributes towards spreading the impact over a larger surface. In this case, it is the hard back of the chair that absorbs most of the impact.



Child safety restraints offer protection

Children of different ages need different types of child safety restraints or other safety equipment to minimise the risk of injuries in a collision.

Infant seat (from 0-9 months)

An infant seat should always be installed facing rear, regardless of it being placed in the front or the back seat. The infant seat will be held into place by the safety belt, while the baby is held securely by the belts of the infant seat itself. Infant seats should not be installed so that they are touching or resting against the dashboard. When installing an infant seat in the front seat, the appropriate safety distance to the dashboard is 20 cm or more. If the infant seat is placed in the back seat, the seat in front of the baby should be empty or occupied only by another child. When installing an infant seat in the back seat, the appropriate safety distance to the next seat is 20 cm or more.

Cots and crib-covering safety nets

If an infant, for medical reasons, need to remain lying down during a car trip, you may use a baby cod or the crib from the baby stroller together with the crib-covering safety net. These should always be placed in the back seat of the car. The head of the child should always be aimed towards the centre of the car, for utmost protection.

Please note: Never install the crib from the baby stroller so that the head or feat of the infant is facing forwards. Doing this will severely increase the risk of damages to the child and is also in clear violation of the installation instructions.

Child safety restraints (from 9 months to 4 years)

Once the infant has become a toddler and has outgrown its infant seat it is time to switch to a rear facing child safety restraint. This should be installed in the front seat, facing rear, and be resting against the dash board. It should absolutely not be resting against the windscreen, since these can break due to the long-term pressure. If the child safety restraint is placed in the back seat, it should rest against the back of the front seat. Some child safety restraint, however, are only approved to be used in the front seat, so before installing one in the back seat, make sure that it is approved for this type of usage as well.

Booster seats (from 4-5 years to 10-12 years)

When the child as out-grown its child safety restraint it is time to switch to a booster seat. This is a front facing seat, since the child has now out-grown the rear facing seats. A booster seat will add some height to the child, so that the safety belt can be buckled at the right position and angle. As we have mentioned earlier, the safety belt should cross the shoulder, slightly towards the neck, continue over the rib cage and then cross the pelvis.

Time to change the seat?

It is important to continuously change the child safety restraint as the child out-grows it. When the top of the child's head is at level with the top of the child safety restraint, it is time to go shopping for a new one. When the eyes

and the top of the ears of the child is at level with the top of the child safety restraint, the seat is no longer safe for the child.

What if the child safety restraint does not fit the child?

Some children with disabilities are unable to use the child safety restraint available on the market. This mostly applies to children with different kinds of loco motor disabilities. The Swedish Institute of Assistive Technology together with the local paediatric clinic can help with the special adaptations that need to be made to the child safety restraint or other safety devices in the car.

In the regulations of the National Board of Health and Welfare (SOSFS 2001:12) it is stated that the person recommending a medical-technical product is responsible for the product being suitable, as well as for the proper usage of it. You can also find more information in the Swedish Institute of Assistive Technology's publication on special equipment for persons with disabilities ("Specialanpassade medicintekniska produkter- Hjälpmedel för personer med funktionsnedsättning").

Who is responsible

It is important to know who has the responsibility for a specially equipped product in case of an accident. The manufacturer is responsible for the product only when used in its original form. In the Swedish law of CE-branding (SFS 1992:1534) it is stated that if a product is altered or adjusted, the responsibility is transferred to whoever made the adjustment/alteration (for more information, see the chapter: Who is responsible if something happens? on page 40).

In the regulations of the National Board of Health and Welfare (SOSFS 2001:12) it is emphasised that it is the one that has approved of and ordered the alteration that accepts the responsibility for the product when it has been altered for special needs. This is because otherwise, some Technical Aid Centres refuse to make certain adaptations or alterations even though it would increase the traffic safety of the child. However, most of the Technical Aid Centres in the country have a well established routine for how issues like these can easily be solved.

How can children with disabilities have a safe ride?

-suggestions on adaptations



Sometimes you need a little extra protection

When it comes to traffic safety, children with disabilities have special needs. Since children with disabilities have very different special needs, the need for special safety equipment is very different and individual. It is impossible to give any general advice that applies to all children with disabilities at all ages. However, we would like to stress some aspects of traffic safety that are important to children with locomotor disabilities, impaired vision or hearing, intellectual disabilities and neuro-psychiatric diagnoses. Regarding children with medical diagnoses it is almost impossible to give any general advice, since this group differ immensely from person to person when it comes to diagnosis and treatments. Our advice is to always contact the doctor responsible for the treatment of the child.

Children with Cerebral Palsy

Of children with locomotor disabilities, around 40 percent have Cerebral Palsy. This is a group of children that is very diverse, some children suffer



only minor disabilities whereas others can have severe locomotor disabilities, often combined with other disabilities such as intellectual disabilities. impaired hearing or vision, difficulties with speech and seizures. From a traffic safety perspective it is mainly the child's abnormal muscular tensions that will cause problems. Too high or too low muscular tension, sometimes combined with involuntary movements limits the acceptable seating options. The child simply will not remain in the position that it has been seated in. Some will slide down and find that they are travelling seated on their lower backs with the safety belt below their chin. Children with involuntary movements can make jolting movements with their arms and leg, and might hurt themselves or others. Decreased control of the head and abdomen. impaired hip movement and seizures are also factors that affect the child's seating options within the vehicle. Some children with Cerebral Palsy find it discomforting to shift position, and this, of course, becomes exacerbated in a moving vehicle. If the child has a perception disorder, all the sound and changes in light and scenery associated with travelling can be a source of great discomfort.

Suggested adaptations

Children with Cerebral Palsy often need a specially equipped child safety restraint that embraces the child and thus helps the child to control its body and decrease the risk of involuntary movements. Many also require head, neck and foot rests in order to sit up steadily yet comfortably. Since it is important that the child is sitting steadily in the child safety restraint, a specially designed safety vest might sometimes be a good option. A vest that encloses the abdomen stabilises the body and helps distribute the pressure in case of a collision or a sudden stop. For some children it is enough to use a postural comfort belt with extra padding. In both cases it is important to remember that the safety vest as well as the postural comfort belt has to be used together with a safety belt.

Some children have specially designed seats in their wheel-chairs. If properly designed and adapted, this seat can be used as a child safety restraint. This will provide the child with a stabile and ergonomic place to sit, but these seats are often heavy and bulky and can prove quite difficult to get in and out

of the car

As we have earlier mentioned, it is highly inappropriate to use a groin belt or a seat with any kind of "groin cushion" as these might severely hurt the child's groin and genitals during a collision or a sudden stop.

Children with Spina Bifida or other spinal cord injuries

Of children with loco motor disabilities, around 10 percent have Spina Bifida and an additional couple of percents have other spinal injuries, often as a result of an accident. Children with Spina Bifida have lesser or greater disabilities depending on the location and extent of the hernia and whether or not the hernia have resulted in additional complications, such as hydrocephalus. Children with Spina Bifida often have decreased stability of the abdomen as well as a decreased or unsure perception of their own bodies. Many are also unusually heavy for their age due to lack of mobility and impaired metabolism.

These children often have decreased circulation and sensation in their legs and difficulties with urinal bladder control due to paralysis from the waist down. The decreased sensation of the legs and lower body means that the children wouldn't't notice if they sustain injuries to this part of the body while being lifted in and out of the car. The person doing the lifting must pay extra attention so that the child does not sustain injuries without someone noticing it.

Children with Spina Bifida sometimes have abnormalities in their hip bones, affecting their posture. This can lead to some difficulties when it comes to seating the children in a child safety restraint. Furthermore, these children might have to go through several orthopaedic surgeries resulting in them temporarily having their legs or abdomens in a cask. This too can cause complications when trying to seat the child comfortably within the child safety restraint.

Suggested adaptations

The child safety restraint should be supporting and flexible to give the child a secure seat, with or without a body cask. The child safety restraint should not have too much of a seating impression, since children with abnormalities to their legs and hips often have a larger or wider hip-part. The child safety restraint should be wider than normal and as flat as possible to help the child sit comfortably.

The child should preferably be seated in a rear facing child safety restraint, since this is the safest position for a child with decreased head and abdomen stability. For children with enlarged heads, due to hydrocephalus, this is especially important. If the child has scoliosis (a curvature to the spine) a rear facing child safety restraint also helps protect the spine during a collision or a sudden stop. Since children with spinal injuries have decreased head and abdomen stability, it is important that they have head and neck rests, support for the abdomen and a good postural comfort belt, preferably a four-point belt that best help absorb the pressure of an impact.

Air-conditioning, climate control and car seat heating are very valuable to children with decreased sensation and circulation below the waist. With this equipment, the child as well as the child safety restraint can keep a comfortable temperature all year around. Children with Spina Bifida are especially vulnerable to urinary tract infections due to their injuries. To be seated on a freezing toilet seat or a child safety restraint will increase the risk of such infections.

Children with Osteogenesis Imperfecta (Skeletal fragility)

Children with Osteogenesis Imperfecta, OI, are also a very diverse group of individuals where some have lesser and some more severe forms of the diagnosis. However, everyone with the diagnosis OI has an extremely fragile skeleton and can very easily sustain fractures. They constantly have to be careful not to break their arms, legs, ribs and so on.



Children with OI are often very small for their age and their heads can be proportionally very large to their rather small bodies. They can also, for longer period of time, have parts of their bodies in a cask, due to sustained fractures or planned orthopaedic surgeries. Because of their extremely delicate skeleton, these children are very vulnerable form a traffic safety point of view.

Suggested adaptations

Children with OI should, to the extent it is possible, travel lying down or with only a gentle back support, since this relieves the stress on the skeleton, especially the spine. When the child starts sitting up in the car, they should use a good child safety restraint that is flexible and offer the child a stable seat with or without a body cask. The child safety restraint should have a head and neck rest, support for the abdomen and wide pressure absorbing four-point postural comfort belts preferably with extra padding. It should also be extra wide around the hip-part, since children with OI often have a curvature to the thigh bones and abnormalities to their hips and thus they need extra space to sit comfortably.

Because of abnormalities to their hips and legs, children with OI are best seated on a flat surface. The child safety restraint should not have too much of a seating impression, but should still have a good pressure absorbing ability. It is easy to see why a rear facing child safety restraint is especially suitable for children with OI. Because they often are so petite and small in stature, they can also use these seats longer than their peers, which is a great advantage from a traffic safety point of view.

When driving a child with OI, it is important to drive smoothly and gently. Small, but repeated bumps can cause severe compression of the spinal disks and lead to life-long back problems. The vehicle also needs to have good suspension to ensure a smooth drive. The driver needs to drive as though he/she had a delicate baggage marked "Fragile" in the car.

The use of climate control in winter is important as it seems children with OI are more prone to sustain fractures when they are cold. In summer, air-conditioning will help the child to be comfortable, as children with OI often have a higher normal body temperature due to increased metabolism. The

fact that children with OI are petite also means that their total body area is smaller and they cannot as easily dispose of excessive heat through sweats as other children.

Children with muscular diseases

Of children with locomotor disabilities, around 6-7 percent has some type of muscular disease. Also in this group you will find that the disabilities differ greatly, some children have very small difficulties whereas others have quite severe disabilities. The weakened muscles make it difficult for the child to keep its balance, both when moving and sitting still.

Suggested adaptations

Younger children with muscular diseases are often seated quite well in a normal child safety restraint but they can require an additional neck rest or something to stabilise the abdomen, like a four-point postural comfort belt that helps absorb the pressure of a sharp turn or a sudden stop. A rear facing child safety restraint is especially useful for children that, due to decreased muscular strength, are unable to control the muscles of the abdomen or use their arms to protect themselves in a collision.

Children with muscular diseases need a child safety restraint with an exceptionally good fit, in order for the child to be able to sit steadily and feel secure. It is also important that the safety belts and postural comfort belts are securely fastened in their right positions and securely tightened.

Children with rheumatism

Children with idiopathic arthritis, child rheumatism and other rheumatic diseases suffer from pain in their joints, either permanently or during certain phases when the disease is periodically worsened. The neck pain and pain in different joints of the body can be severe. The pain can worsen due to incautious and involuntary movements, such as careless lifting or driving.

During a long car ride, the child needs frequent breaks to stretch and thus relieve the pain and pressure to the joints.

Suggested adaptations

These children can often use regular child safety restraint and safety belts, but caution must be taken to ensure that the safety belt is fastened correctly and does not cause the child any pain. Supportive neck rests or neck pillows are often very comfortable to a child with a rheumatic joint inflammation. This neck rest is specially made by the child's occupational therapist and is usually smaller than the neck rest available on the market.

It is important to have a careful and smooth way of driving when transporting children with rheumatism, as sudden jolting movements can increase the child's pain.

Children with impaired hearing

For children with impaired hearing, the greatest problem when travelling is

often the communication with the driver and other passengers. When using the STS or the school bus, children with impaired hearing often prefer to ride together with other passengers with impaired hearing, as they may experience difficulties communicating with unknown children and adults.



Suggested adaptations

Under some circumstances, it is possible to have special hearing aids installed in the family vehicle (contact your local Centre for the Hearing impaired "Hörcentralen"). Other than that, the advice is to give special thought to the placement of the child safety restraint in the car, so that the child can communicate with other passengers in the car and be able to read the lips of the driver. Sometimes, an extra mirror does the trick.

Children with impaired vision

Children with impaired vision need to be able to recognise where they are as they are getting in and out of the car. If an adult tells the child where he or she is located in relation to the car, the child can often get into the car without further aid. It is important that the car stops at the same place every time the



child is getting in or out of the car at home, at pre-school, at the school or other known locations. Children with impaired vision often use everyday things, such as a fence, a mail-box or a shrubbery as landmarks to tell them where they are. Using these, the child can easily navigate known environments, thus increasing both their security as well as their independence.

Suggested adaptations

Children with impaired vision do not generally require any special traffic safety adaptations. However, some children with impaired vision are easily blinded by sunlight. Curtains, shades or a cap provides good protection.

Since the child cannot see where it is going, it is very valuable if the driver continually tells the child about the route and what is happening. If the child is using STS, it is also important that the driver provides information about which route the car is taking, if someone else is in the car with the child and other details that makes the trip safer and more fun for the child.

Children with autism and other neuropsychological disabilities

Neuropsychological disabilities such as autism and other disabilities of the autism-spectrum are often invisible and therefore not obvious to people who does not know the child. Children with these types of disabilities perceive the world differently. They have difficulties communicating with people they do not recognise and this is made worse by the fact that many people in the child's surroundings do not understand the disabilities of the child.

Some children with autism-spectrum disorders lack a verbal language; some are, on the other hand, very verbal. The difficulty, however, lies within understanding how the language is used and understood. The child will interpret everything that is said very literally and find it difficult to understand an abstract dimension of thoughts. These children rarely understand jokes, irony or puns.

Due to their disability, children with autism-spectrum disorders also often find it difficult to make a mental image of what is going to happen ahead of time. A strategy that is often developed to compensate for this is that they stick to familiar routines and rigidity in their everyday life. Changes of drivers, schedules, vehicle and seating within the vehicle might trigger a very strong reaction from the child. Many of these children are also hypersensitive to certain sounds and changes of lighting as well as being touched and touching things.

Suggested adaptations

When transporting a child with an autism-spectrum disorder the general approach and understanding of the child is much more important than any special equipment in the car. Many children do not like to be restrained by the safety belt and to add to this, they might have a fascination with belts and buckles. It is not unusual that they can get out of safety belts and other safety equipments, which poses a great hazard to their traffic safety. It is thus

important to choose a safety device that does not open too easily.

The drivers of STS and school busses need to have knowledge about the child's disabilities to be able to adjust their language and their approach towards the child. The absolutely most important traffic safety measure that can be taken is to educate the drivers so that they understand the child's behaviour. It is also important to use a limited number of drivers who are responsible for the transportation, thus making the child feel safe.

Car-pooling should, in the extent that it is possible, be avoided since children with autism- spectrum disorders often find it very uncomfortable to be seated next to a unknown person. If the child can, for instance, travel to school at the same time, with the same car or bus seated at the same seat, the trip will be a much more comfortable experience.

Can children have a safe ride in the wheelchair?



Sometimes you have to compromise

Most of the book so far has been about child safety restraints and other safety equipment for smaller children. But children grow. Many older children and teen-agers with disabilities can be seated comfortably in the passenger seat and use the safety belts, but for those with severe disabilities new problems will arise. Small children can be (rather) easy to lift in and out of a car, but to lift an almost fully grown 15 year old into a car can be incredibly heavy and almost impossible to undertake in an acceptable ergonomic fashion. Also, the teen-ager might not wish to be lifted at all or will suffer pain from the lifting.

Older children and teen-agers usually wish to undertake independent travels with STS and STS drivers are usually forbidden from doing heavy lifting. A whish for protection of the teen-ager's integrity and independence, parents with back problems and stressed out STS drivers are all factors that have to be weighed against traditional traffic safety measures. So, how do you solve these issues? Can children have a safe ride in the wheel-chair? Our answer is that this is possible – provided that it is done correctly



Some important guidelines about travelling in a wheelchair

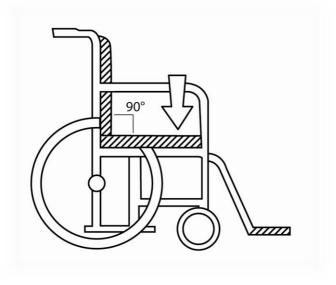
Both in STS cars and the usual minivans that many families purchase it is common that the child remains seated in its wheel-chair during the trip. To make this a safe ride for the child, it is important to know a couple of guidelines that are crucial for the child's safety.

The settings of the wheel-chair during the trip

On many wheel-chairs it is possible to alter the height of the chair, the seating angle as well as the leg and foot rests to generate a comfortable and ergonomic seating position. Unfortunately, the most comfortable seating position is not always the safest one. To ensure maximal traffic safety, keep the following in mind:

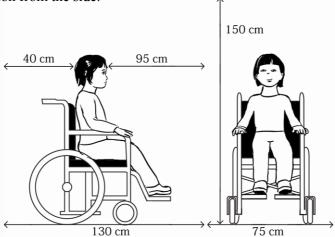
- The seat should be in the lowest possible position.
- The back rest should be locked in an upright position (like on an airplane during takeoff and landing).
- The leg rests should be angled downwards, keeping the feet parallel with the floor

Please note: Sometimes there are medical reasons for why the advice given above is not suitable for the child. Please consult the child's physiotherapist.



Fastening a manual wheel-chair in the car

Passengers in a wheel-chair should be facing front or rear. Riding sideways or in any other position is dangerous and should be avoided at all times. Neither the human body nor the wheel-chair is designed to absorb a collision from the side.



- In front of the head of the passenger riding in a wheel-chair there should be a free space of at least 95 centimetres. Other important safety distances can be seen in the illustration above.
- Strap the wheel-chair in using four straps. Two to be attached at the back of the chair and two to the front. Make sure that the straps are tightened so that the wheel-chair is kept in place.
- Aim the straps diagonally (at about 45 degrees angle) forwards and backwards and, if possible, somewhat to the sides.
- Attach the straps as high up on the wheel-chair as possible (see image on next page).
- Many wheel-chair manufacturers have started using yellow markings on the wheel-chair to indicate where the straps should be attached.
 Sometimes there are even special hooks on the wheel-chair where the straps easily can be attached.
- The anchoring straps may not be crossed or intertwined.
- The breaks of the wheel-chair should be locked during the entire ride.
- The wheel-chair should not be blocking safety exists for other passengers.

Fastening an electrical wheel-chair in the car

When securely strapping in an electrical wheel-chair, most of the same guidelines and advice apply as when strapping in a manual wheel-chair. However, some of the electrical wheel-chairs have special "docking stations", meaning that the chair is anchored to a pre-assembled docking station installed on the floor of the car. This is not as common amongst the smaller electrical wheel-chairs; those should be strapped in just like a manual wheel-chair

Fastenning a special chair or other seating arrangement

Children travelling in special chairs have to be able to use these chairs in combination with the three-point safety belt of the car. The special chair must be safely strapped into the car, using separate safety straps, i.e. not the safety belt, which only holds the child and not the chair.

Please note: A stroller or a baby carriage should not be used to hold the child during transport.

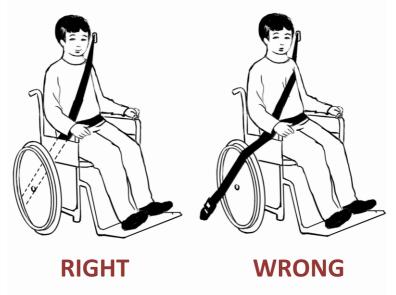


Don't forget to fasten the luggage!

All equipment transported in a car or on a bus need to be fastened. If they are placed loose on the floor or the seats, they can turn into deadly projectiles during a collision. A manual wheel-chair that weighs 15 kilos can turn into a 300-750 kilo heavy pile of metal during the collision, depending on what speed the car crashes in. An electrical wheel-chair that weighs 100 kilos or more (not counting the passenger) can increase its weight up to 2000-5000 kilos in a crash. Even minor equipment can pose a deadly threat. A five kilo breathing apparatus will weigh 100-250 kilos in a crash, if not properly fastened.

A fastened wheelchair + a safely belted child = a safe ride

A three-point safety belt combined with a four-point safety strap attachment
of the wheel-chair to the floor provides good safety in case of a collision.
 Please note: It is important to remember that the safety straps on the wheelchair and the safety belt are two different systems. On holds the wheel-chair
in place whereas the other holds the child seated in the wheel-chair.



 Once again, a postural comfort belt is not a safety belt! They must always be combined with a three-point belt or at least a hip-belt. If a hip-belt is used, it should be resting against the pelvic bone and not the soft part of the waist.

Getting in and out of the car – a hazardous situation

Safety risks do not only occur during the trip. All too often, parents and the drivers of STS and school busses forget that moving a child in a wheel-chair in and out of a car is a risky situation. There are many things you have to pay attention to:

- Always try to park the car on as flat ground as possible before the child gets in and out of the car. If the car floor is not flat, there is a risk that the wheel-chair starts rolling before it has been securely fastened.
- Make sure that the wheels of the wheel-chair have the right tire pressure, in accordance with the instructions of the wheel-chair manufacturer.
- Make sure that the breaks of the wheel-chair are securely fastened and
 adjusted if the child is to be left alone for a couple of seconds on the sidewalk
 or by the road shortly before getting in and out of the car. If the ground is not
 flat, the wheel-chair can start to accelerate and eventually fall over.
- Lifts and ramps for wheel-chairs should have de-railing protection, i.e. upright ledges around the sides of the lift/ramp. The ramp should not have more than a 9 degree angle to still be secure and comfortable.
- Allowing the child to drive the wheel-chair up the ramp by itself makes the procedure a lot smoother. However, remember to keep a watchful eye on the child even once it has proven mature enough for the task. Especially young children are easily distracted and can forget to remain cautious at times.
- If the child cannot drive the electrical wheel-chair by itself the person assisting the child should disconnect the power and manually roll the wheel-chair into the car.
- When the child is using a wheel-chair lift, the break of the wheel-chair should always be securely tightened and an adult assistant should always be riding with the child.

Who is responsible if something happens

Many parents have asked us; "Who is responsible for my child's safety on the road, especially when my child is seated in a wheel-chair during the trip?" This concern mostly applies to travels with STS or school busses, but in reality, the problems are the same when the child is travelling with the family vehicle.



The responsibility of the driver

We have earlier stated that the driver is responsible to make sure that passengers under the age of 15 use the safety belt or other special safety equipment in accordance with the regulations. Accordingly, the driver is responsible not only for the child, but also for wheel-chair and/or the special child safety restraint being securely fastened in the car. In the Swedish Traffic Law (SFS 1998:1276 chapter 3, paragraph 79) it is emphasised that passengers may not be transported in a vehicle in such number or placement that they might pose a danger to their traffic safety. The driver is also responsible for reporting any flaws or lack of equipment that the car might have to his/her employer.

A driver that does not comply with these rules should be reported to the police in case of an accident. In the Traffic Crime Law paragraph 1 it is explained that if someone travelling in a vehicle... in a manner that is directly causal to the accident, lack care or does not obey the general guidelines about safety and carefulness in traffic, will be sentenced for careless driving, which is punishable by a fine.

The responsibility of the entrepreneur

STS and other special transport services are usually run by entrepreneurs who have a contract with the local community or the county council.

Included in their contract are special demands on the safety of the vehicles and their equipment as well as on the drivers and their work descriptions. The Council of Transportation have special regulations (1989:4) concerning, amongst other things, what technical demands that should be made on vehicles within the STS services. The entrepreneurs have a great responsibility for the traffic safety of the vehicles that they operate. Included in this is also the responsibility to educate their drivers about which laws that apply to their situation, how drivers should securely fasten wheel-chairs, how drivers should properly care for customers with disabilities and so on. The entrepreneur should also have established routines for how to report and document incidents and accidents.

According to the Swedish Law of Damages (1972:207), the entrepreneurs also have a financial responsibility, should a road accident occur. In the law, chapter 2 paragraph 1 it is explained that *each who, by intent or negligence, cause damage to a person or an object should reimburse the damage, if not other is stated by the law.* Thus, the law places a great responsibility for damages on the employer, i.e. the entrepreneur.

The responsibility of the wheel-chair manufactures

Most of today's wheel-chairs are not tested and approved (CE-branded) to be used as child safety restraint. The demands that have to be fulfilled in order for the wheel-chair to be approved as a child safety restraint are not always easy to combine with everyday functional demands such as seating comfort, easy driving, flexible steering, low weight, the ability to fold the wheel-chair, and so on.

Thus, the manufactures of wheel-chairs do not accept any responsibility in the event of a collision. Because of this, they do not always mark the spots on the wheel-chair that are most suitable to attach the safety straps to. (You can ask the Technical Aid Centre to help you mark the most appropriate places on the wheel-chair to attach the straps.)

If the driver abides to the principles accounted for in this book most of the usual wheel-chairs on today's market should be able to sustain the impact from a collision without collapsing. However, in case of an accident, the question of damage responsibility is as of yet not fully investigated.

The responsibility of the wheel-chair adaptor

If an accident occurs involving a wheel-chair to which a Technical Aid Centre has made special adaptations, the question of responsibility becomes even more complicated. In this case, the CE-branding is "overruled" by the adaptations and the original manufacturer of the wheel-chair can no longer be held responsible. As we have touched upon earlier, it is best that the parents and the Technical Aid Centre agree amongst themselves as to how the responsibility in case of an accident should be distributed between them. Such an agreement is always best to have in writing.

Standards of their way

The Swedish Road Administration, the Swedish Institute of Assistive Technology and the Swedish Road and Transport Research Institute have for a long time been aware of the difficulties and "grey zones" that exist in this area today. They work both individually and together with researchers from all over the world to improve traffic safety for children and adults with disabilities. A big part of their work is to develop standards for how wheelchairs and safety belts can be made even better from a traffic safety point of view. They also work towards improving standards on how to safely strap in a wheel-chair in a vehicle. These standards can be referred to when agreements are made concerning transportation services (often with a taxi or a bus company). On page ... you will find more information about the standards that are applicable today.

Make demands

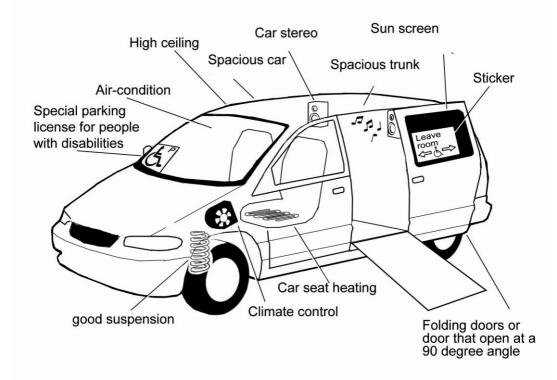
and so on Make sure that demands

municipally negotiate STS purchasing.

like these are also taken into account when the

As a parent you can contribute in many ways. Make demands on those who decide to purchase STS or school transportations from private companies! Demand that prescribed equipment should be properly installed in the vehicles and properly used! Demand that the drivers are given proper education! Every time a driver is not careful with your child's traffic safety, inform his or her superior! In more serious cases of neglect, inform the police. Ask the local municipality or county council's disability council about what quality demands that can be made when the municipally negotiate about the purchase of STS. Quality is not only that the vehicle has the right equipment, but also questions such as how much time can the driver spend on safely placing the child in the car, adjusting all the safety restraints

How do you choose the car best suited for you?



Financial car support

According to the Swedish Law of Public Insurance (1998:890) parents who have children with disabilities can apply for financial support for the purchase and special adaptations of a car from the Social Insurance Office. This support is only given to families whose child has a permanent disability and as a result of this have *significant difficulties with transporting themselves or utilising public transportation*. A prerequisite is that one or both of the parents are living with the child and the car is needed in order for the parent/s to transport themselves together with the child.

The financial car support consists of two parts:

• Basic/purchase support

This financial support for the purchase of a car is as of today (June 2003) 30 000 Swedish Kronor and are means-tested, i.e. depending on the income of the parent/s.

Adaptation support

This financial support should cover the costs for specially equipping the car and/or buying special equipment that the child due to its disability might need in the car. The adaptation support has no upper limit and is not means-tested. Adapting the car can involve installing a ramp or a lift to facilitate getting in and out of the car, as well as adjusting safety belts and safety straps to hold a wheel-chair safely in place during the drive.

Choose the right car and the right company to make the adaptations

Different cars are suitable for different adaptations. Perhaps you can avoid having to make adaptations by choosing a car that already in its original form meets the needs of your child? It is also very important that you choose the right company to make any wanted adaptations. Ask the Technical Aid Centre, your local paediatrician or the Social Insurance Office for

recommendations of good companies that does car adaptations for children with special needs.

Adapting a car takes time

Making the proper adaptations to your car can be a complicated process that takes due time. Think of starting the process as early as possible and ask others for advice *before* you begin to make your adaptations. For more information, ask the Social Insurance Office. The county council Technical Aid Centre and the local paediatrician and/or occupational therapist can also give you advice and suggestions on adaptations and equipment. At the Swedish Road Administrations office for test driving you can have your adaptations evaluated from a formal traffic safety point of view.

Sometimes you need exemptions

Ultimately, the best thing would of course be if the car was as safe after the adaptations were made as it was before, but this is not always possible. Should this be the case, you can apply for an exemption from the usual traffic safety rules from the Swedish Road Office. The company that has made the adaptations for you can provide advice and help with this matter.

Think before you buy

There are many things to think of when a family needs to buy a new car. Try to find a car that will suit the child even as it grows older. Ask the Swedish Road Administration and the Swedish Road and Transport Research Institute for advice. Also, talk to other parents that have children with disabilities for advice and support. Read hand-books or other information on special car adaptations *before* you buy a car. You might find information that is especially essential for your family situation. Suggested reading can be found on page 63-64

It is of course impossible to give any general advice on what car models are more suitable for children with disabilities. However, there are some common aspects that we feel are important to highlight. These are generally more applicable to children with locomotor disabilities and children with multiple disabilities.

High Ceiling

A car with high ceiling will make it easier when parents and others need to lift the child in and out of the car, as well as when safety belts need to be adjusted and other special equipment used. A high ceiling is also important in a mini-van if the child has a wheel-chair with a high back support.

Sliding doors or doors that open at a 90 degree angle

Broad door openings and doors that slide or can be open wide makes it easier to lift the child, or the equipment, in and out of the car.

The placement of the doors

Doors on one or both sides of the minivan? A door or a trunk in the back? Think about the best solutions for different situations. For instance, you should be able to move the child in and out of the car without having to stand in a ditch by to road or pressed against cars parked too closely.

Opening and closing the doors

For some children with disabilities it is important that the handles of the doors are easily manoeuvred. But for a child with ADHD (Attention-Deficit/Hyperactivity Disorder) or Autism on the other hand, it is crucial that the doors cannot be opened by the child while the vehicle is in motion. A central looking system in the car can prevent this from happening.

Stickers that inform

Putting a sticker on the windows of the car is a good and easy way to inform you fellow drivers not to park too closely, and explain to them why they need to leave extra room around your car.

Spacious and flat trunk

It is easier to lift a wheel-chair into a trunk that is spacious and has a flat floor. It is also preferable if you do not need to lift the wheel-chair too high to

get it into the trunk. A loading ramp that slides out from the trunk will facilitate in loading heavy wheel-chairs. The chair can be rolled onto the ramp and then the ramp slides back into the trunk of the car.

Swivel seat

A rotatable seat will facilitate ergonomic lifting of the child in and out of the car.

Good suspension

As we have mentioned earlier, children with disabilities can be extra sensitive to bumpy driving. This means that it is important that the car has good suspension and is suitable for smooth driving. Automatic cruise control might help to make a long trip more comfortable and enjoyable for everyone.

Air condition and climate control

Many children with disabilities have difficulties in regulating their own body temperature and can be especially sensitive to cold and/or heat. Climate control should be used in the winter. When it is cold outside, transport seating cushions and other equipment inside the car and not in the trunk as that will easily make them uncomfortably cold. This is especially important for children with reduced sensation who are susceptible to frost bites and more severe cold related injuries.

Sun screens

Protection from the sun is especially important for children who are unable to regulate their own body temperature and children who might be unable to tell the driver that he/she is too hot or bothered by the sun. A sun screen placed over the window near the child is a good way of preventing this.

Children have a right to special parking permits

The right to special parking licenses for children with disabilities have not always been seen as something obvious in every part of our country. However, the custom is now changing due to an appeal to the Swedish Road Administration.

The matter concerned a 6-year old girl with severe locomotor disability who had been denied a parking permit. The family lawyer stated that:

- The parental responsibility is not extended any more for children with disabilities than for other children of similar age (The Supreme Administrative Courts decision on March 25th 1997, case 12061-95).
- The statutes that govern a case of special parking licenses (TSVFS 1987:11) states the parking exemptions can be granted if a person's disability is manifested so that the person can move only with great difficulty. There are not exceptions regarding children.
- The Swedish Traffic Law chapter 13 paragraph 8 states that a parking license can be issued both to a person with disability who drives the vehicle and a person with disability who is only a passenger. Again, no exceptions are made for children.
- The UN Convention of the Rights of the Child, article 2, states that every child should be guaranteed the human rights and not be discriminated against on the basis of, for instance, a disability.

The appeal was consented to by the Swedish Road Administration, who has final say in these matters and thus a precedent decision has been made

What is stated in the law about children's right to an independent life and traffic safety?



Childrens's right to development and an active life

There are many laws and regulations, national and international, stating that children with disabilities have the same rights as anyone else to an independent life and an active participation in society. Other, more specified, laws and regulations state what kind of technical demands that need to be fulfilled in order to assure children with disabilities the same right to traffic safety as other children.

The Convention of the Rights of the Child

In 1989, the UN General Assembly adopted the Convention of the Rights of the Child (often referred to as the Child Rights Convention or CRC). Sweden, along with almost every other country in the world has chosen to ratify this convention.

The 54 articles of the CRC states that children are human beings with their own rights and the government of each country should to the utmost of their abilities strive towards fulfilling their obligations in accordance with the convention.

The CRC stresses that on every level of decision-making in society, a child perspective should be included. In 1993 a special Children's Ombudsman was appointed by the state, to monitor the rights of children in Sweden. Amongst other things, the Ombudsman makes sure that the Swedish laws and their implementation does not contradict anything in our commitment to the CRC

The CRC states that all children are equal and that no-one may be discriminated (article 2), that the best interest of the child should be a primary consideration (article 3), that all children have the right to life and development (article 6) and that every child has the right to express his or her opinion and have that opinion respected (article12). Although every article in the CRC is applicable to every child, there is a special article concerning children with disabilities. This article stresses the right to an active and full life.

"[...] a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community." Convention of the Rights of the Child, article 23

The Social Services Law

According to the Social Services Law (SFS 1980:620), the municipality has the fundamental and utmost responsibility to assure that anyone within the municipality receives the help and support that they need. The law further states that the municipality has to provide assistance to people with disabilities so that they can partake in society in the same way as anyone else. In order to do this, people with disabilities need to have the same access to transportation as anyone else. The fact that the municipality have the over-all responsibility does not mean that other government authorities lack responsibility.

The Swedish Public Health Service Law

According to the Swedish Public Health Service Law (HSL 1982:763 and 19992/93:159) the municipality and the county council have to provide habilitation, rehabilitation and assistance to people with disabilities living within the municipality/county council areas (paragraphs 3b and 18b). Adaptations and assistance provided should be planned together with the individual in need of it. However, it is not regulated how far this obligation can be taken, and in each individual case, this can be tried by the municipality/ county council.

Children's right to travel and accessible environments

Society's obligation to provide children with disabilities with accessible means of transportation is regulated in, for instance, the UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities, The Swedish Law of STS, The Swedish Public School Law and The Swedish School Bus Regulations.



The UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities

According to the Standard Rules of the UN, people with disabilities should be ensured full participation and equality in society. Each state that has adopted the Standard Rules has a responsibility to ensure that action is taken towards removing all obstacles for full participation for everyone in all spheres of society. Standard Rule number 5 states that:

States that have committed themselves to following the UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities should introduce programmes of action to make the physical environment accessible for persons with disabilities of any kind.

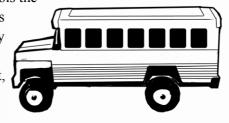
The Standard Rules are not legally binding in the same way that the Child Rights Convention is, but states that have adopted the Standard Rules have a moral and political responsibility to work in accordance with them.

The Swedish Law of STS

In the Swedish Law of the Special Transportation System (SFS1997:736) it is stated that the municipality is responsible for arranging transportation for persons with a non-temporary disability, and for people who have severe difficulties with transporting themselves and utilizing public transportation. The need of the person should always be the primary concern, paragraph 7.

The Public School Law and The School Bus Regulations

The Public School Law (paragraph 7) controls the use of school busses through the School Bus Regulations (paragraph 1). The municipality have the responsibility to arrange school transportation when it is needed to transport, amongst others, children with disabilities to and from school.



Children's right to traffic safety

Children do not only have the rights to accessibility and transportation. They also have the right to a safe ride. This is emphasised in laws, regulations and other national documents.

The Swedish Road Administration'n policy for questions regarding children

The Swedish Road Administration have designed a policy for children that has its base in article 3 of the Child Rights Convention, namely that the best interest of the child should always be the top priority. In their policy document it is stated that The Swedish Road Administration should:

- Through collaboration create the best possible condition for children to freely travel and utilise transportation in a safe manner and in a good environment.
- Remove obstacles for children that might limit their access to the transportation system.
- Make sure that accessibility for children is a factor that is paid attention to when planning new projects, buildings and maintenance.
- Stimulate other actors to acknowledge children's needs of accessibility, safety and a good environment.
- Collaborate with children (or the people representing them).

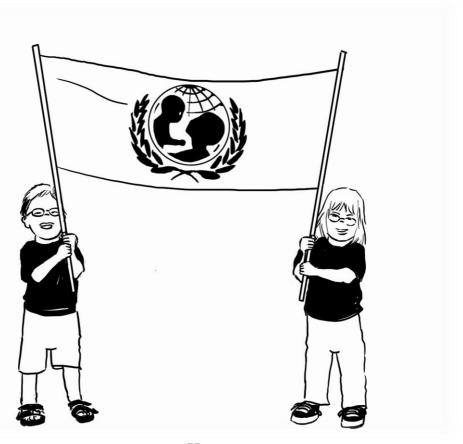
The Swedish "Vision Zero" for Road safety

The main goal of society is that no person should be killed or injured in road accidents. This is the same goal that is stated in the Swedish "vision-zero" for Road Safety that has been adopted by the Swedish Parliament. In the document it is stated that every effort should be taken in order to prevent the risk of people being killed or injured in road accidents. The "Vision-zero" also emphasises that the traffic system must have its base in the needs of those that are must vulnerable and those that are very sensitive to outer trauma. The traffic system should be designed to protect the needs of these groups. One group that is especially sensitive to outer trauma is children, and children with disabilities are probably even more vulnerable.

The Convention of the Rights of the Child

In article 3 of the Child Rights Convention (about how the best interest of the child should always be the primary concern) it is emphasised that society has an obligation to ensure the safety of the child in numerous aspects, for instance when it comes to transportation. In the somewhat intricate article it can be read:

"States Parties shall ensure that the institutions, services and facilities responsible for the care or protection of children shall conform with the standards established by competent authorities, particularly in the areas of safety, health, in the number and suitability of their staff, as well as competent supervision. "Convention of the Rights of the Child, article 3





The Swedish Traffic Law and Mandatory Safety Belt Usage (SFS 1998:1276 chapter 4, paragraph 10)

People travelling in a passenger car should always try to sit on a place equipped with a safety belt and then, of course, use the belt (SFS 1998:1276 chapter 4, paragraph 10). When travelling by bus, the same rules state that if you are seated on a place equipped with a safety belt, the belt should be worn.

If the vehicle has more than eight seats it is considered a bus (The Swedish Vehicle Act, SFS 1972:595), and thus the requirement for safety belt is no longer applicable. But if the bus should happen to have safety belt, the passengers have to use these. As we have earlier mentioned, the driver is responsible for assuring that passengers under the age of 15 use their safety belts (SFS 1998:1276 chapter 4, paragraph 10). This is applicable to any child, regardless of whether they have a disability or not.

In the Swedish Vehicle Act it is also stated that children, up to the age of six shall use a child safety restraint, a booster seat or other kind of special safety equipment for children instead of or together with the safety belt. If the child is travelling in a temporary vehicle that lacks special safety equipment, the child shall use the safety belt when possible.

EU-directive regarding technical demands on busses

The EU Council and the EU Parliament have decided upon safety demands on new busses. These safety demands include improvements on doors and squeeze-protection systems as well as on emergency exits, aisles and stairs within the bus. These rules make a distinction between busses used in the cities and busses adapted for long distance travel. For long distance travel busses, the bus is required to have an extra firm body, which increases the passengers chance of survival, should the bus accidentally tip over. Newly made busses for long distance travel should also have a hip-belt or a three-point safety belt on every seat.

Demands on bus-adaptations for persons with disabilities are more extensive on city busses. People in wheel-chairs should have special places on board the bus. Lifting equipments and ramps should be available for easy access. The bus should also be equipped with devices to hold and support the wheel-chair.

The directive is valid as of January 1st 2004. However, the rules can be applied instantly.

Please note: These demands do not apply to busses already used in traffic.

Don't forget the psychological aspects



A good trip is a safe trip

The technical, medical and ergonomic aspects of traffic safety are important. From the child's perspective, the psychological aspects can be just as important. For many children with disabilities, the trip to day-care or school can completely decide how the rest of the day will turn out. Smooth and nice trip – good day! Delayed, stressful, worrying trip – bad day! For young children and persons with severe mental disabilities the need to feel secure is crucial. When it comes to STS and school busses, this need can be met through a couple of conditions:

Continuity

The familiar and well-known provides security. For many children it can therefore be very important to have the same driver, the same route, the same co-passengers and the same routines for leaving and arriving.

Communication

Personal contact and communication provides security. Security is having a driver that you feel you can trust, someone who listens to what you have to say, in words or in other ways, someone who tells you what is going on during the trip and who else will be riding with you in the car or on the bus. Security is also having a driver that will call the parents and the teacher and let them know if there are any delays.

Competence

Competence provides security. The feeling of security and trust will increase with both the child and the parents if the drivers of STS and school busses are competent and knowledgeable. The drivers need general knowledge about children with disabilities, but also special knowledge about each child's individual wants and needs. Special training in how to approach children with disabilities and their parents should be compulsory.

Calm and smooth driving

A calm driver provides security. As we have mentioned earlier, a smooth and careful drive is especially important for children with disabilities. A reckless drive can not only be very uncomfortable but also medically dangerous for many children. Involuntary movements are reinforced in children with Cerebral Palsy; the pain intensity increases in children already in pain, spasms can be triggered and so on.

Careful time assessment

Being on time as well as taking the extra time provides security. To be able to rely on the STS being on time as well as arriving on time to you wanted destinations provides quality of life. Car-pooling that requires detours and extra time on the road is unfortunate for children with disabilities, who often have decreased physical and psychological stamina. Security is also taking the extra time required for a safe trip, for instance when the child is getting in and out of the car, when the safety equipment is strapped in and so on.





Where to direct further questions

There are many authorities that have a shared responsibility for the traffic safety for children with disabilities. Below, you can find a list of where to direct your different questions.

Your municipality for questions regarding

- Parking permits
- School transportation
- STS
- Purchase of transportation

Your Social Insurance Office for questions regarding

Fincancial car support/ car adaptation support

The Technical Aid Centre and the local Paedicatrician for questions regarding

- Advice on alternative seating possibilities within the car or the STS
- Suggestion sfor technical aids in the car
- Adaptations of the car

The Swedish Road Adminstration for question regarding

- Traffic safety questions regarding cars and safety equipment within the car
- Assessments of the car adaptation possibilities from a trafficsafety point of view
- Laws relating to traffic matters
- Crash-test results

The Swedish Road and Transport Research Institute, vti for questions regarding

- Current research and development, in Sweden and internationally
 The Swedish Institute of Assistive Technology for questions regarding
- Information on available adaptations and aids on the market
- Current research and development, in Sweden and internationally

• Information about current standards

The Children's Ombudsman and save the Children for questions regarding

- Children's rights and the Convention of teh Rights of the Child
 The Ombudsman for People with Disabilities for questions regarding
- Legal rights for children and adults with disabilities
- The UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities
- Accessibility of environments

Addresses

Barnombudsmannen (BO)

Box 7779

103 96 Stockholm Phone: 08–692 29 50 E-mail: bo@bo.se

www.bo.se

Hjälpmedelsinstitutet

Box 510

162 15 Vällingby Phone: 08–620 17 00 E-mail: registrator@hi.se

www.hi.se

Rädda Barnen 107 88 Stockholm Phone: 08–698 90 00 E-mail: info@rb.se

www.rb.se

Vägverket 781 87 Borlänge Phone: 0243–750 00

E-mail: <u>vv@vv.se</u>

www.vv.se

Handikappombudsmannen

Box 22106

104 22 Stockholm Phone: 08–20 17 70 E-mail: info@ho.se

www.ho.se

RBU

Box 21064

100 31 Stockholm Phone: 08-555 931 00 E-mail: info@rike.rbu.se

www.rbu.se

VTI

581 85 Linköping Phone: 013-20 40 00 E-mail: vti@vti.se

www.vti.se

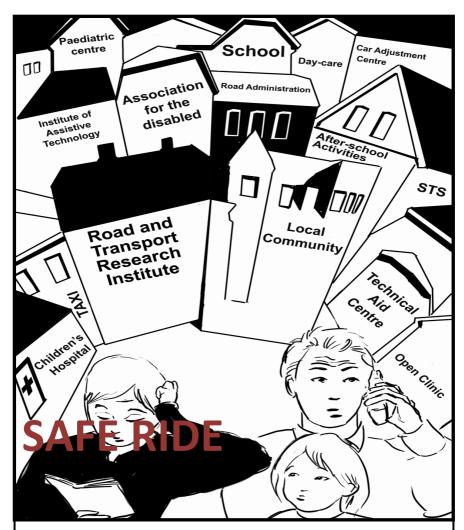
Further reading

Below, you will find examples of the literature that this handbook is based on

- Anund, A. (1998). "Skyddsutrustning för barn i bil i ett användarperspektiv. En studie i tre delar". (VTI Notat 50). Linköping: VTI.
- Anund, A., Sörensen, G., Wretling, P., Törnström, E., Falkmer, T., & Matstoms, Y. (2002). "Trafiksäkerhet vid skolskjutsning Slutrapport" (VTI Rapport 480). Linköping: VTI.
- Autoadapt-BEV. (2002). "Handbok om bilanpassning": Autoadapt-BEV.
- Barnombudsmannen (1999): "Mänskliga rättigheter för barn", Ett informationsmaterial om FN:s konvention om barns rättigheter.
- Björnehult, Å. (2001). "Säker och bekväm resa för rullstolsburna".
 Stockholm: Svenska kommunförbundet.
- Delén, M. (1999). "Trafiksäkerhet för funktionshindrade trafikanter.
 Kartläggning av problembild och definition av åtgärdsområden". Borlänge: Vägverket Publikation. 62
- DELTA-senteret. (2001). "Sikring av funksjonshemmede barn i bil". Oslo: DELTA-senteret.
- Falkmer, T. (1999). "Kartläggning av transportsituationen för barn med funktionshinder". (VTI rapport 448). Linköping: VTI.
- Falkmer, T. (2001). "Transport Mobility for Children and Adolescents with Cerebral Palsy (CP)". Linköping University, Linköping.
- Falkmer, T., Anund, A., Sörensen, G., Falkmer, M., & Gerland, G. (2001). "Kartläggning av transportsituationen för barn med autismspektrumstörning (The transport situation for children with autism spectrum disorders)", (VTI Rapport 469). Linköping: VTI. In Swedish
- Falkmer, T., & Fasth, Å. (1999). "Kartläggning av transportsituationen för barn med funktionshinder. En pilotstudie om vardagsresor för barn med omfattande rörelsehinder". (Notat 71). Linköping: VTI.
- MDD. (1992). "Safety guidelines for transporting children in special seats" MDD/ 92/07). Heywood: Medical Devices Directorate MDD.
- Paulsson, K. & Winnberg-Lindqvist, P. (1997). "Från hinder till möjligheter

 Om hjälpmedel ur ett barnperspektiv". Stockholm: Riksförbundet för Rörelsehindrade Barn och Ungdomar, RBU.

- Paulsson, K. & Fasth, Å. (1999) Man måste alltid slåss på byråkraternas planhalva – Om livsvillkor för familjer med rörelsehindrade barn. Stockholm: Riksförbundet för Rörelsehindrade Barn och Ungdomar (RBU).
- Paulsson, K. (2000) "Det ser så fint ut på papperet Om barn med funktionshinder och Barnkonventionen". Stockholm: Rädda Barnen och RBU.
- Petzäll, J., & Olsson, Å. (1996). "Säkerhet för rullstolsburna passagerare i fordon – Standardisering och funktionella krav". Stockholm: Handikappinstitutet (numera Hjälpmedelsinstitutet)
- Socialstyrelsen (1997:3) "Att resa med färdtjänst" (en uppföljnings- och utvärderingsstudie).
- Vägverket. (2001). "Barn i bil så skyddar du ditt barn". Borlänge: Vägverket.
- Vägverket (1999:149): "Komfort och säkerhet i samband med färdtjänstresor".



Traffic safety for children with disabilities is a complicated issue. It has medical, technical, ergonomic, legal, structural and psychological aspects. Many different authorities have to co-operate and the division of responsibility and labour between them is often complicated. Many parents have sought after a simple and comprehensible publication that describes all the medical, technical, ergonomic, legal, structural and psychological aspects that lies within the complex issue of traffic safety for children with disabilities. This is why we made this handbook.

Torbjörn Falkmer, VTI i Karin Paulsson, RBU

