TRANSPORT FOR THE PEOPLE WITH DISABILITIES: BARRIER-FREE

Torbjörn FALKMER
Division of Preventive and Social Medicine and Public Health Science
Faculty of Health Sciences, and
Swedish National Road and Transport Research Institute, VTI
Linköping, Sweden

Nils Petter GREGERSEN
Swedish National Road and Transport Research Institute, VTI
Linköping, Sweden

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Previous research concerning the transport situation for children with disabilities has shown a lack of reliable data on their travel habits, although such data are essential for producing rules, regulations and guidelines for safe transportation of the target group. The results from the present questionnaire study, which was carried out among 1,060 parents of children with disabilities, showed that the target group travelled frequently in the family vehicle. Most of their journeys occupied a substantial amount of time. Less than a third of all family vehicles were adapted for transporting children with disabilities. There was a large proportion of safety belt users in the family vehicle. Lack of tiedown and safety restraint system procedures meant that journeys by school transportation and Special Transport Systems were a very hazardous means of transport for children with disabilities. The results suggest that school transportation systems must be compelled to use safety belts for children with disabilities, preferably for all children, since children seated in technical aids face an even greater risk in the event of an impact than other children. Tiedown systems must be made compulsory for road vehicle transportation with technical aids used as seating systems.

Road vehicle transport, Children with disabilities, Travel habits, Safety, Restraints, Regulations and standards

Children in general are exposed to increasing risks of fatalities and serious health losses in the traffic system\(^1\). There are several reasons for this. One is that the differences in body segment proportions lead to a higher centre of gravity in a child, which in turn affects body kinetics in the event of an accident. The tolerance of high forces by a child’s body differs from that of adults. The injury pattern in children is quite different from that in adults. In children, injuries to the head are common, whereas severe injuries to other parts of the body are relatively rare. In adults, the reverse pattern is found\(^2\).

Due to these differences in physical structure, safety restraints for children must be designed in a different way from those intended for adults. Several child safety seats, which are approved in accordance with ECE Regulation 44 with amendment 3 (ECE R. 44/03) are available on the European market. These child safety seats should be used in combination with the safety restraint system in the vehicle. The number of users of child safety seats, in combination with safety restraints, was found to be high, i.e., more than 90%, in a Swedish study\(^3\) and, hence, there was a high degree of compliance with national rules and regulations on the use of compulsory safety restraints for children in cars.

Children with disabilities are exposed to an even greater risk of fatalities and serious health losses during road vehicle transportation compared with children in general. Nevertheless, parents and drivers are expected to transport children with disabilities on a daily basis to and from schools, despite the shortcomings in rules, regulations and standards and the lack of information and equipment options\(^4\). Children born with disabilities often do not develop according to the normal weight/height curve. Consequently, they cannot use conventional child safety seats. If a child does not have the normal motor and sensory functions or if it has congenital or acquired anomalies such as lack of one limb or part of it, the common design of the child safety seat cannot ensure safe transport for these children. Thus, they are restricted to transport in technical aids such as their own wheelchairs or customised seating systems. Such technical aids are usually not designed for in-vehicle usage, neither are they crash tested in accordance with ECE R. 44/03. This implies that children with disabilities, i.e., road users with low tolerance to mechanical forces, face increased safety risks when they are restricted to transport in their wheelchairs, technical aids, or poorly fitting child safety seats.

Previous research has shown that not only the capacity of children with disabilities to withstand external forces but also their biomechanical functions need to be more thoroughly investigated. Furthermore, reliable data
are lacking on travel and exposure of children with disabilities with respect to duration, destinations, transport providers, transport procedures, travel companions and free choice of transport.

In public transport, regulations and standards are designed to optimise mass transportation of a standardised population. A criterion for exclusion from the public transport system is usually the combination of being a child and being disabled. In order to bridge the gap between the disabled population’s need for transport and the lack of accessibility in public transport, the special transport system (STS) was created. STS can briefly be described as a public transport service, using fleets of specially designed vehicles or taxis, driving non-scheduled routes. The disabled traveller phones a centre for transportation reservations. In the case of transportation of children with disabilities, regulations and standards vary from time to time and from situation to situation, depending on who is in charge and thus responsible for the transport. This means that in fact the same child with a disability can be transported in the same vehicle with the same driver and still be subject to different regulations and standards on different occasions. An example of this is school transportation, transportation to and from the paediatric clinic and taxi service in specially adapted vehicles for leisure activities. In a study by Falkmer and Fasth it was found that the user groups did not know the regulations and standards well enough. Thus, it was concluded that measures must be taken to increase their knowledge.

Against this background, it can be stated that the responsibility for special needs with respect to transportation of children with disabilities (i.e., the target group for this study) is not clearly expressed. The regulations for technical aids do not prescribe transport safety when using the technical aid for transport in vehicles. Moreover, producers of public transport are not responsible for a technical aid, such as a sulky or a wheelchair, being unable to restrain the high G-forces produced by the event of a collision. The combination of road transport and technical aids for children with disabilities remains a field where there is a need for increased compatibility.

In order to be able to create rules, regulations and guidelines for transportation of the target group, it is essential to know the extent to which they travel and the procedures for their journeys. Furthermore, risks and safety problems, seen from a parental point of view, need to be charted in order to avoid creating unjustifiable rules and regulations.

The aim of the present study was to describe the travel habits of children with disabilities. This report is part of a project aimed at creating a knowledge base for the travel situation of children with disabilities. The overall aim of the project is to use the knowledge base to integrate issues of compatibility between wheelchairs and seating devices and transport vehicles with respect to transport functionality and safety measures. This specific report was based on a pilot study and a literature review. The overall design of the project is shown in Figure 1. The present study focuses only on the travel habits of children with disabilities, indicated by the boxes shown in white in the flowchart.

A questionnaire was mailed to all 1,302 Swedish families registered at RBU - the Swedish National Association for Disabled Children and Young People. RBU is a parental organisation with voluntary participation. It comprises 75-95% of all families with children having
the diagnoses listed below who have experienced significant disability-related problems. The families were chosen on the criteria of having at least one child born between 1983 and 1997 with one of the following diagnoses:
• cerebral palsy (CP)
• spina bifida (i.e., myelomeningocele, MMC)
• muscular diseases (MD)
• short stature
• osteogenesis imperfecta (OI)
• a deployment of children with multiple disabilities (MDC)

If the families had more than one child fulfilling the inclusion criteria, they were asked to focus on the eldest child when filling in the questionnaire. The questions centred on the travel habits of these children. The structure of the questions is shown in Figure 1.

After two reminders, i.e., after a total time of eight weeks, a response rate of 81%, (n = 1,060), was achieved. The non-respondents were not investigated further.

In statistical testing, the Chi-squared test with the significance level of 0.05 was used for comparing distributions of categoric variables and Spearman’s rank correlation to correlate category variables.

For data analysis, a sub-categorisation of ages, diagnoses and “additional disabilities” was made, as described in detail in Tables 1, 2 and 3.

The study was based on children aged 2-16. They were sub-categorised with regard to age, owing to the fact that children of different ages use markedly different solutions for road vehicle transportation. As is shown in Table 1, the age group 2-4 years of age was underrepresented. The reason for this is that for most of the children the diagnosis is not set until the age of 4. An exception from this is the MMC diagnosis.

The parents were asked to state the diagnosis for their children. The children were sub-categorised according to their diagnosis. The following diagnoses were stated by the parents: CP (56%, n = 593), MMC (19%, n = 197), MD (11%, n = 111), short stature (2%, n = 24), OI (1%, n = 15), MDC (17%, n = 184). The parentheses indicate percentage figures and the absolute figures before classification. Note that the total for the percentage figures is greater than 100%. The reason is that 84 subjects (8%) stated two diagnoses. They were classified with respect to the diagnosis that would be assumed to have the greatest impact for the travel situation, which in the vast majority was one of either CP or MMC or MD. The result from this classification procedure is shown in Table 2.

The parents were also asked to state any “additional disabilities” for their children. The children were also sub-categorised according to those “additional disabilities”. Nineteen different “additional disabilities” were pre-printed in the questionnaire. Despite such a comprehensive sub-classification, it was felt necessary to define one of the subgroups as “other additional disability”. Addi-

<table>
<thead>
<tr>
<th>Age (year of birth 1983–1997) sub-categories:</th>
<th>Reason for the sub-categorisation:</th>
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<tbody>
<tr>
<td>1983–1989 i.e., 10–16 years of age (56%, n = 588)</td>
<td>Ages at which traditional child safety seats are not applicable</td>
</tr>
<tr>
<td>1990–1994 i.e., 5–9 years of age (36%, n = 381)</td>
<td>Ages at which traditional child safety seats are applicable</td>
</tr>
<tr>
<td>1995–1997 i.e., 2–4 years of age (8%, n = 87)</td>
<td>Ages at which child safety seats are designed for babies</td>
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<table>
<thead>
<tr>
<th>Diagnostic sub-categories:</th>
<th>Reason for the sub-categorisation:</th>
</tr>
</thead>
<tbody>
<tr>
<td>CP (56%)</td>
<td>The CP diagnosis is the predominating one. It is congenital and usually connected with several additional disabilities. A wide range of problems can be expected to occur in the travel situation</td>
</tr>
<tr>
<td>MMC (19%)</td>
<td>A congenital disability with a relatively homogeneous outcome with respect to travel conditions</td>
</tr>
<tr>
<td>MD (11%)</td>
<td>A progressive disability in which the major feature is weakness. Seating and postural support problems can be expected in the travel situation</td>
</tr>
<tr>
<td>Other (14%)</td>
<td>A mixed variety of non-specific problems can be expected to occur in the travel situation</td>
</tr>
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A QUESTIONNAIRE-BASED SURVEY ON ROAD VEHICLE TRAVEL HABITS OF CHILDREN WITH DISABILITIES

T. FALKMER, N. P. GREGERSEN

Additional disabilities were found within all diagnosis groups. Up to 14 additional diagnoses were given by the subjects. For further analysis, the “additional disabilities” were ranked according to their assumed impact on the travel situation. That means that if several “additional disabilities” were stated, only the one with the highest rank would be used for the sub-categorisation. The “additional disabilities” listed were ranked as shown in Table 3, indicating that “additional disability” No. 1 Mental Retardation (MR) and/or autism, was assumed to have the greatest impact on the travel situation.

The following distribution of the families with respect to residential population density was present (percentage figures for the whole Swedish population are presented in parentheses):
• 26% (24%) lived in cities with > 100,000 inhabitants;
• 40% (41%) lived in towns with 5,000-100,000 inhabitants;
• 11% (19%) lived in villages with < 5,000 inhabitants; and
• 23% (16%) lived in rural areas.

The figures for the whole Swedish population were based on the definition of rural area as communities with less than 200 inhabitants. This definition was not presented on the questionnaire and was thus not obvious to the subjects. This fact may explain why the figures were so similar between the subjects and the whole population, with respect to the two more densely populated sub-categories, but not for the other two sub-categories. If, however, the figures for the two less densely populated areas were added, the following results were given: 34% of the subjects and 35% of the Swedish population lived in communities with < 5,000 inhabitants and in rural areas.

The duration of the journeys was examined in order to establish a travel pattern for the target group of this study. The travel pattern is, however, subdivided into weekdays and weekends, as shown in Table 4.

<table>
<thead>
<tr>
<th>Travel duration</th>
<th>Weekdays n = 1,054</th>
<th>Weekends n = 1,038</th>
</tr>
</thead>
<tbody>
<tr>
<td>No travel</td>
<td>2%</td>
<td>9%</td>
</tr>
<tr>
<td>&lt; 10 minutes</td>
<td>25%</td>
<td>5%</td>
</tr>
<tr>
<td>10–20 minutes</td>
<td>31%</td>
<td>23%</td>
</tr>
<tr>
<td>21–40 minutes</td>
<td>20%</td>
<td>33%</td>
</tr>
<tr>
<td>41–60 minutes</td>
<td>9%</td>
<td>15%</td>
</tr>
<tr>
<td>&gt; 60 minutes</td>
<td>13%</td>
<td>15%</td>
</tr>
</tbody>
</table>

On weekdays, almost half (42%) of the journeys took more than 20 minutes. At weekends, almost two-thirds (63%) took more than 20 minutes. On weekdays, 2% did not travel at all and at weekends 9% did not travel at all.

In order to further establish travel patterns for the target group, the various travel destinations were examined. As shown in Figure 2, journeys to school and day care centres, leisure activities and other activities were performed on a daily basis. School and day care centres were, however, the dominating destination.

As shown in Figure 3, the most common destinations during weekends were relatives and leisure activities. More than one out of four (26%) never used transport to visit friends at weekends.

Furthermore, the transport providers were studied with respect to the different travel destinations.
It was found that in a vast majority of the journeys, the family vehicles were used as shown in Figure 4. It was only in transportation to and from schools and day care centres that school transportation was used to a greater extent than the family vehicle. In all other cases, more than half of the journeys were made in the family vehicle.

Parents were asked whether any adaptations had been made to their vehicles. It was found that 28% were adapted, 70% were not, and 2% of the responding families did not have a vehicle. The sub-category of families with children suffering from MD had adapted vehicles significantly more often (40%, p<0.05). The same was true for sub-categories “MR and/or autism” and “Medical problems” (38% and 31% respectively, p<0.05). Otherwise no significant differences between the sub-categories were found.

The parents were asked about the position in which the children were transported. No more than 0.9% travelled facing sideways in all four different transport providers.

The parents were also asked to state the most common way in which the child was seated inside the four different vehicle categories.

No less than 12% of the journeys in the family vehicle were made with the disabled child seated in some technical aid as is indicated by patterned areas in Figure 5. The corresponding figures for the other transport providers were: School transportation 41%, STS 44% and “Other vehicle” 10%.

The usage of restraint systems was examined with respect to different transport providers. The results are presented in Table 5.

Table 5 shows that 12% of the children with disabilities travelled unrestrained in school transportation. Furthermore, 4% of the children with disabilities were unrestrained during transportation in STS.

The data also revealed that usage of customised seat belts in the family vehicle was significantly more common for the diagnostic sub-category of CP (12%, p<0.01) and the sub-category of “additional disabilities”, “MR and/or autism” (16%) and “Medical problems” (15%) (p<0.001). Customised seat belts are made for postural support, using anchoring points of the belt within the technical aids or within the seating devices. Such seat belts are not designed for safety reasons and, hence, unsafe in an impact. The design of customised seat belts is sometimes misleading the observer to regard it as a safety belt, which can be a fatal mistake in case of an accident.

In school transportation, it was found that children with MMC (17%) and MD (18%) were unrestrained to a significantly higher degree than children with CP (10.6%)
and "Other diagnosis" (4.3%), p<0.05. Furthermore, children from sub-category "None" i.e., no additional disability, were unrestrained six times more often, 24%, as children from sub-categories “MR and/or autism”, 4%, and “Speech problems”, 4%, (p<0.001). Otherwise, no significant differences between the sub-categories were found.

To address the question on crashworthiness, the parents were asked to describe the technical aids and seating devices with respect to adaptations for extra body support.

It was found that in at least three cases out of four...
of each of the four categories of transport providers, no adaptations were used, as is shown in Table 6. The most common adaptation was a headrest and upper torso postural support.

The anchoring procedures for the technical aids and seating devices were reported. It was found that no anchoring procedure at all was performed in 14% of all the cases in the family vehicle. The corresponding figures for school transportation were 9%, STS 9% and “Other vehicle” 16%. The only significant differences observed were that the technical aids, or the seating devices for children aged 5-9 in the family vehicle, were significantly more often unanchored (in 16% of the cases) than for the age group below (in 4% of the cases) and above (in 11% of the cases), (p<0.01).

Parents were asked whether the children with disabilities used the transport without any assistance. The results are presented in Figure 6.

No significant differences between the sub-categories “Diagnoses” and “Additional disabilities” were found with respect to the need to travel with an assistant. For the sub-category “Age”, it was not meaningful to compare children of ages 2-16 with respect to this topic, due to the fact that children in the youngest age category travel extremely rarely without assistance. In addition, the
ability to travel without assistance is part of that natural maturity process among children and teenagers. In STS, personal assistant was the most common travel companion (28%). “Other children” (i.e., not siblings) were the second most common assisting person (10%). In school transportation, “Other children” were the most common (38%), and a personal assistant the second most common travelling companion (19%).

To find out whether the families had different opportunities for choosing alternative means of transport, depending on the population density in their home area, the answers were clustered with respect to population density in the home area.

Figure 7 shows a significant difference between the four different categories of home area, with respect to free choice of transport (p<0.05). In rural areas, 28% were found to be unable to choose means of transport at all. If the figures for “Not at all” and “To a small or fairly small extent” are added, 61% gave this answer in the thinly populated areas. The corresponding overall figure was 50%. For the two sub-categories of larger residence places, the corresponding figures were 47% for the largest and 45% for the second largest. No significant differences were found when analysing the data by using the diagnostic sub-categorisation, “additional disabilities”.

The data were tested for correlation between home area and freedom of choice of transport. A correlation coefficient of 0.106 was found (p<0.01).

For the vast majority of journeys, the family vehicle was used. Most of the journeys occupied a substantial length of time (i.e., > than 20 minutes). This implies not only higher exposure to accident risks, but also a demand for comfortable seating solutions. Furthermore, the demand for personal assistance is greater on longer trips. More than half of the users of school transportation and STS did not travel alone. It may be assumed that the need for assistance during transportation is connected with the type of disability (i.e., the diagnosis) and/or the type of “additional disability” affecting the child. However, it is interesting to note that no such differences with respect to diagnoses or “additional disabilities” were found. In STS, a personal assistant was observed to be the most common assisting person. Rather surprisingly, however, the second most common assisting persons were “other children”. Siblings were not included in this category. In STS, this implies that the “other child” was also disabled.

Although the vast majority of journeys were made in the family vehicle, less than a third of all family vehicles were adapted for transporting children with disabilities. The governmental subsidies for adapting family vehicles are small and the number of applications has decreased, which may explain the comparatively low figure. It seems that families with children affected by MD – a diagnosis where major problems of motor postural maintenance can be expected – had to adapt the motor vehicle to a higher degree. The same applied to children with mental retardation, autism or “medical problems” based on the sub-categorisation in Table 3. The latter three “additional disabilities” are common for children with CP but not for children suffering from MD.

The described group of children with CP and “additional disabilities”, “Mental Retardation (MR) and/or autism” and “Medical problems” was also the group that showed a higher usage of customised seat belts. On the other hand, the children in this sub-category were restrained (i.e., used safety belts) to a higher degree than those in the other groups.

The number of safety belt users in the family vehicle was high. Nevertheless, 1% travelled unrestrained. The corresponding figure for school transportation was, however, quite substantial. More than one disabled child in every 10 travelled unrestrained. Even more disturbing is the fact that almost one child in every five in the most vulnerable of the four sub-categories of diagnosis, MD, was unrestrained. For STS and “Other vehicle”, the corresponding figure was almost one child in every 20.

Although the children were restrained in the family vehicle, some of the technical aids and/or the seating devices were not. Almost one in eight of the transports in the family vehicle was made with the disabled child seated in some form of technical aid. Among these technical aids, one in eight was not restrained at all.

In school transportation, more than four out of ten travelled seated in their technical aids. Almost one in ten of these technical aids was not tied down. Less than six out of ten used safety belts. These figures show that school transportation in Sweden can be a very hazardous means of transport. One explanation for these extreme figures may be that some school transportation vehicles are in fact ordinary buses registered for more than 12 passengers and thus not subject to obligatory use of safety belts by the passengers.

Although this argument does not apply to STS, the results of this study showed that less than two out of three used safety belts when transported in STS. Almost half...
of the transports in STS were made with the child seated in a technical aid. Almost one in ten of these technical aids was not tied down at all. These facts also show that STS travel in Sweden can be another very hazardous means of transport.

With regard to further development of traffic safety related issues for the target group, it is troublesome that it is difficult to find an obvious pattern for the arguments or reasons for restraining children in all four types of transport provider. Not even when analysing the results using the sub-categorisation made in this study could a pattern be found. Nevertheless, in school transportation one explanation for the results could be that the children likely to disturb the driver are restrained to a higher degree (i.e., categories “MR and/or autism”, “Speech problems” and “Medical problems”). However, this pattern was not found for the other transport providers.

The anchoring procedures for all four categories must be subjected to more thorough rules and regulations. From a safety point of view, it is unsatisfactory that so many children travel in their technical aids with no tie-down system in use. The school transportation system must be compelled to use safety belts for children with disabilities, preferably all children, since children seated in technical aids face an even greater risk in the event of an impact than other children. Furthermore, the results show that several of these technical aids are adapted in order to increase postural support, which may have destabilising consequences in a collision.

The expected differences in freedom of choice of transport between the four different categories of home area were smaller than could be expected from the results in the study of Falkmer & Fasth. With the correlation coefficient found, only 1% of the variances could be explained. This shows that it is not accessibility to public transport that is essential for freedom of choice. Perhaps freedom of choice is related more to lifestyle and life situation in general than the population density of the home area in particular?

The prevalence of the disabilities that the children in this study suffer from is approximately the same in all developed countries. Sweden is, however, a small country of approximately nine million inhabitants. Nevertheless, the results from this study could be useful for other developed countries, in which car ownership is common among families, the school system is designed also to take care of children with disabilities and the health care system takes continuous care of the target group for this study. Furthermore, the results from this study emphasize the need for improved rules, regulations and standards concerning the target group and its transport. The results can also help to create a knowledge base for solving the overall problem of little or no compatibility between the use of technical aids and vehicle transportation, due to a lack of comprehensive rules, regulations and standards. However, it is also necessary to gather information on the opinions of parents with disabled children concerning risks and problems during transportation. Furthermore, parents’ knowledge of existing rules and regulations needs to be gathered, together with data on the extent to which these rules and regulations are followed. Some indications concerning the latter have, however, been presented here.