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Handbook guidance promoting a safe journey for children with disabilities – An evaluation

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Abstract

Previous research has shown that both mobility and safety for children with disabilities are reduced, due to several reasons, one of them being lack of adequate and focused information on safety measures to be taken. A handbook was created and disseminated for free to parents of children with disabilities, organised in parental organisations. The handbook was evaluated from a user perspective, by a parental questionnaire survey. The results confirmed the parents' lack of information and further valued the handbook as useful. The parents stated the benefits of the handbook to be largest in contacts with drivers of school transportation and special transport systems. Future development and research should focus on: (i) "early intervention" by occupational therapists and paediatricians by providing the parents the handbook at the clinic, (ii) dissemination strategies towards parents not being members of the parental interest organisations, and (iii) translation and evaluation of the handbook for parents not having Swedish as their native language.

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1. Introduction

The transport mobility of children with disabilities is of vital interest for the individual, as well as for society. Enhanced transport mobility can be related to improved functional health status and a higher degree of autonomy, which in turn may reduce the demand for societal support (Hakamies-Blomqvist et al., 1999). The UN Resolution 48/96 (DPCSD, 1994), Swedish legislation (Socialdepartementet, 1981), and the "Vision Zero" (SNRA, 1996), have in different ways established that the transport system must be designed to meet also the needs of children with disabilities. Hence, strong arguments for advocating the rights for children with disabilities to travel as safe as any other child passenger on the roads are apparent (Anund et al., 2003).

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Previous research has shown that both passive safety and mobility are reduced for children with disabilities, due to multiple factors, one of them being lack of information concerning safety measures to be taken (Falkmer, 2001). The transport situation for children with disabilities is complex and largely unknown (Falkmer et al., 2001b). The capacities of children with disabilities to withstand external forces, and also their biomechanical functions, have not been fully investigated. The literature contain little data on their travel habits and freedom of choice regarding means of transport (Falkmer et al., 2001b). Furthermore, regulations and standards are not well known among the user groups (Falkmer and Fasth, 1999).

Based on this finding, travel habits and travel procedures were investigated (Falkmer et al., 2004; Falkmer and Gregersen, 2001), where it was found that children with disabilities faced an increased risk of injuries and fatalities in the event of an impact in comparison with other children. In particular, journeys with school transportation and special transport systems (STS), (Knutsson, 1997) were found to be hazardous for children with locomotor disabilities (Falkmer and Gregersen, 2001).

Furthermore, parents of children with locomotor disabilities were investigated with respect to the risk they perceived when their children were being transported (Falkmer et al., 2004; Falkmer and Gregersen, 2002).The results showed that entering and exiting the vehicles often required manual assistance and thus was perceived as risky, creating worry among parents. The parents were also worried about professional drivers' lack of knowledge concerning the child and his/her disability, incautious driving behaviour and lack of adequate safety measures. More than half the parents lacked knowledge about the regulations and standards for school transportation and STS. Lack of information thus seemed to be one of the underlying reasons for the parents' worries. It was concluded that comprehensive information, focused on the special needs of children with disabilities in their transportation, would probably reduce the parents' worries significantly.

From the users' perspective, traffic safety for children with disabilities is a complex issue (Falkmer, 2001). It involves not only medical, technical and ergonomic aspects, but also legal, organisational, economical and psychological aspects (Forsman et al., 2004). Authorities on a municipal and county level are supposed to co-operate, but existing models and best practice examples for how to distribute responsibilities are often missing (Paulsson, 2000). Moreover, existing legislation is not transparent and unambiguous, and open for interpretations. This situation often leaves the parents of children with disabilities to solve the problems of their children's transportation on an individual level, without societal support.

In order to facilitate transport mobility for children of all ages, i.e. 0–18 years of age, with disabilities, a handbook was created (Falkmer and Paulsson, 2003) including three chapters about why children are more fragile than adults and the implications this have for general rules and principles for children without and also with disabilities to travel safely. Separate chapter sections for each of the following eight disability groups were provided: cerebral palsy, spina bifida, osteogenesis imperfecta, muscular diseases, rheumatism, hearing impairments, visual impairments, and autism spectrum disorders. A special chapter addressed the complicated issue of how to travel safely sitting in wheelchairs. Furthermore, the choice of cars and applicable laws, in addition to the psychological aspects were addressed in three separate chapters. Finally, the handbook gave advices on where to find more information in two chapters. The handbook, sized to fit in any glove compartment or bag, was printed in sufficient number to be sent out to all Swedish parents organised in parental organisations for children with disabilities, for free.

Any traffic safety policy intervention, such as this one, needs, however, to be evaluated, in order to identify strengths, weaknesses, possible threats and options, along with the target groups' views on their willingness to pay for such a product as the handbook. Such a user perspective evaluation makes it possible to update the handbook accordingly, before disseminating it to a wider target group. Hence, the aim of the present study was to evaluate the handbook from the parents of children with disabilities' point of view.

2. Methods

The evaluation of the handbook was conducted as a sample survey using a questionnaire distributed by mail during November and December, 2003.

The handbook was written for, and directed towards, all parents having one or more children with disabilities, and these parents would, hence, be the ideal target population for the evaluation. However, there were no

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