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Everyday travel for families with children using wheelchairs: parents’ perceptions of constraints and adaptation strategies

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ABSTRACT

There is a norm assuming high mobility in the Western world today, which can increase the social and geographical exclusion of those who have limited possibilities to travel, such as people with disabilities. When it is a child who has the disability, travel-related constraints are likely to affect the whole family’s travel patterns. This study explores travel constraints among Swedish families with children with cerebral palsy who use wheelchairs. A time-geographical framework is employed. Interviews with parents show that these families’ everyday mobility is affected by authority, capacity and coupling constraints, and that it is often a combination of these constraints that makes travelling difficult. The families use different strategies to negotiate these constraints. In addition to strategies controlled by the families, the findings suggest that there is also a need for governmental support and a barrier-free transport system to enhance their mobility.

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KEYWORDS

Children’s mobility; disability; travel constraints; time-geography; family; accessibility

Introduction

Everyone has constraints that affect their mobility patterns and travel opportunities in time and space (Hägerstrand 1970). Some might have more profound travel constraints than others, including children (Fyhri et al. 2011) and people with disabilities. Wheelchair users, for instance, usually have accessibility requirements that can limit their transport alternatives (Velho et al. 2016). Constrained transport mobility is problematic, as it can cause social and geographical exclusion (Lucas 2012) and negatively affect people’s well-being (Delbosc and Currie 2011). Even so, transport mobility research on travel constraints among people with disabilities is still limited, especially regarding the mobility of families with disabled children (Nyman, Westin, and Carson 2018). This study strives to start filling this research gap.

The aim here is to examine the parents’ perspective on how travel-related constraints affect the everyday mobility of Swedish families with children with cerebral palsy (CP) who use wheelchairs. More specifically, this paper will (1) explore which constraints these families face and (2) identify what strategies they use to negotiate them. This study thus contributes to disability research in transport geography by adding a family perspective to a field dominated by research from an individual perspective, focusing mostly on adults with disabilities (e.g. Aarhaug and Elvebakk 2015; Bromley, Matthews, and Thomas 2007). Moreover, this study adds a disability perspective to family research by exemplifying how some families’ travel patterns can be affected by travelling in an inaccessible transport environment with a child who uses a wheelchair.

This paper is based on a time-geographical framework, used as an approach to explore how daily mobility can be affected by three categories of constraints (authority, capacity and coupling),
identified by Hägerstrand (1970). The paper illustrates how these constraints can be interrelated and together affect possibilities for mobility. In this paper, ‘mobility’ refers to everyday travel requiring some kind of transport mode, such as trips for (pre)school, leisure activities, errands and social life.

The paper is structured to first provide a background on the topic, including the relevant literature in the field, and the time-geographical framework. The method section presents the data collection method (i.e. interviews), followed by a presentation of the sample. The following results section presents what travel constraints these families face, and what strategies they use to negotiate them. The paper ends with a concluding discussion, including suggestions for future research.

**Background**

The background will first present different perspectives of ‘disability’, followed by an overview of previous research findings related to travelling with a disability and the mobility of children and their families, respectively. The final part of the background introduces the time-geographical framework.

**Disability**

There are different understandings of and perspectives on childhood as well as disability. Studies related to children in general have often used biological or social research approaches (Holloway 2014). Similarly, disability studies have used either medical or social perspectives on disability. The medical perspective focuses on the impairment as a constraint, while the social perspective recognises inaccessible physical and socio-cultural environments not adapted to various impairments as the problem (Brett 2002). While the social perspective has been preferred, people tend to experience problems due to their impairments (such as pain) that will not disappear even if social and physical barriers are eliminated (Schur, Kruse, & Blanck, 2013). The point of departure for this paper is that disability is the combination of the children’s impairment and an inaccessible environment, usually called the *relational* understanding of disability. In this understanding, a combination of the medical and social perspectives is employed and ‘disability is understood as resulting from complex interactions between the individual and the socio-cultural, physical, political and institutional aspects of the environment’ (Ytterhus et al. 2015, 21). This perspective sees disability as a person-environment mismatch. Disability is thus context-dependent, and whether or not an impairment is disabling depends on the specific situation (Ytterhus et al. 2015). Thus, in this paper the terms ‘disability’ and ‘disabled’ refer to the difficulties the child’s impairment poses in relation to an inaccessible physical and social environment.

**Travelling with a disability**

There is a norm assuming high mobility in Western societies, which can increase the social and geographical exclusion of those who have limited possibilities to travel (Lucas 2012). People with disabilities tend to find it more difficult to travel than others, due to various constraints (Velho et al. 2016). Constraints can affect travel patterns in different ways. Some people with disabilities travel less than others, travel shorter distances (Taylor and Józefowicz 2012), and/or are restricted in their choice of transport mode (Bromley, Matthews, and Thomas 2007).

One important constraint affecting the use of public transport among people using wheelchairs is the physical barriers, for instance in terms of inaccessible public transport modes (Velho et al. 2016). Bromley, Matthews, and Thomas (2007) found that 90% of wheelchair users avoided buses because of their high steps in combination with a lack of ramps, which was a major barrier for them. Inaccessibility of public transport relates not only to the physical design of the vehicles, but also to the accessibility of stations and platforms. If people have to adjust their travel patterns based on which stations and platforms are wheelchair-accessible and equipped with a lift, they might have to take circuitous routes instead of travelling directly to their destination (Kitchin 1998). As a result,
travelling with public transport often takes a longer time for people who use wheelchairs (Ferrari et al. 2014).

In addition to physical barriers, wheelchair users can experience a lack of sufficient information about accessibility (Aarhaug and Elvebakk 2015) and problems with crowdedness. Even if some transport modes have a wheelchair priority area, this area is often occupied by other wheelchairs or push chairs. Due to inaccessible vehicles and occupied wheelchair priority areas, wheelchair users might have to wait quite a long time at a bus stop before they can board (Velho et al. 2016). As a result, wheelchair users tend not to use public transport, instead relying on cars or taxis (Bromley, Matthews, and Thomas 2007).

In general, public transport is adapted to cater to the adult, able-bodied population (Stephens et al. 2017). The combination of being a child and having a disability can therefore negatively affect the possibility to use public transport (Falkmer and Gregersen 2001; Pyer et al. 2010). If accessibility adjustments are made, they are usually for disabled adults (Stephens et al. 2017) rather than children, even though the accessibility needs of these groups can vary. For instance, children using wheelchairs tend to have smaller wheelchairs than adults or use other technical aids (Falkmer and Gregersen 2001).

**Mobility for children and their families**

The family is important for providing transport mobility for children in general (Fyhri et al. 2011). However, most studies on children’s everyday travel focus on non-disabled children, for instance examining what transport modes they use (Easton and Ferrari 2015; Fyhri et al. 2011). Independent travel (e.g. cycling and walking without the company of an adult) can contribute positively to children’s well-being, but has decreased lately (Waygood et al. 2017). Instead, parents are increasingly driving their children by car. A reason for increased car dependency among children is that schools are often located further from home than previously (Fyhri et al. 2011). Schools for children with special needs, such as children with disabilities, are often located even further from home due to centralisation, which increases the need for motorised transportation (Easton and Ferrari 2015).

Children who use wheelchairs might not have independent travel (in terms of cycling and walking) as an option, indicating that the general discussion on children’s independent travel versus car travel may not be relevant. Children with disabilities have generally not received much attention in independent travel research (Ross and Buliung 2018). A study by Wheeler, Yang, and Xiang (2009) showed that children with disabilities used motorised transport more than non-disabled children did. However, in relation to public transport, children with disabilities reported a higher level of difficulties compared to non-disabled children. The study also suggested that the more severe motorial limitations a child has, the more challenging public transport becomes (Wheeler, Yang, and Xiang 2009).

When travelling by car, children who use wheelchairs might need support to get in and out of the car (Stephens et al. 2017), and some need adapted cars. It is therefore difficult for children using wheelchairs to travel with someone other than their parents. These children thus tend to be dependent on their parents driving them to a higher age compared to their non-disabled peers, challenging their perceptions of independency (Pyer and Tucker 2017). To improve children’s independent travel and decrease their reliance on parents, special transport services (STS) can be used. Falkmer and Gregersen (2001) found that for most trips made with STS, children had personal assistants rather than parents as companions.

**The time-geographical framework**

Time-geography provides a useful theoretical framework for studying people’s mobility in time and space, including what resources and constraints affect their mobility patterns (Ellegård and Svedin 2012). A fundamental idea within time-geography is that all individuals have *trajectories* in time–
space and perform activities, alone or with others, that are part of short- and long-term projects (Lenntorp 2004). Activities and projects take time and space, and thus limit the possibilities to participate in other projects simultaneously. Many projects that people want to undertake are not completed due to the competition between different projects (Lenntorp 2004). Travelling is an example of a project (Berg et al. 2014), and staying at home due to travel constraints can thus be seen as a ’failed project’ (e.g. McQuoid and Dijst 2012).

Everyone faces travel constraints, such as the limited geographical distance people are able to overcome within a given time frame (Lenntorp 2004). Within time-geography, the constraints people experience when travelling through time and space can be divided into three categories, identified by Hägerstrand (1970): authority, capacity, and coupling. However, these constraints do not necessarily prevent people from travelling, as people tend to find strategies to overcome or negotiate them (Nyaupane and Andererek 2008).

Authority constraints can be laws and regulations that restrict people’s travel patterns (Hägerstrand 1970). Some regulations specifically affect people with various disabilities, and can differ among countries. Sweden has ‘the Act Concerning Support and Service for Persons with Certain Functional Impairments’ (hereafter LSS), which regulates the external support disabled people can receive from the government. This support includes, for instance, the right to have personal assistants (Von Granitz et al. 2017). However, even with LSS in effect, parents often feel they have to fight for the right to receive governmental support (Brennan et al. 2016; Miettinen, Engwall, and Teittinen 2013). Moreover, authority constraints can also be socio-cultural power structures, such as marginalising or discriminating attitudes from others. These power structures can determine what activities are and are not possible to undertake and, therefore, risk leading to ’failed projects’ (Lenntorp 2004).

In this paper, authority constraints will include all barriers set up by society, i.e. regulations affecting these families, and power structures in terms of physical and socio-cultural barriers in society that can exclude wheelchair users, telling them they are ‘out of place’ (Kitchin 1998).

Secondly, capacity constraints refer to a person’s individual constraints, which can be biological/physical limitations or internal barriers, such as perceptions of anxiety (Hägerstrand 1970). For people with disabilities, the impairment can be considered a capacity constraint, as it can affect their ability to perform certain activities and projects (Löfgren 2006). In this paper, the children’s disabilities are considered capacity constraints. The parents’ capacity constraints are also briefly touched upon, for instance in terms of how they manage travelling with their children’s heavy wheelchairs and auxiliary aids.

The third category of constraints, coupling constraints, is evident in cases in which an individual needs to co-organise activities with others, for instance being at the same place at the same time (Hägerstrand 1970). In the family context, parents picking up children at (pre)school can be considered a coupling constraint (Ellegård and Svedin 2012). Moreover, coupling constraints are common in the lives of people with disabilities, who might be dependent on others for support. Then, several different individuals’ trajectories might have to be co-organised to make everyday life possible (Löfgren 2006). This paper focuses on coupling constraints within the family.

Method

This paper is based on semi-structured interviews with parents of children with cerebral palsy (CP) who use wheelchairs. The focus is on the parents’ perspectives due to the assumption that they often make travel-related decisions within families and are likely to be the ones devising adaptation strategies to enable mobility for the whole family. The researcher did not seek the children’s views, but focused solely on the parents. Moreover, the study was delimited to focus on the experience of parents of children diagnosed with CP, based on the assumption that children with the same diagnosis are likely to have similar support needs when travelling, which might affect coupling constraints.
Interviews were chosen as the data collection method because it is the parents’ lived experiences and perceptions of travel constraints that are of interest. Interviews allow the parent to take on the role of expert while the researcher can be an active listener (Edwards and Holland 2013), which can be beneficial in studies involving disability issues (Kitchin 2000). The interview questions were open-ended and formulated to encourage the respondents to talk freely, thereby enabling a deeper and more nuanced understanding of these families’ everyday travel. The interview guide was structured to first explore how the families travel in everyday life, followed by questions regarding experiences of various transport modes and travel constraints, and how these can affect the whole family’s travel patterns. To test the interview template, a pilot interview was conducted with the mother of a child with CP who uses a wheelchair.

Due to difficulties identifying parents with children with CP who use wheelchairs, the respondents were recruited using various channels. Respondents from an earlier Swedish study (Nyman et al. 2018) were contacted, and eight of these parents wanted to participate. Other parents were recruited through Facebook groups consisting of parents and relatives of children with disabilities. Information about the study was posted in these groups, and those parents who wanted to participate contacted the researcher. Before agreeing to participate, all parents received an information letter detailing the study’s aim and method and the planned distribution of the results. The letter also stated that participation was voluntary and that the data would be handled confidentially.

The final sample consisted of 18 parents (see Table 1). Two of them participated in the interview as a couple, while the other parents were from different households (one was a single parent while the others were co-parents). In total, 17 interviews were conducted. Due to participant self-selection, the sample might consist of parents who feel they have a great deal to share about travelling, while others might have chosen not to participate. The sample included 15 mothers and three fathers. This gender distribution might be the result of mothers often being the main caregivers of children with disabilities (Miettinen, Engwall, and Teittinen 2013) and therefore possibly having more to share than the fathers regarding travel experiences. Another reason might be that mothers are often overrepresented in studies regarding children (Green 2007).

The gender distribution was skewed among the children as well: two were girls and 15 were boys. In Sweden, more boys than girls have CP (Chounti et al. 2013), which may, at least partly, be an

<table>
<thead>
<tr>
<th>PARENT</th>
<th>CHILD</th>
<th>SIBLINGS</th>
<th>PLACE OF RESIDENCE</th>
<th>MAIN TRANSPORT MODE</th>
<th>EXTERNAL ASSISTANCE</th>
</tr>
</thead>
<tbody>
<tr>
<td>MARIA</td>
<td>Boy, 7 y/o</td>
<td>No siblings</td>
<td>Rural</td>
<td>Family car</td>
<td>No</td>
</tr>
<tr>
<td>HANNA</td>
<td>Boy, 15 y/o</td>
<td>16, 21 y/o</td>
<td>Rural</td>
<td>Family car</td>
<td>No</td>
</tr>
<tr>
<td>LIV</td>
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<td>13 y/o</td>
<td>Suburban</td>
<td>Family car</td>
<td>No</td>
</tr>
<tr>
<td>LOUISE</td>
<td>Boy, 2.5 y/o</td>
<td>4, 9, 13, 16, 18 y/o</td>
<td>Suburban</td>
<td>Family car</td>
<td>No</td>
</tr>
<tr>
<td>JULIA</td>
<td>Boy, 6 y/o</td>
<td>No siblings</td>
<td>Urban</td>
<td>Family car</td>
<td>No</td>
</tr>
<tr>
<td>EMMA</td>
<td>Boy, 11 y/o</td>
<td>5, 8 y/o</td>
<td>Urban</td>
<td>STS</td>
<td>Yes, part-time</td>
</tr>
<tr>
<td>CLAIRE</td>
<td>Boy, 10 y/o</td>
<td>10, 12 y/o</td>
<td>Rural</td>
<td>STS</td>
<td>Yes, full-time</td>
</tr>
<tr>
<td>ANDERS</td>
<td>Boy, 7 y/o</td>
<td>14 y/o</td>
<td>Urban</td>
<td>Family car</td>
<td>No</td>
</tr>
<tr>
<td>JANE</td>
<td>Boy, 4 y/o</td>
<td>1 y/o</td>
<td>Rural</td>
<td>Family car</td>
<td>No</td>
</tr>
<tr>
<td>ANNA</td>
<td>Boy, 9 y/o</td>
<td>1.5 y/o</td>
<td>Suburban</td>
<td>Family car</td>
<td>Yes, full-time</td>
</tr>
<tr>
<td>VICTORIA</td>
<td>Girl, 11 y/o</td>
<td>16, 18 y/o</td>
<td>Suburban</td>
<td>STS</td>
<td>Yes, full-time</td>
</tr>
<tr>
<td>SOFIA</td>
<td>Boy, 5 y/o</td>
<td>No siblings</td>
<td>Urban</td>
<td>Family car</td>
<td>Yes, full-time</td>
</tr>
<tr>
<td>JOHN</td>
<td>Boy, 6 y/o</td>
<td>No siblings</td>
<td>Suburban</td>
<td>Family car</td>
<td>Yes, part-time</td>
</tr>
<tr>
<td>LISA</td>
<td>Boys, 7 y/o</td>
<td>4, 6, 8 y/o</td>
<td>Urban</td>
<td>STS</td>
<td>Yes, full-time</td>
</tr>
<tr>
<td>SARA</td>
<td>Boy, 9 y/o</td>
<td>8, 13 y/o</td>
<td>Rural</td>
<td>STS</td>
<td>Yes, part-time</td>
</tr>
<tr>
<td>VERONICA</td>
<td>Boy, 15 y/o</td>
<td>17, 20 y/o</td>
<td>Urban</td>
<td>STS</td>
<td>Yes, part-time</td>
</tr>
<tr>
<td>HELEN &amp; PETER</td>
<td>Boy, 15 y/o</td>
<td>11, 13 y/o</td>
<td>Urban</td>
<td>STS</td>
<td>Yes, part-time</td>
</tr>
</tbody>
</table>

*aAll names are anonymised. 
*bExternal assistance is categorised as ‘No’ if the family has no personal assistance and only a resource in (pre)school or support for maximum one occasion per week. The parents have many care responsibilities in this group. ‘Part-time’ means they are eligible for assistance but the parents still have many care responsibilities. ‘Full-time’ means they have external personal assistance all day and night, or close to it.
explanation for the sample’s gender distribution. The children’s age range was 2.5–15 years. All but four had siblings. There was one set of twins with CP, but only one of them had a constant need for a wheelchair.

Regarding place of residence, five respondents lived in rural areas, five in suburban (a few kilometres from urban centres) and seven in urban (see Table 1). The exact place of residence is anonymised due to confidentiality (as especially respondents in rural areas could otherwise be easily identified). In Sweden, the supply of public transport alternatives is generally lower in rural than suburban and urban areas, making rural inhabitants generally car dependent. Meanwhile, the (sub)urban population can rely more on public transportation (Traffic Analysis 2014). However, in this sample, all respondents had access to at least one car, regardless of place of residence. In Sweden, people with mobility impairments can apply for state subsidies to get an adapted car, meaning that family income level should not limit car access for those with few other feasible transport alternatives (Pettersson 2015). Income levels were not asked about in the interviews, but economy was briefly discussed; no respondents experienced that monetary constraints limited their everyday mobility, partly because of the Swedish support system. Therefore, economy was not further accounted for.

All interviews were audio-recorded (with the respondents’ permission) and transcribed by the researcher. Most interviews were held in Swedish (the interview with Sofia was held in English, as she had migrated to Sweden from an English-speaking country), and the quotes presented in this paper are translated from Swedish into English. The interviews were analysed using thematic analysis, a method that allows for both pre-determined and new themes (Braun and Clarke 2006). The software MAXQDA was used during the coding process. Hägerstrand’s (1970) categories of travel constraints (authority, capacity, and coupling) were used as pre-determined themes. Two themes that emerged during the coding process were ‘adaptation strategies’ and ‘external support’, which presented ways in which the families negotiated the prevailing constraints. Adaptation strategies were not included in the interview guide, but were identified in all interviews during the analysis stage.

Results

The results section is divided into two parts. The first presents travel constraints that the interviewed parents experience when travelling with their children, and the second presents strategies to negotiate these constraints.

Travel constraints

The interviews showed how constraints in various ways affect the project of everyday travel for families with children with CP who use wheelchairs. Authority constraints, in terms of an inaccessible environment, highly affected these families’ travel patterns, especially regarding the use of various public transport modes. Families living in rural areas generally did not use public transport, due to a lack of such alternatives. It was more common that families living in urban or suburban places had used public transport before they had a disabled child. However, these families no longer used public transport in their everyday life when travelling with their child who uses a wheelchair.

In line with previous research (e.g. Bromley, Matthews, and Thomas 2007; Ferrari et al. 2014), the parents experienced difficulties related to stairs, for both getting to platforms and boarding trains and buses. In larger cities, local buses were often wheelchair-accessible but were still not an option for everyday mobility since the wheelchair priority area was often occupied by push chairs (also mentioned by Velho et al. 2016). It was not feasible in everyday life to wait half an hour and hope that the next bus could accommodate them, since these children had to get to (pre)school and their parents had to get to work (i.e. projects steered by other authority and coupling constraints):
It’s very frustrating because it takes such a long time before we can get on-board something. Usually they’re full, and if there’s one that isn’t full then it’s an old bus or tram and you can’t get on-board anyway. (Lisa)

Physical inaccessibility and crowdedness can be considered authority constraints, since it is the design of public transport modes (and their wheelchair priority areas) that limits travel possibilities for wheelchair users. Spatial planning can also be a constraint, for instance regarding parking in urban areas. Parking was experienced as difficult by parents who used cars due to inaccessible public transport, as they often had large, wheelchair-adapted cars:

It’s kind of … “How do I get there? How long will it take?” but above all … “What do I do with this living room on wheels once we arrive?” (Julia)

Julia, Anders and Sofia, who all lived in rather large cities, experienced parking to be such a profound constraint that they avoided some trips. However, parking was never mentioned among respondents living in rural areas, and rarely among those living in suburban areas, except when visiting urban centres.

Moreover, capacity constraints, mainly related to the children’s impairments, were found to be restrictive for these families’ everyday travel. In addition to the wheelchair, these children had many auxiliary aids (tools for ‘compensating’ for the disability, as one parent put it) that needed to be transferred back and forth to (pre)school every day. Some needed an extra wheelchair, equipment for physiotherapy, and aids for outdoor activities. John explained that his son used such equipment every day and that they had borrowed his father-in-law’s trailer for the trips to and from preschool before they got an adapted mini-van, because it was impossible to accommodate all the equipment in a regular car.

Furthermore, the parents explained that they found it very difficult to carry all the equipment and at the same time push their child’s wheelchair if travelling by public transport, meaning that a combination of the child’s and the parents’ capacity constraints (i.e. ability to carry equipment) could be restrictive in the transport mode choice. Similarly, the parents’ capacity constraints in terms of physical strength could also be a barrier to travel, as they found it heavy to lift the child and wheelchair in and out of the car and public transport vehicles:

(The father) still manages travelling alone with (disabled son), but I can’t do that because I can’t lift him and I can’t lift the wheelchair into the car. So that’s a constraint. (Helen)

As a result of authority constraints in terms of an inaccessible environment combined with capacity constraints related to the children’s disabilities, the lives of these parents were highly affected by coupling constraints. Coupling constraints were mostly found between the child and the mother, as the mother was often the main caregiver (in line with Green 2007; Miettinen, Engwall, and Teittinen 2013). However, coupling constraints could also involve others, for instance in cases in which the whole family travelled together or when travelling with a personal assistant or others outside the family. Due to coupling constraints, the person(s) taking care of the child (whether a family member or an external assistant) also experienced the travel constraints related to the disability (e.g. the need to overcome physical barriers with a wheelchair).

**Strategies to negotiate travel constraints**

Due to the difficulties these families encountered with public transport, a common strategy for enabling mobility was to travel by car. Most families had cars specially adapted to their children’s disabilities. The adaptation strategy was thus to get a new, bigger car to accommodate the child. While this could be a matter of simply changing cars for families living in the countryside, who had always relied on cars for their mobility, some living in larger cities referred to car dependency as something unpleasant. Anders, father to a seven-year-old son with CP and a 14-year-old daughter, questioned the family’s car ownership and explained:
We did (rely on public transport) with his older sister, so we would have done that. We wouldn’t have a car, for instance. / … / We would have been members of a carpool for situations when we needed a car. There’s no other reason … having a car now, it’s only for him. (Anders)

Similarly, Sofia lives with her husband and their five-year-old son, who uses a wheelchair, in a metropolitan Swedish city. Sofia had previously relied on public transport, but had to buy a new, large car when they had their son:

Now we have two cars. So we live in the city, family of three, and we have two cars. And I mean we live really in the city, right next to two subway stations, lots and lots of bus stations … we live so close to all the public stops, yet we have two cars. (Sofia)

Furthermore, as a result of car travel being the most feasible travel option for the children, they were dependent on their parents to drive them. Due to chauffeuring and other coupling constraints related to care responsibilities, an adaptation strategy many families used was to have one parent (most often the mother) decrease their working hours or even quit paid employment. Anna lives about 15 kilometres outside a medium-large city in Sweden with her husband, a nine-year-old son with CP using a wheelchair, and a 1.5-year-old sibling. Her son goes to school in the city centre instead of the suburb where they live, since the nearest school is not adapted to his needs. He is eligible for full-time personal assistance, and the sibling goes to preschool. Yet, Anna does not work. She explained that it is difficult to manage things because she drives her son to school in one city (even though there are good public transportation links), while job opportunities in her field of education are mainly located in a larger, neighbouring city. The project of providing mobility for her son is thus prioritised over her own mobility and everyday activities:

(If he hadn’t had a disability) he would’ve gone to school here, where we live. We would’ve taken the bike to school, not the car. / … / Before, he also went to preschool in (city centre), because they couldn’t take care of him at the preschool in (suburb), so I drove him there every day. And then I worked in (other city), so I drove … what is it? It’s like 40 minutes extra every day, and the same on the way back. So today … we drove him for five years. It’s a huge detour. It’s almost like … I mean if you’re supposed to be able to work yourself … it’s not feasible because it impinges on your working hours and such. / … / Like this Monday … first I had a meeting in (city centre) and then I had to drive back to (suburb) to pick up his sister at preschool and then I took the same way back to drive … he was going swimming, so I had to go back to school to get him and drive that short distance to the swimming hall so they could get there. / … / For me, it took about two hours, just to drive around. (Anna)

Moreover, some parents mentioned situations in which they had to have another adult with them to enable mobility for their children, because of the parents’ own capacity constraints. For instance, Maria, mother to a seven-year-old son with CP, said it could be possible to travel by train if her husband went along. She experienced it as too difficult to deal with physical constraints in terms of stairs at the entrance to a train if she travelled alone with her son, but if his father was there too, they could lift their son and the wheelchair together. The strategy of adaptation to the capacity constraints of the child (i.e. disability) and the parent (i.e. physical strength) in combination with authority constraints (e.g. an inaccessible physical environment) could thus lead to increased coupling constraints if more adults were needed to enable mobility.

Parents’ capacity constraints in terms of physical strength could also affect car travel, as it was experienced as heavy to lift the child and wheelchair in and out of the car. To negotiate constraints related to heavy lifting, some parents ran most of their errands at a shopping centre so they would not have to take the car to different shops and other service points. Others, such as John, who has a six-year-old son who uses a wheelchair, planned their trips carefully:

You plan it a bit more. If you order a package, then you could perhaps choose the delivery address as … where you go grocery shopping. So then you won’t have to go to another store to pick up the package and then go grocery shopping and then go home, you know. You think before you do stuff … Find a parking place where you can reach both stores that are in opposite directions, so that you park in the middle, and things like that. (John)
Another common strategy was to leave the disabled child at home with the other parent or a personal assistant when running errands that did not directly involve the children (e.g. grocery shopping). Most parents mentioned this as a strategy, and many felt guilty leaving their child at home since they would not have done so if he or she did not have a disability. Many parents said they wished they did not let the disability be a constraint, but sometimes it was experienced as too troublesome to travel with their children. Sara and Julia exemplified this:

I go grocery shopping when I don’t have him. I mean these short errands … errands that take three minutes and then it takes 15 minutes to get him in and out of the car … it’s way too complicated. (Sara)

When I have the opportunity, I do that by myself because it’s easier that way. That wouldn’t be my choice if I had a normally functioning child, I’m sure. (Julia)

In families with more than one child, leaving the child at home could also be a negotiation between the needs of the disabled child on the one hand and those of the siblings on the other. Even though the family’s mobility was adjusted mostly to the child with the disability, the whole family’s mobility could be constrained. A strategy for providing mobility to the other family members was thus to leave the child using a wheelchair at home. Lisa has five children, of whom two have CP but only one has a constant need for a wheelchair. The quote below concerns the son with the most profound disability:

We’ve talked about … it’s very sad, but he’ll probably have to stay at home more in the future. It’s a very difficult compromise, because you don’t want to leave one of your children at home, but it’s this balance like “how restricted should the siblings be?” / … / We really dislike the idea of leaving a child at home, so then we don’t travel as much … We seldom go anywhere without him, but then we all travel less instead. (Lisa)

To be able to leave the disabled child at home, there needs to be someone else there to take care of him or her. Coupling constraints within the family could decrease if the child could instead be coupled with someone else. Thus, a strategy was to apply for personal assistance. In general, parents who received governmental support in terms of personal assistance found it easier to cope with other travel constraints. In addition to reducing coupling constraints within the family, personal assistance could also be a strategy for coping with the parents’ capacity constraints, such as help lifting the child and wheelchair into the car.

However, to overcome coupling constraints within the family, there was also a need for other transport alternatives than parents driving the children by car. The families could apply for special transport service (STS), which usually entails an adapted taxi car that provides door-to-door transportation for people with disabilities. STS is steered on the local governmental level in Sweden (Pettersson 2015). A combination of personal assistance and STS was thus a strategy that could be used to decrease coupling constraints within the family, and at the same time increase all family members’ possibilities for mobility. Parents in families receiving governmental support in terms of personal assistance and STS worked full-time to higher extent and seemed to have more positive feelings and experiences related to everyday mobility, compared to parents who lacked this support. In addition, they seemed to have less guilty feelings about the siblings’ mobility. Claire explained that the siblings’ mobility depended on her disabled son having personal assistance. If they did not have an external assistant (e.g. due to sick leave), the parents could not manage the siblings’ leisure activities.

However, not all families were eligible for personal assistance or STS, even though they had applied for it (see also Brennan et al. 2016). While it is the parents who can choose to apply for this support to negotiate constraints in everyday life, the decision lies in someone else’s hands (i.e. authority constraints). Hence, the families need to have adaptation strategies that they control themselves (e.g. change car, adjust work situation, leave child at home), but are also dependent on adaptation strategies that are controlled by others (e.g. governmental support).
Concluding discussion

This paper contributes to mobility research by combining the disability and family perspectives, showing that the project of everyday mobility for families with children with CP who use wheelchairs is affected by many different constraints, which these families try to negotiate and overcome. For these families, it is usually a combination of authority, capacity and coupling constraints (see Hägerstrand 1970) that makes everyday mobility difficult. The children’s disabilities, in combination with an inaccessible transport system not adjusted to their needs, increase their need for support from others. For instance, due to the wheelchair these children need (capacity constraints) and public transport not being physically accessible or too crowded (authority constraints), they have to be driven by their parents (coupling constraints) if they do not have external support (authority constraints) in terms of personal assistance (with whom the child can be coupled instead of parents) and STS. This paper thus contributes to time-geography by illustrating how it is the interrelation of various constraints that can affect mobility patterns. Furthermore, the findings support the relational understanding of disability, meaning that it is both the actual impairment of the child and the inaccessible environment that are disabling (Ytterhus et al. 2015).

All family members’ everyday trajectories could be affected by the constraints related to the disability, and they therefore had many ‘failed projects’ (see Lenntorp 2004; McQuoid and Dijst 2012). Failed projects could include, for instance, skipped trips and leisure activities, or the parents’ limited possibilities to accomplish the project of work. However, the family could also act as a constraint on the disabled child’s mobility, for instance when leaving him or her at home to prioritise the mobility of the other family members, or in terms of avoiding trips that included heavy lifting for the parents. Due to such constraints, the child as well as other family members risk becoming socially and geographically isolated. However, as the results show, the families used different strategies to negotiate the constraints and enable mobility.

One important strategy used for completing travel projects was to travel by car instead of struggling with inaccessible public transport. While all families were car dependent, the results suggested that car dependency could be a more profound adaptation for those living in cities. Families living in cities with children using wheelchairs might have more limited mobility opportunities than those living in rural areas, since they cannot take advantage of the greater supply of public transport and experience more difficulties with parking. Thus, the geographical context seems to matter and affect what constraints these families encounter, and how various constraints are experienced. A suggestion for future research is to further explore the differences between urban and rural areas.

Moreover, car dependency assumes that parents drive their children, leading to coupling constraints. Car travel can thus be considered an adaptation strategy for coping with authority constraints related to public transport, but is not without its own difficulties. Coupling constraints still exist and other constraints can emerge, such as heavy lifting (i.e. parents’ capacity constraints) and parking problems (i.e. authority constraints due to insufficient parking possibilities for wheelchair users). A conclusion is thus that, even if these families use several different strategies to overcome travel constraints, there is also a need for decreased authority constraints if these families are to be able to lead a mobile life. If physical barriers were reduced and society became more adapted to wheelchair users, the children’s disabilities and the accompanying need to use a wheelchair and other auxiliary aids might be experienced as less problematic. A suggestion for transport planners and policy-makers is thus to make more public transport modes wheelchair-accessible (i.e. easier to enter), have specific wheelchair priority areas on buses (to reduce problems with crowdedness), and offer better handicap parking possibilities in cities. While such adjustments cannot ensure all travel constraints are removed (see Velho et al. 2016), improving physical accessibility might increase opportunities for mobility among these families.

Furthermore, this paper indicates that the opportunities for everyday mobility might increase for the whole family if they receive external, governmental support, such as personal assistance (see Von Granitz et al. 2017). Governmental support can reduce coupling constraints within the family,
making it easier for these families to have individual daily trajectories, rather than having to constantly negotiate their trajectories due to constraints related to the disability. Thus, while governmental support could be important for disabled people’s mobility (and thereby their possibilities for social and geographical inclusion; Lucas 2012) in general, it might be even more important for these families, as it affects several individuals’ possibilities to undertake projects in everyday life (such as work). A suggestion for future research is to compare families’ travel patterns before and after they receive external, governmental support, to investigate what effects it can have on the whole family’s mobility. Comparisons could also be made between families with children with various disabilities, as well as non-disabled children, to explore similarities and differences among these families.

The interviews in this study indicate that intersectionality might affect mobility opportunities. While no class differences were noted (likely due to the Swedish welfare and support system), the results indicate that disability and gender intersectionality might affect the mobility of mothers, as they are the ones with the most care responsibilities in these families and who tend to adjust their working situation. The combination of being a woman and having a disabled child could be explored in future mobility studies. A final research suggestion is to explore mobility and perceptions of constraints from the perspective of other family members, such as siblings, but also the disabled children themselves. Children might have different perceptions and experiences of constraints than adults (e.g. Holloway 2014; Pyer et al. 2010), and their perspectives could therefore be useful in developing transport policies aiming to enhance transport mobility possibilities for children with disabilities and their families (see also Stephens et al. 2017).

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References


