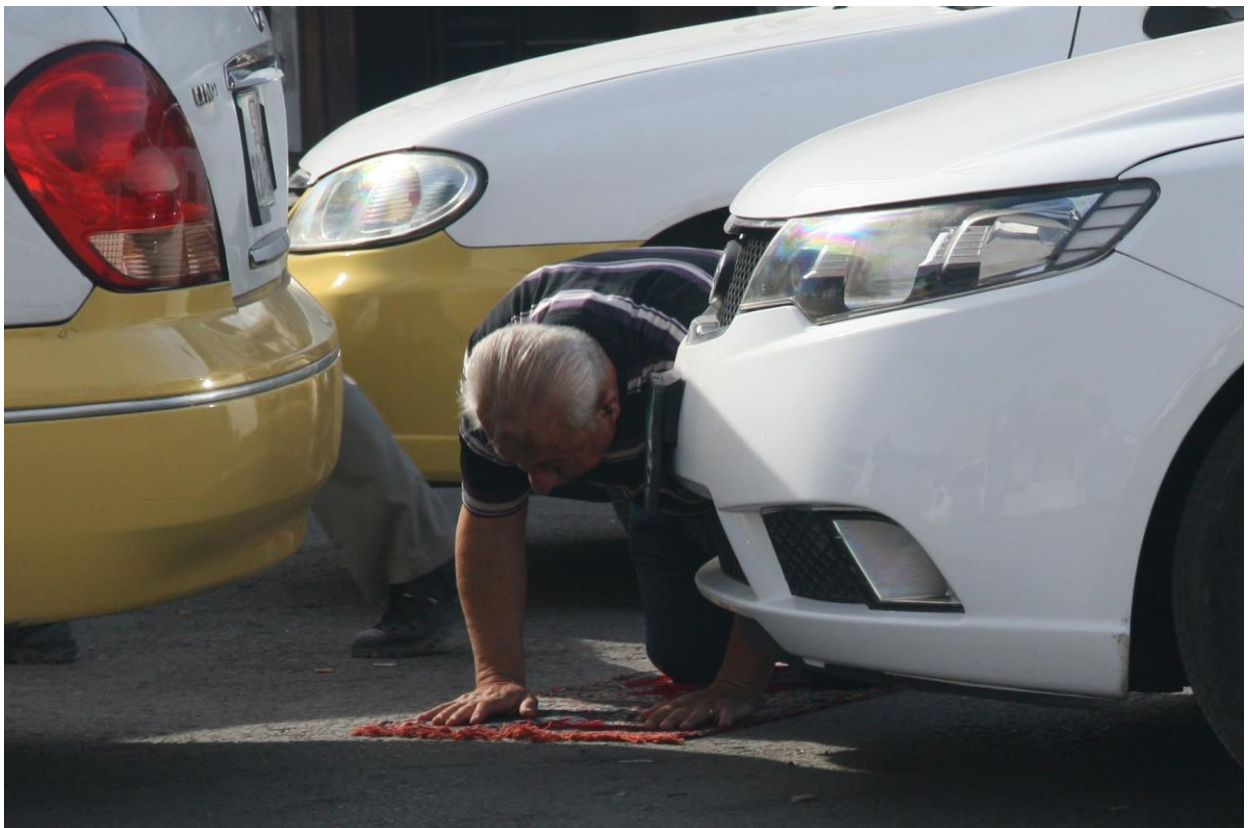


# Stuck?

A look at the daily lives of people with a limited mobility in Jordan



Master's thesis for the department of Geography, Planning and Environment, Nijmegen school of management

Klaas Wierenga

Supervisor: dr. R.A.H. Hoekstra-Pijpers

Second reader: dr. J. Schapendonk

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## Acknowledgements

I want to express my thanks to my supervisor, Roos Hoekstra-Pijpers, who wonderfully gave me the trust and feedback to finish this project. I could not have wished for a better supervisor.

I want to thank Ahmed Hariri, my relentless translator, who insisted on calling me an excellent researcher also when with great regularity an interview that I thought was arranged for, had to be cancelled, because of reasons that I had not foreseen. Without his help and friendship, his social network, his excellent English, his patience and his knowledge of the situation of refugees in Jordan, this research would have not been possible. It was Ahmed who introduced me to the community and rehabilitation centre Souriyat across borders.

I also want to thank everybody at Souriyat. Many of the patients were willing to be interviewed, but also did what they could to offer friendship in spite of the enormous language barrier. I admire their resilience and friendliness. I also want to thank the staff of Souriyat, and Yomen Ghalawingi in particular. Thanks to them, I always felt welcome to come to Souriyat, for work or just for a conversation. Thanks to their expertise and network I was able to interview many more people.

I also want to thank Ayoub Zuraikat , who greatly helped me understand the situation of people with disabilities in Jordan. More than anybody else, he was able to think with me and not only describe his own situation, but also come up with advice on how to proceed and who to interview and find information that was not accessible to me because of the language barrier. It was him, who for example pointed me to the existence of very recent census data. Local knowledge and academic thinking combined.

## Summary

This research tries to assess the consequences of transport shortfalls for people with a low mobility in Jordan, mainly people with disabilities.

These consequences are described in terms of the capacity for activity participation, a focus taken from social exclusion and capabilities literature. From Nussbaum's (2006) list of essential capabilities, 4 activities are deduced as mobility related indicators of essential capabilities: visiting friends and family, religious places, medical facilities and grocery shops. Inspired by embodiment literature on disabilities, not only the mere capacities for activity participation are studied but also the myriad of enabling and disabling preconditions.

The sample comprises people with many different kinds of health issues and several healthy people. The levels of mobility are very diverse. Transport inadequacies and non-participation are both easy to find. Buses for example are very hard to access with a disability and many people struggle to see their loved ones. But it remains hard to estimate the importance of transport as a cause for non-participation, as compared to the influence of mainly health and social stigma.

# 1. Introduction

## 1.1. *Ever growing Amman*

This research will assess the effect of shortcoming personal mobility on capabilities of people living in urban Jordan, mainly Amman. Mobility and transportation are issues of interest especially in Amman, because of poor infrastructure, congestion and a public transport system that needs updating.

In the early 1920's Amman was a small settlement with between 2000 and 3000 inhabitants; less than a century later, it is a metropole hosting almost 3.9 million urban residents in 2015 (Jordan. Department of Statistics, 2015; for a better historical overview of Amman's growth, see Potter et al., 2009). Much of this growth has been unplanned (Makhamreha & Almanasyeha, 2011) and occurred in shocks. Unlike most cities, the development of the city of Amman did not follow patterns in its economic function, but has mostly reflected political developments in the surrounding region (Potter et al., 2009). Because of its relative political stability, Jordan as a country and Amman in particular have over the years received refugees escaping violent conflicts in mainly Palestine (1948, and 1967), Lebanon (1975), Iraq (1991 and 2003 onwards) and Syria (2011 onwards). The burden of the Syrian crisis on Jordan's public expenditure and services is particularly heavy. Economic challenges preceded the refugee crisis, with annual GDP growth rates dropping from 5.5% to 2.7% between 2009 and 2012 (Dahi, 2014). In the years thereafter the estimated fiscal costs for the budget is 1.8 percent of GDP in 2013 and 2.4 percent in 2014 (Nasser & Symansky, 2014). A more recent study however states that largely thanks to international aid, Jordan has gained a net profit from the influx of refugees (Philips, 2016).

Apart from the sheer numbers of people it hosts, Amman seems to be strongly oriented to personal motorised transport: pedestrian-friendliness is poor throughout most of the city and only an estimated 30% less wealthy Jordanians ever use public transport (Potter et al., 2009). Many streets have slowly become more like highways than public spaces for social or economic interactions, with many lanes, few intersections and many tunnels and flyovers (Tawil et al., 2014). But even with these measures in place, large parts of the city are heavily congested, especially during rush hour. A report by UNHABITAT (2012) estimates the economic loss caused by congestion and delays to be USD 1.2 billion/year in Amman, compared to USD 85 million in Damascus, a city of more or less similar size (p. 60, these numbers are from before the Syrian crisis).

Although there is some government involvement concerning fares and routes of busses and service taxis, the city of Amman does not have a centrally planned public transport system. The need for better public transport has long been acknowledged and a Bus Rapid Transit (BRT) system was planned to open in 2011, but due to political disagreement and rumours of corruption, the implementation of the project remains unfinished until today (for an analysis of both the need for and the issues hampering the implementation of the BRT, see Shalan, 2013). Also a planned light rail system connecting Amman to the neighbouring industrial city of Zarqa was cancelled, this time due to lack of funding (Roy, 2009). Both projects now have an unsure status.

Not everybody is equally affected by the difficulties involved in moving about in Amman. This study is taking a closer look at a few intersecting groups that are more than averagely likely to experience transport problems: refugees, the poor and the disabled.

## *1.2. Theories: capabilities approach, mobility and disability*

This research will make use of theories about transport related social exclusion, handicap and capabilities. The capabilities approach has in recent years gained much attention. It is however a rather abstract approach, and consequently it needs a lot of operationalisation to find indicators for capabilities and apply the approach in empirical contexts (see for an example of an attempt at operationalisation Anand et al., 2009). Mobility itself is not mentioned as a capability in the most used list of essential capabilities by Nussbaum (2006). It is however a very interesting theme that plays a supportive role in many of the other capabilities as personal mobility greatly determines the possibility to undertake activities outside the home. Kronlid (2008) even argues that mobility itself should in fact be considered a capability.

Literature about social exclusion bears some resemblance to the capabilities approach, as it also moves away from monetary measures of deprivation and emphasises the importance of participation in activities or 'opportunities'. In literature about social exclusion, mobility has been a major theme (Church et al., 1999; Farrington & Farrington, 2005; Hine & Mitchell, 2001; Levine & Garb, 2002; Preston & Rajé, 2007). However, literature about the link between mobility and the capabilities approach is not yet very abundant, let alone empirical studies with operationalised indicators of the role of mobility in the realisation of (essential) capabilities. I am aware of only a few exceptions (Nordbakke, 2013; Nordbakke & Schwanen, 2014), but these studies are both about elderly people in Western countries. It is therefore both theoretically and empirically interesting to analyse the role played by mobility in the capabilities of people in a non-Western context. The literature body about transport related social exclusion hereby functions as an example.

Literature about disability is marked by a long lasting discussion between what are called the medical and the social model of disability (Mitra, 2006). The medical model treats disabilities as merely bodily issues, to which medical professionals provide both diagnoses and solutions. The social model locates the problem of disability in the social and physical context that functions to exclude people with bodily particularities. A much followed middle way provided by the WHO (2001) uses the concept of functional limitations to describe which daily activities are made impossible by the interaction between bodied and their environment. A very different approach is provided by embodiment literature on disability, which tries to portray an accurate picture of daily life with a disability. This paper tries to provide and use a partly synthesis between the approaches of functional limitations and embodiment, that tries to describe the contingent circumstances that enable or disable participation, which is useful also outside disability literature.

## *1.3. Social relevance and current events*

What makes this research particularly interesting today is the enormous numbers of refugees with disabilities. In Jordan, the UNHCR counts 656 thousand registered Syrian refugees<sup>1</sup>, but actual numbers are suspected to be higher, for example because the Jordanian borders have been closed for single Syrian men 'of military age' since 2013, forcing unknown numbers of refugees to enter illegally and remain unregistered (Turner, 2017). Among refugees both disability and poverty are very frequent. Many have liquidised the assets they were able to bring from Syria and used the money together with their savings in the first years in Jordan (Achilli, 2015). But already in 2013 a study by UN Women (2013) found that a stunning 47% of households' paid employment came from children. A study from 2014 revealed that 25.9% of Syrian refugees in Jordan have an impairment, and 8.4% was severely impaired. One in 15 Syrian refugees in Jordan has been injured as a result of war. These

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<sup>1</sup> As of 2017-02-01: <https://data.unhcr.org/syrianrefugees/country.php?id=107> retrieved 2017-02-11.

issues have a severe impact on the daily life of refugees: 18% of refugees has difficulty performing daily tasks (HelpAge International and Handicap International, 2014). The report often mentions a hampered mobility as one cause of difficulties with daily tasks. However the precise consequences of this issue have not been assessed. This research will try to get a better view on the consequences of hampered mobility in terms of participation and loss of capabilities.

#### **1.4. Questions and outline**

To sum up, this research will explore theoretically the relationship between mobility and the capabilities approach and it investigates the advantage of an embodied perspective on the functional limitations approach to disability, that studies the contingent circumstances that enable or disable participation. Empirically, this research tries to show the consequences of mobility issues for the participation levels of people in a non-Western context. In an attempt to address the aforementioned theoretical and empirical knowledge gaps, the following research question was formulated:

*Which essential capabilities are under threat for people with a reduced mobility in urban Jordan, as a result of difficulties in participating in activities?*

To analyse this question in more detail, it is relevant to distinguish between different kinds of mobility (pedestrian, motorised, public or private etc.) and between different kinds participation that are related to essential capabilities.

*Which modes of transport are most indispensable for making participation possible?*

*Which forms of participation are most vulnerable to a lack of mobility?*

*Which forms of participation are most urgently missed when impossible?*

*What do people themselves consider the greatest barriers to their participation?*

In parallel, the research gives a few preliminary answers to a few more theoretical questions:

*To which capabilities is mobility an essential precondition?*

*Can the study of enabling and disabling circumstances be a useful addition to the functional limitations approach to disability?*

The paper will start with an overview of the most important theoretical branches it makes use of: social exclusion literature, the capabilities approach and literature about disability. The methodology section tries to make this discussion more concrete, and uses the insights from the literature to create a set of both quantitative and qualitative research methods that can best portray the complexities of the relation between mobility and daily life of the target groups. After an elaborate discussion of the results, the last chapter briefly shows the main consequences of a limited mobility for participation and contains a discussion on the theories that inspired the research, the relevance of the empirical results and the methodology that was used.



## 2. Theory

### 2.1. Social exclusion

Many studies and discussion into the role of transport in social life, start from the theoretical framework of social exclusion and its relation to transport. The term social exclusion has been used to describe many different statuses and processes, some of which are not very different from more familiar terms like poverty, deprivation or the underclass. For this reason, some authors reject the term altogether.

In a very different response to this conceptual ambiguity, Hine and Mitchell (2001) have argued that the term 'social exclusion' is very useful, precisely because of the diversity of phenomena associated with it, which no other term could summarize. But the main contribution of the social exclusion framework seems to be a focus on networks. As there are social, economic and cultural networks, this focus implies a shift away from only material indicators of deprivation, but the material cannot be overlooked. Disconnection from economic networks can also lead to a lack of access to non-economic opportunities the network can offer.

A slightly different way of conceptualising social exclusion is offered by Burchardt et al (1999). Their starting point is that social exclusion is non-participation. Taking non-participation as the starting point, they arrive at the following definition:

*An individual is socially excluded if (a) he or she is geographically resident in a society and (b) he or she does not participate in the normal activities of citizens in that society (p. 230).*

This definition of social exclusion as non-participation is a much followed choice, perhaps because participation in activities can be easier to measure than membership of networks. Two difficulties remain: what are normal activities; and is every individual who does not participate indeed socially excluded?

The first question is a technical one, and can be answered by a list of normal activities in a particular society at a particular moment. Burchardt et al. (1999) provide such a list for Britain in the 1990's. Application of the same definition in a different spatio-temporal context would entail adaptation of this list. This adaptation is relatively easy for homogeneous societies, but for segregated societies with very different groups that undertake quite different activities, the process is a lot more complicated. When different activity patterns are shown: should the conclusion be that an entire social group is socially excluded? Or do different social groups mutually exclude each other although being very inclusive internally? How to prevent that social exclusion becomes just a complicated way of describing segregation? Burchardt et al. (1999) mention the example of the black population in South Africa under Apartheid, which was obviously excluded from power, and from some parts of society, but was it excluded from society as a whole?

The second question is a more theoretical and perhaps normative one. Because even when a clear cut list of normal activities can be drawn up, what can be actually said about those individuals who do not participate in them? Might they not be just uninterested? Do they have their alternative activities? Why should all individuals in a society have a similar pattern of activities?

Burchardt et al. (1999) also discuss the issue of voluntary non-participation, but they doubt its existence. Even self-declared voluntary non-participation might be instructed by hostility from the wider society, or by a very limited trust in one's own capacities. But the question behind this ambiguity is why social exclusion must be seen as a problem. If non-participation is a problem only

for the unhappiness of the individual, it is only involuntary non-participation that matters. If normal participation is considered to be in the interest of society, all – or all abnormal – non-participation is a problem.

## *2.2. Approach to handicap*

Although disability has only a partly overlap with social exclusion and mobility issues, the body of literature about disability does have some interesting and relevant views to offer. Therefore a short and non-exhaustive review of different ways to think about disability can be of help at this point.

What is usually referred to as the ‘old’ or medical model, focusses on health issues themselves. The patient is seen as having a physical problem that needs to be both precisely defined and fixed by experts. The best solution is the solution that brings the patient closest to ‘normality’ (Mitra, 2006; Haegele & Hodge, 2016). This model has provoked a storm of critique, because it is alleged to put people with disabilities in a ‘sick role’ (Parsons, 1975 in: Mitra, 2006). This role is professionally established to fit the categories of health professionals, without much consideration of the experience of the ‘owner’ of the disability (Marks, 1999) and reinforced by the perception of society at large (Brittain, 2004). But perhaps the biggest problem: the importance attributed to medical knowledge has given the professionals not only the power to decide on the categories of disability, but also on their solutions. As a result, solutions are looked for in the domain of the adaptation of the disabled body, and not in the domain of societal improvements (Brittain, 2004; Mitra, 2006).

Most opposite to the medical model is the social model of disability. It is however a little delusionary to call it one model, as it appears to be more a collection of critiques to the medical model. A categorisation of these critiques is given by Pfeiffer (2001, in: Mitra, 2006). They share however some important arguments, which start at the conceptual separation of impairment and disability (Haegele & Hodge, 2006; Bingham et al, 2013). Impairment is seen as a physical attribute of the individual that is not inherently disabling, but disability is alleged to be a social construct. It is society that imposes disability on individuals with impairments (Haegele & Hodge, 2016; Mitra, 2006), curbing their full participation both with physical obstacles and cultural resistance (Brittain, 2004). Because the social model finds the nature of disability in society, social change is its proposed solution. This approach has been criticised for ignoring the day to day experience of having a disability. This day to day experience could teach us at least two things: that for people who have a disability, this is an “essential aspect of their lived experience” that is not reducible to societal oppression (Haegele & Hodge, 2006) but at the same time this lived experience varies greatly from person to person (Marks, 1999), depending for a large part on the much neglected agency of people with disabilities (Paterson & Hughes, 1999).

A much practiced middle way between the extremes of the medical and the social model is based on the concept of functional limitations. First coined by Nagi (1965, in Mitra, 2006), this term refers to “an inability or limitation in performing socially defined roles and tasks expected of an individual within a socio-cultural and physical environment” (p. 315). In this view, disability is one possible last stage, in a three stage process of pathology, impairment and disability. Pathology describes interruptions of normal body processes, an impairment describes limitations in the performance of certain tasks, and disability is only manifest if that bodily task is necessary in the environment and the social role of the individual (Bingham et al., 2013). This approach bears great resemblance to the definition of social exclusion as non-participation by Burchardt et al. (1999) but with two important alterations: it is not the actual participation that matters, but only the ability to participate, and secondly this ability is only relevant on the basis not only of the local culture but also the role of the individual in that culture. This sensitivity to cultural contexts has great implications: the social

environment determines which social role is desirable for the individual and thus whether an impairment is relevant enough to call it a disability.

The 'middle way' between the medical and the social model offered by functional limitations has been thoroughly elaborated by the WHO (2001) in the International Classification of Functioning, Disability and Health (ICF) (the former International Classification of Impairments, Disabilities and Handicaps, ICIDH). Again, impairments are mere bodily problem, but what follows are called activity limitations (an activity being the execution of a task or action) and participation restrictions. In this model, participation does not refer to the performance of a social role but to involvement in a life situation (Mitra, 2006).

Because the WHO developed this model mainly as a classification tool, the role of the psyche in shaping the truly very personal experience of living with a disability is not its first priority. This lived experience is the focus of another approach to handicap, which comes from the phenomenological perspective of embodiment. In an attempt to overcome the sharp controversy between the medical and the social model, Marks (1999) defines disability as "the complex relationship between the environment, body and psyche, which serves to exclude certain people from becoming full participants in interpersonal, social, cultural, economic and political affairs" (p. 611). Here, the explicit reference to the psyche creates explanatory flexibility to explain why individuals with very similar disabilities, living in the same environment, can nonetheless have very different experiences of living day by day with a disability. "Embodiment is a dynamic, lived position that intersects mind, body, emotion, social, self and other, and operationalises new and challenging forms of representation and articulation" (Inckle, 2014, p. 389).

One important virtue of the embodiment perspective is the shift away from the binary analysis of functioning. The WHO model of functional limitations tries its best to accommodate many experience focussed functionings, like being able to walk in public without feeling ashamed. But its essential limitation is that it consists out of binaries: an individual is either capable or incapable of a functioning. This makes the model practically applicable, but however complicated, it struggles to capture some essential aspects of the experience of living with a disability. Inckle (2014) for example describes what she calls the paradox of '(in)visibility': "This paradox operates so that while on one hand(!) a visibly disabled person is always hyper-visible as a spectacle of the Other, at the same time, and by the same process, we are simultaneously denied the platform of self-representation" (p. 391). But experiences like this are rarely without exceptions. Incorporating a phenomenon like this in a binary model of functional limitations, would involve asking people with disabilities the question: are you able to represent yourself (in certain contexts)? And the true answer would take forms like: sometimes; if I really want to and put in the necessary effort which is only when I had a good night sleep; only when my sister is there too; not when this bully from across the street is there; not in summer, when it's too hot to wear long clothes etc.

### 2.2.1. Lesson from handicap literature

In this research, constrained mobility is the starting point, not disability. This is important because the task of this research is not to describe disability, whether as an accurately classified set of functional limitations or as an embodied experience or yet otherwise. But disability literature does offer some interesting lessons that can form an inspiration for renewed discussion about social exclusion.

First, we can learn that social exclusion resides both in a particularity of the excluded and in a structure that is part of society as a whole. Society has a strong inclination to 'fix' abnormalities.

“Contrary to received wisdom, the reversal of segregation can mean the exacerbation of xenophobia and prejudice [...] Integration is not a celebration of difference, but assimilationism, an anthropophagic form of social control ...” (Paterson & Hughes, 1999). However, when we advocate the right to be different in name of an excluded group, it is important not to ignore the differences within that group. One shared abnormality does not make a group homogeneous, nor does it miraculously solve the human desire for homogeneity.

Because exclusion is an interplay between the individual and the environment, studies of exclusion can also focus on two levels: on the macro level, we can study the structures that function to hamper the participation of the abnormal, and on the micro level it is important to look at precisely what effects this exclusion has on the people in an excluded group. This way, we make sure not to lose sight of the agency of excluded people, both individual and collective.

The study of functional limitations and participation is a useful tool to study both exclusionary mechanisms and consequences of exclusion for the individual. But the focus on the ability to perform tasks struggles to do justice to daily reality, partly because performing tasks is not the only thing that matters, partly because the ability to perform tasks is rarely constant and mostly depends on a myriad of contingencies, among which there are ambitions, priorities, effort and willpower. Few things are truly impossible. In most cases, the question is which ambitions we find so important that we are willing to put in the necessary effort and persistence.

### 2.3. Capabilities

The capabilities approach includes many of the lessons learnt from disability literature. Like the Nagi approach and the WHO framework, it ascribes great importance to the ability to perform day to day tasks, but immediately it stresses the importance of individual freedom. The capabilities approach is about opportunities of “what people are actually able to do and to be” (Nussbaum, 2006, p.70). It is important to note that capabilities are opportunities. The task of governments lies in creating capabilities, not functionings.

The emphasis on individual freedom runs through the entire theory and is underlined by its dual focus: on the one hand, Nussbaum (2006) gives a list of 10 essential capabilities, that each individual should have in order to live a life of human dignity. This list makes the theory more or less applicable in real life (in contrast to Sen’s version of the theory (1993), which in principle values all capabilities equally). But on the other hand the theory stresses that its core is the claim that every individual must have the real opportunity to pursue his/her idea of the good life. This way the approach inherently values the agency of the individual, however oppressed or excluded.

The list of essential capabilities is as follows:

1. *Life – Able to live to the end of a normal length human life, and to not have one's life reduced to not worth living.*
2. *Bodily Health – Able to have a good life which includes (but is not limited to) reproductive health, nourishment and shelter.*
3. *Bodily Integrity – Able to change locations freely, in addition to, having sovereignty over one's body which includes being secure against assault (for example, sexual assault, child sexual abuse, domestic violence and the opportunity for sexual satisfaction).*
4. *Senses, Imagination and Thought – Able to use one's senses to imagine, think and reason in a 'truly human way'—informed by an adequate education. Furthermore, the ability to produce self-expressive works and engage in religious rituals without fear of political ramifications. The ability to have pleasurable experiences and avoid unnecessary pain. Finally, the ability to seek the meaning of life.*

5. *Emotions* – Able to have attachments to things outside of ourselves; this includes being able to love others, grieve at the loss of loved ones and be angry when it is justified.
6. *Practical Reason* – Able to form a conception of the good and critically reflect on it.
7. *Affiliation*
  - A) Able to live with and show concern for others, empathize with (and show compassion for) others and the capability of justice and friendship. Institutions help develop and protect forms of affiliation.
  - B) Able to have self-respect and not be humiliated by others, that is, being treated with dignity and equal worth. This entails (at the very least) protections of being discriminated on the basis of race, sex, sexuality, religion, caste, ethnicity and nationality. In work, this means entering relationships of mutual recognition.
8. *Other Species* – Able to have concern for and live with other animals, plants and the environment at large.
9. *Play* – Able to laugh, play and enjoy recreational activities.
10. *Control over One's Environment*
  - A) *Political* – Able to effectively participate in the political life which includes having the right to free speech and association.
  - B) *Material* – Able to own property, not just formally, but materially (that is, as a real opportunity). Furthermore, having the ability to seek employment on an equal basis as others, and the freedom from unwarranted search and seizure.

(Nussbaum, 2006)

The precise implications of the capabilities approach for issues of mobility are mentioned and operationalised in the next session about methodology. Here it is important to give some attention to an important theoretical nexus between capabilities and mobility, which is formed by Sen's theory of access. In Sen's original study (1981, in: Preston and Rajé, 2007) of the Bengal famine, he states that the cause of the famine was not the absence of food, but poor people's lack of access to it. Preston and Rajé (2007) apply this statement to social exclusion: "social exclusion is not due to a lack of social opportunities but a lack of access to those opportunities" (p.153). A similar thing can be said of capabilities: capability loss is due to a lack of access to social opportunities. This makes the theory of access or accessibility very central to this thesis.

Following Farrington & Farrington (2005), accessibility is defined here as "the ability of people to reach and engage in opportunities and activities". As this definition shows, being able to reach and to engage are equally important. Distance as a separation in Euclidean space is only relevant for the ability of people to reach opportunities and activities. The ability to engage is determined by other factors, like age, gender, ethnicity, cultural values or income. When mere distance prevents people from reaching opportunities and activities, this spatial separation may be overcome by many different means, such as telephone, or internet, or mobility. When mobility by foot is constrained or insufficient, transport can play a role. In sum: transport is one but not the only way to increase mobility; mobility is one but not the only way to overcome spatial separation; and spatial separation is one, but not the only constrain to accessibility.

In this thesis, only spatial separation is under scrutiny, and only mobility as a way to overcome it. This allows me to use the discussion on the relation between accessibility and mobility offered by Levine & Garb (2002):

*'Mobility' is defined here as ease of movement; accessibility is defined as ease of reaching destinations. The concepts are related, but readily distinguishable. Where destinations are close by, great accessibility can be afforded even if mobility is constrained; where destinations are remote, mobility may be high without concomitant high-level accessibility (p. 197).*

(The “ease” with which an individual reaches a destination is defined as the generalized costs, which is a way to capture both the time and money spent on travelling in one figure.)

According to this theoretical difference, mobility and accessibility are fundamentally different goals. On the one hand, accessibility may be considered the ultimate goal of mobility, and it may even be hindered by the congestion that can result from high mobility. On the other hand: accessibility as a policy goal prompts the political question of which destinations should be easy to reach, whereas mobility leaves the choice of destinations up to the individual.

Two side remarks: mobility is often defined as moving behaviour instead of ability to move. For reasons of clarity, moving behaviour is here referred to as movement, and mobility means ease, i.e. generalised costs of movement. As a consequence, an increase in mobility is not necessarily reflected by a growth in movement. Besides: lack of transport opportunities is a relative idea. Transport can always be quicker, cheaper, closer, more comfortable or accessible etc. In a certain sense, almost every individual has a lack of transport opportunities, that limits activity participation.

### 3. Methodology

#### **Philosophical assumptions or worldview**

The purpose of this study is to show the way in which - and the degree to which - limitations in people's mobility can cause social exclusion in Jordan, social exclusion being defined as non-participation. The main target group of the study is people with impairments, because they very often face constraints to their mobility and they are relatively easy to find and identify. But the mobility of able bodied people is in its own way constrained and as such relevant to the study.

Much literature about social exclusion and disability has been written from a transformative worldview and methodology, as elaborated by Creswell (2013). When Mertens (2003) describes transformative research, the participants or even 'the community' forms the starting point for the research and the issues of interest are those problems that the informants themselves select as being important. Also the research methods and the ways in which the results are communicated largely depend on the opinion of the target group.

There is no such thing as a community of people in Jordan with a limited mobility, and even as a category, these people are very diverse.<sup>2</sup> Perhaps the biggest problem of people with mobility limitations in Jordan is not social exclusion but something else. There is no pretention in this paper of addressing the most fundamental or most important issues of the target group. The issue of study was chosen from a theoretical interest in the consequences of limited mobility. People with impairments are an important target group but not the only one. There is no target group that defines the problem; the problem defines the target groups.

#### **Methods and operationalisations**

Much research about mobility, accessibility and sometimes also transport related exclusion has used either of two measuring instruments, known by the terms Potential Path Areas (PPAs) and Action Spaces (ASs). PPAs are a way to circumscribe the area that an individual can reach, given the constraints posed by time, road networks and transit availability etc. It was developed first in time geography. The term Action Space on the other hand refers to the set of locations 'with which individuals have direct contact as the result of day-to-day activities' (Horton & Reynolds, 1971). The term stems from behavioural geography. For an extensive overview of both concepts, their variations and different modes of operationalisation, see Patterson and Farber (2015).

Both terms derive their relevance from the assumption that many activities have a specific geographical location, and the more of these locations are within easy reach, the more activities are at one's disposal. The term Potential Path Area is perhaps more obviously about the potential to reach certain places, but AS can be used for similar purposes. As it describes the areas that directly surround places we visit daily, all locations within an AS are familiar to us, and require only a minor change of daily routine to visit. Both instruments are therefore suitable to measure the ability to

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<sup>2</sup> An often coined critique on populism accuses it of falsely picturing 'the people' as a perfect unity that is under threat of external individuals or groups. The circular argument is perfected when individuals or groups are seen as external because they threaten the real 'people' (See for example Pels, 2011). I think a similar critique can be applied to some of the emancipatory literature about disability. There is no such thing as the disability community, united against everything that threatens its members. As one of the respondents of this study said: *"a disability is a very personal thing. So my disability is my problem"* (Informant 4, Personal Communication, 2016-04-13).



participate, not actual participation. This is arguably more respectful to the freedom of choice of the individual attached to the impairment.

But the use PPA's and AS's also comes with a few theoretical problems that need mentioning. Although the PPA is a constraint-based measurement instrument, it produces a dichotomous outcome: an opportunity is either inside or outside the PPA, and thus, the individual is either able or unable to reach it. In reality, the ability to reach most places is far more a matter of priority, and it would be more interesting to know what sacrifices would be necessary to participate in certain activities. Is it painful? Will it make someone else very angry? Is it exhausting? Is it complicated to sort out? In short, we need to know the costs of participation, not only in time, but also money, effort, shame, pain, uncertainty etc. And we need to know if there are certain conditions that make it easier or harder from one moment to the other? The neglect of the limiting role of money (travel fees, fuel costs) is all the more remarkable, as most studies spend much effort on incorporating the limits imposed by distance and time budget (for example Kwan & Hong 1998), and some do even analyse the effect of income (Casas et al., 2009).

Apart from these complexities, the relevance of PPA's or AS's is still subject of discussion. Is a big PPA or AS a good thing? AS's primarily analyse movement, not mobility. Movement itself is a desirable thing only if we talk about joy-riding. In most cases, movement is just a nuisance that costs time, money, congestion and emissions. PPAs on the other hand are about mobility which is more relevant. But still the size of a PPA cannot say what is really interesting: which desired destinations can and cannot be easily reached? Some PPA studies have tried to solve this issue by combining a geographical PPA with data on "opportunities". This approach however still forgets two things: of many opportunities an individual needs only very few (e.g. grocery stores). More opportunities is not necessarily better: more diverse opportunities is better. Secondly, some very important "opportunities" are the houses of friends and family. They are not on locations that are the same for every respondent.

Apart from these issues, the application of PPAs and ASs is rather demanding. Reconstructing AS's, involves collecting information about all the locations where people go in a given time-slot. This used to be done using travel diaries, a method that is now gradually replaced by the use of GPS-trackers. Both methods make the data collection very demanding. GPS-trackers are simply expensive and recollecting them after the research period would involve going back to all informants after the research period. This was simply impossible. Using PPA's adds the difficulty of constructing a geographical area that is within reach, given a certain time budget. This is a difficult task in Jordan, as walking time is unpredictable because of slopes and poor infrastructure, travel time with public transport is unpredictable because there are no schedules, and even trip duration by car is hard to predict because traffic is very variable.

Another problem is the availability of data on "opportunities". In many Western countries it is more or less feasible to create lists of different kinds of businesses in a given area using the yellow pages. In Jordan, such a method is much more difficult. Although there is a yellow pages website for Jordan, it is much harder to find addresses, or see on the internet what a business exactly does. But what's more important: businesses do not create the only interesting opportunities. The capabilities approach that forms one of the starting points of this research, instructs for a much broader focus.

Because of all these reasons, this research will not construct PPA's or AS's. Instead, the method is kept much simpler and mainly consist of a questionnaire, that allows to directly ask individuals whether or not they can reach different opportunities. This way, it is up to each individual respondent to determine if geographical vicinity is a sufficient condition for an opportunity to be



within reach. In an attempt to escape the dichotomy between being able or unable to reach destinations, respondents of the questionnaire were also asked about the costs of reaching different opportunities and about what conditions can make it either harder or easier to do so.

In addition to the questionnaire, the research set-up contains in-depth interviews, which help to interpret the results of the questionnaire. The questionnaire contains mainly closed questions, and the results are analysed statistically. This approach yields interesting statistical relations, but statistics are not enough to prove causalities, let alone understand more complex networks of interlinked phenomena. The in-depth interviews are an attempt to fill this gap. Besides, the interviews shed some light on the aforementioned embodiment of living with an impairment in Jordan. This portrayal is supported and made more vivid by some visual imagery of infrastructure and public transport in Amman. Together, these three methods create an image of the subject, that hopefully does some justice to it.

The research design used in this study looks most like a case study. The general phenomenon under scrutiny is transport related social exclusion. The case is that of people with a constrained mobility, living in Jordan. The methods used are diverse, both quantitative and qualitative and meant to supplement each other (Creswell, 2013).

Furthermore, the research is largely deductive. Theory provides the central assumptions and hypotheses, which strongly determine the collection of data. The theoretical concepts and hypotheses are operationalised to work in a specific context and tested, which renders some comments on the theory (Saunders et al, 2011).

The use of qualitative methods does however leave open some opportunity for unexpected outcomes, outcomes that might not fit the categories of the initial theory. In this case the research might include 'a whiff of induction'.

### *3.1. Structured interviews / questionnaire*

The choice for a questionnaire was a compromise between a very quantitative approach on the one hand and a qualitative approach on the other. Questionnaires offer the chance to ask both open and close ended questions. As a result, they can at the same time provide data that can be very easily compared and more interpretative information (Saunders et al., 2011). This was needed to analyse both the differences in abilities to perform certain tasks as the reasons behind those differences.

A questionnaire takes little time of both informant and translator, which allows the researcher to interview a larger number of informants. In this case, a large number of informants was desirable, not so much for a statistic analysis, but because disability can mean anything from an amputated finger or one malfunctioning eye, to complete paralysis. The resulting constraints in mobility also vary not only in degree but also in nature. In order to do at least some justice to this enormous variety, I needed to interview many different people.

Of course, I could have chosen one specific type of disability and interviewed a smaller number of informants with very similar disabilities, hoping the effects on their mobility were also more or less similar. That would have resulted in a greater internal validity: more in depth knowledge about one specific category of informants. There are however two drawbacks to this in depth approach: first it would have made finding the right informants even harder than it was now. Moreover, it would have partly eroded the external validity of the study, making it harder to say anything about the more general issues of mobility and disability in Jordan. Considering the scarcity of literature on mobility

and disability in Jordan and the Middle East in general, a more explorative approach seemed justified.

Another practical issue was the language barrier. Doing a questionnaire with a translator is easier than interviewing more in depth, because both the questions and the answers are less complex and need less explanation. This also reduces the risk that information gets lost in translation.

### **3.1.1. Finding and selecting informants**

In order to assess the influence of a limited mobility on a people's patterns of activities, I wanted to interview a range of people whose mobility was limited to various degrees. This is why people with impairments are an interesting target group for this research. Bodily impairments appear in many different forms and even very similar impairments can affect people's lives in many different ways. A limited mobility is a relative term, there is no such thing as unlimited mobility. People who can go anywhere they want, as often and quickly as they want, do not exist. To capture as much as possible of the range of people with different degrees of mobility, it is also interesting to include able-bodied people in the sample.

#### **Bias**

Finding informants was a problem. Because of the cultural stigma, many people with a handicap are more or less hidden away. As a result, all my informants belong to the fraction of people who are not too afraid to show and discuss their disability with a foreigner. I have no idea of the size of this fraction, relative to the total number of people with a disability in Jordan. The only clue I have, is that the problem is bigger among Jordanians than among Syrian refugees. Many of the Syrians have disabilities resulting from war injury, and there is less of a stigma on injuries than on disabilities from birth. But the problem remains that in both samples there is a certain bias, and it is very hard to estimate its size.

On the one hand this bias has a clear advantage. Most of the questions in the questionnaire are about mobility issues and the use of public transport. People who are hidden away by their families because of their disability have very little to say about their use of public transport. On the other hand though, the result is a thesis about mobility issues that highlights the problems that only a certain share of the population with disabilities is facing. While reading the rest of this thesis, it seems good to keep in mind that for many disabled people it does not tell the core of their problems.

#### **Searching and creating a network**

My best chance to find informants with disabilities was to use the help of Handicap International, an international NGO that organises medical care and rehabilitation for people with disabilities. I was unlucky though, as the local office told me they did not have the time and resources to help me find informants.

In the meantime, I was trying the snowball method. I slowly found my way into a network of health professionals specialised in disabilities. My translator introduced me to a community centre hosting several dozens of injured Syrians, most of them in the process of recovering and rehabilitation from war injuries. Many of them were my first informants.

From there I tried to get contacts of as many professionals as possible, asking if I could interview some of their clients. As a result I was able to join a few medical missions to various places outside Amman, where I could interview some patients when they were waiting to receive free medical care. This seemed ideal, but on most of these days there were few patients who actually had a visible

disability, so it was difficult for me to decide who to interview. And the second problem was the availability of translators, as most of the bilingual people were needed to translate for the doctors.

Later I tried to find some informants in a hospital that treats many Syrian refugees with war injuries. Most of the hospital patients had recently become injured, and were not able to tell me much about life with a disability in Jordan. So I was hoping to find a physical therapist, treating people who did not sleep and live in the hospital, and had more experience with living with a disability in Jordan. Physical therapy was given in a special small office that was closed on most days, and it was run by handicap international. So I also gave up on that.

At this stage I directed all of my attention to finding Syrian refugees with disabilities. They were the main focus of the research. The other groups - Jordanians, both with and without disabilities, and able bodied Syrians - were a little less essential to the research as they were only control groups. As I was not sure if I would be able to interview all these groups, I planned to search for the less essential groups when the most important work was done.

That was a mistake. Towards the end of the research time, the networking effort started to pay off, but then I had to do interviews with many different groups of informants all at the same time. And besides: Jordanians with disabilities appeared to be even harder to find than Syrians, because I didn't know any places where they gathered or lived together. As a result, the sample contains 4 Jordanians (compared to 37 Syrians). This was one of the most important things I have learnt: to better plan the different tasks, doing simple ones when the complicated ones still need more preparation.

## **Selection**

Because the main focus of the research was on mobility disability, I specifically looked for people with bodily impairments that are likely to hinder mobility. At first consideration this may seem a rather straightforward category, that is also rather easy to spot. People in a wheelchair are very likely to be very constrained in their mobility. But actually many kinds of impairments can result in a mobility disability. In my experience, the most frequent exception was spinal injuries. Several times I started an interview supposing I was dealing with a fully able bodied informant. But when asked about health issues, the informant explained that mobility was an pressing problem because of spinal injury. As a result, in medical facilities, I did not need to be very selective in who to interview. If I could not see any issue that could affect mobility, there was always the chance that a less visual issue would occur. And if not, I could still include somebody as an able bodied informant.

After all, physical impairments are not the only possible reason for not being able to travel as much as would be desirable. It is interesting to see if the reason why mobility is hampered, matters for the effects. On that account, also able bodied individuals were included in the sample. The able bodied informants were selected without any specific logic or criterion. Some of them received medical care from a mission that I joined. Some of them were shop owners that happened to be in the vicinity and available for an interview. Some of them were friends of mine or of my translator.

## **Women**

At first instance, I planned to exclude women from the sample. Women in many Arabic countries face not only physical or financial limitations to their mobility, but also cultural restrictions. Telling apart which restrictions have a purely practical nature, and which are of cultural origin would require a full study on itself, with a very different theoretical background and methodology. For the sake of clarity, it would be easier to leave women out. Apart from that, most of my interviews were

translated by a man. I did not want to risk intimidating women by approaching them with two men, asking for an interview.

In the course of the research however, I came across two women, who tempted me to make an exception. My main reason for these exceptions was that these women lived on their own, instead of with family. This meant it was completely up to them to decide when and where to go. Both of them led very active lives, with many activities out of the home. Their experiences with mobility were too valuable not to record. And fortunately both times there was another woman willing to translate.

### 3.1.2. Questions and their evolution

This research tries to describe and analyse the interlinkages between disability, constrained mobility and non-participation. This parallels the chain of impairment, disability and handicap. When a bodily impairment makes a person unable to make use of public transport, we can speak of a disability: a misfit between a bodily impairment and the way in which most societies have organised their long distance mobility. If this disability prevents people from taking part in activities that are considered normal, the resulting social exclusion can be described as a handicap.

The questionnaire had to provide some more clarity into patterns of impairment, constrained mobility and social exclusion, and their interlinkages. The first step towards understanding these patterns is the selection of good indicators. There is no use in asking people whether they are socially excluded. When these patterns of impairment, mobility and exclusion are more or less clear, it becomes possible to search for linkages between them, first by simply comparing patterns. Are people with a constrained mobility more often socially excluded? But it is more interesting to also make people themselves reflect on the causes of their constrained mobility or their social exclusion, of course without using the term.

The process of translating these abstract concepts into common language questions is the subject of the next few paragraphs. In the first few interviews, the questions were tested and adapted. Some of the questions were still too complicated or turned out to be completely irrelevant to the informants. During the research time I kept changing details in the phrasing of the questions, trying out which phrasing was the easiest to understand for the informants. Here is an overview of the main theoretical concepts, and how they were translated into a questionnaire.

#### **Impairment**

As mentioned earlier, I decided to include people with all kinds of bodily impairments in the sample, because there are many impairments that can result in a mobility disability. As a result, there was no need to precisely assess or categorise the type of impairment in the questions either. So I just asked the informant to generally describe his/her health.

#### **Mobility disability, movement and mobility**

The first theoretical concept that needed an indicator was mobility disability. In second instance, I wanted to know if and how far the informant could walk or otherwise move independently. This seemed to be an easy way to reduce the enormous variety of issues indicated by the word mobility disability into one single indicator.

However, it turned out to be a very hard question to answer. Many people have no idea how far they are actually able to walk because they have never tried. For others walking uphill or downhill is almost impossible even though walking on flat surfaces is perfectly fine. Terrain matters, as do traffic

and obstacles. Some people can walk where ever they want, as long as somebody accompanies them. So this question was too simplistic.

In the course of the interviews I quickly changed the question to: what is the limit for distances that you cover walking as opposed to using (any form of) transportation? This was much easier to understand, but as a result some informants gave me an idea of the actual limits of their bodies, others just told me how lazy they are, or what is efficient for them. So most of the answers were not anymore about what is physically possible, but about what the informant usually does, about movement instead of mobility.

Both movement and mobility turned out to be easier to study where it concerned the use of public transport. Of various ways of public transport, I asked every informant if it was possible to make use of it, and if they ever did. In most cases, the answer was a clear yes or no. For some people however even telling if they were able to use a certain mode of public transport was quite complicated. For example: a blind person is able to make use of taxis but only under certain conditions: somebody else must wave down the taxi, and the driver must be very sure about the destination, because the blind person cannot tell the driver when to turn left or right. Similarly, some people can make use of busses, but not in rush hour, because they need a place to sit down.

This problem was more or less mitigated by questions like: do you ever experience problems with using transportation? Are there moments that you would like to use a certain mode of transport or reach a certain destination but you are not able to? Scarcity of time and money were mentioned many times as problems, but also problems related to disability.

### **Participation and capabilities**

Finding out the effects of hampered mobility on participation was the most important goal of the questionnaire, which is why there were nine questions in it that had this purpose. This large number had a clear cause: the double focus of the capabilities approach (Nussbaum, 2011). On the one hand, the capabilities approach provides a list of most essential capabilities; on the other hand it emphasises the importance of a positive freedom to make life choices and act upon them.

Most of the questions in the questionnaire were about the list of essential capabilities. Some of these capabilities clearly require mobility. Checking the reachability of destinations related to these most essential and mobility related capabilities seemed a good first step.

- In the list of essential capabilities, the second capability is bodily health. To guarantee bodily health, every individual should be able to access medical care, which usually involves going to a doctor, clinic or hospital. Thus, the questionnaire should check if respondents are able to reach any such opportunity.
- Capability number four is Senses, Imagination and Thought. This capability includes both the right to education, and religious expression. Because both education and religious expression are often practiced out of the home and involve some travelling, the corresponding destinations – schools, and religious places – were included in the ‘checklist’.
- The seventh essential capability is affiliation. This includes among other things the ability to relate to and live with others. This ability has a mobility component, as one should be able to at least sometimes visit some loved ones. It is relatively complex though, because even individuals with the greatest possible mobility are not able to visit all their loved ones at all times. In the case of medical facilities or religious places, we can perhaps say that being able

to reach just one random location does justice to the capability. With friends and family, this does not work. This is another case in which the simple dichotomy between being able or unable to visit loved ones is far too simple, but the follow up question (see below) did yield some useful information.

- The tenth and last essential capability is control over one's environment, of which one component is the ability to pursue and own property. This capability too is rather complex. We cannot maintain that every individual should be able to pursue any kind of property. Because this study is mainly concerned with the mobility components of capabilities, this capability was operationalised as the ability to reach shops.

These four activities have been selected as indicators for non-participation and loss of capabilities. Of course they are a very minimal reflection of the sheer inclusiveness of the capabilities approach, but they are an indication of the capabilities that most obviously require mobility.

As said earlier, what is most interesting to find out is whether people are able or unable to take part in different activities, but to what costs and under which conditions they are. In order to get a better view on the costs of reaching different activities, respondents were asked both how much time and how much money they would spend on a two way journey to reach them. It would have been nice on this basis to also construct an approximation of the mobility of each respondent (mobility being defined as ease of movement, i.e. costs per km in both time and money) but this requires also more accurate data on distances. Besides, such information is only useful if also the time and money available to informants are known and it is possible to say anything about the share of their budget, that informants spend on transportation. Now thought, the answers are good enough to compare destinations on the basis of how much time and money it costs to reach them.

Apart from essential capabilities, Nussbaum (2006) stresses the importance of personal freedom. Every individual must be able to determine his/her own priorities on what opportunities matter to him/her. Coming up with only a checklist of a few predetermined activities would certainly not do justice to this aspect of the capabilities approach.

Therefore, the questionnaire ends with a more open question about personal freedom. Respondents were asked to imagine their mobility was suddenly restored to normal levels. This question was adapted to each respondent, and was sometimes about owning a car and unlimited fuel, sometimes about being healthy again or having more spare time. Initially I asked what the informant would do first with a car, as I believed this would yield information about which activities they missed most. And perhaps I was only too right about that. The first answers I got were about one-off unique trips to touristic locations. This of course shows a trend: people with disabilities usually miss doing trips and tourism. But I wanted to know what would change in normal circumstances, eliminating all other factors. That's why I decided to change the question to focus on daily life. Looking back I think asking both – what would be the first thing to do with a car, and after that, what would change in daily life – would have been the best way to assess the loss of capabilities caused by constrained mobility.

### **(Almost) irrelevant questions**

Just before I started interviewing, another question was added after a suggestion by Peter Damrosh, a researcher on public transport in Amman. He wanted to know how residents of Amman find their information on public transport. There are no maps or time tables or anything of that sort. I added this question, and it was striking to see the cultural difference unveiled by it. Every single one of my informants looked a little confused when first confronted with the question. For them it was only too

obvious how you find out where the bus goes: you ask the person standing next to you at the bus station. And if by asking you cannot find out the exact details you need, you just try.

Another question that showed my initial unfamiliarity with the culture and way of living in Jordan was the question about transporting goods. I wanted to know how a handicap would affect a person's ability to acquire the objects he or she needs. When I first came to Jordan, I discovered that the gas used for cooking came from large and heavy tanks. So I took the gas tanks as an example, wondering how a disabled person would ever replace it, when it had run out. But Jordanians seldom live alone, and especially people with disabilities rarely leave their families. And apart from that, the tanks were delivered by small trucks, and the drivers often carry them as far as to the kitchen. So the answers were rather predictable: in the vast majority either the truck driver or a family member would carry the tanks. The stories for other large objects were very similar.

### **Lessons**

Throughout the process I learnt a perhaps obvious but important lesson: a questionnaire needs testing. Before I started using the questionnaire I had showed it to several experts and asked for feedback, but they had as good as no comments. But only a couple of interviews were enough to discover a couple of deficiencies, mostly because the phrasing of the questions was still too abstract and theoretical.

Another mistake that I made was to make changes while conducting the interviews. The advantage is that the new question is not again a theoretical one, designed at a desk. But this comes with a drawback: the theoretical consequences of changing a question are not immediately clear. This is what went wrong when I changed the question about walking distance from what distance people are able to walk to what distances they usually cover by walking. A similar thing happened with the question about owning a car. The initial question – where would you go first – was not flawless, so I changed it into what would change in your daily life. Both question have their strengths and weaknesses, so I wish I had kept them both.

### **3.1.3. Recording and analysis**

#### **Recording**

As mentioned earlier, most of the interviews were done with a translator. I had several acquaintances who were able to translate, so I asked whoever had time. This was mainly because I did not have the budget to pay a translator, and I did not want to ask too many favours of one person. This is a slight disadvantage, because when they do more interviews, translators gain a better understanding of precisely which information is needed. This makes the interviews both quicker and less awkward for the informant, which brings down the risk of nonresponse.

Sometimes the informant was English speaking. This made longer conversations a lot easier, so I used those interviews to ask some more questions about their experience of living with a disability in Jordan, the stigma, the inconveniences etc.

During the interviews I used to type the answers on my laptop. The questions were simple enough not to need recording, and with the translation in between, recording would be rather inefficient. Another advantage of typing the answers is that it forced me to go on asking until I was sure I had a satisfying answer. Sometimes that was difficult because an informant would give 3 or 4 answers that were not really relevant to the question.



## Analysis

The data from the questionnaire were put together in a big dataset and analysed, each question forming (at least) one variable. The first step was often to look all the answers to one single question, and find a way to bring down the variety to an analysable level. Sometimes, this demanded only a little calculation: one way travel times became two way travel times, and all data about how often respondents use public transport were brought down to per week frequencies etc.

Analysing the answers to the more open questions, mostly about limitations and destinations, required some coding. In most cases, All the answers were gathered into one clean sheet and given tags. These tags were then counted. Sometimes respondents gave multiple answers to one question: they used a transport mode for several destination or experienced more than one issue as an obstacle for reaching a certain destination. In these cases, all answers were tagged and all tags counted: the total number of tags can end up higher than the number of respondents. There are two reasons for this. First, the alternative was to judge with hindsight which answer was most important, which was often impossible. But more importantly, the underlying question in all cases was: for what share of the informants does each tag describe reality, and not, how can respondents best be divided among the different answers. In other words, it is not a zero sum game.

The issue of health deserves special mentioning. The answers about health conditions were categorised twice, once according to the cause of the health issues, and once according to their visibility. Both sets of categories received their own variable in the dataset. Within each set, the tags were mutually exclusive, because their function was to categorise respondents.

Here we come across the difference between core variables and background variables. Core variables contain information about the subject of the study itself, in this case mobility and participation. Background variables only provide other information that might or might not be relevant to the subject, depending on the outcomes of the analysis. Health for example was not an interesting variable in itself. There are far better data available on the exact frequencies of different kinds of health conditions among both native Jordanians (Jordan. Department of Statistics, 2015) and Syrian refugees (HelpAge International and Handicap International, 2014;). But health conditions – both their cause and their visibility – appeared to be very relevant for making categories to analyse other variables.

To test the relations between different variables, a number of statistical tests were performed (using IBM SPSS Statistics 23). The kind of test performed depends on the type of variables. In all cases the categorising variable was qualitative (nominal or ordinal), never quantitative. The difference was made by the outcome variables, which were sometimes also qualitative, but sometimes also quantitative. Comparing two qualitative variables can be done by showing frequencies in cross tables and a chi square likelihood ratio test to calculate the significance of the differences in small samples. Comparing a quantitative variable using qualitative categories can be done by just calculating the means of different categories, but to give a figure for the significance of the difference, one needs an ANOVA test. When the ANOVA test compares the significance of the differences between more than two categories, the significance level itself does not tell which categories are different from each other and which are not. Comparing all categories with separate T-tests raises the chance of type-1 errors to unacceptable levels, but this can be prevented by a so called post hoc test, of which the Bonferroni type was used. The Bonferroni test presents the significance of the differences between each individual category (Ott & Longnecker, 2001). Table 1 shows the background variables of all respondents.



**Table 1***Background variables of all respondents*

#	months in Jordan	sex	age	residence	dwelling	visibility	health cause
1		31 man	50	Mafrq	private	invisible	disease
2		15 man	49	Mafrq	private	invisible	life event
3		36 man	51	Mafrq	private	invisible	life event
4		28 man	22	Mafrq	private	visible	war
5		34 man	35	Mafrq	private	invisible	life event
6		40 man	21	Amman	centre	invisible	war
7		18 man	23	Amman	centre	visible	war
8		21 man	29	Amman	centre	visible	war
9		8 man	29	Amman	centre	visible	war
10		3 man	24	Amman	centre	visible	war
11		7 man	15	Amman	centre	visible	war
12		36 man	18	Amman	staff centre	healthy	healthy
13		22 man	26	Amman	centre	visible	war
14		23 man	21	Madaba	private	visible	war
15		38 man	23	Madaba	private	invisible	life event
16		36 man	55	Madaba	private	invisible	life event
17		43 man	24	Amman	private	healthy	healthy
18		42 man	21	Amman	private	healthy	healthy
19		37 man	62	Irbid	private	invisible	disease
20		39 man	62	Irbid	private	invisible	life event
21		42 man	53	Irbid	private	invisible	disease
22		36 man	34	Amman	private	healthy	healthy
23		12 man	25	Balqa near Amman	centre	visible	birth
24		30 man	55	Balqa near Amman	centre	visible	war
25		10 man	24	Balqa near Amman	centre	visible	birth
26		48 woman	44	Amman	staff centre	invisible	war
27		42 man	31	Amman	centre	visible	war
28	Born and raised	man	32	Amman	private	visible	disease
29		30 man	51	Amman	private	invisible	disease
30		54 man	44	Amman	centre	invisible	life event
31	Born and raised	woman	61	Amman	private	visible	life event
32	Born and raised	man	32	Amman	private	visible	life event
33		42 man	23	Amman	private	visible	war
34		36 man	46	Amman	private	invisible	life event
35		16 man	27	Amman	centre	visible	war
36		36 man	22	Amman	centre	visible	war
37		26 man	41	Amman	centre	visible	war
38	Born and raised	man	23	Amman	private	healthy	healthy
39		42 man	33	Amman	private	invisible	life event
40		36 man	19	Amman	private	healthy	healthy
41		42 man	19	Amman	private	healthy	healthy

### 3.2. In depth interviews

Because the questionnaire was not focussed on the issues of stigma and because talking about it is not always easy or appropriate, I decided to ask some additional questions about it after normal questionnaire interviews, whenever it seemed fit. Also I arranged an interview with a radio host, working for a weekly programme about rights for people with impairments.

I wanted to hear a few stories of what it feels like to live with a handicap in Jordan, what problems were experienced as the most pressing and what solutions people with an impairment would come up with themselves. This yielded 2 long interviews and 7 short conversations. These interviews were very helpful, mainly because I could ask very open questions. In the questionnaire, I was checking variables that I had designed myself.

### 3.2.1. Selection

The people I interviewed more deeply not only had an impairment themselves, but were also somehow engaged with improving the lives of other people with disabilities. That way I was sure they were able to tell not only their own story, but also reflect on the stories they had heard from many other people. Furthermore, I preferred if long conversations did not need translation, so I looked for people whose English was good enough for that.

For the rest, I mainly just stumbled upon people, by creating a network of professionals working with disabilities.

### 3.2.2. Questions

There are three main things that in depth interviews with open questions could add to the information gained from the questionnaire. First, the sample of the questionnaire is small and biased. There is a very big group of people with impairments so hidden away that I would never be able to interview them, but interviewing people who have more experience on the topic does shed some light on their condition.

Second, the questionnaire yields a lot of information about mobility and the statistical relations it has with different forms of participation, but these statistical relations can prove very little about how the interlinkages actually work. Also it is very hard to compare the influence of mobility with other factors that also determine what a person can and cannot do. Speaking more in depth to people with an impairment did shed some light on that.

Thirdly, the less structured conversations gave me a chance to try and understand some more of the influence of background, history and culture on how people think about to impairment. This was especially relevant where it concerned the influence of the cultural stigma on handicap, a topic that few other informants were comfortable with talking about.

The questions of the in-depth interviews reflect these three subjects. Informants were asked to share their knowledge about other people with disabilities, about the influence of mobility on their daily life relative to the influence of other factors, and about their understanding of the cultural stigma on disabilities.

### 3.2.3. Recording

Most in depth interviews were not really planned, because I came for a questionnaire, and sensed an opportunity to ask some more questions after the questionnaire was finished. That meant I could not record all the conversations I had, so most of the time I would take notes on my laptop. The interview with the radio host was planned and fully recorded.

### 3.3. Accessibility: photography and measurements

A third pillar of my empirical research was focussed on accessibility. I wanted to show more exactly and more visually what makes infrastructure and public transport accessible or inaccessible for people with impairments.

This is a tricky process, because I am not physically impaired myself. Most of my information about what makes places and things inaccessible comes from other people, and a very small part of it comes from the memory of walking on crutches before. As a result, it is easy for me to overlook things that for a person in a wheelchair would be a very significant obstacle, just because I don't experience it as such.

I have tried my best to show as many as possible of the things that my informants had told me about.

#### 3.3.1. Selection of places

The places I was interested in were obviously public places that many people have to pass through to get to their destinations, or places that are themselves important destinations, receiving high numbers of visitors. So my focus was on public transport and busy areas in the city centre. Apart from these very busy places, I also selected some random place in residential areas of Amman.

The complete list of the kinds of places I took pictures of is as follows:

- Busses
  - Busstations & busstops and the roads and pavements around them
  - Bus entrance
  - Bus interior
- city centre
  - curbs
  - shop entrances
  - road crossings
- random curbs & sidewalks
  - irregularities & bumps
  - trees and other vertical obstacles
  - size (width and height)

The methodology combines four different research methods, each providing information about their own set of topics. An overview of which method was used for which topics is shown below. The next section contains the results of all methods combined, ordered by topic.

**Table 2**

*Research topics and methods*

	Literature study	Interviews	Questionnaire	Photography
health	x		x	

Cultural stigma	x	x	x	
infrastructure	x		x	x
Walking distance			x	
Public transport		x	x	x
participation	x	x	x	

## 4. Results

This section presents the results of the research. Most of the results are about the causal chain, running from bodily impairments, via limitations in mobility to non-participation. Although the link between health and mobility is not the primary focus of the research, health is often used as an easy variable along which respondents can be compared to each other, to show some stark differences. Therefore, the section starts with a paragraph about the health situation of the respondents.

Parallel to the causal chain of impairment, constrained mobility and non-participation runs the issue of shame and stigma. The second paragraph is an attempt to better understand the influence of this less tangible issue on mobility and especially on participation.

Paragraph three and four are about mobility. The third contains the results about pedestrian mobility and number four is about the use of public transport. Both paragraphs elaborate also on the many different troubles experienced when trying to get from one place to the other.

The last paragraph is about finding patterns in participation and tries to trace those patterns back to earlier mentioned issues: health, stigma and mobility.

The different paragraphs combine data gained from different research methods. A scheme of which topic was researched using which techniques is shown in the previous section.

### 4.1. Health

The causal chain under scrutiny in this research starts with bodily impairment. As mentioned earlier, what matters about an impairment seems not to be the precise bodily aspects of it, but rather how it is experienced and how the impaired person interacts with the surroundings.

The in-depth interviews suggest that shame determines much of the reluctance of people with impairments to go out and participate in society. The role played by shame is however not equal for all people with impairments, but is alleged to depend heavily on the style of upbringing and the influence it has on mind set. Many children with bodily impairments are brought up in secret, and are being told from very young age that they are unable to do anything of importance. But people who have acquired an impairment at later age, did not get this dissuasive upbringing. The questionnaire is however a very inadequate instrument to examine if the upbringing makes a difference for the later mobility or social exclusion of a person with an impairment. As mentioned in the methodology chapter, it is very hard to come across people who are ashamed of their bodily impairment, precisely because of that shame. They most often don't expose themselves to many people, let alone strangers or even foreigners. As a result, the sample includes only three people who have an impairment from birth, and they are the ones that are not too ashamed to be interviewed, probably at least partly due to a very supportive upbringing.

But secondly, the questionnaire was not designed with the issue of shame in mind, there are no questions in it that address the issue of shame directly. It is too easy to just assume that shame is a more severe issue for those people in the sample whose health issue is congenital. A slightly better indicator might be found in the visibility of the health issue. Pain in the back might cause less shame than being in a wheelchair, just because it's invisible from the outside.

## 4.2. Stigma

Many respondents report that their biggest frustration is not all the practical problems that come with having an impairment, but the sheer lack of cultural acceptance. Handicap is stigmatised and tabooed. With the questionnaire being a very poor instrument to collect information about this issue, we have to look at other sources of information. The national census of Jordan reports that directly inquiring about the presence of disabled family members led to a lot of denial, but since in 2015 the term functional difficulties was used instead of disabilities, the measured percentages of people with impairments doubled in most regions<sup>3</sup>.

The informants of my in-depth interviews confirmed that lack of awareness is the most frustrating issue they are facing. There are two main questions that I wanted an answer to, the most important being: what are the consequences of the stigma in daily life? Or how does an impaired person notice that he or she is approached differently by the people around him or her? And secondly, I wanted to better understand what causes and reinforces the stigma.

First of all, it seems that impairment is seen as a rather aggregate phenomenon: *“the stigma came from making the connection, that says that if you are disabled, then you are lacking. Then you can’t. Then you’re weak. So [in Arabic] the word ‘disabled’ correlates with the word ‘ill’”*

(Informant 4, Personal Communication, 2016-04-13)

This means individuals with impairments are treated as less intelligent or less independent, in some ways similar to how one would approach a child. Their capabilities or their possible contribution to others seems never to be the basis on which people interact with them.

- *“Because society thinks of the disabled as less of a person, usually [...] when we go to a place for instance to buy shoes, we are not addressed. They don’t talk to us. They talk to the escort. ... It’s not just with clerks, even with doctors. A person as educated as a doctor would still talk to the escort.”*

(Informant 4, Personal Communication, 2016-04-13)

- *“People need to see me as a person like anybody else. When I walk the street everybody looks. And when I want to help in any kind of work, people stop me because they think I can’t.”*

(Informant 2, Personal Communication, 2016-02-14)

- *“they interact with disabled people out of either pity, which runs out very soon and is disrespectful, or religion [religious duty red.]. Both motives make me the object of something, instead of leaving me a person.”*

(Informant 3, Personal Communication, 2016-03-24)

The cause of the stigma is perhaps much harder to pin down than its consequences, but together the comments of different informants do portray a picture. The radio host says:

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<sup>3</sup> I requested the information from the General Population and Housing Census in an email to the department of statistics of the Jordanian government. I was sent a document which goes by the title General Population and Housing Census 2015, Main Results. I have tried my best to find it online, but it seems to be not yet published. The data that is used, however are available at:

[http://www.dos.gov.jo/dos\\_home\\_e/main/population/census2015/index.htm](http://www.dos.gov.jo/dos_home_e/main/population/census2015/index.htm) (viewed 2017-02-11)

Earlier censuses are available at: <http://web.dos.gov.jo/sectors/social/social-census/> (viewed 2017-02-11)

*people make the link that if this family has a disabled child, than it goes to say that this person's sister and brothers would mostly likely not get married, because people would start to think, you know, if they married [somebody from] that family their children are going to have disabilities. So disabled people are for the most part kept secret." (Personal Communication, 2016-04-13)*

Several informants agree that parents (and also the wider social environment) play a very big role in either encouraging or discouraging their child to participate. I asked a disabled employee of an organisation that helps other disabled people with depressions what made the difference between him and his clients. His answer was: *"Character and social environment. Even when they were able-bodied they were not very independent."* (Informant 7, Personal Communication, 2016-04-20). The radio host agrees on both factors:

*For the most part the difference is two elements: first element is the person's own personality. Some people are just defined and it's just built into them to fight back and to choose to live. The second and probably more important is the support that the person gets. So if the family and the group of friends are supportive in pushing that person to ... become an independent individual, that person will do it. But for the most part the family and the group of friends are too overprotective, or they don't allow the person to go to places and to do stuff. Or they are not supportive. They are afraid of shame. (Informant 4, Personal Communication, 2016-04-13)*

But supportive parents are not always enough. Informant 1, who is also an activist for the rights of the disabled recalls:

*For example when we had a project with a school and the school is made accessible and the staff is educated and made aware of the issues of disabilities. After we finished the project, many of the children with disabilities dropped out. Why? Some teachers just don't like the children with disabilities. They are afraid for example for the child to fall, and ask the parents: who is responsible then? They put pressure on the parents, so if the parents are not very strong, the child will drop out. (Personal Communication, 2016-04-11).*

Again, the radio host agrees:

*The law says that those people have to be mixed with other abled students in the schools. [...] But the school is not ready for that. ... The teachers refuse to take responsibility for the students. Because what they say is you might get bullied. And we are not gonna take that responsibility. ... Some families, some parents would actually like to give their son or daughter a chance, they believe in that person. But as soon as they start to expose that person, the reaction they get from culture, from society, shocks them back into taking that child back in, and going back to exclusion" (Informant 4, Personal Communication, 2016-04-13).*

Literature about disability in Jordan confirms this image and expands it. Al-Aoufi et al. (2012) add that a disabled child is often seen as a punishment from God, which not only explains the embarrassment but also reduces the urge to seek medical treatment.

The stigma is reinforced in many different ways.

- As said, parents have to be very strong to give their impaired child a proper education. And as long as impaired people are poorly educated, their capabilities will indeed remain relatively limited.
- When children with disabilities go to special schools and adults with disabilities live in special centres, they are able to make use of services that were once very hard for them to access. But the disadvantage is a reinforced segregation. People with disabilities mostly know other people with disabilities. *“And that might be an issue. Disabled people need to have abled friends. ... Disabled people are not getting the chance to befriend abled people. So they are kind of locked on in their own communities”* (Informant 4, Personal communication, 2016-04-13).
- The media portrayal of people with disabilities is often one of pitiable helplessness. *“If you try to get a sample on most Arabic media news shows or talk shows or whatever, the portrayal of a disabled person always has a very sad melancholic music background. There’s always pianos and violins and humming”* (Informant 4, Personal communication, 2016-04-13). The radio host himself tried to fight this image with counter images of people with disabilities managing to achieve high goals, like PhD researched or travels round the world etc.

### 4.3. Infrastructure and walking

The most basis form of human mobility is walking, but how much people walk is certainly affected by environmental factors like among other things convenience of facilities for walking (sidewalks, trails) and perceptions about traffic and busy roads (Owen et al., 2004).

Both in scientific literature and in popular blogs, it is rather easy to find complaints about situation of pedestrians in Amman. This problem has an effect on the entire population of Amman, but poor people and especially people with physical impairments are affected more than average. Poor people need to walk more because they can’t afford to always use public transport or a car. For people with impairments, it is far more challenging to overcome the physical obstacles that poor infrastructure throws at them. For people with a physical impairment, the list of frequent obstacles is rather long:

- Amman was built on 7 hills, which makes flat surface a scarce convenience. Even for a fully able bodied person, covering somewhat larger distances especially in the downtown area can be a serious workout. But using a wheelchair or a walker on the many slopes and stairs is absolutely impossible. There are however also some almost flat areas where using a wheelchair could be a convenient way of moving about.
- Few places in Amman have convenient sidewalks. Often the pavement is absent, broken, full of garbage, baldy lit, blocked by parked cars, garbage containers, terraces or market stalls, or trees planted in the middle of them. An extra issue for wheelchair users is the scarcity of ramps combined with the height of the curbs, which can vary greatly, up to half a meter.<sup>4</sup> Many sidewalks are not wide enough to accommodate two people next to each other, or a wheelchair, or a blind person with a helping dog. For blind people this comes on top of the risk of stumbling over irregularities.

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<sup>4</sup> <http://www.csbe.org/publications-and-resources/urban-crossroads/moving-in-amman-the-pedestrian-experience/>



- Amman is crossed by many busy roads and traffic is in many places quite fast. Suitable places for crossing are scarce. At some places, this problem is addressed by big walking bridges. For able bodied people, these bridges mean just the inconvenience of climbing up and down the stairs and not looking at all the garbage left on them. With a wheelchair or a walker however it is impossible to get up and down them.

Underneath are some pictures that illustrate the walking infrastructure of Amman.



**Picture 1** *Pavement interrupted by terrace*



**Picture 4** *Pavement interrupted by trees*



**Picture 2** *Walking bridge for crossing bussy road*



**Picture 3** *Pavement with unnecessary steps in Downtown area*



**Picture 5** *Pavement suddenly ceased*

To be short, the infrastructure of Amman does not seem to encourage walking, but the outcomes of the questionnaire suggest that most people are willing to walk long distances none the less. On average, the respondents estimate to cover 2.09km maximum without using motorized transport. But this number is not very relevant without a comparison. As I am not aware of any data on average walking distances in Jordan, this comparison has to be made with data from other regions.

Data about walking distance can be presented in a number of different ways. The International Transport Forum for example, reports that in different OECD countries, the length of an average walking trip varies between 0.7 and 2 km (ITF, 2012). The same reports presents some numbers in more detail, showing for example the percentage of walking trips shorter than 1 km, between 1 and 2 km, etc. The Norwegian National Travel Survey (2013) attempts to show how the choice for different travel modes depends on the length of the trip, presenting for different distance intervals the percentage of trips made on foot as opposed to other modes of travel.

In this research walking distance represents the distance people estimate as the maximum distance they usually cover without using motorized transport. This means that the concept of walking distance is stretched a little to incorporate all 'independent' movement, notably also riding a wheelchair. The average maximum walking distance of 2.09km may seem quite a high number but it should be kept in mind, that this number is not a distance they would daily walk or the average trip length, neither is there a way to check if these estimations are accurate.

The soundest possible comparison can be made using data from the Norwegian National Travel Survey (2013). The report states that in Norway 68% of trips under 1km are made on foot, for trips between 1 and 2,9 km the zest for walking has gone down to 29%. The percentages for longer distances are too small to be compared to the very small sample of this research.

For several reasons, it is impossible to convert the data from the present sample perfectly into the Norwegian format. For example: when a respondent claims to walk no more then 1,5km, it is impossible to say which share of the trips with a length between 1 and 3km he or she does on foot. In order to make at least a comparison that makes some sense, I have assumed that people with a maximum walking distance between 3 and 5km walk all trips up to 3km and always use transport trips longer than 3km. Even with this very conservative assumption, the sample indicates that a sizable 71% of trips under 1km are made on foot, and 32% of trips between 1 and 3 km. Both numbers are slightly higher than the figures from Norway, which already is one of the nations in the OESO where people walk the longest distances (ITF, 2012).

The target group can be expected to have a very diverse walking distance. In general poor people walk more to save transportation costs, but people with impairments generally reduce their mobility entirely (ITF, 2012). In the sample the resulting trend is peculiar: healthy people appear to walk the shortest distances before seeking the aid of a motorised vehicle. The longest distances are covered on foot by people with war injuries, but this figure is heavily influenced by an outlier: a paralysed man in an electric wheelchair with a range of 20km. He can reach any destination within 10km and get back again without ever needing transportation. Without the outlier, the average walking distance of people with war injuries drops to 1.66km. Another issue with these averages is caused by a high non-response. Some people gave no answer at all, some just said long or short, without any quantification. Those answers have been left out of the calculation. The last column of table **(number)** shows the number of answers from which the average walking distance was calculated, as a fraction of the number of respondents with a health issue of a certain cause. This fraction says a little about the validity of the average walking distance, this validity being the highest for people with a health issue resulting from a life event and for healthy people. When we compare these two

groups, it remains remarkable that healthy people are a lot less willing to walk than people with a health issue, even more so when we consider that the healthy people in the sample were on average also a lot younger than the respondents with a health issue resulting from a life event.

**Table 3**

*Average walking distance and age for different health categories*

cause of health issue	Average walking distance	response rate	Std. dev.	Average age
birth	?	0/3		27
disease	1.5	3/5	0.87	49.6
life event	2.28	9/10	1.64	45.9
war	2.59	9/16	3.13	28.3
healthy	1.46	7/7	0.94	22.6
total	2.09	28/41	2.04	34.12

Perhaps more interesting than the average walking distance of the respondents is to know what determines their willingness or ability to walk. The largest group did not report any specific limits to their walking distance which was to be expected, because the questionnaire did not contain a question about this specifically. Fortunately however, most respondent gave rather elaborate answers, which made it possible to deduct some of the necessary conditions for them to walk. These conditions have been coded and summarised into 4 categories that reflect the similarities between a very large range of small problems. The categories are (1) wheelchair; (2) wheelchair/walker/crutches/prosthesis; (3) needs breaks/pain and (4) company.

For 8 respondents (20%) their problems with walking are determined by the wheelchair, but these problems are very diverse: it is for example very hard to climb slopes or stairs, get across rough terrain or high curbs. Five respondents (12%) have the choice of using a wheelchair or a walker, prosthesis or crutches, depending on what they are going to do. Using crutches or a walker makes one more manoeuvrable which is easier for example in shops, and it is easier to put them in a taxi, but standing a long time or bringing heavy things, is easier in a wheelchair. All in all, having multiple walking aids to choose from seems to enable people to overcome a larger range of problems.

Six respondents (15%) said their walking distance is limited by sheer pain. Most of them need breaks when they walk, so given a lot of time, they can actually walk quite far. For some of them, the pain and consequently their walking distance depends partly on the weather because their issue gets worse when it is cold. Three respondents (7%) reported that their walking distance depends on company, somebody to lean on while walking, especially on stairs and other tricky bits or help in case something might go wrong.

#### **4.4. Transport**

There are three types of public transport in Amman: taxis, busses and service taxis, mostly called services (pronounced serveeses). Normal taxis are yellow, can be waved down from the side of the road and drive with a meter, a small device that calculates the fare depending on both distance and travel time. The rates are set by the government and are affordable by Western standards. A one way fare from the city centre to the edge of town in daytime should never cost more than 5 dollars.

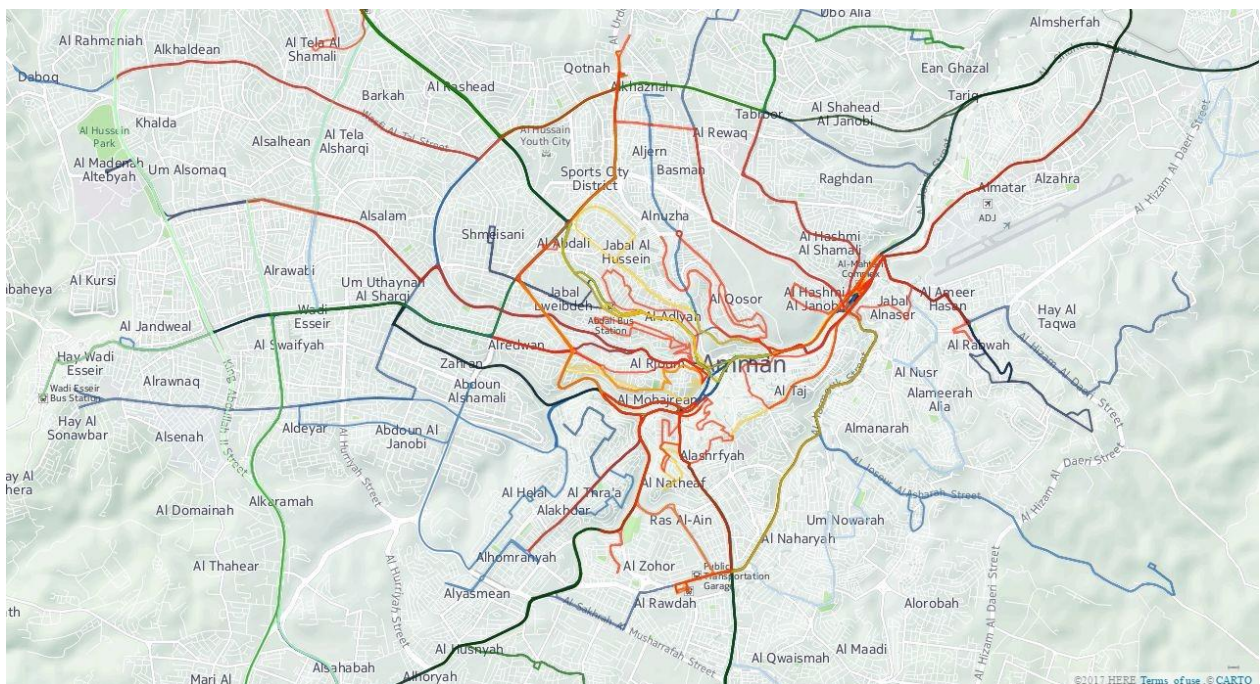
There are several types of busses in Amman, but most of the busses servicing only to Amman as a city are of either of two types: big busses with numbers that indicate their destination and small busses that all look outwardly the same, called coasters. All busses have fixed fares of mostly around



half a dollar, but never exceeding 1 dollar on routes that stay in the city. Busses leave when they are full, which means the frequency of service depends on crowding. Intercity busses work roughly the same, but are slightly more expensive.

Service taxis are white taxis that operate like busses: they have fixed routes, fixed fares and depart when they are full, which means 4 passengers. Fares are similar to bus fares, but often the routes are shorter. The fare is not cheaper for people who get out half way.

An overview of the routes of busses and services is provided below. Service taxis are shown in red, coasters in green and busses in blue. The darker the line, the higher the frequency of the line. The data used to create the map, are from a private project to create a transit map of Amman. The routes were recorded with GPS-applications on cell-phones, the information about frequencies was generated with a small survey among passengers and drivers.<sup>5</sup>



**Picture 6** *Transit map of Amman*

When viewed online, the map is interactive and allows zooming and adding or removing the different types of transit one by one. Clicking on a line shows its destiny and frequency.

[https://kwwierenga.carto.com/viz/37c75bf4-690f-11e6-8e19-0ef7f98ade21/public\\_map](https://kwwierenga.carto.com/viz/37c75bf4-690f-11e6-8e19-0ef7f98ade21/public_map)

There are a few big hubs where many of the bus and service lines depart. The biggest and most important bus station is the Mhatta complex or Raghadan bus station, which also hosts many market stalls mainly for very cheap food and clothes. Some respondents who reported to get groceries there also indicate that the biggest disadvantage of the Raghadan bus station is its crowdedness and the congestion surrounding it. A Crowded bus station makes the busses fill up more quickly and raises the frequency. But congestion around a bus station makes it difficult for busses to reach it, which makes the frequency of busses very unpredictable. Apart from the difficulty of planning a journey, this unpredictability is a nuisance because there are few places where one can sit down when waiting without getting very dirty clothes. The second biggest hub is the North bus station or Tabrbour

<sup>5</sup> For more information about the data collection for the transit map: <http://mappingamman.blogspot.com/>.

station which looks a lot cleaner, has even been made wheelchair accessible, but does not host markets and much fewer bus and service lines.



**Picture 7** Mhatta or Rahadan bus station, with market stalls



**Picture 8** Tabrbour bus station. Clean but relatively empty

Some areas are better serviced than others, something the map does not fully capture. The reliability for example of the given frequencies varies greatly and the map is also unable to show how some frequencies change during the day. In general though, the density of routes is greatest around the downtown area and the adjacent parts to the West. Less serviced areas include the South East of Amman, large areas of West Amman and the far South of the city.

But perhaps more important is the pattern of the routes: the system bears some similarity to a star shape. It is easy to get from the centre to the edge, but going from one edge to another is far more difficult, and often involves many stopovers. This makes it very time consuming, because every transfer includes waiting for the next bus. It is also very expensive, because the fares for small distances often are not lower than for the entire journey. This is partly reflected in the results of the questionnaire, where coverage is most often mentioned as a reason not to use buses.

Apart from these main transport modes, there are minibuses and uber, both of which are expensive but a lot easier for certain categories of people. Several respondents reported to make use of private minibuses, because the drivers understand the life of handicapped people and are more patient and understanding. The minibuses also have more space to accommodate a wheelchair, but the fares are more than twice as high as those of a normal taxi, so it is more profitable to use them with more than one person. Uber was used by the only blind informant in the research. Before Uber existed, he was not able to wave a taxi down himself, so he needed somebody to do that for him, often he would ask the janitor of a building. The Uber application makes this a little easier, although the application is not blind-friendly. As a result, a blind person still cannot get around independently. For blind women, it can also be very dangerous to travel alone, because of the risk of kidnapping.

### **Different health issues**

As mentioned in the section about stigma, some informants state that people who acquired an impairment at later age, are less likely to give in to the stigma and let it determine their life opportunities. Unfortunately however, it is very hard to check this hypothesis statistically, using the data collected for this research, mainly because only two of the informants had a congenital impairment.

Exploring the relevance of the cause of impairments for the use of public transport more in general does however yield some relevant statistics. First, the ability to use different forms of public transport does vary slightly depending the cause of the impairment.

**Table 4**

*Ability to use different modes of public transport for different health categories*

	taxi (n=40)	bus (n=41)	service (n=24)	total
birth	0%	50%	50%	2
disease	100%	80%	75%	5
life event	91%	64%	50%	11
war	67%	50%	43%	16
healthy	100%	100%	100%	7
significance	0.040	0.082	0.161	41

The table shows that the ability to use taxis varies more between people with different types of health issues than the ability to use busses or services (with an  $\alpha$  of 0.040 it's the only transport mode with significant differences). But there is a rather straightforward explanation for this: only a few severely handicapped people are unable to use taxis, whereas being unable to use busses or services is more common among all informants. These most severely handicapped people are mostly impaired as a result of war injuries or congenital issues.

When it comes to how often people use public transport, however, it is much harder to discover any significant pattern of difference between the people with different causes of health issues. Table 5 shows the average number of (one way) trips that informants of the different groups make weekly using each transport mode. In these averages, the people who were unable to use the transport mode have been left out. Although the averages are very different from each other, none of these differences are significant, because within each category, the standard deviation is very high, often around twice the value of the mean. Simply stated, this means that among people with impairments resulting from whatever cause, there are some who travel very frequently and some who travel as good as never.

**Table 5**

*Frequency of using different modes of transport for different health categories. Trip frequency is the frequency is the total of all transport use frequencies.*

Health cause (n)	frequency taxi (n=40)	Std. dev.	frequency bus (n=41)	Std. dev.	frequency service (n=24)	Std. dev.	Trip frequency	Std. dev.
Birth (2)	0	0.00	0.25	0.18	0	0.00	0.13	0.18
Disease (5)	1.80	2.56	6.54	10.51	0.57	0.72	7.37	9.72
life event (11)	2.60	3.13	1.18	1.92	2.67	2.42	3.85	6.32
War (16)	2.34	2.30	0.50	0.55	2.67	1.86	2.21	3.00
Healthy (7)	4.93	8.91	2.76	3.05	2.33	2.55	8.69	8.28
Total (41)	2.90	4.37	2.15	4.08	1.90	1.90	4.28	6.36
significance	0.645		0.325		0.688		0.116	

The influence of health was also tested in another way, using a variable that shows whether or not a health issue is visible from the outside. The visibility of a health issue turns out to predict with even

greater accuracy people's ability to use public transport, but still fails to predict the frequency with which people do so. Only the frequency of all trips together surpasses the significance limit of 0.05. The problem is the same as before: the variation in trip frequency of each transport mode is so big, that the differences between categories don't exceed the differences within categories. With this information it is possible to conclude that health does determine if people use public transport, but has very little effect on how often they do so.

**Table 6**

*Frequency of using different modes of transport depending on the visibility of health issues. Trip frequency is the frequency of all transport use frequencies*

	Taxi ability (n=40)	Taxi freq.	Std. dev.	Bus ability (n=40)	Bus freq.	Std. dev	Service ability (n=24)	Service freq.	Std. dev.	Trip freq.	Std. dev.
Healthy	100%	4.93	8.91	100%	2.76	3.05	100%	1.49	2.55	8.76	8.28
Invisible	93%	2.32	2.91	93%	2.65	6.63	88%	2.10	2.46	5.45	7.68
Visible	61%	2.35	2.57	37%	0.60	0.72	27%	1.00	1.00	1.74	2.31
total	80%	2.90	4.72	68%	2.15	4.83	63%	1.68	2.19	4.29	6.36
Sign.	0.037	0.450		0.000	0.633		0.009	0.774		0.026	

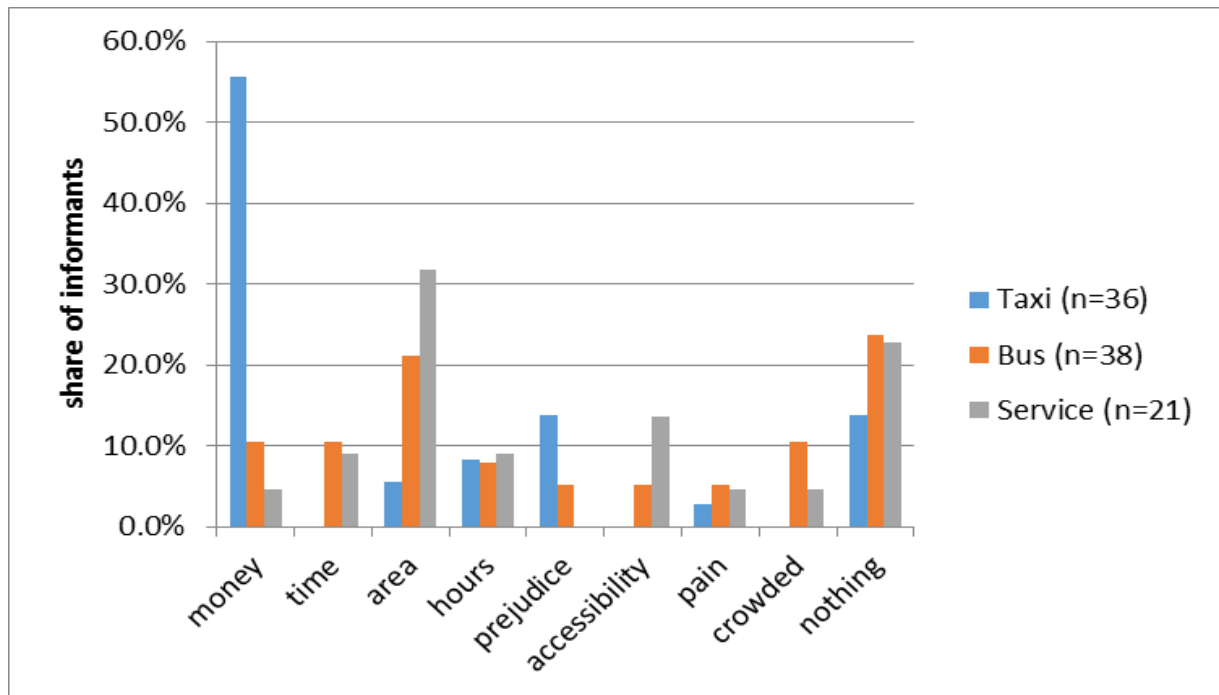
## Limits

It is time to take a closer look at what stops people from using public transport. Unfortunately only very few of the answers to this question are from people who are actually unable to use public transport. The resulting information therefore tells us more about things that make public transport inconvenient but not impossible to use, than about impregnable barriers.

The answers given by informants were very diverse and had to be coded in order to be comparable. Eight categories of inconvenience were created, starting with the costs of travel, both in terms of time and money. Some people answered the area where they lived or their destinations were in areas where public transport is not or only scarcely available. For others, public transport was sometimes too much of a nuisance on certain hours of day, sometimes because of congestion, sometimes because of limited service hours. Some people mentioned that taxi drivers mostly don't pick up people with wheelchairs, for others the physical accessibility was the problem. For some people, using public transport is mostly painful. This does not necessarily stop them altogether, but limits for example the distance they travel, or it makes them use services only if they can sit in front of the car. For other people congestion is the main inconvenience, for example if they cannot stand in busses. Some of these inconveniences overlap, in which case there are several values for one informant.

The frequencies with which people mentioned different types of inconveniences are summarised in graph 1. What the graph does not show, is that the differences between bus and service are far from significant (0.834), the differences between taxi and bus come close (0.071) and between taxi and service there is a significant difference (0.026).





**Graph 1**

*Share of respondents experiencing limitations to using different modes of public transport.*

The graphs does show a few things.

- money is a far greater limitation for using taxi than for bus or service use. The explanation is simple: a taxi is more expensive.
- The advantage of taxis is also clear: they are the quickest way of getting around (except for car owners) and nobody mentions time consumption as an inconvenience of taxi use.
- Another advantage of taxis is their coverage. Buses and especially services are often mentioned to be unavailable in places where people need them. Perhaps this problem could be partly explained by a lack of knowledge, because especially services depart from many different places and informants might not be aware of all available options.
- Service hours are a problem for all modes of transport alike, although the reasons might be different for taxis. At night, taxis are still available and most of them are unoccupied so it is very easy to wave one down, but they do raise their prices. During rush hour on the other hand, it takes much longer to find a taxi that is not yet occupied and trip prices are also slightly higher because they depend on travel time. On top of that, certain destinations are almost impossible to reach by taxi during rush hour, because taxi drivers know that there is heavy traffic on the way back, and don't risk the extra time loss in an empty car. Busses and services on the contrary are more reliable during rush hour. They don't change their routes and the frequency goes up, because it takes less time for a vehicle to fill up. At night the opposite is true, it takes more time for them to fill up, so the frequency is lower and



eventually, service stops altogether. This differences are not shown by the data, but they do determine the choice for a transport mode.<sup>6</sup>

- Prejudice is mentioned most often as an obstacle for using taxis. The simplest explanation is that taxi drivers decide whether or not to stop and take on a passenger, and there is anecdotal evidence that they are more reluctant to stop for people with visible health issues. Busses and services on the contrary are stationary and the passenger can choose to get on.
- A more surprising outcome is the inaccessibility of services, which seems to be even worse than that of busses, although the current sample is not sufficient to prove this difference to be significant.
- When transport is painful, the mode of transport does not seem to make much difference.
- Crowding is a nuisance especially for bus users, they have to stand up. Taxi users mentioned the problem also, but only in combination with rush hour (in rush hour it just takes longer to find an unoccupied taxi). These issues were labelled as 'hours'.
- All in all, the ability to use taxis is constrained for a larger number of people than the ability to use busses and services. The main explanation is money: independent of one's physical condition, the prices of taxis make it impossible for most informants to use them as often as they would like.

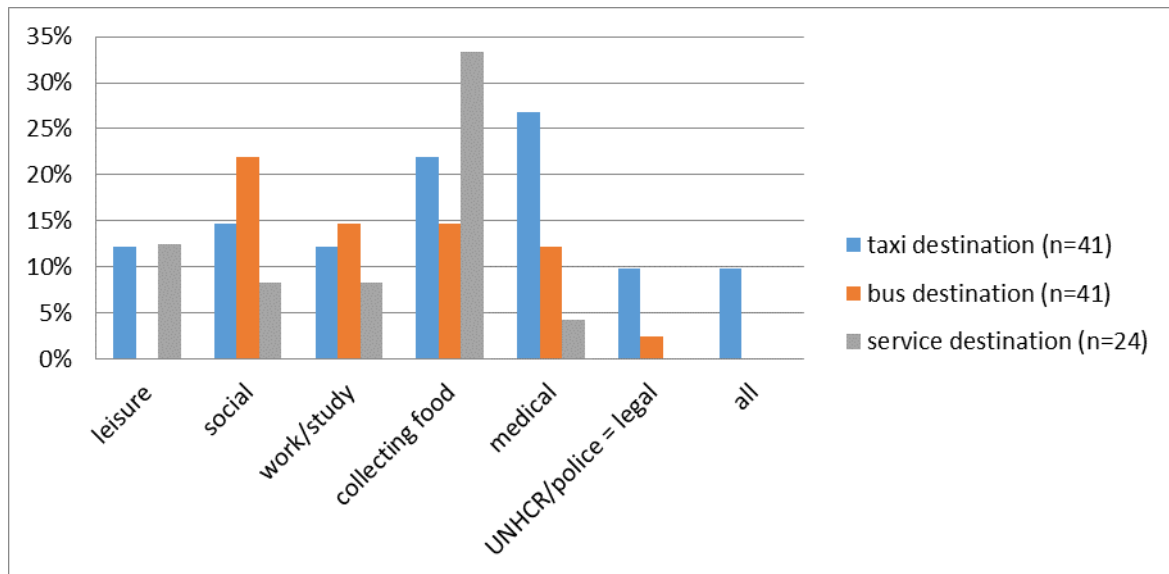
On top of this analysis, it would be nice to present some data on how the limits for using public transport vary depending on physical health, but the sample is far too small for such an analysis.

### **Destinations**

The differences between modes of transport are also reflected in the kinds of destinations they are used for. Again, the questionnaire contained an open question about this matter, and the answers were coded afterwards, to fit a limited number of categories. And again, one transport mode can be used to reach several kinds of destinations, so there is not necessarily one answer per informant. Graph 2 shows the percentage of respondents using each transport mode for each type of destination. The categories are rather straightforward, except perhaps from legal. This category includes all activities necessary for legal procedures, such as renewing residence permits or UNHCR registrations. Remarkably, the differences between the use of busses and services are significant (0.045), as opposed to the differences between taxis and busses (0.092) and between taxis and services (0.169).

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<sup>6</sup> It would be interesting to study the precise consequences of this mechanism in economic terms. Taxis are normally considered as a luxury good as opposed to the inferior good of busses and services, but speaking strictly in terms of 'material' utility, these positions change in heavy traffic. There may however still be a more intangible, cultural value of being in a private taxi that makes it worth waiting for in the heat, noise and smog of passing busses on a dusty summer afternoon.



**Graph 2**

*The percentage of respondents using each transport mode for each type of destination*

A few conclusions can be prudently drawn from the available data.

- The bus is never used for leisure, perhaps because people see it too much as an inferior good, perhaps because most leisure activities are undertaken at night, and at night busses operate less frequently.
- For social activities, the bus is very important. This can be partly explained by visits to relatives living in different cities. Long distance transport in Jordan is very cheap by bus, very expensive by taxi and very rare by service.
- For work and study, all modes of transport seem to be of almost equal importance.
- Groceries shopping is the most important purpose for using public transport and services are the most favoured transport mode for it.
- Trips to doctors or hospitals are mostly made by taxis. At least two explanations are possible: perhaps hospitals are located in places where few busses and services go, or it is just inconvenient to use bus or service when you need medical treatment.
- Legal issues require few trips, which are mostly done by taxi, which might be an indication that government buildings are not in very accessible areas.
- Some people use taxis for everything they do. Again, there are two possible explanations: they are either very immobile or rather rich.

#### **4.5. Participation**

Now that most of the dependent variables have been analysed, it is time to pay some attention to the end of the causal chain. What do the data show about participation?

In general, it is possible to say that most of the respondents are able to undertake the 4 activities selected beforehand as essential: visiting friends and family, going to a mosque, church or other religious place, reaching a doctor, clinic or hospital for medical treatment and doing grocery shopping. Groups of respondents with different health statuses do however score differently on

some forms of participation. Health was analysed in two way, according to the visibility of health issues, table 7 and according to the cause of different issues in table 8.

**Table 7**

*Share of respondents able to reach different destinations, depending on the visibility of health issues*

health vis.	friends	mosque	medic	groceries
healthy	86%	100%	100%	86%
invisible	86%	100%	100%	93%
visible	58%	56%	100%	58%
total	73%	79%	100%	75%
sign.	0.138	0.001	-	0.046

**Table 8**

*Share of respondents able to reach different destinations, depending on the cause of health issues*

health cause	friends	mosque	medic	shops
birth	50%	0%	100%	50%
disease	100%	100%	100%	75%
life event	82%	100%	100%	91%
war	56%	60%	100%	63%
healthy	86%	100%	100%	86%
total	73%	79%	100%	75%
sign.	0.186	0.001	-	0.392

### Medical facilities

I am happy to report that all respondents reported to be able to reach some sort of medical facility, if necessary. But a number of them did not give this answer wholeheartedly. For five respondents (12.5%) the problem is money, some would need to borrow money if they really had to go to hospital, some had agreed with a doctor to bring the frequency of treatment down to less than half of what was recommended in order to cut costs. For 7% respondents, the problem is distance. They go to small clinics instead of hospitals because the former are closer. But even inaccessibility can be a barrier for people in need of medical treatment: the blind man manages to get dropped off in front of a hospital, but will never find his way into and inside the building without an escort. The simple dichotomy between ability and inability to reach a medical facility obscures all the barriers that can be overcome, but only in case of dire need.

Another reason why reaching medical facilities appears to be less of a problem than reaching other places, becomes clear when we look at the group of respondents with the lowest mobility: war injurers living in centres. These centres provide medical care internally, making it one of the few things their patients can easily access.

### Religious places

Visiting religious places is a little harder, or at least, fewer people report to be willing to overcome the necessary barriers for it. This is interesting, because mosques are scattered very densely throughout the entire country, and Amman has one on the corner of every street. Respondents who did regularly visit mosques all said it was within 5 or sometimes 10 minutes walking from their home. It cannot be distance that stops people from going to a mosque. The accessibility of mosques might be an explanation. One respondent reports that many mosques were not accessible for a wheelchair,

but it is not impossible to find one that is. A few others visit mosques regularly with their wheelchair. One informant reports not to go to the mosque because he cannot kneel down in prayer, but another informant solves the same problem by praying seated. Although none of the respondents has mentioned it, I want to leave open the possibility that shame is what stops people from going to mosques, partly because all respondents in the sample who do not visit religious places, suffered from visible issues, either war injuries or congenital issues. The role of shame is again very hard to pin down and needs a different research set up. Also hard to assess is the urgency of the problem. All respondents who were unable to visit religious places lived in centres that had makeshift mosques. None of them elaborated on what the difference between a real mosque and a makeshift centre mosque means to them. Practically, it means the absence of lectures by professional Imams, so it might hamper religious education. Another topic that would require a different kind of research to better understand.

### **Shopping**

Reaching grocery stores can be difficult not only for people with visible health issues. In the sample also one respondent with an invisible issue (a double hernia) and a healthy but very busy person did not manage to do their daily shopping on their own.

Doing groceries obviously involves more than reaching a shop. Getting into a grocery shop brings its own issues and so does transporting groceries back home. Basically there are three kinds of places to do daily shopping in Jordan: there are small supermarkets rather densely scattered around each city in Jordan, there are big international supermarkets, mostly in shopping malls, and market places, sometimes around bus stations, sometimes in city centres. Small local shops are closest for most people but relatively expensive. Most groceries are cheaper in the big supermarkets in shopping malls and fruits and vegetables are very cheap in some markets in city centres and some large bus stations. But there are obviously fewer of those, so for most people the malls and markets are further away. As a result, many people face a choice between spending money on further transport or more expensive groceries. The larger amount of groceries you can transport, the more profitable it becomes to shop in malls or markets. These considerations might seem rather marginal, but for 15% respondents, money is the most limiting factor for doing groceries. Those people need to be thrifty.

For people with a handicap the choice is a little more complicated: big malls make a normal shopping experience possible also for wheelchair users, because they have flat floors, ramps, elevators, special toilets etc. But of course, an impairment also makes the extra travel a bigger issue. The local supermarkets on the contrary maybe easier to reach, but most of them have very narrow pathways, which makes them practically inaccessible for wheelchairs. This explains the 15% of respondents reporting accessibility as the main hindrance for doing their own groceries. There are several possible solutions to this problem: some people can swap their wheelchair for the walker, and in urgent cases, some order their groceries from outside the shop, by shouting to the staff. The shop owner will then gather them into a bag and the customer can pay outside. Some shops also have a phone service with home delivery, but I don't know the cost of such a service. Both options require the customer to know exactly what to get. You can't look at promotions, check out new products, compare prices etc.

Of course nobody starves because of the inability to reach shops, and the sample shows that the problem can be effectively solved by centres and sometimes parents or spouses. But being able to do groceries is an important precondition for having the choice of where and with whom to live. Many respondents in the sample do not have that choice. Being able to feed has cost them an important part of their freedom.

Apart from daily shopping, the questionnaire also contained a question about the transportation of bigger purchases. In many cases the gas tank was an easy option, and often I would also pick a piece of furniture and ask the respondent how it had been transported to the home and taken inside. This had never been a problem. Gas tanks were mostly replaced by a family member and shops mostly have a delivery service for bigger acquisitions. Respondents who lived in centres were not asked this question, as the furniture in centres is not their property. Where it concerns the capability to own things, the transportation seems not to be the problem.

### **Friends & family**

Being able to see friends and family is perhaps emotionally the most important of the four indicators of participation under scrutiny. But it is also rather complex. Most people have quite a number of individuals they call friends or family, some of which are easier to visit than others. But seeing one specific relative or friend is arguably more important than visiting one specific grocery store, clinic or mosque. One does not just stick to the closest friend. The result is, that visiting a friend or relative usually involves much higher costs, both in time and money (see for further details the section about costs in time and money below). This explains perhaps why there are also healthy people and people with invisible issues who are unable to visit friends or family. Other than that, the reasons for being unable to visit loved ones were very diverse.

The most important barrier to seeing loved ones is the Syrian conflict and the closed borders between Syria and Jordan: many respondents had (most of their) family in Syria, and were unable to meet for years. But this study is about accessibility and exclusion, not about separation by war. So respondents were asked specifically about problems with respect to seeing relatives and friends in Jordan.

Accessibility of real estate forms appears to be the most important limitation for visiting relatives and friends, 12% of respondent mention this as a problem. A person with an impairment can choose to live in an accessible home, but cannot force all family and friends to do the same. For 10% of the respondents, a lack of time is their biggest barrier. All of them are very busy with work or studying. Seven percent of the respondents cannot visit relatives or friends who live in specific areas that are very hard to reach by public transport. Another 7% simply cannot regularly afford the travel to friends who live far away. One older Syrian man was afraid of trouble with locals, and went outside as little as possible, giving up visits to both his brothers living closeby.

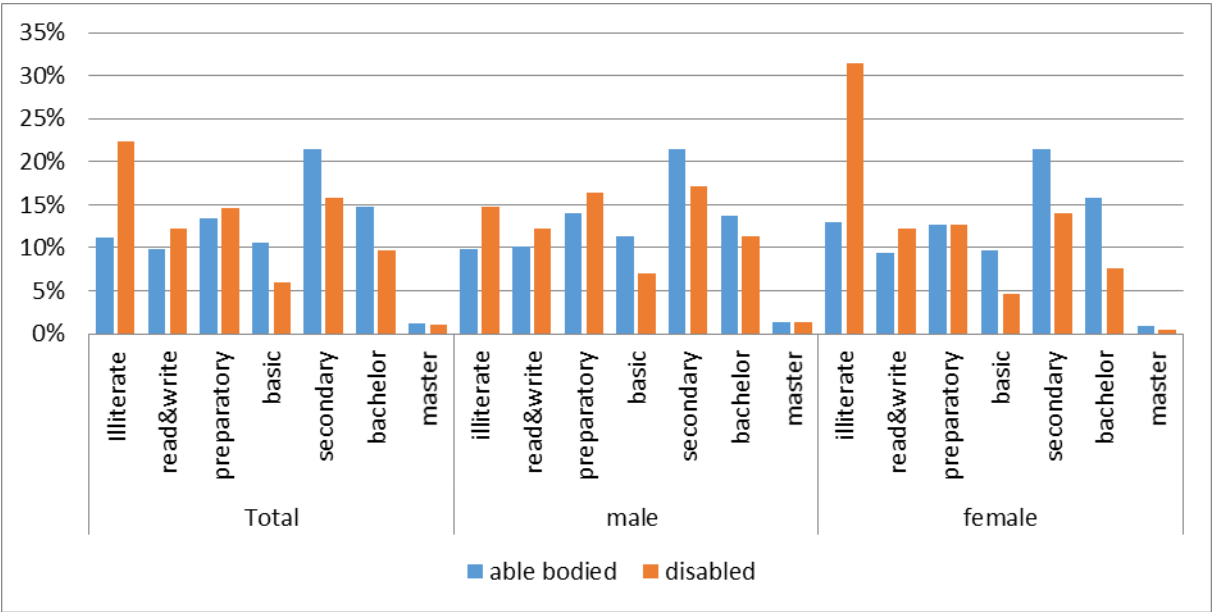
One might wonder: what is the importance of being able to actually visit friends or family, why don't the loved ones visit the impaired person? Only if two relatives or friends are both incapable of travelling, the problem becomes acute. But when we take a closer look at the group for whom getting into and out of building is the problem, we come across two rather poignant problems. Although patients in a community centre can receive visits from loved ones, it is hard to find privacy there and especially with respect to family, one does not only want to see one relative at a time, one wants to enjoy the company of the whole group, which is very hard to organise in a community centre. This becomes all the more bitter when we realise that often these people can't be present at their loved one's weddings, birthdays or funerals. Here we see social exclusion in one of its most heartfelt forms.

### **Education**

The questionnaire also contained a question about the transport of school going children. However, very few respondents had school going children. The few who did, either had their oldest childer walk the younger ones to school (1 respondent), or let them walk by themselves (3 respondents), or had them taken by a school bus (4 respondents), the price of which was included in the school fee. So

the questionnaire tells us little about the effect of transport on education attendance. There is however some information from other sources available about this subject.

It is alleged that a disability of a child often hinders its education, not a disability of a parent. One of the informants mentioned in an in-depth interview a recent study published by the Higher Council for Affairs of Persons with disabilities claiming that only 3% of disabled children in Jordan get education (Informant 4, Personal communication, 2016-04-13). I have not been able to find this report, because all publications of the council in question are only available in Arabic. There are however also very different figures available. According to AlMakhamreh (2015), 49% of disabled children reach secondary education. Both figures do not present a comparable figure for able bodied children. Using data from the population and housing census of 2015 (Jordan. Department of Statistics, 2015), it is possible to show some more systematic data. Graph ... compares the highest attained level of education between people with and without disabilities (aged 13 years and above), split out in male and female.



**Graph 3**  
*Highest level of education attained by people with and without disabilities (aged 13 years and above), split out in male and female.*

On the one hand, the figures clearly show that average education levels are much lower among people with disabilities than among their able bodied peers. Especially among women with disabilities, the illiteracy rate is a shocking 31%, compared to 13% among able bodied females. On the other hand, the total percentage of people with disabilities with any education certainly exceeds 3%, and 10% even makes it to a bachelors degree.

It would be interesting to find out if the high rate of school dropouts can be to some degree explained by transportation difficulties. The stark differences between males and females do however suggest other causes, as it is not much harder to transport a woman than a man.

**Participation and health**

The previous sections are an attempt to estimate the degree to which respondents in the sample are able to participate in activities that are very normal in their society. To summarise these abilities, one variable was created that shows the number of destinations that a respondent can reach: friends and family, religious places and grocery stores all count as 1. So a respondent who can reach all three has

value 3. This variable was called participation. Medical facilities were left out of the comparison, because every respondent is able to reach those.

Two questions now remain: to what extent does participation correlate to health? And to which extent is it related to the ability to use transport? The tables below show the average scores for participation, divided by the visibility of a health issue (9) and its cause (10).

**Table 9**

*Average scores for participation, divided by the visibility of a health issue*

health.visibility	Mean	Std. Deviation
healthy	2.71	0.76
invisible	2.79	0.58
visible	1.72	1.23
Total	2.28	1.07
Sign. (ANOVA)	0.007	

**Table 10**

*Average scores for participation, divided by the visibility of a health issue.*

health.cause	Mean	Std. Deviation
birth	1.0000	1.41421
disease	2.7500	.50000
life event	2.7273	.64667
war	1.8000	1.26491
healthy	2.7143	.75593
Total	2.2821	1.07480
Sign. (ANOVA)	0.037	

The results are as expected: people with visible health issues, either congenital or resulting from war, score the lowest average values on overall participation. More hopeful are the standard deviations, which are also highest in these same categories. This means there is a large variation: some of these respondents participate very little, some very much.

### Participation and transport

Now we must take a look at the variation in participation levels related to the use of public transport, first aggregately, then disaggregately. Table 11 shows the difference between users and non-users of public transport modes, in the average number of different activities undertaken. Also standard deviations of the average participation levels are shown, as well as significance levels of these differences.

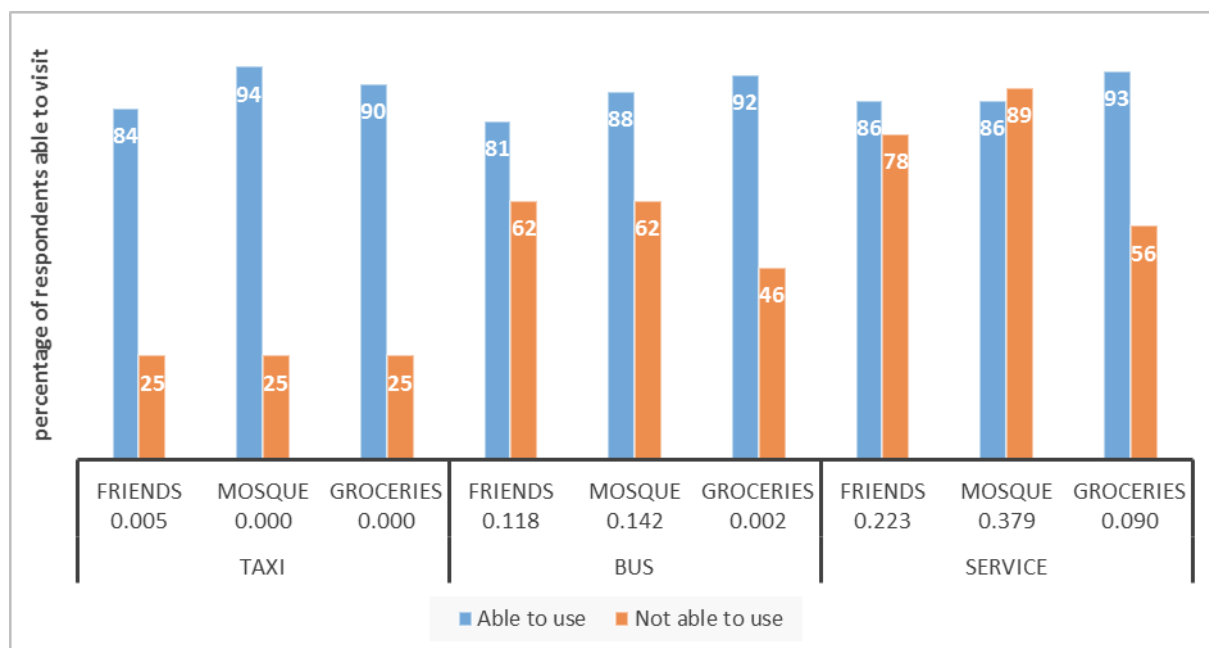
**Table 11**

*Difference between users and non-users of public transport modes, in the average number of different activities undertaken*

ability	taxi	Std. Deviation	bus	Std. Deviation	Service	Std. Deviation
No	0.750	1.035	1.692	1.437	2.222	1.093
yes	2.677	0.653	2.640	0.638	2.643	0.633
Total	2.282	1.075	2.316	1.068	2.478	0.846
Sign.	0.000		0.004		0.534	

Again, the results are rather predictable. Especially respondents who cannot use taxi or bus have a much lower average participation than those who can. And again there is some hope to be found in the standard deviations, which show that even those who are unable to use any public transport are not all confined to their dwelling places.

Graph 4 summarises the most important results obtained so far. It shows the percentage of respondents who can participate in each activity, and separates those who can from those who cannot use each transport mode. Underneath the bars we find the (two sided) significance of the difference between each couple.



**Graph 4**

*Share of respondents who can participate in each activity, depending on the ability to use different transport modes.*

The main things that we can now conclude are:

- People who cannot use a taxi are much less likely to participate than people who can.
- Not being able to use services does not make one much less likely to participate.
- Doing groceries is either the hardest activity or the one that people most easily give up if public transport is too difficult to make use of.
- People living in centres keep occurring as group with least participation. This is probably due to an overlap of factors: most of them have visible war injuries and are unable to use public transport.
- Does it matter? Living in centre means everything is provided, but very little contact with outside world. Handicapped people have handicapped friends etc. Souriyat as a prison.
- Last question: what would you like to do more?

### Costs in time and money

So far, the approach to participation and mobility has been rather absolute: one is or is not able to use a bus, visit friends etc. But most of the time, things are not that dichotomous. With a lot of effort, money, time, help etc. many more opportunities are open than we usually take. The questionnaire was designed to exclude the role of help, by asking what respondents were able to do on their own, without company. But still the remaining complexity is very hard to analyse.



To reflect at least to some degree the complexities of the considerations and trade-offs people have to make, table ... shows the average amounts of money and time that respondents have to spend on a two way travel to certain destinations.

**Table 12**

*Costs in time and money involved in reaching different kinds of destinations.*

	friends	mosque	medic	groceries
travel time	2.6	0.23	0.87	0.63
std. dev.	1.89	0.15	0.67	0.72
travel cost	6.96	-	3.16	1.2
std. dev.	7.12	-	2.97	1.7

It is clear that reaching friends is most demanding, both in terms of time and money. Walking to a mosque and back is usually least time consuming and free. Note that medical facilities are far more expensive to reach than shops, although the gap in travel time is not very wide. The most probable explanation has already been given earlier: when they need to go to hospital, most people prefer a taxi to bus or service, whereas groceries are most often done by service.

The role of effort is very crucial for understanding how people with impairments make their choices, but impossible to quantify. Let me therefore give an example. I am interviewing a young man in a community centre for people with an impairment. He is paralysed and uses a wheelchair. The question is: are you able to visit friends and family. The guy answers: "one cousin is a patient in Jordan, but he comes to visit me here (in the centre where I am staying). The rest is still in Syria." What should I do with this answer? What stops him from seeing most of his loved ones is the war in Syria. But this study is about accessibility and exclusion, not about separation by war. There is only one relative that he still sees, but he never visits him. The friend comes to the centre. Does it matter to my informant that he can never visit his cousin in his house, and all the talking has to happen in the centre? I didn't ask. And what makes it even more complicated: I think he could visit his cousin, if he really wanted. But it is quite an effort. Getting out of the building, carried off the stairs by staff, being pushed in the wheelchair or driven in a car, which also means being lifted into the car and having somebody fold the wheelchair, then being lifted out of the car and into the wheelchair again, and then getting into the friends' house. And all of that again in reverse on the way back. It's just easier for the friend to come to the centre.

Everything costs effort, often both of the person with a disability and of the people around him/her. And it is hard to always ask other people for a favour. The blind man for example has a few bars or coffee shops where the staff knows him. That makes things easier. *"Usually I talk to the staff of places that I often visit, and then on later visits they help with getting out the taxi, getting back in, getting to the bathroom etc."* (Informant 3, Personal Communication, 2016-03-24).

### Unfulfilled desires

One important question remains. At the end of each interview each respondent was asked what difference it would make, if their main limitation was suddenly removed. For some the question was about health: if you would suddenly be healed, what would you do? For others: it was about transport or time: if suddenly you had a car or a lot of spare time, what would you do? The answers tell us something about the loss of which abilities the informants themselves value most.

The answers to this question have been categorised, and the result is shown in table 12. Some informants mentioned several kinds of activities, so the frequencies do not count up 100%.

**Table 12***share of respondents mentioning different kinds of activities as their most wanted*

Most wanted activity	
leisure (nature)	50% (11%)
social	42%
work	26%
nothing	13%
mosques	5%

We can see that half of the respondents long to undertake some kind of leisure activity, some of whom explicitly mentioned they missed being in nature. When a specific place was mentioned, it was often very touristic, rather far away and difficult to reach by public transport. Also the inability to see friends and families comes to the surface as an important problem. Looking at the previous paragraphs, it is not difficult to see why: it is the destination with highest average costs, both in time and money. Some people would love to work. For Syrians, only certain jobs are allowed in Jordan, so some of them cannot do their former job because of their nationality.

Some good news here too: five respondents would not change much in their activities, in ideal circumstances. Of these respondents four were paralysed and one had lost a leg. In principle, this can mean several things: these people could have lost all ambitions, perhaps the question sketched a hypothetical situation that did not really take away the real curb to their ambitions, or these respondents were in fact happy with their possibilities as they were. A closer look at the un-coded answers reveals that two respondents experienced ethnicity as a Syrian as more limiting than their disability, for another respondent the disability itself made working impossible, not the immobility. In this case the question did indeed not work, as a hypothetical car could not solve the most important problem. One respondent said a car would make everything cheaper and easier, but would not change the activities actually undertaken. One more respondent reported to just love his dwelling place, and feeling no urge to leave it.

## 5. Conclusions and discussion

### 5.1 Conclusion

It is now possible to say a few things about what limits the mobility of the respondents in the sample and how these limitations reduce some of their essential capabilities.

#### 5.1.1. Walking

Walking in Amman is not very easy, the city seems to be designed for cars rather than pedestrians. Part of the difficulty comes from the many steep slopes on which the city was built, but many problems can be ascribed to the very poor infrastructure. If provided at all, sidewalks are often blocked and pedestrians are forced to hit the road. Sometimes individual civilians are to blame for parking their car on sidewalks or blocking them with piles of garbage. But often it is also just bad planning, for example when trees with low branches or restaurant terraces make the going impossible. For able bodied people, most of these issues are not very hard to overcome. Leaving the sidewalks to walk on the road is safe and easy in most places. For people with impairments however, albeit small ones, getting up and off the sidewalks can be a great nuisance and peril.

In spite of all these troubles, the respondents do walk quite long distances. The general phenomenon of the privileged walking less than the deprived is reflected in the data, but none of the differences between types of disability are anywhere near significant because of the large variation in walking distance. The longest distances were covered by a completely paralysed man in an electric wheelchair, a category in which many other respondents cover only very short distances.

#### 5.1.2. Public transport

Taxis are abundantly available in Jordan and only few people are unable to use them. For a majority of the respondents though, the costs of using taxis limits the frequency with which they do so. We could say the prices of the taxis are too high or we could say the disposable income of the informants is just very low. This research cannot decide on that. It is however possible to say that more accessible modes of public transport are more expensive. Busses and services are cheap but very difficult to use with a disability. Taxis are easier to use, apart from the risk that drivers do not stop for people with a clearly visible disability, but they are more expensive. These problems are most stringent for people with either war injuries or congenital issues, mostly visible issues. These groups are least able to use public transport and even when they are, they do so less frequently.

The cheap forms of public transport have another problem: their coverage. In Amman, the periphery is well connected to the centre but poorly to other peripheral areas. Respondents often mention especially services not to be available in the area of either their homes or their most frequent destinations.

There are also specialised minibuses driven by people who understand what people with disabilities need, but they are twice as expensive as normal taxis. Perhaps this also explains why only a few respondents mentioned their existence. A next step towards a better participation of people with disabilities in Jordan could be a subsidy for their specialised transportation.

#### 5.1.3. Non-participation and transport

People who cannot use a taxi have the lowest levels of participation of all groups. This does however not mean that the taxi is the most important transport mode. Rather, it means that not being able to use a taxi is a good indicator of low participation, which might be due to other problems. Not being

able to use services does not make one much less likely to participate. Again, this does not mean that services are not an important transport mode, rather it means that the inability to use services is more equally spread among people with different levels of participation. The use of buses is in this respect in between taxis and services, it does predict participation better than the use of services but less accurately than the ability to use taxis.

Transport modes also tend to be used for different purposes. The taxi stands out as the primary mode of transport for reaching medical facilities and plays a more average role in all other kinds of destinations distinguished in this research: leisure, social, work, food and legal. Taxis are the only transport mode that is used for everything by a small fraction of respondents. Buses stand out as the most important way to reach family and friends or work/study, and play a more average role in reaching grocery shops or medical facilities. They are very unlikely to be used for leisure activities or police/government buildings. Services are the single most important transport mode for collecting groceries, but are less than average for all other destinations.

#### **5.1.4. Non-participation and other causes**

Not all non-participation is due to transportation problems. Of all the reasons that could possibly hold people back from participating in opportunities, a few were mentioned enough to draw a more or less systematic conclusion.

##### **Accessibility**

Accessibility is a problem in Jordan. Not only the streets and sidewalks are full of steps, stairs bumps and slopes, also buildings are hard to access and elevators and ramps are scarce. For medical facilities the problem of accessibility was mentioned only by a blind man. Grocery stores on the other hand, especially the small local shops, are told to be inaccessible by 15% of respondents, 12% brought inaccessibility up as a problem for visiting friends and family. There was only one respondent who experienced accessibility as a problem for visiting mosques, and not even for all mosques.

##### **Shame**

The problem of stigma and shame appears to be very pressing for people who live with a disability in Jordan. The effects are very hard to measure but all informants who had disabilities were unanimous in their narrative: people with disabilities are so severely infantilised, and getting from one place to another costs so much effort and money, that very often it is just easier for them not to participate. There are however stark differences between people with seemingly very similar disabilities. Some people prove that it is possible, with a lot of effort, courage and money to attain a level of participation that is very similar to that of their able bodied peers. These people unanimously state that it is mainly social support that makes the difference.

In this respect, current events and the near future can be very interesting. Among the enormous influx of refugees, there is a very large share of people with disabilities that are not congenital but acquired at later age. Although this research has not been able to prove it, some informants have claimed that the difference between congenital and acquired disabilities is very important, because people with acquired disabilities have grown up with able bodied friends, and have tasted the possibilities of a non-secluded life. Allegedly, they are less likely to accept the cultural stigma on disabilities to limit their possibilities. In this respect, the coming years could be a window of opportunity for a more substantial improvement in the position of people with disabilities in Jordan. Again, this research has not been able to find proof for this idea, but it is an interesting idea, because of the large influx of refugees with acquired disabilities. If all those refugees refuse to accept the stigma and try everything they can to participate as much as possible, together they could succeed.

### 5.1.5. Capabilities

Now we have arrived at the main questions of the research: are there capability under threat, and if so, is limited mobility – i.e. the time and money involved in moving – the threat?

Leisure appears to be what the largest fraction of the respondents (50%) misses. If we were to categorise this under a capability, I think number 9 – Play, the ability to laugh, play and enjoy recreational activities – would be the most fitting. This capability was not included in the methodology because the link with mobility was not immediately apparent, but when respondents give a reason why they were unable to undertake the leisure activities they desired, the answer was mostly the cost of travelling (10%) or a lack of time (7%). So I think it is fair to say that limited mobility is a threat for the ability to undertake leisure activities. But can we say the entire capability of playing, laughing and enjoying recreational activities is under threat? That is very doubtful and it depends on our interpretation of the capabilities approach: if we take it as a list of what people should be able to do, we can say that people will most likely be able to find other playful and leisurely activities. If on the other hand we emphasise the importance of the freedom of choice, we have to say yes, many people cannot choose the kind of leisure activity they want to undertake. With this approach, it is however very unsure if there is any earthling to be found whose capability of laughter, play and recreation is not severely narrowed.

The ability to visit family friends seems to be under threat as well. Of the measured indicators of participation, it was the one that the least people overall were capable of. And the reason seems obvious: reaching loved ones costs more time and more money than reaching other kinds of destinations. Respondents mention accessibility (12%), time (10%) and money (7%) as the greatest obstacles. The severity of this problem is underlined by the high number (42%) of respondents who would visit family and friends more often if they could. Looking at those numbers, I think it is fair to say that for a significant number of people the capability of affiliation is under threat, partly because in this case I would argue that the solution of finding other love bonds to substitute the most desired ones is not fitting. But is limited mobility the threat? Again, I think the numbers suggest that for a significant number of people, mobility is the main problem, but accessibility of buildings forms an important second most widespread obstacle.

Medical care was within reach for all informants, which means at least that limited transport is not an important threat to the capabilities concerned with health and bodily integrity. However, it seems that poverty is. Some informants would be willing to borrow money for medical care if needed, others had brought down the frequency of treatment to save money, several informants needed surgery but could not pay for it.

The ability to get groceries is under threat, but for most respondents, the problem is inaccessibility or lack of money (both 15%). It is small local supermarkets that are the problem, not the big shopping malls. They are both relatively cheap and accessible also for wheelchairs, but not as ubiquitous as the smaller supermarkets. The associated capability of control over one's environment involves much more than the ability to reach grocery shops, for example the ability to seek employment. The relevance of employment is underlined by the 26% of respondents who would want to work if their health, their mobility or if the government allowed Syrians to work. We can conclude that for a significant number of people the capability of control over one's environment is under threat, because two aspects of it, employment and getting groceries are difficult or impossible. But the causes are very diverse, and include health, inaccessibility, lack of money, national laws and lack of mobility.

For the capability of senses, imagination and thought, two indicators were analysed: the ability to reach religious places (mostly mosques) and schools. Mosques are abundant in Jordan, and few people have difficulty to reach one. Some respondents claim that a minority of mosques is accessible, but nobody was unable to find one that was. Other religious places are far less densely scattered but no problems were reported about reaching them either. Ergo: mobility seems not to be a threat to religious practice. About education, the questionnaire revealed very little information, only that reaching schools was not a problem for the few respondents with school going children. However, census data reveal that school dropout rates are much higher for disabled children, especially girls, than for their able bodied peers. With these data, we can conclude that the capability of senses, imagination and thought is under serious threat for people with disabilities, but it is hard to say if limited mobility is the threat. The only clue that the data reveal is the stark differences between boys and girls, which suggests that transportation is not the main problem, as it is not much harder to bring a girl to school than a boy.

## *5.2. Discussion*

### *5.2.1. Validity*

One of the problems of this research is that causalities are very hard to track, let alone to prove both with quantitative and qualitative methods. Quantitative methods can prove correlations, but correlations are no causalities. There is always the possibility of an explaining third. That is why in the end we must speak of associations, connections etc.

An example of this is the relation between mobility, for example the ability to use taxis, and participation. It turns out that people who cannot use taxis are far less likely to be able to visit loved ones, mosques and shops. But this does not mean that the ability to reach these destinations depends on the use of taxis. It is very well possible that the true explanation is health again: perhaps only people with a very bad health condition are unable to use taxis, let alone visit loved ones, mosques or shops. Statistically, this research is not able to tell which relation does more justice to the truth.

Another example of the difficulty of using statistics is the relation between health and mobility. Health has in this research been analysed in two ways, once according to the cause of health issues and once according to their visibility. In most statistical tests, the visibility of health issues seemed to have more significant relations with for example participation than the cause of health issues. But the cause of health issues was split out into 5 different categories, whereas the visibility created only 3. This means that the categories made by health visibility contained more respondents, which makes a significant result more likely. This is another reasons why we have to be very careful to draw conclusions from the significance of statistical correlations.

Apart from these very fundamental issues, there are many smaller issues that affect the validity of the research. Those have been mentioned in the methodology. A few things need mentioning here:

There is some discussion on the question if it is better for people with disabilities to live with each other in their own communities or mixed among the rest of the population (see for an example about education Gaad, 2004). This research is not a good basis for any judgement on that question. Only four different centres were visited, and these centres were very different from each other. Some appeared to be normal homes with disabled people living together; others actually had a more or less professional management. Apart from that, also the inhabitants of the centres were often the most severely disabled respondents in the sample, which makes it impossible to say anything about

the influence of living in a centre. The only thing this research can do is illustrate part of the advantage of specialised centres: in some cases, the concentration of people with disabilities made it possible to provide some services collectively, such as physical therapy, daily meals or a makeshift mosque. This saved the inhabitants of the centres a lot of travelling.

The information in the results section about infrastructure all concerns the city of Amman, whereas the information about walking distance was gathered from respondents living in a few different parts of Jordan as well. The infrastructure in other cities in Jordan is slightly different, the city of Mafraq for example is very flat, and the infrastructure in villages is even more different from that of Amman. There were not enough data to make a sound comparison of these differences, but it could be interesting to measure.

It would have been interesting to compare the limitations experienced by respondents with different kinds of health issues. People with visible disabilities that do not directly affect their mobility are for example very interesting, because they can provide a clue as to the precise role of the cultural stigma. Such an analysis however requires a much larger sample to reveal any valid information.

### 5.2.2. Scientific relevance

#### **Capabilities and mobility**

Mobility has turned out to be a relevant precondition to the realisation of more capabilities than expected. When asked what difference a car would make to the activities they undertake Many respondents mentioned different kinds of leisure activities. This was an important addition to the research as leisure also belongs to a capability, namely the ability to play. This capability was not included in the methodology because the link with mobility was not clear from the outset. This proves two things: it really is necessary to ask also open questions, as closed question run a very high risk of not capturing information that is very important to the subject of a research. But secondly and more important here: some capabilities can have a mobility component that is not very obvious at first glance. This suggests that the combination of the capabilities approach and mobility could be analysed more thoroughly than this research has done so far.

#### **Enabling and disabling circumstances**

As said in the methodology, this research has attempted to move beyond the binary logic of functionings. Many times, respondents were first asked if they were able or not able to perform a certain task. This information is interesting. But even more interesting were the answer to the subsequent questions: do you ever experience difficulty with this task? What stops you, or does not stop you completely but makes you do this less frequently? I think this approach can be very fruitful, and can be an important addition to the functional limitations approach to disability.

Researching enabling and disabling circumstances does make interviews more demanding. During the interview, an informant has to be willing to share more information and think about the motives for small everyday decisions. And to give respondents the biggest possible freedom in their answers, the questions need to be open, which means the answers need to be coded afterwards.

#### **Money**

I wonder about the role of money. Informants said the difference between participation and non-participation of people with disabilities is made by the support of the social environment, primarily parents but also wider family and friends. But at the same time they report to often make use of taxis, sometimes even the minibuses which are twice as expensive as taxis. For people with disabilities, many things cost more effort and more money. What are for example the costs of a

wheelchair, or even an electric wheelchair? Perhaps for this purpose, Asset theory could prove a very useful framework for this endeavour (see for example Putnam et al., 2005).



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