Summary

Accessible? Not by a long shot

Experiences of people living in the Netherlands with physical disabilities as a mirror of society

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Summary and discussion

S.1 Summary

S.1.1 This study

Striving for an accessible society

For some years now, a good number of policies have been issued with the aim of enabling as many people as possible to participate fully in society (Bredewold et al. 2020; De Klerk 2007). Social participation has thus been an important ultimate objective in recent years within the overall effort to transform the social domain. The 2015 Social Support Act (Wmo 2015) in particular aims to enable Dutch citizens who have a physical, mental, or psychological disability and/or psychosocial problems to participate with others on an equal footing (Kromhout et al. 2020: 84). Participation in society on equal terms is also a goal of the United Nations Convention on the Rights of Persons with Disabilities (CRPD), which the Netherlands ratified on 14 July 2016. Through the “Unhindered participation!” programme, the government has been working to give practical effect to the CRPD since 2018. The aim here is to initiate a social movement, together with partner organisations, that will lead to noticeably fewer barriers, so that people with disabilities can also live as they wish (Ministry for Health, Welfare and Sport [VWS] 2018, 2020).

The Wmo 2015 puts considerable emphasis on the kinds of support that should enable people to participate in society. The facilities offered by municipalities are intended for those who cannot participate in day-to-day life either on their own or with the help of their own support network. The CRPD puts the focus on society at large. The basic principles are full inclusion in society, freedom to make one’s own choices, and independence from others. In keeping with what is referred to as the social model, the CRPD starts from the premise that disabilities actually arise only in interactions with society. If people with physical disabilities are limited in their abilities, it is not primarily because of their disabilities, but mainly because society erects barriers that exclude them. Participation on equal terms, then, requires an accessible society.

Holding a mirror up to society

In the present study, we look at society from the perspective of people in the Netherlands who have physical disabilities. Of course, this group is not the only one impacted by exclusion, but it is one of those for whom equal participation in society does not happen just like that. About 9% of adults who live independently have a moderate or severe physical disability, while another 15% have a mild disability (Putman et al. 2017). No more than half of those with physical disabilities can visit friends and acquaintances just as they wish, and fewer than a third can make trips or journeys as they wish (Grosscurt et al. 2019). People with severe disabilities in particular would like to be able to do more (Van Hees et al. 2018). Notwithstanding the considerable attention that both the Wmo 2015 and the

CRDP have generated for participation, the extent to which people with physical disabilities have been able to participate in society has not increased in recent years. The proportion of people with a physical disability who indicated that they could live as they wished actually dropped (Knapen et al. 2020).

When it comes to accessibility for people with physical disabilities, the first thing that is often mentioned is the barriers that make access difficult or impossible for someone with a disability. But accessibility is also about the experiences people have once they have already gained access to a particular place. For example, it is about the experience of being able to be yourself without having to adapt too much, of being able to move around independently, of "belonging". In other words, accessible places are places that people not only *can* get into, but that they also *would like to* get into, just like everyone else.

Accessibility is therefore about more than just physical or other practical barriers. As with other groups facing exclusion, the barriers experienced by people who have physical disabilities are also part of a deep-rooted social structure. What people think about physical disabilities, and existing prejudices about those who have them, are also an important part of this structure.

"Ableism" is the term used to describe the many ways in which people with disabilities face exclusion or are at a disadvantage as a result of how society is organised. The complexity of the exclusionary mechanisms can be described in terms of four levels (Den Brok-Rouwendal 2005). Whereas cultural ableism has to do with the values in a society in relation to disabilities, institutional ableism is about the ways in which things are organised, and interactional ableism is about the contact between people with disabilities and those without. Finally, internalised ableism refers to the way in which ableism in a society can affect how people with disabilities view themselves, the inequalities they accept, and the difficulties they may have standing up for themselves. It is clear that, when we talk about an accessible society, we are talking about more than just physical barriers.

Research questions

Although an accessible society in principle concerns all of its facets, we will focus here on the public places people frequent in their free time. We are concerned not only with the purely public places, which in principle everyone can access and where everyone is equally at home, but also with the places that are widely accessible but where there is also a certain proprietary element. These "semi-public" or "pseudo-public" places include cafés, community centres, gyms, and shops. Different population groups encounter each other in both types of place, which are regarded as exerting a unifying effect in a diverse society (Van Eijk and Engbersen 2011; Peters et al. 2010; Peterson 2017; Valentine 2013). They are therefore also places where people can make contacts outside their own circle of acquaintances. When it comes to people with disabilities, much attention is often paid to the close contacts from whom they get support (see, for instance, De Boer et al. 2020). The contacts outside the circle offer more information and opportunities than this sometimes small circle of acquaintances is capable of offering (Litwin 2003; Warner and Adams 2012).

They thus also offer those with a disability independence and autonomy from those closest to them, and the possibility of organising their lives as they see fit.

This study addresses three interrelated research questions, the second and third of which are more-specialised versions of the first. The first, general, question is:

1. *What barriers do people with physical disabilities face when visiting public places, and how do these barriers affect their ability to participate fully?*

After painting a general picture of the barriers people face when visiting public places and how these shape their experience, we will look at the differences among types of places. The ideal of an accessible society is that all types of places are equally accessible to everyone, so that everyone has the same choices. In practice, this is not the case. The second research question is therefore as follows:

2. *What differences are there between types of public places in terms of how accessible they are to people with physical disabilities, and what are the barriers that play a role in this?*

Finally, we will look at differences among people with physical disabilities, who comprise quite a heterogeneous group. Someone with a physical disability might also be, for instance, female, an engineer, young, a father, an extrovert, of Turkish origin, or poor. It is well known from the intersectional literature that the experience of belonging to a minority group can depend on a person's other circumstances and characteristics. Those who belong to two minority groups at the same time could face so-called double exclusion. Similarly, having one's own resources can counteract exclusion and make it easier to participate in society with a physical disability. Because a physical disability often makes it difficult to acquire resources, barriers can accumulate. The final research question is:

3. *How do other individual characteristics affect the barriers that people with physical disabilities face when they visit public places?*

Method

To answer these questions, we used a mixed-methods approach, meaning that we combined two forms of research. In order to gain insights into the barriers that society imposes on people with physical disabilities, we first conducted interviews with 38 people who have physical disabilities or chronic illnesses. On the basis of an overview of the places that had been important to them in previous years, they talked about their experiences of visiting these places, but also about their personal circumstances, their motives, and the deliberations they engaged in in organising their lives. These interviews revealed a detailed picture of the barriers people face in participating in society and how that affects their lives. In view of the coronavirus crisis, we conducted the interviews online.

Second, we used quantitative data, namely from the National Panel of the Chronically Ill and Disabled (NPCG) and the Health Care Utilisation Survey (OZG). We tried to gain insights into the accessibility of places based on differences between the people who visited them. The idea behind this was that, if the severity of a physical disability shows a strong correlation with the probability of visiting a type of place—that is, if people with a severe disability are significantly less inclined to visit this type of place than are people with a less severe or no disability—that is an indication that this type of place is poorly accessible. In addition to differences between types of places, we also explored the relationship of other individual characteristics to visits people made. The findings from the quantitative analyses constituted the framework, as it were, for answering the second and third research questions.

S.1.2 The social side of accessibility

In answering the first research question, “What barriers do people with physical disabilities experience when visiting public places, and how do these barriers affect their ability to participate fully?”, we relied on what the participants said during the interviews.

Various practical barriers

All participants in this study, without exception, said they feel they cannot participate on an equal footing, and many feel that their situation is not sufficiently taken into account. In the stories that people told, a lot of attention was paid to practical barriers. The barriers that people face are quite varied in nature, and how they are experienced also depends on the disability in question. Here we will mention four points that came up time and again. One shortcoming that was often mentioned was the lack of toilets that are actually accessible (see also Meijer et al. 2019). That can count as a reason not to go somewhere, but also, if such a place is visited, not to drink anything the whole evening. A second practical problem that often came up was the poor physical accessibility of many catering establishments and shops, especially those in historical city centres, where buildings are often too cramped, pavements and squares are difficult to cross, and parking facilities are far away. A third problem that keeps coming up is the limited number of wheelchair spaces in theatres, cinemas, stadiums, and other large venues. As a result, people in wheelchairs often have to book far in advance, and are often unable to sit with the person or people they have come with. Finally, it is often difficult to find the information that is needed in order to prepare for the visit. And if information is available, it is often not up to date or not precise enough. Online information from other people with physical disabilities can be of help here.

Being treated nicely, and rudely

Social barriers were discussed less directly and openly during the interviews. In any case, other people often featured positively in the stories. However, it did emerge that others also have a negative influence on the accessibility of places. The most direct forms of social barrier consist of being treated rudely, which happens regularly in public spaces and catering establishments. In situations such as this, people are treated as “different”. For example, participants with visible physical disabilities often reported being stared at. Although they said they have got used to it, they still adjust their behaviour accordingly. People also have to deal with crass and disrespectful remarks. In public transport, for example, some fellow travellers ask questions that are too personal. People also find that they are being treated in a condescending manner. For instance, they are ignored in a shop or café, or treated in a derogatory way. People also have to deal with impatience. Visually impaired people are regularly called names in the street because they are “in the way”. In general, hearing-impaired people find that many people with hearing make little effort to communicate with them, even though this is quite possible.

Social consequences of practical barriers

In addition to these negative attitudes, it emerged that practical barriers often have a social side as well. This is the case when practical barriers mean that someone in the room is isolated from others and is thus, for all intents and purposes, excluded. Second, physical barriers can make a given disability more noticeable. If you can get in easily, a disability is much less noticeable than if someone has to perform all sorts of feats to gain access. When the focus is disproportionately on the disability, people are also more likely to be seen and approached as a “person with a disability”, whereas it is nicer and more egalitarian if the other sides of a person are seen. Third, poor physical access often means that people need extra help and are therefore extra-dependent on others. This also puts the person with the disability in an unequal position. For example, asking for help can be annoying at a get-together with colleagues or can embarrass someone in a situation where they do not know others well. Practical barriers therefore create both exclusion and inequality in interactions with other people.

Social and institutional causes of practical barriers

Social and practical barriers are also intertwined, in the sense that physical accessibility is in many ways a consequence of the acts and omissions of others. This means that practical barriers take on an emotional valency that goes beyond just being a nuisance. For example, when neighbours leave things out on the pavement, it is not only that it is more difficult to pass—it is also frustrating and creates the felt need to have a word with them about it. If an acquainted shopkeeper whom the disabled person knows sees no real need to see to it that the entrance to their shop is accessible since, after all, anyone with a disability can just go in through the back, those people are surely going to feel unwelcome. It is more or less the same as when practical barriers have institutional causes, such as when a new building does not meet accessibility criteria even though these are well known. The fact that accessibility is apparently not given enough priority sends the message that society does not consider it important for people with physical disabilities to participate fully.

Others can ease practical barriers

A third aspect of the intertwining of practical and social barriers is that others can mitigate practical barriers. If there were no practical barriers, there would be no need for this, but the truth is that people make a big difference. For instance, participants in the study mentioned the benefits of having well-trained and attentive staff, such as a supermarket employee who will accompany them through the aisles, or a trainer who gives them some good pointers. People who take that kind of approach can enable participation in society without engendering feelings of inequality. Strangers who are not affiliated with a particular place can also make things easier, for instance by pulling over for a mobility scooter or by fetching an article from a higher shelf in a supermarket. Of course, friends, family, and other acquaintances can also make it easier for someone with a physical disability to overcome practical obstacles, and they do this rather a lot. That said, many people with physical disabilities do not want to place too much of a burden on their support network, and it's not always a given that someone will be willing to make allowances for what a person with a disability can and cannot do.

A lot of extra work

The consequences of the barriers that people encounter are significant: it costs them a lot of hidden work (Goodwin and Ebert 2018). For example, people with physical disabilities are often forced to make detailed preparations for a visit they will be making. They have to get information on accessibility and transport, and organise everything well in advance. They also need to coordinate with others from whom they may also need to generate some understanding of their situation. In addition, they have to consider potential unforeseen blockages, such as a lift that may be out of order. This extra work requires more time and energy of those with physical disabilities (who often have less energy to spare in the first place) than is required of people without disabilities, just to get to one or another meeting place. These extra efforts often go entirely unnoticed. Hidden within the extra effort that people with physical disabilities have to make in order to engage in an activity, is an inequality when it comes to opportunities to participate. And this flies in the face of the ideal of equal participation. If the burden of having disability were more equally distributed in society through improved accessibility, people with disabilities could participate more fully and independently.

Emotional work and social skills

Besides the extra work involved at the practical level, people with disabilities also have a lot of emotional work to do (Hochschild 1983; Scully 2010; Wilton 2008). Because people with disabilities are aware of the prejudices others hold, they make extra efforts to manage social interactions. This requires quite some emotional investment. People with visible disabilities, for example, told of first encounters they had had. They were aware of the feelings and expectations they aroused in others, and did their best to make them relax as quickly as possible. The fact that others often have little sympathy for their situation and do not appreciate the extra effort they have to make also costs emotional energy. For example, in the interviews people said that they regularly feel angry, frustrated, or sad about this. Because people without physical disabilities have little awareness of this emotional burden, sharing feelings about it often fails to elicit understanding or lead to any kind of shared experience. Several participants said that they feel they also had to represent others who have disabilities. They feel responsible for investing that bit extra in relationships in order to contribute to a more accessible society. They try to make their presence felt and to show that they are people who can take part and communicate just like anyone else. And this, too, requires an emotional effort.

In this light, it is understandable that social skills make it easier to participate in society, probably more so for persons with disabilities than for others. After all, more often than others do they have to ask for help, break through prejudices, explain what they need, and stand up for themselves. They are also more likely to have to deal with agencies, for example, to get assistive devices or amenities. For instance, people said that they see others around them who are less able to get things done because they do not dare to stand up for themselves, or because they have difficulty finding their way to one or another agency. Some said that they had gone through a process of teaching themselves how to overcome social barriers.

Transport and assistive devices as crucial prerequisites

Although the focus of this study was on the accessibility of public places, the participants' stories make clear that whether or not to visit these places is strongly influenced by a number of crucial prerequisites that have to be met before a place can be reached. First, transport is often already a significant barrier. Travelling takes a lot of energy, and can also be stressful because a lot can go wrong. Participants indicated that special transport was not very punctual, with the result that they have to plan ahead in order to be on time and thus have to spend a lot of time waiting around. Also, some participants said they find that using special transport carries its own stigma. Public transport offers more independence, and a lot of the participants said they were quite happy with trains. Local public transport is seen as less accessible. One problem here is that bus drivers sometimes can't be bothered to activate the kneeling feature, so people who depend on it cannot get on the bus. Finally, participants talked about what a big difference it makes to them to have a suitable means of transport. Having an adapted electric bicycle, a hand bike, or an adapted car can open up many possibilities.

This also applies to a well-fitting wheelchair, a guide dog, or an adaptation in the home. These assistive devices and adaptations are necessary in order for people with a disability to be able to move about properly and to organise their lives as they want. However, many participants mentioned the problems they experience when applying for assistive devices. They had to deal with long wait times, but also with decisions they did not agree with and with complex bureaucratic processes in which agencies often sent them from pillar to post (see also Kromhout et al. 2020). In the experience of many participants, then, applying for facilities is really difficult, with the result that they have had to go through lengthy legal procedures. This process is not only extremely time-consuming and costly, but also tiring and stressful. People who have difficulty getting assistive devices also found that the opportunities they had to participate were hampered while they were waiting: they could hardly go anywhere for months, or even years, and they reported that they sometimes had little energy left to do anything. In addition, that made it difficult to participate in society in the long term because it led to physical deterioration.

S.1.3 Types of places

To answer the second research question, “What differences are there between types of public places in terms of how accessible they are to people with physical disabilities, and what are the barriers that play a role in this?”, we combine findings from the quantitative part of the research (Chapter 6) with the experiences of participants that emerged in the interviews (Chapters 7, 8 and 9). We discuss the most important findings in relation to public spaces in the living environment, public facilities, places to play sports, civil society, entertainment venues, and online places.

Public spaces: unpredictable obstacles on the street and accessible supermarkets

Every activity outside the home begins and ends in public spaces, the accessibility of which is therefore crucial to being able to participate in society. This applies in particular to the residential environment, where, according to the interviews, many people with physical disabilities organise a large part of their lives. Yet this public space emerged as quite inaccessible. A smaller proportion of people with severe disabilities regularly go to a park than do people with mild disabilities (23% versus 40%), and a smaller proportion go to a postbox or an ATM (50% versus 66%) or a supermarket (67% versus 90%). It is precisely these places in the neighbourhood that people with physical disabilities have been visiting less in recent years (Knapen et al. 2020).

It came out in the interviews that public spaces feature many unpredictable physical obstacles. Scooters, litter bins, and the like lead to awkward and dangerous situations for people who have difficulty walking or use a wheelchair, or who have a visual impairment. Coping with these situations takes energy and makes people feel unsafe. In one’s own neighbourhood, it is even more frustrating that it is one’s neighbours who thoughtlessly leave things on the street. Physical barriers are the greatest in city centres because of pavements and squares that are difficult to cross, the hustle and bustle, and the distances to parking facilities. Strangers often offer help in public spaces, something that was emphasised by many people during the interviews. On the other hand, people with disabilities are also often confronted in public spaces with impatient reactions or blunt remarks from strangers.

The situation in supermarkets seems better than in public spaces, according to the interviews. People with different disabilities reported few physical barriers, and socially people also generally feel that they are safe and can get the help they need. One consideration here is that many people are familiar with their local supermarket and that staff know them too and are able to help them. The fact that quite a few people with severe physical disabilities do not or hardly ever visit a supermarket could be related to their having to get to the supermarket through less-accessible public spaces. Another factor may be that grocery shopping can be difficult as a practical matter. Participants’ experiences in shops other than supermarkets are less positive. Smaller shops in particular are often physically difficult to get into because of thresholds and other obstacles. Staff sometimes overlook people with physical disabilities, show little willingness to help, treat them as mentally disabled, or do not believe them when they ask for special consideration because of their disability.

Public facilities: community centres appear to be easily accessible, but only for a few visitors

Because public facilities are financed with public money and also serve social purposes, it is an important requirement for them that they be accessible. The accessibility of libraries can be questioned if we look at who visits them: while 15% of the participants with a mild disability visit a library regularly, only 8% of those with a severe disability do so. The interviews did not provide an explanation for this. If we look at visitors to community centres, we see in any case that few of those who participated in the survey visit a community centre regularly (just under 10%). We also see that the severity of the disability is not a factor. The community centre thus seems to be a readily accessible facility for a small number of visitors.

Among the participants in the interviews, community centres were not a popular place either, which is partly because they feel they have a relatively low status (Van Melik and Pijpers 2017). For example, one participant said she did not feel drawn to the visitors she met when she went to take a look at a community centre. Participants also said that they do not see a visit to a community centre as participating in society, but experience it as something separate. According to the figures, this viewpoint is held especially in cities, because in more-rural municipalities, community centres and village halls are more popular among people without physical disabilities. Incidentally, the negative image community centres have does not extend to specific activities that take place there, such as taking a course, nor to initiatives in which local residents run a meeting place together.

The interviews also focused on government buildings. While these would seem to be relatively easy to access, the bar is also high here. When people with physical disabilities wanted to follow a debate in the Lower House of the Dutch Parliament about the CRPD, they were really disappointed to find that they had to follow it through a video link because of a shortage of wheelchair spaces in the public gallery.

Places to play sports: readiness to adapt and individual solutions

People with severe disabilities come to sports venues to play sports relatively infrequently. While 11% of the participants with mild disabilities regularly visit a swimming pool, this is true of just 5% of those with severe disabilities. The difference is even greater when it comes to visiting a gym (16% versus 4%). The difference also appears to be significant for sports clubs, including sports associations. While 29% of the participants with mild disabilities regularly visit a sports club, this is true of just 12% of those with severe disabilities. Sports venues therefore do not seem to be easily accessible to people with moderate or severe physical disabilities.

The interviews show that, even more than other activities, doing a sport confronts people with their physical disability and that customisation is often necessary. Many participants whose disability arose or worsened later in life went through a personal process of learning to cope with their changing capabilities. Sometimes helped by rehabilitation centres, they said goodbye to sports they used to enjoy, but also found new sporting opportunities. However, standard sports facilities are often not accessible to them, for example because the ambient lighting is too dark or because there is no patient lift in a swimming pool. One participant said that he can play sports without a problem at his own club, but that he often has to forego an outing because the other side does not have an accessible toilet. In situations such as this, a lot depends on the willingness (and ability) of providers to make adjustments for a participant. In some cases this willingness is there, and sometimes it is very strong, but in other cases participants feel it is lacking. Since visiting regular sports venues is difficult for some participants, they looked for and found alternatives in individual sports, such as cycling with an adapted bicycle. However, the high cost of the assistive devices they need is a barrier.

Civil society: manners make the difference

Civil society can be defined as that part of society that lies between the market, the state, and the private sphere—the organised relationships in which people voluntarily connect with each other based on a common goal or ideal (Dekker 2002). Although civil society has a connection to physical places, social connections and social processes also play a major role here. Although it is often hoped that civil society will bring population groups into contact with each other, exclusion is a problem here too. If we compare the rates of people's attendance at creative associations, such as choirs and drama clubs, we see that those with severe physical disabilities participate somewhat less often (16%) than those with mild physical disabilities (22%). In the interviews, these associations were mentioned hardly at all.

The figures also show that, although many participants have monthly or more-frequent contact with neighbours, this was true of a smaller proportion of those with a severe disability (76%) than it was of those whose disability was mild (85%). Certainly when combined with the fact that their disability is a reason for participants to look for contacts close to home, this suggests that networks in the immediate neighbourhood are not very accessible. For about half of the participants, contacts with neighbours and fellow neighbourhood residents were a topic of conversation, mostly in a positive sense. Participants often experience this contact as warm, with the intensity of the contact varying greatly. Although neighbours regularly exchange help, some participants stressed that they are not dependent on their neighbours and do not want to be. They emphasised, for instance, that they themselves provide help or that they can ask others for help. The desire to avoid dependency may explain the lack of contact. Some indicated that they feel that neighbours keep their distance to avoid being burdened, or that they themselves keep their distance to avoid giving the impression of being dependent.

No difference emerged when it came to attending religious gatherings: about 15% of the participants visit a church at least once a month. Thus, although not many people attend religious gatherings, these seem to be accessible. The stories of six interviewed participants who said they were involved in a church or Islamic association illustrate why.

It emerged that, when people actually visit a religious community, they find an etiquette oriented towards being accessible, where giving help is a matter of course and people can easily ask for it. The fact that the network that people build up in a religious community is often in the neighbourhood helps here too.

Finally, a large proportion of the participants turned out to be active as volunteers, citing as their motivation the fact that they want to do something for others, experience satisfaction, and have social contacts. Compared to paid work, the advantage of volunteering is that people can generally decide for themselves how much they will work and what they will do, which means that the work can better suit their needs and abilities. However, the interviews also show that it is not always easy to find suitable voluntary work. Some experience discrimination or little flexibility in their search for work that matches their abilities.

Some of the respondents are committed to promoting accessibility, often as volunteers in an interest group. In addition to the aforementioned motives, the fact that people are very committed to improving accessibility also plays a role. Discrimination or exclusion within the organisation they work for did not come up in relation to this form of commitment. However, interviewees said they find it difficult to raise the same issues over and over again and to bring about real change, and that in turn leads to frustration. They also indicated that they found it a disadvantage to set themselves apart as a group with this volunteer work.

Going out is often quite an undertaking

Judging by the figures, entertainment venues and attractions such as museums seem to be among the least accessible of all places. Of the participants with mild disabilities, about half (46%) regularly visit a café or restaurant; of those with severe disabilities, only a quarter (26%) do. Similar differences emerge for visits to a cinema or theatre (50% versus 25%) and to a museum or attraction (56% versus 26%). If we also look at the other factors that influence whether people with disabilities visit these places, it turns out that it is not only physical disability that plays a role, but also the level of education and employment status. This indicates that socio-economic factors also play an important role in the accessibility of these places for people with physical disabilities. The limited accessibility of these places is therefore partly connected with the question of prerequisites. Going out is often expensive, and that creates financial barriers. In addition, for most people, a lot of entertainment venues are not that close. Transport can be expensive, complicated and tiring, requiring both financial resources and a companion—someone who can drive, for example—in order to enjoy both getting there and being there.

But at venues themselves, too, going out also comes with barriers, starting with the practical ones. Many respondents said that bars, restaurants, and cafés are physically difficult for them to access because of cramped toilets, the need to take stairs, thresholds, and crowded or busy rooms, especially in the older premises in historical city centres. In cinemas, theatres, and concert halls, physical accessibility is often quite good, according to our respondents, but a good deal less so in the film houses that are often somewhat older and smaller. It can also be frustrating that even new buildings are not designed to be very accessible. Furthermore, visually impaired people can find it difficult to find their way around theatres. Another recurring theme is the aforementioned scarcity of suitable places for people who are wheelchair-dependent or who need a place that is suitable on other counts. Places where crowds gather, such as festivals, also have practical barriers. For example, people with physical disabilities often have to settle for a place off to the side somewhere.

Within the social barriers, we can distinguish between the people who work in the places (and therefore also represent the policy of the organisation), strangers, and the social network of those with disabilities. Participants said they expect the people working at venues to help make it possible for them to visit them like everyone else, even when there are practical barriers in the way. Just as we saw with the places where people play sports and with government buildings, staff can also make a big difference when they go out And they regularly do make such a difference, but it is not that obvious. For example, participants perceive a lack of understanding and awkwardness in the attitude of staff. Another factor is that employees have a different idea of what counts as equal participation. For a staff member it may seem a small thing to sit apart from the person or people you came with, but it was important to many participants in the study.

When it comes to going out, strangers play a role similar to that which they play in public spaces. Many strangers will act normally or sociably, but participants also report being stared at or having to deal with blunt remarks or questions. The hospitality industry in particular seems to offer little protection against this.

Precisely because nightlife venues are not easily accessible in other respects, the social network that someone with a disability has plays a major role in being able to go out. First, being with others makes it easier to visit places, for example because they provide transport. But their influence on accessibility also seems to be strong in the place itself, especially in crowded entertainment venues, such as when someone helps a person with a visual impairment to get around in a room full of people or when friends hang out together at a festival. But it is not always a foregone conclusion that others will show their solidarity. Sometimes friends will choose a venue that a person with a disability cannot access, or they may go off on their own once everybody has got into a venue. Many participants find it important not to burden their friends and family too much, so they accept being on their own for a while), when going out.

Online participation: a valuable addition, but not a replacement

Finally, we look at online meeting places, which are becoming a growing part of the social infrastructure. People with severe disabilities are no less likely to use the internet to meet others than those with mild disabilities (41% versus 45%), so these places seem to be easily accessible. When it comes to seeking contact with peers, too, we see no differences between people with mild and severe disabilities (7% versus 9%).

In the interviews, several participants indicated that they are building a network online. This is possible thanks to the internet, because online contact requires little energy, for example, or because it does not carry any unpleasant consequences. Especially for those who have very little energy or who can become quite irritated by stimuli, this can be a godsend. Others said that they prefer online meeting places for a first encounter, because it is precisely then that the physical disability often plays a major role and is accompanied by awkwardness. Once this first hurdle has been crossed, in-person contact also becomes easier. Although we found low percentages, participants also reported using the internet for contact with other people who have a disability. They might be looking for reliable information on accessibility, but perhaps also for emotional support. In these places, they do not have to fear being treated rudely by people who do not understand their situation. However, participants also mentioned that they avoid contact with peers because they do not feel at home in peer groups, or that they prefer contact with people without disabilities because otherwise they feel excluded from society at large.

So, while digital encounters can bring great benefits, participants also stressed that they are no substitute for in-person contact, which many prefer, in some cases referring to it as “actual” contact. Participants also stressed that being present somewhere, for example at a meeting or a demonstration, can also be important because you want to be seen and to exert influence. Although digital accessibility (including in the case of demonstrations) can therefore be a valuable additional option, the accessibility of “actual” places remains a prerequisite for full participation in society.

S.1.4 An interplay of factors

Just as we did in answering the second research question, for the third research question, “How do other individual characteristics affect the barriers that people with physical disabilities face when they visit public places?”, we will use both quantitative and qualitative findings. In certain respects the two sources complement each other, while in others they are separate. Four relevant factors emerged in one or both approaches. We discuss here, in turn, education and financial possibilities, having a social network, having a migration background, and gender.

Training and financial opportunities

The quantitative analyses showed that people who have a physical disability and a low level of education visit fewer places overall than do those who have a physical disability and a higher level of education. It was also found that participants who were not in paid work visited fewer places of entertainment, and that having a severe disability was also more of a hindrance to going out for them. Both findings may have several explanations, but it is plausible that financial barriers play a role.

The importance of financial resources was frequently mentioned in the interviews. Respondents with little money experience many obstacles to participating in society. Not only are their opportunities to engage in activities limited, since they have little money to live on, but visiting places can also be more expensive for them because of their disability. The fact that not all places are accessible means that cheaper options have to be eliminated. One participant also mentioned that she was unable to take advantage of a discount offer for theatre tickets because of her disability. On top of that, a lack of money can make it difficult to buy assistive devices, and that in turn also makes it more difficult to visit places.

It also became clear that a weak financial situation is often a consequence of having a physical disability. For some people with physical disabilities, it is difficult to find or maintain paid work. In addition, the disability comes with high costs, for example the purchase of assistive devices or medicines that is not reimbursed. A number of participants are assisted financially, for example by parents, but for many this has the disadvantage that it makes them feel unequal. Since many people with physical disabilities also have to cope with severe financial shortages or poverty, they face an accumulation of obstacles to participating in society.

Social network

In the quantitative analyses, it was found that participants living alone go to the cinema or the theatre less often than do those living with others, and that having a relatively severe disability is also more of a factor in whether and how often people in this group visit a sports club. That having a partner would make this easier seems to be a plausible explanation. However, it turned out that people living alone are more active in other areas. For example, they are more likely to visit a supermarket or a community centre, the latter especially if they have a severe disability. People living alone thus seem to have slightly fewer opportunities to visit places outside the home, while the wish or the need to do this is perhaps greater among them.

In the interviews, the importance of having a social network came up in many ways, and was usually discussed in positive terms. Not only partners but also other family members, friends, and neighbours can make a big difference. Social contacts make it easier to undertake activities, and also contribute in indirect ways to the ability of a person with a disability to participate in society, for example by helping out financially or giving them a lift. People did mention that they do not like being too dependent on their social network. They also said that too much strain on a partner can put pressure on the relationship.

The interviews also showed that a physical disability can place a heavy burden on the social network. For those who became severely disabled in later life, this often meant the loss of friends and other contacts. The fact that the disability makes it more difficult to maintain contacts plays an important role here: it takes more energy to visit someone or to go on outings. But a lack of understanding on the part of others also plays a role. Participants said that others often did not notice the effort they had to make and were reluctant to take their disability into account. Building a new network can also be difficult for the same reasons. Contact with others who have disabilities may be easier, but many participants do not want to limit themselves to these. Being fully part of society means not being separated from it and thus also having contact with people who are not disabled. Online contact can also offer a solution, but as noted above, this is not a genuine alternative to “actual” contact. As with financial resources, the differences in social networks reinforce the differences between the opportunities that people without a disability have in society and those that people with a disability have.

Migration background

The quantitative analyses did not provide any information on visits to places by people with physical disabilities and migrant backgrounds, as this group was not sufficiently represented in the data. Based on interviews with eight people from this intersection, we did see some clear patterns.

On the one hand, migration background can be associated with additional exclusion in various ways. Participants with a migration background sometimes experience additional discrimination because they are considered “different” or less capable both because of their disability and because of their migration background. People with a migration background who have a physical disability and who do not speak Dutch that well may have further difficulties in coping with the extra work involved in participating in society. Within their own family, or the wider ethnic group, there may also be shame, condemnation, and a lack of understanding in relation to the physical disability. Finally, in multilingual situations, communication between those with a hearing impairment and their relatives may be particularly difficult and can lead to exclusion within their own family.

On the other hand, having a migration background also emerged as an additional resource. It frequently also means there is an international network and a country of origin where it is possible to take a holiday or stay longer, thanks to family ties. For many people, both these holidays and the international networks prove to be a valuable part of their lives. It should be said that, when visiting their country of origin, people do experience more accessibility problems than in the Netherlands, which makes them appreciate their Dutch situation.

Gender

A clear finding from the quantitative part of the study is that male participants visit far fewer public places than women (see also Van Hees et al. 2020). The fact that women are more often to be found in churches, creative societies, and libraries is in line with known patterns in the general population (Wennekers et al. 2019). But that they can also be found more often at sports clubs, in swimming pools, in restaurant and cafés, in cinemas and theatres and on the internet, is less well recognised. This might indicate that this difference can be found only or primarily among people with physical disabilities. That being said, the analyses also showed that the lower rate of male participation is not more pronounced among participants with severe disabilities than it is among those with mild disabilities. This makes the notion a little less plausible.

In the interviews we found neither support nor an explanation for the difference found. The male participants did not appear to be less active or to experience more barriers. Also, gender hardly came up as a topic of discussion. Only the story of Paul, who is a transgender man, about the macho ethos in his gym (see Chapter 10) shows that places can be marked by a gender-specific etiquette that not everyone feels at home with. A possible explanation for the fact that the differences between men and women were not discussed more often is that those for whom this is an issue were not among the participants in the study. The group of participants turned out to be relatively active in several respects, and significantly more women participated than men. It could be that a category of men who may experience more barriers was left out of the picture.

If the difference is specific to people with disabilities, a possible explanation could be friction between "masculinity" and living with a physical disability. Whereas masculinity is usually associated with values such as physical strength and autonomy, physical disability is associated with weakness and dependence, and that can make it difficult for men to reconcile both identities (Barrett 2014). In an American study, men with a physical disability placed less value on bread-winning and social status than men without, but by the same token they also placed more value on self-reliance (King et al. 2020). This contrast is seen as the main explanation for the difference between men and women in their use of healthcare: while women make more use of healthcare services, men often prefer to look for solutions themselves (Pattyn et al. 2015, Verbrugge 1985). As we have seen, when visiting public places, people with physical disabilities often find themselves in a position where they are dependent on help, or where people spontaneously offer help and thus address someone's need for it. This may be more bothersome for men than for women. Although the current study does not provide any clarity, the large difference on this score does suggest that further research is needed.

S.2 Discussion

S.2.1 Added value and limitations of the study

A lot of the research on the social participation of people with physical disabilities in the Netherlands today was done for monitoring purposes, and is therefore descriptive in nature and based on figures (College 2019; Grosscurt et al. 2019; Knapen et al. 2020). In undertaking the current study, we have tried to get a better understanding of the stories behind the numbers. We looked at the social side of things to explain why people in the Netherlands with physical disabilities still have far fewer opportunities to organise their lives as they see fit. We combined two research methods so as to use the strengths of both. Firstly, we analysed existing data in a more comprehensive way, and that gave us rather detailed information about visitors to specific types of places, as well as an indication of how accessible these places were. It also provided information about the differences within the large and heterogeneous category of "people with physical disabilities" for whom these places appear to be more accessible or less so—differences that we did not have such a clear picture of before. Secondly, we conducted open-ended interviews in order to get a picture of the perspectives that people with a physical disability or chronic illness have on society. There are many images and prejudices about minority groups. Open-ended interviews are a good way to get as good a sense as possible of the interviewee's actual experience.

Experts with personal experience with physical disabilities who commented on an early version of this publication generally recognised its findings. Criticisms related primarily to the fact that the findings were already well known. This publication is thus intended primarily for those who do not have a physical disability. We expect that many of them are less well aware of the picture presented and of their own role in it.

As a methodological limitation, for the quantitative part we can question the assumption that the accessibility of places can be gauged based on who visits them. The attraction of this approach is that it does not require accessibility criteria to be drawn up in advance, but rather takes into account all the factors that seem to matter. But sometimes people have to be somewhere or want to be there so badly that they are prepared to straddle major barriers and face down the unpleasantness of inaccessibility. Another limitation is the lack of a comparison group without a physical disability. We were thus unable to get a full picture of the overall influence of a physical disability on whether a place would be visited. The only place for which we were able to compare people with mild disabilities with those without—the community centre—showed a significant difference.

One note is worth making on the qualitative part of this study. It has to do with how representative or otherwise the participants in the interviews were. When it came to recruiting participants, efforts were made to ensure distribution as well as diversity, both in terms of the nature of the physical disability or chronic illness and in terms of place of residence, level of education attained, and other individual characteristics. For example, we made an effort to speak to people from migrant backgrounds, a group that is often underrepresented in research. Although we managed to speak to a diverse group of respondents, the group appears to contain people who are more active than average, a relatively large proportion of whom are also committed to accessibility. Although this was not our intention, it is understandable that it happened. Those who are active in life are more likely to participate in research, and those who are committed to the subject are more likely to be recommended by others as potential participants. However, there were also many people among the participants who are less active, and we paid close attention to their perspective in our analysis. However, it is conceivable that the picture that emerges here is somewhat distorted, in the sense that participants are more critical when it comes to accessibility but also more capable than average of overcoming barriers.

The interviews took place during and after the first wave of the coronavirus. In the interviews, situations that arose during the coronavirus crisis were referred to regularly, but the conversation was largely about the situation before the pandemic struck. One way of ensuring this was to ask participants in advance to make a timeline of places that had been important to them in the previous 10 years. And because this situation was not so far in the past, it seems plausible that the findings were distorted either not at all or only slightly by the COVID-19 crisis.

S.2.2 Striving for an accessible society

It became clear that the goal of participation in society “on an equal footing” or of “full inclusion in society” has not yet been reached. Although some participants indicated in passing that the situation has improved in some respects, they still said they face quite a few barriers when visiting public places. Participants who are actively working on accessibility also find that they are often not heard and keep having to propose solutions to the same problems again and again. The picture that emerges here is therefore in line with what the monitors tell us, namely that people with physical disabilities have not started to participate more fully in society in recent years, and have even started to see fewer opportunities to do so (Knapen et al. 2020; Kromhout et al. 2020).

What also became clear is that there are quite a few contributing factors here. However valuable each step in the right direction may be, there are no easy solutions to ableism, which is also deeply rooted in Dutch society and which thus touches on various policy areas and on the thinking and actions of individuals in Dutch society. Here we will first look at the issue of how to improve the accessibility of public places, and will then briefly discuss the broader social context, which is also important when it comes to trying to create a more accessible society.

Accessible places: more-stringent requirements

This study confirms the great importance of practical barriers, to which society devotes considerable attention. However, both the actively engaged participants in this study and experts with personal experience with physical disabilities we spoke said they are disappointed at how little progress has been made. They have found that the knowledge that is available is often not used, and they say that experts with personal experience with physical disabilities should be involved earlier in the process. They have also found that good intentions, commitments, and plans often fail for financial or organisational reasons. Their experiences are in line with the shadow report with which a number of stakeholder organisations evaluated compliance with the CRPD (Schoonheim and Smits 2019). Although this report also recognises the social efforts that have been made, the organisations identify the lack of binding frameworks as a major stumbling block that hinders real change. Although being able to participate equally in society is a right, the organisations have found that there is “a lack of awareness on the part of the government regarding the obligatory nature of the UN Convention on Disability and a reticence to deploy tools that will lead to actual change” (Schoonheim and Smits 2019: 8)

The complexities involved in improving accessibility at the local practical level are highlighted in a study by the Amsterdam Court of Audit on accessible toilets (RMA 2020). Considerable social and political attention has not led to the achievement of the standard agreed in the municipal council in 2018. The Court of Audit attributes this to the high costs relative to the social benefits considered by the municipality. It also found a lack of perseverance on this front within the municipal organisation. The example shows that good intentions and guidelines are non-binding and that real improvements are often not made if there is no actual requirement to make them. The Court of Audit also pointed out that the actual number of accessible toilets is significantly higher than the number of toilets operated by the municipality, so that privately operated accessible toilets are a welcome addition. This shows that the social movement that the government is pushing for (vws 2018, 2020) does indeed offer a promising route to improvement, but also that, in and of itself, it is not enough.

This example from Amsterdam shows that not much is known about the actual accessibility of public space, whether at the municipal or the national level. Implementation of the CRPD is monitored in terms of participation in public life by looking at the activities undertaken by those with disabilities and at the level of satisfaction they express with what they have been able to do. However, the factors that stand in the way on this score are largely left out of the picture. It would be helpful if the monitoring were expanded to include more specific indicators of accessibility.

In addition to the practical barriers, the current study also gives insights into the social aspects of inaccessibility, which are just as important. When it comes to venues and other places, the people who work in them and who thus represent the organisation, such as supermarket staff, football coaches, front-desk staff, volunteer coordinators and ushers, are of primary importance. It emerged that people with physical disabilities regularly encounter denigration, prejudice, and a sense of awkwardness. Another problem is that many people are not aware of the role they could be playing in enabling equal participation. In thinking too casually about such issues as making a person with disabilities sit apart from the person or people they came with in a theatre, or situations in which they have to follow a meeting online from home, they overlook both the considerable importance that such matters can have for many people with physical disabilities—and those without—and the role they themselves could play in guaranteeing their right to them. A proper, considerate approach, which even today is still a matter of hit or miss depending on who is involved, should be taken consistently and across the board in public organisations, private companies, and associations. Attention to accessibility is thus also important when it comes to training staff and volunteers.

Awareness and familiarity: more equal contact

The study shows that people with physical disabilities regularly encounter awkwardness and a lack of understanding, not only from people in the aforementioned roles, but also from strangers and acquaintances they meet when visiting venues and other places. The broad consensus is that prejudice and misunderstanding are rooted in separateness, and that the remedy is contact on equal terms (Allport 1954; Paluck et al. 2019). A number of participants in this study also took this perspective as their starting point and put it into practice by refusing to be held back from engaging in activities, by consciously making their presence felt, and by making a point of being sociable.

In recent decades, many lines of separation have been erased, most notably in housing (Bredewold et al. 2020; De Klerk 2007). But the ultimate ideal whereby people with disabilities can actually blend into society has not yet been achieved. How difficult it is to actually bring this about is shown in the evaluation of the Participation Act, which aims to help as many people as possible find work, preferably with a regular employer (Van Echtelt et al. 2019). Although there have also been successes (for young disabled people who have the capacity to work, the opportunities to work have increased in recent years), many people also ended up sitting at home because they did not have access to sheltered workplaces. Although many employers indicated that they were prepared to employ people from the target group, this generally did not happen.

The Appropriate Education Act, which also aims to promote desegregation, has not yet led to a drop in the number of participants in special education: 70,000 children are still in special education.[1] Although special education also has its advantages, it deprives children both with and without disabilities, and their parents, of the opportunity to become familiar with each other. It is worth noting, however, that segregation in education primarily concerns children who have a mental or psychological disability (College 2018), and that the Participation Act seems to be working out relatively well for those who have physical disabilities (Van Echtelt et al. 2019).

In addition, it is possible to foster awareness by increasing visibility through other channels, such as by running projects in schools, making playgrounds inclusive, and raising the profiles of people with disabilities in the media, in non-stereotypical situations and roles.

Having one’s own resources as a crucial prerequisite for participating independently

Although social environments outside the home can throw up a lot of barriers, it has become clear that people are hindered just as much from participating in society by not having the means to get around more easily and to organise their lives more in keeping with what they would like. These include financial resources, adaptations and assistive devices. The income status of some of those with a disability has worsened in recent years (Van Echtelt et al. 2019). And although the use of these individual facilities—notwithstanding the objectives of the Wmo—has increased in recent years (Kromhout et al. 2020), the participants in this study regularly find that they do not get what they need.

Interviews also revealed a picture of inefficiency and arbitrariness. Some respondents told of incomprehensible decisions on applications they had made. The applications were rejected based on what they considered to be incorrect arguments, or they were given inappropriate assistive devices that could be used either not at all or only rarely. People also talked about a lack of clarity around the responsibilities of institutions. Sometimes officials conceded that the consequences for the person in question were unjust, but said they had to stick to the rules. As a result, people have to make do for a long time without the assistive devices they need, and that in turn severely limits the opportunities they have. In addition, people often feel misunderstood, angry, and frustrated. The comprehensive accounts given by the participants in this study fit the picture that is now becoming increasingly clear, of overly complex regulations that make it impossible for implementing agencies to use “the human touch”. This has significant consequences for those who are dependent in this connection on those authorities (Kromhout et al. 2020; TCU 2021).

Note

1 See https://www.nji.nl/nl/Databank/Cijfers-over-Jeugd-en-Opvoeding/Cijfers-per-voorziening/Speciale-scholen.