THE COMPLEXITY OF INCLUSION FOR THE PHYSICALLY DISABLED



Jiska Stad-Ogier, in an interview with Nienke Sluimer

"We all profit from increased physical accessibility. Everybody knows someone who pushes a stroller, a grandmother with a walker, someone with limited sight. Somewhere in life, everyone has to deal with it."

Jiska Stad-Ogier

Inclusive cities are not defined by the accessibility of the physical realm alone, it is rather a complex interaction of physical characteristics, policy regulations, established assumptions and probably numerous other aspects. Urban residents with a physical disability find themselves in this web of norms, standards, and rules that makes their inclusion in society a debatable topic. Measures that we take for granted can turn the simplest activities like daily routes to school, work, or other events into a challenging endeavour. This essay will try to unravel a number of aspects that play a huge role in the experience of inclusiveness for individuals with a physical disability, consulting the knowledge and experiences of Jiska Stad-Ogier. Jiska is an expert striving for an inclusive society for physically disabled people, both from personal and professional perspective. Jiska has cerebral palsy, which induces chronic fatigue and means she has to use a wheelchair when moving outside. Despite her physical challenges, she studies notarial right, has a part-time side job, practices several hobbies, and is active in multiple volunteer initiatives. She is a co-founder of 'Wij Staan Op!' ('We Stand Up!') – a foundation that strives to increase societal inclusion from the perspective of young adults with a physical disability.



JISKA AND HER WHEELCHAIR Source: author'

2 MILLION DUTCH CITIZENS ARE PHYSICALLY DISABLED

People with any kind of physical disability form a group of more than 2 million individuals¹ – and that is only in the Netherlands. Furthermore, the group of people with limited mobility level is increasing due to an aging population. This suggests that there is enough reason to consider the physically disabled in the design and management of our cities, especially since such amendments usually benefit other groups in society as well: think of parents with strollers and people temporarily using crutches, a wheelchair, or a walker. On the other hand, recognising the inclusion of people with a physical disability leaves us with an endless range of needs and desires that can have a highly contrasting character. Jiska considers this as one or the largest challenges when it comes to the inclusion of people with a physical disability: the notion of inclusion is so extensive, that it is almost impossible to grasp. Hence, Jiska does not believe in full inclusion.

"It is not a very popular statement, but I believe it is correct. We are not able to achieve 100% inclusion. Creating spaces where everyone feels fully at ease is not a realistic goal. However, we can make great steps forward." In short, the complexity of inclusion is not an excuse for designing a public realm that serves only its largest group of users.

Jiska is convinced that the intentions of politicians, urban planners, municipalities, and local institutions are often right, but that there are a number of established norms that prevent inclusion.

1. Factsheet Mensen met lichamelijke of verstandelijke beperkingen, Sociaal en Cultureel Planbureau, 2012. www.scp. nl/Publicaties/ Alle_publicaties/ Publicaties_ 2012/ Factsheet_ Mensen_met_lichamelijke_ of_verstandelijke_ beperkingen/ Factsheet_ Mensen_met_een_beperking org

DO NOT DESIGN BASED ON YOUR UNDERSTANDING: CO-DESIGN

First, measures intended to serve people with a physical disability are generally designed behind a desk. According to Jiska, building standards are rarely based on the actual experience of permanently disabled individuals and if they are, the standards are usually tested with a small group of people and barely updated over time. She calls for a much more co-creative process: "you cannot ask me to design an accessible city, because what is accessible to me is inaccessible to others. You have to do it together. I think that inclusion requires the involvement of the intended users already from the beginning of the process. If not, you cannot expect to develop an inclusive space." Furthermore, the few times that people with disability are consulted, the expectation is that they will receive no financial compensation. Jiska says "this is based on the idea that such trials are for one's own good, and that you should be happy that your wishes are taken into account." – a highly counterproductive practice, Jiska believes, especially when considering the multitude of undesired expenses disabled people usually have.

BE REALISTIC ABOUT PARTICIPATION: SOME PEOPLE JUST NEED HELP

Second, policies seem to focus more and more on maximising participation of people with a physical disability in society. "The authorities increasingly proclaim that everybody has to participate. That is demanded from various institutions. However, society is not designed for such levels of responsibility. We are requiring people that have never had the possibility to enjoy fitting education to handle their own affairs and secure their financial situation", Jiska says. It is not uncommon that educational institutions are unable to offer the right support for students with a disability and it happens too often that their buildings turn out to be inaccessible after all.

INVESTMENT IN AN ADJUSTMENT IS SO MUCH MORE: FRIENDS, SELF-ESTEEM, INDEPENDENCE

And finally there is the issue of money. Making adjustments for a relatively small group of people is often simply too expensive. The focus is typically on the direct financial benefit from an investment. What is not considered is the stress experienced when one's outdated wheelchair breaks down for the umpteenth time, which has a negative effect on a person's energy level, well-being and also spending. "When we are able to take an active role in society it needs to be realised that we are paying consumers. If the goal is to maximise inclusion, investments *need* to be made." Furthermore, since the market for people with a physical disability is rather unattractive, there is a limited level of technology innovation. Jiska believes that there is much to gain from more advanced technology in wheelchairs or lifts, for example. Such innovations have the potential to increase one's level of independency and facilitate inclusion.

There is much to win if we look beyond money and investments. Jiska very much encourages us to consider the amount of joy, happiness, and calm that is offered when one can fully take part in society, and the societal benefits resulting from this. She names five practical steps that help us move forward in the process of including people with a physical disability.

1. Increased availability of accessible toilets

A pressing frustration for people with a physically disability is the lack of accessible toilets in public areas. The need for a toilet is human, but it can be very challenging to find a public restroom that has sufficient adjustments. It is argued that more than half of the wheelchair-accessible toilets in public space are in practice not accessible at all. This is for example due to thresholds that are too high, doors that are too small, or toilets located on floors only accessible by stairs. Another pressing example Jiska comes across regularly, is when sinks have adjusted height and a long and easy handle but the water tap is way too small for anyone (even people without any disability) to put their hands under.

At the same time, you cannot expect to have an accessible toilet in all public properties, restaurants, or bars. It is not only increased availability of accessible toilets, but perhaps also better indications of where to find them elsewhere that can take away a great deal of stress. Formal institutions and municipalities have to take responsibility for this, as we explain below.

2. Simplified laws based on trust

In the Netherlands there are so many rules and regulations that people with a disability have to deal with: the participation act, accessibility rules, health insurance, the social support act, and many more. Jiska names the complicated regulations around designated disabled parking spots. While car parking is nowadays often regulated through mobile applications, this does not yet exist for special parking spots. Municipalities can individually decide on their policy for disabled parking spots, affecting the rules and availability of such parking spots as well as the prices for licences. The multitude of laws and regulations to look into can take a lot of energy from people that usually already struggle with their energy management. Unfortunately, mistrust has become a ruling factor, requiring proof for all sorts of care demands. Jiska advocates for mutual trust, to be treated as an individual agent that has the power to make decisions based on individual needs. Furthermore, Jiska would like to see officials at different levels in society take a leading role in safeguarding the rights of people with any kind of disability and decreasing the complexity in laws and regulations.

3. Treat people as individual agents

Jiska's wish to be treated as an individual agent can be practically translated to the information provision of services and institutions. Daily life would be a lot easier if restaurants, shops, museums, and other

2. nederlandsinstituut-voortoegankelijkheid. nl/2014/08/12/66procent-van indervalidentoilettenontoegankelijk-enonbruikbaar/





Source: author's personal archive

institutions clearly described the access to their venue on their website. Nowadays, this is often a matter of yes or no, while disabled individuals can very well decide for themselves if they are able to enter a building. Jiska says "I want to be the one making that choice". She encourages the use of pictures and simple measurements to give a clear impression of a venue's level of accessibility: the restrooms, the threshold.

4. Develop education about disability and wheelchair use

Established assumptions impede participation of people with a physical disability in society because of wrong images and prejudice. People with a physical disability are often put in boxes: they are either old or highly active youngsters and athletes. Jiska believes that education about disabilities from an early age would be highly advantageous in terms of the way people with a disability are approached. Educational institutions can take a great role in this by offering children the chance to experience how it feels to use a wheelchair or a walking cane, thus improving understanding from an early age.

5. Municipalities and the government have to take responsibility

The government and municipalities have to take greater responsibility in facilitating accessibility levels for physically disabled residents. People cannot be forced into making physical adjustments, but it can be supported from above. "At the moment you give out a permit, you can enforce people to meet certain accessibility measures and organise trials with experience experts" says Jiska. Small entrepreneurs should be supported in their efforts to increase the accessibility level of their property: "you cannot expect a small entrepreneur to raise the street level that leads to their property, for that one wheelchair user that visits weekly." Too often the responsibility of such measures is passed back-and-forth, resulting in no progress at all.

Finally, inclusion requires openness. It requires laws to be more flexible, based on individual needs. It requires institutions, large and small, to make an effort towards increasing mental and physical accessibility. In essence, apart from financial investments, it requires all parties to be open and clear about their needs, wishes, and expectations.

