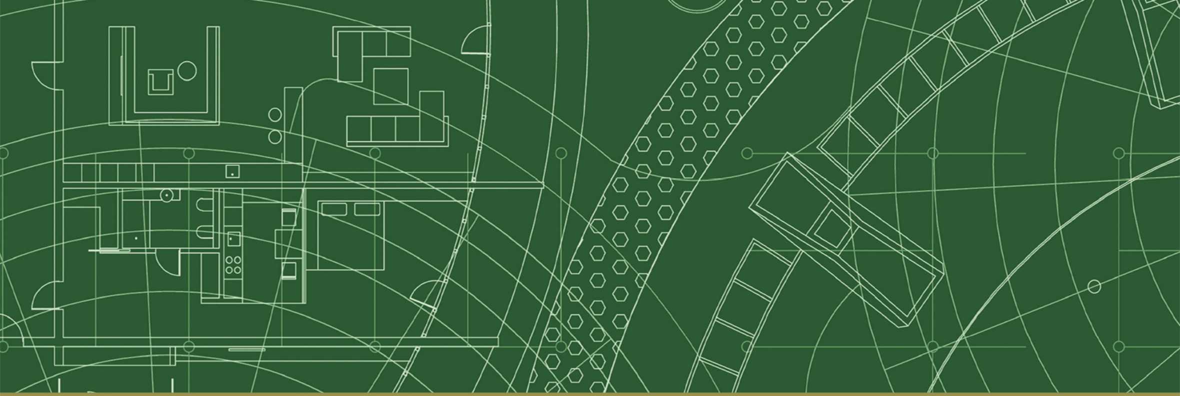

Interdisciplinary Disability Studies

ACCESSIBILITY DENIED. UNDERSTANDING INACCESSIBILITY AND EVERYDAY RESISTANCE TO INCLUSION FOR PERSONS WITH DISABILITIES

Edited by
Hanna Egard, Kristofer Hansson
and David Wästerfors

ROUTLEDGE

Accessibility Denied. Understanding Inaccessibility and Everyday Resistance to Inclusion for Persons with Disabilities

This book explores the societal resistance to accessibility for persons with disabilities, and tries to set an example of how to study exclusion in a time when numerous policies promise inclusion.

With 12 chapters organised in three parts, the book takes a comprehensive approach to accessibility, covering transport and communication, knowledge and education, law and organisation. Topics within a wide cross-disciplinary field are covered, including disability studies, social work, sociology, ethnology, social anthropology, and history. The main example is Sweden, with its implementation of the United Nations Convention on the Rights of Persons with Disabilities within the context of the Nordic welfare state. By identifying and discussing persistent social and cultural conditions as well as recurring situations and interactions that nurture resistance to advancing accessibility, despite various strong laws promoting it, the book's conclusions are widely transferable. It argues for the value of alternating between methods, theoretical perspectives, and datasets to explore how new arenas, resources and technologies cause new accessibility concerns — and possibilities — for persons living with impairments. We need to be able to follow actors closely to uncover how they feel, act, and argue, but also to connect to wider discursive and institutional patterns and systems.

This book will be of interest to scholars and students of disability studies, social work, sociology, ethnology, social anthropology, political science, and organisation studies.

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Interdisciplinary Disability Studies

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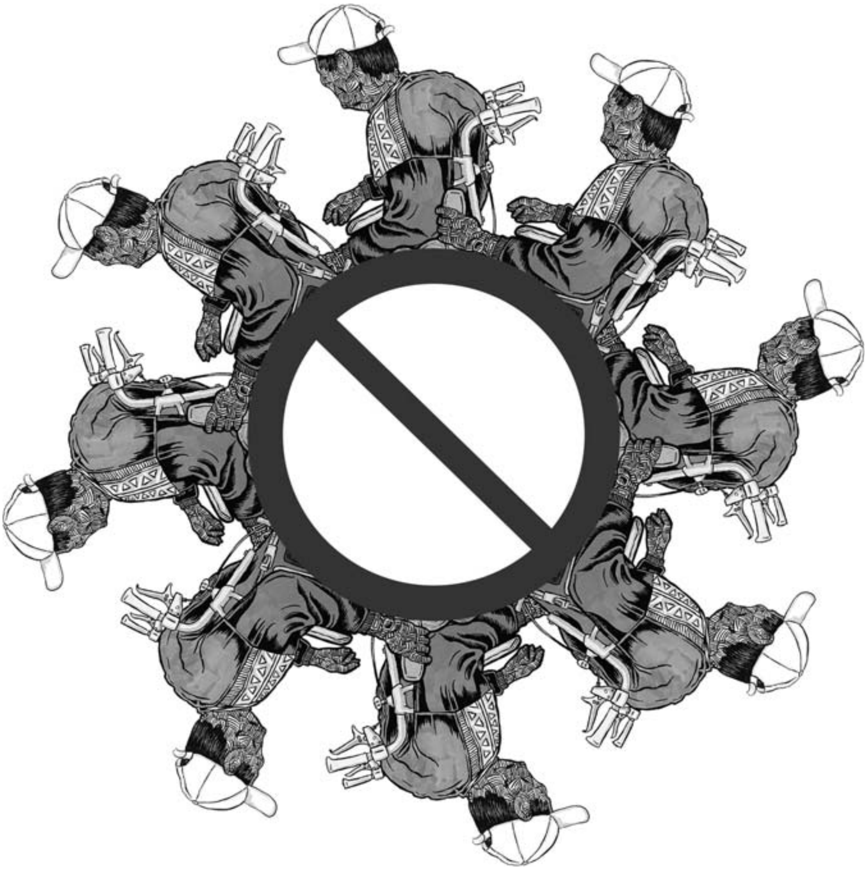

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Introduction

Into the fields of stubborn obstacles and lingering exclusion

Hanna Egard, Kristofer Hansson and David Wästerfors

Accessibility today has a contradictory character. One the one hand, people with disabilities are welcomed and included, with ambitious promises in a range of policies and declarations. On the other hand they are bypassed and excluded from everyday practices. We might describe today's societal condition as one of almost grandiose prospective accessibility and continuously emerging inaccessibility. The equality and inclusion that so many declarations and institutions ostensibly aim for – most notably the United Nations Convention on the Rights of Persons with Disabilities (CRPD) from 2006 and its article 9 – are combined with a remarkable slowness and reluctance to meet the rights, needs and wishes of the people these declarations and institutions are said to safeguard and protect. It is no exaggeration to say that no area in society today wholly and unconditionally lives up to the CPRD, and similarly there is no institution that does not display an ambivalent practice of including-whilst-excluding.

This book explores this contradiction. There is an enigma here, waiting to be researched and theorised, and there is a peculiar tension, one which is morally charged and potentially explosive. There seems to be a prevailing inertia within the fields of accessibility today that we as researchers do not yet know how to identify and explain. It is for this purpose we have collected the contributions to this book.

The book covers three areas: *city and transport, knowledge and education*, and *law, institutions and history.* Sweden is our primary case, but our ambition is wider. We wish to set an example of how to bring about a social, scientific and humanistic journey through crucial contexts and circumstances in today's society by presenting and discussing what we find to be valuable and intriguing methods, theories and findings regarding accessibility and its contemporary resistance. Our compilation covers such disciplines as disability studies, social work and sociology, but also ethnology, cultural geography and gender studies, political science and law, architecture, history, anthropology and linguistics. Similarly, the contributions to this volume exemplify a range of theories and methods, from participant observation within the ethnographic tradition to historical analyses using archive data, from critical disability theory to ethnomethodology, from Erving Goffman to Mary Douglas, with due space given to Judith Butler and Sara Ahmed somewhere in between.

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Our idea is to show how the burning issues of accessibility today constitute a set of dynamic and elusive phenomena that demand to be studied through equally dynamic and inventive approaches. As resistance to accessibility seems to slip between our fingers, we cannot settle on a single method or theory. We need to be able to analyse history and the law, schools and the universities, transport systems and urban settings, institutions and society's use of language. We need to be able to follow actors closely to uncover how they feel, act and argue, but also to draw the line to wider cultural and institutional analyses, discourses and systems. Some contributors insist on taking a normative stance, almost berating or reprimanding those responsible for inclusion and accessibility, whereas others cultivate a pondering attitude, curiously dissecting the barriers, hindrances and frictions and teasing out their dimensions.

We think all these approaches are needed, and we think academia should be spacious enough to bring them into the same room, not only to stimulate debate, but to inspire (and perhaps puzzle) students. If we are to understand and explain the stubborn obstacles and lingering exclusion of today's fields of accessibility, we need to be able to shift perspectives and move as quickly as our target, i.e. slippery society. If the resistance to accessibility today takes various forms, and even transforms itself as society transforms, we need to equip ourselves with a corresponding plurality and dexterity.

Multiple angles for multiple forms of resistance

City and transport

We begin this book with four chapters centred around what has almost become a cliché of accessibility issues: city and transport. The cliché exists for a reason; to be denied full and equal access to buildings and shopping malls, restaurants and churches, public spaces and within public transport systems, remains the standard experience of many people living with disabilities (Mazurik et al., 2014; Lid & Solvang, 2016; Bezyak, Sabella & Gattis, 2017), even though the CPRD proudly states that 'all aspects of life' should be open for all, and that the nations signing up to the convention should take appropriate measures to ensure 'the identification and elimination of obstacles and barriers'.

Hanna Egard dives into the fact that city centres are full of half-measures which, in practice, only grant access to people with disabilities with the help of staff or passers-by. With the help of a rhetorical analysis of how such 'solutions' are legitimised and normalised by professionals working with accessibility, Egard shows how recurring lines of argument such as 'just as good' and 'the only way' convince professionals and reproduce inaccessibility. She points to the fact that many adaptations are defined as 'ugly' or 'unthinkable' in certain settings, thereby drawing on a conception of purity that disability supposedly should not 'disturb'. When accessibility is outcompeted by other norms, it means that the city's half-measures are conserved and made accountable. Researchers therefore need to keep a close eye on conflicting norms, values and interests as they play out in the urban landscape and in professional discourses, and equip themselves with concepts to analyse the rhetoric and cultural assumptions at play. What stands in the way of accessibility today is not only economic resources and knowledge, but rhetoric and culture.

Vanessa Stjernborg focuses on the bus journey and travellers' experiences of barriers, as they emerge through complaints filed with a public transport organisation, particularly regarding getting on and off the vehicle. Using a time-geographical approach, Stjernborg shows how today's constraints for people with disabilities can be understood in terms of capability, coupling and authority. Passengers reporting difficulties in going by bus mostly invoke a combination of individual capacity, power relations and misuse of accessibility equipment. If researchers document the content of complaints filed with the bus companies, they may start to understand the complex fights and negotiations that take place just to get onto a bus, including the intricate coordination of tools, individuals and time slots. Stjernborg contends that travellers living with disabilities are competing for access to urban space, often leading to confrontations with discriminatory bus drivers and experiences of injustice. The bus trip is not a trivial detail in today's society. Access to public transport can mean the difference between an active life and a life of isolation or marginalisation.

Throughout the book, accessibility is analysed as a politically charged issue and this is the case also on the ground, among volunteer workers who seek to monitor its implementation. **David Wästerfors** analyses how two 'accessibility detectives' – living with different disabilities – watch and report accessibility faults to their municipality and how it is that they find this time-consuming and demanding activity both rewarding and fun. By following the detection of inaccessibility in urban settings – missing signs, wrongly placed ramps, too-narrow passages or the absence of contrast markings – accessibility and its resistance can be captured in a less 'boxy' and more dynamic way. Using an ethnomethodological approach, Wästerfors argues that the detectives' techniques, emotions and personal involvement in fault-finding can be identified, and understood as the folk version of the ongoing fight for inclusion. Society is not only full of obstacles and discrimination, it also harbours zealous detectives who refuse to be pushed into passivity or silence, but engage in artfully elaborated ways of uncovering hypocrisy. As the formally responsible actors continuously evade the accessibility norms of today, other actors are watching their every step.

In the last chapter of this first part of the book, **Kristofer Hansson** shares Stjernborg's interest in public transport, and focuses on travellers' feeling of insecurity in everyday situations when using buses and trains as well as the public transport organisations' public discourse on accessibility and safety. From a Foucauldian perspective, various institutions and administrative arrangements can be said to exert control over the city's bodies in and through the transport system, but as Hansson shows, the recurring association between 'being safe' and 'having access' does not seem able to handle travellers' experiences of insecurity and risk. Researchers need to keep track, both of people's experiences and companies' discourses – moving between an ethnographic and a discursive level – to explain how it is that recurring complaints and dissatisfaction expressed by people with disabilities using public transport seldom translate into political change.

Knowledge and education

To get deeper into the analytical issues surrounding accessibility is to gradually come to grips with the fact that these do not only concern how settings make people more or less capable, or how disabling processes are reproduced. They also revolve around the dynamics of the distribution and use of *access-mobilising capabilities* within society: where we find them, where we cannot find them, how they play out, and how they are economised and withheld – and thereby made into explosive political and emotional issues. This is certainly the case when it comes to the book's second theme, knowledge and education, which deals with widening participation, sexual access, social recognition and activism (Honneth, 1995; Taylor, 1992; Shuttleworth & Russell, 2007; Anderson et al., 2018).

First, **Patrick Kermit** presents a qualitative analysis of hearing-impaired students' everyday situations in school as they struggle to manage situations where they are made to stand out as different, sometimes even pretending to hear. Kermit finds that these students – children and adolescents aged between five and 16 years – struggle with bottled-up frustrations and disappointments, and that they experience an utter lack of social recognition for the demanding efforts they engage in every day in school. Researchers need to point out and analyse the excluding practices and circumstances that put hearing-impaired students in a position where they show poorer results than others, and display more psychosocial problems and loneliness; they also need to encourage professionals to design and develop inclusive practices that recognise student diversity. Erving Goffman's concepts of *stigma* and *passing* are crucial to Kermit's analysis, and he uses these to show how students in this school context stretch their capabilities to perform as others, and how social recognition turns into a sparse resource.

The chapter by **Sangeeta Bagga Gupta, Giulia Messina Dahlberg** and **Lars Alméns** describes and illustrates non-inclusive practices in institutional arenas. The authors use what can be called 'the everydayness of gatekeepers and gatekeeping' – who is included in which practice, by whom, when and why? The study draws upon recent anthropologically inspired work by some of the authors, focusing on issues of identity-positioning generally and what gets glossed as functionality and race/ethnicity specifically. From these studies they show how individuals learn to be their own gatekeepers and circumnavigate possible barriers by aligning with people who are in positions to eliminate various thresholds. Bagga Gupta, Messina Dahlberg and Almén suggest that their findings call for making visible a plurality of spaces across institutions. This means that issues of participation and marginalisation – as spelled out in policy – need to be attended to in terms of practiced policies and in tandem with what people and institutions (schools, adult education centres, public authorities) do with policies.

In the next chapter, **Elisabet Apelmo** and **Camilla Nordgren** guide us into the university, and its more-or-less subtle ableist structures and practices, with the help of a collaborative autoethnography about working with impairments and being disabled employees in academia. Apelmo and Nordgren draw on their own experiences as instructors and researchers and pinpoint inaccessibility in everyday situations stemming from the idea of 'the normal employee'. The ongoing individualisation of problems in the work environment, along with diffuse responsibility, are identified as the main obstacles to accessibility. While waiting for the responsible person to raise his or her hand, so to speak, Apelmo and Nordgren suggest that change can be achieved by becoming 'crip killjoys', i.e. breaking the silence in academia and saying a collective 'we are *unwilling*' instead of 'we can't', and making others pay attention to injustice. While a privileged person may experience what Sara Ahmed calls 'flow', employees with disabilities face barriers in the university's often stressful work life.

Julia Bahner analyses barriers to accessing sexuality using data from ten projects by civil society organisations, including self-advocacy organisations, sexual rights organisations and organisations working on behalf of people with disabilities. These projects mainly aim to give information about sexuality and relationships, sexual and gender identity issues and experiences of disability services in relation to sexuality. Bahner's reading of the narratives in books, handbooks, videos, websites and other online materials serve to identify and illuminate a range of barriers to equal sexuality being touched upon and dramatised for educational purposes: (1) information barriers, (2), psycho-emotional barriers, (3) relational barriers, (4) support-related barriers, and (5) policy barriers. The barriers, Bahner argues, can be understood within a social hierarchy in which disabled people are marginalised and devalued compared to non-disabled people. She also exemplifies the need to combine individual and structural factors in the analysis, as well as the importance of studying access not only in physical settings but in cultural and psychological domains.

In the last chapter in this part, **Liz Adams Lyngbäck, Mia Larsdotter** and **Enni Paul** present three cases of language inaccessibility during the COVID-19 outbreak. By drawing on concepts as linguicism, ableism and audism, the authors examine the oppressive consequences of normative ideas about ability, consequences that fail to turn into objects for change even though they are well-known. The authors use ethnographic and netnographic observations within activist and non-governmental groups to show how deaf, hard-of-hearing and people with cognitive disabilities are affected by the pandemic, the massive information campaigns and the turn to online education. They identify blockages in access to vital healthcare information due to institutionalised language inaccessibility. The authors also show how activists, non-governmental groups and stakeholders formed coalitions to overcome the barriers. This chapter illuminates the value of capturing an acute global event – the medical and social drama of the pandemic – and to theorise the event from the standpoint of accessibility as it unfolds in front of our eyes.

Institution, law and history

The book's final theme – institution, law and history – deals with the broadest possible picture and larger stories, such as how disability, exclusion and paternalism are reproduced by state policy, bureaucracy and institutional settings (Goffman, 1990; Imrie, 1996; Altermark, 2017). These chapters are full of details and careful descriptions as the authors draw on tangible cases and close-up accounts to capture the long lines of exclusion, and the seemingly all-pervasive ether of resistance to accessibility.

Eric Svanelöv and **Lena Talman** use observations of group homes to identify and analyse barriers to everyday decisions within the homes that, both in themselves and by extension, can underpin inaccessibility to the wider community and to lifestyles and cultural resources of any kind. Despite a policy which aims to facilitate people with disabilities to live like others do, group homes for people with intellectual disabilities carry institutional features that complicate this ideal. Support staff are available at all times to fulfil residents' requests, but in practice the routines and the institutional flavour of the interactions may represent obstacles, for instance in terms of strict timeframes, strong expectations to plan activities, normative assumptions about 'proper' conduct and interests, as well as the existence of restricted areas within the home. Svanelöv and Talman's chapter reminds us of the importance of not taking for granted the promises of policies before they are applied in institutions, but to pay close attention to the daily contingencies in empirical research *in situ*, and to train our eyes to see the subtle ways they govern people with disabilities.

Barbro Lewin's chapter highlights bureaucratic resistance to accessibility in and through the implementation of the law – or rather, its lack of implementation. Lewin presents data from the applications of a handful of adults who lost the support provided to them under the Swedish Act concerning Support and Service for Persons with Certain Functional Impairments (known as LSS). In handling these applications, bureaucrats use a range of restrictive strategies, despite the fact that the applicants' needs are constant over several years and their problems and impairments chronic. The LSS legislation is an exceptional welfare reform with a strong citizen focus, but the exercise of authority itself is far from legally certain. Lewin points out the importance of scrutinising the legal procedures when disability is being assessed in and through the bureaucratic discourse, and points out several strategies put to use, for instance to withhold information and help, to steer the applicant towards traditional (and less supportive) home services, and to diminish the needs of the applicant by withholding relevant facts. Personal assistance through the LSS legislation is a crucial resource for many people with disabilities to access wider society, and bureaucratic obstacles to application processes equal accessibility obstacles.

In the final chapter in this section, **Jonas E. Andersson** gives us a historical overview of accessible architecture in Sweden, from minimum requirements to universal design. With the development of functionalist architecture in the 1930s, minimum requirements were soon integrated into the building act and implemented through a housing loan system. The requirements evolved into the concept of accessibility which regulated architectural design for housing and public buildings. With the reform to the building act, however, these requirements went from being detailed and mandatory to becoming a 'mandatory functional requirement', which basically is open for interpretation. The building market has criticised the requirement as cost-generating and part of the reason for the ongoing housing shortage. Receptive to these claims, governments in recent years have allowed legal changes which place the responsibility for realising accessibility and usability into the hands of the market. At the same time, the national disability policy has introduced universal design as the new objective for removing obstacles to the inclusion of people with disabilities.

To wrap up the book, we give the floor to **Rannveig Traustadóttir** for some free and critical reflections in an afterword. Traustadóttir was the inspiring keynote speaker of the seminar we arranged at Malmö University in October 2019, in which several of the authors participated. In parallel sessions we discussed the ideas and drafts that eventually ended up as chapters in this book, and Traustadóttir commented on our work already at this stage.

A dynamic approach for a dynamic phenomenon

What we have learned by working with this book is not only the value of alternating between methods, theoretical perspectives and datasets to capture what accessibility is about, but also of not assuming that this simultaneously tangible and elusive issue can be nailed down once and for all. As society is reconstructed and transformed, so also is accessibility. New arenas, new social and cultural resources and new technologies take the stage (Egard & Hansson, 2021), and simultaneously new accessibility concerns – but also possibilities – emerge for persons living with impairments.

One might think that accessibility can 'be fixed' or 'be done with' once and for all, but it is an ongoing project which requires a rebuilding of society (Shakespeare, 2014). The installation of a proper ramp at the entrance of the gym is not enough. Professionals taking this seriously need to also take into account how the new and separate entrance is used when the gym is open to its members but staff are not present; the app connected to the gym; the machines inside; and the structure of the classes. The transport system, the availability of personal support and personal assistance in the wider community, the normative assumptions hovering above and between us regarding what is 'proper' and 'suitable' for this or that person, the fine weave of emotional and discursive fibres that can be found in each and every situation – to study resistance to accessibility today demands a creative gaze and a spirit of ingenuity.

Researchers, like the United Nations itself – whose 2006 convention, the CRPD, looks complete but requires constant monitoring and follow up to get nation-states to actualise its intentions – have to be on the move. Accessibility is not a fixed thing on a checklist, but a self-expanding problematic and a moving target. Administration and health care, urban settings, public transportation systems and schools, university, workplaces, institutions and the law, digital settings and digital tools – in countless contexts, circumstances and situations, we find strong expectations around having a certain body-mind, presumably one defined as 'normal'. These expectations not only create obstacles and delays, but also lead to exclusion from social contexts, identities and roles, as well as dependences, emotional distress, complaints and political protests.

We have also learned that although several issues in disability studies play a vital part in accessibility studies today, not all of them are considered. We may address accessibility and its resistance without once and for all defining what disability 'is', or exactly which theory spells out what it means to live with disabilities in today's society, since access to this or that arena, resource, practice or identity might very well be problematic for the field members, and intriguing to pinpoint in scholarly works, in any case.

In a both more figurative and substantial sense, we may say that the inclusion and exclusion at stake in accessibility studies are a matter of the capabilities of mobilising resources towards social (and physical) participation. To strive for inclusion of people with disabilities is consequently to strive for full citizenship and the formation of social capital. This, in turn, is associated with better quality of life and more power for persons with disability. This is why societal work with accessibility is about maximising social inclusion and, as a result, empowering people who are often quite marginalised. When activists as well as officials, the signatories of the UN convention as well as local politicians – in short, any of the actors engaged in disability accessibility – try to 'improve mobility mechanisms' by removing barriers, and designing settings and communities that welcome all individuals, they are simultaneously aiming at 'effective social inclusion' (Kastenholz et al. 2015: 1262).

Accessibility from a political point of view, then, is about more than fighting and overcoming physical and social barriers inside a building; it is about granting all citizens full rights to participate in 'all aspects of life', as the UN convention puts it.

There is repeated evidence showing how disabled people are relatively excluded from a range of contexts and resources, such as literacy, professional activity and income, etc. (EC 2007). Since around 15 per cent of the world's population presents with some kind of disability (WHO 2011), this is not a small issue. Discussions of the need for ramps at a school entrance, or tactile paths in a city centre, for instance, can quickly extend to a discussion of societal membership at large, since even if every local discussion of this type is not explicitly charged with wider matters, it is charged implicitly. Schools lead to education which leads to jobs and income; city centres are full of people who are engaged in all sorts of things, including a great variety of lifestyles and political opinions and – sociologically speaking – ordinary identity reproduction. A ramp and a tactile path can make a difference for individuals in terms of taking part in, or being kept out of, exactly what they want to do in life and what they might contribute, from every perspective: culturally, economically and personally.

That is why analyses of resistance to accessibility are often emotionally and politically charged. When we call the gym owner and ask about the accessibility of a new, unmanned, entrance procedure, with a tiny opening suited for one mainstream body at a time, it is no wonder that the conversation is sensitive and full of implied reassurances and accounting practices. And when we ask people using wheelchairs to describe how they manage to go about shopping without baskets they can place in their laps, with only a self-checkout available, it is no wonder that the reply holds both sarcasm and resentment. The gym owner knows that the entrance should be accessible for all, and the disabled shopper knows he or she has certain entitlements and protections which remain unfulfilled.

Still, in social reality the resistance is there, and it is embedded into the norms that are proudly declared from above. The enigma of the not-so-ideal accessible society is not merely an issue for academic seminars or textbooks in disability studies, it is an enigma in and for everyday life.

This makes it relevant to go on exploring and creating new knowledge in this area. To study accessibility is to study exclusion and its constant drama, and in a democratic society this can hardly be considered either ungrounded or unfashionable.

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We are very grateful to all contributing authors as well as to Forte, *The Swedish Research Council for Health, Working Life and Welfare*, whose grant (registration number 2017–00762) made our work possible.[1] We hope that this volume will give researchers, students and practitioners the tools to continue detecting and explaining the phenomena of 'accessibility denied'.

Note

1 All three editors of this book have contributed with an equal amount of work throughout all the stages of the production.

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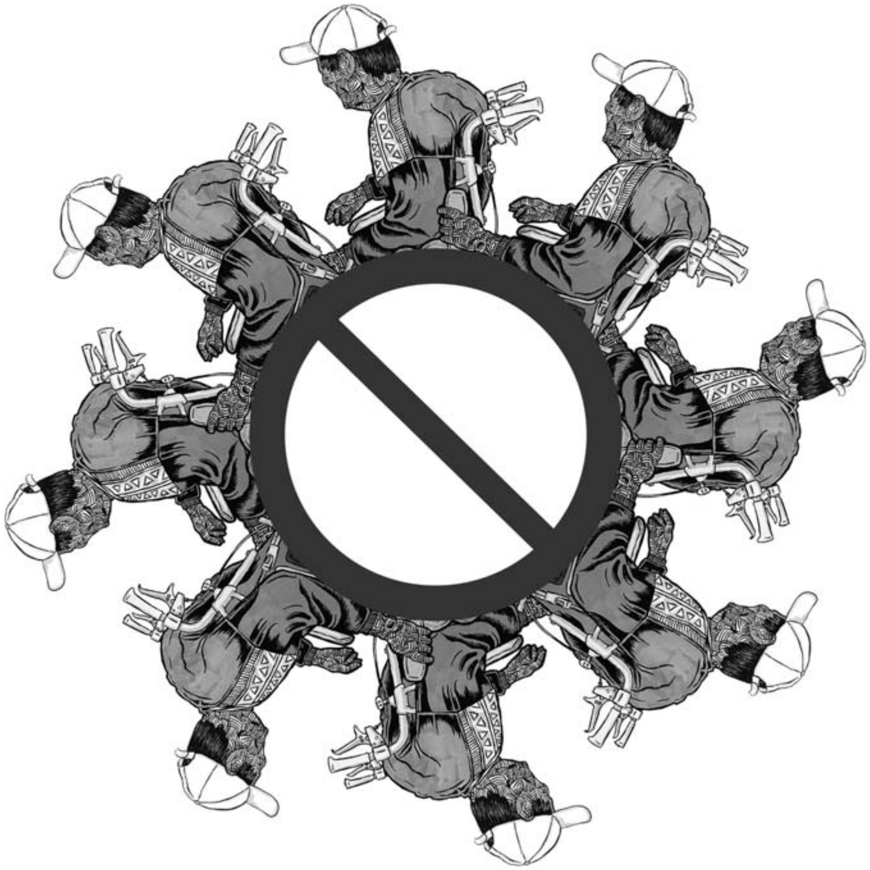
Part 1

City and transport



Artwork by Sam Sohlberg

1 Accessible enough? Legitimising half-measures of accessibility in Swedish urban environments

Hanna Egard

Staircases are tangible illustrations of inaccessibility: they often lock out and exclude people with disabilities from entering an establishment independently and safely. Although staircases might be an overused and almost clichéd illustration of inaccessibility it is still a fact that many establishments are only accessible via a staired entrance. While conducting fieldwork as a part of a research project entitled 'Accessibility and its resistance'[1] I and the other researchers found staired entrances to all sorts of establishments, such as pharmacies, health care providers and service centres, shops, restaurants, pubs, art galleries and travel agencies. When interviewing accessibility officers and building permit administrators – the professionals who are formally responsible for enforcing regulations on accessibility in the built environment – I found that they were well aware of these obstacles to independent access and participation. One of them even said: 'If you go for a walk on the pedestrian street here, I think, I can promise you, 90 per cent of all entrances have two, three steps up.'

During our fieldwork we came across well-planned areas with, for example, wheelchair-accessible entrances, paving and suitable contrast markings. But we also saw and experienced the opposite: uneven cobblestone paving, tilting pavements, unmarked crossings, narrow doors and steep stairs. This inconsistency in accessibility means that people with disabilities are both included *and* excluded as citizens and consumers in the urban environment (Hansson, 2019). Since accessibility is unpredictable it takes planning, time, effort, creativity and help from others to deal with obstacles and hindrances in shopping malls and city centres, and many people with disabilities tend to prefer well-known areas or settings, which they know how best to navigate (Mazurik et al., 2015; Lid & Solvang, 2016; Wästerfors, 2020).

The forms of accessibility measures required under the Swedish planning and building act depend on whether or not the building is listed, if it is to be reconstructed or if it is open to the public (Svensson, 2015; SFS, 2010: 900). What is required is, in other words, a matter of judgement, which means that technical, cultural and financial aspects are investigated and taken into account. These investigations and decisions made by professionals at the municipalities, as well as their rhetorical and cultural forms, will be the focus

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of my chapter. The aim of this chapter is to understand the rhetorical and cultural construction of such obstacles and how inaccessibility is reproduced and ignored in Swedish cities even when it is tangible, known and obvious.

Half-measures in the urban environment

In this section I will focus on how professionals responsible for accessibility work at the municipalities deal with so-called ‘easily eliminated obstacles’. This term, coined in a government bill in Sweden in 1999,[2] refers to obstacles to accessibility and usability in buildings that are open to the public. According to the regulation these obstacles are to be removed if deemed ‘reasonable to remove in view of the benefit of the measure and the conditions at the place’, and as long as the financial implications for removing them are not ‘unreasonably onerous’ (Section 5 BFS 2003: 19). Level differences and lack of contrast markings at entrances are examples of easily eliminated obstacles (BFS 2013: 9). As highlighted in a previous publication based on our fieldwork, a combination of handrails, doorbells and portable ramps are commonly used to deal with staired entrances (Hansson, 2019). But, as an interviewed accessibility officer pointed out, this combination of accessibility measures is not necessarily safe, and it is questionable if it fulfils the requirements of the law:

> As if it would be all right to throw out a ramp or rail, it is nothing, it is not safe to use, it cannot be used independently, and because of that we usually do not approve it. But it is, it is the very minimum of what is required to get a building permit, if that is the starting point, although we have a legislation that is quite strict, that says accessibility for everyone, then you should depart from that.

According to the accessibility officer, the described combination of accessibility measures is the very minimum of what is required for a building permit, but it is not in accordance with the intention of the legislation or disability policy. The aim of the policy and regulations is equal and independent access and usability for everyone (Svensson, 2015). The use of a portable ramp is not sufficient since, first, it is not safe and, second, it does not ensure independence or being on equal terms, since someone who cannot climb the stairs will have to ask for help by pressing the doorbell and waiting for the staff to fetch the ramp and help them up. As our fieldwork shows, city centres in Sweden are full of these kinds of half-measures.

There are different ways of understanding and explaining this inertia around accessibility work and stubborn inaccessibility. Previous follow-ups and research on Swedish urban planning has found that the accessibility perspective is not yet fully integrated at the municipal level, and that there is need for more accessibility officers, recourses, routines and knowledge to enforce and supervise the implementation of the regulations in an effective and sufficient way (Hallgrimsdottir et al., 2016; National Board of Housing, Building and Planning, 2018; Zotéeva, 2018). According to international disability scholars, the lack of resources and knowledge is a symptom of the multidimensional oppression of the disabled and constitutes a disablist practice (Imrie, 1996). Able-bodied conceptions and ideology dominate the social-spatial ordering of society and inaccessibility is therefore reproduced as something ‘natural’ and ‘acceptable’ (Kitchin, 1998).

My point of departure in this chapter is that such half-measures in the urban environment can be understood as a hybrid construction at the intersection of conflicting norms, values and interests in society. The requirement of accessibility is a strong norm underpinned by conventions, policy and legislation, but this is also the case for other norms, policies and regulations. As pointed out by Rob Imrie (1996), form and aesthetics tend to be prioritised over functionality and accessibility as long as architecture and design are defined mainly as art. Moreover, as shown by the disability researcher Camilla Nordgren (2009), the norms on full participation and accessibility are also challenged by norms on security and fire safety.

In my analysis, I use the conversation analyst Anita Pomerantz’s (1986) concept of ‘extreme case formulations’ to identify how inaccessibility and exceptions from the accessibility norms and regulations are justified, normalised, and legitimised by different sorts of descriptions and arguments. My argument is that a rhetorical and cultural analysis can be a way to identify resistance to accessibility today, and that not only should policies, legal frameworks and the UN Convention on the Rights of Persons with Disabilities (CRPD) be studied, but also the ways of reasoning and legitimising strategies employed by professionals who are formally responsible for enforcing accessibility requirements. Since my informants’ arguments and descriptions depart from how accessibility is usually defined and understood, I will start by discussing the concept of accessibility more generally before I proceed to my analysis of their rhetoric.

Standards, and moments of congruity

Accessibility is a general principle of the CRPD. As stated in the convention, accessibility is a prerequisite for the full enjoyment of human rights for people with disabilities. Without accessibility neither equal opportunities nor independent living nor participation in all aspects of life are possible. Although accessibility cuts through and underpins all parts of the convention the term is not clearly defined, and accessibility is used in different senses in the convention (Lawson, 2018).

The CRPD defines accessibility as an *ex ante duty*, which means that it is a duty that should be fulfilled in advance to ensure independent access. When used in this sense, accessibility addresses measures that should be designed, planned and implemented before the need for access is raised. Accessibility, then, is about the minimum standards, regulations and guidelines on a group level that should be used in the built environment and in design (CRPD, 2014). Used in this sense accessibility is an objective, evaluable and measurable concept (Iwarsson & Ståhl, 2003).

Since this way of defining and implementing accessibility is based on standards on a group level, an establishment can be defined as accessible even though it is not built for someone outside the standardised norm (Imrie, 1996). Within disability studies and the disability movement, a subjective definition of accessibility is therefore advocated (Imrie, 1996; Iwarsson & Ståhl, 2003), one which is more focused on actors' practices and experiences than on standards. Accessibility defined from the individual or subjective perspective thus departs from the more everyday way meaning of 'accessible', which is often associated with something being approachable, attainable, available or possible to take part in (Iwarsson & Ståhl, 2003).

The individual and subjective definition of accessibility opens up a situational and contextual understanding of accessibility. Used in this sense accessibility is situated and describes a moment of congruity between the individual capacities and environmental demands (Lid & Solvang, 2016). Congruity can be achieved by different means, such as design and environmental changes, but also through technical aids and assistance (Hedvall, 2009: Lid & Solvang, 2016). This situated and contextual understanding of accessibility is actually also found in the CRPD, in the sections in which accessibility addresses different forms of live assistance that should be available to ensure access when it is needed. Used in this sense, accessibility is granted by getting help from others (CRPD, 2014) and not only by an accessible physical environment or design that matches the functional abilities of the individual (Iwarsson & Ståhl, 2003). I argue that this actor-oriented understanding of accessibility within the convention is less known, since UN conventions are typically seen as universal declarations and standardisations.

When accessibility is tied to a specific situation, the meaning of the concept starts to overlap with another concept in the CRPD, that of 'reasonable accommodation'. Unlike accessibility that is to be fulfilled in advance, reasonable accommodation is required in a given moment and situation, i.e. when it is needed and asked for. Reasonable accommodation, then, is an *ex nunc* duty, that is an immediate duty that rises in the moment a person requires modifications and adjustments to enjoy the human right of access (Nilsson, 2018). The difference between accessibility and reasonable accommodation is not clear-cut, but the duty to continuously work with accessibility measures on a general level precedes the duty for reasonable accommodation on an individual level (Nilsson, 2018; CRPD, 2014).

Methods and data

During a period of three years (2018–2020), I and two other researchers[3] conducted fieldwork in small and large municipalities in Sweden. Our main methods were thematic qualitative interviews and go-alongs (Kusenbach, 2003) with persons with disabilities, but we also studied, for example, reports on so-called easily eliminated obstacles presented to one of the municipalities where we conducted fieldwork. Although we used a number of different methods, all the data emerges from concrete situations and places, so the narratives, experiences, descriptions and arguments we found show everyday dealings with accessibility and inaccessibility. This chapter focuses on the municipal work of enforcing and implementing the rules and regulations on accessibility in general and, specifically, on easily eliminated obstacles.

This chapter is based largely on data collected through interviews I conducted with six professionals who are involved in some part of the process of initiating and supervising accessibility work at the municipal level. Three are accessibility officers, two administrators of building permits, and one is a traffic planner. Although their specific tasks and responsibilities differ, my thematic analysis reveals recurring patterns across their experiences of, and reasonings on, accessibility measures. I have analysed reports on easily eliminated obstacles based on the type of barriers they concern and on how these barriers are dealt with. In particular, I have tried to focus on how the interviewees account for the municipal decision on the measures requested.

How accessibility is questioned and downplayed

A recurring theme in the interviews was an affirmation of the importance of accessibility and the need for improvement. The accessibility officers, traffic planners and building permit administrators all displayed knowledge about existing shortcomings in both newly built environments and existing premises. They all pointed out the need for more time and resources, and for enhancing knowledge and skills at their departments and elsewhere. The importance of accessibility for all and different forms of measures might be questioned by colleagues at the same or other departments, or by builders, architects or general public. All of the interviewees had previously or recently experienced a lack of knowledge of disabling barriers and an ignorant and negative attitude towards accessibility issues from colleagues and others. As the traffic planner I interviewed said:

> There are questions that I get quite often, sadly enough, questions like ‘Do we really have to work with this when, so few are in a need of the measures?’ ‘Is it really that important?’ ‘Can’t we just ignore it?’

To deal with negative attitudes to accessibility seemed to be a part of their work. They all talked about how they tried to change others’ attitudes by explaining and arguing for the importance of accessibility. From their perspective the negative attitude was due to ignorance and they insisted on the need for education and training since a disability perspective is not a part of general knowledge or education.

The described experiences of the interviewed professionals are in accordance with previous Swedish research and reports which highlight a need for more recourses, time, efficiency, knowledge and full implementation of an accessibility perspective at municipalities (Hallgrimsdottir et al., 2016; National Board of Housing, Building and Planning, 2018; Zotéeva, 2018). But although knowledge, time and resources might contribute to change and to removing many barriers in the future, there are still many different interests that must be dealt with in urban planning. As a matter of fact, research on traffic planning shows that conflict of interest is an actual barrier to accessibility (Grönvall, 2004).

When accessibility measures at a given spot are described and discussed in the reports on easily eliminated obstacles and interviews, the complexities of implementing norms and regulations on accessibility become evident, as well as the conflicts between them. The accessibility norm may be challenged and sometimes even outcompeted, although the accessibility officers claimed the importance of accessibility for all.

To pinpoint how and when inaccessibility is rhetorically and culturally legitimised I will use Anita Pomerantz's (1986) concept of 'extreme case formulations'. Formulations of this kind are justifications, defences, explanations or arguments that are built on maximising the case or description to convince others. Everyday statements such as 'everybody does it', 'all the time', 'completely' or 'everywhere' are some common components of the formulations. The extreme cases are used to defend the legitimacy of an argument, to propose that a phenomenon is objective rather that socially constructed, or to argue that a behaviour is right since it is common (Pomerantz, 1986). The extreme case formulations in this chapter are articulated to describe obstacles to accessibility as 'normal' and 'legitimate' since they, for allegedly objective reasons and circumstances, cannot be dealt with. Furthermore, the accessibility measures that the interviewed professionals implemented are legitimised since they are common and something of a praxis, although they do not contribute to accessibility for all.

To illustrate this, I will present and analyse three extreme case formulations. In the first two, half-measures are legitimised and conceptualised as acceptable by being described as 'the only way' and 'just as good' as other ways of dealing with accessibility issues. In the third example the extreme case is built upon designating accessibility measures as something objectively ugly and inappropriate in the specific context. The design of accessibility measures is here conceptualised as disturbing the aesthetic or historical atmosphere. To understand why accessibility measures are conceptualised in this way, and why inaccessibility is sometimes legitimised and normalised, I will use the anthropologist Mary Douglas's (1966) analytical focus. In her famous study of purity and danger Douglas focuses on what is considered as impure, dangerous and dirty in the given culture to reveal cultural classification systems and social order. I will use the same analytic focus to understand why accessibility measures are sometimes, but not always, seen as a disturbance or distortion – something 'dirty' – of the architecture or design.

'The only way'

The combination of portable ramps, handrails and doorbells was stated to be the 'only way' to ensure access for wheelchairs users to establishments with staired entrances. The expression was, for instance, used by the previously quoted administrator of building permits when explaining why there were still so many entrances with stairs and steps in the local pedestrianised street:

ADMINISTRATOR 1: If you go for a walk on the pedestrian street here, I think I can promise you, 90 per cent of all entrances have two, three steps up. Unfortunately, we found out that the only solution that works in [name of the city], that makes the roadworks department satisfied and us fairly satisfied is that we recommend doorbells and detachable ramps. The point is that – and handrails of course and – the point of it is –

ADMINISTRATOR 2: with contrast marking.

ADMINISTRATOR 1: and contrast markings on the steps and such things, but… The accessibility into the place needs to be solved in some way. That you ring, the owner gets out, puts down the portable ramp, a ramp that, by the way, does not fulfil the gradient required by the law, if it had it should have been about five, six metres long. The idea is that two rails are put out and that the shop owner then gets out to help the person to get inside with the wheelchair and up the stairs. It is the only solution. The only way –

ADMINISTRATOR 2: The temporary solution. Yes Exactly, Yes.

ADMINISTRATOR 1: Because if you want something permanent, then you would need a permanent ramp, and the roadworks department would not agree on that.

The way the administrator presented the use of portable ramps and associated accessibility measures implies that he knew the requirements of the regulation. He also implied that a permanent ramp would be the ideal measure from an accessibility perspective, but it was not a realistic one, in his point of view. His colleague's interjection, 'the temporary solution', further stressed this point of view and knowledge further since it implied that a portable ramp is only provisional until a better solution is possible. Still the combination of handrails, portable ramps and doorbells was described as 'the only solution' since the roadworks department opposes permanent ramps. An extreme case formulation was thus put to use, and legitimised the interviewees' approach. Later in the interview, it emerged that the roadworks department finds permanent ramps bulky and a hindrance for outdoor seating, cleaning and snow clearance.

By presenting the use of portable ramps, handrails and doorbells as a compromise between accessibility and maintenance the use of these accessibility measures is legitimised. Further, the combination of accessibility measures is described as something of a local model, which implies that it is common. All together these descriptions contribute to the construction of portable ramps and associated measures as an extreme case (Pomerantz, 1986). In this way the portable ramps are legitimised and perceived as right and acceptable, although this does not contribute to independent access or fulfil the objectives of the regulation, or requirements on the ramp gradient.

'Just as good'

Inaccessibility may also be legitimised by presenting special arrangements for disabled as 'just as good' as those for able-bodied. These kinds of formulations are found both in plans for new housing estates and in reports, on easily eliminated obstacles, on existing premises. Although the special arrangements, such as a system of ramps instead of a lift, might seem equal when presented in a document, the special arrangements require extra effort and time compared to those for able-bodied. One of these formulations was found in a report on easily eliminated obstacles made to the municipality on a staired entrance to a nineteenth-century building. The municipality required the installation of a handrail, portable ramp and contrast markings. The handrail and contrast markings were installed, but the portable ramp was rejected by the owners of the building. In a joint statement attached to the report, the owners explained that a portable ramp was not needed since a rear entrance could ensure independent access to the establishment: 'It is possible for a wheelchair-bound [sic], who wishes to enter the shop without assistance from staff, to do so with a wheelchair, on their own, and without hindrance enter the shop via the gate at [name of the street] and the entrance to the shop from the courtyard' (SBN 2017-002887, *my translation*).

Entrance through the backdoor was legitimised by asserting that it had worked before and that 'only two handicapped' (sic) had asked for assistance over the last decade. These descriptions are both ways of rhetorically justifying that a portable ramp is not needed. But 'just as good' and 'only two handicapped' are not formulations that are built upon extremes and maximisations. Rather the arguments are built upon equalising the different entrances and minimising the need to use the back entrance by referring to that it has only been needed twice. The back entrance is by these means constructed as just as good, or even better, than the suggested portable ramp since it has been used before and since it is described as ensuring independent access, which a portable ramp does not. Although the formulations are not extreme, the report shows that the owners' descriptions and arguments convinced the municipality, which dropped the request of a portable ramp, although entrance through a backdoor is not in accordance with the regulation's principle of access on equal terms (Svensson, 2015). The argument 'just as good' was interpreted as equalising and thereby implicitly 'fulfilling' the requirements of equality.

A visit to the establishment raised questions of how thoroughly the municipal investigation had been since I found out that the described 'independent access' through the backdoor was a mere fabrication. To get to the backdoor which, according to the owners' statement, would ensure independent access for wheelchair users, required a 60 metre detour through two locked and heavy doors.

'Does it have to be white?'

A third way of legitimising inaccessibility is by referring to measures as inappropriate in the given context. These kinds of formulations are built upon the importance of preserving a special architecture, style or cultural heritage. The potential conflict between form and function is also acknowledged in the regulation which states that the historic, cultural or artistic value of a building is not to be distorted when changes are made (Svensson, 2015; SFS, 2010: 900). In the interviews there are several examples of obstacles and barriers that were presented as acceptable by referring to this part of the regulation. Removing uneven cobblestones, changing an entrance or removing a staircase can all be presented as 'unthinkable' due to historical or cultural value. The extreme case (Pomerantz, 1986) is here constructed by stressing the importance of preserving the specific architecture or historical period. In the interviews there are examples of when even easily eliminated obstacles such as contrast markings were framed as 'unthinkable'. Even in buildings where several accidents and falls had taken place, markings have been ruled out on the basis of the cultural heritage norm. There is also resistance to accessibility measures in newly built premises, and tactile paving slabs or benches with backrests can be met with protest from architects. If the design of the measure does not fit, if it is not in accordance with the surrounding design, colour or style it is perceived as inappropriate and a disturbance. The measures challenge the social order and, similar to our cultural (and often implicit) definition of dirt, the measures are defined as 'a matter out of place' (Douglas, 1966: 36). This categorisation might explain why the measures arouse strong feelings and are conceptualised as ugly and inappropriate – or in Douglas's words, as 'dirty'. Like a stain on a carpet or clashing colours they are to be avoided so to not distort the design or architecture.

Contrast markings, too, are neglected not just in historical locations, but also in newly built premises. The reports on easily eliminated obstacles show that contrast marking tends to be forgotten in the latter, and several reports studied concern this accessibility measure. One of the studied reports contains no fewer than 30 remarks on missing or inadequate contrast marking in a newly built concert hall. According to the interviews the contrasts in colour between the surface and the line could be perceived as 'ugly'. One of the interviewed accessibility officers summarised a protracted discussion about the colour of a contrast marking as follows:

ACCESSIBILITY OFFICER: 'Couldn't it be – does it have to be – couldn't it be red?' she says. [Interviewer laughs] No it can't, since then there will be no contrast if it's grey and red. No, there has to be a contrast of light.

The argument the accessibility officer was recounting concerned the colour of contrast marking on a large staircase. The landscaper suggested a red flower-patterned marking since she found the traditional white contrast line ugly. The accessibility officer, on the other hand, insisted on white due to the need for contrast. Since the contrast marking is all about enhancing contrast of light and colour I, as indicated in the quote, started to laugh during the interview. Apparently, the accessibility officer did not have to convince me of the importance of contrast, but during the interview she described to me what a hard time she had had to convince the landscaper. Despite the accidents that occurred on the unmarked staircase it took a long time to add the traditional white contrast marking.

This argument and conflict between security and design shows how accessibility measures can be neglected and inaccessibility normalised even in newly built premises due to the framing of strong contrasts as ugly or inappropriate.

Conclusion: legitimising half-measures

To put lines of contrasting colour on steps might, from an outsider's point of view, seem quite easy to do. A staircase or step might also seem easy to replace with a ramp. But as my interviews with professionals show, the framing of some obstacles as 'easily eliminated' is misleading. The term positions stairs, steps and other obstacles from a merely instrumental perspective. The objects are perceived as 'in the way', as hindrances to full participation and inclusion and as something which therefore cannot be removed quickly enough. As the psychologist Kathrina Mazurik and her colleagues (2014: 197) point out, instrumental perspectives 'lead us to neglect the diversity of meanings and values associated with obstacles'. As their study of a shopping mall shows, visitors with disabilities deal with obstacles and hindrances pragmatically. They are not preoccupied with whether or not they are discriminated against or excluded. Instead, they have accommodated to the environment and focus on running their errands and getting on with everyday life.

Stairs and lack of contrast markings are all part of the wider urban environment and cultural context in the shopping mall and elsewhere. Although from a technical or even economic perspective they might be easily eliminated, from a socio-spatial one they stubbornly linger on. Such artefacts are all part of the socio-spatial ordering, layout and design, and if and when they are to be removed or changed, this order is challenged. If a staircase is replaced with a ramp there is a need to use some of the space of the street or pavement which might challenge the way maintenance work or outdoor seating is organised. From a maintenance perspective the ramp might be perceived as an obstacle or hindrance if the conflict of interest is not dealt with. Even changes that seem even smaller, such as a white line on a step, might challenge the socio-spatial order by challenging the design, architecture or historic value of a building. Something more drastic, like removing or changing the staircase of a listed building, might be considered sacrilege.

The half-measures of the urban environment are legitimised and normalised by referring to conflicting interests' that cannot be dealt with in any other way. As my analysis in this chapter shows, maintenance work or preservation of a design may be considered more important than ensuring independent, equal and secure access. As Rob Imrie points out (1996), these norms and practices are disabling and reproduce disability both spatially and socially. Architecture, planning and legislation that prioritise cultural heritage, form and aesthetics over usability ignore the socio-political impacts of the built environment. Space is an active constituent of social relations and power and defines who belongs and who does not (Imrie, 1996; Kitchin, 1998). When accessibility is outcompeted and downplayed, its very meaning is stretched to its limits. Although access is not completely denied, it is conditioned, dealt with when it is needed and therefore unpredictable. To visit the healthcare centre, pharmacy, post office or to go for a stroll is only possible when the circumstances are 'right': when the doorbell works, the staff have time to help out or a friend, personal assistant or passer-by can help you find your way. Half-measures that ensure reasonable accommodation rather than independent and equal access reproduce what Imrie (1996) calls the 'stereotypical disabled' who is subordinate, dependent and in need of special arrangements. Although previous research shows that people with disabilities adapt and find ways to manage obstacles and hindrances, it is also evident that they have to plan their visits, ask for help and be creative (Mazurik et al., 2014; Lid & Solvang, 2016; Wästerfors, 2020).

Both lack of accessibility – such as staired entrances – and accessibility measures – such as a ramp – may challenge the socio-spatial order of the city and arouse strong feelings. Interviews and go-alongs from our research project are filled with experiences of frustration and shame to relief and pride (see also David Wästerfors' and Kristofer Hansson's chapters in this book). The expression of these feelings reveals that both accessibility and inaccessibility challenge the social order of our culture and ways of classifying spaces and places. What is perceived as 'a matter out of place' (Douglas 1966: 36), depends on the cultural context.

To eliminate or change artefacts that hinder mobility and participation is therefore not only about technical skill and competence, but also about negotiating and compromising between conflicting norms and values of socio-spatial, rhetorical and cultural ordering. To be able to convince other departments, colleagues or the general public, the accessibility officer, traffic planner or building permit administrator has to present accessible measures and design as a part of, or in accordance with, the design, architecture or layout of a place. To present accessibility measures or a specific design as an improvement for everyone, not only for people with disabilities, is a common way of legitimising and normalising accessibility measures and so-called universal design. In the interviews, ramps, contrast markings and other measures were described as enhancing access and safety for parents pushing prams and the general public. Accessible design and measures are, in other words, formulated as what Pomerantz (1986) calls extreme cases, which legitimise a need to adapt or change the socio-spatial ordering of the pedestrianised street, or to make exceptions from the planned design or architecture of the planned construction.

'Barrier removal means rebuilding society', as the disability researcher Tom Shakespeare (2014: 39) puts it. As highlighted in this chapter, barrier removal is not to be framed as easy in any way. Shakespeare questions if a barrier-free society is even achievable since the implications are extremely far-reaching. Even though a barrier-free society is probably a utopia that can or will be attained, the conflicts of interests, norms, values and regulations that circumscribe barrier removal must be acknowledged and openly discussed.

Notes

1 The chapter was written as part of a three-year research project entitled 'Accessibility and its resistance: Everyday deviations from spatial and social practicability for persons with disabilities' carried out through a collaboration between Lund University and Malmö University and funded by Forte, *The Swedish Research Council for Health, Working Life and Welfare*. The project is ethically approved (dnr 2018/145).

2 *Regeringens proposition 1999/2000:79 Från patient till medborgare – en nationell handlingsplan för handikappolitiken.*

3 David Wästerfors and Kristofer Hansson, the other editors of this anthology.

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2 The bus trip

Constraints, hierarchies and injustice

Vanessa Stjernborg

> The driver just hit the gas and the customer had to hold fast to the armrests, close to falling out. In the end, the customer could not take it anymore and asked the driver to stop the bus, which also happened. However, the driver was not helpful and the customer had to roll the wheelchair backwards out of the bus…

The narrative above is an example of how buses can become a domain accessible only for some passengers, a domain which sometimes requires confrontation and negotiation even to be accessed. The speaker describes how the driver did not kneel (lower) the bus, nor open the middle doors, so the passenger had to enter the vehicle from the front. The passenger explains how they were stuck in the narrow passage inside the bus, trying to reach the designated space for wheelchairs. However, after a while they 'could not take it anymore'. The bus became a closed domain, negotiations failed and the passenger saw no other option than to leave the vehicle.

This is a situation in which the passenger was 'stranded' and 'overlooked' (cf. Egard & Hansson, 2020). Such situations may create feelings of frustration and a fear of public transport which, in the end, may lead passengers to avoid traveling by public transport at all. Research shows passengers with disabilities continue to face widespread challenges, despite active efforts to remove barriers in public transport systems in several parts of the world (Bezyak, Sabella & Gattis, 2017; see also Kristofer Hansson's chapter in this book). These barriers have been shown to be not only physical, but also social and attitudinal. A commonly reported barrier, for instance, is the attitude of the driver (Park & Chowdhury, 2018).

Under Swedish societal goals and legislation, public transport is a domain that should be accessible to all. However, experiences with public transport vary. Although Sweden was early to implement legislation on accessible public transport for disabled people (Swedish Parliament, 1979: 558), a recent investigation on behalf of the government has revealed several shortcomings, with organisational responsibility and regulations on accessibility found to be fragmented. The writers of the review concluded that accessibility is not handled as an integrated part of the overall quality system, but rather as

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individual efforts (Trafikanalys, 2019). Researchers have also criticised how public transport has become more and more adapted to an 'ideal traveller': an able-bodied, financially stable passenger, who primarily uses this mode of transport to get to and from work during regular office hours (Lubitow et al., 2017).

In the light of the climate crisis, together with growing urbanisation, the role of public transport in daily commuting has gradually increased. There is in Sweden a strong ambition to increase the market share of public transport relative to cars. This puts pressure on the effectiveness of the public transport system and may affect working conditions for drivers (such as greater time pressures), changed routes or the withdrawal of bus stops, for instance. A more effective system may benefit daily commuters by decreasing commuting time, but it might also be a challenge for passengers who need extra time, help and support. It is reasonable to believe that such a development would lead to conflicts between societal goals, illustrating the complexity of accessibility issues in public transport. Public transport should not be viewed as a single element; it is situated within a societal context, competing with other societal functions.

This chapter aims to provide new knowledge about how travellers experience barriers in public transport. The focus is on bus journeys, particularly on getting on and off the vehicle. The empirical material for this study consists of complaints concerning accessibility issues on buses received by the Greater Stockholm Local Transit Company (SL) between January and October 2018, with emphasis on travellers' personal negative experiences using public transport.

SL is the main actor in public transport in the Stockholm region; it is responsible for the metro, buses, commuter trains and boats, as well as public tenders for public transport. Around six procured companies run the various parts of the transit network. According to SL, about 900,000 trips are made daily in the whole region using public transport (Storstockholms Lokaltrafik, 2021a).

SL has made a comprehensive work on accessibility in public transport for many years and, for example, has established guidelines about accessibility for children, older people and disabled people. These guidelines were created in 2008 and have since been revised six times. The guidelines cover everything from the personal treatment of disabled people and employee education, to information in stations and aboard vehicles (written and verbal). Under the guidelines, all employees must complete a basic course about accessibility in public transport every three years (Trafikförvaltningen, 2018).

According to SL, all buses in Stockholm are low-floor buses with the accessibility function of 'kneeling', which reduces the height difference between the vehicle and the kerb. All buses are also equipped with a ramp by the middle door and the driver is responsible for manually unfolding the ramp when necessary. Buses have a designated space for wheelchairs (Storstockholms Lokaltrafik, 2021b).

Public transport and everyday mobility: a time-geographical approach

Public transport can play a pivotal role in society, ensuring access to education, employment, daily activities and social interaction. It enables citizens to be a part of society, yet accessibility in public transport remains a complex area.

Situated in a societal context, public transport exists within competitive environments with scarce resources. The market-oriented economy has limited capacity to handle larger differences among citizens and only allows differences to a certain degree (Berg & Grönvik, 2007). Public transport is often regarded as important for achieving other societal goals and public values such as economic growth and environmental sustainability (Stjernborg & Mattisson, 2016). Conflicts of interest, together with conflicts of goals, can create barriers, which may influence the possibilities for individuals to stay mobile. For instance, the speediness and effectiveness of the transport system can favour some, while creating barriers for others, depending on individual capacity and potential for movement.

Barriers in public transport differ in character. They may be physical (narrow pavements, high kerbs, vehicles without ramps), informational (shortcomings in design, a lack of available information channels) or social (other passengers, drivers, staff). Organisational deficiencies can also create barriers.

Movement and mobility

To understand barriers in public transport, we need to consider how movement occurs. Movement is located within a context of time and space (Cresswell, 2006). *Mobility* is more than movement; it includes factors such as type, strategies and implications of the movement, and it is a concept loaded with power and meaning. It is not only corporeal or physical, it is also temporal and concerns the individual's spatial access to places and activities (Cass, Shove & Urry, 2005). In spatial terms, mobility is shaped by a variety of tangible, intangible, individual, contextual and environmental barriers.

Mobility is essential in people's daily lives for managing everyday activities, participating in society and maintaining social relations. The possibility to be mobile is associated with independence, freedom and wellbeing. Limited mobility may result in social deprivation, marginalisation and exclusion (Urry, 2007).

Access to mobility varies and is unevenly distributed. People's capacity for being mobile varies and may change with time and during the life course.[1] Questions of differential mobility can be related, on one hand, to age, gender, class, ethnicity and the capabilities of different bodies. On the other hand, it can be related to economical resources, namely financial capital (and access to travel documents, for instance), cultural capital (such as higher education and professional qualifications) or access to vehicles and transport infrastructure. *Mobility justice* refers to structural inequalities based on differential capabilities and possibilities to be mobile (Sheller, 2018). A time-geographical approach is a useful means of understanding human movement and activities in time–space.

Time geography

Time geography is a bottom-up approach to the study of human movement and activities within the context of time and space (Miller, 2008). This approach was developed in the 1970s by the Swedish geographer Torsten Hägerstrand, who emphasised the need to study individuals' daily activities and movements in relation to their everyday environments (Hägerstrand, 1970). Hägerstrand focused on relations in time–space and the context in which individual movement is situated. Activities put demands on time and space, and a variety of resources are necessary to fulfil them. Activities establish daily paths, weekly paths and life paths. Beyond this, individuals have different roles and different temporal and spatial projects that shape everyday life, and these generate the patterns of daily life which mostly revolves around a few nodal places, the home being the most central (Ellegård & Vilhelmson, 2004).

In the time-geographical perspective, we recognise how our lives are controlled in different ways by our physical condition, employment, family situation, economic conditions, working conditions, working hours, accessibility in society, societal rules, guidelines and so on. In this approach, structures and hierarchies in society are given greater visibility, both on a micro and a macro level (Kjellman, 2003). Analyses of mobility in time–space require awareness of constraints that enable and limit movement.

Time geography includes some central analytical concepts, such as individual trajectory (how the person moves in time and space) and projects (refers to individuals' activities in daily life). Some projects are more dominant, some projects are wrecked and never fulfilled, and can create restrictions when moving in time–space. Projects in time–space may compete for access to space, which often leads to injustices. The competition results in some individuals having to stand aside and wait for their projects, or sometimes to abandon them altogether. An example is how people with a wheelchair often must wait for other passengers to enter the bus before the ramp can be used. The introductory quote in this chapter is an example of a wrecked project, when the passenger felt no option was available other than to leave the vehicle.

The projects create hierarchies in daily life, where some projects become more dominant than others, while others are pushed aside or never fulfilled at all (Åquist, 1992).

Sets of constraints

Within the time-geographical approach, we can identify at least three significant aggregates or sets of constraints: capability (or corporeal) constraints, coupling (spatial) constraints and authority (systemic/structural) constraints. *Capability constraints* are restrictions on activities due to human biology and/or the tools available to us in living our lives. Humans have basic needs, such as the need to eat and sleep. The physical and mental capacity of our bodies varies. The tools that individuals have access to also vary and depend on individual knowledge, type of housing, technical equipment (such as access to different modes of transport) and so on.

Coupling constraints are restrictions caused by the need for coordination among individuals and between individuals and tools. Most projects in daily life require coordination so that the individuals and tools involved are in the same place at a certain time. During this time, the place, the individuals and the tools are occupied and are unavailable to participate in other projects (Åquist, 1992; Kjellman, 2003). For example, if a passenger with a wheelchair would like to travel by bus, it requires coordination in time–space. The individual and the bus must be in the same place at the same time (according to a timetable), the accessibility equipment (the ramp) of the bus must be used as intended, and the space designated for wheelchairs must be available (not occupied by someone or something else).

Authority constraints are about hierarchies and power relations. Hägerstrand uses the concept of domains to refer to 'a time–space entity within which things and events are under the control of a given individual or a given group' (1970:16). Access to different domains varies for different individuals; some domains are not accessible at all, others are accessible by invitation or by payment, and some can be accessed only by putting up a fight. Domains differ in character; they can be small, like a place in a queue or a preferred seat, or they can be larger and have varying types of legal status, such as the home, the nation and so on. Some domains are temporary, such as a seat on the bus, while others are permanent.

These three different types of constraints interact in several ways, both directly and indirectly. They are also closely related to power; a higher income, for instance, normally gives greater access to domains (Hägerstrand, 1970).

Methodology

The empirical material for this chapter comprises the 389 passenger complaints concerning accessibility on buses received by SL for the period between January and October 2018. The complaints, which are publicly available, are divided by SL into the following categories: 'kneeling the bus/closeness to the kerb/ramp'; 'elevator/escalator availability'; 'escort service'; 'timetables'; and 'other' (for an overview of the complete material, see Stjernborg, 2019).

This chapter is specifically concerned with complaints related to 'kneeling the bus/closeness to the kerb/ramp', the largest category with a total of 214 complaints. All the complaints concerned buses in Stockholm and were communicated to SL through different channels, including social media (e.g. Facebook), phone and email. The empirical material was compiled in an

Excel file with information on the points of origin and destination, the date and time, route number, the channel through which SL received the complaint, and a brief description of the complaint itself. In some cases, where the traveller left written complaints, the description is in the travellers' own words. In other cases, descriptions were summarised by the SL customer service employee who received the phone call. Most of the complaints were left by telephone.

The complaints describe only the passenger's perspective and interpretation of the situation and do not include the bus driver's perspective. Several of the passengers describe their declining health and functional limitations, and/or the use of a mobility aid. In some cases, complaints are left by passengers who were travelling with strollers and described the same challenges as those with personal mobility issues.

A qualitative content analysis was conducted in a stepwise manner, with a focus on both the manifest and latent content (Graneheim & Lundman, 2004). The researcher read the complaints repeatedly and in full, to create a feeling for the text and content. The next step was to identify meaning units, which were then condensed and grouped. The data was analysed using a time-geographical approach. Three themes were identified: a) negotiations about the kneeling function/the ramp; b) stopping far from the kerb; and c) being refused access to the bus/being left behind.

Negotiations about the kneeling function/the ramp

The largest theme concerned the misuse (or disuse) of the kneeling function of the bus. A recurrent complaint was that travellers had to negotiate to convince the driver to use the equipment. According to the complaints, drivers gave different reasons for not using the equipment as intended. For instance, they claimed they did not know how to use the function, or that it was out of order. In some cases they simply refused to use it without giving a reason.

Several of the complaints describe this misuse (or disuse) of the kneeling function as a recurrent challenge. Some also describe how the traveller used the blue button – a special button on buses which lets the driver know a passenger wants to use the kneeling function – only to have their request ignored. Some of the narratives describe the behaviour of the driver as rather offensive.

The narratives often include a short description of the traveller's physical health, explaining the importance of the accessibility equipment being used as intended. Physical health becomes a capability constraint for getting on and off the bus.

> I travel with crutches […]. The drivers think that I can get on in the same way as anyone else. I've had to complain about the drivers every time I take the bus.

Several narratives describe how declining physical health often entails the use of an aid, such as a walker, a wheelchair or crutches. The coordination between the individual, the aid and the vehicle create coupling constraints, making it harder for passengers to enter the bus and creating barriers in public transport. Some of these complaints were by travellers with strollers, describing similar challenges when the kneeling function was misused.

The complaints also describe the difficulties that arise when travellers with capability constraints do not bring an aid, since their need to use the kneeling function may not be obvious. In this case it is about visibility, and some passengers find that one needs to bring an aid simply for the functional limitation to 'become visible', which might facilitate negotiations with the bus driver:

> It feels like it takes a wheelchair or a walker, otherwise you almost have to beg to make them lower the bus. It's a tiresome experience and in some cases, it can also be worse than that when some drivers get really unpleasant as a consequence of a request to lower the bus. Some also refuse to lower it.

Some complaints describe how drivers insulted passengers who requested that the bus be lowered:

> An elderly lady was about to get off the bus with a shopping cart and asked the driver to lower the bus. He refused in spite of several requests and the lady tried to struggle on with the cart, pushing it along, but it got stuck in the gap between the pavement and the bus. Another woman had to help her off. Later, the driver mocked the lady with a friend who was sitting next to him.

Another narrative describes how the bus driver had a negative and disparaging attitude and refused to kneel the bus, leaving the traveller with feelings of worthlessness.

Other complaints concern misuse of the accessibility ramp. For example, one narrative describes how a driver refused to help a passenger with a wheelchair use the ramp and laughed when other passengers had to help the traveller board. Some complaints describe how passengers were hurt getting on or off the vehicle, or felt unsafe travelling by bus.

> The passenger fell backwards and hit her head. A week later she still has a bump in the head and a scratch mark on her leg. There were kind fellow passengers who helped her and made sure she got home.

Some complaints note that part of the problem is that the drivers are stressed and working under time constraints that do not allow them to ensure that all passengers are getting on or off safely. One narrative describes how the driver initially refused to kneel the bus and thereafter showed dissatisfaction because of the extra time the traveller needed to enter the bus.

> The passenger feels that drivers' stress about departing on time has become worse and she doesn't feel safe travelling by bus. There isn't enough time to get on when you have a walker and the problems with drivers who don't lower the bus or open the doors in the middle have increased lately.

This is an example of how mobility is hierarchical and a resource that is not equally available to everyone. The passengers in need of some extra time may be regarded as a burden in a system increasingly focused on efficiency.

> We asked the bus driver to lower the bus for her to more easily get on the bus, but the driver refused. After a long time, he lowered the bus and then sat there complaining loudly because it took a bit longer for her to get on the bus and to sit down. To try to speed up the whole thing he also pointed out that there was a line behind her.

Many of the complaints describe the important role of other passengers. Several narratives describe how getting on or off the bus would be impossible without help from other passengers (see also David Wästerfors' chapter in this book).

Stopping far from the kerb

Another theme in the collected material is how the bus may come to a stop so that there is a gap between the vehicle and the kerb. The narratives include descriptions of authority constraints because of hierarchies and power relations.

The behaviour of the bus driver is described as essential in determining whether some passengers can travel on public transport or not. Several of the complaints describe drivers with nonchalant or abusive attitudes, rendering travellers with capability and coupling constraints even more vulnerable. The three constraints (capability, coupling and authority) normally interact in several ways, both directly and indirectly. This is also apparent in the complaints.

> I am waiting for the bus, it's dark and I have reflectors on my crutch which are clearly visible. When the bus comes, he stops so far from the pavement that I can't get on. He lets other passengers get on and then drives a bit further on, but it was too long a step for me there too. New passengers are let on first. He then lowers the side of the bus and with great effort I get on the bus.

In the quote above, power relations become visible, as well as the interaction between the different types of constraints. The traveller is affected by capability constraints because of a condition that requires the use of a mobility aid. They are also affected by coupling constraints because the accessibility equipment is not used, making it difficult for them to enter the bus. At the same time, they are forced to wait until other passengers have entered the bus, illustrating authority constraints (and hierarchies).

Being refused access to the bus/being left behind

Some narratives describe situations where travellers are left on the street and are not even allowed to enter the domain of the bus:

> A passenger who needs a cane to walk asked the driver to lower the bus for him to get on but instead got the door closed on him and the driver drove away.

One complaint describes how a traveller with a wheelchair was left on the street several times:

> On numerous occasions the bus driver has ignored the passenger and closed the doors and gone off.

Another complaint describes how the traveller was told to take the next bus because the driver was unwilling to kneel the bus:

> … when the passenger's mom asked the driver to lower the bus, the driver refused to do so and instead referred her to the next bus.

Thus, projects in time–space compete for access to space, which often leads to injustices, with some individuals having to stand aside and wait for their projects to be accomplished, while other projects are never fulfilled at all.

Conclusion: access to public transport

An analysis of travellers' complaints about barriers in public transport show that travellers repeatedly have to negotiate with drivers to make use of accessibility equipment. The bus becomes a domain that is accessible only for some passengers, and which sometimes requires a fight and negotiations before it is made accessible. In some cases, the bus becomes a closed domain when negotiations fail and travellers are left on the street. Mobility can therefore be seen as a resource that is not evenly distributed (Sheller, 2018). The uneven distribution is seen in the complaints in various ways, as are the power relations between the driver, the passenger and other passengers.

The complaints illustrate a reality in which accessibility cannot be taken for granted, and resistance to accessibility in those transport-related situations is apparent. Challenges around boarding or getting off the buses are frequently described as recurrent and as evoking feelings of vulnerability, unsafety and frustration. Some even question if their presence on public transport is desirable.

Public transport, including buses, should, after payment of the fare, offer accessible domains for all. In fact, this is specified in the law on accessible public transport for disabled people (Swedish Parliament, 1979: 558). However, public transport is situated within a societal context and competes with other projects in time–space (or with other societal ambitions and goals), which may result in injustices. The competition results in some individuals having to stand aside and wait for their projects, or abandon them altogether (Hägerstrand, 1970). Accessibility is repeatedly seen to be given lower priority in the interplay between the driver, the vehicle and the surrounding context. This creates inequalities because of differential capabilities and possibilities to be mobile.

Thus, despite legislation, ambiguous goals and a transport policy that aims to support accessible public transport, and even though there has been extensive work on physical accessibility (with low-floor buses, ramps and so on), the accessibility challenges in public transport for some passengers remain obvious. Generally, there has overall been less attention paid to the social dimensions of accessibility, such as the behaviour of the driver. This greater focus on physical barriers may have been influenced by the social model of disability, which distinguishes between impairment and disability. Impairment is considered to be individual and private, while disability is regarded as structural and public. Disability is viewed as a social construct, created in the interaction between society and the individual (Shakespeare, 2017). However this model has been criticised for its rather narrow view of disability focusing mostly on physical impairments and failure to account for differences between disabled people (e.g. McRauer, 2006; Oliver, 2013; Goodley, 2013; Kafer, 2018). Much of the focus of the social model has been on the built environment, such as pavements, buildings and transportation technologies. This may have prevented disability scholars from applying a more comprehensive approach (e.g. Shakespeare, 2017), and the lived experiences of disability have generally gained less attention (e.g. Kafer, 2018).

Access to public transport can mean the difference between an active life and a life of isolation and marginalisation. That one has to negotiate with bus drivers about the use of accessibility equipment, that the guidelines of the operators are not followed, and that discriminatory behaviour seems to occur regularly, are social practices that limit accessibility in public transport. Highlighting social practices that counteract efforts to build an accessible society is important, not least to understand everyday resistance to inclusion faced by persons with disabilities. However, further research is required from a user-oriented perspective, on how well accessibility adaptations in public transport actually work and how trips are experienced, including comprehensively identifying the variety of social practices that hinder ambitions to ensure that an accessible public transport system is available to all citizens.

Note

1 A useful theoretical term in this context is *motility*, meaning the potentials and capabilities for mobility by individuals and groups (Kaufmann, Bergman & Joye, 2004; see also Egard & Hansson, 2020). It implies a consideration of physical ability and capacity, the individual desire or aspiration to be mobile (or not), and access to transport and telecommunication systems. Motility thus addresses three dimensions; the social conditions of access (for example conditions making it possible to use the transport system), the skills to use it, and mobility plans (and the actual use of transport to fulfil those plans) (Dubois et al., 2015:102).

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3 Monitoring the standard – here, now and in person

Detecting accessibility faults as an engaged citizen

David Wästerfors

'I'll show you,' he says, and drives around a corner to a sign on the floor.

A few minutes after we meet at the railway station, Richard, a retired engineer in his sixties who uses an electric wheelchair because of a muscle disease, shows me a glaring accessibility fault. It is inside the railway station complex, which is filled with shops, cafés, restaurants and lots of passing travellers. The symbols on the floor instruct wheelchair users to go in a certain direction to find the lift but, as Richard says, it is wrong.

We move in the indicated direction and only find escalators and an ordinary staircase. There is no way for a wheelchair user to proceed. Richard explains that, in fact, one needs to go in another direction for the lift, and shows me the way to a spacious lift. We would certainly not have found it by following the arrows on the floor. The misdirection is because of the ongoing – and long-running – renovation work taking place in the building. Lifts and stairs have been moved to new locations, but some of the signs have still not been moved or changed.

Richard has reported the fault to the managing company.

We go back to the inaccessible escalators and stairs, and consider the difficulty of going up a floor if you know nothing about the station but trust the signs. It might seem a trivial concern, a 'luxury' in the Western welfare state of Sweden, but it can turn out to be an insurmountable barrier, we conclude. Like everyone else, people with disabilities count on infrastructure. They can be as occupied and stressed as anybody else, they can be committed to this or that, and have others depend on them.

As we talk, Alfred shows up. He is Richard's friend and co-worker at a local disability organisation. Like Richard, he is an accessibility detective. Alfred is also in his sixties and has a visual impairment, making it hard for him to see things directly and without a blur. He says that engaging with the work of finding accessibility faults in the local environment has really changed his mindset. He had not thought about it in the same terms before, though disabled himself, but now he can detect poor accessibility 'almost everywhere': in shopping malls, cinemas, museums, squares and parking lots, inside libraries and government buildings, in digital settings and the healthcare service. Edges on streets, pavements and at entrances must be low but

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still marked, to be manageable both for wheelchair users and the blind. Signs must be written in correctly contrasting colours to be readable for all, and they should be placed at certain heights. Websites must be usable by all users, and in concerts and lecture halls, at receptions and in offices, the acoustic environment must be suitable for a range of hearing impairments.

This is the second time I have met Richard and Alfred. Both are deeply engaged with their volunteer work of identifying and reporting accessibility faults in their municipality in Sweden, including alerting the public and the media. They have published satirical videos about the errors they find, and routinely use the municipality's apps and webpages to report their observations to the traffic department and other institutions, and then they follow up each case to see if and how the fault is rectified. They have good contacts among officials and managers, but they also have to 'nag', as they say, to have the faults amended.

There is 'always something', Richard and Alfred say. Things are never settled; officials and managers are never fully informed. 'Amateurs' – untrained officials – keep showing up and innovations complicate things, as do aesthetic trends. Richard and Alfred find new faults every day. Still, they enjoy their work. It is fun and exciting but at times it also feels endless, the enemy immense.

Accessibility on the ground

In this chapter I will analyse some of the practical, emotional and personal aspects of engaging in accessibility politics 'on the ground', and how such an engagement is part and parcel of today's society and its paradoxically nebulous accessibility politics. There is a formal equivalent to this engagement within building committees in Sweden's municipalities, since, under the Swedish Planning and Building Act and the prescriptions of the Swedish National Board of Housing, Building and Planning, they should monitor accessibility, initiate supervision and take action whenever they find deviations or shortcomings (see Boverket, 2018). But my focus is not the implementation of formal inspections, or their inherent deficiencies.[1] Instead, I will consider Richard and Alfred's activities as a form of mundane detective work from the standpoint of the relatively subordinated but attentive citizen. What they do is both similar to and different from what municipalities do – or should do – but it is also an engagement in its own right.

Laypeople detectives are policy-equipped – they know the law and people's rights, are familiar with a range of previous cases (cf. Zotééva, 2018), and keep close contact with the local building committee – but they work also beyond policies. I do not intend to liken their work to inspections by the authorities or policy evaluations, but to keep it as probing, embodied and 'lived' as it seems to be. Richard and Alfred are watching and conceptualising today's resistance to accessibility on their own initiative, and they try to disclose and defeat it in a tangible, 'in the field' manner. Although their approach is precise, methodical and accountable – like the municipalities' work is supposed to be – it is also flexible, personal and plastic. To analyse this work is to both recognise and understand people's close-up fights against exclusion and discrimination. The detectives find a orderliness to the world that they see as demonstrably troublesome and illegitimate – it makes the social world unnecessarily constricted – and they call for change.

My approach lines up with the effort to not get trapped in a 'boxy' way of understanding accessibility (Shakespeare, 2014, pp. 33–42). Sometimes we imagine an ideal linearity: society at time 1 is inaccessible and discriminatory, and should be moved to another and superior state at time 2, when it will be accessible and inclusive: 'barrier-free' (Williams-Findlay, 2020, p. 134). This can be done, we presume, through the forceful use of political power, unambiguously informed by the latest declarations of rights, most notably the United Nations Convention on the Rights of Persons with Disabilities (CRPD). Society should, as it were, move from one box to another, removing barriers and, ultimately, transforming the whole social organisation (cf. Shakespeare, 2014, pp. 12–16). Most likely, however, this is not how it happens and the reasons are manifold. First, there is no precedent for such historical shifts, and no good arguments for the existence of a reachable utopia waiting around the corner (Shakespeare, 2014, pp. 34–38).[2] Rather, there are good arguments that social change takes place stepwise and moves both forward and backward, and that the progression towards increased accessibility entails slowly defeating the new and everchanging forms of resistance or inertia that pop up. Change does occur, but not in the sense of travelling from one discrete box to another. Moreover, society at time 1, the imagined point of departure, is itself fluctuating in several ways – mostly not due to disability politics – and this extends and complicates people's accessibility work. Society is, like the railway station in my introductory example, constantly being reconstructed, so that earlier efforts to ensure accessibility (the signs on the floor) become obsolete and new inaccessibilities emerge. To imagine accessibility as something that is possible to 'get done with' once and for all leads one to gloss over its processual and socially embedded nature – a nature that we often recognise in people's situated experiences and through close-up inquiry (cf. Kastenholz et al. 2015, p. 1278,[3] see also Patrick Kermit's chapter in this book). Not only is the Fully Accessible Society a moving target, amorphously dynamic depending on people's changing practices, wishes, individual impairments and conditions (Shakespeare, 2014, p. 37), but the point of departure and the means by which to advance also fluctuate.

A boxy way to understand accessibility also glosses over the politics of everyday life. We run the risk of overlooking the fact that politics is part of people's daily practices – sometimes in engagements that are not even defined as politics (Luhtakallio & Eliasoph, 2017) – and that disability politics is not simply a top-down activity for professional groups and authoritative declarations by seemingly righteous governments. To 'move' society in a disability-friendly direction is not only a matter of paragraphs in formal policies, decisions or evaluations, but a set of tangible and mundane 'trouble dealings' (cf. Emerson, 2015; Wästerfors, 2021). It is a practical, emotional and even personal project. This is not to say that 'grand' politics and interests should not be taken into account; rather, exclusion and ableism do not merely manifest 'above' us or far away, but here and now, within concrete situations and everyday troubles (see also the chapters by Patrick Kermit and by Elisabet Apelmo and Camilla Nordgren). The rights that the politicians are debating and advocating can be tried, examined and played out in and through the gaze and practices of laypersons who become accessibility detectives in the streets.

Methods, data and concepts

The research underpinning this chapter emerges from the Swedish research project that initiated this book. It entails a diverse set of data on accessibility, and resistance against it, in various settings in Sweden during 2018–2020. The main methods are qualitative interviews and go-alongs (Kusenbach, 2003).[4] We interviewed 36 persons of various ages, from various socioeconomic backgrounds and living with various disabilities (mostly physical, but also some cognitive, perceptual and combinations of disabilities). We accompanied around 20 of these informants on their daily errands to get a close and more dynamic understanding of their dealings with accessibility, thereby combining more informal interviewing with fieldnotes and photos. We also interviewed ten representatives of establishments indicated by the persons with disabilities, and collected registered complaints to municipalities (cf. Hanna Egard's chapter in this volume).

As we analysed the data, we started to identify Richard and Alfred – the joint focuses of this chapter – as the main accessibility detectives of our project. Their habit of critically exploring their surroundings, and of inspecting and scrutinising places and situations from an accessibility point of view, really stood out. Still what they do is far from unique. Indeed, poking around and observing faults in one's settings is commonplace in our data (cf. Wästerfors, 2021). Sometimes people do not formally report faults but simply sigh over them, mutter, whine or complain in private, or call the responsible persons and/or upload an image on social media with a critical remark ('here I am, and I cannot do my shopping', cf. Hansson, 2020; Egard & Hansson, 2020). Richard and Alfred, however, embody what the geographer Rob Kitchin (1998, p. 352) calls 'resisting disablist practices', and they cultivate this within a local association. Their performance summarises and 'thickens' what many of our other informants also do, and since we met them several times, we could ask more about it and revisit their activities (cf. Holstein & Gubrium, 1995, on active interviewing).

In this chapter, I draw theoretically on ethnomethodology, interactionism, phenomenology and studies of disability politics. I have come to look upon detecting inaccessibility in everyday life as practical action and practical reasoning in unity (Lynch, 2001, p. 131). It is done and accounted for, accounted for and done – and it is a local achievement, performed by members of society with experience of disability-and-exclusion, and informed by the norms of how society should, ideally, be. It is a situated exploration of the real-world policies of accessibility and inclusion in materialised forms. It thereby illustrates the double-edged sword of ethnomethodology, both as an active investigation of the methods through which members of a group or setting construct the social word, and a more distant acknowledgment of the investigations already performed, before the researchers entered the scene (Lynch, 2001, p. 132).

Detecting inaccessibility is an embodied, concerted and emotional procedure, anchored in laws and policies. It depends on interactions with others and with the environment, both of which can be said to 'answer' or respond to the investigations and manipulations of the detective who, in one way or another, finds the orderliness problematic in the light of how it should be. It depends on a living subject manoeuvring a body (or parts of it) in a certain place or situation, carefully attending to what does not fit, match, correspond, alleviate, help or include. It involves feelings like indignation and resentment, but also excitement and joy. I suggest that this detection contains a component of folk methodology, one which is personal and sometimes also tacit. As the philosopher Michael Polanyi (1958) describes, it is learned by example and imitation, and it relies on our body. The knowledge produced comes forth by 'dwelling' in things (Polanyi, 1967, p. 18, 21), not by simply applying a theory – even though the detectives certainly are equipped with accessibility norms to use as a yardstick – but by interiorising and extensively using it. The personal aspect shows itself not only in the fact that the detective tries out various places or situations with his or her person at the centre – 'here *I* cannot enter', 'it doesn't fit *me*', 'it's too dark *for me* to see', using a personal subject as a sort of mannequin – but also by the fact that subjects report the faults, legitimise them in person and sign their complaints with their own names. I do not mean to say that this work is personal in the sense that it is dependent on personally experienced disability. It is personal in its engagement and practical accomplishment.

This concreteness and personalness can be contrasted with the abstract declarations and policies of today, and it gives flavour, colour and body to the often rather dry perspectives of authorities and evaluations. Although a systematic assessment of accessibility with a set of recommended strategies as benchmarks is certainly a powerful act,[5] it is also powerful, in a different sense, to bring experienced 'folk assessors' into social science, to capture their continual practice of assessing and its dynamic sensitivities. Moreover, this has a politically subversive side.

Detecting these faults is, I argue, a downplayed version of dissidence performance. Analogous to the Charta 77 movement in the harsh regimes of the communist bloc in Europe once upon a time, the ulterior motivation is cleverly manufactured: it grips the language of power and reverts it to itself. The dissidents of Eastern Europe could say: 'You (the government of Czechoslovakia, at the time) have signed petitions on human rights, then how come *this case*, and *this* and *this*, etc., prove they are not valid?' Similarly, citizens in many states today can argue that given what the governments have actually promised to the disabled, the situation experienced here, now and in person, simply will not do.

Techniques of fault finding

'You get used to it,' Richard says, using the Swedish phrase *det sätter sig*, roughly meaning 'it sinks into you', or perhaps something like 'you get configured to doing it', 'it almost becomes automatic'.

When I express mild surprise about all the faults Richard and Alfred show me over the course of a single day, they account for their gaze by referring to the fact that they are now trained in accessibility and can hardly stop detecting faults. During the go-alongs and in interviews, they demonstrate and report their techniques. They look and feel, they point out to one another and describe, they follow the conventional paths for citizens – in the aisles of a shopping mall or a cinema entrance, in pedestrian zones – to check if they are functioning. They go back and check specific junctures or troublesome spots that they have identified and reported before.

Richard, for instance, points to a crossing in the downtown area, saying 'that one we've been "on".' We pass the spot and Richard explains that the pedestrian crossing was 'too narrow' next to the traffic light, so that Richard's electric wheelchair bumped into the signal pole. He dramatises the initial attitude of the roadworks department: 'well, well, we'll change that in two years'. But he got them to do it quicker than that, by 'nagging' and by using a 'good contact'. So, within the detective techniques is also a rhetorical competence and facility in networking. It is not enough to go around 'seeing' faults: one needs to report them and to successfully drive the cases. It helps to go back, report again, follow up on the promised remedies and remind the relevant officials. It is not simply a matter of checking once and spotting errors, but of monitoring settings over time and trying them out repeatedly.

Often, Richard points out, the municipality has some sort of consultant who knows the formal regulations on accessibility – the minimum dimensions of a public toilet, for example – but does not always know why they exist, what their purpose is, as Richard sees it. Then constructors may work with too-narrow margins, or combine things that, taken separately, provide accessibility but, when joined together, actually reduce it (cf. Shakespeare, 2014, p. 37). Richard and Alfred often refer to the need for education, but they are also eager to underline its practical and – in my words – immersive aspects. It is not enough, they say, to know on paper what accessibility means; the consultant or constructor should have tried out a wheelchair themselves, for instance, or walked 'like a blind person' in the streets. Then they would get closer to understanding 'what it's all about,' and would not make so many errors, Richard and Alfred argue. Some municipalities and university programmes do include such experiments, and they are often accompanied by personal insights. Alfred dramatises such insights: 'Now, I understand better how it is to not be able to reach the buttons in the ticket machine!'[6]

Richard and Alfred offer a wealth of anecdotes with this message. Knowledge of accessibility is better employed, they argue, when it comes with (some kind of) immersion: it goes 'deeper' and becomes more meaningful. Alfred tells me about an occasion when he came across some tilers laying out tactile paths. Out of curiosity, Alfred asked the workers if they knew what these tiles were for. 'They didn't know!' They just did the work of tactile paving, but had no clue about the purpose behind it. If this is the case, no wonder things go wrong sometimes, or 'weird' and 'hasty', as Alfred puts it. He did get the impression that the tilers were doing a good job, but could also imagine the many troubles they might create just by not really knowing what they were doing. Many informants in our research project use a similar line of reasoning to debunk popular arguments based on economics for not providing accessibility in the first place. Many faults could be avoided from the beginning, at no additional cost, simply by knowing more, they argue. They do acknowledge the cost of amending, reconstructing or removing existing structures but, they counterargue, if the responsible actors had known more to begin with, the extra cost would have been avoided.

Thus, embedded in techniques for finding faults is a component of critical review which takes into account politics, the economy, education, various impairments and competence. It is a multi-layered practice with both evaluative and persuasive aspects. When Richard and Alfred walk their rounds, they prepare themselves with arguments and anticipate officials' responses and how to respond to them, moulding their own attitudes, as accessibility detectives, accordingly. They have a catalogue of examples in their minds, and they explicate these to each other and to me, so that they can artfully close the gap between formal (or promised) accessibility and accessibility *in situ*.

Of course, the formal rules of an accessible pavement or intersection with no barriers are far from tacit: one can look them up on websites and in protocols (see, for instance, Boverket, 2018).[7] The detective practice that I focus on in this chapter amounts to a bit more. Ethnomethodology helps us here; it is common in such studies to admit and make a point out of the fact that the researcher's temptation to systematise folk methods and their enactments risks transforming them (Lynch, 2001, p. 140). It is hard to systematise what people do, and in trying to do so, it might turn into something else: an abstract logic, a mere application of norms – a boxier view. *In situ*, detecting what is not accessible is not simply a matter of concluding 'this is not accessible' from a given observation, as if measuring the world with a norm in mind. Rather, it is a routinised practice with several layers and implied ingredients. If we go down the route of ethnomethodology, the researcher's way out of the problem – to potentially over-systematise an everyday phenomenon so that it risks becoming alienated from everyday life – is to describe *the members' own ways out* (cf. Wästerfors, 2021). Thus, I try to describe here Alfred and Richard's ways, which are embodied and lived in their time and their space (Lynch, 2001, p. 142). I do not try to make them more systematic or tidy than they actually are.

It might be helpful to see how I document in my fieldnotes what is happening when Richard and Alfred do *not* spot a failure of accessibility. At such moments I simply write things like 'he is carefully scrutinising the doorway and the spaces [in the toilet]', '"it looks right", he says.' Or: 'We go up and take a look at the exit to the cars and the parking area, which also looks "good".' Sometimes I note that we start talking about other things than the immediate surroundings, since the surroundings seem accessible. We might discuss, for example, Alfred's vision problems, or a previous workplace and its accessibility problems, the problems in the public library, or where we are heading to next, a specific outdoor area, etc. My notes become brief in such passages and the conversations seemingly empty – until we find another failure in the immediate environment to focus on. This is, of course, partly due to the theme of the project and how I communicated it when presenting my research interest, but it also illustrates Alfred's words at the start of this chapter: once you are used to detecting accessibility faults, you start seeing them almost everywhere, and if you do *not* see any in a particular place, you start hastening to 'the next one'.

In my notes and transcripts, vocabulary itself becomes more elaborated when faults are detected. Richard and Alfred specify their reasonings more, and I ask more follow-up questions. When the role of the meddler or nitpicker has been performed and no more faults seem available, the lights of the 'show' are dimmed and it goes into standby mode.

There is, in other words, a performative aspect to this practice, entailing an expectation to be eloquent, articulate and persuasive 'in character', and more reserved, unobtrusive and terse when there is nothing to comment on. Interactivity is sharpened when you are on the scent. The accomplishment of detecting inaccessibilities requires materials to interact with and, certainly, an audience to engage (see also Elisabet Apelmo and Camilla Nordgren's chapter).

Feeling the faults

The informants for this research project often vented their frustration at the lack of accessibility. This and related emotions are, I argue, both the most expected and most often displayed in our data. At the very core of the problematic lies frustration; people with disabilities are promised accessibility and yet it does not materialise, not fully or constantly. Our informants talk about the burden of having to point out rights that everybody should know and respect. They mutter or snort when others make way for them, help them out, or act demonstratively 'kind', even though there are laws and policies that guarantee our informants should be able to do things on their own (cf. Wiseman, 2014; Egard & Hansson, 2020).

This, we note, may be a motivation for political engagement and is also coupled with discomfort or 'stickiness' in everyday interactions (Hansson, 2012; Wästerfors, 2021). Ideally, society should be designed so that disabilities play no role but, in practice, people's impairments and conditions are brought into focus again and again (Shakespeare, 2014, p. 2633), and situations become awkward easily and for many reasons (cf. Wiseman, 2014, pp. 147–148). Others might feel obliged to not show what they think, and people with disabilities might feel obliged to not show that they understand perfectly what others think, and so on. What Erving Goffman (1963, pp. 83–88; 1971/2010, pp. 219, 224, 267) calls 'civil inattention' – to be seen, but also politely left alone – becomes complicated, and embarrassment in public places is given an extra layer. In the research project we encountered a variety of responses: from informants who refuse to feel embarrassed about the ignorance and blunders of others and retreat into sarcasm, critique, anger or silent sourness, to those who are drawn into embarrassment out of courtesy and feel mortified by the accessibility mistakes and inferior accessibility work of others.

These emotional aspects – associated with accessibility and resistance to it in general – are narrated and touched upon in the encounters with Richard and Alfred, but other feelings are still more striking. There is a sense of fun and excitement in stumbling over new findings and reasoning about them. Richard and Alfred enjoy their activities, even while considering them a serious matter. They talk about the 'absurdities' that the municipality is responsible for, laugh at them and elaborate on sarcastic and entertaining images of ignorant and simple-minded officials. They find it fun to get the officials working, to initiate errands and make their digital reports, engage all those who, on paper, *should* be engaged in accessibility work, but perhaps tend to forget about it, get distracted, or lapse into laziness. The relative accessibility of the local reporting system that Richard and Alfred use, a website and an app, seems to smoothen and stabilise the process. It is easy to report faults and tick the 'accessibility' box on the form, and when you get a case number back from the municipality it is easy to remember and keep track of it. The very success of their work is also a source of joy; to see things change in their surroundings and to know that their efforts make a difference.

Thus, while frustration is commonplace, other emotions are also involved in the more precise practice of revealing and exposing inaccessibility. There is an 'a ha!' quality to this detective work, as when Alfred looks around in a cinema we visit and brightens up. 'Find a fault!' he says to me, challenging me to see what he sees. I quickly give up, and Alfred explains that there are steps in front of the clearly marked emergency exit, and no lift or ramp. 'You're right', Richard says, 'How did they think *there*?' – implying, of course, that 'they' did not think at all. Later, we find another emergency exit without steps and our excitement softens a bit, but still the detectives are suspicious. Since there are no clear signs indicating that one exit is suitable for wheelchair users and the other is not, the situation is confusing. In an emergency one might well head towards the impossible exit.

Embodied perceptions and sensations are integrated into our go-alongs. A too-sharp edge, for instance, is not only a disturbing obstacle on the way from point A to B, cognitively identified and verbally pinpointed. It is also bodily irritating: you feel its existence in your body, you may even sense a sting of pain, and you feel the effort you need to get over it. I have accompanied several people when too-steep (or absent) ramps, for instance, caused a lot of sweat, much like the everyday labour of opening, say, an impossible can or a rusty lock. You have to work at it, repeatedly. Challenges like these can be painful and, as the philosopher Drew Leder (1990, p. 75) points out, they disrupt intentionalities. The actor is in the midst of doing something but gets interrupted and is reminded of his or her body (Hansson, 2020). Even as you bump into an obstacle, you also bump into your own body; the body is not a transcendent means in the background anymore but is suddenly put in the foreground. Wrongly placed tactile tiles are much the same; you 'bump' into a void or a bicycle stand, and the flow of walking is interrupted. This is the disability version of what the sociologist Jack Katz (1999) in his phenomenological study likens to being amputated in traffic, as your driving is cut off by other drivers and you get angry.

When Richard and Alfred try out the bumps in their city and neighbourhoods, encountering them *is* their intention, so coming across obstacles and exclusion becomes temporarily welcome – it gives them a receipt, so to speak, of their work's importance. Still, the painful side remains. Richard complains about uncomfortable passages (for instance, ways full of bumps and potholes) – 'if I had driven there today, I would have got backpain' – and in a more metaphorical respect there is an underlying pain in their fight against ableism and exclusion at large. Leder (1990, p. 75) argues that pleasure tends to maintain our intentional links to the world (for instance making a bond out of shared enjoyment), whereas pain tends to cut them off, inducing self-reflection and isolation. Pain makes time and space more constricted: 'We are no longer dispersed out *there* in the world, but suddenly congeal right *here*' (Leder 1990, p. 75). Our attention is drawn to our own bodies and a particularly painful body part, and the world of potential actions and movements becomes smaller.

Remedying or eliminating this smaller and more constricted world is what accessibility is about. The detectives' mission is to make the world larger and less constricted, for all.

This means that the emotional landscape of monitoring accessibility is patterned but varied (cf. Cahill & Eggleston, 1994). Next to frustration we find not only lighter forms of discomfort and irritation but also the subtle, sarcastic joy of disclosing society's hypocrisy: things are not as promised.

With some of our informants, there seems to be a distinct contrast between, on the one hand, talking of and observing society's shortcomings – with pleasure, putting the world on stage and your body in the background – and, on the other, relapsing into more private talk of impairments, diagnoses, rehabilitation or habilitation, or just of everyday life, which implies other things than the pleasure of political engagement (cf. Apelmo & Nordgren's reflections on Sara Ahmed's sociology, in their chapter).

The critique of society that we find in the detective business is, in other words, emotionally expansive (Leder 1990, p. 75): filled with new possibilities and pleasures. This is clearly noted during the go-alongs. We point, we sigh and we laugh – all these faults are enjoyable to contemplate. And, on social media, activists create smart entertainment out of this logic of social critique, see for instance #RampFail, #Accessibilityfail, #WheelJoy and *Wheelchair Mafia*.

Detecting in person

> '*Then* I can read!' [if the sign is put at the instructed height]
> 'I can't get in *there*.'
> 'The last time I had to *wind* my way through.'
> 'I need *65* [centimetres]!'
> 'It was hell to find my way there [at that workplace].'
> 'I cannot read what the time is [on a new public clock].'
> 'What gets better for us, gets better for you.'
> 'Nothing of what we talk about … makes it worse for others.'

There are many notes and phrases in our data indicating the individual self as a resource. To get close to accessibility *in situ* and experience how it fails can be greatly facilitated by being there in person, especially if you are informed about laws and policies, and live with a disability or are in close contact with those who do. The lines quoted above can be juxtaposed with the general declarations of the United Nations, such as the right to 'take part on an equal basis with others in cultural life', and that all nations 'shall take all appropriate measures to ensure … access to cultural materials in accessible formats' (Article 30, CRPD). The UN principles should, in substance, be 'enough'. Everything seems to be there in the convention; a barrier-free society is articulated. But, in practice, the declarations are like a weak magic spell, trying to conjure up an ideal society but only doing so under perfect (unreal) conditions. Richard and Alfred's formulations in interviews and fieldnotes are personal and close to lived experience, whereas the UN declarations are uniform and normative.

The words quoted above, which were spoken by Richard and Alfred at various points during our go-alongs, can also be juxtaposed with official evaluations and reports. Richard and Alfred translate their observations and dress them in uniform terms whenever they report faults, and they have also contributed to official documents. 'I can't get in there' turns into 'impossible to reach the entrance', 'no referrals to alternative entrances' and 'inaccessible door phone' – making for a drier discourse. The personal foundation – the 'I' of the observations – is removed, and both indignation and enjoyment are replaced by factual statements, but still the very detection is personally based. I would not say that accessibility faults always need a person to be detected and highlighted, but personal experience may nurture a dynamic and clever critique. To carefully observe accessibility in practice is helped by dwelling on situations and settings (Polanyi, 1967, p. 18, 21), not just quickly inspecting them at a distance and with a form in your hand.

Many of our informants practice a test-it-yourself attitude, and Richard and Alfred epitomise it: acting like a mannequin, measuring arrangements with your own person as – for the time being – the size and standard. To be personal in this work is a way to shift the balance: this is *me*, and *I* cannot enter, so it is *not* accessible enough – rights are not realised, no matter what others say. The 'I' is, in this respect, far from pointless. Sometimes, informants are met with the argument that there are other and equivalent settings accessible, if not this precise one: again, personal involvement can fruitfully be used here. As Alfred puts it: 'I don't want to go to *any* pub to drink a beer, I want to enter *this* pub.' If dressed in subjective terms, even opponents will understand that any pub will not do. My friends are here now, my life is situated, material conditions matter.

A personal foundation for detecting faults can also be a source of disagreement and rhetorical variation. On one occasion, for instance, Richard and Alfred discuss whether they should tell the cashier at a cinema about accessibility concerns in the building. The argument against is 'she cannot do anything anyway', and the argument for is that by informing her she 'gets it into her head' and general awareness increases at the cinema. If you leave behind the protocol, so to speak, and go around yourself to detect faults, it turns into a more personal question how exactly to deal with your findings.

Listening carefully to detectives like Richard and Alfred, though, shows that a personal foundation does not exclude universal ambitions. It is not a matter of putting yourself above others, but of assisting others through your personal example.

That is what is meant by the two last quotes in the list that opened this section: 'what gets better for us, gets better for you', and 'nothing of what we talk about … makes it worse for others'. Alfred and Richard frequently refer to parents with baby strollers or travellers with heavy luggage who have similar needs to wheelchair users. Most accessibility adaptations are beneficial for all, or at least they do not hinder anybody (cf. Shakespeare, 2014, p. 34, on the academic discussion of universal design). The detective's person is, in a sense, anyone, and his or her client is the citizenry in general.

Conclusion: watching things to make the world less constricted

In this chapter I have discussed a case of volunteer work to identify and report accessibility faults in urban settings, and conceptualised its practical, emotional and personal aspects. If we look closely at the folk methodology used for this volunteer detection, we find that it is a situated exploration of real-world troubles, embodied and performative, and is continually integrated with painful as well as joyful emotions. It is fun to disclose a hypocritical society – there is a clear ‘a ha!’ quality – but it is also frustrating to, again and again, find new evidence of ignorance and exclusion. It is exciting to try out accessibility yourself, in person, but it can be disheartening that society ‘never learns’ or only half-heartedly tries to realise its proud declarations and policies issued by a range of standard-setting institutions, from the UN to the municipality building committees. To capture such detective activities, researchers benefit from ethnomethodological, interactionist and phenomenological ways of looking at them, revealing them as broader than merely illustrative examples of citizen engagement.

This is because, on close inspection, it becomes clear that an accessible society is a moving target. It cannot be settled and pinned down due to its own intrinsic conflicts, imperfections and developments, even though accessibility is sketched out in national laws and UN declarations. And, no matter how radical, accessibility will never eliminate all problems associated with various impairments, as Shakespeare (2014, p. 42) points out: ‘there will always be residual disadvantage attached to many impairments’. Consequently, accessibility work also needs to be constantly adaptable, strategic and moving. From the point of view of people living with disabilities and personally engaged with the issue, accessibility is not something one can get over and be done with. To commit to watching and improving things in this area is to start using a processual and constantly emerging set of practiced discrimination-sensitivities, a set of elastic and bendable ways of monitoring society.

If society is dynamic, the observation of disability rights must also be dynamic. This is the logic that motivates the detective work and drives it towards multiple and adaptable practices. The detectives are doing a lot: they are watching the setting, measuring it, comparing it with other settings, performing their attentiveness and networks, feeling things and engaging their own bodies for this purpose, drawing on various impairments and relations in their biographies, as well as the law and human rights work, as energising and legitimising yardsticks. They are observing, scrutinising, complaining, reporting, explaining and rejecting others’ excuses; they are criticising and controlling, following up on cases and analysing patterns. Detecting these faults is a multi-layered and serious activity.

This seriousness is worthy of note. An accessible everyday life is far from a trivial thing, even though the context of this chapter and my investigation is Sweden’s prosperous welfare state with problems that, perhaps, seem rather luxurious. First, what is defined as ‘trivial’ is a matter of power, where a collective or ideology may kidnap an issue and reduce it to unimportance, for instance by arguing ‘well, this library is *a bit* inaccessible, but you *do* have access to all books digitally,’ or ‘well, an inaccessible toilet here or there … we have so many more important things to take care of in our shopping mall’.[8] In people’s everyday lives, neither public toilets nor libraries need to be seen as trivial, and as social scientists it is our job to study the processes by which such definitions emerge rather than to uncritically accept them. Trivial for whom, and said to be so in which context?

Second, what is defined as trivial at a certain point might be deadly serious at another or from a general point of view. In October 2016, a disabled woman was found dead in a toilet inside a shopping mall in Malmö, Sweden.[9] She had attended a conference nearby and got stuck in the toilet, which was most likely equipped with an outdated alarm which was not directly linked to the security guards. The woman's right to personal assistance had also been reduced recently, so she was on her own. She was not found until the following morning. If this had occurred a year ago, a personal assistant said to the Swedish media, 'me or somebody else could have stood behind the door' [since at that time, the woman's rights to assistance were wider]. 'It has happened many times that things have not worked out in the [so-called] accessible toilets.'

Accessible toilets and personal assistance are hallmarks of the endeavour to ensure and expand everyday citizenship (Wiseman, 2014, pp. 184–209). As society generates volunteer detectives to monitor how these and other declared rights are treated in practice, social scientists need to conduct studies detecting the character, significance and value of mundane detecting. Even though citizens may rightfully request more efficient inspections from the authorities (cf. Zotééva, 2018), we also need to recognise and understand how laypeople outside offices relentlessly keep an eye on things to make the social world less constricted and less unjust – here, now and in person.

Notes

1 It has been shown that the municipalities in Sweden do not fulfil their duties when it comes to inspection of accessibility; see Zotééva, 2018.

2 This is true also regarding disability in general, as Shakespeare (2014, p. 33) points out: 'Disabling barriers make impairments more difficult, but even in the absence of barriers, impairment can be problematic.'

3 Kastenholz et al. (2015, p. 1278) call for such studies in their article on tourism and accessibility: 'Also an in-depth qualitative approach would be relevant to better understand how these persons [with disabilities] actually manage to overcome some of the identified constraints, which negotiation strategies they use to continue to pursue their desire to travel and why they are mostly not able to overcome other constraints…'.

4 Data were collected together with Hanna Egard and Kristofer Hansson, the other editors of this volume.

5 See, for instance, Mesquita and Carneiro's (2016) assessment of the adaptations of European museums to visitors with visual impairments.

6 See Patrick Kermit's chapter in this volume for a critique of this perspective as an academic statement, and the problems of taking on the role of others in order to understand disability.

7 See also Boverket's website: https://www.boverket.se/sv/PBL-kunskapsbanken/regler-om-byggande/boverkets-byggregler/tillganglighet/ (accessed 20 January 2021).

8 These are lines informants sometimes say they have heard when complaining about or discussing accessibility in everyday life.

9 See, for instance, *SVT Nyheter*, the news bulletin on Swedish public service television, https://www.svt.se/nyheter/lokalt/skane/handikappad-hittades-dod-inlast-pa-varhushustoalett (accessed 20 January 2021), and https://www.svt.se/nyheter/lokalt/skane/neuroforbundet-larmet-pa-toaletten-hade-brister (accessed 20 January 2021).

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4 Traveling insecurely

The association of security and accessibility in public transport

Kristofer Hansson

> The drivers can be unpleasant, especially bus drivers. I avoid taking city buses because there they are so stressed that they automatically become very, very unpleasant to me. It can be pure personal attacks.

These are the words of a young and active woman who likes to have the freedom to use public transport to go to the city centre or various shopping centres. Like other young people her age, she likes to hang out with friends, buy clothes and visit coffee shops. One can say that public transport is the infrastructure of her freedom to explore and develop a different lifestyle. But it is not friction-free for her to use this societal infrastructure. Here she is telling me her experiences of using different forms of public transport and how she relates, especially, to the bus drivers operating city buses. The woman, whom I will call Anna, uses an electric wheelchair which she manoeuvres on her own. As the quote attests, Anna doesn't feel secure when using city buses. Her personal experience is that bus drivers are under stress and therefore, she emphasises, unpleasant to the extent that it could be perceived as violence. This, as we will see in this chapter, is not her only negative experience of public transport.

As Vanessa Stjernborg describes in her chapter in this book, such feelings of insecurity often exist among people living with disabilities (cf. Stjernborg, 2019; Trafikanalys 2019; Egard & Hansson, 2020), although, of course, not everyone has these experiences. Using public transport is not uncomplicated; it is related to different prior experiences of what we could call a failure in using buses or trains. These experiences can be, as Anna describes, of a bus driver who is unpleasant or directly violent, but it can also be direct failures with using the bus or train. What these experiences seem to articulate are *feelings* that public transport is not really for people with disabilities. Sometimes these feelings become so strong that the person chooses not to use public transport at all (cf. Egard & Hansson, 2020). *Being secure* – which can be seen as the opposite of insecurity – when using public transport can therefore be seen as a central feeling in creating accessible public transport for all (Lucas, 2012).

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Being secure is firmly on the agenda when public transport is discussed in Sweden today (Berg, 2020). It can be seen as a buzzword for the organisations working with public transport and especially in relation to questions concerning gender equality, mobility of the elderly and disability rights (Henriksson & Lindkvist, 2020). Security covers most parts of the journey: how to get on the bus, if the train is on time, whether the surroundings are threatening and so on. In this chapter I will look more closely at how security within these organisations is framed by analysing the reports and websites describing their activities. Above all, I want to analyse how the organisations working with public transport link security to accessibility. This analysis can then be used to better understand the insecurity travellers may feel when using buses and trains. So, at the end of the chapter, I will return to Anna and a few others I have interviewed to describe why they do not feel secure when traveling by bus or train. My aim is therefore to analyse how security has become a central matter for organisations in public transport, how it is linked to accessibility and to illustrate why this link needs to be problematised.[1]

Method: studying public transport

This chapter examines how everyday processes in public transport can be viewed in relation to formal promises of accessibility, and what this says about the underlying social and cultural inertia in the societal work to fulfil those promises. Governments, the European Union and the United Nations strongly defend progressive disability politics as is highlighted in the introduction to this book and in various of its chapters. Yet, when I as a researcher turn to citizens using, for example, wheelchairs, I instead find experiences of negligence and resistance to their use of public transport. How, then, can the everyday experiences of Anna and others like her be understood in relation to societal discourses about accessibility?

My ethnographic work aims to answer this question by improving understanding of the hindrances and resistance that people like Anna encounter in everyday life. In interviews with 15 persons with various disabilities, I used open-ended questions to create good conversations. Some of the individuals also participated in a go-along, where we used public transport, such as buses and trains, together (cf. Kusenbach, 2003). For an hour or two we travelled around using various forms of public transport, and continually talked about the journey. This was a way for participants to point out hindrances and obstacles, but there were also situations where I observed frictions in public transport that my interviewees did not always reflect on during the observation or interview. My observations were initially documented in notebooks and later transcribed on the computer as a coherent ethnographic fieldnote. I also used my phone camera to document the hindrances that arose. These photographs are part of the ethnographic observations that make up the empirical basis for the analysis in this chapter.

This ethnographic material is supplemented by three interviews with officials who work on accessibility in public transport authorities. These interviews provide a background to how different organisations work with accessibility in relation to public transport. Based on the topics that came up in the interviews, I conducted specific searches on Google to look for documents and webpages related to 'disability', 'accessibility' and 'security' in the context of public transport. I selected 17 documents and webpages for close analysis, and use quotes from four in this chapter. Only documents that are accessible on the internet were selected. These documents and webpages were categorised by theme and analysed with a focus on how security is described. These include statements and political programmes for how public transport should work with accessibility, and internal (but available online) organisation reports and investigations. Before I present the themes uncovered by the research, however, I will discuss the Foucauldian concept of *dispositif de sécurité*, which can help us understand how security has become a central topic in many societies today and why it is related to accessibility.

Security and the modern city

> The city wants a uniformity so that the traveller recognises himself and thus can feel safe.
>
> (*my translation*)[2]

Security is a key issue for the modern city and a recurring concern in public debate. There is an expectation that the city can mobilise safe places for its inhabitants, but also that one lives in the city for a sense of security it gives (cf. Cowan, 2005). In other words, as the quote above, from a consultant, suggests, the city has a uniformity that can give the individual traveling on public transport a feeling of security. The city can, from this perspective, be seen as a community where public interest and concerns are valued and taken into account. To use a philosophical metaphor, it is a space that protects its inhabitants from the wilderness outside the city walls. The philosopher and historian Michel Foucault saw this as one of the central themes in modern society and its urban planning, and it was something he presented in his lectures at the Collège de France between 1977 and 1978 (Foucault, 2007). Through knowledge – or *biopower*, to use Foucauldian terminology of the power over *bios* (life) – the city is planned with the intention to create security for its inhabitants. Through knowledge the modern city has as its assignment to control social bodies and in this way ensure a secure life for everyone (cf. Dillon & Lobo-Guerrero, 2008). This is what Foucault defines as 'power over life' (Foucault, 1978).

How does this philosophical perspective relate to public transport? In the modern city, public transport is one of the central actors in creating security for those living within it or in its environs. With the support of buses and trains, for example, the goal is to foster a space that is both environmentally friendly and socially sustainable (cf. European Commission, 2009; Berg, 2020; Henriksson & Lindkvist, 2020). In this way, public transport is one actor among many in urban planning, and can secure life and create freedom for its inhabitants to move around. How the European Commission relates to transport that is *safe and secure* is evident in its own words: 'Transport provides access to many of our freedoms – the freedom to work and live in different parts of the world, the freedom to enjoy different products and services, and the freedom to trade and to establish personal contacts' (European Commission, 2009: 16). The commission also points out that this freedom will probably increase as European cities become more multicultural and as society ages.[3]

From this perspective we can talk about public transport as a *dispositif de sécurité*, a security apparatus, in the urban setting, and how various institutions and administrative arrangements maintain and enhance this form of control over social bodies (cf. Dillon & Lobo-Guerrero, 2008; Agamben, 2009). It is therefore more than a discourse about security; rather, it is a control that is set in motion in all different parts of the urban environment. The European Commission may of course be one of these institutional and administrative arrangements. In this chapter I will look closely at how institutions in Sweden are enhancing this kind of control, and why it is hard to step outside this way of arranging the world – or, more specifically, arranging the city and its public transport. First, however, I will highlight one more theoretical aspect. This is a change from the older perspective on biopower that focuses on the population, to a more modern understanding which can be seen as much more heterogeneous (cf. Dillon & Lobo-Guerrero, 2008). This *heterogenesis* helps us see that power relations between institutions and administrative arrangements are constantly being re-established (cf. Larroche, 2019).

The form of biopower analysed in this chapter is not fixed and immutable; it is instead a form of continuously changing governance in relation to the security of the population, where the population's welfare should be seen as its objectives and means (Foucault et al., 1991). In today's city, security not only aims to 'protect its inhabitants from the wilderness outside the city walls'; also, it is constantly evolving, adapting to its inhabitants and changing. The inhabitants are no longer seen as an amalgamated mass inside the city walls, but as possessing everchanging diversity in terms of gender, disability, ethnicity, age, and so forth (cf. Berg, 2020; Henriksson & Lindkvist, 2020). The population's welfare encompasses everything from security from stress (Fitzgerald, Rose & Singh, 2017), to creating the inclusive city (Prince, 2008), to generating more wealth (Hansson, 2019), to mention some examples. These fluctuating processes are central to understanding how the public transport is part of this new way of working with security in an urban setting.

The researchers on public transport Malin Henriksson and Christina Lindkist reason that we can see such a change in society, and in a volume about social sustainability and public transport they argue that questions about gender equality, mobility of the elderly and in relation to disability rights are today more on the agenda (Henriksson & Lindkvist, 2020). At the same time, they argue, there is an unclear understanding of security for groups who are often categorised as 'vulnerable', and institutions and administrative arrangements have problems identifying these groups 'in addition to the traditional categories' (Henriksson & Lindkvist, 2020: 14, *my translation*). They point out that 'class' and 'ethnicity' have not been included in analyses of public transport and, as I will argue, 'disability' has also been downgraded from time to time. So, the security of populations affected by inequality focuses foremost on the majority, leaving outside groups that do not fit into constricted categorisations (cf. Hacking, 1999). Thus, it might be argued that security primarily covers certain groups in society and leaves others outside of what public transport should and could be. But today we can see a change, and organisations and companies are working hard to make trains, buses, platforms and the whole journey secure and thereby accessible. So, even as Anna meets hindrances and limitations when she uses public transport, there is a form of *dispositif de sécurité* emerging from public transport organisations.

Security as a category

Although this says little about actual experiences of accessible public transport, Sweden is a pioneer when it comes to public transport and disability. Already in 1979, a law was put in place that stipulated disability adaptations to public transport (SFS, 1979: 558).[4] Despite the law, however, public investigations and individuals have pointed to shortcomings, as we saw in the beginning of this chapter. More recent reports in Sweden have noted, for example, that people with disabilities are more absent from public transport than other groups (Trafikanalys, 2019). At the same time, government institutions argue that more people in society should be able to use public transport (cf. Svensson, 2019). This is in line with political goals that society's public transport should not only be accessible, but also usable *for all*. This is clarified in the UN Convention on the Rights of Persons with Disabilities (CRPD) which was ratified by Sweden in 2008 and which came into force in 2009. Sweden also wishes to see itself as a leading nation in implementing the 2030 Agenda for Sustainable Development (Regeringskansliet, 2019), which has further sharpened discussions about public transport for all in recent years.

I focus here on how this idea of public transport *for all* has, in recent years, become intimately intertwined with a discussion about security. Thus, when societal institutions present arguments about shared and accessible public transport, they also argue that this is a matter of security. In this way security becomes a sort of recurring concept for companies that work with public transport, and is used in many different contexts. The traveller should feel secure, not only when using buses and trains, but also while waiting for the bus and train to come, or for that matter, while traveling to the station. When public transport is presented as a mode of transport that everyone should be able to use, security is also related to this discussion, in at least two ways: first, as a way of measuring people's experiences of public transport, and second, as text in different documents and webpages.

Security as number

To measure through surveys is in many ways central in traffic analysis in order to make visible how travellers relate to public transport: there appears to be a need to count (cf. Larsen & Røyrvik, 2017). I will illustrate this through an example of how this measurement can look, and how numbers are presented. In one report from Region Gothenburg, quantification is central.[5] Under the title 'Obstacles to the Journey' we read that 54 per cent that have a disability and are passengers are 'unable to maintain their balance' in the bus or train, 47 per cent think it is 'stressful when getting on and off' buses and trains, 7 per cent think that it is 'difficult to get out of the home' and 18 per cent 'feel unsafe to ride' (Lindahl, 2008, *my translations*). What is of interest here is not the different percentages, but what they represent; how security is translated from individuals' feelings (like Anna's, in the introduction), to numbers and percentages. Through this quantification a naming practice takes place, one which make public transport – and security – intelligible for those who are in charge (cf. Eliassen, 2008; Hansson, 2020). This naming process is important, not at least for politicians who distribute tax money to public transport. But these numbers also call for a specific *dispositif de sécurité*, namely that security is transformed from individuals' experiences and feelings, into numbers, percentages and charts. These figures thus become a form of social categorisation for how to relate to security (cf. Hacking 1999; Hansson, 2020), but they say very little about the subjective experiences of insecurity.

It is not easy to transform data from the 'real' world and then present them in figures, and it is of course not easy when these data consist of answers based on people's experiences of different emotions. What, for example, is the experience with respect to emotions when it comes to stress 'getting on and off' the bus? Or, what emotions can an imbalance create for the traveller who has come close to falling, or has even fallen, when a bus started to move? Using sociological terminology we might say that human lifeworlds are colonised by the system world, that the phenomena of security are rationalised and made predictable and transparent (Habermas, 1989). The numbers can, in this way, be seen as a process of transformation, where the experiences of the travellers are framed in what I would call a *dispositif de sécurité*, namely the power relations that structure how we talk about public transport. But this is not the only way that this *dispositif* comes alive. In the next part of the chapter I will analyse how the organisations use words instead of figures to enhance and maintain the power relations that structure how we are supposed to talk about security.

Security as text

In the documents from the public transport organisations, the word 'security' often appears in short, concise sentences. The public transport operator for Region Skåne, for example, writes: 'Work actively to ensure that all our traffic is perceived as safe, secure and accessible to travel with' (Skånetrafiken, 2016: 9, *my translation*). A similar formulation from Region Stockholm is: 'The traffic administration must design attractive customer environments so that passengers perceive them as clear, accessible and safe' (Region Stockholm, 2020: 11, *my translation*). On a webpage about Region Halland's public transport we read under the heading 'All about accessibility':

> The goal for Region Halland's public transport is for everyone to feel that it is easy, safe and comfortable to travel with us. We therefore work continuously to develop and improve our traffic and our vehicles. This is so that public transport will be accessible to everyone, even for you who have some form of disability.
>
> (2021, *my translation*)[6]

We can understand from this text on the homepage that we all – but especially people who 'have some form of disability' – should feel secure when traveling by bus or train in Region Halland. In this way security – in relation to accessibility – is framed as something that people with disabilities can expect when they use public transport. It is also a security that is linked to improved traffic and vehicles. Security is linked to accessibility since it is through so-called safe travel that people with disabilities should feel that they can use public transport just like everyone else. In this way, security seems to be enacted in many parts of the organisation. This enactment is also central when, for example, Skånetrafiken, above, points out that traffic should be 'perceived as safe, secure and accessible', or when Region Stockholm emphasises that passengers should perceive the environments 'as clear, accessible and safe'. I would argue that these texts become a part of how the organisations frame public transport and how they see accessibility as a question of security.

In 2012, Region Västra Götaland implemented a strategy for disability adaptation of public transport. In its report, security is again a central feature of public transport for all:

> A better quality and greater security in public transport is requested by most travellers but is critical for a person with a disability to be able to take a trip. What is necessary for some is good for everyone. Despite all the measures that have been taken to complete all the steps in the whole journey, there are several shortcomings that make it difficult, and in some cases impossible, to travel by public transport if one has a disability.
>
> (Västra Götalandsregionen, 2012: 14, *my translation*)

So, already in 2012, security was central. A recurring moral about designing environments and products that suit everyone is here paraphrased as ‘what is necessary for some is good for everyone’. Security becomes in this text a question that concerns ‘everyone’. It is not only for persons with disability, it is good for all users of public transport. To focus on security in the organisation is therefore something that can benefit all users. At the same time, the report highlights that there are shortcomings that create hindrances to accessibility, hindrances which the public transport needed to work on.

This perspective on security is developed further in the same report under the heading ‘Increasing security in travel’:

> For a person with a disability, security can be crucial for their journey. The whole journey consists of many different parts and it is important that every part works, for example when boarding and changing. The traveller needs to feel confident that what has been promised actually works. Equally important is the human response, where drivers have a key role. It should be clear to the traveller which help they can get in connection with the trip. Special consideration must be given to the security aspects of traveling, both inside and outside the vehicle.
>
> (Västra Götalandsregionen, 2012: 18, *my translation*)

Security is here defined not only as physical or environmental, but also as a matter of social relations. This is a division where security is seen as something that can be developed both through better technology and through better relations between humans. Security is also something that is both inside the bus or train, and outside on the platform, in the station or elsewhere. But what is central is that the person with a disability should feel secure when traveling on public transport: ‘security can be crucial for their journey’, as Region Västra Götaland puts it.

Thus, security becomes more than a number: it becomes a text which emphasises that security can be found almost everywhere, and is something that the organisations must work on continuously through ‘design’, ‘development’, ‘improvement’ and so on. It also becomes a term which is closely linked to accessible public transport: all organisations appear to suggest that a secure public transport system is also an accessible one. The links between these two words can be found in various areas: ‘on and off the vehicle’, ‘in all the steps of the journey’, ‘in the human response’ and so on. Security becomes a *heterogenesis* which is re-established constantly in relation to the different contexts in which it is enacted (cf. Larroche, 2019). It becomes difficult to talk about accessibility without also mentioning security; it is as if accessible public transport is manifested through, and framed through, a discussion about security: a *dispositif de sécurité*.

'What if something goes wrong?'

I will now return to Anna, and other persons I interviewed, to share their experiences of using buses and trains. My main focus here is not on those who feel it works for them to travel by bus or train (though I have also interviewed such individuals), but on those who can give us an understanding of what it means to travel insecurely. I will do this by looking closely at the feelings people express when they meet limitations, resistance, hindrances, or even violence in public transport (cf. Reddy, 2001; Egard & Hansson, 2020). The focus of this analysis is to understand how people's naming of emotions also affects how they feel in these situations – in their lifeworld (cf. Stearns & Stearns, 1985). This is a critical perspective for studying what the naming process can tell us (cf. Hacking, 1999), but also to see it in relation to how public transport organisations see security.

In the quote that opened this chapter, Anna can be said to be naming an emotion and at the same time also naming specific bus drivers as 'stressed' and therefore unpleasant. In this she is like a detective, helping me to see which parts of the city are accessible and which are not (see also David Wästerfors' chapter in this book). In my interview with Anna I asked her to tell me more about her problems with unfriendly bus drivers.

> They shout at you. They call me ugly things. They claim that it is not their job [to help Anna on the bus]. I have come across those who have said that they are not allowed to leave the cab. Then my friend countered with: 'Are you glued to the chair? Then it will be hard to go home from work later.' He muttered something. And someone even yelled at me: 'you are not allowed to ride the bus without a personal assistant'.

This unpleasant treatment and negligence is problematic to say the least, and for most people it would probably create a reluctance to return to this means of public transport. But with Anna, this behaviour also risks hindering her use of public transport and creates unpredictability and feelings of insecurity since she doesn't know if she will get the help she needs to access the bus and to get on and off safely. Once, she says, a bus driver started to drive before she was in her place, which is very risky since the wheelchair might start rolling away, uncontrolled.

In this way it is 'not only' an emotion, but also a naming process of how Anna relates to public transport. Together this risk creates major obstacles to using certain types of public transport – sometimes such big obstacles that she is left behind – and sometimes actual danger (cf. Stearns & Stearns, 1985). We can talk about hindrances to accessibility that are not physical but that have emerged in a social situation and later transform into an emotion (cf. Lid & Solvang, 2016; see also Hanna Egards' chapter in this book). This comes up repeatedly in the interviews. An older woman – here called Josefin – who uses a mobility scooter, describes this feeling in an upset tone:

> What if something goes wrong? Who do I call? How do I get help? All ticket offices and stations are closed. If I'm out in the dark one winter, how do I rebook a trip? How do I? [Imitating a conductor] 'But that wheelchair space is occupied.' 'That train does not run, and neither does this.' 'We have no seats.' How do I get home? Am I calling the police? What do you do? I do not know, no one can answer me on this.[7]

There are many ways to read Josefin's words. What I find central to them is the unpredictability and feeling of insecurity when public transport, and society as a whole, is not available to give her the security and confidence that she feels she needs, in this example, to use the train. This quote also highlights many different situations that can create hindrances to accessibility: the need for help like Anna requires, non-existent stations, insufficient accessible seats and so on. But it can also be seen as an unravelling of what accessibility should be when it comes to public transport in Sweden. Josefin's questions hang in the air, so to speak, and are a direct critique of insecurity in public transport.

The persons I meet do not always explain these emotions to me, but I can understand in the moment of the observation that the situation is developing to become something that will hinder or limit them. One such situation occurs on a warm summer day during a go-along with Lars, an older man who uses a wheelchair. Lars has the right to a personal assistant, who is with us on the journey. We start the day traveling by bus to a larger city and then change to a city bus. Everything goes smoothly for most of the day, but as we wait for the bus home, things change. We are standing five metres from where the bus should stop. All of a sudden, the bus arrives at the platform. All three of us move towards the entrance, but so do all the other passengers. These are mostly young people who are on their way home from school. In just a few minutes, the bus becomes crowded and the last one to get on is a father with a child in a pram. There is no place for Lars and his wheelchair. What happens next can be seen as a transformation, as this specific place turns from an opportunity to move freely using public transport between different cities into a *critical place* where the man is hindered from being part of this specific journey (cf. Hansson, 2019). This critical place is reinforced by the fact that the bus driver makes no effort to communicate with Lars, but chooses to simply close the bus doors and drive away.

Lars gets angry and irritated, and we talk about it. A couple of minutes later a new bus arrives and this time there are fewer people on the platform, so we get places on the bus and go back together to the smaller city where he lives. Of course, I cannot say anything about how this experience affected Lars at that specific moment, or on future trips using public transport. But it is these kinds of experiences that many of the interviewees in this project reflect upon as bad experiences, which later generate feelings of insecurity and a sense of unpredictability – in Josefin's words: 'what do you do' if something goes wrong? This is a question that not only makes 'traveling insecurely' visible, but also calls into question the political goal that society's public transport should be usable *for all*.

Conclusion: security as a moral and legal issue

In this chapter, I have tried to understand how (1) accessibility and security are linked in various ways, and (2) how security at the same time is a problematic word which gives different perspectives on what accessibility can be. Through interviews with people who use a wheelchair or mobility scooter, I have been presented with the realities of experiencing difficulty in using public transport more or less regularly. My interviewees expressed feelings of insecurity when using buses and trains, which, in their own words, creates inaccessibility in the moment, but also in the long term. The question lying at the heart of their feelings seems to be: Do I dare to travel and use public transport? When I then turned to public transport organisations in Sweden, I encountered guidelines that public transport should be accessible so that the individual can feel secure traveling on their buses and trains. These guidelines are also familiar to the persons I interviewed, and seemed to increase their frustration: how can it be that public transport, which should be useful for all, is not useful to them? It is as though the issue of public transport *for all* is not a political but a moral and legal issue (cf. Brown, 2001; Brännström, 2005).

Through the Foucauldian concept of *dispositif de sécurité* – seen as a security feature in the urban setting, and one which enhances a form of control over all social bodies (cf. Dillon & Lobo-Guerrero, 2008; Agamben, 2009) – we can argue that public transport has become increasingly permeated by a discussion about security as a moral and legal issue. It can be found almost everywhere, but in relation to accessibility it is seen as central to developing buses and trains and designing platforms in relation to legal issues. Likewise the question about the human response to the traveller has become more of a moral issue: What is good customer service that creates a secure environment for the traveller? When the traveller feels secure, proclaim the organisation texts, the traveller also has an accessible journey. The individual should simply dare to travel by bus or train, and not be afraid that something might go wrong. And if something does go wrong, the texts suggest, there will be help. In this way, *dispositif de sécurité* takes the form of language – and sometimes of figures – within organisations that frame certain social bodies, but not others, in public transport, and define how the problems that arise should be handled in relation to these social bodies.

But the social bodies that are engendered – enacted – in texts and in figures are not the same as the actual bodies that travel by bus or train and experience insecurity. Rather, there is a risk of discrepancy between the organisations' way of control over public transport on one hand, and the individual experiences that people have on the other. The individual experiences often only fit into the rhetoric if they are transformed into the organisations' way of looking at security. This risk creates frustration as experiences are transformed into moral and legal questions about how security should generate accessibility, not what is actually done to make travel secure. Meanwhile, certain bodies risk falling outside the *dispositif de sécurité* and continue to travel insecurely.

Notes

1 The chapter is based on a three-year research project entitled 'Accessibility and its Resistance: Everyday Deviations from Spatial and Social Practicability for Persons with Disabilities' carried out in collaboration between Lund University and Malmö University, and funded by FORTE: *Swedish Research Council for Health, Working Life and Welfare*. The project has received ethical approval (dnr 2018/145).

2 This quote is from a report from the company Trivector (2019: 17), which was assigned to provide a picture of how municipalities in Sweden work with public transport and accessibility.

3 What is not discussed in this chapter, but is closely related to questions concerning security, is the growing threat of attacks after 11 September 2001. In the document cited in this chapter the European Commission reflects upon how the attack changed the relation to public transport and security: 'The 2001 White Paper did not refer to security. After the attacks of 11 September 2001, however, a security policy was developed. Nowadays there are EU legislative measures on transport security for most transport modes and for critical infrastructures' (European Commission, 2009: 10). I argue that this was a central change also for people living with disability, but a more genealogical analysis is not possible in this chapter.

4 There has been some early research in the field which has tried to problematise and highlight the obstacles that people with disabilities face in Sweden. See for example: Carlsson, 2002; Iwarsson & Ståhl, 2003; Wretstrand, 2003.

5 Sweden has 21 regions – or regional councils – and two of their most important responsibilities are public transportation and public health care.

6 https://www.hallandstrafiken.se/tillganglighet (accessed 14 April 2021).

7 This quote previously appeared in a Swedish-language publication (Egard & Hansson, 2020).

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Part 2

Knowledge and education

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5 Struggles for inclusion

The unrecognised toil of hearing-impaired students

Patrick Stefan Kermit

Between 2006 and 2009 I participated in a series of video-recorded observations of Norwegian hearing-impaired children in mainstream classrooms and kindergartens.[1] The children – aged between five and nine years – had all received state-of-the-art hearing technology in the form of cochlear implants, and we had been pointed in their direction because we had advertised our research interest in observing hearing-impaired children who 'did really well' in mainstream schools or kindergartens.

Indeed, the children were apparently doing well. To my naked eye, it seemed that they went along with other children as easily and naturally as those with typical[2] hearing would have done. When we started analysing our video recordings, however, another picture emerged. Going through the cumbersome procedures of transcribing the tapes, it became clear that the children applied a wide range of techniques designed specifically to create the general impression that they were managing as if they had typical hearing. For example, a five-year-old boy would often reply 'yes' when someone addressed him, be it with a question or a simple assertion. He pronounced his 'yes' with such a noncommittal intonation that the word could pass both as a question – 'yes?' – and as a confirmation – 'yes'. His conversation partners were often satisfied with the reply, but we were left wondering: did the boy understand what the others were saying to him, or had he learned that, by giving this reply, he could save himself the embarrassment of admitting that he did not follow fully? It soon became apparent that the complexity involved exceeded this simple either/or question.

All the observed children struggled daily to manage, on a number of levels. They struggled to hear and manage the limitations of their hearing technology, especially noise. They struggled to manage in the absence of inclusive practices that accommodated children with hearing impairments. They struggled to manage the numerous situations in which they risked standing out as different, and they struggled to avoid being seen as different in a negative or shameful manner by their peers and by the responsible adults. Avoiding being seen as different was something the children mainly sought to accomplish by pretending to be like their peers: in this case, by pretending to have typical hearing. In the following sections I will analyse this behaviour,

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mobilising the sociologist Erving Gofmann's concepts of *stigma* and *passing* (Goffman, 1968/2005; see also David Wästerfors' chapter in this book). At this point, however, it suffices to point out that pretending to hear, and avoiding being seen as different, seemed of great importance to the children. Pretending to hear, as the five-year-old boy managed with his perfected 'yes' intonation, is an exceptionally demanding activity. Hearing-impaired people attempting to appear as typical-hearing persons must work very hard, because once they start to pretend, they must continue to do so and avoid making errors that could reveal what they are doing. They must always be on their guard, ready to repair or amend any slip-ups that might occur in what is, in essence, a constant performance, where the hearing-impaired person acts as if they were another person. This acting demands constant vigilance and a self-imposed constraint to always strive to understand, to mobilise what hearing capacity one might have, to stretch cognitive abilities to interpret and reason in order to fill the gaps of meaning when hearing becomes difficult. It is difficult to keep up such a constant pretence. None of the children we observed were completely successful in pretending to hear, so they struggled also with bottled-up frustrations and disappointments they alone knew about and which they alone cared about.[3] They struggled to manage the physical and mental exhaustion caused by this daily struggle. Finally, they experienced an utter lack of recognition for their struggle.

Understanding the complex nature of hearing-impaired students' struggles is important when assessing the meaning of the concept of inclusion. The literature suggests that little has changed since our 2006 observation, and radical efforts are needed to develop and design inclusive practices that recognise student diversity and promote mutual recognition, both amongst peers, and between students and responsible adult professionals. In the Nordic countries, the majority of hearing-impaired children and adolescents attend their local mainstream schools as students in what is expected to be an inclusive setting. Little is known about the practices these students are subjected to, but there is ample general evidence that it is more difficult to be a hearing-impaired student than a typical-hearing student.[4]

Inclusion and hearing impairment

Focusing on hearing-impaired children and adolescents in inclusive educational settings calls for a brief overview of the concept of inclusion itself. The principles of inclusion and inclusive education were laid down in the 1994 Salamanca Declaration of the United Nations (UNESCO, 1994), which the Nordic countries signed along with 91 other countries. A quarter of a century later, the intention that, for example, Norwegian and Swedish public schools should be inclusive is expressed in the education acts of both countries (Opplæringslova, 1998; Skollag, 2010).

The research literature on education and inclusion is comprehensive, and inclusion is a term that can be understood and explained in different ways, depending on the context in which it is used (Haug, 2004, 2016; Olsen, 2010). In some contexts, inclusion is used simply to describe the 'placement' (Haug, 2016) of disabled students in ordinary schools and classrooms, but the theoretical ambitions attached to the concept are normally more advanced. Influenced by the traditions of *disability research* and *disability studies*, the UN Convention on the Rights of Persons with Disabilities (UNCRPD, 2006) states that everyone should be able to attend the same schools and, at these schools, everyone should have the same academic and psychosocial opportunities for development and growth.

In light of these traditions, inclusion may be seen as suggesting a move away from an individual focus on the student regarded as having special needs – the traditional approach taken in special education – and instead to focus on collective educational practices. In this respect, inclusion is to education what the concept of universal design is to the principle of accessibility. Both inclusion and universal design promote the idea that human practices and attitudes have to change in order to create a society for all, and both refute the notion that individual people with impairments should be adapted or modified so that they can fit better into the community of non-impaired people. Instead, educational practices and the physical environments we design and build should be shaped in ways that enable everybody to take part and have equal access. This implies a sharp critique of traditional ways of designing teaching as an activity meant to suit the needs of the imagined average or typical student (Kermit, 2019b).

Giving up the idea of teaching the average or typical student suggests a deepened understanding of the relation between human equality and that which is unique in every individual. Here, inclusion can be framed as a concept with profound normative implications and ambitions. Inclusive education seeks to fulfil every student's universal and equal right to education, and at the same time takes into account that every individual student must have the opportunity to develop his or her unique potential to the fullest extent possible. We owe this understanding to, among other scholars, philosophers Charles Taylor and Axel Honneth. In his essay 'The Politics of Recognition' (Taylor, 1992b), Taylor analyses what he sees as a tension between two fundamental recognitions, both characterising modernity and the development of modern society. On one hand, modernity is characterised by a recognition of the principles of universal human equality, dignity and rights. At the same time, it is fundamental to the modern understanding of individuality that every individual brings something unique into the world. When it comes to inclusive education, this suggests that every student must be allowed to develop self-respect as an equal possessor of inalienable rights, and must, at the same time, be given the opportunity to develop the self-esteem and self-confidence associated with having realised a unique identity (this is also central to the concept of recognition suggested by Axel Honneth, 1995). Taylor points out that even though modernity presents us with historically unprecedented freedom to choose who we want to be, identity formation has also become more precarious and vulnerable. In the context of education and inclusion, this warning prompts the understanding that every student must be allowed to experience relations in which mutual recognition is expressed. This recognition must confirm the student's authenticity such that the student is both recognised as equal to others, and recognised for that which is particular to him or her.

Thus, inclusion can never be established where there is a tacit assumption that typical students are more authentic than students considered to have special needs. Unfortunately, this assumption lies at the root of many well-intentioned interventions in special education. Inclusion is not at odds with the idea that a student is entitled to be taught according to the level of his or her abilities. What it is opposed to are practices where some students – the ones considered 'special' – are denied the opportunity to experience the membership (Antia, Stinson, & Gaustad, 2002) in a group of peers that many typical students take for granted. In the instances where inclusion is used to signify only the placement of disabled students, as mentioned above, it is likely to only be a token recognition of equality which fails to develop practices suitable to support a society of members.

Inclusion which does develop these supportive practices requires a radical approach, with dramatic changes to historic educational practices that are designed only to suit the needs of an imagined typical student. This means that inclusive practices must resist the division between 'us' and 'them' in terms of typical and not. Further, this also implies a rejection of the notion of inclusion as a kindness extended by the typical who, propelled by good will, try to make good for other groups. On the contrary, the recognition both of that which makes everyone equal and of that which is special to each individual implies a sharp critique of such charitable ideas. Indeed, in the following, I will suggest that the idea of inclusion as a kindness might itself be seen as discrimination.

Inclusive practices in Scandinavia

Nordic kindergartens and schools in general appear to have failed to develop and establish inclusive practices where hearing-impaired children and adolescents are brought together with typical-hearing peers. This was the conclusion of a 2018 review of Nordic research on educational practices linked to hearing impairment and inclusion (Kermit, 2018). The result is in line with other reports on inclusion and disability in a Nordic context (Finnvold, 2013; Tøssebro & Wendelborg, 2014; Haug, 2016). The absence of inclusive practices strongly contrasts with the abundance of policy documents and legislation presenting inclusion as an important goal in these school systems (Olsen, 2010).

All the barriers to learning and development confronting hearing-impaired children and adolescents cannot be reduced to the one question about inclusion. Having said this, kindergartens and schools in countries like Norway and Sweden generally design their teaching and their practices to fit the typical pupil who constitutes the imagined student norm (Holmström, 2016).

Two broad and related aspects of this situation are apparent for hearing-impaired children and adolescents. First, on average, they achieve poorer academic results compared to their typical-hearing peers (Hendar, 2016). Second, they display more psychosocial problems (Laugen, 2017; Olsson, Dag & Kullberg, 2017) and more loneliness (Kermit et al., 2014) than their typical-hearing peers. It is likely that many hearing-impaired children and adolescents struggle to achieve a feeling of membership (Antia et al., 2002) in their peer groups that many typical-hearing peers take for granted. There is no sharp divide between these two aspects of inclusion, but in the following, I present them briefly and separately before turning to wider interpretations.

Psychologist Ola Hendar has conducted two large surveys in Sweden and Norway, both focusing on hearing-impaired students' academic outcomes (Hendar, 2008, 2012). It is because of his work we can state with a high degree of certainty that hearing-impaired students – as a group – achieve poorer academic results than their typical-hearing peers. Hendar applies his results to a model of development while analysing how the results can be interpreted in light of psycholinguistic theory. He finds access to language (whether spoken, signed or a combination of the two) to be a decisive factor in learning and academic development.

A study included in the 2018 review (Kermit, 2018) by applied linguist and Deaf Studies scholar Johan Hjulstad and his team (Hjulstad et al., 2015) reviews the international literature on how academic inclusion can be achieved in educational settings where hearing-impaired and typical-hearing children and adolescents are together. This study also confirms the importance of access to language, pointing out that hearing-impaired children and adolescents must be provided with the opportunity to develop language – again, spoken, signed or both – while interacting with peers. The study documents a general lack of research on how to promote inclusive practices. What research exists, more often than not, presents general assessments rather than specific examples or cases. In addition to language and peer communication, the researchers identify other ways to achieve academic inclusion, including organisation, attitudes, early intervention, use of technology, noise reduction and reduced group sizes.

Even children with minor hearing impairments have greater risk and prevalence of psychosocial problems compared to their typical-hearing peers (Laugen, 2017). A number of studies (Kermit et al., 2014; Rekkedal, 2015; Olsson et al., 2017) discuss the psychosocial situation for hearing-impaired children and adolescents in Norway and Sweden. Between them, these studies substantiate that hearing-impaired children and adolescents experience more loneliness and have weaker relations to their peers than typical-hearing children and adolescents. Many hearing-impaired adolescents do not have a single friend. Further, they are subjected to more exclusion and negative behaviour from their peers compared to other adolescents.

Studying inclusion closely: the use of the hearing loop system

Against the backdrop of the review presented in the previous section (Kermit, 2018), in the following, I discuss a secondary analysis (Heaton 2008) of selected qualitative data from a 2014 study of adolescents with sensory impairments (Kermit et al., 2014). 'Secondary analysis involves the utilisation of existing data, generated for the purpose of one or more prior studies', write educational researchers Andrew J. Hobson and Bronwen Maxwell (2017: 172, with reference to Janet Heaton 2008: 1). They emphasise that secondary analysis is done with the intention of pursuing research questions different from those in the original study. The secondary analysis conducted in this chapter is directed, first and foremost, at mapping the complex struggles hearing-impaired students face on a daily basis in schools that are inclusive mostly on paper. These are struggles of different, yet intertwined natures. Hearing-impaired children and adolescents struggle to hear, they struggle to bridge the gap between what is offered in terms of inclusive practices and what is needed, and they struggle to preserve their identity and sense of self in a situation where they regularly receive the tacitly conveyed message that having typical hearing is a more authentic way of being in the world than that of being hearing-impaired.[5]

The data mobilised here addresses the seemingly trivial issue of hearing loop systems. As a Nordic welfare state, Norway has a policy of fitting classrooms with hearing loop systems whenever there is a student who is entitled to have such a system due to a hearing impairment. This, however, does not mean that teachers at these schools automatically use the hearing loop systems consistently and routinely. The research of disability studies scholar Ann Mette Rekkedal (2015) suggests that neglecting to use the hearing loop systems, or using them in ways that are of little use to the hearing-impaired student, is both common and widespread.

Our informant,[6] John, who is in his mid-teens, described to us his teachers' use of the hearing loop system in his classroom:

> They [the teachers] do not always remember to use the microphone [hearing loop system] so, in almost every lesson, I have to remind them that they must put it on. That is, after three years, my class teacher has finally started to adapt.
>
> So I have to remind them about using the microphone and that they turn it on from time to time […] well, it would surely be nice if they could learn a bit more and if they knew a bit more, because what they know is what I have told them…and that's not really enough.[7]

There is reason to believe that what John describes is an everyday experience for many Norwegian hearing-impaired students (Rekkedal, 2015). John told us that he is the one who is tasked with the responsibility of reminding teachers to wear the microphone and to make sure his fellow students also use their microphones. John must attend to this 'in almost every lesson'.

It is a reasonable interpretation that John is not happy with this responsibility. For one, no other student in his class is reported to have a similar extra responsibility in the classroom. Secondly, his teacher's behaviour constantly conveys a tacit message to all students that microphone-wearing is something one must do to be nice to the hearing-impaired student who does not meet the typical standard of hearing and thus has special needs. Using the hearing loop is not a consistent routine that teachers are bound to follow, nor is it based on the understanding that, since John is equal to his peers, and shares an equal right to education, securing his access to learning is as obligatory as securing every other student's access to learning. It must be emphasised that this latter framing must be carefully phrased: since Nordic educational models are, in general, based on the belief that students' learning processes benefit from being able to discuss and learn from each other, it is a flawed view that the typical-hearing people should accommodate John's needs because these needs are 'special' and thus call for compassion. On the contrary, as suggested in the introductory section of this chapter, there is another aspect of reciprocity in play. Neglecting the use of the hearing loop system might also be seen as a discriminatory act against John, not simply an incidence of somebody forgetting to be charitable. Indeed, the principle of universal equality suggests that when John's access to participation is impeded by teachers' practices, the classroom community misses out on the unique contributions John could have made.

Bridging the gap between what is needed and what is offered

John's experience is, on one hand, an everyday example, illustrating that his school and teachers have not adjusted their practices because there is a hearing-impaired student attending. This does not reduce the importance of addressing the underlying problem. Teaching in John's class is designed to cater to the imagined average, typical-hearing, student. Moreover, since routinely and consistently using the hearing loop system is a small and relatively simple change in practice, it is implausible that John's teachers have adopted more advanced measures to promote inclusive practises as long as they have failed to adapt this simplest of routines. The result is that it is John who must bridge the gap between what he needs and what is offered, and he must do this over and over again. John did not tell us explicitly about the psychosocial costs of what it means to be in his position, but he did remark that trying to understand his teachers and fellow students using hearing technology wears him down to the extent that he has to forego informal and social interactions with his peers and instead try to find quiet places at school where he can be alone:

> Actually, I spend a good deal of time on my own, but that's really ok, because I can relax then [...] It's no problem to initiate contact with others, but I seldom feel like I want to. When I am tired I am not

> interested in spending time with others. […] I use hearing aids all the time and that makes you tired. […] It's ok [to wear hearing aids], but it means there's this constant level of loud sound all day long, no distance, just straight in all day long, that wears me out. There's a lot of noise [at school] but yet some places I can slip away, empty rooms for smaller classes, I use to slip into them from time to time.

It is well established that using hearing aids is associated with fatigue, sometimes even chronic fatigue (Werfel & Hendricks, 2016; Camarata et al., 2018; Gustafson et al., 2018; Wang et al., 2018). My qualitative data contributes the deeper understanding that this fatigue is not only because of the use of hearing aids. John is exhausted, not only because he strives to understand what teachers and peers are saying and thus 'strains his ears' (or rather his brain). What exhausts him is also that he is on his own and left to fend for himself[8] in a social setting where few seem to care about his need for a quieter learning environment. Attending school is not something he can choose not to do. Instead, he must seek to alleviate the strain caused by too much noise by finding solutions on his own, for example slipping away into an empty classroom. In other words, fatigue is as much the result of socially created conditions as of individual problems with hearing technology.

Passing and shame

John is on his own and has the responsibility of being the one who must always ask. What he is asking for is the fulfilment of his undisputed rights, but since the tacit message from his teachers is that using the hearing loop or securing a quieter learning environment comes second to teaching typical-hearing students, John is made to look like someone who must ask for compassion and consideration. Because the teachers have neglected to implement a consistent routine, of using the hearing loop system unprompted, they have instead instituted another routine. This is that John must, over and over, single himself out as untypical, as different from his peers. He must admit to having a need the other students can afford to forego, and is thus left in a vulnerable position by adults who fail to see that their actions create exclusion instead of inclusion because the school environment they establish is inaccessible to the hearing-impaired student.

Another informant, Fiona, was explicit when she explained how she deals with this form of inaccessibility. Her experiences are similar to John's: teachers neglect to use the hearing loop system and to structure class discussions so that one person speaks at a time:

> It happens all the time [that the teachers and other students neglect to use the microphones properly] because they switch too fast from the teacher to the student who is talking […] it's too fast for me and I have to turn around [to see who is talking]. But I never say anything, I just sit there.

However, John and Fiona handle their teachers' failures differently. Fiona does not ask the teacher to use the hearing loop system when the teacher forgets it. She also chooses not to ask the teacher to make sure she has time to identify the speaker in class discussions. 'I never say anything, I just sit there', she told us. From an adult perspective this might seem irrational and something that could have adverse effects on Fiona's future chances for further education and employment, but this misses the essential point. Fiona's behaviour is highly rational. She is dealing with another kind of struggle, the struggle of managing stigma. For this, her strategy is to lie low and not draw attention to herself. This is an example of a behaviour that sociologist Erving Goffman has dubbed 'passing' (Goffman, 1968/2005). Among hearing-impaired people, passing can take a number of forms and employ a variety of strategies, but what they all have in common is that the hearing-impaired person who is passing is trying to act as if he or she were typical-hearing (Kermit, 2019b). Passing is something hearing-impaired people can do because a hearing impairment is often hard to detect. Among the strategies Goffman describes are to '(1) sit next to someone with a strong voice; (2) choke, cough, or get hiccups, if someone [asks] a direct question; (3) take hold of the conversation […], ask someone to tell a story [one] had already heard, ask questions the answer to which [one] already knew' (Goffman, 1968/2005: 127). Other, maybe even more familiar strategies, are – like Fiona's – to simply keep one's head down and avoid attention, or say 'yes' in a non-committal manner to questions one is unsure of having understood correctly (Kermit, 2019b).

In Goffman's theory on stigma, passing is a symptom, revealing that the person who passes experiences the particular forms of exclusion associated with stigma. In the author's words, to be stigmatised is to live under the constant tacit suspicion that one's way of being in the world is less authentic than another's:

> The attitudes we normals[9] have towards a person with a stigma […] are well known […] By definition, of course, we believe the person with a stigma is not quite human. On this assumption we exercise varieties of discrimination, through which we effectively, if often unthinkingly, reduce his life chances.
>
> (Goffman, 1968/2005: 15)

There is a myriad of ways in which one can experience having one's authenticity as human questioned. I suggest that the lack of interest John and Fiona's teachers show in consistent use of the hearing loop system is an example of this questioning, as their practice sends the tacit signal that these students come second to their typical-hearing peers. The teachers would probably protest if they were to be confronted and accused of deliberate discrimination, and this is exactly the point Goffman tries to make. The exclusion of John and Fiona is not intended, but the result of unreflective practices and attitudes. As Goffman points out, even if this is done 'unthinkingly', it still effectively reduces 'life chances' through exclusion and the constant questioning of John's and Fiona's authenticity as humans. To be excluded, and thus questioned, is the essence of what it means to be stigmatised.

Passing is a way of managing stigma, and this struggle is directed both outwards and towards oneself. Outwards, to try to convince others that one is, in fact, like everybody else and – in Gofmann's words – 'quite human'. Towards oneself, to preserve one's identity and image of self, and uphold to oneself the conviction that one is, despite all, authentic. The latter is Goffman's central point, and coincides well with a central theme in critical theory and Charles Taylor's theories on recognition and identity. Exclusion and stigmatisation are forms of misrecognition, and misrecognition affects a person's sense of authenticity negatively, maybe even to the point where a person can start to believe that one is of lesser worth compared to others (Taylor, 1992a).[10] Documenting that young, hearing-impaired students are passing gives cause for concern. In line with Taylor's ideas about authenticity as well as general theories on developmental psychology, growing up and becoming an adult is the process whereby one strives to realise one's unique potential. When one is a hearing-impaired child or adolescent who is passing, one struggles not to become the best possible version of oneself, but to appear as someone else, as the typical person. This is not an accusation of students like Fiona. On the contrary, passing is a very rational strategy when one is left with no other options. Goffman's theory is a theory about social interaction, and at its foundation is the premise that stigma arises as a result of how people encounter and treat each other. The sociological insight is a rejection of the idea that stigma should be explained, for example, with reference to impairment. Stigma is the result of human actions, not of some kind of natural law. This point has been firmly grasped by disability scholars, who reject notions of disability as an individual tragedy caused by a person's body, and promote the view that disability involves different forms of discrimination (Oliver, 1996; see also Eric Svanelöv & Lena Talman's chapter in this book).

In the context of this chapter, the absence of inclusive practices is one example of such discrimination, even where it is not actively intended (Meyer, 2003). The implication of this analysis is that an inclusive school, accessible to most students, can only be realised when unquestioned exclusionary practices are articulated and openly confronted.[11]

That stigma is socially constructed does not mean that the consequences of stigma have no physical implications. On the contrary, a central aspect of passing is that it is labour-intensive and tiring. The hearing-impaired person who is passing is faking 'normalcy' – in Goffman's terms performing *as* someone whose authenticity as human is not questioned – and must be inventive in coming up with ever-new ways of improving this performance. Active passing is not something the hearing-impaired person can quit doing once he or she has started to do it: the impression of normalcy must constantly be upheld. This means that people who are passing must always be on their guard, ready to repair or amend any slip-ups that occur in their constant performing of the passing. This demands constant vigilance and a self-imposed demand to always strive to appear like everybody else. For a person with a hearing impairment, this means striving to understand, to mobilise what hearing capacity one might have, to stretch one's cognitive abilities to interpret and infer, in order to fill gaps in meaning whenever hearing become difficult.

This suggests that the tiredness often attributed to the wearing of hearing aids or cochlear implants is not simply the strain of picking up sound, or the challenge of exposure to noise. Certainly, overcoming the limitations of technology, especially when listening conditions are sub-optimal due to the presence of many different sources of sound, is hard work in itself. However the struggle to listen and understand what other people say cannot be reduced to physical barriers. In addition to the effort of hearing is the effort of constantly mobilising one's cognitive capacities in order to make sense of whatever one can hear, and to react to it in a way that convinces others of one's competence and authenticity as a human.

These intertwined elements – of struggling to hear and struggling to manage stigma – are not well understood in current research on inclusion and hearing impairment. Nevertheless, in the context of this chapter, where the lack of inclusive practices is described as a phenomenon containing elements of discrimination, at least some of the effects of having one's authenticity as a human questioned, can be brought to light. Fiona told us that she feels vulnerable, and that being hearing-impaired is something shameful she seldom discloses. In the following extract, Fiona told us about something that happened when she attended a church weekend camp as a part of the preparatory course for confirmation (a widely celebrated event for adolescents in Norway). Fiona had noticed another girl she did not know well and decided to approach her.

> I didn't tell her right away that I was hard-of-hearing, I didn't. But then I discovered that she seemed really nice and seemed to be someone who could be my friend. And so I told her…and then she just said: 'I know.' And I was very relieved that she actually wanted to be my friend. Because I have always experienced that when I tell people I'm hard-of-hearing they just go, 'Oh! Really?', and then they go away…but she just said 'I know' and remained there…she didn't go.

Friendship presupposes the kinds of mutual recognition and attractions that cannot be instilled by rights or adult intervention (Frønes, 1998; Kermit, 2012). Having said this, Fiona here expresses the expectation that being hearing-impaired is something that might disqualify her from being attractive as a friend. This is not necessarily something Fiona has learned only from experiences with peers who shun her when they understand that she is different. The absence of inclusive practices at her school may suggest to her that adults also consider her second class to her typical-hearing peers. As discussed in the introduction, when forming her identity, Fiona may already have started to wonder whether or not her way of being in the world is authentic and equal to those with typical hearing.

Passing by smoothing out and bottling up frustration

Benjamin, who is in his mid-teens, was also interviewed as part of the qualitative study in which John and Fiona participated. Benjamin combines attending his local school and attending the deaf school in the municipality, spending three days a week at the first facility and two at the second. In the interview, he described his experiences of attending both schools positively, and nothing he said hinted at problems he might experience. When we talked to Benjamin's mother, she confirmed a very good relation and cooperation with the local mainstream school. She told us that the local school, both the teachers and the management, were forthcoming and had expressed a sincere commitment to establishing inclusive practices to meet Benjamin's needs. In general, the mother told us, she thought they had achieved almost as much as one could hope for in terms of adaptations. Benjamin had typical-hearing friends and participated in a number of leisure activities in the community. Benjamin's mother continued:

> He comes home and tell me he is fine and that school is ok, but at the same time I can see when he gets home that he is completely exhausted. It's about him wearing hearing aids, it's about noise, he spends an incredible amount of energy just to hang on when there is spontaneous communication…and he doesn't get it all…and then he has to ask them to repeat…and then he gets it and he understands why they laughed… only then it isn't funny anymore. So, he gets terribly tired.
>
> […]
>
> There is a lot of frustration he will show only at home. He will cry even without knowing what he is crying for. He comes home very much on edge, he is tired, angry, but unable to explain why.

It is important to note that Benjamin himself did not mention his exhaustion and his frustration when interviewed. There may be a number of reasons, or combinations of reasons, for this. The point, however, is not to determine the correct reasons, but to suggest plausible hermeneutical interpretations, particularly those that can shed light on barriers to inclusion. One such interpretation is that Benjamin will routinely answer that he is fine whenever he is approached by adults outside the inner circle of the family. Keeping a straight face and assuring others that everything is fine is, of course, something many of us do from time to time. It may also be suggested that such responses are gendered and are typical of teenaged boys. However, I suggest that assuring others that everything is fine could also be classified as a form of passing, although this does not necessarily mean that Benjamin was trying to pass when he was talking to us. There is no reason to doubt that Benjamin's local school is very forthcoming and has tried to implement more inclusive practices. Benjamin has friends he spends time with, both at school and outside school. His mother's description of how he bottles up frustration and shows it only to his close family might, nevertheless, tell us that even what Benjamin understands as 'fine' is not what one of his typical-hearing peers might designate by the same phrase. Even if Benjamin's teachers try to adjust their practices, Benjamin still puts in a tremendous effort to ensure that things stay 'fine'. In addition, whenever things turn out less than fine, it is Benjamin who has to deal with the disappointment and bottle it up until he comes home.

This suggests that it is important to ask the question: what does it mean to do well? Even if Benjamin is supported, it seems he must still struggle considerably and he still has to bridge the gap between what is offered and what he needs. To do fine in this context might as well be another way of saying 'I am managing the things I must manage', and this, in essence, is what John and Fiona are also doing. This, again, touches on the question of adult responsibility and whether an adult – here, a teacher – can say that the hearing-impaired student is doing well. One might claim that John, Fiona and Benjamin are all managing exceptionally well, but certainly for John and Fiona and even for Benjamin, managing is something they must themselves take responsibility for. None of these three students are recognised for the enormous and exceptional effort they put in every day and every hour just to manage the demands they face.

Recognising the struggles of hearing-impaired students

Persons with sensory impairments often find that other people make assumptions on their behalf about how life with their disability 'is'. This can be banal even in instances where people with typical vision take for granted that they understand what it means to be blind simply because they can close their eyes for a short while and experience not seeing. Similarly, they can put their fingers in their ears and imagine how it is to have impaired hearing (Kulick & Rydström, 2015). The philosopher and feminist Iris Marion Young has analysed such reductionist attitudes where the complexity of the lives of others are reduced in a simplistic fashion. She uses the phrase 'asymmetric reciprocity' (Young, 1997) emphasising that humans are not mutually 'symmetrical'. Even though we are all humans, we do not mirror each other so completely that we can easily understand how it is to walk in another's shoes. On the contrary, since there is a multitude of ways of being human, it would be arrogant to believe that we could fully understand what it means to be another person. Young promotes a notion of equality founded on mutual respect for diversity, and a particular respect for that which in others we do not understand fully.

This point is central to this chapter. The review by Kermit (2018) surveys a number of studies that describe how adults (here mostly teachers) fail to grasp even quite simple aspects of what it means to be hearing-impaired, but still behave as if this is not a problem. Even if excuses are made on behalf of these adults, examples like the ones presented in this chapter, such as the frequent failure to use hearing loop systems routinely and consistently, cannot be so easily brushed aside. It is exactly because neglecting to use the microphone is so frequent that it is a call for concern. If responsible teachers choose not to reflect on the importance of using the hearing loop – regardless of whether the hearing-impaired student asks for it – this is a choice that will stand in the way of that student, barring him or her from participating and experiencing equality. This is absolutely not to say that using the hearing loop system is the ultimate solution to inclusive teaching for hearing-impaired students. Rather, the failure to understand even the importance of simple measures like hearing technology render it plausible that other, deeper reflections on what inclusive practices might look like are also absent.

Having taken Young's reservations into account, the qualitative analysis developed in this chapter allows for a fairly comprehensive description of the situation of many hearing-impaired children and adolescents. An important result of this study is the qualitative analysis that allows the construction of a sketch describing the many-faceted ways in which hearing-impaired students might struggle. The enormity of the task these students are confronted with every day is under-researched, and its elements may be known to research as isolated, rather than intertwined, issues. There is need for further attempts to map out a more complex and multifaceted understanding of how these factors intertwine and how they produce a complex of struggles in the lived experiences of hearing-impaired students. The factors touched upon in this chapter comprise: (1) the struggle to hear and to manage the limitations of hearing technology, especially in noise, (2) the struggle to manage exhaustion, (3) the struggle to manage in the absence of inclusive practices,[12] (4) the struggle to manage situations where one is made to stand out as different, (5) the struggle to manage one's stigma, sometimes by undertaking (6) the struggle of passing. One must also: (7) struggle to bottle up the frustrations and disappointments one alone knows about and one alone cares about, and (8) experience an utter lack of recognition of the struggle one carries out every day.

A central aspect of the analysis is that the struggles of hearing-impaired children and adolescents could be substantially eased if responsible adults were to adopt more inclusive practices. The obstacles and barriers to equal participation facing hearing-impaired students in this study have less to do with hearing itself and the more to do with discrimination. Since discrimination is a social practice and not the consequence of some kind of natural law, we are free to decide for ourselves if we want to rid ourselves of it. This is not a naïve wish, but rather a profound sociological insight, to distinguish between social and natural reality (Berger & Luckmann, 1991: see also Slee, 2018).

Finally, it is argued that the sum of everyday trivial obstacles that hearing-impaired students encounter in accessing academic and social inclusion might be underestimated as a risk factor to their health, well-being and self-perception. Further, mobilising the ideas of critical theory, such as Axel Honneth's (1995), might help to better understand the underlying moral psychology driving hearing-impaired students in their struggle to manage their lives. Framing their toil as a struggle for recognition might be a way to combine moral, social and psychological insights into the lives of hearing-impaired children and adolescents. The struggle for inclusion that students carry out every day is, among other things, a struggle to form and maintain a self-understanding as authentic and equal to one's peers. Practices associated with passing thus constitute a cause for alarm. A person who is passing seeks recognition, not of his or her authentic and equal self, but of the pretended 'normalcy' he or she seeks to impress on others. In other words, the reward for passing is, at best, polite recognition of the passing person's efforts, but not a recognition that confirms his or her authenticity as a human and a peer, and certainly not recognition of that which is unique to the person.

Conclusion: struggling for us, not 'them'

The qualitative analysis in this chapter allows the development of a comprehensive description of the everyday struggle of hearing-impaired students, particularly focusing on the intertwined notions of managing shame, passing and exhaustion while struggling to bridge gaps between what is offered and what is needed. These phenomena affect both the mental and the physical health of hearing-impaired students.

In both health sciences and special education, there is a long tradition of focusing mostly on individual hearing-impaired students, and less on the social factors that constitute the situations where these students struggle. A critical analysis of inadequate efforts to develop inclusive educational practices in Nordic schools and kindergartens suggest that hearing-impaired students are still mostly regarded as students with individual problems. As a result, hearing-impaired students have to fend for themselves as best they can in a situation where the general educational practices are designed to suit only the imagined, general, non-disabled, 'typical' student. This chapter implies that new and more radical efforts are needed in order to develop and design inclusive practices that recognise student diversity and promote mutual recognition, both among peers and between students and responsible adult professionals. In addition, there is need for research that combines different insights regarding hearing impairment in order to form a more complex understanding of the struggles confronting hearing-impaired children and adolescents.

In this chapter I have not addressed the underlying question of why inclusive practices seem so hard to establish. However, by focusing on the seemingly trivial case of the neglect of the hearing loop system, I have sought to demonstrate that the barriers to inclusion are not always technical or epistemological (in the sense that we do not know what to do). Routine and consistent use of the thousands of hearing loops systems already installed in schools all over Scandinavia could be achieved tomorrow. All it would take is for teachers to start using the systems consistently and routinely – without having to be prompted by a student – and to adjust classroom or group practices such that only one student speaks at a time – indeed, the latter is probably something many teachers already strive to establish. I will not try to suggest how something this simple, yet at the same time so formidable, can be achieved. Nevertheless, I point out that the idea that teaching practice is designed to suit only an imagined 'typical' student probably does little to accommodate any number of students who – for a myriad of reasons other than hearing impairment – cannot identify with this imagined norm. Thus, to strike a more careful balance between that which is universally equal and that which is individual and particular, is a place to start when searching for inclusive practices focusing less on needs deemed to be special, and more on the collective task of promoting solidarity in spaces for learning and development, both collectively and individually. And, of course, starting to use the hearing loop system every day, even if no one has specifically asked for it, is probably a good way to begin creating such spaces.

Notes

1 I conducted this research with two colleagues, Odd Morten Mjøen and Astrid Holm (Kermit, Mjøen & Holm, 2010). The term 'kindergarten' is used here as the best available translation of different Nordic terms designating what are also often labelled 'early childhood education and care facilities'.

2 In this text, I try to shed light on social processes whereby some children and adolescents are made to stand out as different in an unappreciated manner, and being 'made to stand out' is a social process, not a natural one. I thus need a term to identify those who are seldom made to stand out as different. For this latter group (if indeed they are a group), I use 'typical' throughout the text, knowing well that choosing such a term is fraught with difficulties since our attitudes and beliefs are embedded in our language and the words we choose. Using 'typical' is thus something I do while trying to avoid terms that more explicitly suggest a differentiation in moral and social status, since formulating a critique of such differentiation, in itself, is the most important objective of this text (see also the concluding paragraph of the next section).

3 This kind of exhausting struggle is described also for other groups, se for example the work of Ilan H. Meyer (2003).

4 Clinical research, for example, attests that hearing-impaired children and adolescents report a high prevalence of fatigue and health problems associated with stress (Camarata et al., 2018; Gustafson et al., 2018; Werfel & Hendricks, 2016).

5 This is a core aspect of what Erving Goffman (1968/2005) characterises as stigma.

6 The participants in the qualitative part of the study were ten sensory-impaired adolescents aged between 13 and 19 years, and seven of their parents. Written informed consent was obtained from all adult participants and from the parents or legal guardians of the non-adult participants. Observing all participants' right to deny participation, verbal co-consent was also obtained from non-adult participants. Sensory-impaired adolescents might be regarded as potentially more vulnerable research participants compared, for example, to adults without sensory impairments. In order to prevent ethical transgressions, extra care was taken to discuss the consent form with the adolescent participants in their preferred language (spoken or signed Norwegian). Here, it was emphasised that consent should be voluntary and informed, and that it could be freely retracted. Further, the study observed the recommended guidelines for sociological empirical research involving children (Ennew, 2009) as well as recommendations from sociological childhood

studies (Morrow & Richards, 1996). Since the data presented in the following text are qualitative, quotes are fitted with fictive names and approximate ages. The original 2014 study by Kermit et al. was approved by NSD, Norwegian Centre for Research Data (https://nsd.no/nsd/english/index.html), the national ethics board for educational and sociological empirical research in Norway.

7 All the quotes presented here were originally published in Norwegian in Kermit et al. 2014. The translations are mine.

8 This is also addressed by Sæbø, Wie & Wold (2016).

9 This famous text was written more than 50 years ago. In his book on stigma, Goffman distinguishes between the stigmatised and the non-stigmatised, and refers to the latter group as 'normal'. It is worth nothing, however, that Goffman never tries to define exactly who belongs to one or the other of these two groups. His tacit message is that both the idea of stigma and of normality are socially created and thus are contingent; they can be changed by our decisions. 'Normal', in this context, might then just mean those who have never (or very seldom) experienced having their authenticity as humans questioned.

10 This point is also central to the understanding of what it means to be an 'other', famously analysed by Simone de Beauvoir (1949/1961).

11 For an insightful discussion of these issues, I recommend the 2018 book *Inclusive Education Isn't Dead, it Just Smells Funny* by Roger Slee (2018).

12 This chapter has focused on the use of hearing loop systems as a straightforward and common example, but it is only one of many.

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6 Gatekeepers and gatekeeping

On participation and marginalisation in everyday life

Sangeeta Bagga-Gupta, Giulia Messina Dahlberg and Lars Almén

> After a rather long lunch break in town, Yara and the researcher get back to the school. Tanja, the special teacher, enters and sits next to Yara. Yara multitasks at her computer: she writes on a document, reads the text on some PowerPoint slides and hastily browses across different windows. She also flips through a book on her desk. Tanja sits next to Yara and both attempt to sort out a concept in the course assignment. It is a stressful situation for Yara.

The ethnographic vignette above is created from a fieldwork day at a school where Yara, whom we were shadowing in one of our projects, was completing an important assignment for a vocational course in an adult education programme she was pursuing to become an assistant nurse. Yara has various diagnoses and her grappling with institutional framings highlights her attempts at identifying and accessing avenues for support. The example illustrates what can be called 'the *everydayness* of gatekeepers and gatekeeping' – a key theme explored in this chapter in terms of an interest in who is included in what practice (including textual practices), by whom, when and why. This chapter aims to illuminate the everyday mundane nature of norms that both enable but also disable people's participation, and lead to marginalisation in and across the institutional arenas of which they are members. In other words, the aim is to critically understand the 'doing of' participation and marginalisation *in situ*. We will try to accomplish this by focusing on: (1) social practices and the doing or playing out of participation or marginalisation in everyday life inside and outside different institutional settings, and (2) on the nature of 'declared' and 'practiced' policies (Bonacina-Pugh, 2012) that frame participation or marginalisation.

Our chapter illuminates the contemporary patterned norms of participation where even in resource-strong nation-states like Sweden, serious concerns about marginalisation are reported despite the existence of declared policies for supporting a one-society-for-all agenda. The study draws upon some of our recent anthropologically inspired research that has focused upon issues of identity positioning generally, and what gets glossed as functionality, race and ethnicity specifically.

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As the introductory example illustrates, Yara receives individual, tailored support, and she displays competence in navigating it for her needs in specific situations. Yara, like some other individuals whom we will meet in this chapter, has metaphorically and literally become her own gatekeeper. This means that she knows which doors to knock on and how to get those doors opened. Yara effectively manages to solve a difficult, high-stakes situation (the preparation of an important assignment) through her knowledge about searching for, and succeeding in obtaining relevant, concrete support that matches her actual needs in specific situations. After shadowing Yara in different settings across three years, we know that she obtained her vocational degree and, despite her diagnoses, has learned to be her own gatekeeper and to circumnavigate possible barriers by aligning with people who are in positions to eliminate various thresholds (at least partially; related ideas are discussed by Groce & Scheer, 1990; Shepherd, 2020). We see gatekeeping, an analytical concept, as both a result and a prerequisite for participation or marginalisation that relates to norms about difference aligned to various dimensions of functionality, race and ethnicity, etc. In this study, we turn our analytical gaze to the doing of gatekeeping, and argue that accessibility today can be understood in terms of these gatekeeping procedures.

The two functionally disabled named groups that we specifically focus on in this chapter – deaf and Attention Deficit Hyperactivity Disorder (ADHD) – have seen dramatic changes in their demographic profiles since the turn of the century. Over 95 per cent of deaf children in Sweden (identified as severe to profoundly deaf) receive cochlear implants (surgically implanted advanced hearing aids) aimed at restoring hearing, while the number of children diagnosed with ADHD has seen dramatic increase. While deaf people constitute a traditional category, whose numbers are stable across time (8,000–10,000 deaf individuals and 30,000 users of Swedish Sign Language, henceforth STS), the diagnosis of ADHD has given rise to a relatively new group that has grown dramatically in Sweden.[1] Another named group focused on in this chapter relates to what is perceived as large-scale migration in Global North spaces like Europe, including Sweden. Functionality, socioeconomic status, gender, immigrant identity positionalities and technological tools appear relevant markers that have a bearing on issues of participation and marginalisation as well as inclusion and exclusion in the three projects from which we draw our data. Our analyses are presented in terms of the whats, whos, wheres and hows of the gatekeeping patterns that shape (in)accessibility through the scrutiny of everyday mundane life.

The next section explicates our theoretical framings and highlights some previous research. The specificities of the datasets we draw upon are presented in the section on methodology and data. The section called ‘The everydayness of gatekeeping across settings’ spells out two analytical themes that illustrate the gatekeepers and gatekeeping functions in play in and across people’s lives, including policies. The chapter ends with a discussion of the relevance of going beyond the dichotomised binaries that mark understandings of functionality, ability–disability and other identity positionings.

Difference, performativity and going beyond binaries

Issues regarding diagnoses and other identity positionings are salient across time, where functionality, race, ethnicity and mobility – as a constant state of transition from one position to another, one practice to another and across digital–physical spaces – mark human existence (Sacs, 1995). We have previously argued that functionality, ethnicity and mobility contribute to what is being recognised as *normal–diversity* (Bagga-Gupta, 2017a & 2019; Bagga-Gupta & Messina Dahlberg, 2018; see also Khubchandani, 1997; Machart, Clark & Dervin, 2014). Furthermore, functionality is a dimension that is relevant *for all,* given extended life spans and increasing understandings regarding potential *temporary* disabilities across the lifespan (Cureton & Wasserman, 2020). In addition, different kinds of mobilities constitute dimensions of human existence in the twenty-first century. For instance, while transitions to adulthood entail risks and challenges for all young people in contemporary societies, this is compounded for those who are, for various reasons, marked as different, i.e. being 'an-other' (see also Patrick Stefan Kermit's chapter in this book). Such Othering takes place, for instance, through different *named* functional disabilities or different external markers like skin colour, physical attributes, choice of attire or raciolinguistic markers (Rosa, 2019). Perceived difference, either because of temporary or permanent markings and labels that relate to a set of norms, leads to a greater risk wherein gatekeepers and gatekeeping barriers of various kinds are encountered. This is a key reason why societies institute policies and support structures for the inclusion of difference.

The literature describes mainstreamed students as gatekeepers for the inclusion of disabled students in classrooms and their acceptance of disabled students is seen as important for the latter's sense of inclusiveness (Adams, Harris & Jones, 2017; Naraian, 2010). Our analysis nuances this picture by indicating that although difference is a dimension of normal–diversity, people like Yara are themselves tasked with *and* contribute to their own inclusion in various ways. Parents of functionally disabled individuals too are reported to act as gatekeepers in their mundane marking of mainstream students as 'normal' (Adams et al., 2017), and as a corollary their disabled children as 'abnormal'. This leads to functionality being placed outside of normal–diversity. Furthermore, some studies highlight that engaged parents are important enablers, i.e. gatekeepers, for the inclusion of disabled individuals across settings (Sagen & Ytterhus, 2014). In line with our opening example, teachers (Naraian, 2010; Sagen & Ytterhus, 2014) and para-professionals (Naraian, 2010) are also considered important gatekeepers for the inclusion of disabled students in mainstream classrooms. Research indicates that policy functions as a gatekeeper – an issue we will empirically discuss – whereby the inclusion of disabled students in mainstream education is made more difficult (Naraian, 2010; Sagen & Ytterhus, 2014; Östlund, 2015).

Furthermore, a ‘chicken or egg’ dilemma, between an intervention in a pedagogical activity and its outcomes not only constitutes a common characteristic of (educational) research but is particularly prominent in recent scholarship that deals with issues of groups marked through difference. This mainstream stance has, we argue, ideological and, possibly, problematic shortcomings in that inclusion or participation as desirable outcomes tend to be framed in terms of a relationship of direct causality with the studied interventions themselves. This means that there is an important lack of critical discussion regarding connections between interventions, their results and ideological framings that interventions often build upon.

Drawing upon theorising that calls attention to a third position which goes beyond binaries like disabled versus abled, inclusion versus exclusion, immigrant versus native, etc., enables us to raise alternative queries that focus on identity-positionalities and the playing out of participation, inclusion and policies from the perspective of everyday life. The broad policy focus, on how to optimally deal with people’s participation and mitigate marginalisation, in itself calls attention to the need for illuminating how policies are *practiced* in ‘everyday life everywhere’ (Bagga-Gupta, forthcoming-d).

The study presented in this chapter also attempts to go beyond the established binaries of the medical versus the social, the native versus the non-native perspectives on inclusion or integration and exclusion or segregation; such binaries continue to frame the scholarship in areas *labelled* or connected with disability, race and ethnicity broadly. Going beyond binaries is, we argue, what allows for the identification and problematisation of gatekeeping, the boundary work that exists in participants’ everyday lives from non-normative positions and that, in various ways, reinforces inaccessibility.

Theorising on the nature of human identity, discussed in different disciplinary domains, has for some time drawn attention to the playing out or the *doing* of identity, rather than the essentialised characteristics that are focused upon in mainstream identity-sector scholarship. This *performative* stance – which, in theorising, may be called sociocultural perspectives, integrationism, activity theory, etc. – illuminates people’s participation or marginalisation through *labelling practices.* Naming people *as something* is, in such a framing, consequential for their participation (Hacking, 2006; Bagga-Gupta, 2018). Participation and marginalisation processes are also riddled with dimensions of hegemonies. Decolonial framings draw attention to the power dimensions inherent in the *hegemonic order of things* across settings, and in particular in the knowledge production enterprise (Heller & McElhinny, 2017; Santos, 2018). Aligning with these framings means that research needs to move beyond mainstream linear and monolithic universal epistemologies (in our case, with regards to participation and inclusion), including programmatic methodologies. Decolonial framings, together with sociocultural perspectives, integrationism, activity theory, etc. on issues of identity, communication and learning, recognise the role of power differentials in human life; here, participation and marginalisation are understood as entangled dimensions of action. We refer to the entanglements of these two theoretical clusters as a ‘Second Wave of Southern Perspectives’ (henceforth SWaSP).[2] Assumptions at the intersection of these two framings view binaries like man–woman, native–immigrant, disabled–abled, young–old, etc. as reductionistic. Instead, the analytical thrust lies in understanding any characteristic related to identity as situated in a context that, in turn, determines and co-creates the category itself, or put differently, in terms of *its performance in mundane everyday actions*. Such a focus upon human action necessitates taking into consideration dimensions of time, space, participants and various types of tools.

Understanding the doing of identity – as it relates to issues of participation and marginalisation – relates to what becomes relevant or marked in a particular setting. Thus, difference when marked as being tall or short may, in itself, not be significant in a community where body length constitutes a non-consequential dimension of human variation. However, in a community that places high value in sports like basketball or volleyball, body length can become a characteristic that determines how members get marked and organised. Here tallness or shortness may be a value-laden differentiating characteristic. Similarly, the ability to hear or not hear has been shown to not be of consequence in communities like Martha’s Vineyard off the coast of New York and Massachusetts in the eighteenth century where everyone – deaf and hearing alike – used American Sign Language (Groce, 1985). In such communities being deaf is not consequential or in need of being marked, since everyone shares the intellectual tool of communicating in a given signed language.

Similarly, in communities where diversity has over time constituted a dimension of life and where individuals follow different religions, have different dress codes, different greeting habits, different food traditions, etc., people, at a general level, accept difference as a dimension of normalcy, even when they box one another into different named groups.

Studying the doing of identity

With the above as points of departure, the study presented in this chapter acknowledges a long-standing critique of research that focuses on demarcated essentialised identity categories based on difference like abled-disabled, race and ethnicity, gender, class and what the scholarship on intersectionality has highlighted as ‘etceteras’ (Yee, 2020). Such essentialisms over-generalise issues by studying individuals marked as disabled or those who can be boxed into racial and ethnic groups as monolithic super-categories (Rosengren & Öhngren, 1997; Machart, Clark & Dervin, 2014; Bagga-Gupta, Feilberg & Hansen, 2017). This study also aligns itself with the growing awareness that understanding equity as well as participation and marginalisation adequately or relevantly requires studying people in more than one societal arena or phase of life. People live their lives navigating different institutions and settings, so focusing on only one setting or life phase – for instance preschool, middle school, high school – in order to understand participation and marginalisation can, at best, present a fractured picture. This study therefore engages with data from multiple projects where we have shadowed individuals and groups in and across a range of settings, including physical–digital spaces. It strives to juxtapose individuals and examples from different settings. In addition to Yara, we will meet Fatma who, unlike the rest of her secondary school classmates, wears a headscarf, and Eva, a blind schoolteacher. It is the analysis of everyday existence in which individuals with different markers live across different settings, rather than essentialised identities in one setting, that enables a critical reflective illumination of participation and marginalisation processes.

We draw upon multiscale ethnographic data from three projects (two of which are ongoing) in the Communication, Culture and Diversity research environment[3] of which we are members. First, the Swedish Research Council project 'Participation for All? School and Post-School Pathways of Individuals with Functional Disabilities' (PAL) 2017–ongoing; second, the societal developmental project *Delaktighet och Teater* ('Participation and Theatre', DoT) 2012–2015; and third, the research project 'Digitalisation Initiatives and Processes' (DIP) 2016–ongoing.

Project PAL focuses on the two named groups: deaf individuals and those who are diagnosed with ADHD across different life arenas. Project DoT focuses on how communities constituted by signers, speakers and writers, irrespective of their hearing levels, negotiate meaning-making in the mundane processes involved in theatre production and consumption. Project DIP deals with the lives of adults and students who are members of technology-infused secondary schools and the tensions in the explicit discourse of equity and the one-school-for-all ethos on the one hand, and implicit and explicit marginalisation in mundane everyday lives of participants in schools, on the other hand.

The data in these three projects was generated through our direct involvement in the field, i.e. our presence in a physical location or through engagement in shared digital spaces where the people we follow live parts of their lives. We have thus shadowed individuals across sites (particularly in Project PAL), in line with what has been framed as a new mobilities paradigm (Sheller & Urry, 2006; Landri & Neumann, 2014), including the practice of 'go-alongs' (Kusenbach, 2018; see also David Wästerfors' chapter in this book). The latter is particularly suitable for following participants on the move and, in our projects, participants are indeed in a constant state of motion across both physical and digital sites. The go-along methodology provides researchers with a toolkit that enables following participants in the daily arenas and practices that are part of their own routines (Scott, 2019).

'Ethnographic miniatures' (Geertz, 1973: 20), such as Yara's opening example and the examples in the next section, constitute some illustrations of gatekeeping and gatekeepers. These examples emerge from video–audio recordings of naturally occurring life in and across different institutional sectors and in online settings, informal discussions and interviews, and policy documents used in Sweden. The specific arenas that are part of our data include schools, higher education settings, workplaces, homes, support services (like healthcare, employment agencies, insurance agencies, etc.), theatre, leisure settings etc.

The methodological approaches used in the projects are not mere instruments for data generation. Rather, irrespective of whether it concerns conversations, observations, go-alongs or text and policy scraping, our approach takes a dialogical stance, wherein we see ourselves as part and parcel of the data-creation process. This process is a result of a dialogical co-production of knowledge among researchers and between researcher(s) and participants (see also Bagga-Gupta & Messina Dahlberg, 2021). It is through this lens that the reader should understand the vignettes, or the 'ethnographic miniatures' presented in this chapter. Specific issues or themes that have arisen from such analysis illustrate how identity markers play out in relation to gatekeepers and gatekeeping practices. Gatekeepers and gatekeeping are complex intertwined phenomena which the next section unknots and illuminates through a focus on the mundanity of people's lives.

The everydayness of gatekeepers and gatekeeping

Education is a salient gatekeeper which enables inclusion into mainstream society. The ethos of the Swedish compulsory school system is conceptualised in a framework that strives for inclusiveness. All students are expected to be able to participate in it on an equal footing. Schools are required to compensate students who face challenges due to race and ethnicity or socio-economic disparity, physical or intellectual disability (SFS 2010:800). Nevertheless, the high degree of freedom that teachers in Sweden enjoy to shape their instructional activities confers upon them a pronounced gatekeeping role that can lead to exclusion and marginalisation, as the following example illustrates.

> Fatma is attending a German language lesson. The students' desks are arranged in three rows, with eight desks in each row, grouped four and four. Only girls from the class are present in this space; the boys sit and work in an adjacent room. The teacher divides her attention between Fatma's classroom space and the adjacent room where the boys from the class are making oral presentations. Fatma is seated alone in the front right row. The other girls work in pairs. In addition to Fatma's spatial position that singles her out from the rest of the students, she is the only student who dons a headscarf. Furthermore, she is not working on the German assignment like the rest of the class, but on an essay in Swedish. While the teacher explicitly notes that Fatma is working on the 'wrong subject', she proceeds to assist Fatma with the Swedish language essay.

Fatma is excluded from the classroom in different ways. First, her focus on another school subject excludes her from learning German, risking that she lags behind the rest of the class in the lesson. Second, she is excluded from the class community, because she works with another school subject and is *de facto* not part of the class discussions about the language assignment. Third, Fatma sits on her own, while the other girls sit and work in pairs on the lesson assignment.

The teacher (un)wittingly acts as a gatekeeper whereby Fatma is excluded in several ways. By allowing Fatma to work with another school subject, she seems to encourage Fatma to not focus on German, thus limiting Fatma's possibilities to engage in the class community and learn German. Given that the teacher disregards the routine of directing students where to sit and whom to work with during lessons, she also acts as an obstructive gatekeeper in Fatma's spatial inclusion during this lesson. Fatma is the only student who sits on her own. Having said this, the teacher also acts as a facilitative gatekeeper, enabling Fatma's engagement with the main societal language.

Grouping students in gendered groups is enabled through the gatekeeping of the teacher in this lesson. This *practiced* policy contrasts with the *declared* policies in place (cf. Bonacina-Pugh, 2012). While the Swedish National Agency for Education highlights that:

> … based on international conventions, children have the right to meet girls and boys during their education and work together[4] […] if it is reasonable, the school should be allowed to temporarily separate the children into groups or use other organisational and pedagogical interventions, to avoid the occurrence of sensitive situations for individual students or groups of students. For example, a segregation can be made during swimming education where girls and boys are separated.
>
> (2017:14 & 5, *our translation*)[5]

Going beyond pragmatic issues of why groups are formed, creating gendered learning spaces illustrates a practiced policy wherein the teachers' independence overrides the declared policy of gender-integrated classrooms. In this sense, the teacher becomes a gatekeeper when Fatma's class is divided into two. This gatekeeping is manifested literally in the physical door that separates the two classroom spaces and which only the teacher uses.

However, gatekeeping is not necessarily a teacher's privilege. The next example of the everydayness of gatekeepers and gatekeeping across settings is also from school: a grade 8 history lesson. This highlights how teacher and students co-construct gatekeeping and the role of functionality in these processes. While the social science teacher Eva is blind, her functionality is not explicitly obvious in the lesson that we use illustratively here. Functionality plays into Eva's ways-of-being in the classroom setting in specific ways. She repeatedly asks students for the time. Furthermore, she does not comment on or otherwise react to the breaking of declared classroom and school rules; for instance, listening to music during the plenary phases of the lesson, handing in mobile phones on entering the classroom, arriving late. During the lesson, the students move around the classroom space. This results in Eva not knowing where in the classroom a student has, without permission, moved to. She uses technologically mediating tools through her braille-enabled laptop to attend to classroom administration, for instance, reading student lists to mark attendance.

In this example, able-bodied students set the limits for the teacher who cannot see the classroom or them. In comparison with how they negotiate classroom spaces where teachers are able-bodied and can see, these students navigate classroom spaces and their own ways-of-being more freely during Eva's lessons. The students themselves become agents of gatekeeping when they choose to break institutional rules, like listening to music, moving seats or not turning in their mobiles on entering the classroom. The teacher's control further decreases when a fundamental classroom interactional order of temporal control is handed over to the students, when Eva repeatedly asks for the time.

However, here technology acts as a gatekeeper that enables inclusiveness. Digital tools are facilitative, in that a blind person can take care of tasks that an able-bodied sighted person can. Eva listens to, or reads using braille, emails, booklists and notes on where students are seated. Digital tools enhance the teacher's agency vis-à-vis the students' agentic advantage. With technological tools, the teacher can be seen to reclaim temporal control from the students and can check the laptop to hear or feel what time it is.

Policy as gatekeeper

A second theme that we illustrate in this chapter has already been touched upon: the role that policies play in how access is enabled and disabled for participants in the course of their lives and across settings. Thus, for instance, while declared policies call for girls and boys to be co-members in educational settings, a teacher's autonomy enables how policies are practiced. In contrast to the declarations of policies or the ways in which participants envisage policies to play out in settings (i.e. perceived policies), our gaze here is on teasing out the promises in policies and how policies play out in social practices, i.e. practiced policies (Bagga-Gupta, forthcoming-d).

Sweden follows international conventions (for instance, the UN Convention on the Rights of Persons with Disabilities since its ratification in 2008, the UN Sustainable Development Goals). The Swedish Discrimination Act (SFS, 2008:567) also constitutes an overarching policy that shapes the work of national, regional and local authorities and councils. The Discrimination Act is furthermore binding on both government and private bodies and requires institutions to follow a wide range of directives with the intent to include everyone, create a democratic basis for everyone's participation and mitigate marginalisation. Article 9 of the UN Convention, which the Swedish government is obliged to adhere to, requires that member-states support persons with disabilities with the intent that the latter can live independently and participate fully in all aspects of societal life. For deaf people this includes having access to professional STS interpreters.[6] Such laws and directives can be understood as declared policies but there are also two further levels of policies: *perceived policy*, i.e. how individuals and institutions interpret policy declarations, and *practiced policy*, i.e. how these policies play out in everyday lives (Bonacina-Pugh, 2012).

Access to STS interpretation has emerged, in our analysis across Project PAL and Project DoT as a key dimension that enables deaf people's participation in settings where everyone cannot use STS. One such dimension has been explicated in terms of 'the circus of interpretation policies' (see Weckström & Bagga-Gupta, 2017, 2020; Holmström & Bagga-Gupta, forthcoming). Interpretation services in Sweden are structured through declared policy directives in different domains wherein county councils or regional authorities are tasked to make this provision available and prioritise situations for support when resources are meagre. However, and more significantly, responsibilities are also based on who is tasked to pay for the provision. The following, in part, illustrates the 'circus' of interpretation services, where interpretation responsibility:

- *in everyday life* lies primarily with the regional authorities, for instance, private meetings at banks, leisure time activities at sports, pubs, visits to health services, some – not all – general meetings at workplaces;
- *in educational contexts* lies with the county councils and regional authorities such as higher education and people's high schools, but the financial responsibility lies with the institutional setup[7] that needs the services; and
- *in working life* lies primarily with the regional authorities, for instance, meetings, seminars, conferences, courses for further training, but the financial responsibility lies with the institutional setup that needs the services.[8]

Policies function as gatekeepers in that the provision and payment responsibilities enumerated therein act as roadblocks to participation. This is poignantly illustrated by the fact that deaf people are required to invest time and energy to support the work of interpreters to mediate communication in activities where everyone does not know STS. They are required to take responsibility for their own participation in such activities, for instance, by booking an interpreter, providing them with logistical information, etc. Hearing participants, who are not knowledgeable in STS, are neither required to, nor allowed to, order an interpreter. Thus, the latter's *inability to use STS* is not marked, it is the deaf person's *inability to hear and talk orally* that is marked as being the cause of the use of interpreters. The responsibility to create an inclusive activity, in which all participants have equitable conditions for participation given their different communicative possibilities, is exclusively bound to the deaf individuals' inability to hear and talk orally. Furthermore, the interpretation costs are borne by public funds if the deaf person who has ordered the interpreter for a meeting participates passively at the meeting. However, if this deaf person leads the meeting, then it is that person's employer who is required to bear the interpretation costs. If the deaf person is an entrepreneur, then their company is required to cover these costs.

Practiced policies that have been identified in the analysis in terms of who has the right to access services, who is responsible for and pays for them, what happens when a meeting organiser forgets to order interpreters, etc. create a number of roadblocks for deaf people's participation in societal arenas, i.e. their accessibility (Weckström & Bagga-Gupta, 2017, 2020; Holmström & Bagga-Gupta, 2019, forthcoming). Our recent studies, for instance, indicate that deaf individuals are positioned as both *patients* whose needs authorities and employers decide upon, but also as *citizens* who have a say in which services they can access, whose opinions are solicited, and who are tasked with making sure that interpreters are present at different activities.

The second theme we illustrate here is aligned with a 2020 report by the Swedish National Association of the Deaf titled 'Right to Interpretation, No Interpreting Issue'.[9] Here this national NGO highlights its frustration with the splintered nature of interpretation services – both in how declared policies are formulated, but also how these shape deaf individuals' possibilities to access arenas in a resource-healthy democratic society in the Global North. Our analysis and the frustrations recently presented by the association indicate that the nature of declared policies and practiced policies both function as gatekeepers and gatekeeping mechanisms for deaf individuals' participation in societal arenas.

Conclusion: practiced norms of participation

Our findings call for making visible a plurality of spaces across institutions. This means that issues of participation and marginalisation – as spelled out in policy – need to be attended to in terms of practiced policies (see Bonacina-Pugh, 2012; Gynne, 2016) and in tandem with what people and institutions like schools, adult education or authorities *do* with policies (see Bagga-Gupta, Messina Dahlberg & Winther, 2016; Bagga-Gupta, Messina Dahlberg & Vigmo, 2020). This puts the spotlight on the role that policies themselves play, i.e. their agency, in how access is enabled and disabled for participants in the course of their lives and across settings.

Thus, the legal framings created in legislation and policy are artefacts that aim to significantly shape the possibilities to participate in society for specific groups that are required to be marked as belonging to such groups. Policies of support and inclusion, are mutually bound to conditions that mark individuals and groups as being in need of such support or even protection, as is the case, for instance, in the Swedish Discrimination Act.

Gatekeepers – people, institutions (like interpretation agencies) and policies thus have agency. Gatekeepers could have formal as well as informal agency, where gatekeeping often overrides formal agency. Teachers, parents and policies all have formal agency and act as gatekeepers including and excluding people, as we have seen in the case of students marked with disabilities or ethnic Otherness. However, as Eva's example shows, students, whose formal classroom agency tends to be curtailed, can act as gatekeepers for the disability-marked teacher. At the same time this example highlights how technology, which is often understood in terms of artefacts without agency, can act as a gatekeeper. Students, too, can act as their own gatekeepers. Yara, for instance, chooses to visit the course teacher's office to elicit support for completing her assignment. Fatma chooses to work on her Swedish essay during the German language lesson. In the social science classroom, students' actions shape the teacher's possibilities of participating or being marginalised; the students choose to answer in the affirmative (or be silent or respond in lieu of another student) when a blind teacher takes attendance. Students display agency when they do not hand over their mobiles to the teacher or leave them in the designated box. They choose to work on their assignments or watch YouTube videos. A teacher chooses whether Fatma should focus on her German assignment or her Swedish essay. A teacher chooses to group the students at specific desks or delegate this choice to the students. The teacher appears to divide the class according to gender.

Such examples highlight how gatekeeping is not necessarily connected to human agency alone but is a phenomenon that arises from interactions between participants-in-(inter)action-with-tools of various kinds, who have an unequal distribution of agency, for instance through (dis)ability or other identity positioning. A tenet of SWaSP theorising – and in particular sociocultural perspectives – relates to the need to recognise the shifting shades of human traits and their situatedness across social practices that fall into a continuum, rather than as mutually excluding poles of a dichotomy. Thus, not all short members of a community that deeply values basketball can be without expertise in other areas of that or some other sport. Not all people can be placed at the far ends of the scale of being deaf and not deaf, or hearing and not hearing. A point of departure from the SWaSP framing adds to this conceptualisation of a linear continuum by framing these ideas in terms of 'meshwork' (Ingold, 2015) or a non-linear dynamic continuum. This means that a person's characteristics or attire may stick out in specific ways that are marginalising in some – but not all – settings. This may sound both minor and self-evident. However, as both our analytical themes and examples illustrate, such marginalising is not a totalising issue in one and the same setting, nor across different settings.

Tenets of decolonial framings that are part of SWaSP call attention to the need to shift focus from the marginalised labelled Other to the non-marked norm, and to the boundaries that are drawn between binaries in everyday actions and activities that in themselves create 'an-other'. A SWaSP framing enables going beyond the *naturalisation* of hegemonies regarding communication and identity on the one hand, and on the other hand, the by-and-large continuing *marginalisation* of scholarship where social activities are focused. A key concern of this chapter is to illuminate accessibility and participation as they play out in everyday life, rather than in terms of homogenised monolithic categories deployed for marginalised individuals. Here understandings about identity, wherein 'people are made up' (Hacking, 2006), is central to how support services are planned and organised for labelled persons and named groups. Thus, an important issue in this study has been finding viable ways of re-centring and re-balancing (in)accessibility and gatekeeping by turning the analytical gaze *in the middle of things*, for instance on social practices as they play out *in situ*.

Recognising the shifting values placed on the relevance of human difference in terms of functionality, skin colour, attire, gender and the innumerable intersectional etceteras across time and space is thus a key message of this chapter. What, in one situation, is a norm or an asset can turn into a disadvantage in another space and time. The functionality of not being able to hear in a community where everyone signs has different consequences for an individual's participation compared to a situation where few or no members of a community know a specific signed language, as our discussion on STS interpretation illustrates. Being a recognised user of more than one named language in school can be seen as a disadvantage in specific spaces and not others, and the consequences of not being able to see can shift when technologies extend a blind person's abilities. These points highlight an important tenet of SWaSP framing: norms and naturalisations do not constitute a given but are situationally bound.

This study contributes the analytical insight that being free from disabilities is the norm that itself excludes disabled people from settings that are meant to be for 'everyone'. We note this occurs differently in Fatma's example, wherein the majority language, Swedish, which she is focused upon, and attire which marks ethnicity, constitute norms that exclude students who deviate in terms of where they or their parents are born or because of their attire. The dichotomy between included and excluded, abled and disabled, majority and minority students or abled and disabled individuals as they are identified (or stigmatised) is based solely on specific characteristics or place of origin. As our ethnographic explorations highlight, Othering processes are common irrespective of the identity characteristics that individuals and groups are boxed into.

Ethnographic studies like the one presented in this chapter illuminate the types of assumptions and shortcomings that intervention studies do not make explicit. Such assumptions relate to whose norms, why, where and when, are taken for granted in the scholarship that focuses on participation and marginalisation across the areas of disability, race, ethnicity, gender, etc. The salient point of our analysis is that which empowers and provides access in one context or situation will not always be relevant in another setting. Special arrangements and support in educational activities, for instance, are important dimensions in the everyday lives of people who are different from the norm in one way or another. At the same time, it is the very handling of such special arrangements that requires specific knowledge and competences as to how they can be used in the most appropriate way for any given task or situation. In that, we argue, lies the balancing act that many individuals in our projects struggle with over the course of their lives.

Notes

1 For more information on statistical data see: https://www.sdr.org/item/319-hur-manga-dova-finns-det; https://sdr.org/component/k2/item/320-hur-stor-andel-av-befolkningen-ar-dov; https://openarchive.ki.se/xmlui/handle/10616/46702 (accessed 18 March 2021).

2 For more on SWaSP, see Bagga-Gupta (2017b, forthcoming-a, forthcoming-b, forthcoming-c), Bagga-Gupta and Carneiro (2021), Bagga-Gupta and Kamei (forthcoming).

3 For more information on the Communication, Culture and Diversity research group and the different projects see http://www.ju.se/ccd.

4 Swedish: *För att tillförsäkra barn den utbildning de har rätt till enligt internationella konventioner är det enligt Skolverkets mening viktigt att låta flickor och pojkar mötas och arbeta tillsammans.*

5 Swedish: *skolan, tillfälligtvis, om det är rimligt, bör kunna använda gruppindelning eller andra organisatoriska och pedagogiska åtgärder, för att undvika att känsliga situationer uppstår för enskilda elever eller grupper av elever. Det kan till exempel avse simundervisning där flickor och pojkar skiljs åt.*

6 See Bagga-Gupta, Messina Dahlberg and Winther (2016) and Holmström and Bagga-Gupta (2019, forthcoming) for empirical analysis on declared and practiced policies in the Swedish context.

7 The government has set aside resources for interpretation services at universities and colleges. Special resources are available for the Swedish People's High Schools (*Folkhögskolan*) through the National Special Schools Authority.

8 Provision for video relay services exist but are not relevant to this discussion.

9 Swedish: '*Rätt till tolk, ingen tolkningsfråga*', https://www.sdr.org/component/k2/item/1828-rapport-ratt-till-tolk-ingen-tolkningsfraga-pressmeddelande, 25 March 2020.

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7 Still waiting for the hand to be raised

On being crip killjoys at an ableist university

Elisabet Apelmo and Camilla Nordgren

> I start to forget things. When I leave my home for a conference, I notice that my suitcase is very light. As I arrive at the hotel, I realise that I have forgotten to pack some of my clothes, two charging cords, props that I was going to show during one of my two presentations and leaflets for my new book. Afterwards, I remember myself running between different sessions at the conference. Several months later, I find out that I forgot one of my dresses at the hotel. A couple of coursebooks disappear the weeks before the doctor gives me a certificate of illness.

This chapter is based on collaborative autoethnography about being disabled in contemporary working life. It draws from the two authors' experiences as instructors and researchers at a Swedish university. One of us (Nordgren) has a visible, permanent impairment and is a wheelchair user. The other researcher (Apelmo) has long-term experiences of burnout, resulting in fatigue and sleeplessness, and invisible cognitive impairments like problems with memory, attention and concentration. Research shows that for the majority of those who are burnt out, cognitive impairments and sensitivity to stress remain for several years after the first diagnosis (Glise, Wiegner & Jonsdottir, 2020; see also Kågström, 2016).

Disabled people are underrepresented in academia (Sheridan & Kotevski, 2014; Brown & Leigh, 2018; Mellifont et al., 2019) and disabled academics are hindered from fully participating and have to prove their existence as productive and 'good enough' employees (Waterfield, Beagan & Weinberg, 2018). Disabilities *per se* have major impacts on opportunities to gain employment in the academy and to become established in the field. Furthermore, disabilities can lead to missing out on career opportunities (Saltes, 2020) and, for those with invisible impairments, to not disclose them can lead to missing out on accommodations (Waterfield, Beagan & Weinberg, 2018; Öhrn, 2020). Inequalities in the workplace may be maintained in subtle ways, for example through a preference for sameness (those already established are attracted to those similar to themselves), leading to a cloning of the organisational culture (Essed & Goldberg, 2002). Being selected because of sameness is a privilege, and this – as is true of privilege in

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general – is not something that is apparent to those who are privileged. Writing on universities, justice and equality, researchers have explained how privilege is taken for granted:

> Moving in rooms that are designed according to my body type or being judged by people who are similar to me, supports my feeling of being free, autonomous and self-helped. It allows me to feel that I entered the room, through education or up the career ladder of my own power.
>
> (Brade, Schmitt & Sandell, 2014: 4, *our translation*)

The privileged person experiences what cultural theorist Sara Ahmed (2012) calls *flow*. Writing about its opposite, she describes how longstanding traditions within the university have led to: 'the sedimentation of history into a barrier that is solid and tangible in the present, a barrier to change as well as to the mobility of some, a barrier that remains invisible to those who can flow into the spaces created by institutions' (Ahmed, 2012: 175). This barrier can be about being one who is not asked, chosen or acknowledged; instead, one is the one for whom experiences are stopped. It can also be about feeling unwanted because of alleged unproductivity (McRuer, 2006). Disability studies scholar Fiona Kumari Campbell (2009) describes the problem of (able-bodied) colleagues, who most likely have never reflected on their privilege (see also Bain & Tremain, 2015). Our introductory quotation in this chapter illustrates the experience of gradually shifting from being privileged by virtue of able-bodiedness, to developing cognitive impairments and facing barriers in a stressful contemporary working life. This is also a shift from being seen as promising, to being regarded as less productive by others in the workplace, often in a subtle and vague way.

Having an impairment in an environment where impairments are rare could be perceived as a representation of diversity. However, several authors have questioned the very idea of diversity, since it often hides exclusionary sexism, homophobia, racism and ableism (Mohanty, 2003; McRuer, 2006; Ahmed, 2009, 2012). The postcolonial feminist writer Chandra Talpade Mohanty points out that universities are politically and culturally charged spaces in which ideas about class, gender and ethnicity are created and reproduced, and in which different social groups fight over the legitimate production of knowledge (Mohanty, 2003). Diversity is what Ahmed (2009) calls a 'happy word', one which breathes consensus, unlike racism (or ableism) which points to injustice and inequality. Crip theorist Robert McRuer links the talk of diversity to what he describes as a neoliberal 'discursive climate of tolerance', where disabled people seem to be included and work side by side with able-bodied people while their subordination is maintained (2006: xx). Several scholars have also highlighted that rhetoric about diversity constructs certain categories of people as problematic and in need of support, while others become invisible (Ahmed, 2009, 2012; Brade, Schmitt & Sandell, 2014). Thus, the problem is attributed to those who are excluded rather than the institution (Ahmed, 2012). These scholars suggest a shift in perspective, from the individuals who are regarded as outsiders or in the margins, to a focus on exclusionary mechanisms and patterns of action such as inaccessibility or discriminating attitudes among those who are insiders or at the centre (Brade, Schmitt & Sandell, 2014). In this chapter, by focusing on examples of inaccessibility, we highlight processes that hinder change or make change impossible in the academic workplace. This perspective opens up a critique of the forms of resistance to accessibility that exist within academic walls.

How, then, can change be achieved? For this, gender studies scholars Merri Lisa Johnson and Robert McRuer (2014) suggest the figure of the *crip killjoy*, referring to Ahmed's *feminist killjoy* (2010). The crip killjoy does not say 'I can't', which is about ability, but 'I don't want to' – I am unwilling. This means a refusal to maintain a hard working pace or 'to act in accordance with the system of compulsory able-bodiedness – that requires individuals to mask, suppress, and disregard discomfort' (Johnson & McRuer, 2014: 136) in the form of, for example, fatigue, pain or medication. Being a killjoy can also be about being alert and repeatedly paying attention to injustice (Ahmed, 2012).

Inspired by this shift of perspective, this chapter draws from disability studies as well as feminist theories to explore how working life is made to include some bodies but not others, and to what effects. How is ableism reproduced? Which bodies do not fit into contemporary working life? And how do these aspects constitute obstacles to accessibility? We also discuss possible strategies for social change by being crip killjoys (Johnson & McRuer, 2014).

Cripistemologies and collaborative autoethnography

Drawing on historian of science Donna Haraway's (1988) ideas of situated knowledge, Johnson suggests the notion of *cripistemologies*[1] to designate 'thinking from the critical, social, and personal position of disability' (Johnson & McRuer, 2014: 134). Our knowledge and experiences are dependent on the situated body and are influenced by, for example, gender, class, ethnicity, sexuality and functionality. Our different experiences orient us in different ways: some things are perceived as central, interesting and engaging, while others are relegated to the background (Ahmed, 2006). The notion of cripistemologies invites coalitions between people with experience of different types of disabilities as well as allies: 'The production of knowledge about disability comes not only from being disabled but from being with and near disability, thinking through disabled sensations and situations, whether yours or your friend's' (Johnson & McRuer, 2014: 141). From this position, ableist ideas about the normal body and the normal way of thinking and feeling are criticised and may be exceeded (Wendell, 1997). Ableism marks out what is a healthy body and a normal psyche and which emotions it is acceptable to express. The normal adult is assumed to be independent and productive. Normal people master their body and consciousness, while disabled people tend to be seen as a problem or a vulnerable group that drains the system (Campbell, 2009).

In this chapter we use collaborative autoethnography to explore situated knowledge about disabilities and the workings of ableism, trying to make 'a better account of the world' (Haraway, 1988: 579). Collaborative autoethnography is described as a qualitative method 'that enables researchers to use data from their own life stories as situated in sociocultural contexts in order to gain an understanding of society through the unique lens of self' (Chang, Ngunjiri & Hernandez, 2013: 18; see also Leigh & Brown, 2020). It has three components. First, the personal and embodied experience is written down as an *autobiography.* Second, the experience is put in its sociocultural context, that is, as an *ethnography.* Finally, collaborative autoethnography is *collaborative* (Corroto & Havenhand, 2015). By using this method, giving concrete examples from our everyday working life and going close to the experiences in the analysis, we hope to shed light on the complex obstacles to accessibility.

We began with writing self-narratives on the chosen subject: How are the universities made to include some bodyminds, but not others, and to what effect? We then read each other's stories, and compared and reflected on them verbally. After that, we returned to our autobiographical writing, developed the self-narratives and collaboratively put them in their sociocultural context, relating them to previous research and theory (Chang, Ngunjiri & Hernandez, 2013; Corroto & Havenhand, 2015). The narratives are written in first person to emphasise the autobiographical point of view. Our names are omitted, since we do not find them relevant. Some of the quotations may seem impairment-specific, but an accessible work environment is better for everybody. Physical accessibility is good for employees who have temporary impairments, aching bodies or are pregnant, just to name a few, and everybody benefits from good light and sound environments. Stress may have physical manifestations, like increased pain, and having physical impairments in an inaccessible work place may lead to stress.

Obstacles to an accessible workplace

In our autoethnographies we have a wealth of examples of inaccessibilities at the university. Below, we have chosen a selection representing everyday situations, related to four themes: *physical (in)accessibility, open-plan offices and the flexible worker, crip time* and *diffuse responsibility.*

Physical (in)accessibility

A working place is not a neutral room: 'objects, as well as spaces, are made for some kinds of bodies more than others' (Ahmed, 2006: 51). The spaces in which we are supposed to carry out our work, indoors as well as outdoors, may be seen as an expression of ableism, as in the following example:

> After a reorganisation, our new department gathers in a renovated building. My first lecture with students who had just entered their

> programme ended up in a hall where the podium was downstairs via quite a few steps. No elevator or other accessible entrance were available. By the entrance, there was adapted seating for people using wheelchairs. Thus, the hall was built for students using wheelchairs but not for lecturers using such aids. This disclosure started an intense process where the whole building was examined in terms of accessibility. A long list of imperfections was made.

The lecture hall, with accessible wheelchair spaces for the audience but with an inaccessible podium for the speaker, constitutes wheelchair users as passive listeners, not as active lecturers or students (Shildrick & Price, 1996; Inckle, 2018). This incident led to a number of administrative measures pending the reconstruction of the halls. Initially, instructors with movement impairments were told not to book these halls. Later, the Swedish Work Environment Authority closed down the halls. This aroused new reactions, now among able-bodied colleagues. Some had initially expressed support and showed indignation that a newly renovated building had inaccessible halls, but when it became a fact that the halls could not be used at all and lectures were to be held in another building – meaning they would have to move – colleagues disapproved.

The next quote deals with inaccessible objects:

> Other classrooms are flat. The lecturer's desk, where you put your computer and notes, is adjustable in height. However, these tables must be adjusted by putting pressure from above, meaning that it is impossible to lower the table if you do not stand. When this happens, I must always ask some student to press down the table.

Despite legislation and updated buildings, the disabled lecturer cannot rely on accessibility and will thus be constructed as dependent on help and support. The rooms and furnishings are obviously built for able-bodied lecturers. It appears as if disabled academics are unable to 'meet the standards of university environments' (Waterfield, Beagan & Weinberg, 2018: 328), not the reverse, that it is the university that does not meet the accessibility standards. We interpret these two quotations as expressions of the 'discursive climate of tolerance' (McRuer, 2006: xx). At a first glance, disabled employees seem to be included and tolerated, but there are apparently limits to this inclusion and tolerance.

It is not only buildings that need to be accessible. It is also crucial to be able to transport oneself to the building.

> Going by car is my only way to get to work. At none of the university buildings, were disabled parking spots initially arranged. In the building where I usually work, we argued for three or four spots since we have employees, students and visitors in need of such parking. The answer to this request was that regulations required only one spot according to a mathematical model. However, they would try to arrange two spots. The

> same numbers of spots have been arranged outside the other buildings too, but only after several reminders. The actual need seemed to be of no importance. The access to these spots has however been limited from time to time. For six months, a container was parked in one of the spots, and other spots had a three-hour limit, making it impossible to park the whole working day.

Demands for accessibility in university buildings have been raised repeatedly, by us and by our colleagues, disabled or not, in the disability studies research group. We see these as examples of crip killjoys persistently asking for justice. This struggle for basic accommodation is also described in a Canadian study, which discusses a parking situation which was solved only after colleagues threatened to paint a wheelchair sign on a spot (Waterfield, Beagan & Weinberg, 2018). The consequences of not finding an accessible parking spot on campus include having to go to work much earlier in the morning and accounting for having to drive around in search for a spot, just in case. The problem is thus not attributed to the organisation (Ahmed 2012) and instead becomes individualised: it is our problem, since students and colleagues expect us to be on time for lectures or meetings.

Being a researcher means off-campus work too, doing fieldwork or taking part in seminars or conferences that involve travelling and staying overnight.

> When I recently registered for a conference, I found out that the recommended hotel was inaccessible for wheelchair users. While other attendees would probably stay at the recommended hotel, I had to find another one. This involved missing social interaction, opportunities for meeting acquaintances, brainstorming with colleagues, benchmarking and collaborations for future projects.

Meetings and kick-offs sometimes take place outside campus. A conference room at a hotel or restaurant is booked, sometimes in combination with a social event. All such events must be booked from procured suppliers and via a contract. When planning for a two-day workshop, it became obvious that accessibility was not one of the requirements when the university made the procurement.

Inaccessibilities make some work difficult or impossible to accomplish. While accessibility is never solely about physical accessibility and technological solutions (Mitchell, Snyder & Ware, 2014), it is essential that all the university's premises and the areas outside and between buildings (the latter are often forgotten) comply with the applicable legislation on accessibility (see SFS, 2008:567; SFS, 2010:900; SFS, 2011:338). In the UN Convention on the Rights of Persons with Disabilities (2006) on which Swedish accessibility legislation is based, the right to a 'work environment that is open, inclusive and accessible' is recognised. 'Reasonable accommodation' should be offered, but only so far that it does not constitute 'a disproportionate or undue burden'

(UN, 2006). Where the limit of the reasonable lies can, of course, be debated. Theatre scholar Carrie Sandahl argues that 'disabled peoples' unreasonableness and burdensomeness are sources of ingenuity', and suggests a shift of perspective: 'let us go beyond accommodation, which assumes we start with mainstream and flex to include disability. Instead let us start with disability's unreasonableness and burdensomeness to significantly remodel the mainstream' (2018: 94).

Open-plan offices and the flexible worker

> Some buildings at the university have activity-based offices. In our building, there is a recently built open-plan office. The employees are encouraged by the managers to think positively: our office landscape is better than the activity-based office we might get in the worst case. We are expected to adapt our bodies. If the noise level becomes disruptive – if someone is talking on the phone or with a colleague – we are supposed to take our computer and books and move to smaller, lounge-like spaces with the possibility of a closed door, but where the cosiness factor is valued above the ergonomics.

What types of bodies are open office landscapes and activity-based offices built for? The answer may seem obvious: the idea behind flexible workplaces is, of course, that they are occupied by flexible workers who, influenced by the space, also become more quick-witted. Creative encounters occur with the new people who show up at the next desk, and new thinking is stimulated (Germundsson & Danermark, 2016).

Calling upon positive thinking, as in the quotation above, shifts the responsibility from the employer to the employee. This way of thinking is a method originating from positive psychology and aims to reshape negative emotions and thus reach the goal of happiness. Instead of being critical or complaining, the employee becomes a good team worker who is happy and malleable (Ehrenreich, 2009; Binkley, 2011; see also Sandell, 2016). In *Flexible Bodies*, anthropologist Emily Martin (1994) notes that flexibility has become something of a fashion in neoliberal economic discourses, and is seen as inherently positive. Service, products and processes are sold with flexibility as a seductive argument. This thinking characterises much of today's working life. One example is in consulting and staffing companies; another is in activity-based offices. Here, it is claimed, versatile and adaptable employees work, who can quickly respond to changes as well as initiate them. Claims for rights in terms of employment or work environment are often seen as rigid and unconstrained (Martin, 1994). 'Might it be the older employees who are a bit rigid and slow in getting used to it [the activity-based offices]?' a young guest lecturer asked one of us with a smile in one of the university's dining rooms.

Psychologist Agneta Sandström emphasises the importance of delimiting impressions in everyday life when burnt out (Kågström, 2016). Physical possibilities to shield from sound, light and movement are needed. When someone else is moving in one's field of vision, even when far away, it means that extra information needs to be handled. Thus, for a person who is burnt out, working in an open-plan office is impossible (Kågström, 2016).

> Just knowing that someone can interrupt me at any time makes it more difficult to concentrate. I am also told by the occupational health service to do breathing exercises and take short breaks with gymnastic movements each hour. I really do not want to do that in front of my colleagues. I have nightmares about open-plan offices, and of having to move again and again. When I began to work part-time after the first sick leave, I got a private office in a building three kilometres from my other colleagues. It is far from optimal, but the best solution at hand for the moment.

Health and mindfulness exercises, together with the use of assistant devices and medication like sleeping pills or antidepressants, are examples of self-care. 'Good citizens' are expected and disciplined to work on their bodies and minds (Foucault 1976/1990; see also Alftberg & Hansson, 2012). Like positive thinking, these exercises make us even more effective and productive (Binkley, 2011; Bornemark, 2018). Yet the mindfulness culture's goal of a life in total balance is impossible to reach, and may increase stress and anxiety (Kågström, 2016). If employees still do not fit into the changing world of work, they must take responsibility and choose to work part-time or change their job (Sandell, 2016). Again, responsibility for problems in the work environment is individualised (Kågström, 2016).

Already in 1928 Virginia Woolf (1928/2004) had emphasised that the design of the rooms we live in influences our thinking and creativity. For a person with a cognitive impairment, thinking is disturbed in an open-office landscape. For a person with a hearing impairment, it becomes even more difficult to follow a conversation because of background noise (Germundsson & Danermark, 2016). In both cases, the effort leads to increased fatigue. In the words of Ahmed (2006), the rooms put bodies in order. They function as a supportive extension of some bodies but not others. The less flexible bodies and minds that would have gone unnoticed in another type of environment suddenly become noticeable as deviant, as interrupting a conversation by asking 'What did you say?' (Germundsson & Danermark, 2016) or by asking for silence – or for a parking space. The special solutions for disabled employees described in this and the previous section, such as staying at another hotel or getting a workplace in another part of the city, instead of accessible premises for everyone, can have both social and career effects. However, our open-office landscapes affect everybody's social interactions. Creative meetings do not occur, as those who can, work at home, leading to fewer meetings than in the former cell offices.

Some bodies can benefit from flexible working life while others cannot. The question then is which bodies do not fit in. The human geographer Robyn

Longhurst (2001) writes about the pregnant body, which is difficult to control and threatens to leak. The same could be said about the aging body. But also, about the asthmatic or the diabetic body, the one whose shoulders and neck are aching, the one who does not hear or see so well, the one who is a little slow in movement or thought, has a temporarily twisted ankle or a spastic hand; all these have difficulty being fully flexible. It is hard to draw a sharp boundary between the normal and the disabled (Campbell, 2009). Functionality varies with the context and the form of the day. Accessible premises are good for large groups who are often not seen as disabled but who have temporary injuries or illnesses, or repetitive strain injuries that cause disabilities. Campbell (2009) points out that the vast majority of people are actually in the grey zone between the two socially constructed categories of disabled people and able-bodied people.

Crip time

> Newly employed, I tell a colleague that I have seen the librarians taking a coffee break together each morning. She answers that that is not possible for instructors due to their workload.

Time is key in the university. Instructors' working hours are often scheduled to the minute, and working overtime in the evenings, on weekends and during holidays is fully normalised (Johnson & McRuer, 2014; Brown & Leigh, 2018; Leigh & Brown, 2020). Not even a short coffee break seems possible. According to the Swedish Work Environment Authority (AFS, 2015:4), the employer has responsibility to ensure that employees do not have an unhealthy workload. An unhealthy workload is defined as 'when job requirements exceed resources on more than a temporary basis. This imbalance becomes unhealthy if it is prolonged and if opportunities for recovery are inadequate' (AFS, 2015:4:6). These provisions are binding regulations.

However, a time study from the Swedish National Agency for Higher Education (Högskoleverket, 2008) shows that university instructors are estimated to work an average of 52–53 hours, almost the equivalent of a seven-day week. Lecturers and professors work the longest hours, about 57–58 hours a week, including 15–16 hours in the evenings or on weekends.[2] Thus, if fulltime work is 52–58 hours a week, being on sick leave on 50 per cent and only working 20 hours a week, with cognitive impairments that make one less efficient, leads to a considerable difference in numbers of hours worked and in amount of work done. Underlying this workload are factors such as the economisation of higher education, administrative functions that have been cut even as administrative tasks have increased and instead been placed on instructors and researchers, and constant reorganisation (such as those that cause the nightmares in the previous section) to increase economic efficiency. Reorganisations also lead to anxiety, stress and a reduced desire to work (Högskoleverket, 2008), and demand flexibility and adaptability of the employees (see also Martin, 1994). These changes are closely associated with the introduction of neoliberal forms of governance from the private sector into the universities and other public sectors, the so-called New Public Management. To be able to control the quality and effectiveness of work it has to be documented, measured (preferably quantitatively) and evaluated. The philosopher Jonna Bornemark (2018) describes this as the growth of two parallel realities. On one hand are core activities: teaching and researching in the case of the university. On the other hand is the documentation of the core activities. Lived reality is always complex, but in the evaluations, it is only the measurable parts that count. Thus, there is a risk that the core activities have to adapt to their documentation. This development has both increased administrative workload and led to feelings of meaninglessness and ethical stress as time for core activities decreases (Bornemark, 2018).

With an increasing workload follows a need for recovery for everybody, but especially for people who are burnt out (Kågström, 2016).

> When burnt out, there is a need for regular breaks and time for recovery (for example outdoor walks) during the working day. When teaching, it is customary to have 15 minutes break each hour. But when instructors and/or researchers gather it is often for two-hour meetings or seminars without breaks, or only one break if it is a three-hour seminar. The research group has a one-day seminar at a local conference hotel. When we begin again after lunch, I look out through the window and try to ‘close’ my ears. My head is already overloaded with information. I go to the restroom, and then I stay in the foyer for a while, to get time for recovery.

While the need for rest is acknowledged for students, staff are expected to work without regular breaks. Sneaking out into the foyer becomes a silent way of resisting. Campbell (2009) discusses time as a factor that stops disabled people, who often need more time in general and flexible working hours. What feminist studies researcher Alison Kafer (2013) calls ‘crip time’ is more than extra time:

> [I]t requires reimagining our notions of what can and should happen in time, or recognising how expectations of ‘how long things take’ are based on very particular minds and bodies. We can then understand the flexibility of crip time as being not only an accommodation to those who need ‘more’ time but also, and perhaps especially, a challenge to normative and normalising expectations of pace and scheduling. Rather than bend disabled bodies and minds to meet the clock, crip time bends the clock to meet disabled bodies and minds.
>
> (Kafer, 2013: 27)

Using a wheelchair implies that one needs more time to move around, given for example the lack of parking space, inaccessible public transport and the unsuitability of stairs as an alternative when lifts are full or not functioning.

> Lecturing takes part in lecture halls and in buildings spread around the city. Thus, moving around is common and an imperative. For each occasion, you must bring your laptop, books and other material. Carrying around heavy and ungainly items is an obstacle for anyone, and especially for those with mobility impairments. When a couple of students with hearing loss entered one of the educational programmes, it appeared that the lecture halls were not equipped with hearing loops. Thus, movable speakers had to be collected by the lecturer and brought to the hall. When not able to carry these around, you have to make special arrangements, asking someone else to bring them for you. Such special solutions always are at risk to fail due to the human factor; this also has happened. These occasions have ended up as stressful situations, moving around and trying to find the speakers or the person who should bring them.

A solution to remove disabling conditions for some individuals (students with hearing impairments) results in disabling conditions for someone else (lecturers with mobility impairments). Such temporary, *ad hoc* solutions, aiming to compensate for rooms built for the able-bodied, result in extra workload and thus a more stressful working life. Yet, if an employee refuses to make up for inaccessibilities, there may be consequences:

> On one occasion, I cancelled the lecture after waiting 20 minutes for the speakers to be delivered. I refused to give a lecture and risk discriminating against students with hearing loss. The incident quickly became known to the highest level of management at the university and I was contacted and asked to explain my decision. I felt like being reprimanded by the management.

The employee acted as a crip killjoy by disrupting one of the university's main activities, and, consequently, the lack of accessibility was made visible.

Diffuse responsibility

As our examples have shown, hindrances in the university environment are manifold. These shortcomings could be expected to be of interest to the management, yet the quote below shows the contrary:

> When inaccessibilities have been highlighted, the reaction from responsible departments and staff has been that the remarks are disturbing and sometimes even unachievable. Departments send the tasks to other departments or to other institutions outside the university, i.e. the municipality or the property owners. Years have passed and the inaccessibility remains. No one raises her/his hand saying, 'I have the responsibility and I will see to it that this is solved'.

Disability studies scholar Tanya Titchkosky (2011) confirms these procedures and highlights that disability and access are entailed in bureaucratic practices that in the end exclude disabled people. Responsibility for managing accessibility issues (for example, reporting errors) is often placed as an additional task for disabled staff. It has been claimed that all energy that must be put into asking for, reminding about and finding out solutions, compensating for an inadequate environment, is also an indication that disabled faculty do not fit into higher education (Stone, Crooks & Owen, 2013). Furthermore, there are a number of invisible impairments, permanent or temporary, or invisible effects of visible impairments, which employees may not want to reveal for various reasons (Bain & Tremain, 2015; Brown & Leigh, 2018; Hannam-Swain, 2018). Coming out as a disabled person always involves a risk of being stigmatised as deviant and that the diagnosis will define the person instead of being considered part of a complex identity (Goffman, 1963/1990; see also Patrick Kermit's chapter in this volume). The person may be seen as troublesome by colleagues, students and administrative staff, as someone who creates extra workload for others, is accused of inventing, exaggerating or being lazy. In addition to the time it takes to undertake accessibility work, emotional work is also required to deal with the resistance the person encounters (Brown & Leigh, 2018; Inckle, 2018).

Conclusion: when accessibility gets stuck

Our analysis of the autoethnographies in this chapter have shown several examples of inaccessible objects and spaces in the built environment at the university: lecture halls, open-plan offices, furniture, outdoor environment and conference hotels are made for flexible and able-bodied employees. Furthermore, the organisation of work according to neoliberal forms of governance leads to parallel realities, higher demands on performance and productivity as well as an increasing administrative burden on the employees. This causes both ethical stress, and stress related to demands to become more effective.

The answers that are given to inaccessibilities are often special solutions that lead to missed social and career opportunities. The responsibility for reporting inaccessibility, for reminding about these and to find *ad hoc* solutions, becomes extra workload for disabled employees. Moreover, instead of solving the broader problems in the organisation of work, employees are encouraged to think positively and devote themselves to self-care, with the goal of working even more effectively. Thus, in both cases, the responsibility is shifted from the employer to the individual employee, who is constructed as demanding, dependent and/or deviant. An additional aspect is the diffuse responsibility for accessibility. With so many parties involved, the demands for accessibility get stuck within bureaucracy.

Based on our findings, we see ableist structures and practices within working life and the neoliberal organisation, together with the individualisation of work environment problems and diffuse responsibility, as the main obstacles to accessibility. Accessible premises are fundamental, with the goal of finding general solutions (Brade, Schmitt & Sandell, 2014). However, a completely accessible world and universal design is impossible.[3] 'Unless paradise is paved into a parking lot, most of the earth's surface is going to be too rough for my wheelchair,' as author Nancy Mairs puts it (1996: 105). Different needs, depending on type of impairment, may be in conflict. Thus, awareness is also needed of invisible and ableist institutionalised practices and able-bodied standards that are taken for granted. The focus has to shift from the problematised outsider to how ableism, built on the idea of the normal worker, with a normal body, normal way of thinking and feeling, and normal pace of work, excludes some. Crip time is about flexible university organisations and employers, not flexible employees. The inflexibility and the ever-increasing demands on efficiency of the work organisation stops already-disabled persons and is in itself disabling. Thus, flexibility has to be introduced on several levels at the university. If the starting point is taken to be 'disabled peoples' unreasonableness and burdensomeness' (Sandahl, 2018) when organising and rebuilding working life, the need for individual special solutions would decrease, and employees would not have to disclose their impairments.

We are still waiting for the person responsible for accessibility to raise his or her hand. Meanwhile, is it possible to speed up change towards an accessible working life? Bornemark (2018) suggests forms of micro-resistance, such as prioritising core activities over administrative tasks. Some employees make the individual choice to quit, but when many do it at the same time, as we have seen in the Swedish care sector, it becomes a political issue that drives change (Bornemark, 2018). The latter could be seen as an example of being crip killjoys. Saying 'I am not willing' is an act of resistance. It may encompass the refusal to work in inaccessible buildings or a refusal of self-care techniques that have as their only aim, helping to become a happy, flexible and productive employee. Johnson and McRuer (2014) admit that it is sometimes easier to say 'I can't', referring to the impairment. However, we believe that the possibility to say 'I don't want' also depends on the individual's social position (Mulinari & Sandell, 1999). It may be difficult for a lone instructor or researcher to be a crip killjoy, and a refusal to be willing and able to face resistance can result in temporary employment not being extended. When working on this chapter, we certainly realised the difficulties in being a crip killjoy. In some cases, decisions had to be taken quickly. Being in a hall full of expectant students, it was difficult to choose a path that would affect many students negatively. The same ambivalence occurred when there was a chance colleagues would be affected. In order not to place the responsibility on the individual, with the punishments that, as we have seen, may follow, we imagine that a collective '*we* are not willing' from those with the protections of employment, and those who are permanently or temporarily disabled and their allies, is more realisable and effective.

Notes

1 From the derogatory term ‘cripple’.
2 The study was based on diaries kept during one week by 106 instructors and leaders.
3 See, e.g., Apelmo (2016) for a discussion on universal design.

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8 Access to sexuality

Disabled people's experiences of multiple barriers

Julia Bahner

> My most important right is to be respected for the trans person I am. (…) My most important right is to decide over my own life.
>
> (RFSL Stockholm, 2020: 21)

In the past few decades research as well as disability rights activism have shown the different kinds of problems that many disabled people experience when trying to express their sexuality (Shakespeare et al., 1996; Chappell & de Beer, 2019; Shuttleworth & Mona, 2021). The issues faced include being prevented from expressing one's sexual identity by family members or staff in group homes (Gill, 2015; Toft, Franklin & Langley, 2019), inadequate sexuality and relationships education (Löfgren-Mårtenson, 2011), or a lack of information in rehabilitation about how an injury may change the way one can have sex (Angel & Kroll, 2020).

The international scope of the research and activism highlights that the problems described are not individual, but are often shared across contexts as well as impairments. Disabled wheelchair users may experience physical inaccessibility, while lack of access to appropriate disability services can hinder a Deaf or a Blind person from accessing social gatherings or online dating communities. Prejudice about disabled people's perceived attractiveness or abilities in the sexual realm – compared to normative standards – are experiences shared by many, albeit with different connotations depending on the specific context. For instance, insecurity and low self-esteem can lead to barriers in exploring one's body and sexuality (Wiseman, 2014; Liddiard, 2018; Abbott et al., 2019).

Against this background, I will in this chapter[1] explore *sexual access*, namely the various barriers that disabled people face when trying to access opportunities for sexual expression (Shuttleworth & Mona, 2002).

Perspectives on sexual access

Access to sexuality must be understood within a general framework of disability experience. The shared experiences of barriers to sexual access can be attributed to widespread disability discrimination, i.e. *disablism* (Oliver, 1990),

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and societal structures that are not constructed accessibly and therefore hinder disabled people from leading full lives, i.e. *ableism* (Campbell, 2009). In other words, my perspective rests on a social model understanding of disability, meaning that disability is understood as something that people with impairments may experience in inaccessible environments and societies – and not as an inherent fact due to a bodily or mental feature (Oliver, 1990).

To this perspective I add necessary aspects of the political and relational nature of the experience of disability, namely how cultural imagery of disabled existence often impacts negatively upon disabled people's views of themselves and what life opportunities they can imagine (Kafer, 2013). In other words, impairment cannot easily be separated from disability; both are influenced by political and cultural views. Similarly, not everything is about inaccessibility or discrimination: some impairments entail, for example, chronic pain or fatigue, which can be negatively experienced by the individual even when they have access to medication, a supportive work environment or otherwise accessible surroundings (ibid.). While the medical model of disability one-sidedly emphasises disability as a problem of impairment requiring medical solutions, the social and relational–political models of disability further expand both the perceived problem and its solutions to the social and structural domains. My approach thereby rests on a *multifactorial understanding* of disability, which highlights the interaction between individual and structural factors (Shakespeare, 2013).

Taking a similar approach, anthropologist Russell Shuttleworth (2007) argues that *access* is often understood in a narrow and technical way, with focus on contexts such as schools, workplaces and the built environment – obscuring more complex, cultural and psychological domains such as sexuality. Although access to various physical environments also interferes with opportunities for sexual expression, unique aspects in relation to sexuality 'are the cultural meanings of sexual attractiveness and desirability, which often combine with other barriers to compound the problem of sexual access for disabled people' (Shuttleworth & Mona, 2002: pagination missing). Thus, in their pursuit for sexual expression and relationships, many disabled people face a combination of logistical and sociocultural factors (cf. Bahner, 2020).

These barriers to sexual access can be understood within a social hierarchy in which disabled people are marginalised and devalued compared to non-disabled people in general, and in the 'dating market' and 'sexual attraction hierarchy' in particular (Emens, 2009). Not least the psycho-emotional impact of living in an ableist and disabling society can demand special consideration, acknowledgement, peer support and specialist services in order for disabled people to access desired psychological, social and cultural contexts of sexual expression (Shuttleworth & Mona, 2002). While there are, of course, many disabled people who have been successful in realising their wishes in the sexual domain, this chapter focuses on issues described by those disabled people who struggle in various ways.

By analysing narratives about barriers that disabled people experience in different situations related to sexuality and relationships, I aim to illuminate the interaction between individual and structural factors. The chapter is based on an analysis of materials published between 2000 and 2020 dealing with sexuality and disability from disabled people's perspectives. These were produced by Swedish civil society organisations with the aim of educating disabled people about their sexual and reproductive rights. The projects were run by self-advocacy organisations, sexual rights organisations and organisations led by non-disabled people and working on behalf of disabled people. Materials from ten organisations' projects were collected, comprising books, handbooks, videos, websites and other online materials.[2]

Building on a qualitative content analysis (Altheide & Schneider, 2013), my approach combines a first-stage descriptive analysis of manifest content followed by a more interpretive analysis of latent content. Specifically, I started with categorising the materials according to project aims. This resulted in three themes: (1) information about sexuality and relationships, (2) sexual and gender identity, and (3) disability services. However, several projects have multiple foci. The themes corresponded directly with the organisation type responsible for the specific project. For instance, RFSL, a national association for Lesbian, Gay, Bisexual, Transgender, Queer and Intersex Rights conducted several projects about disabled people who identified as lesbian, gay, bisexual, transgender or queer (LGBTQ).

When analysing the materials further within each category, the main guiding question was: what kind of (sexual) accessibility problem is described? The following themes were categorised: (1) inadequate information, (2) psycho-emotional barriers, (3) relational barriers, (4) support-related barriers, and (5) policy barriers. From this analysis it became apparent that projects aimed at certain groups catered to those groups' particular needs, for instance, those targeting people with intellectual disability focused on issues around autonomy and self-determination in group homes, relationships with staff and family members, and the need for specialised sexuality and relationships education. Likewise, a project by an organisation representing persons with spinal cord injury focused on how to handle bodily changes following injury and offered tips on sex aids and toys, among other things.

In other words, the latent content analysis revealed that materials differed in terms of aims, scope, target group and so on. The results must therefore be interpreted with this in mind: they are based on different understandings of disability and the problems that are in focus, which relates to the kinds of organisations and the aims they had for the project. I will now analyse examples from the materials within each category.

Inadequate information

The background to a majority of the materials is an experience of inadequate sexuality and relationships education in special schools, which can be understood against the fact that seven out of the ten projects targeted people with intellectual disability. Additionally, however, two projects by an organisation representing youth with mobility impairments were based on the notion that these young people had not received adequate sexuality and relationships education in relation to their specific lived experiences of disability. Inadequate sexuality and relationships education leads to a lack of knowledge about all things relating to sex, sexual identity and relationships. When, for instance, in the case of persons with intellectual disability, young adults and adults move to assisted living facilities or start working in assisted workplaces, they may be happy to meet new peers and potential sex partners – but often lack adequate resources to access information and support.

A project called *The right to live my life* was conducted by a cultural pedagogy association in the city of Uppsala in 2014–2017. The resulting report details the thoughts and experiences of participants with intellectual disability who use disability services. One of the participants, who was interviewed about experiences of barriers in their group home, said: ‘Many people need training about relationships, body language and boundaries – like when you get training about other things, like shopping or taking the bus’ (Kulturparken Uppsala, 2018: 17). Other participants in this project described their insecurity about whom to talk to about sex and relationships when not wanting to involve parents, and the lack of information in group homes about sex and relationships, including not knowing how to find information on the internet. For some this resulted in questions about practical things such as how to masturbate or use sex toys and aids, but also in a more profound lack of knowledge and understanding about personal integrity, boundaries and what constitutes sexual abuse. The project aimed to present alternatives for improvement in these settings, and many of the participants’ suggestions revolved around education for both service users and staff.

The *Sex in movement* project was conducted by the Swedish Youth Federation of Mobility Impaired, a self-advocacy organisation, together with a local branch of the Swedish Association for Sexuality Education (RFSU) in 2016–2019. It explored questions such as: What possibilities do I have to have sex? Which practices work? How can I give and receive pleasure? A number of short films were produced and uploaded on a dedicated website, which is still available.

The film *Something New* depicts two young men having sex in bed (RFSU Stockholm, 2019a). Simultaneously, we see a young woman pleasuring herself with various objects on different parts of her body. But while the young men express boredom both during and after sex, the young woman exhibits pleasure and excitement. In the following scene it turns out that one of the men is friends with the woman. She tells him what great sexual experience she had last night when her partner was away: ‘It feels like every time [I masturbate] I find new ways to explore my body. And it’s so cool with all the different sex toys that are available nowadays!’ The conversation inspires the man to start exploring new ways to have sex with his partner using an electric toothbrush, olive oil and candles. The films were intended to be both educational and inspirational examples of ways to explore one's body and sexuality as a disabled young person, and fill an experienced lack of imagery and information for this particular group.

In 2006, an organisation of spinal cord injury survivors produced films and a handbook in the *Lame limbs and dry panties* project (RG, 2006). These films were also meant to inspire and educate by showing discussions among young adult and middle-aged women and men with spinal cord injury. One of the topics of discussion dealt with physical changes to the body following injury which necessitate new ways to have sex or to be intimate with a partner. A middle-aged man talked about the long process of getting to know his 'new' body, to build confidence and integrity, and to eventually find ways to have sexual pleasure. Masturbating, experimenting with aids and having open communication with one's partner were stressed. Other discussants also shared tips on bowel and bladder control and on sex aids that stimulate erection or vaginal sensation, as well as the need to mentally allow oneself to explore the body in new ways. These films have a somewhat more individual and medical focus, which is not surprising considering that the project was conducted in collaboration with a rehabilitation centre. Like the *Sex in movement* project, however, the films were intended to fill experienced gaps in information and support in a particular context.

Another example of peer support comes from the 2011 *KISS* project of the Swedish National Association for People with Intellectual Disability (FUB). This association is primarily run by parents of children, youth and adults with intellectual disability, as was the project. Youth and adults with intellectual disability were interviewed and asked to submit stories about their experiences around sexuality and relationships. The project resulted in a website and accompanying teacher's guide (Granér et al., 2009). One of the participants shared a story about parenthood:

> One day a week we receive help from a support pedagogue. We got the contact through the habilitation services. We get help with planning and shopping. We also discuss a lot. […] We have a good life and sometimes I'm surprised how well it has turned out for me. Planning and a good network are important. Don't be afraid of asking for help!

This and other examples on the website offer both a description of a problem but also possible solutions, showing that not everything about disabled people's sexuality is 'doom and gloom' but that there are also good examples. A difference with this material is that it also directed participants toward other sources of information and support, that is, not only within the community of disabled people but also professionals. This may be due to the fact that *KISS* was aimed at people with intellectual disability who may have greater need for help from professionals in accessing information and support, and that the material was produced by non-disabled people.

Psycho-emotional barriers

Multiple materials illuminate how disabling barriers and ableism in society can lead to emotional and mental health issues. For example, participants with intellectual disability in *The right to live my life* project introduced previously shared stories of having been bullied in their youth and how this resulted in a general sense of insecurity and low self-esteem and, with regards to sexuality, constant worries about what others would think about a disabled potential partner and about looking and acting 'right' (Kulturparken Uppsala, 2018). Insecurity and low self-esteem can also be risk factors for being abused or tricked when dating and socialising online, when there is a stronger desire to meet someone and be able to show others that one is 'normal' than to stay safe and thereby lose the opportunity to meet someone at all (cf. Hollomotz, 2011). As one of the participants explained: 'Everybody wants love or friendship, sex or affirmation. You would rather have bad relationships than no relationships' (Kulturparken Uppsala, 2018: 23). Examples like this shed light on the need to combine educational opportunities with empowerment and sometimes more individual therapeutic support, according to the project report.

Similar experiences were shared by persons with other types of disability experiences who identified as LGBTQ in *The disability project* of the Swedish Federation for Lesbian, Gay, Bisexual, Transgender, Queer and Intersex Rights (RFSL) in 2014–2017. The project report highlights a theme of psycho-emotional strain related to not being able to express one's sexual identity in the disability community (RFSL Stockholm, 2013). Participants who were interviewed for the project reported that having to hide their sexual identity resulted in feelings of loneliness, lack of energy and difficulties meeting people. One person reflected:

> I imagine that the intersection of being disabled and LGBTQ makes a person quite invisible everywhere. That I generally fall outside of some kind of gender matrix or desire because my body is not perceived as normal, and therefore I'm not read as lesbian or queer because I kind of don't have a sexuality.
>
> (ibid., p. 29)

This experience recurs in other materials, for example in the *Prejudice and pride* project by Forum Skill, a resource organisation which runs projects and activities with human rights as a starting point. This project focused on norms around love and sexuality and included an easy-to-read book with reflections by disabled and non-disabled persons on their identity, sexuality and family life, including queer, trans and various family formations. The project also released a short film, *Tessan=Victor* (Forum Skill, 2011), about a physically disabled trans man's quest for recognition as disabled *and* trans. This followed Victor's journey through the gender reassignment process with its ups and downs, both mentally and practically, in relation to disability services and the health care system.

A more recent project by RFSL focused on similar issues but in relation to people with intellectual disability. The project resulted in three books based on stories told by persons with intellectual disability who identified as LGBTQ. These stories add another dimension to the problems described by Victor, namely that people with intellectual disability seem to have more difficulties making their voices heard and opinions believed compared to disabled persons without intellectual disability. One example dealt with not being allowed to decide one's own name even as an adult trans person, illuminating the paternalistic approach to persons with intellectual disability in general and those with LGBTQ identities in particular (RFSL Stockholm, 2018). In both the film about Victor and the books, the aim was to combine information about rights with offering role models for how rights can be asserted.

Another theme relating to psycho-emotional barriers concerns insecurity and low self-esteem and how these could raise barriers to exploring one's body and sexuality. In another project by Forum Skill, *This is how sex works*, the focus was on developing easy-to-read sexuality and relationships education materials in collaboration with people with intellectual disability. The resulting handbook is full of facts and images about the body, sexual identity and sex, and examples from disabled people's lives. One of the examples details a physically disabled man's insecurity about the willingness of personal assistants to provide support during masturbation or non-normative sexual activities such as threesomes and BDSM[3]: 'I can regret not [trying out different kinds of sex] earlier in life. Maybe I didn't want to earlier. Or was the wait due to me thinking about what my surroundings would say and think?' (Forum Skill, 2015: 103). Similar thoughts were described by a participant in another handbook published by the Swedish Federation of Youth with Mobility Impairments for the project *A secret known by many* which focused on sex, relationships and personal assistance (Svensk, 2011):

> It can be difficult to like one's body when it doesn't obey or do as one wishes – it can influence one's charisma, and one's belief in oneself and one's ability to meet a partner or to have sex.

This example relates to issues around personal and bodily integrity in general, as well as integrity in relation to personal assistants specifically. Using the example of this participant's situation, the handbook discusses how to negotiate potential needs for assistance around sexual situations. It emphasises the importance of choosing assistants with whom one feels safe, and thinking through the type of help needed and discussing it with them beforehand. As such, this and the previous example about BDSM show how difficult it can be to be in a situation of dependence with disability service staff when one has a non-normative body and/or sexuality. Difficulties can arise both on a personal level, in terms of low self-esteem or insecurity about one's body in relation to societal ideals, as well as in relationships with others. This will be discussed further in the following section.

Relational barriers

Participants in the various projects shared their thoughts and experiences of social barriers in terms of self-presentation and relationships. A film with discussions among spinal cord injury survivors began with the questions ‘Who regards you as attractive?’ and ‘How do you meet someone?’ (RG, 2006). One of the women replied that it is important to be ‘clean and tidy’, to wear nice clothes, to look as ‘ordinary’ as possible, and to ‘use what you’ve got’, for instance your eyes. In short, to have confidence, flirt and use one’s charm. Other women talked about learning to accept one’s new body, to continue using makeup and to be outgoing. The male discussants agreed, one of the young men said that he sometimes even used his wheelchair to attract attention from women, but also acknowledged the need to look fresh and wear nice clothes. Another added that eating healthily and exercising is especially important when one is a wheelchair user. In other words, the potential social barriers with prejudice and breaking bodily norms were not discussed as social and normative barriers but were met with solutions that were ascribed to individual responsibility, illuminating a more medical approach to disability.

By contrast, another theme emerges in the materials focusing on issues among persons who identified as LGBTQ, namely prejudice about disability, including invisible impairments, and the ways in which this affects one’s opportunities at social events and in the dating scene. Many participants in various projects felt a need for peer support groups and arenas for disabled LGBTQ people, especially since there were common experiences of not feeling welcome or included in LGBTQ spaces due to inaccessible venues and/or lack of knowledge about disability. A project report by the LGBTQ rights organisation RFSL (2013) gives examples of participants who said that the lack of role models who are ‘both disabled and sexual’ led to insecurity in their identity as well as in navigating different communities. Some participants recounted having to compensate for their accessibility needs in order to be able to attend LGBTQ events, which took a lot of energy and resulted in impairment effects. At the same time there were experiences of not being able to express an LGBTQ identity in the disability movement due to its strong heteronormativity. One of the participants spoke of their lack of ‘erotic capital’ in the ‘dating market’, communicating a more structural view of disability:

> I don’t think I’m that affected when having sex, but instead it’s my sexual capital, my erotic capital, my value is devaluated with my impairment. I mean, say what you want but aids are not sexy.
>
> (ibid.: 23)

As such, the participants who identified as LGBTQ argued for a need to understand dating issues beyond the individual level, and pointed to the societal norms and value hierarchy around gender, the body and sexuality.

For participants with intellectual disability family members could become an added problem. Some spoke of barriers to expressing their sexuality to parents or other family members: ‘Parents decide if sex is allowed’ and ‘Parents can be overprotective and continue to view their adult children as children’ (Kulturparken Uppsala, 2018: 16). The latter can include issues with parents acting as limited guardians and restricting how the individual uses their money (limited guardians are appointed according to the LSS law[4] to support decision-making). This relationship with parents is not wholly negative; many rely on them for necessary support, both social and practical. However, participants also reported feelings of involuntary dependency on parents’ help in daily life with things that were not covered by formal support systems, making desired levels of independence more difficult to achieve. For LGBTQ participants with intellectual disability these issues could become even more complicated, for instance when deciding if and how to come out:

> I didn’t want to have a bad relationship with my family. … I didn’t want to risk that my family would disappear. … I was afraid to hear: We don’t want to see you ever again. Afraid that the family would ostracise me.
>
> (RFSL Stockholm, 2019: 13)

This example illustrates the complex relationship between the sometimes-necessary informal support and societal norms. In other words, while there are generally expectations on young adults to start preparing for a more independent lifestyle, with less influence from parents, those with intellectual disability often face a different situation. The type of impairment can therefore also be a factor in sexual access. The next section will dig deeper into the formal support structure.

Support-related barriers

For persons with intellectual disability who rely on professional support to exercise their independence, things can become difficult when staff reluctance and organisational boundaries hinder sexual access. This is discussed at length in the report by the *The right to live my life* project. For example, some of the participants with intellectual disability said that staff lacked education on how to talk about sex and relationships, that staff acted unprofessionally (based on their own values rather than on knowledge), that there was a lack of staff of the same gender with whom they felt comfortable talking, and that there were many new staff with whom they didn’t feel comfortable talking about sex. As one participant said, ‘When they ask about what support you need they should also ask about relationships, boundaries and sexuality’ (Kulturparken Uppsala, 2018: 17).

The report also gives examples of organisational routines or decisions by individual staff that hindered residents’ sexual expression, including lack of privacy or inadequate routines for ensuring privacy, staff deciding that sex was not allowed in group homes, that sleepovers were not allowed due to organisational routines or fire safety, or that staff were not willing to assist with and around sex due to insecurity around legal or other regulatory frameworks. Furthermore, there were problems with accessing support around social activities where one would potentially meet sexual partners, for example when such support was only available during office hours due to staff scheduling or there were not enough staff to help with attending events. Some participants felt that they did not have any influence on decisions about activities (ibid.).

Similar experiences were recounted in one of the other projects by an interviewee who was a physically disabled male user of personal assistance:

> It turned out that her assistants had said that they would resign if we had sex. I don't know why they said that. It was only one assistant who wanted to help us. But they only worked one night every other week. Talk about scheduling one's sex life….
>
> (Forum Skill, 2015: 96)

A comparable scenario plays out in a film produced by the self-advocacy organisation Grunden. Their project, *We breathe the same air: about gender equality in LSS and SoL*, specifically targeted persons with intellectual disability who receive support through the Social Services Act (SoL) and the Support and Services to Certain Persons with Functional Disabilities Act (LSS). The project aimed at supporting individuals in understanding and securing their rights to be treated fairly in issues to do with relationships, parenthood, and choosing activities and work placement outside of the traditional gender norms. In five films and a handbook, different scenarios exemplify difficulties that can arise. The film *Anna & Linnéa* tells the story of how a lesbian couple are hindered from spending time together in Linnéa's group home due to a previously set time for washing hair (Grunden, 2012a). The staff member says: 'If you can't keep your routines when Anna is here, then Anna needs to go home'. Linnéa argues for her position, to which the staff member replies that if so, they may have to make a note in her file about this situation. Linnéa gets upset and takes Anna to her room, where Anna tries to calm her as they lie together on the bed. Soon, a staff member enters the room and Linnéa exclaims: 'What are you doing? You're supposed to knock!' The staff member explains that they are just trying to do their job.

The film *Alone* from the project *Sex in movement* which focused on youth with mobility impairments, shows a more positive narrative (RFSU Stockholm, 2019b). It starts with a young man who, after a few tries, is finally content with how his assistant styles his hair. In the next scene he is sitting on the couch with his boyfriend and says 'closer', prompting the assistant to help him move closer. He then signals through eye contact to the assistant to leave the room, and the two young men start to kiss and cuddle. Suddenly, the assistant comes in with a glass of water – clearly interrupting. Although this situation is uncomfortable, the young men continue to cuddle and enjoy themselves after the assistant has left. In both this and the previously discussed film, a key message is that disabled service users have a right to privacy and to relationships, and that staff should not be obstacles to this.

An older project directed at young personal assistance users with mobility impairment, *A secret known by many*, emphasises the need for courage and strong self-esteem as important for standing up for oneself and demanding one's rights. To illustrate some of these points it tells the story of 'Stefan' who uses personal assistance around the clock. He says that he wants his relationship with his assistants to be social and informal, and that he discusses everything with them, including sex, love and relationships (Svensk, 2011: 33). Dating is also discussed and not least how to manage assistance during intimate moments. Talking about such issues beforehand is recommended. Similarly, the handbook discusses how to manage assistance whilst cohabiting with a partner. Various opportunities for employing partners or family members as assistants are discussed in relation to independence and their influence on the romantic relationship: 'The partner can help out during the night so that the couple can avoid having an assistant in the bedroom and ensure privacy' (ibid.: 46, 49). This example gives a somewhat different idea of how to manage potential support-related barriers, namely to develop self-esteem, demand a certain type of service relationship – or simply arrange support within other relationships.

The examples in this section are intended to show how reliance on staff can put service users in a position of dependency, and that their sexual opportunities may be circumscribed by negative attitudes, lack of knowledge or organisational boundaries. This hinders sexual access which may be further compounded when organisations are not willing to allocate adequate resources for educating staff or hiring more staff. However, the more positive examples can also be read as wishful thinking by the projects or individual participants and as describing how things should be rather than as examples of how disabled service users experience such situations in general. On the other hand, the choice to give such examples is also understandable as they offer positive role models to individuals who may feel isolated with their thoughts and insecurities – indeed, this was one of the explicit aims of some of the projects.

Policy barriers

Some of the access barriers that informants in the various materials discuss relate to (lack of) support at a societal level, and the way that the construction of services and their implementation pose barriers to living independently in general and for sexuality and relationships in particular. A blog post in the project aimed at young personal assistance users with mobility impairment details the experiences of the special transport system under the rubric 'A barrier to love?' (Förbundet Unga Rörelsehindrade, 2012). The author, who uses a power chair, describes various problems that arise when she travels with her husband, who is also a power chair user: there is not enough space for two chairs on special transport or trains, which makes travel more expensive and impractical, and they do not have enough assistance hours to cover the extra time needed for longer travels (see also Vanessa Stjernborg's chapter and Kristofer Hansson's chapter in this book). Overcoming these problems would mean 'feeling normal' and 'being able to live a life like others'. The example illustrates how social policy impacts on service users' possibilities for sexual access – but also how it influences their feelings of self-worth and being seen as a 'normal' citizen.

Another issue concerns the economic situation, which was highlighted by interviewees in *The right to live my life* project. Participants who live in group homes or similar supported accommodation reported high living costs in relation to their incomes, leading to difficulties attending social events with a financial cost, including visits to coffee shops, pubs and the cinema – all popular dating activities (Kulturparken Uppsala, 2018). Participants, primarily those with intellectual disability, also spoke of a lack of meeting places (online and offline) where they felt safe and welcome.

Other issues detailed in this project concerned couples in which one or both live in special accommodations, and who experience a range of issues: finding accessible housing, difficulty when meeting someone belonging to another municipality with different policies, issues with secrecy regulations in relation to sharing information about support needs, and a risk of losing assistance following marriage (Kulturparken Uppsala, 2019). The lack of regulation of limited guardianship, especially when family members act as informal guardians, can also pose obstacles to couples whose family members do not approve of the relationship for some reason (ibid.).

As mentioned earlier, the *We breathe the same air* project dealt with issues relating to disability services and the ways in which different laws and policies influence the daily lives of people with intellectual disability. One of the examples in the project handbook concerns a situation where the Public Health Agency declined an application for adoption by disabled parents on the grounds that personal assistance services may impact negatively upon parenting abilities and the mother–child connection (Grunden, 2012b). Although it is not possible to know the extent to which this problem occurs generally, the project's examples were all based on participants' experiences. The example does not give enough background information on the details behind the agency's decision, and it is therefore difficult to interpret its meaning. However, the point that Grunden makes is that everybody should have the same opportunities for fair and equal treatment in applications for support, and that decisions should not be based on prejudice about disabled persons' parenting abilities.

The examples in this section show how the lack of a policy on sexual rights for disabled people exacerbates many of the problems discussed: when no one is responsible for ensuring sexual access, it is easily left aside by otherwise busy and often underfunded service organisations. If sexual access is not recognised as a legitimate issue, opposition towards it can more easily continue. The projects' materials therefore have a strongly educational slant, informing about disabled people's rights in order for individuals to be able to counter barriers, but also giving examples of how we can work together to achieve change on individual, organisational and structural levels.

Conclusion: the struggle for sexual access

This chapter has analysed various types of materials from ten projects dealing with sexuality and disability from disabled people's perspectives. The following themes were categorised: inadequate information; psycho-emotional barriers; relational barriers; support-related barriers; and policy barriers. The analytical framework of the social and the political–relational models of disability, in combination with the concept of sexual access, has shown that multiple aspects shape the totality of sexual inaccessibility for people regardless of impairment type. The complex relationship between the personal, social, cultural and policy levels – and the ways these intersect – greatly impacts on disabled people's opportunities in their sexual lives, including psycho-emotionally.

Mirroring general power hierarchies in society to do with gender, racism, heterosexism and ageism, it is evident that, in certain respects, some groups of disabled people fare worse than others. A majority, seven projects, were aimed at people with intellectual disability. The need for information about the body, sexual expression, sexual identity, as well as support with communication and accessing spaces for dating and socialisation, indicates a widespread lack of adequate sexuality and relationships education and inclusion in mainstream society (Löfgren-Mårtenson, 2011; Lukkerz, 2014; Gill, 2015). Many participants' experiences reveal attitudes and practices of paternalism based on a view of intellectual disability as incompatible with adulthood (Lövgren, 2013) and especially for persons with intellectual disability who identified as LGBTQ (Toft et al., 2019). The materials give several examples about feeling pressure to be bold and forward in order to be seen as an adult, resulting instead in even more insecurity. This insecurity and low self-esteem can also lead to barriers in exploring the body and sexuality (Wiseman, 2014; Liddiard, 2018; Bahner, 2018, 2020).

There are also major issues concerning lack of knowledge among staff about sexual rights, and organisational aspects that lead to limitations on privacy and relationships. Here, issues related to gender and sexual identity are also evident (Vehmas, 2019; Björnsdóttir et al., 2017). These obstacles necessitate careful analysis within the specific contexts of the types of opposition that individuals face when demanding sexual access. But, as some projects suggest, individual education and empowerment may not be sufficient when organisational structures allow staff to circumscribe freedom and rights – illuminating the structural nature of ableism and disablism.

Furthermore, sexual access is also a question of access to necessary and desired support at the policy level. When a disabled person is reliant on a segregated system of housing, transport, education and work, their economic and social situation is undoubtedly negatively influenced, and thereby their feeling of being part of society: of being a full citizen (Pettersson, 2015; FUB, 2020; Sépulchre, 2020).

Kafer's (2013) notion of the relational–political here comes to the fore again: it is difficult to separate impairment from disability; they are intertwined and both are influenced by culture. Furthermore, Shakespeare's (2013) multifactorial model of disability shows that when citizens are categorised based on impairment, they are disabled by inaccessibility in various situations, as well as psycho-emotionally by prejudice. Lived experiences vary depending on type of disability or access needs, but the common denominator is the need for careful contextual analysis. Adding the perspective of sexuality to this complexity necessitates an understanding of sexual access as highly influenced by what surrounds it (Shuttleworth & Mona, 2002). The fight against sexual inaccessibility therefore entails a fight against general inaccessibility – and vice versa (Karlsson, 2020).

When analysing sexual access barriers – perhaps the most intimate in a person's life – it is therefore necessary to consider solutions from multiple perspectives, including societal, organisational and cultural. Opposition to a more accessible society thus impacts upon disabled people's opportunities to realise their sexual rights – and in a broader sense, disabled people's rights to citizenship, independence and to autonomous lives.

Notes

1. The chapter is based on research carried out within the project *Sexuality – an access issue*. It was funded by FORTE: *Swedish Research Council for Health, Working Life and Welfare* (dnr 2018–01830) and ethically approved (dnr 2019–05817).
2. The projects included are: (1) *Lame limbs and dry panties* (2004–2006) by RG Active Rehabilitation, focusing on spinal cord injury rehabilitation, (2) *Prejudice and pride* (2008–2011) by Forum Skill, about sexual identity and norms and aimed at people with intellectual disability, (3) A *secret known by many* (2009–2012) by the Swedish Youth Federation of Mobility Impaired, about sexuality and personal assistance services (4) *We breathe the same air* (2009–2012) by Grunden, a self-advocacy organisation aimed at people with intellectual disability, about gender equality in disability services (5) *KISS – About the body, feelings and sexuality* (2011), sex education materials by FUB – The Swedish National Association for People with Intellectual Disability, (6) *This is how sex works* (2012–2015) by Forum Skill, sex education materials developed in collaboration with people with intellectual disability, (7) *The right to live my life* (2014–2017) by Kulturparken Uppsala (a culture pedagogy association), aimed at policy development for people with intellectual disability in group homes or day centres, (8) *The disability project* (2014–2017) by RFSL and RFSL Stockholm (the Swedish Federation for Lesbian, Gay, Bisexual, Transgender, Queer and Intersex Rights), aimed at disabled LGBTQ people, disability rights organisations and disability services organisations (9) *Sex in movement* (2016–2019) by RFSU Stockholm and the Swedish Youth Federation of

Mobility Impaired, focusing on sex education and cultural representation, and (10) *I am the storyteller* (2017–2020) by RFSL Stockholm, a narrative storytelling project with LGBTQ people with intellectual disability.

3 BDSM is an acronym for bondage and discipline, domination and submission, sadism and masochism: a variety of often erotic practices or roleplaying and fetisches.

4 The Act concerning Support and Service to Persons with Certain Functional Disabilities.

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9 New barriers and new possibilities

Confronting language inaccessibility in and around a pandemic

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In this chapter, we will explore cases of language inaccessibility through examples from before and during the COVID-19 pandemic. The examples illustrate inaccessibility of information during daily press conferences, hindrances to, as well as possibilities of, digitalisation of education, and language barriers emerging through the widespread use of closed captioning for prerecorded online lectures. Although the examples are from Sweden, the issue of language inaccessibility considering the particular groups affected – the deaf, the hard-of-hearing, and people with cognitive disabilities – will bring together aspects of what perpetuates and pervades inaccessibility in respect to communication that are relevant for a wider audience.

The pandemic has had far-reaching consequences due to the precautions and restrictions to keep the virus from spreading, affecting everyone around the globe. Several initiatives to document how the developing pandemic has affected accessibility, and in particular people with disabilities, have been launched (cf. Kritfunk, 2020; Johansson, Forsell & Gustavsson, 2021). With people blocked or hindered in their movement, the duty to provide and protect citizens in society has led to increasing use of online working, online health and social services and online education. Communication via mobile and digital technology has suddenly revealed underutilised avenues of accessibility *for some*. The potential consequences for all citizens during the COVID-19-pandemic offer us a lens which partially reflects restrictions we all have experienced but also refracts an image of how only certain types of bodies have power over accessibility. With this unequal distribution of influence, some groups are affected more severely due to the intersection of language issues with ableism. In this chapter, using critical research perspectives, we will examine: (1) how ideas about ability lead to (re)-oppression in the forms of ableism, linguicism and audism, (2) when and how changes reversing language inaccessibility can come about, and (3) how oppression, once it is known, still doesn't change practices.

To do this, we will employ an analysis of how organisations in Sweden were forced to solve problems in real time. We made observations of practices we were directly involved with: the move to online instruction, meetings in organisations of all kinds moved to video conferencing platforms and language

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access in mass media. These observations frame the three examples in the chapter and serve as 'teachers of accessibility' in the form of real events, real discrimination and real lives (see also Patrick Kermit's chapter in this book).

The method of ethnographic and netnographic (Kozinets, 2015) description and interpretation, informed by findings in previous studies of the life conditions of deaf people and people with cognitive disabilities, led to the enquiry around which this chapter is organised. This inspired the combination of theories interrogating assumptions about ability, deafness and language use in digital contexts. The materials collected include field notes from meetings, open letters, social media posts and newspaper articles on conditions and consequences of imposed regulations, governmental agency announcements, communication to university employees and participant observation in online courses and activities. We employ examples of pandemic-related changes and restrictions based on materials used in our earlier work as well as for the purpose of this collaborative project. This has resulted in the development of the notion of language (in) accessibility, which emphasises the processual, non-dualistic nature of how social arrangements grant or deny access to populations.

One of the authors is a member of the Stockholm University working group on issues regarding the deaf and hard-of-hearing and Swedish Sign Language (DH-STS) in respect to accessibility and higher education. As course organisation questions about moving online began to be actualised at the university and solutions were offered to adapt to the restrictions, attention was brought to the DH-STS working group by students, employees and organisations outside the university. As discussions developed within DH-STS as well as with university leadership, material was collected for two objectives: to ensure accessibility and to study the exchanges about the measures which gave rise to adjustments as well as to new obstacles. Initially the documentation and collection of material was used to exemplify the implications of new policy implementation for deaf people's access when meeting with university leadership. This dual nature of the objectives is also reflected in the dual nature in academic activism (see also Apelmo & Nordgren's chapter for a discussion on their autoethnographic position).

Another of the authors is involved in the Participatory Action Research collective, and works for its consultancy arm, Begripsam,[1] which draws on members' own lived experiences of cognitive and perceptual impairments or difficulties. The aim of the consultancy, the collective and the research is to improve access to and usability of devices and structures in digital society for citizens at large and citizens with cognitive difficulties specifically. Simultaneously, the collective is testing and developing methods for such research and implementation in cooperation with the Royal Institute of Technology, KTH, Stockholm, and the Department of Design at Lund University. To achieve this, methods of cooperation have to be developed through collaboration (by academic researchers, designers, developers, social agents of change and co-researchers-as-users) working to educate each other in digital and web literacy (Johansson, 2019). This process creates a shared knowledge of internet use, digital literacy, participants' difficulties and needs as well as how these processes of change are connected to accessibility and full participation. During the COVID-19 outbreak the work process took on a whole new dimension, when developing this knowledge occurred simultaneously with needing to use that knowledge: needing to get online to learn how to get online.

Ableism, linguicism and audism

To unpack the relationship between disability, deafness and language use, we turn to the oppression triumvirate of *ableism, linguicism* and *audism*. [2] Ableism is the idea that able-bodied (healthy) persons are preferable and superior to those who are considered non-abled (the disabled) (Campbell, 2009). Linguicism is a form of 'linguistically argued racism' according to linguist Tove Skutnabb-Kangas (2000) who coined the term, as opposed to biologically or culturally argued racism as in ethnicism or culturalism. Audism, which is the oppression of the deaf, their communication in sign language, and as a result their culture, intersects with the previous two systems (Bauman, 2004).

Ideologies, practices and structures promoting the idea of a 'correct' language (re)produce an unequal division of power and resources (both material and immaterial) between groups (Skutnabb-Kangas, 2000). There are ideas about being able to comprehend through communication and language that border on not being seen as weak, inferior, unlearned or not 'of sound mind'. Those who are said to have excellent speaking skills or command of the language create the hierarchy and resulting inequality of linguicism. Take for example resolving a breakdown in communication. This requires both sides to locate a problem which has to do with misunderstanding to which each contributes. Linguicism attributes fault to one side, the minority side: the person or group lacking in capacity in the dominating language. This linguicism is due to a lack of perspective about other types of communication and linguistic systems that differ from one's own, and is a clear example of where inaccessibility emerges.

Audism, as a subset of both ableism and linguicism, interrogates taken-for-granted ideas about why it is better to talk than to sign, a view that positions deafness as inferior to hearing. It is important to understand in reference to accessibility and language for people who are deaf and communicate in a signed language the interrelated notions of audism and ocularcentrism[3] (sight-centredness), which is at the centre of being deaf, in that it entails what it means to experience the world through vision, as well as separatism. Being separate, from the perspective of the deaf sign language community, emphasises that they often feel most included in everyday signing environments which are apart from the mainstream, rather than feeling isolated from the latter, as hearing people often perceive it. This negative understanding is due to the lack of knowledge about the harms of audism, which perceives deaf people as inferior because many do not use hearing and speech. Audism also comes into play in the provision of interpreting services into sign language, and is why text-based translations should be viewed *not* as making spoken language accessible, but as a *special type of exclusion* which is based on withholding the opportunity to use the only natural language that is fully accessible to deaf people.

The prioritisation of digitalised accessibility replacing sign language interpretation (i.e. closed captions in Swedish instead of interpreting in sign language) is a particularly illuminating example of the Swedish legislation on language status and minority language rights being conflated with an adjustment for a disability group the hard-of-hearing who use Swedish and not Swedish Sign Language (STS). The legal protection for STS as it stands (March 2021) is primarily about the right to a certain kind of bilingualism: to learn sign language first and then Swedish, the right of children (hearing or deaf) of deaf parents to mother tongue education in sign language, and that deaf people, to some extent, have access to interpretation in certain everyday situations. In Sweden, sign language is juridically neither considered a mother tongue (unless your parents are deaf) nor a minority language, but is stated to be the first language of deaf people and granted a certain level of special protection from the authorities. However, in which instances (or to what length) this protection is granted is not clearly specified (SOU, 1997:192; SFS, 2009:600; SOU, 2019:18). In the discourse of the public authorities, sign language rights are primarily linked to an expression of the need for an alternative means of communication as a result of an impairment rather than a linguistic cultural affiliation (Larsdotter et al., forthcoming).

This brings us to the point of the often-taboo subject of talking about deafness as a disability (Lane, 2002). Difficulties to read, write, and comprehend in Swedish in this case can have different origins. Conflating cognitive disability groups with language minority groups without sensitivity to these origins is related to the harm of audism and ableism through linguicism, and the hierarchies they create. If a person does not have the physical anatomy to use sound and is deprived of acquiring a visual-gestural language, it will result in a cognitive disability. This lack of access to human sign language, with its adverse and long-term consequences, makes it very difficult for hearing people to begin to untangle what disability vis-à-vis lack of hearing is and is not. (For a discussion of delay versus disorder in deaf and hard-of-hearing populations see Matthew Hall, 2020.) The main complicating factor in comprehending this difference is the notion of ‘deafness as disability’ from a majoritarian perspective, making it difficult if not impossible to understand capital ‘D’ Deaf.[4] These are people who belong to a signing deaf community, either from birth or through relationships formed with members of such a community, and *want* to be deaf in a cultural sense and stay securely connected and immersed in a sign language-based Deaf culture. This contrasts with the majority (hearing people’s) view of being deaf (with a lowercase ‘d’), which is defined by social (barriers to sound) and medical (measurements and levels of hearing) models of disability. In essence, the claim is that the deaf are those individuals who cannot hear. What divides Deaf and deafness groups is the languages and modalities they use. In addition, hard-of-hearing people form a subset of hearing people who hear less well, but who nevertheless share the dominant language and culture. This means that, when referring to the deaf *and* the hard-of-hearing, we are in fact always talking about two distinct language-using groups (see Obasi, 2008). Yet these two different language communities: hard-of-hearing Swedish speakers and deaf STS signers, are often placed in a single disability category.

Moreover, medical definitions place hearing impairment on a single continuum (from hearing to not hearing), which leads to the common misconception that their communication is on a corresponding continuum from more Swedish to less. That continuum fails because Swedish and STS are two distinct natural languages, with no continuum between them. Hearing people very commonly hold this misconception about the culturally deaf and their visual-gestural language modality (Adams Lyngbäck, 2016; Higgins, 1980; Padden & Humphries, 1988). Not only are Swedish and STS as distinct and unintelligible to one another as English and Korean, the different sensory skills needed for spoken and signed languages set them worlds apart (Bellugi, Poizner & Klima, 1989).

Combating ableism, audism, linguicism, and their combined effect in the form of *language inaccessibility* depends on fighting against inequities from a number of standpoints in disabled, deaf and minority language communities. This is done by first revealing then intervening, instead of, for instance, waiting for an institutionalised form of fairness by the authorities. This cultivates the practice of an ‘active equality’ (Colton & Holmes, 2016). How society responds to a crisis or disaster illuminates inequity (Uekusa, 2019), which is why we begin by presenting the exclusionary effects of an urgent and long-lasting crisis – the COVID-19 pandemic – to show how a lack of social justice in education contributes to oppression by denying language access.

Signing in (of) a crisis

In their observations on how COVID-19 information was made available, the Swedish National Federation of the Deaf (SDR) and National Association of Deaf, Hard-of-Hearing and Language Impaired Children (DHB) were quick to point out the lack of accessible information in the frequent news conferences held during the spring of 2020 with representatives of the Swedish Public Health Authority and the Swedish government, which gave citizens statistical information about new recommendations and directives. The press conferences quickly developed into a recurring nationwide event and were followed by ‘everyone’ to know how to protect themselves, their families and friends, local communities and society more broadly. But, as is often the case, the mode of communication, and the type of language used at the press conferences, was not accessible to all (adults) in the country, even though all were supposed to follow the recommendations. Thus, the press conferences renewed the visibility of the barriers to access of information in a time of crisis which marginalised groups face, such as the disabled and non-dominant-language users. In an open letter to a number of national authorities[5] the SDR wrote about the 33 days during which no information was provided in STS by the authorities during the crisis, and how the preceding state of events had led up to yet another failure to provide public service announcements and information for the safety of signing deaf citizens. The responsibility yet again fell on civil society and activist organisations to provide interpretations or translations. This campaign for accessibility in the communication of emergency information by the Swedish authorities has its roots in the 2017 terrorist attack in Drottninggatan, a major shopping street in downtown Stockholm. That was when the organisation ramped up its demand that officials have resources in place in the event of future crises, a demand which was partly successful.

In spite of the progress made after 2017, the lag in information provision and the blockages in channels for adapting the COVID-19 emergency press conferences persisted. Once this situation improved, and materials were produced, DHB and other organisations[6] were quick to point out issues related to comprehensibility in Swedish and STS in the information. This example shows the ingrained persistence of ableism, linguicism and audism which prompted all of these organisations to act, point out oversights and produce appropriate materials. An ableist view assumes that these groups should get their information second-hand, through assistance and in a language not fully accessible to them in a crisis which requires as clear and accurate information as possible. Instead, it took many weeks and even then continued to be difficult to secure acceptable levels of accessible information. This shows that even though the laws and regulations for equal access are in place, language inaccessibility persists even in critical conditions. Once the knowledge of language accessibility (and the knowhow required to achieve it) was redistributed, and manifested in live broadcasts in the form of sign language interpreting (for the deaf) and closed captioning (for the hard-of-hearing), the reporting and press conferences on the COVID-19 situation were at least in a form that reached these groups at the same time as the hearing and Swedish-speaking public.

But why is it still the case that it is necessary to struggle to gain access to information? SDR and DHB, non-governmental/activist organisations which prioritise language access issues, are the ones providing the adaptations and not the national authorities.[7] The information from the government and public organisations is directed towards the centre of the population and its imagined standard of language. As STS is still not recognised as equal in status to one of the spoken minority languages, the language rights of people with sign language as their main or first language are expressed in the Language Act as similar to a language that shall be protected and safeguarded by the public (SFS, 2009:600).

Institutions fall short of ensuring the participation of all citizens precisely in moments when communication becomes a moral responsibility. People in positions of power and influence decide what is determined to be in the national interest or what constitutes a public health emergency. It is not entirely clear if these decision-makers reside within media companies, the authorities or the political bodies, contributing to the opaqueness of who exactly misses the mark on accessibility. The example of the COVID-19 information shows that there were lines drawn between those who hear and those who don't use sound, between subgroups with different disabilities within them as well as between majority and non-majority language users. The language and ability subgroups reached in a crisis construct the *de facto* 'national interest' and equate it to the 'interest of the norm' in the form of language and modality used as well as adaptations made for disability. Those who are reached by the message are those who hold a particular set of abilities and capabilities resembling those held by the sender representing the government of the nation. Who of those residing in a certain geopolitical area are being addressed, about what, and when? This enquiry reveals how the parameters of language inaccessibility are inadvertently shaped.

We can view this example of language inaccessibility as knowledge 'out of place'. The communication and language conditions of these groups are known but are not prioritised on the necessary agendas until, first, the consequences are made obvious and blatantly clear and/or, second, the knowledge falls in place. The question of creating accessibility necessarily lies with those who are responsible for democratic and just treatment of all parts of the population. The national authorities and the governing bodies determine what is in place and out of place through how they allocate funds to employ people with competence in providing accessible communication. Those in power control the discourse and the subsequent activities to be undertaken. To keep the position of 'the ones who govern', they are obliged to negotiate (Fairclough, 2015). As this example of access to information in crises shows, a newly won struggle is only temporarily resolved because it is repeatedly subject to negotiation. In the words of the political activist, philosopher and academic Angela Davis (2016) 'freedom is a constant struggle', as the next example will illustrate.

Text versus sign language

With the COVID-19 outbreak, in March 2020 Swedish universities called for all classes to move to online instruction. The crisis led to lectures being recorded using videoconferencing services on a far greater scale than ever before. These organisation-wide changes actualised difficulties about the directives regarding interpreting and closed captioning of text or signing. For deaf students it was decided that all instruction in real time would be sign-language interpreted according to the course schedule. For deaf and hard-of-hearing students all recorded course material would be subtitled by each department. The reason for the closed captioning of all recorded teaching materials was that instruction had to be as accessible for deaf and hard-of-hearing students as it was for hearing students (we will return to this *audio-centric* misunderstanding below).

Between the initial outbreak of the virus in mid-March and 1 May, exceptions were made to the interpreting rule (that only ‘real-time’ instruction would be interpreted to sign language) since it was a practical impossibility for the sheer volume of new material to be closed captioned for students who otherwise use interpreters. Instead these materials, in courses where deaf and hard-of-hearing students were enrolled, were equipped with recorded sign language interpreting. Thus, for the first six weeks of the pandemic closures, interpreters were available both for classes delivered on video conferencing platforms as well as for the pre-recorded lectures that were being produced.

However, during the autumn semester in 2020, directives about sign language interpretation were given and a new situation arose. Under the new directives, when a pre-recorded lecture has been equipped with closed captions, deaf students no longer have access to interpretation of its content. Thus, a central misunderstanding, namely that closed captioning is an adequate replacement for interpretation into STS became an accessibility rule of thumb. What this revealed was the mixing up of two issues: one regarding closed captions and the other access to sign language interpretation, a conflation of accessibility measures that emanates from a hearing norm. This led to the persistence of a form of audism from before the onset of the COVID-19 outbreak, which broke down into a blatant example of discrimination which remains difficult for the responsible authorities to comprehend, because they are hearing.[8] If a hearing person is able to listen (and see and read) a lecture, to have equal access through interpreting, the deaf person is able to ‘sign read’ or listen with the eyes or vision: *syssna*, derived from the word *lyssna*, ‘to listen’ in Swedish (Institute for Language and Folklore, 2019).

Students have pointed out to the DH-STS working group at Stockholm University, as well as in online discussion forums in deaf organisations,[9] that closed captions of lectures in informal speech as well as formal academic language, are at times extremely difficult to decipher. This is exacerbated by the poor quality of the digital image the subtitles appear on, as well as the use of simultaneous PowerPoint presentations with text that may be obscured by the running closed captions at the bottom of the screen. Deaf students must resort to reading their way through their educational programmes in multimodally presented sub-standard Swedish, which is not even their primary language. Even worse, there were occasions where students were told to individually apply for sign language interpretation for each lecture, unit or event as a special case of need due to an additional disability and, after applying, some even had that request rejected. In light of the unfair conditions for deaf and hard-of-hearing students, hearing instructors became aware that if they pre-recorded their lectures these groups would not have equal access and would be at a disadvantage.

Participating in a pre-recorded lecture equipped with text in closed captions requires deaf students and deaf teachers to constantly switch between two different languages: Swedish (closed captions) and STS. This leads to a heavier cognitive effort and brings with it a higher likelihood of misunderstanding and miscommunication. Moreover, the interpreter takes over the paralinguistic features of talk, including stress, tone and liveliness, etc. – all this is lost for deaf people who do not have access to sound alongside captioning, which further complicates their access to the content.[10]

Confusing language interpretation between two different languages as interchangeable with providing multiple modalities of a single spoken language is a mistake often made by hearing individuals for a number of reasons. The understanding of a deaf person's literacy in a second language as primarily a language used in a written form builds on knowledge of sign linguistics, deaf education competence and perspectives from deaf lives, and is rooted in an acknowledgement of their experiences as legitimate forms of knowledge.

At the end of the autumn term in 2020, a document entitled 'Sign language interpreting of pre-recorded lectures replacing live lectures in campus-based courses during 2021' was sent to Swedish universities and colleges as well as individual programme providers with permission to issue degrees. The sender of the document was the administration for national funds for targeted educational support at the Ministry of Education, and the document was based on consultations with the national reference group consisting of representatives from higher education institutions for this purpose. There was no consultation with the DH-STS working group prior to the decisions leading to these changes, but the group was informed in a joint meeting as a result of the pressure it had exerted. Briefly, the document recommended that as long as COVID-19 conditions persist, and restrictions are in place, students should have access to sign language interpretation of lectures regardless of format. Instead of letting 'in real-time' or 'face-to-face' determine which lectures are interpreted, it is the form of programme as 'campus-based' which is used to support the argument to allow for exceptions to accessing interpreting services for pre-recorded lectures, i.e. when it *replaces* a live lecture which was supposed to have been sign language interpreted in real-time. Thus, the crisis made it possible, for the second time, for an exception to be made. Earlier in the year, when the restrictions first went into effect, the Office for Interpretation Services made the first exception that interpreters would work online and with pre-recorded lectures as it was deemed to be reasonable as well as fair to do so. Now, a second exception based on consultations with deaf students and special-interest groups enabled a broader range of lectures to be interpreted, regardless of whether they were live or pre-recorded.

Digitalisation: going online to get online

During the COVID-19 pandemic, when upper-secondary schools and further education were called to move to online education, students with intellectual disabilities were not included as their participation in digital education was not seen as possible. As ableism and linguicism coincide as pervasive systems, the question of who gets access to what in schools in terms of instruction has to be examined in terms of what (digital) literacy is understood to be. Several studies have shown how students with cognitive disabilities are not afforded opportunities to develop languages, literacies and use content-specific tools (Berthén, 2007; Reichenberg, 2012; Martínez-Alvaréz, 2019). This body of research shows that normative ideas about what (both digital and non-digital) language use entails affects what students with intellectual disabilities are afforded to learn. There is, in addition, a perceived (in)ability of students to participate in (digital) literacies and language use, which creates hindrances to future participation due to a lack of teaching. However, action research (Johansson, 2019) has highlighted and actively works for enhanced possibilities for groups which were previously excluded from being able to participate in digital literacies.

When the pandemic hit, the research collective Begripsam, which focuses on digital literacy by being directly involved in making digital services understandable and 'user-friendly', had to go all-digital. The pandemic revealed that being able to 'go online' was assumed to be a skill everyone possessed. This assumption builds on the presupposition that everyone receives what is required to be able to do so in their basic education.

One of the ongoing Begripsam projects involved adult former students of special education, with low literacy skills, participating in the development and design of an accessible digital learning platform. This group represents the kind of students who, in the secondary school lockdown, were not expected to be able to participate in distance learning. With the onset of the COVID-19 outbreak all Begripsam workshops, including training courses for designers of web accessibility, had to co-occur because all participants now had to attend remotely from their homes which entailed 'going online to get online'. This was overcome by providing alternative instructions in several modalities (written, spoken and filmed) and extra one-on-one resources. Within days, all participants were online from their homes. These seemingly insurmountable obstacles were cleared by tapping into an already existing (though still under development) structure and organisation. Testing in a real-life situation produced a long list of valuable insights which would most likely not have been detected otherwise. The most obvious one being that one cannot be expected to master something in which one has not been instructed. It is not the ability of students in special education settings that primarily sets the boundary for what they can learn but the level of adequate teaching that makes learning possible.

The absence of such teaching by the most qualified teachers who can analyse the conditions required for concept development is a consequence of the intersection of linguicism and ableism. Far too many schools and other educational efforts for students with cognitive disabilities fail to recognise that digital competence and being able to communicate digitally are important life skills for everyone. There is either a lack of knowledge or priority, or both, that it is possible for students with cognitive disabilities to learn how to use digital technology and participate in digital literacies. Revealing these oversights and misconceptions can bring change in teaching practices, making it possible for people with cognitive disabilities to participate in online communication – as shown in the example from Begripsam. Also, knowing what can go wrong (since it did go wrong) acts as a feedback loop in developing activities and systems. What to expect and what to do in the event something goes wrong is the primary focus of comprehensibility of digital services, instead of perceiving situations where digital communication does not work as dependent on the cognitive abilities of the persons involved.

Conclusion: changing the question

The COVID-19 pandemic created new barriers as well as new possibilities for inclusion, as shown in the empirical examples discussed in this chapter. All three examples make visible how hindrances that are created by not being taken into account by the majority society can be overcome – but the driving force behind removing obstacles are activists, interest groups and those who are themselves affected. For instance, the example on participation in digital education for people with cognitive disabilities shows that ideas on who can use digital technology creates barriers for participation in online education. Linguicism and ableism saturate teaching practices where students with cognitive disabilities are not offered instruction in how to use digital technology for communication and participation in education, and thus, during the early part of the pandemic, it was believed that these students could not participate in online education like others in the same age groups who were moved to online instruction. But, as the example from Begripsam shows, it was indeed possible if and when adequate instruction and accessible digital devices and content were provided.

Similarly, it was the actions of non-governmental organisations that made the lack of access to COVID-19 information visible and led to the adaption of communication modes. It was the deaf and hard-of-hearing students themselves who raised their voices about the difficulties of participating in education during the move to online education, as sign language interpretation during live lectures was replaced by closed captioning of pre-recorded lectures. With the help of a special-interest organisation, a temporary change in regulations was put into place.

These examples show that communication solutions as well as obstacles are due to societal choices and priorities, and not because of a false notion that certain types of bodies individually and independently create the conditions or that one standardised solution will fit all. Ableism, audism and linguicism can take the form of institutionalised discrimination, for example how government services such as COVID-19 information or participation in online education due to the pandemic are made inaccessible to people with disabilities, the deaf or minority language users. As these are systems of oppression, and inaccessibility is a form of limiting freedoms we use the notion of 'institutionalised inaccessibility' to refer to how the majority in society constitutes the limits and boundaries for its citizens in how attitudes and beliefs shape decisions in institutions.

Accomplishing affirmative social change can come about through responses to a crisis such as the pandemic but this also requires multiple forms of transformation. There is a clear tendency to see digitalisation and technical development as inevitably good for accessibility. This conceals the fact that one size does not fit all and that digitalisation and technical development can be formed in many different ways to fit groups and individuals not taken into account in current digital practices. This invisibility helps reinforce commonly agreed upon practices (cf. Winther Jørgensen & Phillips, 2000) that promote institutionalised inaccessibility in the form of ableism, linguicism and audism.

To remedy inequalities, taking empirical examples of what happens in response to a crisis requires studying consistent forms of social discrimination at a structural level and how they play out in everyday lives as Shinya Uekusa (2019), a sociology of disaster scholar at Aarhus University, concludes. An uneven distribution of negative consequences may come as a surprise to some, but seldom to those who hold subordinate positions in hierarchies, as discussed in this chapter. Successfully contesting the current social order to promote changes demands action, but the groups being oppressed, disadvantaged or discriminated against are left with the task (of educating, of mobilising, of defending, of struggling), as is evident in all three examples.

Our examples of language inaccessibility in this chapter provide lessons that must be constantly retaught since, even though we believe we are democratic, the system does not take everyone into account. Even when adaptations and accommodations are made in what is believed to be an inclusive way – as in the example of closed captioning of online lectures – just following guidelines and checklists seldom suffices. Providing closed captions in text, now that it is required and made technically possible on a large scale, was a huge feat but even new and improved universal solutions will always require novel and particular accommodations. Realising the continuing process of 'literacy of accessibility' is part of being socially literate in matters of difference and disability.

Here it is useful to consider the work of Ann Curry-Stevens (2007), a scholar of adult education and social work, who provides a description of a knowledge process that rests on three pillars: equity, activism and social literacy. Social literacy requires the development of awareness of one's own position and connection to others unlike oneself in structural power relations (Kimmel & Ferber, 2014). Our shared goal in an accessible society is accurate learning about disability as a relation between socially constructed conditions and minority bodies (Evans, Assadi & Herriott, 2005; Barnes, 2016). This challenges us all to be, on an individual level, willing, open and capable to be 'uncomfortable' in coalitions with others unlike oneself, utilising what philosopher Erinn Gilson names *epistemic vulnerability* (2011), i.e. valuing the precarious position by admitting to not knowing, being willing to learn from others and valuing others' experiential source of knowledge. Gilson defines this as the active choice of being open to not knowing (for example what harms or limits people who have a cognitive disability or who are deaf), to being open to possibly getting it wrong and getting corrected, and a willingness to enter situations of not knowing. Vulnerability in this sense is not an individual feature nor a negative state; rather, it is a potential for change by being affected and affecting others (Snyman, 2015). Getting it wrong but being willing to acknowledge being wrong and ready to be 'disturbed' by becoming the 'Other' (Gilson, 2011) is how to go about 'righting' that wrong. But because it is difficult to embark from ignorance since it hurts, this gets ignored or, worse, the blame is placed on the excluded group for making others feel bad (cf. ibid.). This tendency can be named invulnerability in its worst form: people in power who are unknowing and resist change to avoid feelings of guilt and consequently harm others.

There is a fundamental stubbornness inherent in inaccessibility, as linguicism, ableism and audism are immanent features in so many of our institutional practices such as education. Being excluded from education closes off from community in the long term; being excluded from health information about a dangerous virus can permanently separate from community through illness or death. Connectedness to others' lives is a required condition to gain knowledge. Calls and actions for change, on the other hand, draw on knowledge sources that are underutilised and under-theorised. Proficiencies which are perspective-based operate by illuminating how others' agendas are connected to our own, often historically. Being in coalitions requires valuing the necessity of discomfort (having to make mistakes), calling attention to one's own ignorance as a source of oppression, realising how another person's bodily dimension of knowing is key to seeing oneself and one's own learning (Logue, 2013). Knowledge, in the form of epistemic vulnerability, is needed for illumination, since inaccessibility as a phenomenon is enacted in new and obstinate forms for each situation in which it arises.

We conclude by insisting that at least the questions about inaccessibility be changed. The barriers are well-known and researched. Still, change doesn't occur. What has yet to be explored is what unites a will for change and how coalitions between different groups form to present united fronts and political will by holding together: a common threat makes for a common goal.

Notes

1 *Begripsam* is a play on words combining the Swedish for 'to understand', *att begripa*, in its imperative form *begrip!* with an abbreviation of the nouns for 'society', *samhälle* and 'together', *tillsammans*. At the same time the suffix *-sam* may indicate a 'condition', thus making *Begripsam* equivalent to 'Understandable' or 'Understandish'.

2 *Ableism* (Campbell, 2009), *linguicism* (Skutnabb-Kangas, 2000, 2002), *audism* (Pelka, 1997; Bauman, 2004; Bauman, 2008; Eckert & Rowley, 2013; Reagan, 2020).

3 Ernst Thoutenhoofd (personal communication 27 August 2020) describes ocularcentrism in *Ocularcentrism and Deaf People: A Social Photography Project*

(1997) as how deaf perceive the world and because of that develop signed languages, not the other way around. Later works on Deaf Pride, Deaf Gain and Deafhood build on similar notions.

4 Capital 'D' deaf and deaf in an audiological medical perspective are distinguished by the notion of culture, a shared language and pride united through experiences of audism, ocularcentrism and separatism (E. Thoutenhoofd, personal communication, 15 August 2020) as opposed to diagnoses and categorisations based on the difficulty or inability to hear.

5 The Swedish Public Health Authority, Swedish Civil Contingencies Agency, Healthcare Guide 1177, and Swedish Public Service Television. Healthcare Guide 1177 is a site for information and e-services for the public on health and healthcare by Swedish county councils and regions.

6 Many organisations mobilised resources to communicate information in suitable formats on their websites in response to the COVID-19 pandemic. FUB, the Swedish National Association for People with Intellectual Disability (FSDB), the organisation for the Deaf-Blind in Sweden, and the Swedish Aphasia Association all responded with information for their members in online articles such as 'Advice for people with deafblindness and relatives about the Corona virus and Covid-19' (30 March 2020).

7 DHB is a coalition for the political interests of different groups based on contrasting communication systems and accommodations including intellectual or cognitive disability and multiple disabilities in combination with sign language, Swedish or other commonly used minority languages.

8 In the discourse of the authorities, sign language is, admittedly, the first language of the deaf. However, in the subcommittee study in preparation for minority language legislation referred to in the works leading up to the approval of the Language Act, the authors argue that they believe that, 'even if the deaf themselves see themselves as a linguistic and cultural minority', sign language is primarily 'a way […] to be able to communicate with the surroundings despite their disability' (SOU, 1997: 192, pp. 94–96, our translation).

9 In one online Facebook discussion forum, hard-of-hearing students, who also sign, raised concerns that texting would be taken away in favour of sign language captioning. The situation, content, type of presentation as well as the personal preference of the bilingual/bimodal/multilingual learner all determine what is considered 'quality accessibility' for members of these communities.

10 Even more long-term implications are connected to the reduction of interpreting between Swedish and STS. A deficit in linguistic parity arises: new concepts and key ideas in abstract terms also are required in sign language, which is a very important aspect of interpretation in higher education and in research.

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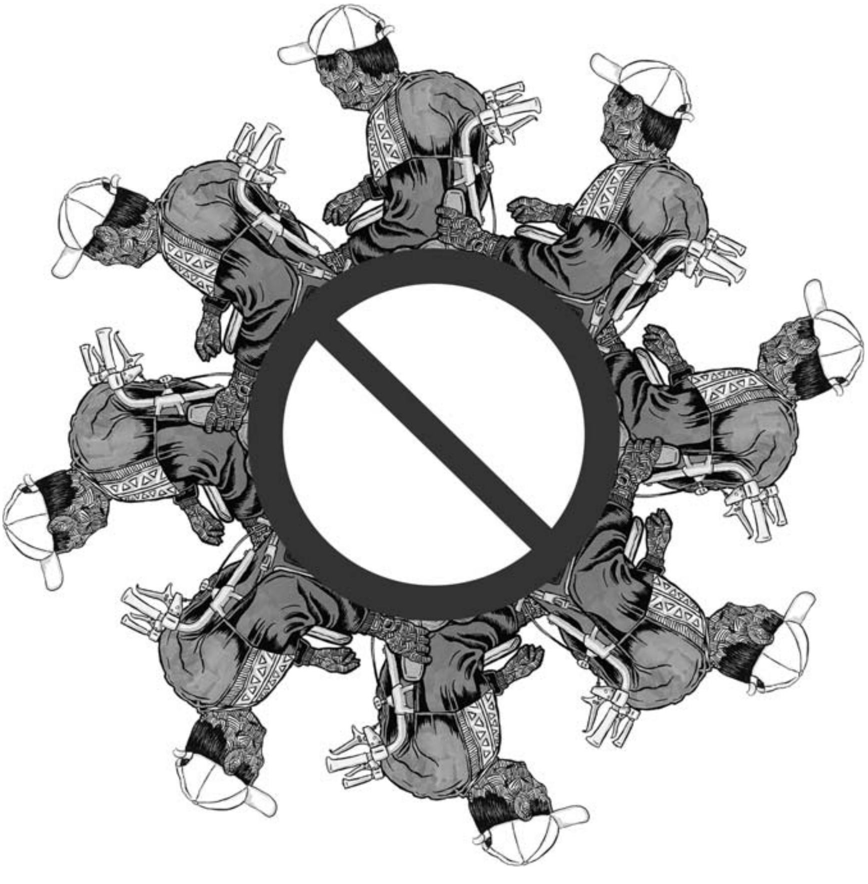
Part 3

Institution, law and history



Artwork by Sam Sohlberg

10 It is supposed to be a home

Barriers to everyday life decisions in group homes

Eric Svanelöv and Lena Talman

> In a group home with several apartments along a corridor we noticed that at midday many of the residents' doors were open, meaning that everybody who walks along the corridor of the group home could see into the apartments and see what the resident did. We noticed that there are many scheduled support services during this time and asked the staff members why the doors are open. It is because it is easier to provide support.

Imagine that it is time for you to move to your first apartment. You are very excited and have probably planned this for a long time. You have been thinking about which area to move to, how big an apartment you want or can afford, and perhaps you have looked up who already lives in the same area so that the neighbours are nice. The choice of area and apartment is yours. Now, imagine that instead of your own choice, you are assigned an apartment of two rooms and a kitchen in an area that you have not selected, and that you will live very close to neighbours with whom you must hang out, even if you don't like them. In addition, you have a variety of people to help you in your everyday life. People that are with you in your most private sphere, but you have not been allowed to choose them for yourself. Now, you are probably thinking that you would never accept that, but this is the reality for people labelled and diagnosed with intellectual disability. It is a reality that encompasses hierarchical power relations, diminished decision-making and normative codes of conduct for residents in group homes. This chapter aims to elucidate barriers for everyday life decisions that, we argue, can by extension, also underpin inaccessibility to societal community for people with intellectual disability. The chapter takes as its point of departure Erving Goffman's notions of institutions and their characteristics and focuses on group homes in Sweden.

Group homes

The home is one of the most fundamental aspects of independence, privacy, freedom of choice and the construction of identity. People living in group homes may experience barriers to accessibility in their own homes because of

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normalising codes of conduct that guide residents to that which is considered right and appropriate behaviour. Group homes in Sweden are not institutions, however, they can have institutional characteristics, with organisational scheduled social care and ideas of fostering residents towards doing what one should do to be 'normal' (Svanelöv, 2019). The Swedish legislation concerning Support and Service for Persons with Certain Functional Impairments (LSS), which aims to facilitate equal living conditions, societal community participation and accessibility, has the support service of housing with special services, so-called group homes, available for people with intellectual disability (SFS, 1993: 387, §9). These group homes often consist of smaller apartments gathered around common areas with support staff available at all times. The group home is a unique residential setting as it is an institutional living arrangement, the private home of the residents, as well as a workplace for staff (Clement & Bigby, 2010; Svanelöv, 2019). Staff in group homes play an influential role in everyday life decisions for residents and how support is organised (Berlin Hallrup, Kumlien & Carlson, 2018; Talman et al., 2019). That said, staff members are also influenced and restricted by institutional notions of daily life in group homes and everyday decisions about their scope of action.

Public and private spaces, recreational and sports areas, cultural facilities, digital arenas and other physical and digital environments are often constructed with strong ideas of accessibility. However, accessibility for some can be inaccessibility for others and these spaces, areas, facilities and arenas often lack accessibility for people with intellectual disability (Lindqvist, 2020). Swedish disability policies and legislations (SFS, 1993: 387), as well as the United Nations Convention on the Rights of Persons with Disabilities (CRPD) (UN, 2016), stipulate that everyone should have access to the physical environment, transportation, information and communication, public facilities and services, and cultural and recreational activities. However, inaccessibility persists in every corner of society, both physical and psychological, as well as societal. Inaccessibility can take the form of the lack of a ramp to a museum entrance, or too-small text with long, complicated sentences used to convey important societal or welfare information (see also Liz Adams Lyngbäck, Mia Larsdotter & Enni Paul's chapter in this book). It may also take the form of normalising practices that label people with norm-breaking functionality as disabled and deviant (Sanmiquel-Molinero & Pujol-Tarrés, 2020). How would it feel to be labelled as deviating from the norm, with the possibility to make choices that affect your life taken away, and living in an institutionalised daily life which explicitly and implicitly tells you how to live your life? Norm-breaking functionality becomes a label of disability for people who require help and support in everyday life; support that is often necessary and good, but which also limits freedom of choice and self-determination. Inaccessibility in the wider community relates to barriers to accessibility in everyday living. That is, to have adequate and satisfying accessibility to the wider community outside the group home, it is important to first have accessibility in making everyday life decisions inside one's own home.

To understand life in group homes it is vital to observe the contextual environment, with its activities, symbols and interactions. This chapter relies upon data from group home observations in two separate municipalities in Sweden. These are ordinary group homes, one targeting people with mild or moderate intellectual disability and one targeting people with profound intellectual disability.[1] The first had 15 residents aged between 27 and 83 years, each with their own apartment, a shared common/living room and a kitchen (there was also a kitchen in the apartment). There were also rooms for staff. In total, 50 hours of observations were conducted in residents' apartments, common areas and staff accommodation. The observers stayed in the background and did not interfere or interact with residents or their activities. After a situation was observed, the residents were engaged in conversations about it.

There were six residents in the group home for people with profound intellectual disability, but two had mild or moderate intellectual disability and were not observed. Each resident had their own apartment (open-plan living room/kitchen, bedroom and bathroom). This group home also had a shared common/living room, a kitchen and some accommodation for staff. The four residents observed were aged between 27 and 55 years. The observers' most common role was observer as participant, since the focus was on collecting data rather than participating in the observed activity. We also conducted discussions with staff members concerning questions raised during the observations (Burgess, 1984).

Notions of disability

Barriers to accessibility reside in the social construction of disability. Disability support services and its practice, for example within group homes, should work to reconstruct societal structures and promote accessibility. However, the historical labelling of people with intellectual disability and the contemporary institutional characteristics of group homes can foster discourses of inaccessibility (Mallet & Runswick-Cole, 2015; Svanelöv, 2019). Today's group homes derive from the institutions discussed by Goffman (1990) but have come a long way from the total institutional setting of that time. However, today's group homes still have institutional characteristics which construct and co-construct societal views of disability.

Disability can be viewed in various ways and historically medicalised models of disability have long reigned in the social discourse. Medicalised models of disability, also called individual models, frame certain bodies and minds as atypical, different or defective, and focus on individual flaws and incapabilities. In this diagnostic and functional model, disability practices are about correcting or normalising the pathological individual (Kafer, 2013; Lindqvist, 2020). As a reaction to the medicalised model of disability, a social model has emerged in which disability is viewed as socially structured through environmental inaccessibilities and hindrances (Shakespeare, 2017). For example, a person is paying for groceries in a shop but has trouble giving the right amount to the cashier. In the medicalised model of disability, the problem is that the individual cannot count, differentiate between different-coloured notes or that she or he gets stressed by the queue forming behind. However, in the social model of disability, the problem may reside in the money's appearance – its colour or shape – or the store's organisational policy which only allows one check-out counter and leads to a longer line of customers.

Our view of disability departs from the social and medical models. We view disability as environmental-relational, that is, as residing in environments and social patterns that marginalise and stigmatise individuals due to normative labelling. Disability is reproduced in all social and cultural settings through language. Thus, to say, write or sign is to *do* something in the constructing of disability. Furthermore, we do not view disability and ability as dichotomous, but as mutually dependent in defining one another (Goodley, 2017; Lindqvist, 2020). Disability does not reside in an inability or deficit in the body, but in the inaccessibility of the environment and spaces, and in public attitudes – while there is much talk about disability, it is through the lens of ableism (see also Elisabet Apelmo & Camilla Nordgren's chapter in this book).

No matter the individual or societal view of disability (as social, cultural or relative), disability support service assessments are often based on diagnoses and a medicalised model (Meekosha & Dowse, 2007; Altermark, 2017). Thus, needs assessments can derive from an individual view of disability that constitutes disability support services and legislative interventions as *preventing inaccessibility* rather than *promoting accessibility*, and which view disability support services (such as group homes) as a way to compensate for individual impairment (Thomas, 2002; Goodley, 2017). However, even if needs assessment can be based on medicalised views of disability, the aims of these services are often rooted in ideas of self-determination, citizenship and social inclusion (Lewin, 2019), and the imperative to reform power structures from institutional settings to individual autonomy and equal rights (Altermark, 2017). That being said, there are still institutionalised practices in disability support services that can alter the expected outcomes of the services (Svanelöv, 2019).

Institutional practices are distinguished by restrictions, limitations, fostering, codes of conduct and labelling. These practices can contribute to structural security, but also have an oppressive outcome. Goffman (1990) defines the 'total institution' as 'a place of residence and work where a large number of like-situated individuals, cut off from the wider society […] lead an enclosed, formally administered round of life' (p. xxi). Characteristics of institutionalised settings include hierarchal authoritarian power and a breakdown of social barriers. People in such settings tend to be viewed as a homogenous group, with diminished privacy, and the activities of daily life are often scheduled and carried out with other residents within the institution. The hierarchal authoritarian power in institutionalised settings can also give rise to codes of conduct (Foucault, 1995) and judgement of desired behaviour and symbols (for example clothing). On the other hand, institutions can also be a place for identity construction, and the places from where individuals draw their social status, for better or worse. Today's group homes are, hopefully, not often total institutions in the sense that Goffman (1990, 1958) defines or the hierarchal power settings that Michel Foucault (1995) discusses. Instead, living in institutionalised settings or receiving support or services based on an assessment of intellectual disability can be a vital help and promotor of independence and participation in the society. Yet, it can also be an undesired 'otherness' or label which constructs individuals as different and which problematises access to certain domains outside institutionalised settings such as the labour market or recreational activities. Goffman (1958: 51) argues that disobedience or misbehaviour in one institutionalised setting (for example in daily activity services) often impacts on another (for example in group homes), as different institutions share aspects of fostering and supervision based on normative assumptions of what and how daily life should be.

Accessible inaccessibility

This section discusses how barriers for everyday life decisions underpin inaccessibility for societal community participation, taking as its theoretical departure Goffman's notions of total institutions. The section describes various aspects of group homes with different notions of accessibility, and how these different views of accessibility can construct inaccessibility. Thus, making inaccessibility accessible.

Barriers to accessibility

Accessibility, our observations suggest, has different meanings and understandings for different people in varied power relations as well as in disability policies. Accessibility is related to the societal community and much of the work within group homes is focused on creating opportunities for the individual to be part of society. However, what that community is, and what accessibility is intended for, varies. Goffman's (1958) ideas of institutions encompass control through physical restrictions, for example walls and closed doors, of homogeneously categorised groups of people. Today's groups homes are more open and aim to create a good home for residents; however, they constitute other kinds of barriers where the line between home and the workplace can be hierarchically determined. This can be seen if we go back to the observation at the start of this chapter where open doors to make it easier to provide support make the group home more of a workplace than a home.

In the group homes there are normative ideals of what are considered the 'right' activities and what 'accessible' constitutes. The empirical material shows that residents could ask staff members about activities they wanted to do which were not on the daily agenda. This means that residents explored activities that were accessible or not. Which particular activities were accessible was ingrained in the organisational culture of the group homes, meaning that the residents' conceptions of accessibility could be regarded as barriers and not fitting with the group homes' notions of accessibility. Group homes can be viewed as 'social hybrids, part residential community, part formal organization' (Goffman, 1958: 48) which can hinder accessibility of certain activities.

> 'Can we go to the graveyard today? I want to put flowers on the grave' was a question posed by a resident to a staff member. The answer given by the staff member was that there was no time to go to the graveyard today because there were other planned activities or support services for other residents at the group home. For example, the same evening, a joint TV-watching session was planned.

The strict timeframes and structural planning of activities at the group homes rest on binary, albeit mutually dependent and interchangeable, institutionalised normative views of accessibility and individual experiences of inaccessibility. The group home staff work with the intention of providing good support for the residents and to facilitate social interaction, but the work is based on organisational notions of what is considered a 'normal' way of living. Thus, the group home's prevention of inaccessibility is confined to certain ways of doing which can create barriers to accessibility. Residents' experiences of accessibility, that is, what the individual wants to have access to and what it leads to, can be obstructed by the undesired activities organised by the group homes' structures. Questions like 'Can we go to the graveyard?' or, as other residents asked staff members, 'Can I go to the toilet?' or 'Can I have a shower during the day instead of the evening?', describe practices of accessibility based on institutionalised and time-fixed practices. Practices of accessibility also limit staff members to certain ways of doing in their work to prevent inaccessibility for residents. That is, accessibility of activities must go in line with the group homes' agenda and, as Goffman (1958) writes, 'seeing to it that everyone does what he has been clearly told is required of him' (p. 49).

Sometimes activities that the residents want to do are acceptable to some staff members even if they are not on the daily agenda. But, for the activity to be accepted as desirable and accessible, it seems to us that staff members have to be interested in the activity. In the following observation we see an example of an activity being cancelled due to staff disinterest.

> The observation that was planned to be done on a public holiday was cancelled due to illness. One of the residents had planned to go to church to listen to a music concert and then she, along with a resident from another group home, would have gone to a restaurant to have dinner. The activity had to be cancelled when the staff who was going to accompany her was sick. We ask why they had cancelled and the staff member who

> called me up said that it does not work with substitute staff, it gets so messy then. We wonder for whom it gets messy but understand that it is for the staff members primarily because she says that they cannot send a substitute with the resident and 'I do not want to go'.

From our observation notes it seems that the activity that the resident wanted to do could not affect routines at the group home. Accessibility is then bound to the staff and the organisational agenda. So, maintaining routines at the group home became more important than residents' needs – another interpretation of why inaccessibility arises within these organisations. A characteristic of institutional settings may be to allow residents in group homes a sense of control by allowing them to choose activities from the group homes' scheduled agenda (Goffman, 1958). However, in the observation above, the sense of individual control can be diminished by lack of interest in residents' activities and explained by organisational regulations such as understaffing.

Organisational inaccessibility

The group homes we observed are structured with different institutional characteristics that formed the organisational support practice and, by extension, the residents' community accessibility, which is key to being part of the society. Yet, the support can also be a barrier for accessibility. An example of inaccessibility we observed was the residents' restricted access to certain common areas, such as kitchen and living room – areas that were created to be accessible for all but are structured by institutional regulations on access or egress:

> A resident walked up to the support staff accommodation room and wanted to have breakfast. The resident was told that breakfast is not served at this time. The resident then asked if he/she could wait in the kitchen (the common area) until it was breakfast-time but was told to wait in his/her apartment.

We would like to highlight three points in this example. First, common areas are constructed as inaccessible areas that are used at specific times, often when there are scheduled activities for all residents of the group homes, for example, watching TV in the evening or eating dinner together at the weekend. Thus, common areas can obstruct accessibility and form residents into a homogenous group through shared institutional activities and timetables that limit the development of individual identities. As Goffman (1958) argues, institutions can utilise scheduled collective activities, such as watching TV with other group home residents in the evening, which aim to take the resident 'out of himself, making [them] oblivious for the time to his actual situation' (p. 64). Second, as residents articulated, the group homes' institutional structure is ingrained in the culture, with defined codes of conduct.

That is, the group homes ‘allow’ or encourage how and when activities occur. The institutional structure within the group homes’ common areas implies that they are formed by controlling (albeit caring) power. The institutional timetable is invisibly visible, meaning that the residents know or ‘feel’ what is considered ‘appropriate’ behaviour and move more cautiously towards that which they know or feel deviates from the constituted timetable. This means that the residents are guided by codes of conduct; one does not necessarily know what is considered right, but one has a sense of what is right, and a feel for what is expected in a given situation (Foucault, 1995). Consequently, the institutional characteristics may construct a contextual community based on normative and organisational codes of conduct. Third, not only are common areas inaccessible, but the residents’ apartments can be a place of banishment. When residents do not have the freedom to access areas in the group home designed to be open to all, and are subjected to institutional constraints and timetables, the home itself can become a symbol of inaccessibility.

This leads us to ask, for whom are common areas created, for whom are they designed and what kind of community do they support? These questions may seem easy to answer, as Swedish disability policy documents describe common areas as having the purpose of strengthening and facilitating social interaction and of being a meeting place for residents, with the group home staff committed to ensuring comfort and structure (National Board of Health and Welfare, 2018). This means that common areas are supposedly created for the residents as a group and designed for individual residents, with institutional controls for creating community. However, the structure of common areas in group homes aims to prevent inaccessibility rather than promote accessibility. With this, common areas can become controlling and, in some cases, are only ostensibly accessible. The institutionalised purpose of ensuring comfort and structure within group homes, specifically within common areas, can be positive as it creates opportunities for social interaction between residents and staff members which may not have happened otherwise. However, the character of, and time frame for, activities in common areas can be exercised as an institutionalised way of preventing inaccessibility. The problem is that, according to our interpretation, what is considered inaccessible derives from normative assumptions about individuals who are homogenously grouped together and labelled.

Sometimes, even the use of one’s own apartment is restricted due to the organisational structures of the group homes, as we see from the observation that opens this chapter. Similarly, in the group home in the observation notes below, there is only one staff member on duty at night, and that staff member is allowed to sleep during the night shift if the residents are asleep. Therefore, the main purpose for the afternoon staff members seems to be to make it easier for the night shift staff instead of meeting the needs of the residents.

> Me and the two staff who work this day (a regular and a substitute) are sitting in the common area drinking coffee when the regular staff

> discovers that one of the residents has disappeared. She asks the substitute where the resident is, and the substitute says: he is in his apartment resting on his couch. The regular staff member answers: he is not allowed to do that, because then he will not sleep tonight, and it becomes difficult for the staff member who works nights to sleep if he is awake. The regular staff goes to the resident's apartment to wake him up.

Under the Swedish Act concerning Support and Service for Persons with Certain Functional Impairments (LSS) (SFS, 1993: 387, §6), necessary staff must be available to provide the support and care needed to create good living conditions (see also Barbro Lewin's chapter in this book). LSS also states that the aim of this legislation is for individuals to have the opportunity to live like others do (§5). Something that others quite often do is to take a nap in the afternoon or in the evening, and often this means that they choose to go to bed later. But this may not be possible when one lives in a group home, since the institutional structures focus on staff members' needs instead of residents' needs. Thus, residents may be fostered to internalise appropriate norms (Goffman, 1958). However, what is considered appropriate differs depending on group homes' resources and where they focus their attention. For example, it may be important that the resident does not eat too much too close to lunchtime, but it might not matter that the resident lies in bed too long. Another example of institutional structures in the group home that affects residents relates to staffing, which is seldom customised to the needs of residents, as the observation note below shows.

> We arrive at the group home at 8.30 am. Two of the residents are up and clothed and they are waiting for their taxis to take them to their daily activities. Two staff members are also waiting; they cannot help the other two residents who are going to their daily activities until these two have left. The other two residents are scheduled to leave at about 9.30. One of the residents has a home-day (every resident has this once a week for washing, cleaning and shopping) so he must stay in bed whether he wants to or not as the staff does not have time to pick him up until all the other residents have left. The second set of residents leave at 9.45 am and the staff members then go to the resident who has a home-day to help him/her get up and have breakfast. The staff discuss how many sandwiches the resident should have for breakfast and agree that one sandwich is enough because the resident slept so long it is almost time for lunch. The resident eats the sandwich very fast and seems really hungry. We wonder if the resident might have wanted another sandwich.

Here the institutional structures of staffing and the staff members' normative notions of what time to eat breakfast and what time to eat lunch is stronger than the residents' needs. In the group homes there are sanctioned ways of behaving, both for residents and staff, which rest upon a normative structure. Support services aim to help residents in their daily life, but with organisationally regulated resources that lead to specific codes of conduct being internalised by both residents and staff members (Foucault, 1995).

Conclusion: barriers to constructing a home

Group homes are not total institutions in the sense that Goffman (1958) writes about. However, group homes in Sweden do have institutional characteristics in the form of scheduled support, normative codes of conduct internalised by both residents and staff members and hierarchal power relations that restrict access to activities outside the group homes' agendas. There are also different aspects of accessibility within the group home context, where the group homes' strong organisational power relative to that of the residents takes precedence. If institutional structures in one's home are barriers to accessibility, for example through inaccessible common areas, decision-making processes and possibilities to run errands outside the group home, the social community outside the group home becomes inaccessible.

Activities that do not fit into the group homes' agenda of support are often omitted, with explanations of what is considered normal in a given situation and context. To receive the disability support service of housing in group homes the individual must uphold specific disabilities that are established and confirmed by medical diagnosis. Thus, residents in group homes are labelled as having norm-breaking functionality, but the group homes' institutional characteristics form support as normative and hold individuals to specific codes of conduct that give precedence to specific kinds of accessibility. However, just as residents are constrained by institutionalised norms of accessibility, so too are staff members. Often, staff members aim to facilitate residents' independence and well-being, but do so unintentionally (and perhaps intentionally), through the scope of structural and organisational limits.

The group homes and legislated disability support services are intended to promote accessibility to community and society at large, however, their institutionalised character can itself create barriers and inaccessibility. As our observation notes show, many barriers remain to accessibility in everyday life. To increase accessibility, the organisational focus of the group homes should be the promotion of accessibility in scheduled and unscheduled activities, and to reformulate notions of normative and appropriate behaviour. Otherwise, the accessibility of the societal community for residents in group homes can be difficult to achieve. Thus, inaccessibility in everyday life underpins the inaccessibility of societal community. Goffman (1990) argues that individuals are tied to social entities with obligations, expectations, and desired and undesired outcomes. However, if individuals experience barriers in one of the fundamental aspects of daily life – the home – due to its institutional characteristics how can individuals be part of, and have access to, other social entities?

Note

1 All empirical material was preceded with approval from the Ethical Board of Uppsala, Sweden (2015/39/1; 2013/375), and followed the Swedish Research Council guidelines for good research practice (2017).

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11 Making the law invisible

How bureaucratic resistance makes support inaccessible

Barbro Lewin

The Swedish Act concerning Support and Service for Persons with Certain Functional Impairments (LSS) (SFS, 1993:387) is an important welfare reform which aims to create the conditions for persons with disabilities to participate in society on an equal basis. This special law is an exception to universal legislation and complements the Social Services Act, which has a lower degree of ambition. An overarching intention of the LSS is to diminish the power gap between the authorities and the individual through a strong legal rights construction. This implies appropriate support to participate in different areas of life, such as day-to-day living, education and work, culture and leisure activities, as the individual chooses. In short, the law is about having control over one's own life and the possibility to live like others (Government Bill 1992/93:159; Lewin, 1998).

This welfare reform was enacted on 1 January 1994 in Sweden. However, as this chapter will show, its implementation has been problematic, and the power gap has not diminished as intended. National authorities and governmental commissions in Sweden have pointed to problems in the performance of various measures under the act, and the relations between bureaucrats and applicants when it comes to applying for LSS supports (IVO, 2016; Socialstyrelsen, 2020). In a prior study I have shown how the needs of persons with intellectual disabilities have been diminished and distorted in administrative procedures to obtain legally certain decisions on their applications (Lewin, 2017). In this chapter I will develop this further, describing the accessibility aspect of the implementation of the LSS and the administrative behaviours encountered by persons with intellectual disability. Central to this chapter is to understand how administrative resistance to accessing support can be made visible. I will describe and discuss various materials concerning rejected applications, both for personal assistance and for LSS Contact Persons. The latter will be described in the next section.

The applicants I discuss were referred to me in my capacity as a disability rights researcher and activist as they had encountered problems in the administrative procedure when applying for support. They all experienced the administrative procedure as having become more restrictive over time, and all raised the question: 'How is it possible that I have been denied LSS support

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that has been so beneficial and appropriate for me for such a long time and with no change in my needs?' As I will discuss in this chapter, the administrative procedure can be seen as documenting bureaucrats' strategies to withhold support provided by the municipal authority under the LSS.

The legal context of the Swedish LSS support

The LSS includes ten specific supports with different intentions and scope that are supposed to guarantee good living conditions and make the act appropriate for many persons with substantial disabilities. Different supports have different warrants, or normative needs, for the right to support. These can be found in both the government bill and the legal texts. The intent of the individual rights law, LSS, is to give priority to such needs. Resources must be provided, irrespective of the municipality's financial status (Government Bill 1992/93:159; Lewin, 1998). Under the LSS, persons belonging to three different categories have influence,[1] both on the administrative procedure in getting support, and in the performance of the given support. A procedural rule under the law is the right to appeal to the Administrative Court. Another is the so-called 'Lex Sarah', which regulates abuse (deviation and non-conformance with legal practice) in the administrative procedure and in the performance of support (Socialstyrelsen, 2014).

Legal certainty, encompassing both formal and material aspects, is a higher goal of all public services. The formal aspects are legality, objectivity and equal treatment. A legally certain implementation of a welfare rights law, such as the LSS, also demands predictability. To predict which needs give the right to a specific support, the applicant must know the warrants for different support measures. The principle of proportionality is also relevant, and refers to the balance of interests and a consideration of the consequences to reach an intended democratic goal. These principles are well established in the Swedish Constitution. The specific values that make up the unique value foundation of the LSS give the material aspect of legal certainty (Lewin, 2019).

At the political-administrative level, there are three prerequisites for legally certain implementation and for citizens' trust in the public service: an understanding of the significance of the reform; a will to realise the intentions of the reform; and the capacity to guarantee financial resources and the competence to realise the reform (Vedung, 2016).

Swedish municipalities are responsible for the major part of LSS implementation[2] and are expected to implement it within the limits of municipal self-governance, a right that is enshrined in the Constitution. Municipal routines and guidelines are interpretations of national legal intentions. The municipal political committee has overarching responsibility for the implementation of the reform. With the help of municipal bureaucrats at different levels, rights under the LSS are supposed to be transmitted to those who qualify: individuals with specific needs, i.e. people living with disabilities. Frontline bureaucrats are steered by higher administrative levels at which cases are discussed and new legislation and policies are presented. The administrative procedure is delegated by the municipal political committee to the frontline bureaucrats and ends with a final decision which constitutes the municipal exercise of authority. The latter concept is not used in the law but signifies the municipal exercise of power to grant, or not to grant, citizens their legal rights (Warnling Conradson, 2018).

Investigation documents are compiled by frontline bureaucrats using a flow scheme with a number of different steps: (1) information gathering, (2) assessment of expressed needs, (3) comparing expressed needs with normative needs (the warrants for the right to different supports), and (4) compilation and communication of materials to the applicant before the final decision. In all these steps the frontline bureaucrat can communicate information from the investigation to the applicant for control and to express an opinion on the foundation of the final decision, that is, the exercise of authority (Socialstyrelsen, 2014, 2015 & 2016).

Under the Administrative Procedure Act (SFS, 2017: 900) the citizen has the right to put two fundamental demands on the authority: to get information about how the case is handled, and to influence its handling. This gives the citizen a strong right to participate in and influence the administrative procedure. The interests and duties of the citizen are clearly stated in the act's legal rules on service and communication: Under §6 the authority shall help the person to manage his or her interests. But the applicant also has the duty under §23 to provide certificates that can prove the disabilities and needs at issue. Under §25 the authority shall communicate all material of importance for the final decision. The individual shall only in exceptional cases have to take his or her case further to court (Government Bill 2016/17:180; see also Warnling Conradson, 2018). The United Nations Convention on the Rights for Persons with Disabilities (CRPD) (UN, 2008), is not included in Swedish law but is to be considered when implementing LSS (Swedish Agency for Participation, 2021; see also Funktionsrätt Sverige, 2021).

The text of the LSS and the Administrative Procedure Act does not always clearly show what is right or wrong, or which actions can be accepted within the limits of legal certainty. When the text does not give clear answers, administrative ethics can guide frontline bureaucrats so that their actions are according to the intentions of these acts and other norms. Administrative work is about choices and weighing the interests of all involved parties. In a sense, the bureaucrat is supposed to understand the construction of the whole democratic system (cf. Lundquist, 1988).

There is usually room for interpretation within the limits of the law, which can be generous or restrictive, depending on whose interests are promoted or threatened. A certain degree of caution must thus be employed when interpreting the wording of the text in applying the law. Considerations about the actual individual circumstances and consequences of the decision must also be made. Common legal principles and the facts of the individual case may be important as sources of law, as long as they are situated within the framework of the political intention of the law (cf. Lundquist 1987, 1988 & 1998; Erlandsson, 2018; Lind & Fridström Montoya, 2018).

Here, it is useful to understand what a *Contact Person* under the LSS is, as the concept is widely used in health and care. Under the LSS, the Contact Person is a specific support which can complement LSS Living Support and Service when a person feels socially isolated and needs somebody outside the staff network. The purpose of this should be elaborated, as it is widely misunderstood, and there is no clear legal praxis for it as yet, to my knowledge.[3] Certainly, the intention and scope of LSS Support and Service in Daily Living is broad. Many areas of life other than personal and home care are involved, and may be fruitfully compared to the more limited ambition of home services provided under the Social Services Act (Socialstyrelsen, 2016). Participation in leisure and culture activities is specifically mentioned in the text of the LSS for this support, and mostly refers to opportunities to take part in collectively arranged activities. The self-evident good personal treatment that can be expected from staff must always be there when it comes to the performance of LSS support. But professional support should *not* be included when a frontline bureaucrat considers whether an applicant is socially isolated. To counteract deep loneliness, a non-professional contact, a human being is needed, and the life area concerned is Social Interactions and Relations (Socialstyrelsen, 2016). The primary intention (the warrant) of the LSS Contact Person is to fill this need for non-professional contact – a fellow human being who can be a friend, not a professional. Contact with such a fellow human being also provides a possibility to fill the secondary intention of the support: to experience leisure and culture activities (Government Bill 1992/93:159).

Methods as a disability rights researcher and activist

This chapter is based on material from administrative procedures concerning five individuals who made applications for LSS support that I helped with as a disability rights activist. The source material comprises prescriptions and handbooks from the National Board of Health and Social Care, policies from the municipality, and documents concerning frontline bureaucrats' investigations. The material also includes complaints from the five individuals, two appeals and verdicts of the Administrative Court and, finally, the mail communication between the bureaucrats and myself. All persons involved are anonymised and their characteristics are mixed up to further anonymise them.

I have analysed the data by looking at its content (Kuckartz, 2019) and identified themes relating to the behaviour of the bureaucrats in the administrative procedure. I will discuss these themes in relation to the legal context. In doing so, I pay particular regard in LSS to Lex Sarah – a law that states that the staff are obliged to report misconduct in elderly care and care for people with disabilities – and, in the Administrative Procedure Act to §6 on service duties, and §25 on the communication process.

Methodologically, this study is based on participatory research (Starrin, 2005). The applicants were referred to me in my capacity as a disability rights researcher and activist. I helped them complete the application procedure for support on a no-fee basis, as an advisor or trustee, and they were all informed about my double role as a no-fee agent in their contacts with the administration and as a researcher. The applicants also participated in communications with bureaucrats concerning complaints to the municipality and appeals to the Administrative Court, and we went through the content of the correspondence with the bureaucrats together. The applicants made comments and additions to my proposals and agreed to all the steps I took to further their applications for complaints or appeals. All materials concerning the applicants – investigations, complaints, appeals and verdicts – were shared with me. The applicants (or, in two cases, the trustees) signed a document permitting me to use the anonymised documentation on their participation for this chapter. The applicants did not participate in the analysis or in writing this chapter.

Static needs, varying decisions

The needs of the persons who contacted me as a disability rights activist are described in the frontline bureaucrats' investigations. All had made complaints on the administrative procedure to the municipality and two had appealed to the Administrative Court. All had received appropriate long-term support and then lost it, although their needs had not changed. All applicants have intellectual disabilities and disorders: they cannot be 'cured', and their needs will not disappear.

The strategy to give time-limited decisions generally constitutes a major problem for persons with intellectual disabilities and disorders. To guarantee social security, such decisions should not be time limited. The new Administrative Procedure Act does not address this. It is suggested that this problem can be solved in LSS and other relevant special laws (Government Bill 2016/17:180; Bäckman, 2018). As the use of time-limited decisions concerns the exercise of authority and not the administrative procedure, it is only commented on briefly, in connection with one of the cases.

Three of the persons I worked with had lost long-term appropriate support in their daily living. Their needs had not changed, and they wanted to have LSS Personal Assistance again. The other two felt very lonely and wanted to again have an LSS Contact Person, which is, as described earlier, a form of non-professional support.

Among the first three, one application for continued municipal Personal Assistance under LSS was denied in the autumn of 2019. The applicant's trustee lodged a complaint regarding the administrative procedure to the municipal scheme for opinions and complaints, but it was not handled according to the municipal policy. A superior bureaucrat informed the trustee that it would be better to appeal to the Administrative Court. The trustee felt forced to do so and the original complaint was attached to the appeal. It was denied in the spring of 2020, stating that no certificate was provided to prove the applicant's needs. The trustee had expected that the political committee would allow his adult child continued right to support that had been granted him for such a long time as it was clear that there was no change in needs. This reasoning was rejected by the court as not relevant, as the applicant's support had been time-limited.

The second person had also lost her right to LSS Personal Assistance which she had had for a long time. Apart from an intellectual disability, the applicant had substantial physical disabilities following a major stroke. She appealed to the Administrative Court and was denied. She was told that she had not provided a certificate proving her right to LSS support. Instead she was given traditional home service under the Social Services Act, with punctual practical support. However, this did not function well in her experience.

The third person also needed substantial care and support in her daily life and lost her longstanding appropriate support. She did not consider the support she was now provided under the Social Services Act as meeting her needs. There was no flexibility due to the strict schedule, and the new staff were a problem as she could not relate to them and make herself understood. She felt isolated, frustrated and worried.

The last two persons each wanted an LSS Contact Person. One was a woman with a traumatic background and several psychiatric illnesses as well as mild intellectual disability and disorder. She had no relatives and experienced difficulties in making friends. She often did not feel at ease with the staff at the group home where she lived. She had two LSS supports: Living Support and Service and Daily Activities. A third LSS support, the Contact Person, was withdrawn in the autumn of 2019. The reason for this was that the applicant was not considered socially isolated: she was in permanent and continuous contact with group home staff. Her complaint was about the omission of relevant warrants for the right to a LSS Contact Person: a non-professional support by a person with great engagement and interest in other human beings (Government Bill 1992/93:159).

The last person had Down's syndrome, was socially isolated and needed a LSS Contact Person. Like the other person, he used to have this form of LSS support earlier, someone he had liked and whom he wanted to meet again regularly. He also had Living Support and Service and Daily Activities. This person only had one contact outside the staff network, was very isolated, and could not make friends. A complaint had been made on the same grounds as the former person. His trustee took his case to the Administrative Court. The case is not yet concluded (March 2021).

Complaints to the municipal system

The administrative procedure for all five persons led to complaints by the applicants which were lodged in the municipal scheme for opinions and complaints. Two appeals to the local Administrative Court concluded with a denial. Before and after the municipal exercise of authority there were email communications between the superior bureaucrats, who were responsible for the respective cases, and myself. These concerned the policy for handling complaints as appeals, and their practice in doing so. There were routine answers to the complaints from the superior bureaucrats, with somewhat varied content. Some examples, from different cases, are given below:

(1)

> Permission to lodge comments has been given in connection with the communication procedure. If the decision of the investigation is a rejection or partial rejection of the application, the decision may be appealed.

(2)

> There are no limitations in the guidelines of the municipal authority as to which complaints can be lodged, or in which areas. The authority has judged that the complaints go under the Administrative Procedure Act.

(3)

> We do not handle complaints on the administrative procedure. They are referred to the Administrative Court.

(4)

> The administration of complaints is primarily intended as an instrument for other types of standpoints, for instance concerning questions of treatment or actions that may lead to a deviation report under Lex Sarah [to the municipality or the Health and Care Inspectorate, IVO]. Standpoints that concern assessments or the content of decisions should not be administered as complaints as there is already a scheme for administration – namely through trial in court. Sometimes a lodged document may contain standpoints both on the assessment of a case and on the design of the administrative procedure. In such cases, it may be appropriate to handle the case both as an appeal and as a complaint concerning a certain part.
>
> (*my translation*)

One superior bureaucrat commented on this tendency to refer complainants to the Administrative Court by quoting the Parliamentary Ombudsmen (JO, 1999/2000)[4] that '[t]he authority must be very generous with the interpretation of what can be an appeal'. This bureaucrat also saw a problem when a person turned to the municipal authority how a document should be interpreted:

> That could be experienced as pressure from the authority not to complain. It is a difficult balancing act, and different persons naturally think differently about this question. But the most favourable still is that a process in court is started during the period of appeal, expressing discontent with a decision. Not to do this would mean that the person loses the possibility to appeal a decision.
>
> (*my translation*)

What can be learnt about bureaucrats' administrative behaviours?

The administrative procedure may be discussed both from a purely legalistic view – is the behaviour of the bureaucrats legally certain? – and from the point of view of administrative ethics when the wording of the law cannot cover all situations. When analysing the material it is possible to find similar themes and patterns for all five applicants. I choose to consider these as strategies, as they seem to be routinely used. They concern the administrative style – the frontline bureaucrats' behaviour – in personal meetings and contacts with the applicants and myself.

The first step in an investigation is to gather information on an applicant's expressed needs. This is usually done through personal contacts and meetings. Applicants complained of great frustration, of not being seen or listened to, and that the frontline bureaucrat did not understand the difficulties in daily life caused by their cognitive disabilities. The applicants did not feel informed or helped by the frontline bureaucrat about navigating the administrative procedure, which certificates were needed and the warrants for a positive decision to get support. They did not feel they had any influence on the administrative procedure. This *strategy to withhold information and help* has the consequence that the applicant's needs are diminished. This strategy also leaves room for a tendency to steer applicants towards the Social Services Act – that is, a *strategy to steer towards traditional home services* despite the inappropriateness of the support for persons with intellectual disabilities and disorders.

Frontline bureaucrats usually presented applicants' needs correctly in the second step of the investigation, the assessment of expressed needs. In one case, however, a telephone contact that conveyed points of view that the applicant found important was noted, but facts that were important for the final decision were not documented. A complaint was lodged but not handled. The result was a final decision allowing insufficient support. The formal demand objectivity was not met, and the applicant's needs were diminished. This is an example of a *strategy to withhold relevant facts to diminish the needs of an applicant.*

The strategy to diminish needs was also used in the third step of the investigation. In this step the frontline bureaucrat relates an applicant's expressed needs to normative needs and makes an assessment of the right to support. The normative needs, or the warrants for the right to support, are described in LSS and the LSS Government Bill. The needs can be distorted when there is *a strategy to omit important warrants.*

As mentioned earlier, in the fourth step, all materials needed for the final decision should be compiled and communicated to the applicant. But the law does not give examples of materials that should be communicated. My findings show that warrants for different LSS supports were not always documented and communicated. This was evident in the two cases that applied for an LSS Contact Person. The argument for a denial in the exercise of authority was that the support given by LSS Support and Service in Daily Living staff was sufficient to create good living conditions. The applicants' needs were thus distorted and they were denied the right to LSS Contact Persons.

When applicants made comments in the communication step – which they did in all five cases – these were only attached to the investigation, without being commented on or argued against and, most importantly, without effect on the exercise of authority. The *strategy not to consider the points of view of the applicant* means that the final decision was regularly taken without any possibility for the applicant to influence the assessment, and there was no predictability as to what the result of the exercise of authority would be. The refusal to consider critiques and questions was very frustrating for applicants. They experienced power abuse; they could not use their legal right to influence the foundation of the final decision.

If an applicant is not satisfied with the communicated assessment and the other steps of the administrative procedure, they can lodge a complaint to the municipal authority. Under Lex Sarah, this complaint must be handled in a specific way. This was not done in any of the cases studied. There is thus a *strategy to not handle complaints according to municipal policy.* The routine email response from all higher bureaucrats was, as quoted earlier, that the complaints did not concern the administrative procedure. Instead, *a strategy to refer complaints to the Administrative Court* was invariably used.

Two applicants felt forced to go to the Administrative Court while the others withdrew appeals that had 'mistakenly' been sent to the court. In the former two cases, two important and useful points were made by the court. First, the court pointed out that its task is to conduct a substantive examination. The court is not a supervisory authority like the Health and Social Care Inspectorate or the Parliamentary Ombudsmen. Complaints regarding the administrative procedure should be handled by the responsible authority, that is, the municipality or the national supervisory authorities. Second, under the Administrative Procedure Act, the applicant has the duty to provide certificates or other information to make it likely that the warrants for the right to support are fulfilled. This was in fact known to some of us, but we relied on the strengthened service duty under the new Administrative Procedure Act: that frontline bureaucrats would help the applicant manage his or her interests and make it possible to influence the administrative procedure by providing sufficient information to prove his or her need. As noted earlier, one superior bureaucrat interpreted complaints as appeals to the Administrative

Court and referred to a statement of the Parliamentary Ombudsmen about being generous in interpreting what can be an appeal. The applicant then felt forced to appeal.

Thus, frontline bureaucrats employ a variety of strategies and practices that diminish and distort the needs of the applicants. Superior bureaucrats do not handle complaints in a legally certain way. All complaints were closed with referrals to the Administrative Court.

Bureaucratic strategies and their consequences

All the strategies identified in the previous section have negative consequences for applicants. They threaten access to LSS support and are not in line with the citizen focus of the LSS and the Administrative Procedure Act; moreover, they hinder applicants' access to a range of settings and contexts since these persons need personal support to navigate in society. This suggests that the law is made invisible by bureaucratic resistance.

Strategies that diminish or distort the needs of the applicant can be difficult to uncover for an applicant or trustee who has not read the appropriate bills, legal texts and handbooks. The power gap between the frontline bureaucrat and the applicant becomes clear. This calls into question the competence of frontline bureaucrats: do they know the intentions and content of different forms of support, or do they not wish to comply with the law? In either case, the consequence is that the foundation for the final decision is incomplete, and the exercise of authority rests on legally uncertain ground.

In three of the cases discussed in this chapter, the warrants for qualification for LSS support in ordinary living seem to have been changed without informing the applicants. No changes in needs had occurred since these applicants first received support, between ten and 20 years earlier. The support had previously been extended after each decision period. The predictability of the decision – an important formal requirement for legal certainty – was absent. The consequence was that the applicants lost a long-time appropriate support and were offered home services under the Social Services Act which they could not really use.

Thus, inappropriate support, or no support at all, is the consequence of the strategies to prevent access to support. It can also be argued that the proportionality principle is not respected in the consideration of the consequences of the exercise of authority. My suspicion, which I cannot support from this empirical data and can only submit as a hypothesis, is that demands from the administration to hold to budgets is given priority over legal certainty in Sweden. There also seem to be cooperation problems at a higher level in the municipalities, i.e. between local politicians. The LSS includes a legal requirement to cooperate with other relevant authorities such as healthcare services. This is obviously not done when it comes to the will of the Habilitation of the Region[5] to provide certificates regarding an applicant's functioning.

The strategy to withhold information in the fourth step (related to compilation and communication) before the exercise of authority, is crucial for the invisibility of the law. When relevant information about needs assessment and the relevance for the actual LSS warrants is not provided, there is no possibility for the applicant to influence that important step. And their needs may not be fully described. This implies problems with legality and objectivity.

Comments from the applicants may be added at this stage, but are not attended to and contested. The exercise of authority is thus founded on a legally uncertain administrative procedure which prevents access to support. The consequence is a restrictive exercise of authority and inadequate support under the less ambitious Social Services Act. The bureaucrats can hardly, from my perspective, be seen as guardians of democracy. Again, the law that was supposed to diminish the power gap between the welfare state and the individual is made invisible.

Both on the individual and the societal level, legality and openness about the administrative procedure is an important demand of citizens to be able to trust the administration and to find it legitimate. Here, researchers use the concept of the *legitimacy triangle*. The corners represent three demands on the public administration: democracy (as expressed in the LSS and Administrative Procedure Act), cost-effectiveness (when the municipalities make budget priorities), and legal certainty (that persons with disabilities get their legal rights) (Lewin, 2009; Norén Bretzer, 2014). Ideally all three values are fulfilled. Many different interests compete when realising the LSS reform. The municipal political committees express a wish to follow the law but may, in practice, prioritise cost effectiveness, to keep within their budget. The administration may want to be loyal to the power – the local political committee – by following experienced demands to hold the budget. This means less and cheaper support. More concretely that means the less ambitious support under the Social Services Act (a reasonable living level) instead of support under the LSS with the aim to give good living conditions. For persons with disabilities and needs that do not change this is experienced as a serious restriction of welfare.

The overarching strategy not to give applicants the possibility to influence the administrative procedure seems legally uncertain and detrimental. If the bureaucrats do not obey the special rights law – LSS with Lex Sarah – people with certain impairments are unable to access good living conditions. A lack of respect for the citizen focus of the Administrative Procedure Act probably makes matters worse, both for the administrative procedure and the exercise of authority. The fundamental value of maintaining a legally certain implementation of the regulation is systematically neglected. The Administrative Court gave the two applicants whose appeals it heard a hard lesson: they should be more competent than bureaucrats in knowing the warrants of the support, and that they are supposed to provide certificates to prove their needs even when these needs are constant and have remained unchanged for years.

Even when no legal rule can be said to be broken, there is a serious ethical problem with the strategy of presumed consent when it comes to routine referral to the Administrative Court. There is an evident power relation between the municipal authority and the person with disability, which the values of free will and autonomy fostered by the LSS and assisted by the Administrative Procedure Act are supposed to equalise. In this perspective, expressed will – real consent – must be obtained. After all, who knows the interests of the individual better than the person at issue? Are such patronising attitudes acceptable, or do they constitute an abuse of power in connection with LSS implementation? The values of respect for individual integrity, will, and influence seem to be made invisible.

Conclusions: a circle of resistance

The aim of this study is to answer certain questions raised by the applicants I worked with. Has the implementation of the support become more restrictive, in spite of the fact that accessibility to appropriate support is a precondition for participation in society? Are the bureaucrats of the study in compliance with the law? And how can resistance to accessing LSS support be described?

My cases show that in Sweden today, people may lose LSS support that they have had for a long time without their needs changing. This makes it easy to answer the first question: the implementation of the support is indeed more restrictive. High-quality LSS support is replaced by punctual home service under the Social Services Act, with its lower ambition and large staff groups. Such support can hardly be said to be appropriate for persons with intellectual disabilities and disorders.

The answer to the second question, i.e. whether bureaucrats are in compliance with the law, is no. The implementation of LSS legislation, with its strong emphasis on individual influence, the special rules under Lex Sarah and the Administrative Procedure Act, which has signalled a move from an authority focus towards a citizen focus, shows several examples of legal uncertainty.

When it comes to the third question, about how best to describe resistance to access to LSS support, I have found a number of strategies in my data that diminish and distort the needs of applicants. It is evident that frontline bureaucrats have a different view than the law of what material should be communicated to the applicant for information and control. The applicants' lack of information and influence means that the exercise of authority is based on a legally uncertain foundation for decision. Bureaucrats use their power over the applicant so that the right to support is lost. The democratic demands on the administration – the upper vertex of the legitimacy triangle – is neglected when there is no legal certainty. An appropriate support, based on the high ambition of the LSS, has been abandoned for a weaker support under the Social Service Act. The solidarity for the weakest citizens expressed in the special rights law is set aside, without an admission that LSS values are on their way out.

The reflections in this chapter emerge from a relatively small body of material. I cannot show that other municipalities also use a legally uncertain administrative procedure before the exercise of authority where the support is lost. Hopefully future research and reports from the national supervisory authorities will show if the situation is the same in other municipalities, if there are changing trends over time, and if they apply only to certain citizens. If so, the responsibility lies at the national level to enforce legal certainty in the administrative procedure to restore trust in public services.

What will the applicants do now? They have started anew in what can be described as a bureaucratic circle of resistance to granting them LSS support. Here the applicant moves along the circle through the different steps of the administrative procedure – both of the investigations by the frontline bureaucrats as well as the complaints on that procedure. Supervisory national authorities will probably be approached again in spite of the fact that those have little legal power. The Administrative Court will probably also be turned to. The hope is then that the court will find the experienced problems of the applicants to be matters that should and can be handled by the court and not the municipal authority or the national supervisory authorities. And even come to the conclusion that the applicants' needs give them the right to LSS support.

Notes

1 The three LSS categories are: those who have intellectual disabilities or autism, or who have a condition resembling autism; those who have considerable and permanent mental impairment following brain damage received as an adult, as a result of external force or physical illness; and those with some other lasting physical or mental impairment that is clearly not due to normal aging, if such impairments are substantial and cause considerable difficulties in daily life and consequently, an extensive need for support and service.

2 The Swedish Social Insurance Agency (SSIA) is responsible for assessing needs and financing part of the LSS Personal Assistance support. The agency has governmental steering and its organisation and decision-making differs from that of the municipalities.

The right to personal assistance in Sweden is becoming increasingly circumscribed due to governmental cost-cutting goals and political rhetoric that questions the legitimacy of the right to personal assistance (Altermark, 2018). The goals to cut spending are turned into practice by street-level bureaucrats, making up a reality in which now only 15% of first-time applicants are granted personal assistance from the SSIA (SSIA, 2018). Gunilla Järkestig Berggren, Ulla Melin Emilsson and Ann-Sofie Bergman discuss the discretion of frontline bureaucrats and how restrictive strategies result in limited implementation. During the time period from 2008 to 2017, the personal assistance granted by the municipalities increased from 3500 to 4900 persons (National Board of Health and Welfare, 2018) (Järkestig Berggren et al., 2019: 11–12; see also Lewin, 2018).

3 At time of writing (February 2021) a relevant case, 6714–19, with unlimited time duration, was yet to be tried by the Supreme Administrative Court (HFD, 2020).

4 The Parliamentary Ombudsmen are appointed by the Swedish Riksdag to ensure that public authorities and their staff comply with the laws and other statutes concerning their actions.
5 The Region is the other local organisation apart from the municipality in the Swedish welfare system.

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12 Using building requirements as a means to create inclusion

Accessibility and usability at a crossroads

Jonas E. Andersson

> Universal design implies that society is conceived with awareness of the population's diversity, and that people with disabilities can take part in activities of everyday life on equal terms with people without disabilities.
>
> (Proposition, 2016/17: 188, p. 28)

In 2017, the Swedish government redefined the national goal for the disability policy based on the United Nations Convention on the Rights of Persons with Disabilities (CRPD). The goal was to 'achieve egalitarian living conditions and full participation for people with disabilities in society' along with increased gender equality and respect of children's rights (ibid.: p. 22). This redefinition was justified since the previous formulation of the goal had dated back to the ideological landscape of the early 1990s, i.e., prior to the introduction of the convention in Sweden in 2008. The new disability policy provides four means of achieving this goal:

1 Preventing and counteracting discrimination;
2 Suggesting individualised solutions and support to expand and maintain individual independence;
3 Addressing existing deficiencies in accessibility; and
4 Implementing the principle of universal design.

The new disability policy takes the fourth of these, universal design (Story et al., 2011), as the strategic point of departure for the full policy programme. Universal design thus influences the other three key areas. Although the concept of universal design is generally little known, the Swedish government does not see it necessary to implement new regulations to promote its implementation. Instead, the policy suggests an overhaul of existing legislation and regulations for the built environment, targeting easily eliminated obstacles and the inclusion of disability policy into municipal and regional physical planning (Proposition, 2016/17: 188, pp. 64–65).

The principle of universal design is a prioritised dimension in the realisation of the national disability policy. Following the motto of being a

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> country that keeps together, the modern welfare state shall be conceived in such a manner that all citizens can be part of it to the largest extent possible. This increases the possibility for society to promote accessibility and participation for people with disabilities.
>
> (Proposition, 2016/17: 188, p. 28)

Consequently, the new disability policy is closely linked to building legislation and fundamental parameters for the conception of new building designs or for refurbishing existing ones. Universal design thinking is promoted as a principle, a method and a process for minimising risks due to inadequate physical planning and programming of new buildings (SOU, 2019: 23). It is debatable whether the new disability policy will strengthen or weaken the necessary linkages between the accessibility–usability oriented perspective of the previous building act with appurtenant regulations and the brand-new concept universal design in the new disability policy (see also Hanna Egard's chapter in this book).

Disability policies and building acts

In contrast to the new disability policy of 2017, the policy during the 2000–2010 period had a direct impact on the building act. This resulted in the formulation of two new regulations covering a new area of building regulation. These are still in use and cover existing buildings and public spaces in the townscape, and aim at removing conflicts between users and the realisation of the built space. In the previous policy, such conflicts were termed 'easily eliminated' obstacles. The concept continues to thrive, since the very nature of such problems is that they often are persistent due the slower pace of change in the built environment (see also David Wästerfors' chapter in this book). These obstacles can be found in exterior access points to public buildings, in public outdoor spaces as well as in the interiors of buildings.

The Swedish building act promotes user-friendly design in the built environment and long-term sustainable buildings and building practices. Requirements on accessibility are mandatory for any developer for both new and refurbished building projects. The building act places the full responsibility for the fit between future user groups of the building and the architectural design onto the developer. In the absence of real users, for good or ill, building experts like architects and engineers often act as proxies by drawing on their own experiences and preferences.

After Sweden ratified the CRPD in 2008, the building act was reformed once again. To highlight the relationship between the users of the built environment and the physical design of the building, the existing concept of accessibility was converted into something more user-oriented through new twin criteria of usability and accessibility for buildings and physical planning. These provoked little reaction in the Swedish building industry.

However, shortly after these changes to the building act with appurtenant regulations, the building industry started to link Swedish housing shortages with what it labelled the too-far-reaching mandatory requirements of the building act (Nohrstedt, 2009). The Swedish construction company JM AB, one of the country's three largest, with projects in Sweden, Scandinavia and the European Union, condemned the act's accessibility requirements as the key factor in why building costs in Sweden had skyrocketed (Fock, 2010). Three years later, the construction company NCC AB, with a similar portfolio of building projects, presented a report suggesting that the building act was the cause of the national housing crisis (NCC, 2012). The report claimed that it was not only the accessibility–usability requirements but also the legal mechanisms of the system that controls comprehensive physical planning, building design and building permits that had resulted in longer preparatory processes and higher building costs in Sweden than in identical projects in other countries (ibid.).

Aims and purposes

The promotion of universal design to the highest priority area in disability policy challenges the established dynamics of the accessibility–usability requirements of the Swedish building act. At the same time, critiques of the building act, as well as the substantial cost and time implications of accessibility–usability requirements, threaten the realisation of this new goal. The present study is focused on the background of the current building act as a promoter of inclusion for people with disabilities and the conflicts that may arise when national disability policy appears out of step with ongoing reforms to the building act with appurtenant building regulations. This study explores a phenomenon situated in two research fields which are often seen as unrelated – the rights of people with disabilities and technical requirements for building – using a case study methodology (Flyvbjerg, 2004; Yin, 2003). The study focuses on reforms of the Swedish building act that occurred between 1930 and 2020.

The research material was assembled through keyword searches in open and restricted databases for words in both English and Swedish related to access, accessibility, usability, disabilities or handicap, inclusion and participation. Given the nature of building design and physical planning, i.e., as an acquired theoretical knowledge put in continuous practice depending on the assignment and the commissioner (Cold et al., 1992; Schön, 1988), the accumulated research material consisted of research papers and grey literature including exemplary buildings, professional magazines and governmental reports and guidelines. The material was analysed with an intersectional perspective that used the dichotomy between the fully abled body's abilities versus perceptions of the disabled body's abilities, congenital or acquired disabilities (Hill Collins & Bilge, 2020; Norris et al., 2007). The reading focused on building requirements that are of relevance for promoting an appropriate fit between people with disabilities and the built environment, e.g., width of passage, horizontal and vertical communication, gradients and different levels.

A short overview of the Swedish building legislation

Given the relatively slow pace of change in the built environment, existing buildings often solidify past or present views on the relationship between architectural design and the user (Gieryn, 2002). Hospitals and institutions accommodating people cared for through societal means often demonstrate a control mechanism that is present in the architectural configuration of the building (Foucault, 1975; Goffman, 1961). Sweden together with Canada and Denmark are often hailed as one of the best countries in the world at promoting equal rights for people with disabilities and the accessibility and usability of the built environment (Fardeau, 2015). In Sweden like other countries that have included minimum requirements in their building acts rather than in discrimination legislation, the evolution of the modern accessibility requirements in national building acts, national standards or international standards can be studied in real-life settings by exploring modern building design. A common trait of such requirements is the use of biometric data for human beings of different ages and of various abilities to define the minimum measurements for door width, corridor width, threshold height and ramp gradients in guidelines, norms and standards.

In its opening paragraph, the Swedish Planning and Building Act declares that the legal framework aims at 'promoting a societal development with appropriate and equal living conditions for all as well as a progression towards a sustainable environment for present generations and future ones' (SFS, 2010:900, §1). The Swedish building legislation, like in most Scandinavian countries (except Norway), is typically focused on the concept of 'accessibility and usability' rather than 'universal design' (Dion et al., 2015). Already in the programming phase of a new or a refurbished building, conditions for people with disabilities accessing or egressing the building must be evaluated in terms of safety and security for all users by realising certain minimum requirements for accessibility and usability, i.e. physical measurements and spatial configurations for ease of use. The regulations act in two ways: as a design parameter for conceiving the architectural design, and as a technical parameter for the construction of a new or refurbished building.

Compliance with the building act and appurtenant regulations is monitored and supervised by the municipal administration: first, during the building permit phase, and, second, during the construction phase, through a control plan that targets requirements such as accessibility and usability, construction, hygiene and indoor climate and fire safety. This planning will be decisive for future users of the buildings, affecting their sense of safety and security in case of exceptional conditions (see also Kristofer Hansson's chapter in this book). Swedish accessibility and usability requirements are traceable through a series of reforms of the national building act from 1930 to the present day, in parallel with the definition of the national disability or housing policy. A common feature of these reforms is the intention to promote a better national housing standard with improved living conditions.

Under the Swedish principles of civil administration, reforms are prepared by special committees designated by the Swedish Parliament or the Swedish government. These committees explore their assignment through one or several reports. During or at the end of the committee work, the reports enter a consultation process during which opinions are assembled concerning the proposals. These opinions are then considered by parliament or the government and assessed by a legal counsel before being further developed as a parliamentary or governmental bill. This process gives valuable insight into the underlying beliefs or mechanisms that may influence the final orientation of a reform.

The roots of today's inclusive built environment

To understand the emergence of accessibility as a building requirement in Sweden, we must first revisit the early twentieth century. At the time, Sweden ranked among the poorest European countries, with a steady flow of emigrants hoping to build a better life in the United States (Åman, 1976). The country was slowly changing from a predominantly agrarian society into a modern industrialised society. In both rural and urban areas, housing standards were poor, with overcrowded dwellings, inadequate heating and hygiene installations, sanitation or access to running water. The building act of the time was out of pace with the ongoing changes in Swedish society (Nordlander Finn, 1994). An increasing proportion of the rural population left the countryside to find work in industries in the growing cities. Large landowners, along with a rudimentary system for physical planning, hindered the development of new urban settlements with improved housing. The building professions – architects, engineers and builders – had little knowledge about the spatial needs of the growing working-class population (ibid.). Financial and rational building motives determined the layout of new housing for this group.

Social matters concerning children, older people and people with disabilities were discussed both nationally and in collaboration with other Nordic states, for instance, at a large conference held in Stockholm in 1906. While the rest of Europe was involved in World War I, the neutral Nordic countries organised exhibitions on appropriate furniture and housing for the working class; these were held, for example, in Copenhagen in 1917 and 1918. The fin-de-siècle liberal and social-democratic movement largely adhered to the belief that the architectural design of buildings and physical planning are factors that mould the achievement of societal visions. A social hierarchy was detectable in the configuration of the built space. Accommodation for people with special characteristics – the dependent elderly, or those living with disabilities, in orphanages or who experienced work-related injuries and sickness – relied on large-scale institutions that separated such groups from the wider population. Run by parishes or benevolent organisations, the institutions were characterised by a strict division between men and women, with separate dormitories, seating arrangements in canteens, workspaces and chores (Åman, 1976). The institutions turned into profit-generating sites in which childcare, education, eldercare, housing and work opportunities were provided under poor living conditions (ibid.). Seen from a building perspective, the architectural design of these large institutions promoted the introduction of new building techniques, building materials and the programming of built space. Central heating and hygienic installations – water closets and running hot and cold water – became integral building parts (Kolstrup, 1996).

Inspired by Florence Nightingale's requirement of a 'cubicle' of fresh air around the bed of each patient, ventilation techniques for distributing fresh air inside built spaces started to evolve to promote good health among the inhabitants. The emphasis on fresh air and daylight led to larger and more spacious buildings. The older miasma theory, about the lethal influence of bad air on human health, started to give way to the emerging new sciences of bacteriology, medicine, nursing and virology. In 1918, the poor relief act was reformed and supplemented with architectural drawings of prototypes for old people's homes, orphanages and other institutions for children and adolescents (Civildepartementet, 1920). The architectural drawings aimed to create more humane living conditions and even a homelike atmosphere (ibid.). The buildings met minimum requirements and were strictly calculated to meet restricted budgets and be eligible for state grants.

The overturn of the old order caused by World War I led to an architectural reorientation in Europe which promoted a sociological approach to building and physical planning by the end of the 1920s (Lundberg & Tydén, 2010). Architectural design increasingly focused on the fit between user needs and the built environment and, to some extent, was influenced by increased societal support (ibid.). In Sweden, building prototypes promoted by the political fin de siècle movement were closely analysed and heavily criticised for their inadequate fit between users and spatial configuration (Göransson & Sundbärg, 1933).

New ideals: housing that emphasised user-based knowledge

By the end of the 1920s, the Swedish social-democratic movement had gained momentum. In a speech to the Swedish Parliament in 1928, the social democratic politician Per Albin Hansson introduced the concept of *Folkhemmet* as an ideal for the development of the modern Swedish welfare model: 'equality, mutual consideration, cooperation, and kindness persist in the good home environment' (Hansson, 1928). The Stockholm Exhibition of 1930, about architecture, arts and crafts, solidified this meaning by its focus on 'furnishings for small modern apartments, making the furniture adjustable to different uses and arrangement, while keeping high ideals of beauty, comfort, and fitness of material' and aiming for 'pleasant and practical homes for the people of average income' (Hong Rutt, 1933). This Swedish take on new housing and the home environment was less radical than the modernistic

Bauhaus architecture and art in the German Weimar republic, and was based on the art and crafts movement of the late nineteenth century (Eriksson, 2001; Hong Rutt, 1933; Rudberg, 1999). It emphasised a holistic approach, which promoted a fit between human needs, building design and other artefacts in harmony with past aesthetic paradigms and the potential of industrial mass production (ibid.). Although criticised for being 'simplistic', functionalist architecture was integrated into the Folkhemmet, with an everlasting imprint on twentieth century architecture and planning in Sweden (Rudberg, 1999).

Amidst the social problems of the early 1930s – crammed housing and housing shortages, demographic and social change and ongoing urbanisation – the Stockholm Exhibition sought to find new solutions for housing, furniture and housing equipment. The configuration of the individual habitat was defined, with separate bedrooms for couples, children and singles. Space for storage and laundry was introduced. New concepts for kitchens with space for eating were introduced as well as a special space for socialising: the living room. Lifts were installed to transport people or for services such as meal delivery. Prefabrication and modular systems for building were introduced. Anticipating the introduction of the two-week paid summer vacation in 1938, prefabricated wooden modules for holiday homes were put on display. These envisioned a fit between architectural design and the individual user revolving around traditional family values: a married couple with the wife at home, husband outside the home, and two children. The exhibition had an inspirational effect on Swedish architecture, and opened up the view of the home as a machine, and thereby also embraced new ideas about different family constellations and employment for women (Asplund et al., 1931). Consequently, individual dwellings were combined with communal services for co-housing with integrated restaurants and other services. Participatory design processes for architecture were also developed.

However, the common denominator in the architectural designs and objects presented at the Stockholm Exhibition was a focus on the fit between people enjoying the capacities of a fully abled body and the built environment (Rudberg, 1999). People with disabilities were not an intended group of users and they, and other user profiles, were assumed to be living in institutional environments (Bergh, 1996). While having a much more limited impact, alternative ways of living outside the institutions were on the agenda of the organisations defending the rights of people with disabilities that had been formed at the end of the nineteenth and the first half of the twentieth century. At the top of their agenda was inclusion on equal terms with the rest of the population (Persson Bergvall & Sjöberg, 2012). The Swedish association for visually impaired people (in Swedish *Synskadades Riksförbund*, SRF) picked up the new tendencies in architectural thinking. The association promoted an architectural design that integrated user needs, giving architecture a supportive character and including features like handrails, colour cues, tactile cues and appropriate room sizes (see Figure 12.1). New housing concepts and participatory design processes in the new settlements developed by the association in Stockholm and Göteborg during the 1940s and

Figure 12.1 Drawings for the housing estate with space for administration and work ateliers that the SRF planned for its members in Stockholm at the end of the 1940s and realised in 1950. A participatory design process was used to translate special demands of the residents with visual impairments into architecture with spatial cues. The housing is still in use for its original purpose. Originally, the housing comprised of 80 small flats, but this number has decreased since the flats have been combined into larger ones. The architect, Albin Stark, worked with several co-housing projects for different groups during the 1930s and 1940s.

CAD drawings by author after hand-drawn drawings by Stark. Exterior photograph by author, but photograph of handrail courtesy Wiklund.

1950s (Wiklund, 2018). In Stockholm, the settlement was located to the south of the inner city, near access points for buses, trains and metro lines. The configuration of the individual flats centred on visually impaired persons' ability to perceive space through touch and hearing, but also on how much daylight they got. Executed in a functionalist architecture, with two high-rise towers containing living spaces and a large top-lit ground floor with an assembly hall and meeting facilities (originally workshop spaces), the SRF settlement still exists today.

Rethinking building design through systematic measurements

The Stockholm Exhibition of 1930 boosted a drive to rethink contemporary problems and to innovate in the building industry. Using increased pre-manufacturing, rationalisation and new building techniques, the initiative involved architects' offices, housing estate companies and the building industry (Nordlander Finn, 1994). It also proposed a standardisation of building elements based on a deepened knowledge of users and user needs. The initiative included a research project which compiled human biometrics and mapped typical household manoeuvres. This aimed at establishing biometrical information on the interactions between a fully abled user and the built environment. Converted into minimum physical requirements for architectural designs, this was intended to produce break-even calculations that minimised building and production costs. In 1939, merging the existing Swedish tradition of high-quality arts and crafts products with the mass production orientation in architecture and everyday goods, the National Association for Arts and Crafts products (*Svenska Slöjdföreningen*, SSF) and the Swedish Architects (*Svenska Arkitekters Riksförbund*, SAR) initiated a joint venture to explore the constituents of the ideal home environment: the so-called Swedish Architects and Arts and Crafts Housing Inquiry (*SAR:s och SSF:s Bostadsutredning*) (Mattsson, 2010). This was the beginning of a 21-year project that produced a series of reports on appropriate housing design, furniture design and which mapped national habits and the usage of the home environment.

The Swedish Architects and Arts and Crafts Housing Inquiry project assumed a sociological research approach, with a hands-on perspective on activities in daily living. The project accumulated research data through interviews, *in situ* evaluations and full-scale try-outs with voluntary participants, i.e. real-life users (Müller, 1951; Nordlander Finn, 1994). The different movements and adjustments for performing regular household chores were converted into physical measurements that were assembled into charts (see Figure 12.2). The charts described different sizes of dwellings in terms of physical measurements (Nordlander Finn, 1994). The spatial requirements for a standing person to perform food preparation on a counter and other household chores were assembled into national standards for kitchen cabinetry and wardrobe units (ibid.). The measurements considered the user's height in relation to the counter, capacity to move about and to reach and

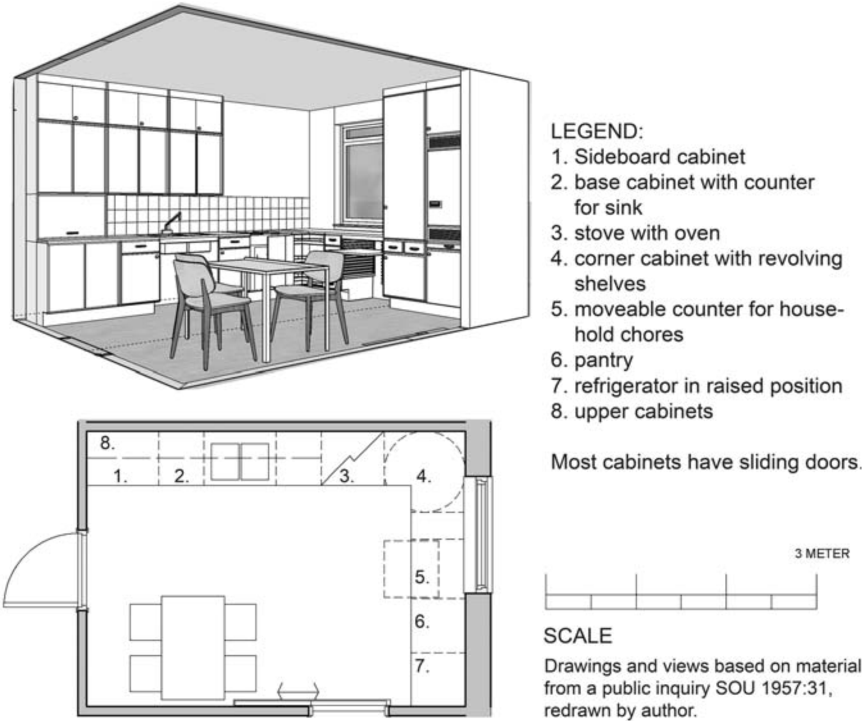

Figure 12.2 Spatial requirements for an adapted kitchen for people with locomotory and respiratory problems, e.g., knee space under the kitchen sink, a corner cabinet with rotating shelves, an adjustable workspace with pull-out counter and a refrigerator adjusted to persons using wheelchairs. The requirements were included in an appendix to the public report SOU 1957: 31 on appropriate housing for people with disabilities.

Figure by author.

stretch for different operations and utensils. Soon, the project detected user-related aspects that challenged the preconceived idea of a household with two adults and two children. The research discovered that an average family often included a person who had special needs due to disabilities that resulted in spatial adaptations, often locomotory, respiratory or visual problems. These findings led the National Association for People with Disabilities (*Svenska Vanförekommittén*), formed in 1911 and consisting of representatives of the seven major organisations for people with disabilities, to join the project in 1943 and take an active part in establishing spatial adaptations of the physical environment to meet the needs of this group of users (Müller, 1951). The needs were mainly linked to the consequences of poor work environments and the low standard of housing, and related to different forms of acquired disabilities with subsequent physical limitations (SOU, 1957: 31). Often, they related to locomotory limitations or visual problems after work-related injuries that required assistive equipment such as a cane or wheelchair. These needs could also refer to problems relating to the lungs and blood pressure due to inhalation of hazardous materials at work or following recovery from tuberculosis.

The spatial requirements which the research project generated also served as guidelines for state grants for improving housing standards in new and existing housing. These grants were allocated to 'families who due to medical reasons had a pressing need for improved housing' (SOU, 1957: 31, pp. 10–11). The intended applicants were families in which one or several members suffered from rheumatism, tuberculosis or physical disabilities (ibid.). The guidelines covered both the location of the dwelling and its architectural design, and foregrounded the relationship between the user and the layout of the dwelling (Regeringen, 1958). The grants proved important for elucidating another topic that was much debated during the 1950s: appropriate housing for the elderly. Following a retirement reform in 1948, the prototype for old people's homes, according to the floorplans for institutions under the reform of the poor relief act in 1918, was subject to severe criticism by retirement organisations (Lo-Johansson, 1952). In the end, existing homes were simply converted into ordinary housing for frail older people in need of non-medical assistance and caregiving. Following the reforms concerning eldercare during the 1950s, in 1959 the state introduced subsidies for adapting the home environment for older persons with locomotory, respiratory and visual problems. During the 1960s, these so-called temporary invalid housing allowances were converted into a permanent system of adaptation allowances for older people with age-related disabilities in 1963 (SOU, 1964: 41). Between 1965 and 1975, the allowances went from including only people with locomotory and respiratory problems to also including cognitive and hearing problems.

Turning the building legislation into a socio-political instrument

Besides the entrepreneurial response, the Stockholm Exhibition in 1930 also led to reforms of the building act. Until 1940 the existing building act, which stemmed from the latter part of the nineteenth century, had been updated by four consecutive reforms (Boverket, 2007). Two reforms pertained to the municipalities' responsibility for physical planning on a comprehensive and detailed level. The two subsequent reforms concerned building requirements for new housing. The reforms supported a more functional type of physical planning process in the larger city regions, to meet the increasing influx of new inhabitants from the countryside. In retrospect, the Stockholm Exhibition, in combination with the social-democratic dominance, in the 1932 elections, favoured the socio-political dimensions of an improved housing standard. Three years after the exhibition, the government assigned a parliamentary committee to explore the characteristics of the Swedish housing market (Nordlander Finn, 1994). From 1933 to 1947, the so-called Housing and Social Issues Committee (*Bostadssociala Utredningen*) analysed the national housing situation, the housing standard, demographics and socio-economic data (ibid.). The committee concluded that most existing housing lacked space and facilities for food preparation, appropriate spaces for sleeping and hygiene installations like running water and water closets. In the construction of the *Folkhemmet*, i.e., the modern Swedish welfare model, the committee saw improved housing standards as key components of prosperity and public health.

During the 1930s and 1940s, two other parliamentary committees continued to analyse building costs, housing and town planning (Boverket, 2007). The shared motivation was to incite changes to the building act and address the poor standard of housing. Preparations for larger state investments in new housing, which would eventually become the Million Programme, were also drawn up (Boverket, 2007). In its final report, the committee proposed a new housing mortgage system which came into force in 1948 (Boverket, 2007). The mortgage system started to implement requirements for upgrading existing housing and producing new housing according to the national goals of the housing policy, based on the findings of the Swedish Architects and Arts and Crafts Housing Inquiry in 1939–1959. It allowed for the installation of heating, new materials, sanitation and running water in existing housing. To be eligible for these loans, the applicants had to be the owner or tenant of a flat, and the target group comprised average persons without disabilities (SOU, 1964: 41). Retired older persons could also apply for adaptations of their flats due to disabilities caused by age- or work-related problems (ibid.). During the 1950s, attention to the relationship between users and architectural design started to expand to also include the living conditions of people in institutions. The struggle to achieve their full inclusion in society gained momentum, mainly thanks to the sports movement for people with disabilities which promoted the so-called normalisation principle (Nirje, 1992).

During the 1950s and the first half of the 1960s, further work prepared for the inclusion of other findings from the Housing Inquiry project (SOU, 1964: 41). The committee report clearly associated the word ‘accessible’ with the needs of people with disabilities (Regeringskansliet, 1966). The majority of key stakeholders also consented to new physical requirements for more equal access to buildings, but which buildings and to which extent caused disagreements (ibid.). In the governmental bill, the focus was tightened to include mainly people with acquired disabilities. The then-minister of communication, Olof Palme, wrote in the government bill to reform building legislation:

> Although the situation of people with disabilities has changed for the better in recent years, mainly through the addition of technical assistive equipment to help them to adjust to the surrounding environment, there is undoubtedly much to be done when it comes to adapting the environment to the special needs of people with disabilities.
>
> (Regeringskansliet, 1966)

In 1966, a new paragraph was introduced in the building act. The paragraph stipulated that public buildings were to be ‘accessible’ to a reasonable extent for ‘people whose mobility is reduced due to age, impairment or disease’ (SFS, 1966: 175). In the building regulations of 1968, the paragraph was reinterpreted to target so-called ‘wheelchair users’ (Statens Planverk, 1967). Besides the functional requirement for maintenance, accessible referred to sufficient access conditions for people with disabilities. The word ‘accessible’ became synonymous with the requirement to create ‘reasonable access conditions’ in various types of buildings (ibid.). In 1969, a set of physical requirements for accessible housing were published based on try-outs in full-scale laboratories at the national technical universities in which fully able-bodied students participated as test subjects (Statens Planverk, 1969). Minimum room sizes for accessible bathrooms and toilets in public building, hospitals and housing were specified (SPRI, 1979).

Forging accessibility as a concept for equal access and inclusion

In 1959, national Swedish radio broadcast a documentary on living conditions for children with disabilities at an institution in Stockholm (Asklund, 1959; Olsson, 2015). The documentary was considered as an infamous attack on a renowned institution, founded by a member of the royal family and enjoying state support (ibid.). The minister for social affairs questioned the journalistic interest in such housing and called for censorship. The documentary raised a public outcry against the inhumane and restrictive living conditions at institutions for young people with disabilities. A parliamentary committee was formed to explore living conditions for people with disabilities who were accommodated at public institutions (SOU, 1967: 53). The committee confirmed systematic abuse by the staff of admitted children and adolescents and concluded:

> The needs of people with disabilities have to be taken into consideration everywhere in society: in social planning, in the production of new housing, in education and at the labour market, in the national insurance system and in cultural activities.
>
> (SOU, 1967: 53)

The documentary resulted in a new law that gave the right to national radio to broadcast critical documentaries on societal matters. Private initiatives started a funding campaign to organise an architectural competition on appropriate housing, so-called Fokus houses (see Figure 12.3), for young people with disabilities (Brattgård et al., 1972; Wallsten, 2013). Architecture students at the national technical universities were eligible to participate. The competition defined spatial requirements for designing appropriate flats within ordinary housing for people with disabilities. During the 1970s, some 700 flats of this type were built, mainly in smaller municipalities (ibid.). The building costs and management of the houses were sponsored to about 55 per

Three prototypes for smaller dwellings for 1-2 persons used in the so-called 'Fokus Husen' redrawn by author, based on drawings for housing in Västerås (Bjurhovda 19) and housing in Göteborg (Brattgård et. al., 1972) both realised by the end of the 1960s. Photographs of the Fokus Housing in Västerås, photographs by author.

Figure 12.3 Three floorplans developed in an architecture competition for students at architecture faculties for the housing prototype called *Fokushuset* which were intended for young persons with disabilities. The three-room unit allowed for two persons sharing the flat, either as a couple or as co-tenants. The floorplans reveal innovations like larger bathrooms, sliding doors to the bathroom and between the kitchen and living room, flexible and movable kitchen cabinetry, and storage inside the flat (Brattgård et al., 1972). Today, this type of housing has been taken over by the municipalities, but the majority are still in use, like the one in the photographs in Västerås.

Floorplans and photographs by author.

cent by the disability movement, while municipalities and regions financed the rest. Today, this type of housing is fully financed and provided by the municipalities, since legal reforms have integrated this type of housing within the municipal care and support for persons with disabilities and older people that started to develop during the 1980s (see Figure 12.3).

In 1971, the building act was once again up for reform. This time, the reform introduced accessibility as a minimum requirement for both housing and public buildings. In the new building legislations, accessibility requirements for architecture and planning came under the common concept of 'accessibility' which was specifically defined as parameters that gave equal access to the built environment. The intended group of users was broadened from people using wheelchairs to include other users who experience 'cognitive problems to navigate in space' (Regeringen, 1971). Consequently, this reform also demanded an update of existing building regulations. The new regulations used the requirements for housing that the housing mortgage system activated for the design of the Million Programme in 1965–1975. The close connection between the building regulations and the housing loan system guaranteed the full implementation of the requirements in buildings from 1976–1989 (Statens Planverk, 1975). Later, these requirements were converted into national standards on appropriate design solutions for housing that concerned minimum specifications for comfortable width of passage, number of storage units, kitchen cabinetry and other accessibility measurements.

With its appurtenant building regulations, the building act of 1971 realised the goals that the parliamentary commissions of the 1940s had formulated: an improved Swedish housing standard with general high quality in housing promoted by state loans and subsidies for home adaptations. However, negative views of the Million Programme architecture – people generally regarded it as high-rise buildings in sterile settlements – anticipated the end of functionalist architecture as a socio-political instrument.

The investment in the Million Programme housing proved that large-scaled planning projects with limited user influence could lead to social problems and stigma (Pech, 2011). During the 1980s, a new type of two-storey residential architecture was produced instead, in which the ground floor was larger to supply accessible surfaces in case of need due to disabilities. In a similar way, the prioritisation of municipal and state interests over the financial investments of private homeowners or property developers suggested that the building legislation was out of step with societal evolution. The building legislation generated a strong public criticism and preparations were made to fundamentally reform the building act (SFS, 1987: 10, 1987). Promoted by the housing loan system and specified building regulations, the concept of accessibility was especially vulnerable to changes.

A new building act was introduced in 1989. The paragraph on accessibility in housing and public buildings was kept, and was identical to the wording used in 1971 (SFS, 1987: 10). However, in this new structure, which had non-binding minimum requirements in appurtenant regulations, accessibility as a spatial requirement became void (Boverket, 1988). As a quick remedy to the apparent lack of influence on the built environment, the newly formed authority in charge of building and planning matters, the Board for Housing, Building, and Planning, commissioned a set of minimum guidelines for accessibility in the built environment from the Swedish Institute for Assistive Technology, which had been established in 1968 to replace a previous organisation from 1911 and was co-owned by municipalities and the Swedish state. This resulted in a publication entitled 'Build up more accessibility' which assembled accessibility requirements from 1965–1989 and supplied explanations with drawings and illustrations (Svensson, 2015). This publication instantly filled the evident void in the legislation on the fit between people with disabilities and the built environment, and was embraced by architects and building companies as an easy guide to accessibility. The success of the publication continues. It is regularly updated, with the latest edition released in June 2020. In all probability, this is the number one Swedish guidebook on accessibility and spatial needs for people with disabilities, not only for the building industry, but for other stakeholders that plan and distribute care, nursing, and support to people with disabilities and older persons.

Consolidating accessibility through agreements and standards

The inconsistencies regarding accessibility requirements in the new building act of 1989 were partly because this reform coincided with the work of an ongoing parliamentary committee on living conditions for people with disabilities (SOU, 1991: 46). In its final report issued in 1992, the committee made several proposals concerning the built environment to improve living conditions for people with disabilities (ibid.). The committee suggested that retrofitting the existing built environment to modern accessibility requirements should also be regulated by the building act (SOU, 1992: 52). In addition, the Swedish acceptance in 1993 of the 22 UN Standard Rules on the Equalization of Opportunities for Persons (United Nations, 1993) prepared for a revision of building regulations that adhered to the new building act. In 1994, the Board for Housing, Building, and Planning issued new building regulations which were a complete makeover of the five-year old legal framework and integrated accessibility requirements introduced during the 1966–1989 period (Boverket, 1993). Once again, accessibility requirements were explicitly linked to users with 'wheelchairs or [who] experience cognitive difficulties in navigating in space' (BFS, 1993: 57). The idea of retrofitting existing buildings to modern accessibility requirements generated some concerns within government, and a committee was assigned to explore the matter further (SOU, 1994: 36).

The committee concluded that public buildings often present physical barriers for people with disabilities, which could prevent their participation in society. Physical barriers that created accessibility problems were therefore identified and targeted for removal on a continuous basis (SOU 1994: 36). The 1990s saw several initiatives to remove physical and perceived societal barriers for the inclusion of people with disabilities. In 1992 the old system, with state grants for home adaptations for disabilities, was reformed (SFS, 1992: 1574). Two other laws on the remuneration of assistants to persons with disabilities and special support and services for people with disabilities were introduced. In 1995, large institutions for people with mental health issues were dissolved and replaced by group living within the ordinary stock of residential housing (SOU 1992: 73). In 1999, a new law on discrimination against people with disabilities in the labour market came into force (SFS, 1999: 130). The new disability policy for the period of 2000–2010 combined these disparate improvements into a ten-year plan for realising the elimination of physical barriers and promoting equal opportunities for all people (Regeringen, 2000a). The building act was reformed to add a paragraph on eliminating so-called easily removable obstacles in public buildings and the public space (Regeringen, 2000b). Requirements on signage and contrast markings in the built environment were introduced (ibid.).

International agreements also highlighted accessibility as an essential right of people with disabilities. In 2008, the CRPD was opened for signatures and ratification (SÖ 2008: 26). The convention raised the matter of accessibility to be usable by a multitude of users and identified the design of the built environment and other specific artefacts as a key element of effective accessibility. Sweden's accession to the convention in 2008 also had an impact on the building act. In the revision of the act and appurtenant regulations, accessibility became part of the new twin concept of 'accessibility and usability'. Since 2010, this twin concept has guided requirements for the architectural design of new and existing buildings without barriers for people with disabilities. As a member of the European Union, Sweden is also part of the EU disability policy programme. In 2010, the European Union established an annual competition, the so-called Access City Award which invites cities with over 50,000 inhabitants to apply to be recognised for their work in making the built environment more accessible and increasing inclusion and participation for people with disabilities (European Commission, 2010).

The period between 2000 and 2011 was also distinguished by international projects that confirmed the link between accessibility requirements in the built environment and the rights of people with disabilities. In response to the ageing population, a guide for manufacturers of different products, the so-called Guide 6, was assembled the International Organisation for Standardisation. Later, another project assembled the international standard for accessibility and usability requirements in the built environment, ISO 21542 (currently under revision). As part of the European disability policy, the European Union is preparing an EU act on accessibility in the public environment which will be implemented by each member state and will require a European standard on accessibility and usability in the built environment. The European standardisation work started in 2017 with a special project group of experts which compiled draft accessibility requirements. After an intense discussion with member-state representatives, the EN 17210 standard was accepted in October 2020.

Accessibility: a responsibility shared between multiple stakeholders

The previous sections have traced the history behind the accessibility requirements of the Swedish building act today. The search for adequate space for a large variety of users in different types of built environments can largely be attributed to the over-arching ambition of constructing appropriate housing at reasonable cost by controlling the square-metre area of the habitat. From 1930 onwards, this ambition has been associated with an aesthetic orientation in building design, i.e. with functionalist architecture. What was originally an initiative of the building market has become a shared interest for investors and society. Over the past 90 years, the minimum spatial requirements for the built environment to be at least partly usable for people with disabilities have been defined and integrated in the professional knowledge of architects and other building experts, but also the legislators behind the building act. The requirements provide a minimum level of accessibility and usability that can be further adapted to personal needs through individualised assistive devices. Through full-scale try-outs in spaces for different usages, the requirements have gone from being random minimum measurements and loose recommendations into hard regulations with which the built environment must comply. National and international standardisation confirm their validity.

This retrospective suggests there has been a conscientious and altruistic ambition by actors in the Swedish building market – architects, building companies and building material suppliers – to define guidelines to eradicate the poor housing situation in Sweden. Analogous to industrial production, the underlying idea has prioritised rationality, systemisation, and standardisation in creating appropriate housing for citizens, with modern hygiene and ventilation. The totality of the measurements falls into the category of minimum requirements that primarily promote the interaction of fully abled bodies with the built environment. By doing so, and without alternative studies, the Swedish building market has assumed that people outside this category can also be accommodated. Measurements including people outside the original intended group have been established as part of the overall quest for acceptance of people with disabilities in society by organisations that defend equal rights regardless of ability. These organisations have initiated and financed parallel studies on impairment and the use of built space. Adopting the same test methods as the building industry in their studies, the fundamental criterion has been to define minimum threshold values for various interactive situations: passing through a doorframe with a wheelchair, progressing up a ramp or crossing the threshold of a door with a cane or wheelchair.

However, it was neither the Swedish building market nor the non-governmental organisations that connected the dots and suggested a strategy for implementing new findings on the minimum fit between the built environment and human beings with all their diversity. Coinciding with other preparations for a political overhaul of the (then-embryonic) Swedish welfare regime in the 1930s, minimum requirements for the built environment were integrated into a comprehensive socio-political strategy to establish an egalitarian welfare model, the *Folkhemmet*. Minimum requirements for housing and public buildings were put into practice through the building act in combination with state subsidies and a housing loan system which lasted until 1989. This implementation occurred in parallel with a shift in cultural and social beliefs during the 1960s: the normalisation principle, which gradually allowed people with disabilities to be included in society on equal terms (Nirje, 1992). This combination of initiatives, originating in the building market, disability organisations and the state's legislative implementation, has been an important asset in realising inclusion in a modern welfare society. Paired with design and technical developments in assistive technologies, the minimum requirements for the built environment can be surmounted further through individually adjusted assistive equipment, thus further lowering the barriers to full inclusion. However, it is an open question whether minimum accessibility requirements will continue to regulate the built environment for the greater good of all citizens since, in the current disability policy, the concept of universal design supersedes accessibility and inclusion.

Conclusion: accessibility requirements today

Given the background described above, and the consistent evolution since the 1930s of spatial requirements to equip both existing and new buildings with a minimum level of accessibility and usability for people with disabilities, it is problematic, to say the least, that the building market criticises the legislative system that has resulted for Swedish building as obsolete, cost-generating and time-consuming (Fock, 2010; NCC, 2012; Nohrstedt, 2009). Already back in the 1980s, building requirements, especially accessibility requirements, were said to be too far-reaching and as having a restricting effect on building design (ibid.). Regardless of their political orientation, four recent governments between 2006 and 2020 (of these two were left-wing and two right-wing governments) have lent a keen ear to the claims of the building industry. This attention is mainly motivated by ongoing demographic changes and permanent housing shortages since the 1990s, which have particularly affected young people, older persons and people with disabilities (Boverket, 2021). In consequence, the building act has been revised multiple times since 2010 and building regulations were updated 12 times between 2011 and 2020. The government also assigned a committee to investigate allegations that identical building prototypes generated different production costs around Sweden. In 2020, the committee concluded that the problem revolved around the fact that the 290 Swedish municipalities in accordance with the local government act formulated their own requirements on types of housing and levels of accessibility and usability (SOU, 2020: 75).

Attentive to the influential Swedish building industry, the government instructed the Board for Housing, Building, and Planning in 2019 to review the legal manner, in use since 1989, with which the authority formulates building regulations. According to the instruction, the government detected 'a need for a systematic review of the regulations for building and constructions' (Boverket, 2020). The intention of the review was to create a 'simplified and consequent framework with a similar structure and level of detailing'. At time of writing in early 2021, the board is rewriting, chapter by chapter, the building regulations so that each paragraph only gives a brief outline of necessary building requirements. Previous regulations included a section on recommendations and general advice which explained, in concrete and direct language, the practical understanding of the legal intent. This will be omitted. According to the board, the reason for this is:

> The national Board for Housing, Building and Planning shall specify the requirements that are expressed in a law or an ordonnance, while the building market shall produce solutions that fulfil these requirements as well as methods to verify that the specified requirement is reached. The new model for writing regulations equips the building market with the prerogatives it demands and needs to be more proactive and assume responsibility for the challenges that the market is facing, e.g., sustainability and financial solutions. The building market has the expertise and can be assumed to distribute resources in a more efficient manner and be better at identifying which solution that needs further evolutive work.
>
> (Boverket, 2020: 6)

This handing over of power from the state to the building industry to define the minimum level of accessibility for the built environment under which people with disabilities can enjoy full inclusion and participation seems hasty and poorly thought through. At best, it will reflect a conundrum in architecture, where examples of accessibility and usability of the built environment are perceived as exemplary models but are, in reality, an architectural rendering of time-related problems (Till, 2009). The change undermines a 90-year quest for improved living conditions for people with disabilities. The vital user-related perspective, which disability organisations have provided during the gradual development of accessibility requirements, is at risk of being forgotten and omitted.

As this chapter has shown, the building industry has always focused on minimum requirements that promote the fit of fully abled body with the built environment. Hitherto, the state has also had a strategy of bringing forward minority groups' demands on the built environment. The propulsion of universal design into becoming the prime objective for Swedish disability policy between 2016 and 2021 over accessibility and usability requirements risks creating a precarious future for people with disabilities. In the absence of minimum requirements defined by people with disabilities, it is yet to be seen if this new focus on universal design will promote ease of use for everyone, or if financial motives for the building market will supersede the matter of inclusion.

Yet, there may be some reason to hope that the move to universal design as guideline could be a positive development. The vagueness of the concept in the Swedish context may reorient the understanding of requirements for accessibility or usability to ensure inclusion of people with disabilities away from being scarce minimum measurements into becoming design parameters for a new, socially sustainable, Swedish welfare state – inclusion for all, regardless of age or disability.

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Afterword

Rannveig Traustadóttir

In essence, this book asks why societies continue to exclude and marginalise disabled people. It focuses on everyday resistance to the inclusion of disabled people on multiple levels and in different areas of everyday life. The attention is on aspects that create barriers to inclusion – in other words on 'inaccessibility' – with the aim to unravel the powers, relations, ideas and practices 'at work' in such a way as to exclude disabled people. The book makes a valuable contribution to gaining knowledge and understanding of the persistent forces behind the continuing exclusion of disabled people. A major strength of the book is the multi-disciplinary approach, the variety of disciplines and theoretical perspectives, and the diversity of methods in exploring various arenas of everyday life, working in concert to create a multi-level and insightful analysis. The contributions examine lack of access in a range of different areas of society such as in man-made public urban spaces and transport; knowledge production and the ways the education system excludes disabled students, often in very subtle ways; the shortcomings of laws and policies in securing inclusion; and the ways in which bureaucracy and institutional practices exercise power and control over disabled people.

Of particular interest and value is the detailed exploration of how the exclusion of disabled people is a part of everyday, often taken-for-granted, practices and performances, revealing how barriers appear in unexpected places that have not previously gained much attention. The book also reveals the gap between the sweeping promises of inclusion in international and national policy documents on the one hand and the everyday reality and lived experiences of disabled people on the other. Quite remarkable for many readers outside the Nordic countries will be to discover that these exclusionary practices also take place in the countries widely considered the 'best' and most advanced; the Nordic welfare states. The Nordic countries pride themselves on their extensive policies of equality, where everyone should have equal access to services, choices and possibilities. While it is true that, in a global context, the Nordic countries have made the greatest efforts to achieve equality, widespread exclusionary practices still prevail when it comes to disabled people, as is apparent in this book.

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This begs the question: why, despite stated goals of equality for all and inclusion on all levels, are so many disabled people still excluded from so many of the key areas of everyday life? The research and analysis in this book attempt to address this question, unravel exclusionary practices and create knowledge and insights that can lead towards inclusion.

In looking for solutions, it is crucial to place today's knowledge and practices in an historical context. It is true that we continue to exclude disabled people. However, we have made enormous progress over the last 50 years or so, regarding the inclusion of disabled people in regular communities and societies. Let's keep in mind that official policies towards disabled people up until the middle of last century were based on the *ideology of segregation and isolation*. In line with these policies, countries around the world built large total institutions to house disabled people, including children, who were kept away from the rest of society. This was largely due to the eugenic policies of the time. The ideology that replaced segregation and isolation was the *principle of normalisation*, which had its origins in the Nordic countries in the 1960s. Yes, it was not until after the middle of the last century that policies of segregation were abandoned and those based on normalisation and integration (as it was called at the time) became national policies in most countries. These policies led to the closure of the large institutions and the development of community-based services. However, many countries still struggle to close the institutions, also in Europe, and some institutions continue to be in operation in the Nordic countries.

The normalisation era made huge gains toward the inclusion of disabled people. Based on the ideology of normalisation and integration, community-based services were established around the world. The first steps were shaky, often characterised by institutional practices within community services. Sadly, the continuation of institutional rules, routines and practices, including the lack of control over one's life, can still be found in disability services, as is confirmed in one of the studies in this volume (see the chapter by Eric Svanelöv and Lena Talman). Disability services as we know them today were developed and designed during the normalisation era. We have inherited a service system based on ideology which aimed to address very different issues and challenges than we face today. Thus, introducing new and innovative policies and practices, based on human rights approaches and a new understanding of disability, can be problematic if the basic underlying ideologies and systems are not compatible with the proposed innovations.

Today's ideology, with its clearest expression in the Convention on the Rights of Persons with Disabilities, emphasises human rights and a social–relational understanding of disability. This new ideology, which has been included in laws and policies in countries around the world – including all the Nordic countries – highlights that societal barriers, in interaction with people with impairments, are the main 'problem' when it comes to the inclusion of disabled people. Thus, it is society and the range of barriers (in man-made environments, labour markets, education systems, practices, prejudices, stereotypes, etc.), that need to be changed, not disabled people. This book, with its focus on inaccessibility and resistance to inclusion, is an important and helpful tool to move us closer towards understanding the societal exclusionary structures and practices, and how these can be addressed in order for our societies to become inclusive of all.

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