

Introduction

Into the fields of stubborn obstacles and lingering exclusion

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Accessibility today has a contradictory character. On 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 CRPD, and similarly there is no institution that does not display an ambivalent practice of including-while-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.

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 out-competed 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 linguisticism, 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 time-frames, 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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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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