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Required to be creative. Everyday ways for dealing with inaccessibility

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ABSTRACT

Today's society promises that people with disabilities can access anything, but in practice there are numerous obstacles, and the ways in which people deal with them can be easily missed or taken for granted by policy makers. This article draws on a project in which researchers 'go along' people with disabilities in Sweden who demonstrate and recount accessibility troubles in urban and digital settings. They display a set of mundane methods for managing inaccessibility: (a) using others, (b) making deals and establishing routines, (c) mimicking or piggybacking conventions, (d) debunking others' accounts and performing local politics. The employment of these shared but tailored methods shows the difficulties to be accepted that people with disabilities still face, as well as the wide-ranging tension that exists between the grand rhetoric of inclusion and modest results. The tension implies that people with disabilities are required to be creative.

Points of interest

- Declarations and policies often say that people with disabilities should have access to anything, but in practice this is not the case.
- This study investigates what people with disabilities actually do when they have trouble accessing various places or resources. The results show their common and practical ways, and these ways are often taken for granted, overlapping, and combined.
- People with disabilities ask others to support them when they face troubles to access places or resources, they make deals with important actors and they develop routines. They also observe, imitate and follow others' actions, to pick out precisely those ways that suit their needs.

- When people with disabilities find their ways in today's society they also act with words. They argue against other people's excuses or justifications for not providing access.
- The study has found a lot of frustration among people with disabilities who get blocked, excluded or delayed. This gives them motives to engage in politics.

Introduction

There are a lot of accessibility promises in today's society. Workplaces, schools, and universities should be accessible to all, as should all premises for culture, medical treatment, sports and leisure activities. Public services, commercial arenas, transport and digital platforms should be designed to ensure that disabilities basically play no role. The United Nations is scrutinizing the adherence of member states to the Convention of the Rights of Persons with Disabilities and its article 9, where independence and participation are tied to accessibility. The European Union is engaged in equivalent work via the Agency for Fundamental Rights, the Unit for the Integration of People with Disabilities within the European Commission, and the Disability Intergroup of the European Parliament. In Sweden, where this study was conducted, inadequate accessibility is prohibited under the Discrimination Act. Public campaigns advocate accessibility and user organizations point out deviations.

But universal access has not materialized. Despite laws and policies, most contexts are designed for mainstream bodies and persons (Figueiredo, Eusébio, and Kastenholz 2012), and exclusion and stigmatization continue to be practiced in blatant or subtle forms (Barnes 2010, 31). Nordgren (2009) argues that people with disabilities face double standards. Norms of equality are easily outcompeted by other norms – e.g. efficiency, economy, safety, speed, aesthetics, the protection of cultural heritage – so that accessibility is celebrated in society at large but marginalized or temporarily forgotten in many everyday situations.

This study aims to highlight some of these everyday situations and explore how people with disabilities deal with them. The purpose is to identify more or less tacit ways of doing practical, everyday things, or *ethnomethods* (Garfinkel 1967; Liberman 2013), that people with disabilities use to accomplish real-world accessibility. The fact that these methods take place in a society that formally has tied itself closely to ideals of inclusion often make them strained. The accessibility sought – a particular kind of social orderliness – is the accessibility everyone is entitled to.

In an ongoing project, two colleagues and I have gathered data from 30 informants with various disabilities to uncover what policy-driven evaluations

overlook: the daily contingencies of navigating obstacles in often unpredictable terrains. Even a familiar setting can be difficult to summarize from an accessibility perspective (in terms of 'high' or 'low' accessibility, 'good' and 'bad' inclusion, etc.). For example, a previously accessible walk might become problematic due to new sandwich boards or unexpected snow, a shop might become surprisingly difficult to access due to new shopping baskets, and a festival might become troublesome when it is relocated from an asphalt surface to the beach. From within, accessibility seems less like a box that can be classified and checked off, and more like an emerging and plastic phenomenon, shaped by local circumstances, actors' ongoing projects, and by the tactics, interpretations and specific impairments of users.

As our analysis evolved, we began to identify different themes. My colleagues will report on other (but related) aspects of our data in separate articles, whereas I became inspired by Liberman's (2013) studies and his take on Garfinkel's (1967) ethnomethodology. In one study, for instance, Liberman shows how a variety of road-users handle an unregulated intersection at the entrance of a university campus in Oregon: pedestrians, inline skaters, skateboarders, wheelchair users, etc. As these actors go about crossing the intersection without getting overrun by buses, cars, or delivery vans, they do not use a single method – there is 'no grand theory of crossing' (Liberman 2013, 20). Instead, they use several methods, such as 'looking and recognizing', 'being oblivious' (like staring at the ground or at one's cup of coffee), 'continuous motion' (slowly moving into the flow of traffic), and subtle negotiations. Informal ways to manage a messy intersection produce orderliness, so that a pattern occurs from within (i.e. 'autochthonously', Liberman 2013, 21). Similarly, upon reviewing our data, I found that no one method accomplished accessibility. There were several methods, and they did not follow regulations or policies, but they are recognized when we discuss them in interviews and during 'go-alongs', and they are employed in various situations. Despite the grand promises made in today's society, there is no 'gift of accessibility' from above, but there are never-ending tactics and struggles that are required to attain the declared rights. Mundane orderliness 'has precedence over rules' (Liberman 2013, 16).

I also become inspired by Emerson's (2015) studies on interpersonal troubles. Not all the troubles identified in our data revolve directly around other people – struggling for accessibility might be a matter of unilaterally making a defective elevator start at a railway station or slowing down a computer game – but in many cases, other individuals are involved. These 'others' are known either by their categorical roles (Emerson 2015, 9; Lofland 1973, 15–16; for instance, shop assistants, traffic conductors, or gym owners), or by more personal connections, such as family members, friends, colleagues, and personal assistants. This means that actors' interpretations and responses are

mutually dependent in ways that resemble the management of interpersonal troubles in general (Emerson 2015, 11). For instance, an actor might downplay his or her irritation in a local shop or cinema, where accessibility troubles emerge, as a way to avoid a scene (and its affective disorganization, see Goffman 1963, 187) because there is a cherished relationship that the actor do not want to risk losing. Interpretations of accessibility may, the other way around, shape relationships, so that an accessible place serves as a starting point for alliances and closeness. Actors may sometimes also downplay the label 'disability-related' in the first place, and interpret their troubles as more general ones that afflict everyone (e.g. 'traffic jam today,' 'such weather!', etc.). Corrective responses are common in trouble management, but people sometimes act subtly and unilaterally. 'The trajectories of troubles vary widely' (Emerson 2015, 12).

A third inspiration for this study comes from Davis' (1972) perspective on how society relates to disability on an everyday basis. Davis (1972: 132) found that people with disabilities reflect upon the implications that they are not considered 'normal, like everyone else,' in interactions. For instance, others frequently 'make faux pas, slips of the tongue, revealing gestures, and inadvertent remarks, which overtly betray this attitude'. Davis argued that such interactionally produced discomfort is especially related to encounters with new individuals; these interactions often ended in embarrassment and a pronounced 'stickiness' (awkwardness). People with disabilities are expected to be ready to receive anything from blunt questions and stares to odd choices of wording or nervous laughs, and they are expected to be more or less responsible for overlooking it as well. A person with a disability often must play along with 'the polite fiction' of surface acceptance in a society that should treat all people equally (Davis 1972, 140).

Our data include several instances equivalent to those described by Davis. Informants describe how others stare at them or start asking quite private questions, and they sigh over the fact that strangers sometimes want to show their unwarranted concern, sympathy, and sense of care by, for instance, patting them on the cheek, ruffling their hair, or needlessly speaking loudly with deliberate articulation. People with disabilities are sometimes treated as nonpersons and sometimes like 'open persons' (Goffman 1963, 126; Cahill and Eggleston 1994, 304) that can be approached by anyone at any time. But our data also reveal heightened tension. Davis (1972, 132–133) argues that (at that time) there was no ready-made shorthand at issue, because individuals with disabilities did not comprise a distinct group or subculture. Today, on the other hand, due to the common political discussions about inclusion and the increased political mobilization of individuals with disabilities, we can argue that there *is* a ready-made short-hand. Any person with a disability *should* have access, no matter what; complete

inclusion and equality are indisputable in citizenship struggles (cf. Sépulchre 2019). A particular aspect of discomfort or 'stickiness' stands out in interactions; frustrations and embarrassments regarding the (banned but practiced) attitudes of exclusion have become embedded into the everyday accessibility methods.

The present study is built upon these sociological strands of research, and it aims to merge them into discussions on both the social model of disability and the bio-psycho-social model, which take into account the interrelationships between body functions, activities, and the environment (Kastenholz, Eusébio, and Figueiredo 2015, 1263). It is crucial to analyze how socially-constructed settings 'limit, restrict, segregate, and even oppress' individuals with different capabilities (Mazurik et al. 2014, 194), but it is also important to expand our horizons into more experiential, more embodied, and less simplifying directions (Shakespeare and Watson 2002). Due to the many different impairments and circumstances in the world, it is unlikely that we can achieve a totally barrier-free environment (Shakespeare and Watson 2002), and that makes it increasingly relevant to understand a bit better what people really do.

Research process

The data for this study are collected within the project *Accessibility and its resistance*, funded by the Swedish Research Council for Health, Working Life and Welfare, in 2018–2020. So-called naturally occurring data (Silverman 2007) are central, in combination with both active and narrative interviews (Holstein and Gubrium 1995). We attempt to get as close as possible to accessibility as an everyday phenomenon by employing ethnographic 'go-alongs' (Kusenbach 2003) in which we accompany individuals with disabilities in their various settings, like city centers, shopping malls, railway stations, work places, restaurants, and cafés. Participants show us a range of routes, activities and errands: how they get to work or school, how they manage computers and digital platforms, how they embark and disembark from buses and cars, how they make a cup of coffee or how they communicate with friends, etc. We speak to participants about what we see and do, and how to interpret various accessibility problems along the way, and participants also recount problems in other situations and contexts, including problems in wider social contexts. The go-along concept combines interviews with observations, and it can stimulate quite unstructured talk about everyday life: 'this bus is not the kind I used to take … ', 'aha, they've closed that shop, I didn't know that … '. The idea is to capture informants' interpretations by accompanying them on outings that they would normally take, and to acquire sensitivity to the informants' lives (Kusenbach 2003, 463).

We have now gathered data from 30 informants (13 women, 17 men) with a variety of disabilities, mostly motor disabilities (cerebral palsy, multiple sclerosis, spinal injury, etc.), but also some cognitive disabilities and some combinations. Wheelchair use is common among the informants, but some have visual impairments, serious allergies, or perceptive difficulties (and combinations). Informant ages range from 16 to 70 years (average 37), and they have various occupations, including receptionists, social workers, cultural workers, care workers, lobbyists, and school staff. Some are students at universities or high schools, some are retired.

This sample is theoretically driven. Our inclusion criteria are experiences with accessibility difficulties, residing in an urban setting, and a willingness to show and narrate. We have also spoken to about 10 representatives of various organizations, institutions, or commercial establishments that our informants sometimes find especially problematic from an accessibility point of view.

In this article, I use the term 'accessibility', because it is commonplace in public debates and among field members, even though I am aware that many researchers consider the term 'usability' more appropriate because it is a less stigmatizing, more process-oriented concept (Iwarsson and Ståhl 2003).

The three researchers involved in this project (situated in three different departments) work part-time with data collection. We started with previous field contacts (e.g. Wästerfors and Hansson 2017; Wästerfors 2011; Egard 2011) and subsequent snow-ball sampling, and then we have met in workshops to share field notes, transcripts, and documents. Our ambition is to identify and explain the mundane processes behind the resistance to accessibility today, so therefore it is vital to get as close as possible to the experiences of the informants. We do not want only sweeping judgments on, for instance, the accessibility of the whole city center for individuals in wheelchairs, but rather concrete examples and personal experiences, shown and narrated. Stories, accounts and emotion work (Hochschild 1983) are looked upon as features integrated into the phenomenon.

Gradually, we have discovered that the mundane landscape of inaccessibility is relatively under-theorized. Researchers sometimes lack the patience to follow apparently dull or uneventful sequences to obtain a more detailed picture of how everyday life might appear to actors with disabilities. To theorize anew (cf. Swedberg 2012), we aim to communicate, in detail, the situations that we see and hear from informants (Emerson, Fretz, and Shaw 1995, 14–16), rather than make quick assessments or statements (although many sweeping ways of reasoning belong to the data). These actors repeatedly wrestle with accessibility in a concrete sense, with doors, edges, staircases, shopping malls, ignorant service providers, obstructing ticket machines, and ill-designed websites.

Of note, my personal background cannot be overlooked. For 23 years, I have privately been accompanying and assisting a close family member who is using a wheelchair, which has shaped my thinking about hands-on ways to manage certain obstacles and barriers. Over the years, this experience has familiarized me with many maneuvers and efforts – in homes, public places, transport systems, cultural venues, digital arenas, at parties, in workplaces, and in many other settings. Years ago, in 1997, I also worked part-time as a personal assistant to a student who used a wheelchair. Together with the project's go-alongs, my experiences seem quite close to what Atkinson (2015, 34) calls 'direct engagement (sensory and interactional) with a distinct form of life', in this case a life full of accessibility troubles.

Results

Using others

Everyday troubles with accessibility are often dealt with in ways that, ironically, reinforce a cultural heritage that the disability movement seeks to combat. Informants show and narrate how they ask and use others for assistance. This strategy alludes to a picture of unwanted dependency, although at closer inspection, the practice is maneuvered by and subordinated to the instructions of the informant. The informants seek the involvement of friends, peers, family members, shop assistants, chauffeurs, strangers in the street, the guy in front of them in the queue, etc. These individuals are often informal others (Emerson 2015, 135–161), but also official ones. Sometimes, the informant merely seeks to tell someone their troubles – 'giving vent to feelings of upset and frustration, asking for feedback and advice' (Emerson 2015, 136) – but more often the informants seek trouble-interventions, i. e. partisan interventions 'against' exclusion and inaccessibility. Sometimes, 'others become extensions of themselves', as described by Mazurik et al. (2014, 203) in their study on individuals with disabilities in a shopping mall.

Elsa, 18 years old and mostly using a wheelchair due to motor difficulties, says 'I almost always have somebody with me,' someone accompanying her in the city and during transports. Thomas and Johnny, of the same age and also using wheelchairs, similarly describe their use of traffic conductors and temporary escorts (often relatives), and Krista, who lives with cerebral palsy, mostly ask her parents to do things in downtown areas, such as bank errands. In several go-alongs, we find that informants often get help from others quite subtly. People move aside to give them space, they might hand them a napkin that is hard to reach, they open doors, unfold ramps, move obstructing furniture or other objects, or read something aloud from a screen at a reception or from the menu in a restaurant. Informants describe,

show, and accept these aids in quite factual manners, indicating the commonness of aids, but it can also be commented on more snappily in relation to how it should be. Informants may sometimes sigh or snort when others make way in a corridor where there should have been sufficient space to begin with, and they sometimes express frustration openly. One informant describes a shopping situation where he could perform almost all things on his own, except for managing self-scanning and reaching for yogurt in the 'for us wheelchair users, impossible cupboard'. The store staff assisted him, but later, he wrote a letter to the shop with complaints, and he showed it to us. 'I have the same right as everybody else to shop all BY MYSELF.'

The need to make sure somebody is 'with you' or close to you often indicates that you anticipate having to deal with unexpected inaccessibility, even though accessibility should be ensured in the first place. I once went along with Zacharias, who uses a wheelchair, from his workplace to his home by bus, and he showed and narrated how the foldaway ramp sometimes gets stuck on the bus floor (due to dirt, rust, or the fact that it was seldom used). So being alone involved too much risk for him. He needed somebody to help him, and he could not always count on other passengers or the driver, and inexperienced helpers did not always understand how the ramp should be placed. When I accompanied Zacharias, his personal assistant elegantly unfolded the ramp, and he could disembark as rapidly as other passengers without a problem, but this task might very well have been problematic if he had been alone. Other instances in our data include asking for help in shops, asking a nearby person to move a chair, asking receptionists to unlock the handicap toilet, or asking siblings to read a sign or explain a riddle in a game.

Others might also get involved to achieve access in a figurative sense, such as accessing an identity as 'anyone' in other people's eyes and then, in turn, accessing regular service and consumption by dodging discriminating and awkward treatment. Bob, in his 40 s and living with cerebral palsy, implicitly 'uses' his kids to appear more 'normal', or as he said, 'to pass' (cf. Garfinkel 1967). Whenever he brings his children, he has a better chance of being addressed as a competent citizen (for instance, in shopping malls and service encounters), despite his conspicuous movements and speech problems. But sometimes people still think 'those cannot be my kids', which imputes discomfort and discontent by detaching Bob from his kids. Bob claims he can sense and understand when this is happening.

To overcome inaccessibility, it appears to be crucial to have an 'other' in the first place. Krista belongs to the informants who complain about the ongoing reduction of hours for government-funded personal assistance in Sweden and the increase in rejected applications (Brennan et al. 2016a), and she is arguing against this development in terms of narrowed accessibility

and inclusion. 'Now I only have 10 hours that I can use per day [with personal assistance],' Krista says, 'and I feel like … if I lost assistance [altogether], who would help me?' The weekend before we met, Krista visited a restaurant for lunch, and her relatives and family members had to lift her over a staircase. 'My parents won't be able to help me my whole life … am I just supposed to sit and do nothing? That's not a fun life at all.' Krista says 'it's sick' that, in any case, people with disabilities have difficulty being accepted in society, and therefore it is crucial to have help getting around. Trusted personal assistants are, as Brennan et al. (2016b, 12) point out, often a 'gateway' to independence.

Relying on others also entails selecting qualified others (cf. Emerson 2015, 138–139); i.e. competent, flexible, and sympathetic persons. Aids should make it possible to form what Emerson calls partisan teams. Informants talk about previous schools with teachers that refused to help, and incompetent assistants that did not understand. These discouraging experiences exemplify the importance of careful selection. There are also instances of experienced hostility from others. For example, in public transportation, other passengers might complain about the informant occupying too much space, or the wrong space at the wrong time. Krista refers to a situation when a lady with a walking frame engaged her in nervy space-competition and 'gave her the worst bitch gaze' throughout a whole bus journey.

It seems difficult to make an empirical distinction between informal others and official others. Many cases are blurry in practice, and people continually use combinations. For example, an informant with a personal assistant might ask others for help when the assistant is occupied or temporarily away. Sometimes, an informant might present a unilateral solution – accomplished alone – *within* the dyadic team. For example, Anders, a middle-aged man using a wheelchair, brought a pillow with a hard surface to a restaurant in one of our go-alongs. At restaurants, he typically cannot find space for his legs under the table and therefore he sits at a distance from the table. His solution was to set the pillow on his lap, and the food was then placed on the pillow instead of the table. Even though he manages the inaccessibility unilaterally, by bringing the pillow himself, his personal assistant helps him by putting a knife, fork, plate, and glass on the pillow, in addition to helping with other things in the restaurant.

Making deals and establishing routines

Another distinct way of dealing with inaccessibility revolve around more or less solid pacts and agreements. An emotional background is the fact that there is sometimes a sense of feeling humiliated, or a sense of displaying a miserable life, when you get help from others all the time, and particularly

when you have to ask for help. Informants might feel segregated and unhappy about not being able to use an ordinary entrance to get into the cinema, having to ring a bell outside certain shops to be helped in or being forced to use the same entrance to a church that is used for the coffin before a funeral. Similarly, they may feel humiliated by not being able to get on stage when invited to give a talk, or being carried over staircases to get into a political party meeting. This seems to become worse when people with disabilities are supposed to have the society on 'their side.' They should not feel this way; rather, others should feel ashamed about not giving them sufficient room and resources.

By making deals with people, these feelings can be contained or avoided. Making a deal helps to 'modulate complaints,' as Emerson (2015, 103) puts it, because vulnerability is not exposed, and there is no image of being self-centered or unable to adapt. Once you and your needs are familiar to employees in a shop, library, or drug store that you usually visit, there might be little or no accessibility resistance. Informants sometimes make deals to always get the same kind of help in moving around, or the same table or service. This strategy elicits help, almost without reminders, and sometimes, in exceptionally smooth ways. One informant, for instance, refers to certain local 'kind chauffeurs', who recognize him and allow him to get on their buses with his electric scooter, despite regulations against it.

In one of our go-alongs, an individual in a wheelchair displayed her deal with the employees at a café, who allowed her to regularly go behind their counter to wash her hands, because it was too difficult to go to the toilet every time. No other guest was allowed to do that, but because the informant washed her hands inconspicuously and without having to ask for it, the exception did not position her as odd or special among other customers. When I went along with Filip, a student with visual impairments, he showed me a range of deals with administrators at the school that help him with books, schedules, and digital platforms, and café employees that help him get his snacks and taking care of his dishes. He also has accessibility-providing deals with teachers, classmates, and family members.

Our data on making deals overlap with data on establishing routines. By going to the same setting over and over, people with disabilities can arrange agreements with the settings' members, and essentially wade through an otherwise quite inaccessible terrain, gain entry to arenas, and access resources in their everyday life without being unfavorably labeled or feeling reduced. In many instances, deal-making and routinization are most evident in arrangements with personal assistants. Trained supporters who can wordlessly and habitually get you where you want to go in the fashion you prefer is a dream for individuals with disabilities and, on occasion, a reality. In one go-along with a man in his 50 s who uses a wheelchair, his personal assistant

sat next to us during a long interview conversation, without my even noticing. Only when he wanted help with his tobacco and, eventually, help getting out of the place, did he essentially 'activate' his assistant, who until then waited in stand-by mode (cf. Egard 2011, 135–153).

To achieve this stage of matching and personalized cooperation is, of course, a project and labor in itself. Elsa, a younger wheelchair user, prefers to have her assistants drive her wheelchair over cobblestones in the city center by tipping the wheelchair and only using the back wheels, but the assistants do not understand. 'They say they cannot drive it like that.' This situation makes the experience uncomfortable and annoying, with discontent on Elsa's side, which turns it into an Emerson-like trouble. Elsa has a range of deals and routines with her assistants, but sometimes, she cannot manage to train them to perform in the way she wants. Consequently, rather than looking upon the deals and routines in our data as fixed or ready-made tools, we should think of them as constant endeavors or 'doings' that make or keep various types of access workable. Although deals and routines can economize actions in solving troublesome access situations, they must be continually refined, and the accessibility created is limited in time and space.

In my personal experiences as a helper and facilitator, I have noticed countless deals and routinizations, and I often found myself contributing to them. Neighbors come by to help out with digital problems, relatives deliver or pick up things, and Red Cross volunteers serve as escorts for some treatment visits. My relative has deals with some receptionists and taxi drivers, occasionally with biographical connections and joyfully shared memories, and there are routinized contacts with local officials and commercial establishments. Indeed, within the research team we have observed that a dynamic network of helpers and supporters seems to evolve around some individuals with disabilities; these people engage in deals to manage day-to-day accessibility in a broad variety of settings and contexts. The formula is, 'I need access to a resource or arena X. For that, I use my deal with A. For resource or arena Y, however, I use my deal with B.' To borrow terms from economic sociology, these are axes of solidarity based on interpersonal trust (Granovetter 1994, 463) that constitute and sustain deals and routines. Sometimes, a payment might be involved, but generally, a small return gift or simply mundane gratitude is sufficient.

These tactics also contribute to managing emotions of discomfort and uneasiness, and in some cases, pronounced 'stickiness' and embarrassment (Davis 1972, 132). When acting on a deal, the actor ceases to be perceived as different, odd, or estranged, and disability is downplayed, or – ideally – evaporates, as 'an exclusive focal point of the interaction' (Davis 1972, 133, 143). Instead, there is an opportunity to 'break through' (Davis 1972, 141), beyond fictional acceptance and, eventually, to be seen as a person. The act

of making a deal and following a routine implies that an actor has character and style. Others might help, but in ways that resemble or are the same as the ways everybody uses help. It is not a matter of unsolicited assistance, steeped in sympathy which comes with a price (Cahill and Eggleston 1994, 306–308), it is a matter of following through on pragmatic, controlled, and sometimes quite dull arrangements.

Much of the frustration that arises with other methods might not arise with deals and routines. They are more relationally sensitive, conciliatory, non-confrontational, and discreet, and therefore, I would argue, they can be deeply appreciated. When I went on go-alongs with Filip to and from his school, he showed me the route he takes almost every day, one carefully tested by him and the staff at a technical aid center, several months earlier. First a walk, then a bus, then another bus, then a shorter walk, and Filip is home. General feelings of comfort and habit are striking as we follow this route. At the same time, though, Filip recounts and points out other routes that he has tried, but had caused discomfort, stressful encounters, and accessibility troubles.

Piggybacking or mimicking conventions

A related way of dealing with inaccessibility is to ride along or share methods that are not explicitly designed for people with disabilities, but still work pretty well. The trick is to know what to pick out from a conventional method, tailoring it for oneself, and pursuing access. In Liberman's (2013, 37) study on crossing an unregulated intersection, 'piggybacking' refers to 'skillfully taking advantage of crossers-in-progress who have already forced competing traffic to make way.' For instance, a jogger might time his entry to follow a van that is successfully moving through traffic. Liberman's (2013, 40) study found that a person crossing in a wheelchair 'will serve as a magnet' for piggybackers, because he or she opens up a clear path, similar to someone crossing with a baby carriage or students crossing with a poster.

Our data mostly suggest piggybacking in a more figurative sense. A striking finding is that informants often use various websites, apps, social media, keyboard shortcuts, or other digital procedures to mitigate accessibility troubles, sometimes in relation to digital arenas, sometimes in relation to spatial ones (cf. Anderberg and Jönsson 2005; Anderberg 2007, 252). Although these procedures are used by anyone in society (living with a disability, or not), their use seems to be a bit more intensified, generalized, and crucial for people with disabilities. For some informants, it is standard to dictate SMS messages (instead of typing) and use voiceover to read texts. Filip uses voiceover for SMS, emails, textbooks, slide decks, and PDFs, and he easily accesses geographical information on the move with his cell phone. This

way, he gains better access to the school and to a political association in which he is active.

Bob (a cultural worker in his 40 s) talks enthusiastically about the 'incredible' number of apps available today that he could only dream about as a kid. He says that many tools are 'not just for persons with disabilities,' and 'I think the Internet and Facebook and all apps – that I think is the greatest accessibility today.' For him, the possibility of using word-processing facilitates regular communication and helps him cut through barriers. He says that, in a way, he 'feels naked' when he writes on the screen.

> Bob: When I write, I can really say what I want without hesitating, I can press delete, I cannot do that when I speak, then I make these sounds [referring to spastic movements with his mouth], but when I write I can erase my spasms.

Although Bob do not always want to 'erase' his spasms – he enjoys communicating face-to-face and on stages, because then he can 'include the whole me' – he still finds computer techniques facilitating. He writes like anyone else, with just a keyboard, a screen and a computer, and in that sense he is riding along and sharing a universal method for getting in contact with authorities, companies, friends, and others, and when expressing himself in stories and other cultural forms. The enjoyment is, to a great extent, emotional. Bob says he have been trying his whole life to 'live with as little adaptations as possible'.

> Bob: I have almost made it into an absurd play, if I can get rid of something [a disability aid] that even smells CP, then I'll do it. (…) My car looks like everybody else's. (…) It might be based on some kind of fear of standing out (…), [but] in my experiences, the people who have seen me as different [in my life] have arranged things so that I have not been allowed to do what I want to do.

Piggybacking conventions might, in other words, accentuate a sense of inclusion and normalcy (and personal authenticity, like Bob's sense of feeling 'naked'), although it might also be coupled with a frustration with society. Why did it take so long? Bob says that he is a 'quite paradoxical' person when it came to adaptations, and that he is 'attacking [segregated society] from different angles' at the same time. He is very critical towards companies that do not hire people with disabilities and outright sarcastic about the lack of basic adaptations and aids throughout his childhood. Now, he says, he loves the new bus stops in Sweden, because they are designed to be universally accessible, and 'it is so intelligent.' They use no special colors, or anything else to mark idiosyncrasies of persons with disabilities, and nothing that makes people think 'what an ugly bus stop.'

This blend of smoothness, aesthetics, and artfulness recur in informants' reports on their use of conventions. New conventions emerging in today's technological landscape might often represent a digital divide (Hansson 2015; Macdonald and Clayton 2012; Harris 2010), but sometimes they

constitute a discreet niche for hands-on accessibility. Thomas, 20 years old and using a wheelchair, often feels stressed in grocery shops, due to the long line of people behind him for the normal checkout registers; however, when self-service registers with self-scanning became available, he usually makes it on his own. That line is broken up; thus, nobody has to wait exclusively for him to finish, which makes the situation less demanding. 'It is only me at that station,' and there are (universal) staff that can help. Other informants find self-scanning impossible and definitely not disability-friendly, but Thomas has found a way. He says that 'the [scanning] technique has advanced so much that he has no problem scanning his goods on his own. For him, the discomfort or stickiness in the interaction (Davis 1972, 132) is associated with the previous grocery shop convention – with stressful queues – not with the new one.

When these arrangements function as desired, it is the method as such that is passing. The method blends in with other conventional methods among people, and that is appreciated. Thomas is not saying that his whole appearance or social identity would be equal to all others' – he is using a wheelchair and looks the way he looks in public places – but he is equal in the ethnomethod he performs.

Debunking others' accounts and performing local politics

A final way for dealing with inaccessibility is to discredit other people's accounts of barriers and, sometimes in close association, driving political projects against them, or at least making political remarks. These instances range from an equivalent to Emerson's (2015, 136) trouble-tellings in small talk during our go-alongs and in interviews, to participating in political campaigns for broader accessibility; i.e. open problem-interventions. Informants ask others to take sides and form an alliance against exclusion, based on the conviction that exclusion is uncompromisingly illegitimate. Antagonists are identified by their excuses and justifications – and informants ironically speculate about them – and their arguments are debunked.

This method does not exclude the use of other methods. A person with a disability may rely on others, make deals, establish routines, and piggyback on or mimic conventions, at the same time that they use political approaches. Actors do not distribute themselves discretely according to, for instance, loyalty, exit, or voice in relation to a discriminatory society (cf. Hirschman 1970); rather, they drift in and out of an array of approaches to suit each situation.

For instance, Bob uses fairly non-political tactics and he prefers to skip adaptations, but simultaneously he articulates sarcasm against society. At a social event in his profession, he asked managers why they did not hire

more individuals with disabilities, and one of the answers he got was that they did not want to buy new (more accessible) desks. 'How would that look!' Bob says with a smirk, "new desks"! I get it, I understand that you want to keep the disabled away.' He openly mocked the managers he met, he says, creating a little scene with so-called affective disorganization (Goffman 1963, 187), and thereby playing with the interactional discomfort. As he recounted the episode in an interview with me, he made me his ally in debunking the evasiveness of the manager's response.

Many conversations in the data are peppered with remarks or grimaces of this sort. The informants continually dishonor others' accounts (Scott and Lyman 1968, 52–53), i. e. they undermine justifications and dispute proposed rationales for maintaining this or that type of inaccessibility.

A distinct case is Sten, a student who has successfully reformed a local sports club in his hometown to make it more disability-friendly. When we first met, he became so engaged in our talk about accessibility – which occurred in the kitchen of a student dormitory – that he fetched some binders to show us copies of meeting protocols, media coverage, and drawings about his project. Currently, people in wheelchairs can access the club, because thresholds and staircases have been removed and lanes have been adapted. The associated restaurant has also been renovated to make it accessible, including the toilet. Sten showed me photos from the local newspaper that described the first 'try-this-sport-day' when people with disabilities were invited. He says that 'an adapted toilet' was the first and most crucial step for the club:

> Sten: [making it possible to] enter with a wheelchair and other aiding equipment, that was project number one that we- that was a start, actually a prerequisite for us being able to include this target group in this whole thing, and for that we had people from the whole municipality with us.

Sten interchangeably talks about 'we', meaning 'we in the club' or 'we in the committee for reform' (in relation to 'the target group'), and 'I', in terms of his own sports activities or his role as a practitioner. Despite his young age, he artfully employs many terms associated with official accessibility discourses, like when he talks about 'internal inclusion' (getting all existing members with disabilities active) versus 'external inclusion' (attracting new members with disabilities). 'We have a new project,' Sten says, and goes on talking about a new elevator that will make the first floor of the club accessible to all.

As I recorded this conversation in Sten's student dormitory, Jonte, another student, joined in, a friend of Sten and also using a wheelchair. He and Sten started talking about how others sometimes viewed their work regarding disability. For example, politicians might say 'should we really put money into this? [accessibility]' They were referring to the financial contributions made

by the municipality to the club and to accessibility reforms, in general. Sten is proud of the club's 'strong cooperation' with the municipality and with public and commercial actors, which were needed for the accessibility reforms in the club, but his (and Jonte's) talk about political work also includes discursive attacks on enemies. The reforms at the sports club would not have happened without alliances against exclusions, which were formed by seeing through others' rationales for maintaining inaccessibility ('it's too expensive,' 'other needs in society are more important,' 'it will only affect a few individuals,' etc.). Sten is primarily advocating the ideal of 'equality' to debunk others' accounts. Everyone wants equality, he says, and 'if you cut the budget for people with disabilities, what will happen to equality?'

In other instances, the use of others – family members, personal assistants, and peers, etc. – are combined with local politics and debunking. For example, one can make others to speak on one's behalf, like letting someone else phone an inaccessible restaurant or railway station to point out illegal obstacles, and thereby allocate the protest to others. Then, in interactions with us as researchers, informants cite these other actors' efforts to fight poor counter-arguments. It seems practically impossible to separate these methods from the politicized landscape of hands-on accessibility at large, because at almost every point there are openings for discussing what I sought to delineate in the beginning of the article: the overall promises and legal prerequisites made by authorities in various positions today, from the UN to the local government. Politics is not making arenas or resources fully accessible, but informants are making politics as they fight for full accessibility on a daily basis. Sometimes, asking others to do this work might relieve some of the pressure from being expected to, time and time again, engage in politics, debunk accounts, or make a scene (Goffman 1963, 185–187; cf. Cahill and Eggleston 1994, 305), when one simply wants to go about one's everyday life.

Discussion

In this article, I have outlined a series of folk methods that people with disabilities use when they – when doing practical, everyday tasks – deal with the fact that they have still not been granted full participation 'in all aspects of life,' as declared by the UN Convention on the Rights of Persons with Disabilities, in addition to many authoritative voices. When my colleagues and I accompany informants with disabilities on daily routes and errands, and listen to how they describe and narrate their methods as a sort of public activity (Lieberman 2013, 1), we find fruitful opportunities for getting a glimpse of what could be called strained creativity, situated in the tension between formal promises and modest results.

Policy-driven evaluations cannot fully grasp these folk ways. Rather, they comprise a sort of people's policy evaluation, a case of endogenous analytical work in people's practices (Lynch 2006, 132). These methods are reportable and accountable for all practical purposes; they are open-ended and adaptable to many situations. To use ethnomethodological terms (Liberman 2013, 43), the coherence of everyday accessibility relies on salient patterns that emerge and become available for resolving or managing local problems. Many methods used by people with disabilities to access arenas and resources are mimetic and arise as evolving patterns, rather than applied (or not applied) rules or policies. Similarly, they cannot be seen as strictly personal ways. People do their things, and their methods become witnessable, accountable, transmittable, and imitable.

Some practical conclusions can be drawn from this study. First, formal solutions of accessibility problems cannot fully succeed unless they are informed by what people do on an everyday basis. City planners may continue to eliminate thresholds, install new ramps, and erect paths for people with visual impairments; however, if they do not *also* consider the running folk methods, for example, the enlistment of others, they will miss the significance of employing staff to assist at railway stations, flight terminals, shopping malls, self-scanning registers, and obstructing elevators, etc. Municipalities and other authorities risk neglecting the importance of financing public assistance and escorts, and include in the bureaucratic definition of 'needs' people's daily errands and outings. In Sweden, personal assistance for people with disabilities is provided by the municipalities and the Swedish Social Insurance Agency, but a long-standing debate concerns whether the authorities have turned too restrictive in application processes (cf. Brennan et al. 2016a). It is very clear in our data that many arenas or resources will never be fully accessible for all without escorts or personal assistants to accompany people with various impairments.

A similar conclusion can be drawn for the methods of piggybacking and routinization. Accessibility depends on a person's techniques and familiarity with technology, but it also depends on the availability of opportunities for collaboratively *trying out one's individual correspondence* – according to exactly how one's impairment and social life look at a particular time – with new apps and programs etc., and carefully rehearsing individual and spatial practices, such as a testing a more feasible route to and from a workplace.

There are also good reasons for reformers and do-gooders to understand the intrinsically dynamic and emerging character of accessibility highlighted in this study. What people do to handle partly unregulated situations – their ethnomethods – are nearly impossible to imagine from a desk (Liberman 2013, 1, 43); it needs to be studied in detail and in situ as the society develops, without relying predominantly on the researcher's preconceptions.

Attractive theories or normative types of schemes might lead to blind spots and reduce people's agency and tactical creativity (cf. de Certeau 1974/1988, 29–42, on uses and tactics) and, simultaneously, ascribe too much power to top-down planning. Even if people's activities do not fit into a single theory – in this case a grand theory of inclusion – they may very well provide practitioners with hands-on solutions. They feed into the current trouble dynamics of inaccessibility, and officials and professionals that work for inclusion (and against troubles) could recognize and strengthen these activities, for instance, by facilitating deals, routines and the supply of 'others'.

My point of departure in this article is, in that respect, slightly ironic. We cannot simply trust that the very generous "solutions" provided by the UN, the EU, and the Swedish government are sufficient. We must get to the root and understand, as much as possible, the spatial, temporal, relational, local, and rhetorical realities that spur actions and arguments. We must pay attention to disability-experienced informants (cf. Atkinson 2015, 39) and try to capture some of the rhythms of their everyday life (cf. Hall and Wilton 2017, 737–738), as they define and handle troubles. We should not start with official declarations with the ambition of conducting analysis with, for example, the UN terms as a benchmark, but instead delineate the official declarations to capture and contextualize the actors' political emotions. The not-so-glamorous task of going about one's life as a person with a disability and facing incalculable inaccessibilities are nowadays clearly marinated in feelings of illegitimately being set aside, as if the benchmarks actually belong to that particular inaccessible sports club, or are integrated into these impossible shopping baskets. The grand declarations are primarily neither not-implemented or not-fully-implemented; they belong and contribute to annoyance, resentment, tiredness, determination and obstinacy in actions among people who continue to do what they would do anyway, but now with feelings like: 'Again, we are let down,' 'well, what did I really expect,' or 'I'll show them.'

To capture this emotional-and-political aspect in research, we can benefit from including Davis's (1972) eye for discomfort and stickiness, ultimately relying on a Goffmanian view of public life (Goffman 1963). The practical orderliness of accessibility takes place autochthonously (Liberman 2013, 21); it originates in the settings where it emerges – but this is also true for emotional orderliness. The settings at issue are not limited to the material entrance to the optician's office in an old house with a too-steep ramp, or the complex digital platform of a bank or a university course, but include the omnirelevant accessibility promises of today, so that emotionally charged politics belong to and are reproduced creatively within the settings. To expect access and inclusion represents a current ideal that is part and parcel of today's accessibility problems; it is embedded into noticeable frustration. On one hand, persons with disabilities are given the right to access but, on

the other hand, they are supposed to have quite low expectations and be prepared to repair access failures. Inaccessibility is the faux pas of today (cf. Davis 1972); however, these faux pas are often left – at least partly – to be covered up by the person with the disability. Thus, the generalizable findings (Atkinson 2015, 37) of this article are not only the strained and creative characteristics of applied accessibility, but also the fact that it is an interpersonal and charged matter.

One informant recounted a situation, where she asked for an accessible toilet during a visit at a workplace closely related to her profession. When, after some troubles, the manager unlocked the toilet, they were both surprised. It was full of boxes, tools, and rubbish. The staff had been using it for storage. The manager turned red in the face. The informant, though, found herself saying something like, 'no worries, it doesn't matter.' She was, in Davis' (1972, 140) words, artfully playing along with the polite fiction of surface acceptance, perhaps striving to sustain an ordinary relationship with the manager and staff. Formally, she had the law on her side, but in practice she had to manage the accessibility trouble on her own, including the associated emotions.

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References

Anderberg, Peter. 2007. "Peer Assistance for Personal Assistance: Analysis of Online Discussions about Personal Assistance from a Swedish Web Forum for Disabled People." *Disability & Society* 22 (3): 251–265. doi:10.1080/09687590701259450.

Anderberg, Peter, and Bodil Jönsson. 2005. "Being There." *Disability & Society* 20 (7): 719–733. doi:10.1080/09687590500335733.

Atkinson, Paul. 2015. *For Ethnography*. Los Angeles, CA: SAGE.

Barnes, Colin. 2010. "A Brief History of Discrimination and Disabled People." *The Disability Studies Reader*. New York: Routledge.

Brennan, Ciara, Rannveig Traustadóttir, Peter Anderberg, and James Rice. 2016a. "Are Cutbacks to Personal Assistance Violating Sweden's Obligations under the UN Convention on the Rights of Persons with Disabilities?" *Laws* 5 (2): 23–15. doi:10.3390/laws5020023.

Brennan, Ciara, Rannveig Traustadóttir, Peter Anderberg, and James Rice. 2016b. "Negotiating Independence, Choice and Autonomy. Experiences of Parents Who Coordinate Personal Assistance on Behalf of Their Adult Son or Daughter." *Disability & Society* 31 (5): 604–621. doi:10.1080/09687599.2016.1188768.

Cahill, SpencerE, and Robin Eggleston. 1994. "Managing Emotions in Public. The Case of Wheelchair Users." *Social Psychology Quarterly* 57 (4): 300–312. doi:10.2307/2787157.

Certeau, Michel de. 1974/1988. *The Practice of Everyday Life*. Berkeley: University of California Press.

Davis, Fred. 1972. *Illness, Interaction and the Self*. Belmont, CA: Wadsworth.

Egard, Hanna. 2011. *Personlig assistans i praktiken. Beredskap, initiativ och vänskaplighet*. Lund: Lunds universitet, Socialhögskolan.

Emerson, Robert M. 2015. *Everyday Troubles. The Micro-Politics of Interpersonal Conflict*. Chicago, IL: The University of Chicago Press.

Emerson, Robert M., Rachell. Fretz, and Linda L. Shaw. 1995. *Writing Ethnographic Fieldnotes*. Chicago, IL: The University of Chicago Press.

Figueiredo, Elisabete, Celeste Eusébio, and Elisabeth Kastenholz. 2012. "How Diverse Are Tourists with Disabilities? A Pilot Study on Accessible Leisure Tourism Experiences in Portugal." *International Journal of Tourism Research* 14 (6): 531–550. doi:10.1002/jtr.1913.

Garfinkel, Harold. 1967. *Studies in Ethnomethodology*. Cambridge, MA: Polity Press.

Goffman, Erving. 1963. "Behavior in Public Places." *Notes on the Social Organization of Gatherings*. New York: The Free Press.

Granovetter, Mark. 1994. "Business Groups and Social Organization." In *The Handbook of Economic Sociology*, edited by Neil J. Smelser and Richard Swedberg. pp. 429–450. Princeton, NJ.: Princeton University Press.

Hall, Edward, and Robert Wilton. 2017. " Towards a Relational Geography of Disability." *Progress in Human Geography* 41 (6): 727–744. doi:10.1177/0309132516659705.

Hansson, Kristofer. 2015. "Digital Delaktighet Utifrån Ett Funktionshinderperspektiv [Digital Participation from a Disability Perspective]." In *Att arbeta med delaktighet inom habilitering [To Work with Participation in Habilitation]*, edited by Kristofer Hansson and Eva Nordmark. pp.169–184. Lund: Studentlitteratur.

Harris, Jennfier. 2010. "The Use, Role and Application of Advanced Technology in the Lives of Disabled People in the UK." *Disability & Society* 25 (4): 427–439. doi:10.1080/09687591003755815.

Hirschman Albert, O. 1970/2004. "Exit, Voice, and Loyalty: Responses to Decline in Firms, Organizations, and States". Cambridge, MA: Harvard University Press.

Hochschild, ArlieRussell. 1983. *The Managed Heart. Commercialization of Human Feeling*. Berkeley: University of California Press.

Holstein, James A., and Jaber F. Gubrium. 1995. *The Active Interview*. Thousand Oaks, CA: SAGE.

Iwarsson, Susanne, and Agneta Ståhl. 2003. "Accessibility, Usability and Universal Design." *Disability and Rehabilitation* 25 (2): 57–66. doi:10.1080/dre.25.2.57.66.

Kastenholz, Elisabeth, Celeste Eusébio, &, and Elisabete Figueiredo. 2015. "Contributions of Tourism to Social Inclusion of Persons with Disability." *Disability & Society* 30 (8): 1259–1281. doi:10.1080/09687599.2015.1075868.

Kusenbach, Margarethe. 2003. " Street Phenomenology. The Go-Along as Ethnographic Research Tool." *Ethnography* 4 (3): 455–485. doi:10.1177/146613810343007.

Liberman, Kenneth. 2013. *More Studies in Ethnomethodology*. Albany: State University of New York Press.

Lofland, Lyn. 1973. *A World of Strangers. Order and Action in Urban Public Space*. Prospect Heights, IL: Waveland.

Lynch, Michael. 2006. "Ethnomethodology and the Logic of Practice." In *The Practice Turn in Contemporary Theory*, edited by Theodore R. Schatzki, Karin Knorr Cetina, and Eike von Savigni. pp. 131–148. London: Routledge.

Macdonald, Stephen J., and John Clayton. 2012. "Back to the Future, Disability and the Digital Divide." *Disability & Society* 28 (5): 702–718. doi:10.1080/09687599.2012.732538.

Mazurik, Kathrina, Michel Desjardins, Ève de Grosbois, Tiiu Poldma, and Jan Gelech. 2014. "Individual Stakes and Collective Ideology in Tension. Looking at Physical and Spatial Obstacles from an Experential Perspective." *Alter* 8 (3): 194–205. " doi:10.1016/j.alter.2014.02.008.

Nordgren, Camilla. 2009. "Dubbla sociala normer. Existenser och effekter i vardagen för personer med funktionsnedsättning." *Nordic Journal of Law and Justice* 32: 2–125.

Scott, Marvin B., and Stanford M. Lyman. 1968. "Accounts." *American Sociological Review* 33 (1): 46–62. doi:10.2307/2092239.

Sépulchre, Marie. 2019. *This Is Not Citizenship. Analysing the Claims of Disability Activists in Sweden*. Uppsala: Department of Sociology, Uppsala University.

Shakespeare, Tom, and Nicholas Watson. 2002. "The Social Model of Disability: An Outdated Ideology?" *Research in Social Science and Disability* 2: 9–28.

Silverman, David. 2007. *A Very Short, Fairly Interesting and Reasonably Cheap Book about Qualitative Research*. Los Angeles, CA: SAGE.

Swedberg, Richard. 2012. "Theorizing in Sociology and Social Science." *Theory and Society* 41 (1): 1–40. doi:10.1007/s11186-011-9161-5.

Wästerfors, David. 2011. "Stretching Capabilities. Children with Disabilities Playing TV and Computer Games." *Disability & Society* 26 (3): 337–349. doi:10.1080/09687599.2011.560417.

Wästerfors, David, and Kristofer Hansson. 2017. "Taking Ownership of Gaming and Disability." *Journal of Youth Studies* 20 (9): 1143–1160. doi:10.1080/13676261.2017.1313969.