

RESEARCH

Patient or Citizen? Participation and Accessibility for Deaf and Hard-of-Hearing People in the Context of Interpretation in Sweden

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Drawing upon ethnographic data from two projects, this paper focuses on interpretation issues in deaf and hard-of-hearing (DHH) individuals' everyday lives. A specific issue is the importance of and the ways in which interpretation services and Swedish – Swedish Sign Language interpreters shape their experiences and participation. Three themes are illustrated, highlighting tensions that facilitate or obstruct DHH individuals' participation. The analysis shows that they are positioned as both patients and citizens. Unequal power relationships position them in passive roles, as patients, with limited possibilities to shape the interpreter services, while they simultaneously shoulder major responsibility for its smooth functioning. The mundane nature of the analysis also highlights how they are accorded the position of citizen within the same services.

Keywords: Swedish Sign Language; interpretation service; participation; ethnography; multidisciplinary

1. Introduction

All laws and public activities in the nation-state of Sweden need to comply with the UN Convention on the rights of persons with disabilities since its ratification in 2009. Sweden thus needs to ensure the full and effective participation and inclusion of people with disabilities (Article 3), support their opportunities to live independently and participate fully in all aspects of life, including having access to professional sign language interpreters (Article 9). Thus, Swedish authorities, county councils, municipalities, etc., are obliged to respect, protect, fulfill, and promote these rights, which confers a *citizen position* on persons with disabilities. However, promises in “declared policies” (Bonacina-Pugh 2012) that aim to provide access and participation opportunities for people with disabilities tend to be diffuse and open to different interpretations. For example, despite accessibility measures enumerated in policy like enabling wheelchair users access to spaces, offering information in Braille or Swedish Sign Language (STS),¹ etc., different professionals often judge these to be someone else's responsibility, and therefore not necessarily a priority for their own institution/s. This means that access to STS interpretation services that are crucial for deaf and hard-of-hearing people's (DHH-people) participation in societal arenas, are enveloped in diffuse restrictions, reservations, and formulations. These services constitute keys that enable DHH-people becoming citizens on an equal footing with hearing people.

In this study, we focus on the everyday nature of social practices in order to illuminate framings regarding participation, accessibility and marginalization in situ for DHH-people in Swedish spaces and wherein STS interpretation services (STS-IS) are involved. Our study draws on data from two ethnographically framed projects: the Swedish Research Council project *Participation for all?* (PAL) (2017-ongoing)² that focuses on the school and post-school pathways of young people with diverse abilities/disabilities, and the Swedish Arts Council project *Participation and Theatre* (DoT) (2012–15).³ While the overarching aim of project PAL is to generate knowledge regarding successful criteria for transition to adulthood, its focus upon issues of participation broadly relates to how functionality issues play out in and across different institutional settings in contemporary Sweden. Project DoT aimed to increase the co-participation of DHH- and hearing-people in the cultural sector through experimentations with visual dimensions of performing arts *for*

¹ In line with both our long-standing efforts to go beyond the commonly used nomenclature of “Sign Language” across everyday and scholarly communication, and following recent discussions regarding abbreviations of “Swedish Sign Language”, we use STS that stands for the Swedish “Svenskt TeckenSpråk”.

² See www.ju.se/ccd/pal

³ <http://urn.kb.se/resolve?urn=urn:nbn:se:hj:diva-48145> (Weckström & Bagga-Gupta 2020).

everyone. Both projects share an interest in issues of participation and equity with regard to adult DHH-people across societal settings.

Issues regarding interpretation have emerged as a key theme in both projects. DHH-people meet and interact with interpreters in contexts like work arenas, various types of meetings and conferences, theater collation, health care services, banks, leisure time activities (gym training, hobbies, etc.). Our fieldwork has also highlighted that engaging interpreters requires time-consuming preparation work that DHH-people and their closest environments are tasked with. This includes uncertainties regarding whether interpreters should be called upon at all, who would be responsible for STS-IS costs, and which interpreters should be engaged in different activities with respect to their different competencies. The overarching aim of the study presented here is, therefore, to illuminate how interpretation issues shape DHH-people's accessibilities/marginalization in their everyday lives. This includes the nature and relationship of national policies and how these shape DHH-people's experiences and participation in and across settings. More specifically, we examine: 1) how the policies pertaining to STS interpretation services play out for DHH-people in everyday life; 2) which facilitative and obstructive dimensions exist in the interpretation service provision; and 3) the nature of communication between DHH-people and non-signing hearing people in the absence of formal interpreters.

2. Background: Policies and previous research

Approximately 1.3 million (out of a total population of 10 million) people in Sweden have some degree of hearing loss. Of these, around 7,400 people are registered STS-IS users in some form (Ds 2016–7).⁴ While this is a small population, the frequency of interpretation usage varies considerably among registered users. Individuals who are deaf from childhood and deaf-blind people tend to, while others use interpreters more sporadically (Ds 2016–7). STS-IS can be categorized into four domains involving interpretation:

1. *in everyday life* (i.e. for leisure time activities, visits to health care services, meetings with bank offices, and some types of general meetings or workplace activities)
2. *in educational contexts* (primarily in higher education and folk high schools);
3. *in working life* (for meetings, seminars, conferences, courses for further training, etc.)
4. *through video relay* (some forms of relay services, like text-telephone services, are not included in this STS-IS category)⁵

Contemporary STS-IS is regulated through different laws, and the responsibility for hiring and financing this service rests on different authorities and principal organizers. The Ministry of Health and Social Affairs argues (Ds 2016–7) that this curtails the provision of a resource-efficient high-quality service. They also stress that the system is confusing and unpredictable for the end-users. The following can illuminate why this is so. Sweden has three levels of governance: national, regional (counties and county councils) and local (municipalities). Twenty-one counties and county councils are responsible for health care that is financed through income taxes. Two hundred and ninety municipalities are responsible for services, such as roads, water supply, schools, public welfare, and elderly care that is financed through income taxes and some charges).⁶ This governance means that responsibilities for organizing the interpreter services for meetings is fuzzy. For example, if (hearing non-signing) school staff and (deaf) parents of (hearing) children participate in a school meeting, it can seem reasonable that it is *the municipality's duty* to hire and pay for interpreters since it is the school staffs' needs to communicate with the parents that is crucial. However, interpreter provision falls under the responsibility of the *county council's* (SOU 2011–83) when the same deaf parents need to participate in other meetings at the same school (see **Figure 1**).

This division of responsibilities is based on the Health and Medical Services Act (2017–30) which sets-out the responsibilities of county councils for STS-IS in *everyday life* situations. Given that resources for these services are limited, a shortage of interpreters results in county councils creating priority lists where activities are ranked. For instance, visits to health care services are prioritized higher than participation in leisure activities (Ds 2016–7; SOU 2011–83). Associations for DHH-people have critiqued these lists because such prioritization means that authorities, instead of the end-users, decide when and who can access interpreters. The National Board of Health and Welfare (2008) has highlighted that, given the significance of leisure time activities for people's well-being, the associations' demands for open STS-IS need to be reconsidered. The Board also indicates that while some DHH-people can handle some face-to-face meetings without an interpreter (with a doctor, for instance), they may need interpreters in group meetings during their leisure time. While the Board supports the associations' demands that DHH-people should influence their own access to STS-IS, the policy stands unchanged since 2008 when the report was published. In addition to being responsible for STS-IS in everyday life contexts, county councils have a hegemonic position with regards to who can access interpreters and for what purposes. This places DHH-people in a *patient position*, as people who need help and whose access lies in the hands of professionals who make decisions regarding what is best for them.

⁴ This, and other similar, references, are conventional ways to present official governmental documents in Sweden.

⁵ A video remote interpreting-service that makes it possible for signing DHH-people and non-signing Swedish-speaking people to communicate with one other from different localities.

⁶ See <https://sweden.se/life/democracy/swedish-government>, and <https://www.government.se/government-policy/municipalities-and-regions/>.

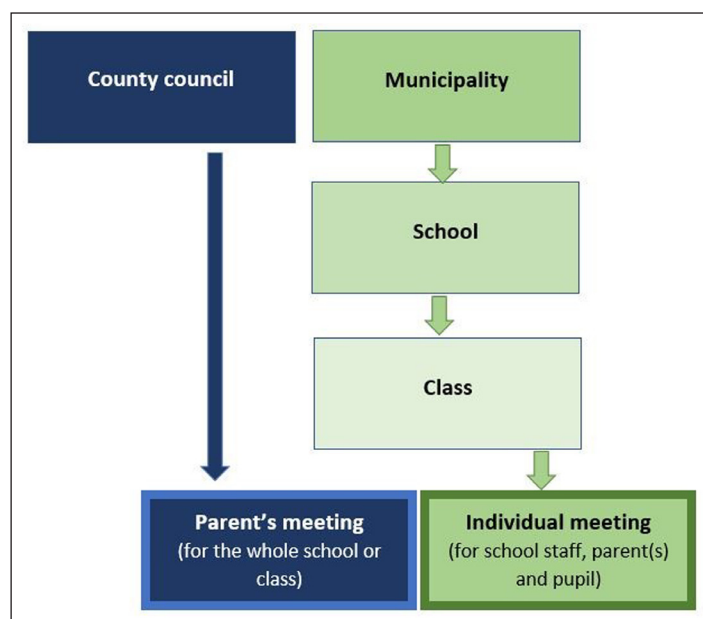


Figure 1: Distribution of responsibilities between county councils and municipalities for hiring interpreters for deaf parents.

The larger existing scholarship of potential relevance for this study exists in separate areas of expertise (for instance, sign languages, interpretation, handicap, and rights and regulations) and only rarely engages with the complexities of participation in everyday life across different institutional settings (Bagga-Gupta 2014, 2017a). Given that our study does not focus interpretation directly but rather on issues of participation and accessibility in everyday life settings for DHH-adults where interpretation has emerged as an important issue, we address specific aspects of relevance to this study in the existing scholarship.

STS-IS constitutes an interesting example of ‘deaf-hearing collaborations’. Such collaborations have been explored in terms of the ‘Deaf-Hearing World’, instead of the ‘Deaf World’ (Bagga-Gupta 2017b, 2019a, 2019b). Interpretation services in the Nordic countries are a public sector responsibility with challenges related to bureaucratic principles for equity issues. Haualand (2018), for instance, highlights that compared to five decades ago, contemporary interpretation is both a profession and a public service. While the interpreter profession is young, the history of relatives who provided translations between oral and signed languages or constructed sign communication is long. The latter support is often discussed in terms of hearing *helpers*, wherein the helpers’ primary goal is seen as supporting deaf individuals’ participation in everyday life activities (Haualand 2018; Lundström 1998). Such support confers a patient perspective on DHH-people.

During the 1960s, deaf associations in different nation-states started demanding formal interpretation services, including interpreter training. Their ambition was to go beyond general *help* from hearing relatives and professionals like priests and teachers, and access rights to an *interpretation service*. This was envisaged as enabling DHH-people to represent themselves and become responsible for various life dimensions through a *professional interpreter* whose role included mediating communication with hearing non-signing people (Haualand 2018). Such calls led to the establishment of interpreter training programs in the USA and, subsequently, other nation-states from the 1960s onwards (Nilsson 1997).

In 1968 the Swedish parliament decreed that DHH-people should be provided free STS-IS, and in 1969, the first interpretation training course was established (Lundström 1998). This education has developed through an increasing number of institutions that deliver such education, and the duration of the programs has increased from six weeks in 1969, to three to four years in 2021. Initially, hearing individuals interested in the interpreter training programs had to be recommended by deaf associations and have good STS skills before they started their studies (Nilsson 2019). In sharp contrast, none of the contemporary interpreter training programs require any previous STS knowledge, and most students today are novice signers or have no previous STS experience. This education is also completely independent from deaf associations today. Thus, the deaf community’s work to establish professional STS-IS has led to the deaf community losing its influence over both the service and the interpreter education (Nilsson 2019).

Contemporary formal STS-IS entails that the interpreter is positioned as a neutral facilitator of communication and is *not* supposed to be a helper. This implies that the interpreter is seen as merely mediating the communicated content between DHH-people and hearing non-signers, and is not supposed to provide suggestions, additional explanations, reveal misunderstandings, etc. This can, however, create curtailed environments for DHH-people, not least when it comes to DHH children and youths. For instance, illustrating the complexities of interpretation in a mainstream educational context where a single deaf student is enrolled, Berge and Kermit (2017) highlight the interpreter’s rather passive role in the classroom. The interpreter places herself in the periphery during informal group-work, waiting for the deaf

student to request assistance. While the interpreter's rationale for doing this is reported as minimizing interference during group-work, the deaf student gets marginalized in this discussion. The classroom is also described as not being optimally arranged for a deaf student and or *zir*⁷ close access to the interpreter during classroom work; the interpreter neither sees this as *zir* responsibility nor raises this with the teacher. While previous Swedish classroom studies also illustrate that DHH-students in hearing non-signing classrooms cannot access STS communication despite the presence of adults who know the language (e.g., Holmström & Bagga-Gupta 2017; Holmström, Bagga-Gupta & Jonsson 2015), other Swedish classroom studies indicate that interpreters (at upper secondary schools) tend to go beyond their primary interpreting roles (Bagga-Gupta 2002). Such studies make relevant the complex nature of interpreters' work in that it is both constitutive of deaf-hearing collaborations and calls upon some dimensions of a helper-profile so that DHH-students can draw maximum traction from interpreters' mediational roles.

Another issue regarding DHH-people's opportunities to be positioned as citizens in societal arenas relates to what Hauser and Hauser (2008:5) highlight as DHH-peoples' needs for *designated* interpreters, i.e., interpreters with both excellent and specific interpreting skills:

The designated interpreter is a dynamic and active participant in the deaf professional's environment, and his or her actions influence communication outcomes and the deaf professional's work performance. The designated interpreter has a thorough understanding of the deaf professional's role, the roles of others in the workplace and those who have a relationship with the workplace (contractors, customers, etc.), the work culture, and the jargon used.

In their examination of the relationship between DHH-professionals and their work environment, Napier et al. (2019:98) highlight the critical significance of how DHH-professionals are represented; here, deaf people's involvement in interpreted situations makes their identity explicit and performed through a 'translated self'. Deaf professionals 'have to represent their professional identity to non-deaf, non-signing colleagues through an "other,"' i.e. the interpreter. They highlight that deaf-professionals' experiences of how their professional identity is represented through interpreters has received inadequate attention. Their study of three deaf-professionals' accounts of their perceptions and experiences of working with interpreters highlights that these professionals 'perceive that their deaf-and-professional identities are not always adequately represented through interpreters, and this can create feelings of stress as it can impact on the way they are perceived by hearing others in the workplace' (Napier et al. 2019:114).

Although it is not unproblematic to be represented through an interpreter, a designated interpreter would have a better sense of supporting deaf-professionals. However, this is not explicated in the work of interpretation service providers. Hauser and Hauser (2008) highlight that coordinators of interpretation services and the interpreters themselves are unaware of the differences between *designated* and *regular* (mainstream) interpreters. Therefore, DHH-professionals often need to make concerted efforts to receive designated interpreters. Furthermore, many hearing (non-signing) professionals who work with DHH-people (who are often not in positions of authority) are unaware of the latter's specific needs or requirements. This is reported as leading to DHH-people being perceived as demanding and haughty (cf. Kermit & Holiman 2018). Hauser and Hauser highlight that '[t]hose who prevent deaf professionals from getting their needs met are not empowering deaf individuals but disabling them' (2008:20).

The situation wherein DHH-people are understood as becoming marginalized through their very work with hearing non-signing professionals may be understood as a consequence of DHH-people's dual status. De Meulder and Murray (2017:139) highlight that DHH-people have 'dual category status, being seen as both a linguistic minority and a group of people with a disability' (see also Bagga-Gupta 2004; Lundeberg & Breivik 2017). In a comparative study regarding the legal recognition of sign languages in Norway and Sweden, Hualand and Holmström (2019:14) suggest that this dual status 'continuously reinforces the subordination of sign languages and their users'. Engaging with Piller's (2017) notion of 'language shaming', Hualand and Holmström (2019) describe the reluctance of governments to provide sufficient resources for implementing sign language-related regulations or activities, the shrinking of sign language environments, and how sign languages and their users are becoming subordinated in the new millennium. They also propose that the dual category status 'can help us to understand why language legislation and language shaming seem to go hand in hand in the context of sign languages' (2019:14). This also illuminates the complex positions that frame DHH-people as both patients and citizens across different contexts. Emery (2006) has examined whether the concept of citizenship is useful to describe the problems experienced by deaf communities. Among other things, he shows that deaf people are denied basic and fundamental rights with regard to social citizenship. While policies, in particular social policies, frame DHH-people within an impairment-based medical perspective, in practice, they are excluded from citizenship framings in many contexts.

Our study goes beyond demarcated areas of expertise, focuses on the complexities of everyday life and this calls for *a-going-beyond* agenda where intersecting tenets of two theoretical framings constitute points of departure.

⁷ We use the gender neutral pronoun *zir* for his/her (<https://blog.hubspot.com/marketing/gender-neutral-pronouns>).

3. A note on theoretical framings

Issues of human communication and identity are central to the present study. The intersection of sociocultural interactionist perspectives on communication/language (Harris 2009; Linell 2009; Säljö 2005) and decolonial framings on identity (Khumbhandani 1997; Maldonado-Torres 2011) constitute a *Second Wave of Southern Perspectives*, SWaSP (see e.g. Bagga-Gupta 2021; Bagga-Gupta & Carneiro 2021; Bagga-Gupta & Messina Dahlberg 2021). SWaSP tenets draw attention to the reductionist nature of fixed binaries like disabled-normal, deaf-hearing, etc. Instead, its analytical interests are aligned towards the situated nature of everyday interactions with the intent of illuminating the *doing of* or the *performative* nature of participation and accessibility across social practices. Human identity and communication are, from these framings, increasingly understood in terms of the *doing of identity* and of *linguaging*, rather than essentialized identity characteristics or bounded language modalities like oral, written or signed languages. Thus, the key issue here is illuminating the playing out of participation and accessibility in social practices, rather than in terms of ideologically framed support for groups of homogenized, essentialized categories or the accounts of people (Lincoln & Guba 1985) positioned as disabled.

Furthermore, SWaSP tenets highlight that issues of participation and equity—as spelled out in ‘declared’ policies—need to be attended to in terms of ‘practiced’ policies (see Bonacina-Pugh 2012; Gynne 2016; Bagga-Gupta 2022) in tandem with what individuals and institutions like higher education, workplaces, NGO’s, and authorities do with policies (see Bagga-Gupta et al. 2020; Bagga-Gupta et al. 2016). These enable going beyond the *naturalization* of hegemonies regarding communication and identity on the one hand, and the by-and-large continuing *marginalization* of scholarship where the nature of everyday life is scrutinized. This means that understanding participation and accessibility relates to illuminating where, when, why, and for whom they become central in people’s lives (Bagga-Gupta 2019b, 2017a; Bagga-Gupta et al. 2017; Finnegan 2015).

Our theoretical alignment means that we analytically engage with the everyday nature of peoples’ interactions with one another and with various resources in their environments. A sociocultural interactionist perspective challenges the mirroring/representational functions of language and in particular, the medical-linguistic, oral-manual binaries that have colored deafness scholarship across time (Bagga-Gupta 2007, 2019a). This means that we center-stage ‘processes, participation patterns and membership in social practices across sites and across identity domains [...and build] the case for an alternative way of conceptualizing the performance of marginalization (and normalization) empirically’ (Bagga-Gupta 2017b:xiv). Herein lies the significance of understanding the mediational role that interpreters and other helpers play in the lives of DHH-people across settings. It is the doing of communication in everyday activities where deaf-hearing people participate that are salient for our analysis.

4. Ethnographically created data

We draw upon rich data sources from the multi-sited multidisciplinary ethnographically framed projects PAL and DoT at the CCD research group.⁸ The majority of the 45 participants in these projects have been shadowed across different arenas through ethnographic participant observations, in which we video-recorded most ongoing activities and interactions. During data creation, we have informally conversed with the participants about what was transpiring in the activities, including their reflections and feelings. Interviews were conducted primarily to learn about the participants’ backgrounds. In PAL, archive data were also created. These include documentation regarding the DHH-people from different authorities, including schools they have attended. In the current study, we have used video-recorded interactions where interpreters are present or salient in different ways. Informal conversations about interpreter issues have also been included in our analysis.

We have worked as ethnographers in the multidisciplinary field of Deaf Studies since the 1990s and represent a deaf-hearing collaborative team. We are both experienced STS users and have worked together over time in different projects. These positionalities reflect a SWaSP dimension in our analytical work.

DHH-people in both projects present a heterogenous profile. This includes gender, diverse sexual orientations, and markers such as being born in Sweden of Swedish parents and immigrant parents, recent arrivals, those who grew up in Sweden, those who are deaf-blind, different educational backgrounds (from compulsory school graduates to those who have higher education degrees), different employment experiences, including being unemployed, diverse family compositions where some have deaf parents, others have hearing parents, some live independently, and others have partners and/or children.

The ethnographic non-programmatically framed analysis of these rich and diverse datasets have pointed to the importance of interpreter issues for DHH-individual’s participation in different contexts. Here some patterns are salient. We have chosen four participants from the PAL-project in order to *illustrate* the most frequent patterns. With the help of ethnographic vignettes created from fieldnotes, video-recordings, and archive data, we present examples from situations and activities that highlight specific themes.

Project PAL was initiated after receiving ethical approval from The Swedish Regional Ethical Committee in January 2017 (Dnr/2016/470-31). Ethical issues are key for ensuring participants’ anonymity, particularly when a small group of

⁸ See www.ju.se/ccd.

Table 1: Demographic background of four cases focused upon in this study.

Case	Kim	Alex	Lee	Drew
Age at project start	Late 20s	Mid-30s	Mid-20s	Mid-30s
Ethnicity	White ethnic Swede	White ethnic Swede	Pre-teen migrant from the Middle East	White ethnic Swede
Deafness	Since birth	Since birth	At 5 years of age due to meningitis	Since birth
Family background	All deaf family	Hearing family	Hearing family	All deaf family
Educational background	Signing pre-school Sign bilingual deaf school University professional degree	Signing pre-school Sign bilingual deaf school University professional degree	Sign bilingual deaf school (on arrival in Sweden) University professional degree	Sign bilingual deaf school
Employment	Permanent employment at a governmental agency, stable income	Permanent employment at a deaf school, stable income	Short-term project assignments, no stable income until recently	Temporary employment, no stable income; (unsuccessfully) tried to establish a private company

DHH-people are in focus. We have therefore chosen to use fictive gender-neutral names: Kim, Alex, Lee, and Drew, when our cases are specifically referred to in the analysis. **Table 1** presents an overview of our participants' demographic profiles.

5. The Everydayness of (Non)participation and (In)accessibility

Interpretation issues emerge as key dimensions for DHH-people's access and their participation across contexts in society. Three key themes that have emerged in our data-analysis from both projects are presented in this empirical section: policies surrounding STS-IS create what we describe as 'a circus'⁹ for end-users, tensions in the service provision, and the engagement of non-professionals instead of professional interpreters. We use ethnographical vignettes to illustrate poignant issues.

5.1. The circus of interpretation policies

In Swedish spaces, STS-IS—provided by the county councils—builds upon a *healthcare perspective*; this 'characterizes a view regarding interpretation users [where the latter] become patients. The need for interpretation services is defined based on an individual's disability and not on the societal goal regarding accessibility for all the country's linguistic minorities' (SOU 2011–83:185, our translation. Cf. Lundeborg & Breivik 2017). In other words, STS-IS is regarded as being directly related to disability policies rather than to language or equity policies.

Our datasets suggest that STS-IS is viewed as a relevant issue *only for* DHH-people and not hearing non-signers. For example, at meetings where all but one hearing participant knows STS, the STS-IS office—as is routine praxis—requires *all* the DHH-participants' names, not names of hearing non-signers (or signers).¹⁰ The norm that underlines such service provision center-stages DHH-individual(s)' interpretation needs for communicating with hearing non-signer(s). For instance, when Drew and his DHH business partner visit the employment agency or the municipality office to navigate administration involved in setting up a company that aims to provide services for DHH-people, they must not only order interpreters but also pay for them from their company resources. It is their deafness and inability to communicate in oral Swedish, not the hearing official's non-familiarity with STS, that thus gets marked and is seen as requiring interpreters.

The circus of interpretation policies also plays out in the positioning of DHH-people as *passive participants* in many societal contexts. Such a gaze upon DHH-people is hegemonic and problematic from democratic perspectives. This is important given that increasing numbers of DHH-people are continuing into higher education and are becoming members of different professions. In our projects, DHH-individuals are employed as theater professionals, project leaders, lawyers, politicians, business owners, teachers, etc. They take an active role in work-life arenas and thus need interpreters at meetings, conferences, seminars, etc., as a regular key dimension of deaf-hearing collaborations. However, current policies decree that when DHH-people are *active participants*, i.e., when they are active citizens in any societal context, for instance, when they (like Drew) own a company, lead a meeting (as Kim does regularly) or play a lead role in a theater production, it is they themselves as owners of a business or their employers who are required to

⁹ We have discussed this concept in our Swedish writings where it is the messiness and confusion that we highlight. Synonyms for "circus/circus" includes "villervalla/mess", "röra/confusion", "bråk/brawl", "ståhej/fuss", etc (<https://www.synonymer.se/sv-syn/cirkus>).

¹⁰ This is possibly related to the need for spreading the costs when participants come from different counties. It is important to note that hearing signers routinely participate in such meetings.

cover costs for interpretation. This means that DHH-employees are more expensive workers (in comparison to hearing employees), and are by extension, less attractive in the labor market. Ear-marked (pun unintentional) funds, primarily for interpretation during *further training activities*, are available for employers from the Swedish Public Employment Services. These resources cannot be deployed for interpretation costs connected with regular work-related activities.

Vignette 1 (see also Vignette 4) illustrates our first theme. Despite zir university education and experiences as a deaf leader, a clear-cut disability perspective disqualifies Lee from an administrative position at an STS-IS office.

The county council, recruiting a new candidate for an administrator position, maintained that only a hearing individual was capable of handling DHH interpreter bookings. Based upon this criterium, Lee was not even short-listed for an interview, despite zir's competence regarding digital booking techniques (e.g., video telephone, e-mail, booking platforms). An ironic issue here relates to the fact that most interpreter bookings come from DHH-people themselves.

Vignette 1 illustrates a clear disability perspective that frames the services in place for providing support. DHH-people are positioned as passive patients rather than as citizens who can be active providers in the service provision.

The work profile of the administrator requires receiving interpreter bookings through different systems, such as telephony, e-mail and through a digital platform. The job description highlights that knowledge in STS was meritorious. A few weeks after the deadline for the job application, Lee contacted the IS director, inquiring about the progress of the selection process. Lee was informed that the application deadline had been extended and that some applicants had been called for an interview. Zir contacted the director again a week later and was told that the recruitment process was over and that the position had been filled. Lee was also informed that zir had not even been considered for the job because zir could not hear and speak on the telephone.

Vignette 1: Positioning deaf applicants as passive patients.

Lee challenged the process and decision by approaching the Equality Ombudsman.¹¹ Zir's trade union was advised to initiate a discriminatory court case. Lee lost the case against the county council but was backed by, and keenly followed by, many DHH- and hearing-people on social media platforms. Another case that illustrates this theme involves Drew and zir business partner. They succeeded in starting the first private company with only DHH-people employed that offers DHH elderly-people care. However, they were forced to shut down their company when the municipality disqualified them. The latter argued that hearing relatives of DHH elderly people would not be able to ring in and talk orally with any company personnel. STS-IS is not envisaged as a practical mediator here.

These cases illustrate the dominating disability perspective in the Swedish public sector, wherein DHH-people are positioned as passive patients, i.e., as disabled people in need of help from abled-bodied professionals. They are not accorded the role of independent active citizens. Furthermore, the circus of interpretation policies illustrates how language shaming ideologies flourish, marginalizing *both* DHH-people and STS.

5.2. Tensions in service provision

Our second analytical theme relates to *facilitative* and *obstructive* dimensions inherent in the very provision of STS-IS. These tensions highlight the multifaceted nature of the services.

5.2.1. Facilitative dimensions

The interpreter's experiences and knowledge, and DHH-peoples access to designated interpreters who have skills for specific activities/work contexts, appear to be key for their participation across settings. In many instances, DHH-people have access to skilled, experienced interpreters, but they don't always have access to designated interpreters regularly. Kim's gym training illustrates this facilitative dimension.

A physical ailment necessitated that Kim – an active sportsperson at the elite level within deaf sports—train with a hearing non-signing personal trainer. Kim was allocated the same interpreter for most of zir rehabilitation sessions. This interpreter was familiar with gym training concepts and could skillfully communicate the trainer's directives. However, Kim was not always satisfied when interpreters unfamiliar with training or gym terminology were sent for zir sessions.

Vignette 2 illustrates Kim's reflections that zir shared with us.

¹¹ An independent government agency that works on behalf of the Swedish parliament and government to promote equal rights and opportunities and to combat discrimination.

I was really lucky to get an interpreter every week. And the same interpreter was present on all but two occasions. The interpreter is a sports person herself and that means she knows what is lunge and what is squat and could sign these concepts clearly. We had a common understanding, and with her, I directly understood what the trainer wanted me to do. However, when I got an interpreter who didn't have the same knowledge, it became a bit more difficult; there were more slips and problems in the communication and she was not as familiar with the exercises as the regular interpreter. I did not understand the latter at the same level. For example, she does not know what lunges are and therefore she used fingerspelling, instead of using the STS sign for it. It was also difficult to understand if I should move forward or backward. So, there is really a difference between interpreters.

Vignette 2: Activity related skills—a facilitative dimension of STS-IS.

Kim's gym training situation highlights that the experienced designated interpreter skillfully uses space, tools, and embodiment tactics, like following Kim's movements and signing in *zir field of vision*. This means, for example, that when Kim squats and the trainer provides oral instructions, the interpreter also squats in front of *zir* and meets Kim's field of vision. When Kim performs exercises, the interpreter moves away, enabling Kim access to *zir* movements via the gym mirrors. And when the trainer calls for 'two left', 'now the last one', etc., the interpreter merely positions *zir* signing hand in front of Kim to mediate the trainer's oral instructions. Such interactional stances illustrate how DHH-people get positioned as citizens rather than as patients. Kim gets positioned as the central participant, and the interpreter's work enables *zir* accessibility to the embodied communication.

Another facilitative example (**Vignette 3**) comes from a situation where Alex is on a routine visit to the nurse at a Child Care Center together with *zir* partner, their baby, and four-year-old child. The presence of the interpreter and us in the small nurse's office together with the family presents logistical communication challenges that the interpreter navigates fluidly.

*The nurse shifts her gaze from the baby who she is measuring, to Alex talking orally first with the baby and then with Alex enquiring about the former's sleeping and feeding routines. Alex's gaze shifts between *zir* baby and the interpreter who shifts her signing from the (lower) level of the weighing table – appearing to both be in Alex's frame of vision and indicating that the nurse is talking to the baby – to the (higher) level of the nurse's body – indicating that the nurse is now addressing Alex. When Alex's older child exchanges some words with *zir* other parent, the interpreter points towards them, and relays in STS what Alex's family members have exchanged orally. When the nurse plots the progress of the baby on the health chart, the interpreter responds to the older child's query explaining in oral talk what the nurse is doing.*

Vignette 3: Enabling multiparty communication—embodied positioning and engagements.

In addition to the frame of vision, the interpreter's fluid engagement with both the DHH-individual and *zir* family in the cramped space are key facilitative dimensions that support Alex's participation. Other routine ways whereby interpreters facilitate DHH-people's participation include mediation of lecture content, keeping up conversations with non-signing hearing participants, and supporting DHH-peoples active engagement in meetings. Here DHH-people are positioned as active and equal citizens in society through the scaffolding provided by interpreters' embodied work.

5.2.2. Obstructive dimensions

Dimensions of obstructiveness in the service provision have also been identified in both projects. The obscure and diffuse nature of the service provision, as highlighted earlier, builds on the fact that responsibility for engaging and covering interpreter costs for meetings, conferences, or seminars, is diffusely regulated through laws or directives. The Health and Medical Services Act (2017–30) merely highlights that the county councils are responsible for STS-IS in everyday life situations. The Swedish Administrative Procedure Act (2017–900, § 13) states that authorities dealing with individuals who are not proficient in the Swedish language or who have a hearing impairment can use interpreters when necessary. Such diffuse framings result in DHH-people often ending up responsible for accessing interpreters to

secure their own participation. This means that DHH-people are tasked with highlighting their interpretation needs, regulating agreements about interpreter bookings, being acutely aware of who will cover their interpreter costs, and ensuring that the interpreters are given access to relevant preparatory and other information. While STS-IS users are not obliged to be responsible for these issues, our analysis highlights that they are usually left without access to interpreters when they do not actively take responsibility (see **Vignette 4**).

Lee was active in a deaf association and was scheduled, together with other DHH-associations, to participate in a meeting with representatives of the Ministry of Employment. The meeting agenda focused on labor market participation generally and DHH-people's and their employers' experiences regarding labor market challenges, including interpretation costs and expertise. When the delegates arrived at the meeting venue, the participants discovered that interpreters had not been booked.

The participants stand and discuss in different constellations in the lobby, attempting to solve the situation wherein the Ministry that has organized the meeting has forgotten to order interpreters. Some use pen and paper or their mobile phones to write and communicate with one another, while others search for information about regulations; some deaf delegates send text messages and some hearing representatives of the ministry talk on their phones – everyone tries to identify contact information for interpreting companies. One of many interpreter companies thus contacted, is in a position to immediately dispatch interpreters. After the booking is made, the delegates are offered coffee and are invited into a conference room. Here, the DHH-delegates discuss the seating arrangements and decide to sit in a row, allocating seats opposite to them for the interpreters. While they continue their discussions in STS and prepare for the meeting, the ministry representatives sit browsing through their papers and speak with one another orally. Roughly 20-25 minutes after the booking was confirmed, the interpreters arrive and the meeting can start.

Vignette 4: Responsibilities for ordering interpreters—the circus of interpretation policies in action.

Ministry representatives tasked with catering for issues of labor market access issues for DHH-people appeared to be uninformed about STS-IS regulations. This example highlights a common non-reflective stance regarding the communication strategies needed at even high-stake contexts. In addition to raising the specter of the circus of interpretation policies, this unintended negligence constitutes an example of language shaming. Policymakers take for granted that they can communicate with all citizens orally in Swedish.

The implicit responsibility shouldered by DHH-people for engaging interpreters tends to be a time-consuming endeavor. All our four cases invest a lot of time booking, scheduling, checking, informing, preparing for their interpreted engagements. This can entail calling or e-mailing STS-IS offices to order interpreters for specific activities. However, it is often a much more complex task that includes negotiating with other DHH-participants in common activities. A dinner table negotiation that involved Lee and two other deaf association delegates attending a political week-long event illustrates this issue (see **Vignette 5** and **Figure 2**).

A team of several interpreters had been booked to provide delegates from different DHH-associations access to seminars, lectures, workshops and meetings.¹² The DHH-delegates were required to schedule their participation in advance in order to streamline the interpreters' work across sessions and time-slots. This meant that DHH-delegates had limited opportunities to access the entire program. For instance, Lee and two other association delegates had to decide and submit their schedule to the STS-IS a day in advance. Given their intensive schedules at the event, they could negotiate these preferences only after dinner (see **Figure 2**). Such meetings lasted about two hours since the three delegates' preferences collided and resulted in lengthy discussions to arrive at a joint decision. In addition, pressures from the interpreter team had to be dealt with through e-mails and text messages that elicited final decisions 'as soon as possible'.

Vignette 5 illustrates the time-consuming preparations, nature of negotiations, and the pressure on DHH-people to deliver information to interpreter teams. It also highlights that DHH-people are positioned both as citizens and patients here. Providing information to interpreter teams is an important task since the latter need to prepare for their work (by contacting presenters to request presentation materials). However, such issues also cause inflexibility that limit DHH-participants' opportunities to adjust their plans or pursue individual interests.

¹² Project PAL data does not include details regarding the engagements of the interpreter teams. We assume, as is routine, that different associations and delegates have ordered the interpreters, and that various county councils have thereafter coordinated the bookings.

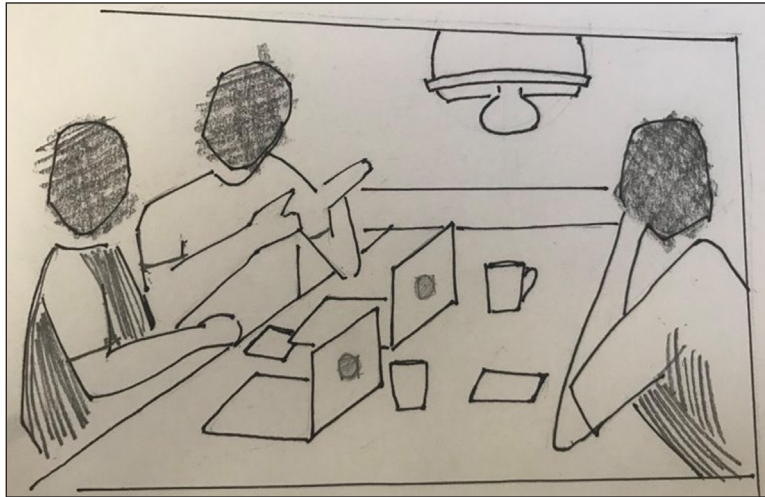


Figure 2: Negotiating interpretation schedules after dinner 'as soon as possible' "asap".

After an hour of negotiating, Lee again asks when N would like to have interpreters for mingling with other participants. Simultaneously, Lee scrolls up and down the schedule on zir computer screen. N takes a look at the same schedule on zir mobile device and sums up what each one of them has prioritized. Lee makes notes about this. At this point, an e-mail message arrives from the interpreter team and Lee appears stressed. "They send and send - calm down! We are trying to arrive at a decision to send them!" Lee signs to zir colleagues at the table. Lee checks zir mobile where zir has received a text message from the interpreter team too. Lee turns to a delegate (from another association) sitting across the room, informing them that the interpreter had sent the text message to ensure that Lee had received at least one of the two messages. Lee expresses zir frustration. The other delegate responds that they need to make decisions quickly, and Lee exclaims that they are almost done, even though their group gets distracted with other issues every now and then.

Vignette 5: Investing time for their own participation—Negotiating interpreter scheduling.

Many DHH-people participate in activities where most participants are hearing non-signers. Here DHH-people's engagement is crucial to enable their own participation. Kim is seated with hearing non-signing delegates at a conference lunch, with the interpreter across the table (**Vignette 6**). The interpreter appears distracted and is focused on zir personal agendas rather than the lunch table communication.

Here DHH-people are positioned as both patients and citizens. The interpreter appears to be primarily ready to interpret the *hearing non-signing delegates' oral communication* (a patient-based perspective). Kim has to repeatedly and actively draw the interpreter's attention to zirself to be interpreted (i.e., Kim has to fight for zir participation as a citizen). This represents a common pattern in the data wherein DHH-people's participation opportunities differ substantially from hearing non-signers' opportunities. Such subordination of STS, and thus, DHH-people, in favor of oral language, constitutes yet another instance of shaming.

5.3. Non-professional mediation

The third salient analytical theme we highlight in this study relates to the communication between DHH-people and non-signing hearing people that is mediated by non-professional interpreters, i.e. helpers, and non-professional communication between DHH-people and interpreters. While gesturing and using writing is a routine strategy employed in deaf-hearing collaborations when interpreters are not present, the triparty phenomenon in focus here involves hearing individuals who know STS and mediate communication. This occurs in a variety of ways and in different constellations.

The interpreter takes up and puts down a small bag and translates when two non-signers start talking. The interpreter shifts attention to her bag, while Kim and the other delegates eat. The interpreter releases her bag and continues the interpretation when the oral conversation resumes. After a while, they become silent again and the interpreter prepares a syringe. Lifting her sweater, she gives herself a shot in the stomach, when Kim starts signing. Realizing that zir signing was not being translated, Kim waves zir hand in front of the interpreter, attempting to catch the latter's attention. When this fails, Kim stretches over the table and touches the interpreter's arm, and the interpreter looks up. Kim signs again, and the interpreter now starts translating orally, holding the syringe out of view under the table. Only after Kim has completed zir conversation, does the interpreter disassemble and put away the syringe back into the bag. The interpreter then draws Kim's attention by leaning to the side, and begins translating into STS what the non-signers are saying.

A little later, the interpreter's gaze wanders around in the room. She starts conversing with the researcher (enquiring whether she should shift a sign holder that could be blocking the ongoing recording view). Kim again starts signing and notices that the interpreter is engaged with the researcher. Kim points at the interpreter, comments in STS "you are funny", waits a little, and tries again to start signing, waiting for the interpreter's gaze to return to zir.

The interpreter's gaze wanders elsewhere after she places the sign holder down. Kim waves intensively at the interpreter, but fails to catch the latter's attention. Kim now brings zir hand directly in front of the interpreter's face, succeeding in getting the latter's attention. The interpreter starts interpreting orally what Kim signs.

Vignette 6: Working to participate—getting the interpreter's attention.

Analysis of data from both projects highlights numerous instances wherein DHH-people participate in activities without the presence of professional interpreters. While hearing or hard-of-hearing individuals with a range of experiences with STS are employed by government agencies and other institutions to mitigate issues of access for DHH-people, family members, and friends with varying STS skills mediate communication in different contexts for DHH-people routinely.

Drew's frustration with the quality of access zir and zir business partner recieved from the hearing non-signing consultant at an employment agency in the process of the signing of a hard-of-hearing agency representative constitutes one prototype of this issue. Despite Drew's written complaints about the quality of the signing and zir concerns about how zir signing was being relayed, including requests to engage professional interpreters, the employment agency continued to use their employees to mediate the communication. Given that such meetings have crucial consequences for the future life trajectories of participants like Drew, and that the consultant can only see 'hands communicating' and hear oral Swedish, rather than the content of what is being (in)correctly communicated in signing, the power differential at play constitutes a striking example of language shaming and marginalization processes. This type of 'in-house' engagement of hearing or hard-of-hearing employees by agencies, schools, and organizations to mediate communication between hearing non-signing officials and DHH-people also displays a dominant patient framing.

When interpreters cannot be secured, healthcare services often rely upon hearing signing family members or friends, rather than using STS-IS available through digital platforms and devices (in some regions). DHH-people's citizenship status is challenged through such practiced policies despite the legislation or declared policies in place. Their rights to equal and professionally mediated participation are weak even in such potentially life-changing arenas. This is an issue to be reckoned with and contrasts with how Lee's job application is handled (see **Vignette 1**).

A third non-professional mediation aspect (that is part of this final theme) relates to specific interpreter stances during work. Both before, in-between, and after a meeting or other activity, interpreters and DHH-people interact in routine ways. When a DHH-individual is alone in an all-hearing non-signing environment, such interaction can be socially facilitative but also intrusive. For instance, at some meetings in health care spaces, private details of end-users have been divulged by the allocated interpreters to other DHH-people or their relatives/colleagues (and in at least one instance with us researchers). While discussing details related to a scheduled health examination of a DHH-patient (in public waiting spaces) can be facilitative for interpreters' work *during* the medical meeting, the visually oriented nature of STS is highly intrusive for DHH-people in such public spaces (given that other DHH or hearing patients could potentially be STS signers).

The three themes that we have presented in this section point towards complexities that arise when analytical attention is paid to the *processes* of participation and access for DHH-people across settings in contemporary arenas in Sweden.

6. Discussion. Processes of Participation and Accessibility

While promises of 'full and effective participation and inclusion in society' are presented in UN declarations that Swedish society has promised to honor, our study indicates that participation and accessibility are complex and that they continue to elude DHH-people. While studies and evaluations continue to point towards gaps between progressive declared policies and people's reports about their experiences, i.e., perceived policies, this study illuminates tensions and the everyday nature of participation and accessibility by putting the spotlight on people's everyday lives across different societal arenas, i.e. on practiced policies. Such a focus highlights processes that underpin social life. These processes shape participation and accessibility.

Our theoretical alignments highlight that people's experiences and previous knowledge are contingent upon their possibilities to interact in different contexts. Such interactions are acutely dependent on DHH-people's access to STS-IS, including interpreters' competencies and professionalism. Drawing on Hauser and Hauser (2008) and based on our empirical analysis, we argue that access to designated interpreters across professional work and leisure time activities is crucial, in order that DHH-people become positioned as citizens in society. An unexpected outcome of the analysis from our projects is that professional interpreters are either not ordered or not available. Instead, DHH-people are, despite the presence of digitally available STS-IS, forced to rely on non-professional individuals for accessing societal arenas, i.e. they are dependent on helpers. Their continuing dependence on non-professional support positions them as patients in need of assistance.

DHH-people in our projects have a range of rich experiences and, in conversations with us, express multifaceted valuable reflections on issues of relevance for their participation in society. Such reflections are uncommonly elicited by those in power. A mechanical view of people's communication and participation relegates DHH-people to the position of (passive) patients. They are subordinated and subjected to what people in authority decide and present orally. In sharp contrast, they are tasked with providing information, preparing, and organizing activities where interpreters are needed. This paradoxically accords them the status of active STS-IS customers. DHH-people are required to shoulder major responsibilities to ensure their own participation and become positioned as citizens (cf. Kermit & Holiman 2018).

The contradictory treatment of DHH-people as both patients and citizens may arise from their dual category status of being positioned as members of both a disability group and a linguistic minority (Bagga-Gupta 2004; De Meulder & Murray 2017). Such a dual status constitutes both 'a burden and a gift'. They have rights to a range of societal support because of their hearing loss. For example, Swedish DHH-people have the formal right to interpreters across their life span and are not required to bear the costs for STS-IS (unless they are entrepreneurs). The disability category status positions them as subordinated members in society, i.e. people in need of support. This limits their opportunities to participate as citizens in society on an equal footing with hearing citizens.

Taking a Second Wave of Southern Perspectives, i.e., a SWaSP framing point of departure, this study suggests that there is a crucial need to go beyond a rights perspective as decreed in the UN convention with regards to interpretation issues. This theoretical framing calls for focusing on the playing out of participation and accessibility in social practices, rather than in terms of ideologically framed support for homogenized, essentialized categories of people positioned as disabled. DHH-peoples' access to different contexts and their participation as citizens—as the rich and everyday nature of our analysis illustrates—cannot build on the 'assumption that "access" for deaf people is tantamount to the availability of sign language interpreters' (De Meulder & Hualand 2019:2–3). Instead, there exists a need to make sign language interpretation services (SLIS) and other language-concordant services relevant. We argue that it is important to see STS-IS for 'what it actually is: a social institution—with funding, research, power, and legal mandates—which interacts on a systemic level with other social institutions like education and health care services. [This] provision ... has become the institutionally normative, often unquestioned, solution to grant deaf people access to education and public services' (ibid.:13). DHH-people's accessibility also needs to be framed by including professionals and educators who are hearing signers; DHH-people can directly communicate with these members of the 'deaf-hearing world' without having to depend upon being interpreted through 'an other'.

The present study importantly highlights the multifaceted and complex nature of interpretation and DHH-people's participation in society and reveals implicit and explicit language shaming ideologies (Piller 2017). It illustrates that

both STS and DHH-people are positioned as subordinated and connected to issues of disability. DHH-people's lives are framed through passive participation and access in 'mainstream' activities rather than in terms of full-fledged members of a contemporary democratic society where everyone is tasked to be active.

Competing Interests

The authors have no competing interests to declare.

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