

# Discapacidad, tecnología y política: la intrincada experiencia de ser duro de oído

## Disability, Technology and Politics: The entangled experience of being hard of hearing

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### Resumen

Cerca del 10% de la población tiene pérdidas auditivas. Combinando recursos analíticos de dos campos interdisciplinarios – Science and Technology Studies y Disability Studies- esta tesis investiga la compleja interacción entre personas, tecnologías y medios materiales. El objetivo es analizar cómo las discapacidades auditivas son ordenadas en el diseño de políticas, en la práctica audiológica y la vida cotidiana. La discapacidad ha sido tradicionalmente tratada como un defecto físico, un problema que puede ser compensado con el uso de tecnologías de asistencia o con medicina. En las últimas décadas, pero, las políticas acerca de la discapacidad han experimentado un giro discursivo. Hoy en día, la discapacidad es conceptualizada como una parte natural más de la diversidad social. Así, en lugar de normalizar al individuo discapacitado, es la sociedad la que debe posibilitar la plena inclusión y participación de las personas con discapacidad en la vida social. Ahora bien, ¿cómo poner en práctica esta visión de la sociedad universal? ¿Cómo traducir los derechos sociales en un mayor empoderamiento para la consulta médica, o en posibilitar ayudas técnicas, incluyendo medios materiales, o contribuir a relaciones más respetuosas entre la gente que vive y trabaja con discapacidad auditiva? Siguiendo de cerca la puesta en práctica de políticas, o el paso del diseño al uso de ayudas auditivas, u observando las vicisitudes de las personas con sordera en su paso desde la clínica audiológica a su casa, esta tesis investiga la transición de la política de discapacidad a la práctica. El resultado es un estudio comparativo y cualitativo de las pérdidas de audición en Noruega y Holanda.

Palabras clave: Discapacidad auditiva; Tecnología; Justicia social; Semiótica material

### Abstract

*About 10 % of a population have a hearing loss. Combining analytical resources from two interdisciplinary field – Science and Technology Studies and Disability Studies - this thesis investigates the complex interplay between people, technologies and material surroundings. The aim is to learn about how hearing disability becomes ordered in policy making, audiological practice, and everyday life. Disability has traditionally been treated as a physical defect, a problem that can be compensated for utilizing medicine and assistive technologies. Over the last decades, disability policy has undergone a discursive shift. Today, disability is conceptualized as a natural part of societal diversity. Thus, rather than normalizing the disabled individual, society should enable the full inclusion and participation of disabled people in societal life. But how to realize the vision of the universal society? How to translate social rights into empowering medical consultation, enabling technical aids, including material surroundings, and respectful social relations among the people that live and work with hearing disability? Following policy to practice; hearing aids from design to use, and hard of hearing people from the audiological clinic and home, this investigates the transition from disability policy to practice. The result is a comparative, qualitative study of hearing loss in Norway and the Netherlands.*

Keywords: Hearing Disability; Technology; Social Justice; Material semiotics

Following the 2006 UN draft Convention on the Rights of Persons with Disabilities, disability has undergone a radical conceptual shift in international policy making. Disability is no longer a purely biomedical condition. Instead, it is a matter of cultural difference and social justice. It is no longer the disabled individual that needs compensation to integrate into normal society. Instead disabled individuals should be included as normal members of the multicultural society. But how does one go from here to secure social justice for disabled people? What is disability anyway, who are disabled people, and what expectations do they have for societal inclusion and participation?

Focusing on the largest and, arguably, least visible disability group, *hard of hearing*, in this thesis I investigate the processes of putting policy into practice. Working with empirical material from the Netherlands and Norway I explore how visions for the inclusive society are sought realized in practice. I study how the new policy objectives manage to translate into empowering audiological encounters, enabling technical aids, inclusive material surroundings and respectful social interactions in everyday life.

Mobilizing the notion of entanglement as a framing metaphor, the ambition guiding the study has been to move beyond, but not ignore, the split between a medical versus sociocultural models of disability. In this thesis, hearing disability is not either a biomedical condition or a sociopolitical issue; it is both – and more. I approach hearing disability as a complex phenomenon in which elements of academic reflections, policy making, professional practices and everyday life entangle to give rise to the diversity of experiences of hearing disability. Detailing these relations, I investigate the enactment and ordering of hearing disability in practice. I study how material and discursive elements are combined to make up the conditions of possibility for hearing (dis-)ability, subjectivity and agency. What this means is that this thesis is not about *the* lived experiences of hearing disability, rather it is adding to the knowledge and reflection about relations between people, things and material surroundings that produce a diversity of such experiences. Based on these descriptions, I discuss expectations for, and experiences with social justice among hard of hearing people.

The research project is positioned in and between two interdisciplinary research traditions; Disability Studies and Science and Technology Studies (STS). With Disability Studies, hearing loss is de-naturalized and politicized and, as a culturally complex and socially situated phenomenon, made operable for social science analysis. With analytical tools from STS, Actor Network Theory in particular, I explore the material enactment and ordering of hearing loss in practice.

In line with the material semiotic tradition that has inspired this project, I have not attempted to map and tell *one* large and coherent story about hard of hearing. Instead the thesis consists of several, different stories from various societal domains. The methodological approach has been explorative and multi-sited. Empirical material was generated through literature review, qualitative interviews and participatory observations. Throughout I have established three loci for the study; 'disability policy', 'audiological practices', and 'lived experiences'. Juxtaposing the material from these partly connected sites and situations I enact hearing disability as an entanglement of disability, technology and politics. I follow policy to practice, technology from design to use, and hard of hearing from the clinic and home. Throughout, I move in and between the ideals and objectives formulated in policy discourse and the handling of hearing loss in practice. I explore the conditions of possibilities for hard of hearing subjectivity and distribution of agency throughout processes of putting disability policy into practice. The political ambition has been to locate research in the mundane practices of everyday life to help make visible an invisible disability, and to politicize practices and relationship often screened into a so-called private realm.

The empirical findings are structured in three thematic parts. In *Disability Policy*, I consider how disability is constituted in the context of European political debates on economic globalization, political liberalism and individualization of care. Then I introduce two country specific analyses in which I discuss ideological shifts and drivers in the disability field. I analyze disability policy as discourses; a space for the enactment and ordering of hearing disability that works to frame the 'problem' of disability and what is considered legitimate and effective 'responses' in the context of Dutch and Norwegian aural rehabilitation policy. The analysis focus on the discourse on solidarity underlying the welfare systems, the conceptualization of disability, the disabled subject emerging in political debates, and the outlined geography of responsibility between individuals, technology and society.

In *Audiological Practices*, I study the design and distribution of hearing technology in professional settings. Hearing aids are the most common intervention in aural rehabilitation programs and, thus, play an integral part of many hard of hearing people's lives. Comparing two different approaches to design and distribution of hearing technologies I reject technological determinism by showing how technology can become an active element of the order-building surrounding hearing disability. Moving from design to distribution of hearing aids, I study what happens when people enters into rehabilitation programs and submit their hearing to professional tests, assessments, and treatment with hearing aids. Working with empirical material from participatory observations in audiological clinics, centres and dispensers, my concern is with the relation between objectification and agency throughout the process of extracting, multiplying, reworking and replacing elements of hearing fundamental to the professional attempts to reconstruct of hearing.

In *The lived Experience of Being Hard of Hearing*, I work with empirical material from a user study in which I have asked how hearing loss is sought ordered in the context of people's broader identity projects. With five individual case studies I explore what hearing disability is made to be through the optics of those living with a hearing loss. I focus on three key issues in today's political debate on disability; *empowerment* in audiological practice; *activation* through hard of hearing careers; and *the equality-difference dilemma* inherent to international policy making on disability. Throughout, I go in-depth on five hard of hearing people's stories. I conclude the thesis by using these individual experiences and viewpoints to reflect on the politics of disability in the light of a broader debate on social justice.

## Formato de citación

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