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### Deafness among the Negev Bedouin: an interdisciplinary dialogue on deafness, marginality and context

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## Summary

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The articles assembled in this doctoral dissertation address diverse aspects of deafness among the Negev Bedouin, the native Arab inhabitants of the southern arid region of present-day Israel. Of special interest are several Bedouin communities where the use of Al-Sayyid Bedouin Sign Language (ABSL) provides the foundation of a signing community shared by both hearing and deaf people. Diverse research questions arise from the Negev Bedouin experience with deafness and with the various state interventions. State interventions related to deafness are set in the context of general neglect and discrimination of the Negev Bedouin, analysing these interventions, as well as other encounters between predominantly Jewish-Israelis and Negev Bedouin, offer the opportunity to examine the complex relations between a disadvantaged minority and the dominant society, its institutions and ideologies.

The articles are all based on intermitted ethnographic fieldwork, carried out mostly among the Negev Bedouin over a period of more than 16 years. Although my fieldwork was not restricted to the Al-Sayyid Bedouin, the village of Al-Sayyid and the same host family remained my residential base for over 32 months of in-residence fieldwork throughout these years. Within Negev-Bedouin society, the consequences of deafness vary considerably between different Bedouin groups as well as along gender lines. The majority of deaf people among the Negev Bedouin are – like the majority of deaf people worldwide – born into families with no previous experience of deafness or signed communication. Within several Bedouin groups, however, exceptionally high rates of deafness occur; as compared with the expected rate of 0.17 per cent of congenital deafness in the general population, the Al-Sayyid Bedouin with an incidence of 2.5-3% constitute one of the highest worldwide incidences of congenital deafness documented so far. Among the Qderat Bedouin too, are comparable high rates of deafness found over several

generations. These high incidences and the consequent emergence of a local sign language account for significant differences in the experience of deafness by both deaf and hearing. Most significantly, both deaf and hearing people are exposed to visual language from a early age.

Over the last decade comparable signing communities and their sign-languages have drawn the attention of scholars from various disciplines, most notably in genetics, disability studies, Deaf studies and sign language linguistics. Each article assembled here represents a dialogue with these different fields of knowledge production. While the articles attempt to make an anthropological contribution to these fields of enquiry, this dissertation also reflects critically on the concepts employed by these debates by engaging with their underlying assumptions.

Hence, various interrelated lines of inquiry inform this research project. I started with a set of rather simple questions concerning the social practices that constitute the distinctive sociolinguistic reality among the Al-Sayyid Bedouin. These questions led to several conclusions relevant to the study of deafness and sign-languages. Foremost, it led me to develop the notion of a *shared signing community*, emphasizing the unique sociolinguistic circumstances where sign languages are developed and used by deaf and hearing alike, a fact often downplayed by both linguists and Deaf studies scholars. The term is now also used by several other researchers to denote comparable cases found elsewhere over the globe. The term has been instructive in shifting the attention to the role of both deaf and hearing signers and the impact of cross-modal (signed-spoken) language contacts. Though not all hearing Al-Sayyid master the local sign language, potential translators are readily available; in fact, skilled hearing signers among the Al-Sayyid outnumber deaf signers.

However, I have shown that not only fluent signers are significant in constituting this sociolinguistic reality. Also those less proficient in communicating in the local sign language, share knowledge grounded in daily experiences and practices related to deafness and signing. Significantly this means that also non-signers appreciate sign language as a proper language and, often demonstrate awareness of the pragmatics of signed communication. Given the still common devaluation of sign language in the hearing world, and given that even within scholarly linguistics it was not until the late 1960s that sign languages were finally recognized as genuine

languages, the widespread nature of such experiential knowledge cannot be underestimated.

My analysis of local communication practices among the Al-Sayyid reveals the importance of practices of translation and mediation. Most deaf and hearing Al-Sayyid are embedded in several diverse language communities such that a multiplex of languages, language modes and domains involve different forms of translation, including signed, spoken and written language modes in Hebrew, Arabic and more than one sign language (ABSL as well as ISL, Israeli Sign Language). Among the Al-Sayyid I show that reliance on translation and mediation is not restricted to deaf people. This enables me to conclude that so long as deaf people are located in positions that allow them also to provide translation, their reliance on translation of spoken communication need not result in disablement or cause social isolation.

At the same time, however, my work also shows that while the social space shared by deaf and hearing is generally accommodating for deaf people, it also reveals to how social structures and practices in shared signing communities should be examined for how they may both facilitate and restrict deaf people.

Finally, shared signing communities do not exclude the possibility of deaf sociality. Triggered by different factors, shared signing communities demonstrate different forms of deaf sociality. Whereas the use of Israeli Sign Language and a preference for deaf-deaf marriages are increasingly associated with deaf sociality, my data suggests that based on the comparison between deaf Bedouin from different communities, young deaf Bedouin from shared signing communities rearticulate such notions in different ways than those Bedouin growing up in families where deafness has newly occurred. Moreover, deaf Bedouin men and women are differently exposed and engaged with such notions.

Another line of inquiry that informs this study of deafness among the Negev Bedouin concerns the impact of interventions targeting deafness. The politics of such specialized state interventions are often overlooked; for they are concealed in state priorities that engender certain interventions rather than others, and by the lay perception that interventions are solely based on the judgment of experts. The Negev Bedouin constitute one of Israel's most marginalized minority groups; many still reside in settlements formally unrecognized by the state, lacking basic infrastructure, including running

water or electricity. Nonetheless, various state services and intervention programs target deafness.

Encounters with the medical establishment (specifically, via the introduction of genetic counselling, audiometry and Cochlear Implants) and educational establishment present a series of challenges. My data shows that Bedouin from shared-signing communities respond differently to such interventions; though deafness here is not easily subjugated to its medical model, local experiential knowledge and practices are challenged by the authoritative knowledge claimed by pedagogical and medical discourses and professionals. The medical establishment presumes that deafness requires fixing or preventing. Accordingly the high rate of deafness necessitates intervention into one of the most sensitive social arenas: marriage arrangement. My analysis suggests that, rather than reflecting ignorance of the genetic explanation, local accounts of deafness among the Al-Sayyid are mainly offered in response to the genetic counselling project and attempt to negotiate local concerns with its implications. Although deafness is generally perceived as manageable, finding suitable marriage partners (for deaf or for hearing individuals) is a growing source of concern. The genetic explanation is partly employed when convenient, but in seeking a marriage partner, people consider many factors over the avoidance of one specific “genetic risk”.

Interventions targeting deafness have diverse unintended consequences: not only do they introduce stigmatizing narratives, they also create differential life trajectories, reducing the social space shared by deaf and hearing. For instance, unequal access to education for deaf versus hearing—and for deaf men versus women—create gaps in literacy, thereby restricting deaf people’s relative structure of opportunities and amplifying gender disparities.

Gender disparities among the Negev Bedouin are often simply ascribed to so-called traditional gender relations. But my analysis reveals the role of state agencies in reinforcing such disparities when opportunities are not equally available to men and women. The introduction of genetic testing for deafness has also had a gendered impact. Given local marriage practices, and despite efforts to avoid carrier labelling, genetic testing is more likely to hamper women’s marriage prospects than those of men.

Still, I argue against an approach that would reduce the condition of deaf Bedouin women to a triple marginality of cumulative oppression: deaf, Bedouin, and female. To do justice to the lived experience of Bedouin women,

their positions and structural constraints are examined from within the context of their own experience and the desires that inform their subjectivities and strategies. My work demonstrates how both deaf and hearing Bedouin women employ their local resources to manoeuvre within their albeit limited structures of opportunities.

I further explore Bedouin women's experience of childbirth in an Israeli hospital and their brief -but significant- encounters with other Bedouin and with Jewish Israeli women. While hospital ethnographies often focus on patient-staff encounters, public hospitals in particular, often impose intimate proximity on strangers whose social worlds do not ordinarily intersect. Such "lay encounters" are loaded with social tensions, as well as social potentials for negotiating these tensions. I suggest these encounter are significant for what they betray of the larger social context in which they are embedded.

The third line of inquiry that informed my investigation was provoked by recurrent references to shared signing communities as isolated. The quest to study the conditions that engender language have made the study of relatively young shared sign languages a cutting edge theme in modern linguistics and cognitive sciences. Al-Sayyid Bedouin Sign Language (ABSL) is currently one of the most celebrated cases of a so-called emerging (sign) language isolate. Since 2005, more than a dozen linguistic articles have been published on ABSL: *all* portray the Al-Sayyid as remote, isolated, and insular.

Though there is little doubt that ABSL is indeed a language-isolate in the strict sense of the word (a language with no demonstrable ancestral language), it certainly did not emerge in the absence of any linguistic models or external influences. All hearing signers, bilingual in the local sign language and the local spoken dialect of Arabic, have spoken language as a readily-available language model. As schooling has introduced most deaf signers to a second (sign) language as well as to some literacy in Arabic or Hebrew, Deaf Al-Sayyid are also increasingly bilingual.

I thus argue that the slippage from "language isolate" to "isolated community" conveniently corresponds to scientists' longing for a natural laboratory. I respond to this tendency to depict the Al-Sayyid as isolated by analysing of social networks, revealing the dynamic nature of this sociolinguistic landscape and underscoring the significant difference between isolation and marginalization. Isolated neither linguistically nor socially, many among the Al-Sayyid are, however, marginalized. The case of the Negev

Bedouin illustrates that marginality can imply quite the opposite from isolation. Whereas isolation suggests autonomy, marginalization involves asymmetry within multiple power relations and dependencies. The socially, economically and politically marginal position of the Negev Bedouin, in general, makes them more dependent on-rather than autonomous from-the surrounding social and political structures.