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

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## Chapter 3:

### **Negotiating (Genetic) Deafness in a Bedouin Community<sup>1</sup>**

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In the winter of 1995, I became acquainted with the inhabitants of a Bedouin settlement in the Negev Desert of Israel. The inhabitants are all of common descent, and are named after their common ancestor, Al-Sayyid<sup>2</sup>. This group, now in its seventh generation, numbers about 3,000 people, nearly 100 of whom are deaf<sup>3</sup>. The use of an indigenous sign language is widespread among the Al-Sayyid, and it provides the foundation of what I call a shared or integrated signing community<sup>4</sup>, shared by hearing and deaf people alike. Since my initial visit, I have spent three intensive anthropological fieldwork stints, a few months each, living with one of the families and engaging in participant observation. The first and longest stint was five months during the spring and summer of 1996.

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<sup>1</sup> A slightly modified version of this chapter was published in Van Cleve, John Vickrey (ed). 2004. *Genetics, Disability, and Deafness*. Washington DC: Gallaudet University press. pp 195-227.

<sup>2</sup> In the original publication of this chapter (Kisch 2004), and my unpublished Master's thesis (Kisch 2000) I used the pseudonym Abu-Shara. However, Sandler et al. (2005) have revealed the actual name Al-Sayyid, while they among others refer to my work; consequently, I have ceased to use this pseudonym. However, I maintained the pseudonyms used for all individuals. To further conceal individuals' identities, some personal details were slightly altered.

<sup>3</sup> These figures were based on the data I had available in 2002.

<sup>4</sup> In the original article (Kisch 2004) I have used the term "integrated signing community", however in later publications I have modified it to be "shared signing community" to underscore the defining sociolinguistic practice of signing shared by deaf and hearing.

Though deafness is common among the Al-Sayyid, pursuit of cure or prevention of deafness is rare. The first time I heard of any such prescription was from Hakima, a woman in her fifties. Most of her children have already married, and yet caring for some of her young grandchildren is part of her daily domestic routine. Hakima's father-in-law was deaf, as are two of her grandchildren. Previous to her marriage more than thirty years ago, however, Hakima could already communicate quite fluently in the local sign language, as her mother's younger cowife was a deaf woman.

Hakima, lately complaining of headaches, asked me to accompany her to one of the elderly local healers. While on our way, Hakima told me that one of her daughters-in-law had been instructed by a healer in the further north Palestinian town of Dahariya not to breastfeed her newborn child. He suggested that otherwise the child might be deaf like some of his nephews. Hakima then complained that today's young women are so eager to waste money on milk substitutes that they find the strangest excuses.

Before we left the local healer's house, I asked the healer if she was ever asked for intervention regarding deafness. She looked at me with amazement. I turned to Hakima and answered the healer with a supposed example: Has she ever been visited by pregnant women who sought a solution for deafness? She answered in a derisive tone, as though she was being bothered with trivialities,

I treat problems [as she spoke, she stiffened her face to demonstrate suffering]<sup>5</sup> . . . deafness [her face brightened up] is from God.

Another man from the Al-Sayyid, who also makes amulets, said, in response to a similar question: "God creates a deaf person, gives him a good job, grants him with good looks, a good brain, there are hearing people who don't have any of this." In both cases, a contemptuous tone accompanied their words, and later on, both went on to proudly demonstrate that they only treat cases of real suffering.<sup>6</sup>

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<sup>5</sup> Square brackets ([ ]) indicate either descriptive elaborations of the interaction or my own comments and questions.

<sup>6</sup> Seemingly, it can be argued that the scornful tone of the local healers does not stem from the fact that deafness is not defined as a sickness or as a problem, but from their experience of the situation as unsolvable, and their avoidance of failure. However, nineteenth-century European history saw several stubborn attempts to cure deafness,

Hakima, like many other deaf and hearing members of this community, regularly encounters different attitudes, discourses, and practices in which the endeavours to heal, fix, and avoid the birthing of deaf individuals is assumed to be fundamental and crucial. The medicalization of deafness is being introduced into this community through two main factors: a genetic intervention program that is attempting to reduce the occurrence of deafness and special education programs for deaf children that promote audiometry and hearing aids. Medical discourse is translated and partially reproduced in local discourses but not fully embraced.

The exposure to medical discourse occurs in various settings, and genetics in particular has acquired a powerful grip on popular imagination (Nelkin and Lindee 1995). Medical and scientific discourse is commonly employed in the promotion of health and cosmetic commodities. Medical discourse is also introduced through high school education, as in lay encounters with various members of the dominant Jewish society. In such lay or semiprofessional encounters, modernization theory and the utilization of modern state services such as health services are often introduced. When it comes to deafness, however, for most members of the community, medical discourse is most prominently conveyed through the actual genetic research conducted and the subsequent attempts to introduce an intervention program.

Several years ago, a genetic research team from the nearby district university hospital<sup>7</sup> identified recessive, nonsyndromic, autosomal deafness among the Al-Sayyid (Scott et. al. 1995). The study used rapid screening tools to determine carrier status for this specific mutation (Scott et. al. 1998). About 100 members of the Al-Sayyid participated in this research, providing genealogies and blood samples. This was followed by attempts to inform and induce more members to provide blood samples and develop a genetic database and consultation project to enable the disclosing of genetic compatibility to potential marriage partners without having to initiate a

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among them surgical. Although none proved to be effective, their practice persisted for several decades (Branson and Miller 2002; Volkov 1998).

<sup>7</sup> The Soroka medical center, Ben Gurion university.

special mutual test, and without disclosing individual carrier status.<sup>8</sup> However, compliance was limited.

I did not follow any actual counseling sessions during my fieldwork for this study, but I did witness people's decision-making process in daily life and the way in which they acted and referred to medical discourse and medical reasoning. In light of the growing exposure to medical discourse, it seems that a complex negotiation process is being held as to the plausibility of the genetic explanation of deafness and its resulting implications. Direct or spontaneous discussion of the findings of the genetic study and its ramifications is infrequent and tends to be indirect and implied. Detection of a child's deafness or the presence of a deaf person do not provoke discussions about the origin of deafness. Deafness, to a large extent, is not perceived as something that calls for explanation. Thus, dealing with the question of deafness and its origins predominantly followed referrals to the medical discourse, or simply to the attribution of deafness to consanguineous marriage.

Before turning to these local accounts, I will provide some necessary context with two brief introductions. First, I will introduce the Bedouins residing in the Negev, the southern arid region of Israel. Second, I will concisely portray the nature of this shared signing community. Following this general introduction, I will turn to the primary concern of this paper: the local accounts of deafness and what I consider to be their significant subtexts.

## SOCIOPOLITICAL SETTING

The native Arab inhabitants of the Negev are former nomads, commonly referred to as Bedouins. Since the establishment of the state of Israel, they have undergone drastic economic, social, and political upheavals that have resulted in deep destruction of the social organization. The Israeli government made a concerted effort to settle the Bedouins in a way that would minimize the use of land resources through the establishment of urban settlements. At present, seven such townships exist, gathering nearly half of the Bedouin population living in the Negev, which is estimated to be more than 120,000 people. The remaining Bedouin population is deprived of basic infrastructures

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<sup>8</sup>An individual carrier detection program could more easily stigmatise women for "genetic incompatibility" and severely hamper their marriage prospects.

(roads, water, electricity, sewage), as they inhabit settlements formally unrecognised by the state. The community discussed in this paper resides in such a settlement.

The Bedouins constitute 25 percent of the population of the Negev subdistrict and live separately from its Jewish population. However, the lack of economic activities in both the unrecognised villages and the townships as well as the scarce qualified manpower render the population dependent economically on the Jewish sector and very sensitive to economic recessions. Most men, but only a few women, are enrolled in the Israeli labor market; unemployment rates are among the highest of the country. Within contemporary Bedouin society, there are considerable variations in education, lifestyle, and women's status. Among the Al-Sayyid, illiteracy rates are still high among women, as well as among elder men. Among the younger men, though, several have in recent years attained an academic professional education and studied law, pharmacology, or medicine abroad. Sixty percent of the Bedouin population is under the age of sixteen, fertility rates are among the highest in the country, and consanguinity and polygamy are common. All Bedouins, as citizens of Israel, obtain a national health insurance and fall under the compulsory schooling law.

Access obstacles, state priorities, and language barriers limit actual exercise and use of these rights and services, however. The government implements policy that is perceived to meet state interests (such as security, population control, and controlling welfare expenses), but other affairs suffer neglect. A case in point is the state's interest in reducing the rate of children who are born deaf, or for that matter, of children that require special services. State authorities have invested considerable funds in a scheme to reduce congenital diseases among the Bedouin population, and part of the genetic intervention program mentioned here is financed by such funds. At the same time, little if anything is done to improve the poor living conditions among the Bedouins.<sup>9</sup> Supreme court intervention has been required to force the state to provide some basic rights and services, such as instructing state authorities to

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<sup>9</sup> With regard to the unrecognized settlement, one could even claim the contrary—some of these conditions are manipulated to advance the implementation of state policy to reduce land use and negotiate land claims (Abu Saad 1997).

establish health clinics in Bedouin villages and to connect schools there to the water system.<sup>10</sup>

## SHARED SIGNING COMMUNITY

In this paper, I refer to the Al-Sayyid as a “shared signing community,” but I recognize that community is a problematic and frequently criticized term. Here I am using it only in the restricted sense of a linguistic speech community.<sup>11</sup> The widespread use of the indigenous Al-Sayyid Bedouin Sign Language<sup>12</sup>, shared by hearing and deaf people alike, is the foundation of this shared signing community. The anthropological and sociolinguistics literature contains evidence for few other such shared signing communities (Branson et al. 1996; Johnson 1991; Groce 1985). The best-known research is Groce’s study of the Martha’s Vineyard community. I use the term here to distinguish the Al-Sayyid from other signing communities that consist mainly of Deaf people.

Harlan Lane et al. (2000) have argued, in their historical comparison of Deaf communities in New England in the early-nineteenth century, that beyond the prevalence of deafness, different genetic patterning contributes to the spread of sign language into the hearing environment. Given the recessive pattern among the Al-Sayyid, deafness is indeed widely distributed among

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<sup>10</sup> A series of petitions have led the Supreme Court to reaffirm that the establishment of health clinics in Bedouin settlements is an essential service that the government must provide. HCJ 4540/00 (Israeli High Court of Justice 2000, verdict # 4540). In 1998, the Supreme Court’s intervention was needed to instruct the ministry of education to connect all Bedouin schools in unrecognized settlements to the water system at once. The ministry argued in its defence that the settlements are temporary and are to be replaced by permanent ones. The school at the unrecognized settlement discussed here has been operating for more than thirty years.

<sup>11</sup> A speech community is defined by Hymes as “A community sharing knowledge of rules for the conduct and interpretation of speech. Such sharing comprises knowledge of at least one form of speech, and knowledge also of its patterns of use” (Hymes 1974:51). Hymes’s definition is tinted by the referral to spoken language to indicate the actual use of language in interaction. The term does, however, apply to signed language as well.

<sup>12</sup> Labeled Abu-Shara Sign Language (ASSL) in the original Article, in accordance with the pseudonym (see .fn. 2) .

families in the kin group.<sup>13</sup> Social realities are not determined by genetic patterns. However, genetic patterning may contribute to the blending of deaf and hearing people. Among the Al-Sayyid, most hearing people are familiar with deaf individuals; many have a first- or second-degree deaf relative. All hearing people are exposed to the viability of fluent communication in sign language and to assimilated, well-integrated deaf figures in the community. Most hearing Al-Sayyid are familiar with the local sign language, though with varying degrees of fluency. This implies not only ease of communication within the community, but a perception of deafness as merely a condition calling for use of signed language rather than spoken communication.

I wish to underscore the distinctiveness of this social reality: deafness does not produce social marginality or isolation, nor does it serve as a postulate for social alignment as a distinct social group. There is no distinct Deaf community in spite of abundant deaf people and the existence of a local sign language. All married deaf people have hearing spouses. No social events roles or activities are reserved for deaf people due to their deafness, except within the education system, which has brought about separation between deaf and hearing.

I have argued elsewhere (Kisch 2000; Kisch 2008a) that deaf members' status, like that of hearing members', should be seen in light of a given dialectical communication web. This web is comprised of multiple languages (Hebrew, Arabic, Al-Sayyid Bedouin Sign Language, Israeli Sign Language); language modes (signed, spoken, written); and language domains representing discourses not shared by all (gendered discourse, medical discourse, religious discourse, and others). Many of these need to be translated and mediated to various members of the community. Members of the community are located at diverse overlaps of these communication domains and are therefore in a position to translate or mediate for different people in different situations; yet in other situations, they would rely on other's mediation and translation. Thus I have argued that the reliance on

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<sup>13</sup> Only four deaf parents among the Al-Sayyid have deaf children; all but one have hearing partners and both deaf and hearing children. Two of these deaf parents create a generational depth of three successive generations of deafness; a deaf grandfather has deaf and hearing children, and one of his deaf sons has deaf children as well. In *Desa Kolok*, such generational continuity is more common (Branson et al. 1996).

translation and mediation is common practice and not restricted to deaf people.

This background is crucial to understanding the context in which the subsequent local accounts of deafness take place. The communication web is permeable and dynamic, enabling the infiltration of stigmatizing narratives that may marginalize and exacerbate the position of deaf people. These processes most evidently occur through encounters with the medical and education establishment. Interactions with the medical and educational establishment can be depicted by what Talal Asad (1986) called “the inequalities of languages,” referring to the permeability of respective languages in relation to the dominant forms of discourse. While Asad uses this concept to address the constraint of “cultural translation” and ethnographic work, I find the concept useful in a broader context. It is relevant for the encounter between a linguistic minority and the dominant establishment, as well as to the authority of medical discourse versus local lay discourse.

## TRANSLATING MEDICAL DISCOURSE

Medical discourse is anchored in scientific discourse. Scientific discourse presumes to constitute a representation of the scientific object, that is, laboratory facts without mediation or human agents (Latour 1993). Local discourse, however, refers to medical discourse as a supplier of one explanation among many, and thus emphasizes the involvement of mediation, often explicitly referring to the “explanation of the doctors.”<sup>14</sup> This implies that one could question the exclusiveness of the explanation, negotiate it, and examine it according to its agents, prescriptions, and implications.

It seems that even a speaker who refers to the medical explanation as a definite, all-embracing explanation does not necessarily grant it precedence. Hence, it is not the “knowledge” of the medical explanation but its positioning in the local discourse that raises important questions concerning social preferences. Every account presents different paradoxes among various social considerations. The paradoxes and the attempts to settle them are the background for offering the local accounts. The examples in the following

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<sup>14</sup>I therefore use the terms medical discourse and medical explanation alternately throughout this essay.

section provide the background for the local accounts that follow and release them from the narrow question of knowledge and ignorance.

### **“The Doctors Say”**

Exposure to medical discourse occurs in diverse settings. For most members of the community, however, medical discourse related to deafness was most prominently conveyed through the actual genetic research conducted in the community and subsequent attempts to introduce an intervention program. Most members of the community are aware of the existence of the genetic claims, even though compliance to the genetic intervention program was low, and even though they might not fully comprehend the concept of recessive hereditary traits or statistical probabilities. It became common knowledge that the medical view denounced consanguineous marriages, but it was not always clear who was regarded as a “relative” by the medical view. The following cases demonstrate the clear presence of the medical explanation in the local discourse and how members of the community selectively refer to the medical discourse.

The following account was given by Abu Saalem, a man in his late fifties, who married two women, both his cousins. All of his children are hearing; one of his many grandchildren is deaf.

Today one hears from the doctors that if you marry from outside the family, you will not deliver mute [deaf children] . . . I don't think that this has anything to do with family or blood. . . . A matter of retardation, that I do believe, I think it's from the blood. Today they [the doctors] can check if one is suitable for the other or not; it's a new thing! If it is the same blood, a retarded child will come. I can believe that. But mute [deaf]—this isn't connected to this thing, I'm sure . . . I don't believe this thing.

Abu Saalem is clearly familiar with the genetic claims; he is even familiar with the genetic testing. Yet with regard to deafness, he chose to phrase the doctors' position simply as a recommendation to refrain from consanguineous marriage. In other words, his initial account reduces what the doctors state to terms of marrying within or outside the family.

Most local references to the medical explanation treat it as an explanation that ultimately denounces consanguineous marriages. This is so in spite of the fact that, ironically, the applied model, as proposed, was intended to

emphasize that the Al-Sayyid could marry each other while still minimizing the chances of bearing deaf children. Testing couples for genetic compatibility would accomplish this.

The medical explanation is present in the community, but it has traveled a long way from the laboratory and the medical discourse that serves it, through the language of genetic counseling, to the way it is used in the local discourse. In a study that focused on nonexperts' definitions and perceptions of the risk values presented by the genetic counselors and the medical team, it was argued that a lot of the information regarding the risk is lost in translation. Thus, likelihood was translated into absolute theoretical categories, and risk was converted to prohibitions and clear prescriptions (Parsons and Atkinson 1992).

Among the Al-Sayyid, the same individual may translate the medical discourse in different ways, depending on context. I find Rapp's (1988, 1999) notion of negotiating most appropriate to understanding these seeming inconsistencies.<sup>15</sup> Rapp contends that genetic counselors themselves deal with the translation of medical discourse into popular and more usable language. In this process, many concepts are under negotiation, albeit not formally. Not only is medical knowledge constructed, but power relations and popular social knowledge are also established.

While some reproduce the medical discourse selectively, others reproduce it quite extensively but restrict it to certain situations while rendering it irrelevant to others. One example of such a rendering was provided by Ikhsen. I met Ikhsen in the shack that served as the local medical clinic. He noticed me talking to a deaf woman, and after he inquired about me with one of his sisters-in-law, who was also present, he turned to me. Because he insisted on staying in the shack, most of the women went outside to wait. His sister-in-law stayed inside.

Ikhsen: We have all become deaf at Al-Sayyid, there are a lot of deaf people. Every family you will encounter has two or three, and there are also a lot of heart diseases in every family. We have a long list of diseases! . . . Deafness is not a disease; it's from marriage. . . . If our sons go and

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<sup>15</sup> See also Jansen (2000) discussion on the manner by which certain cultural idioms related to procreation can be employed to negotiate gender relations and other aspects of the changing social relations.

marry outside, far away, it will be much better. [I asked Ikhsen: And what about the daughters?]

Our daughters? The elderly will marry them.

He smiled when he said this. I looked at his sister-in-law, who sat beside me. She sighed and raised her hands. He had said the last sentences in Hebrew, and she did not understand them.

Then Ikhsen continued: They want . . . do you think it is better for a woman to go and get married far away?! She doesn't know who these foreign in-laws might be. It is better for the women to marry nearby! [But didn't you say that deafness is from marrying relatives? I ask] Yes, this is a problem. But it's still better to marry here.

Marriage outside the family has long been accepted for men and could even be a source of prestige for them, but for women, the contrary is true. They are expected to marry inside the family. Men often adopt prescriptions to refrain from consanguinity themselves, and at the same time, adhere to consanguinity as far as their daughters and sisters are concerned. Men regularly use medical discourse in reproducing patriarchal principles, according to which the introduction of brides from other social groups is desired.<sup>16</sup> However, handing over daughters as brides to foreigners can be undesirable. When nonreciprocal social relations are involved, the receiving of brides—from a group that one would not marry his daughters to—can be understood as an act of domination. The hypergamous principle sustains an endogamous gap between men and women. Thus, elite groups have high rates of endogamy among women, although men take brides from other groups (Kressel 1992).

When referring to the past, people often suggest that there was a lack of alternatives to consanguinity, even if its consequences were known. As the following account illustrates, this incongruity is not a new one. Fawaz is a rather affluent man in his late forties with a number of deaf siblings. He has two wives, both of Al-Sayyid. Fawaz told me about his elder father's consultation with doctor Ben-Assa many years ago.<sup>17</sup>

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<sup>16</sup> Such a marriage is not looked down upon and can serve to establish hierarchic relations or alliances between individuals and groups.

<sup>17</sup> Dr. Binyamin Ben-Assa (1917–1976) served between the years 1954 and 1972 as government physician for the medical service for the Bedouin. He made a significant

Abu-Assa, after research, suggested that if they wanted to get rid of all this phenomenon [deafness]—just stop marrying one another, and there will be no more deaf-mutes. At that time, if you say something like that to the elderly—owwa! Abu-Assa examined this thoroughly; this thing comes from the blood not being compatible. He told them! They listened and knew, but they didn't have a choice . . . they were interested, but there was no one to give them [brides].

The argument put forward here, that consanguinity is a last resort, is a common one. It relates to power relations, class, and prestige within the Bedouin society. Higher rates of kin endogamy are common among Bedouin who lack claim to noble origin (Marx 1967).<sup>18</sup> Fawaz hinted at the existence of class differences in the past. Others indicate that they exist today as well. However, it appears that Fawaz was too proud to enhance this image, and therefore, he added, with a smile,

I will tell you the reason exactly; they know that there is a 90 percent chance that their son will be mute [as a result of consanguinity]. The problem—we have pretty girls—it hurts to give them away.

The reproduction and representation of the medical discourse has yet another discursive value, that is, its contribution to one's presentation of self. In a sociopolitical setting strongly dominated by popular policy concepts of "tradition" and "modernity," people are often conscious of the binary division that regards the acknowledgment of scientific authority as a basic condition of being modern. To demonstrate one's familiarity with the medical discourse is therefore a way to associate one's self with modernity. I do not wish to imply that it is therefore a superficial practice; rather, embracing the biomedical discourse and the concept of the modern are among the multiple and often conflicting internalised idioms and positions of this community. I then wish to join Abu-Lughod's reservation from what can be perceived as Goffmanesque "empty acts of impression management" (1986:238).

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contribution to the understanding and treatment of morbidity among the Bedouin population in the Negev.

<sup>18</sup> Kressel (1992). suggests that such rates might be an indication of communal social isolation. However also groups with high rates of kin-endogamy collaborate in various social, political and economic activities across endogamous groups.

## Speculating

The medical establishment's model presupposes that the high rate of deafness necessitates intervention in one of the most sensitive social arenas, marriage arrangement. My research suggests that the local accounts of deafness are offered mainly as a result of concern with the implications of the genetic explanation. Deafness is commonly perceived as manageable, but finding suitable marriage partners (for deaf or for hearing individuals) is a source of growing concern. From this point of view, it is possible to view the local accounts as alternatives to the medical explanation.<sup>19</sup>

Local accounts draw on various existing idioms related to procreation. The attitude towards the origin of deafness is mostly speculative; most people I spoke to raised a variety of possibilities and did not necessarily endorse one particular stance. Offering one explanation usually led to it being challenged by another. As a result, a new version would be offered, and so on. This dialectic situation makes it difficult to present the different accounts for deafness as an organized typology. Hence it would be most constructive to observe how people frame their speculations.

Abu-Musa is in his fifties. He has two related wives and twelve children. Several of his siblings are among the elderly deaf people in the community. He said the following things to me while helping depict Al-Sayyid genealogies.

One of the sons of our ancestor Al-Sayyid [the ancestor of the whole kin group] took a wife from the Shrukh [a different family from another region]. My father married one of her daughters, and from this union came three mute and three speaking. Then it spread. [Through their children? I asked] No, not at all.

I think deafness isn't a disease; it is God's way. It's being said it comes from kin-marriages, but I do not believe." [So what do you think? I ask] "When one plants seeds, one watermelon comes out like this and another like that. [With his hands, he demonstrated a round one and an oval one.

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<sup>19</sup> The academic discourse on "explanations" (and definitely the discourse on "belief") in itself might reflect a series of assumptions, which are related to modern science. Thus, these terms might grant authorization to the medical discourse (Good 1994). Due to the lack of a more suitable term, I have used the term accounts, despite the problems involved in its use.

And this one is not as good as the other? I ask.] It's a very good one; a watermelon did come out, didn't it?

Today the doctors say it is bad to marry in the family. You must mix, they say. I see some who married not at all from their relatives, and they got much worse. If only the child was mute! But this child is retarded. There is much worse than muteness; the mutes manage; they manage very well. But the retarded, there is no question of managing. There is a difference between hearing and not hearing, I say it, but I don't believe it's from the family. You know, personally, I don't believe as the doctors say; [he raises his voice determined] "yes!" I say; maybe it's not certain.

The words of Abu-Musa underscore a few general attributes of the local accounts of deafness. As mentioned earlier, it is significant to observe the presence of the medical claim in local discourse. It is also significant to note that Abu-Musa left room for multi-causality. This in itself challenges the genetic explanation—which is exclusive—and makes it negotiable.

Abu-Musa employed several challenging possibilities; each one of them refers to existing local notions related to procreation. It is possible to highlight these notions, recognize their subtext with regard to the medical discourse, and follow how they give rise to yet another translation or elaboration drawing on medical discourse and yet other local idioms. Abu-Musa started by suggesting that deafness was "brought into" the family by brides from outside the Al-Sayyid family. The subtext suggests a subversion of the medical discourse on inbreeding. While medical discourse denounced consanguinity, Abu-Musa referred to the patriarchal notion that related women, belonging to the same kin group, carry the familiar, acclaimed family traits. In contrast, unknown women carry unknown traits. As I will further clarify, this account entails some negative connotations about deafness and women.

Abu-Musa then suggested that deafness reflected a difference in seeds. This is a common patriarchal metaphor, often referred to as "the seed and the soil" (Delaney 1991; Leach 1969). In sharp contrast to the previous notion of "brides from outside," the idea of "soil" deprives women of any significant contribution in determining the major character of their progeny. Deafness is then a patrilineal trait (represented in the seed). The idea links this natural metaphor from agricultural reproduction to God's way, which does not require explanation or intervention, but acceptance. This led Abu-Musa to express his doubts as to the extent to which deafness is a problem at all.

Despite the occurrence of the accounts depicted above, “min Allah” (from God) is by far the most prevalent response to dealing with the origins of deafness. In fact, this response does not constitute an explanation of the source of deafness, but rather draws attention to God’s mysterious ways. It does however have a subtext.<sup>20</sup> The will or way of God is an expression for that which is beyond investigation or change (Comaroff 1981). Referral to “God’s will” sees the situation as “natural,” as no more than a variation that needs no explanation.<sup>21</sup> This argument implies that causality is not relevant. Perhaps the search for explanations should not even be attempted, for the will of God is beyond human comprehension. Such comments often act as a closing remark at the end of a long and intricate conversation on the origin of deafness, or as a means for cutting it off. It suggests that the answer or source of the phenomenon should not be sought in human action.

### **“Brides from Outside”**

Let us have a closer look at Abu-Musa’s first account: deafness was introduced by “brides from outside.” This is the only account that implies a negative association with deafness. It suggests that deafness is not an accepted family feature but rather a tainted element from the “outside,” as it “blames” foreign women. While this characterization can be seen as compatible with the medical discourse, in its attempt to present deafness as an undesirable contaminating element, with regard to marriage arrangements, it implies the opposite. The genetic project points to consanguinity as the source of problems, but the foreign brides account suggests that “mixing” with foreign families might be a source of unknown and possibly undesirable traits.

Pointing to “brides from outside” as accountable for deafness is akin to the medical discourse that describes deafness as undesirable. It stigmatizes

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<sup>20</sup> The attributing of phenomena to God’s will is prevalent in another way, which is common in the Christian, puritan world (Groce 1985) but is not depicted in this instance. The will of God as an explicit expression of punishment or warning is a meaning that attributes moral and ethical contexts to the phenomenon.

<sup>21</sup> In a study conducted in India, a process is described that leads deaf people and their families to accept deafness as “Prakritic”—a religious Hindu perception of “naturalness,” which relates to the natural in a sense of belongingness to the world order. Therefore, this perception also releases believers from feelings of guilt and searching for remedies (Jepson 1991).

deafness, but it also stigmatizes women as carriers of undesirable foreign traits. It is therefore not surprising that women in their alternative speculations would question both of these notions. Furthermore, women have their own reasons for preferring to marry within their familiar kin group—because that is where their social network can be put into action and serve as a source of social power.<sup>22</sup>

Samira is a woman in her forties who is married to her paternal cousin. She demonstrates the advantages of being married to a relative: their household is surrounded by those of her brothers and her mother, and she is a cherished sister, authoritative and full of humor. Samira dismissed the idea that the foreign origin of her maternal grandmother would be the reason for her mother's and brother's children's deafness.

A man will never take responsibility upon himself, never say about himself that he has flaws; and a man has many flaws. [Samira laughed and continued.] Yes, that old woman was from the Shrukh [family], but the Shrukh, they don't have mute people at all! [So where is this story from? I asked.] I don't know; it's a mistake . . . but there is no mistake in deafness, it is from God.

Samira was familiar with the doctors' approach; her response to the compatibility tests indicated she was far from ignorant regarding the possibility of having such tests performed.

"I know the doctors say in our family there are many problems because people marry each other. But look. If everyone does the test, they'll stop marrying one another altogether! There are people who married from outside—but the child still has problems."

Samira did not discard this idiom on the whole, but she rejected its association with deafness.

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<sup>22</sup> The structural, material, and ideological analysis of kin-endogamy is the subject of a classical and extensive anthropological debate (Abu-Lughod 1986; Bourdieu 1977; Kressel 1992; Khuri 1970).

## Inheritance, Blood, Seeds

Like Abu-Musa, Samira wished to relativate the cruciality of deafness. Like Abu-Musa (who used the watermelon metaphor), Samira too referred to God and nature.

It's from God . . . For example, in agriculture, the root sprouts into seven generations. Here, take us; my mother is mute, and I don't bring any deaf children. Perhaps my daughter will not, perhaps my daughters' daughters will; perhaps my sons' sons will; it is present in the inheritance. It passes on in the blood; it is mostly present in the man. You plant a watermelon, a watermelon comes out; you plant a melon, a melon comes out. What you plant is what turns up. . . . It is from the man, not from the woman.

Images from the plant realm are used to illuminate that this is a "natural" phenomenon. Indeed, as Mary Douglas points out, "natural symbols" have the power to camouflage the cultural as the natural, which is not subject to human act (Douglas 1996). According to the dominant metaphor of "the seed (semen) and the soil (womb)," women are connected to the "natural" world (Delaney 1991; Ortner 1974). A woman nurtures and supports (pregnancy, breast feeding), but she does not determine the newborn's essence. As Samira clearly suggests, if one would plant a melon seed in different soil, one still would not get a watermelon.

Samira summarized this perspective: "The woman doesn't place anything! She doesn't do anything, doesn't implant and doesn't uproot." All the women burst into laughter. Samira's deaf mother was also present, and until that point, one of the young women translated to sign. But Samira obviously wanted the stage for herself. At that point, she was at the peak of her enthusiasm and was speaking and signing dramatically. Later on, in response to other comments made during the conversation, she relented a bit: "Most is from the man, not from the woman. . . . Maybe 1 percent from the woman and 50 percent from the man."

Samira was negotiating, sometimes even negotiating in numbers. However, the consistency of her words does not lie in presenting a seamless theory, but in the discursive value of her arguments. In that respect, her message is consistent, and the women's laughter implied that they clearly recognized the meaning: "Don't burden women with all this."

The underlying concepts employed by Samira, Abu Musa, and others should be highlighted: inheritance, blood, and seeds (the Arabic word means both seeds and semen) cannot be understood without their patriarchal context.<sup>23</sup> These terms do not refer symmetrically to men's and women's procreative contribution in determining their children's blood. Some accounts may appear as local versions of the medical account, but they often carry a quite contrary subtext in which matrimonial pairing is rendered irrelevant.

Referral to blood emphasizes men's role in procreation. Thus, it enables a challenge to the medical-genetic assumption that interference is needed in marital pairing. The term blood often refers to social relations more than to an individual's body.<sup>24</sup> Unlike in genetics' reference to blood tests representing the genetic makeup, the term blood, as locally used, represents one's patrilineage. It is irreplaceable and not related to marital pairing, and as such challenges the possibility of preventive action. Bourdieu (1977) demonstrates the possible variation in male and female reading of kinship relationships. These cultural idioms can indeed be read and employed in various ways. They are gender dependent, and men and women use them differently with regard to the context and subtext of such readings.

### **"Khulf"**

The following ethnographic example demonstrates yet another account of deafness. Furthermore, it calls attention to the fact that not all wish to propagate endogamy or to praise the family's endemic traits. Many, wishing to conform to modern discourse and its rejection of what is perceived to be "traditional," condemn consanguinity. Yet it is not just the elderly who combine various explanations and draw on local theories of procreation to negotiate the genetic implications.

Faher is an educated and rather religious young man, married to his second cousin, and father of several hearing children. Obviously, he has incorporated major aspects of the genetic discourse.

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<sup>23</sup> The term *Wirathat Dam* represents a patrilineal heir who receives his inheritance due to blood relatedness. *Damaya*, the diminutive of blood (*Dam*), "suggests that maternal links are recognized, yet as a weaker form of kinship" (Abu-Lughod 1986:51).

<sup>24</sup> See Abu-Lughod (1986).

We have many healthy children; they are OK. But if you will check their head, bones, heart, you will find many shortcomings. Why did God choose to do this to us? That is helpless talk. Will we blame and burden Allah for everything bad? [These things were said in the presence of both his parents, who were expressing their scepticism. He impatiently turned to his father.]

That's why they ask at the hospital: Your father, does he have anything? Sugar [diabetes]? Heart? That is the way it goes; hereditary, from one generation to the other! [I then asked Faher again regarding deafness: So that is what you think it is?]

When it comes to deafness there must be something else. [Why? I asked.] I know people who don't have deafness in the family at all, and it still happens. There is something in heredity, but the first reason for deafness is different. When a pregnant woman sees something, she gets so engaged with it, that almost the same element is marked in her child.

Faher here referred to yet another local idiom, a form of marking, locally referred to as "*Khulf*," which is often mentioned in relation to deafness and other conditions. For example, the first daughter of a young couple I knew had fair hair, despite the fact that both of her parents had dark curly hair. I was acquainted with her mother well before she married. I used to visit her often while she was pregnant, and I joined her at the prenatal care clinic. On one of my later visits, her sisters told me, while she brushed the toddler's hair: "She [the mother] was keen on you and brought like you. She marked through you."

The mother was perceived as the active agent who marked the child she carried, though the marking was not intentional. It is noteworthy however that it was not the person who evoked the mother's attention that imposed his or her traits on the newborn. This is an important distinction. If the beggar, the fair-haired person, or the deaf signer were perceived as the active party (as the people who imposed their characteristics on the newborn), it would suggest that they possessed extraordinary or even witchery powers, and thus the marking would be unavoidably stigmatizing. Though compassion was also mentioned with regard to marking, different things can be perceived as occupying one's attention about deafness, such as some other prominent feature of the person. A woman once illustrated *Khulf* by suggesting that she might have marked her son with deafness following her admiration for a neighbor who was a strict and sturdy educator. He was deaf, and she used to observe him while pregnant.

What then is the subtext or discursive value of this account? Unlike genetic explanations, marking is typically monogeneric, that is, it has nothing to do with marital or procreative pairing. It is related to what is perceived to be female nature, challenging the idea that anything can or should be done about it. Like other accounts, it is a speculation drawing on an existing idiom, and it is not presented as an all-embracing explanation of people's deafness.

Faher even extended *Khulf* to a broader theory on deafness. He emphasized that it was not deafness in itself that evoked marking, but it was the visibility and appeal of signing. In this way, he attempted to offer an alternative explanation for how a child can be born deaf, and he suggested what characteristic about deafness could draw the attention of a pregnant woman. Faher also applied the *Khulf* idiom to provide an account of the high prevalence of deafness among the Al-Sayyid, he thus concludes "We live close together, signing is everywhere, and signs engage one's attention."

## Stigma

It is possible to examine two aspects of each local explanation of deafness. One refers to the meaning an account attributes to deafness, that is, what can be learned about perceptions of deafness from a certain way of explaining it. The other aspect relates to the offering of an explanation as practice and its role in the local discourse. The first aspect is secondary to this paper, which focused on the latter. However, although attitudes towards deafness are complex and even ambivalent, local accounts reveal a relative lack of social labelling.

It is significant that there is no single local myth as to the origin of deafness—neither of a particular individual's deafness nor of the high occurrence of deafness. None of the idioms (whether "brides from outside," "seeds," "marking," or others) is reserved to explain deafness only. These modes of explanation also are used to account for other differences between members of the family (height, hair color, character, or general resemblance).

To clarify this last point, it might be useful to resort to a comparative example. I once visited a young woman, Hannan, from a neighboring kin group where deafness had not occurred before she was born. The difference between her account and those of the Al-Sayyid women was striking. She kept on referring to her deafness in the following terms:

It's difficult, very difficult. What can I do? I did not do anything wrong. My father, his heart is in pain over me. Where doesn't he drag me to? He

begged that I be cured, and there is no one to help. [Her mother said,] Look at her, like a flower, pretty and doesn't hear and doesn't speak, poor thing. . . . May God watch over her . . . . Lord of mercy.

Among Hannan's kin group, deafness calls for a cure. Moreover, it seemingly needs to be confirmed that she is intelligent and has other good qualities. The tendency to attribute a wide range of faults due to one human feature is one of the characteristics of social labelling (Goffman 1963). Hannan's deafness was explained by a specified event of maternal fright, a negative form of marking.<sup>25</sup>

I am this way from my mother's belly. My mother remembers that when she was pregnant, she once woke up in fright from an airplane. . . . She too cried over me. . . . There was this noise like an explosion, and she felt something wrong.

From my acquaintance with Hannan and her family members, as well as with other Bedouins around the Negev, I learned of the common perception of deaf people as handicapped and ill-fated. This contrasted sharply with the absence of similar accounts among the Al-Sayyid, hearing or deaf. Deaf people among the Al-Sayyid do not offer personal explanations for their deafness or for the deafness of others. However deaf members of the community, as others, have their own situated perspective with regard to deafness, marriage, and the social priorities entailed.

I visited Hannan with her former classmate Sabriyah. Sabriyah, herself deaf, was still unmarried at that time, but all three of her deaf sisters and her deaf brother had long been married. When Sabriyah declined two different offers to marry a foreign man (not from the Al-Sayyid family), she told me,

And if I marry this man [from a village in the south of Mount Hebron], who will I be there? How will they treat me? Where will I go when there are problems? Here we know each other; and if I have problems, I am close by. If he is rude to me, I will go to my neighboring sister. If he

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<sup>25</sup> According to Groce, maternal fright was one of the most common explanations in the nineteenth century for all sorts of congenital defects, which were caused by panic or anxieties of the mother during pregnancy. In 1863, an article by Hawkins stated that nine out of every ten cases of congenital deafness emanate from the mother's anxieties. He even suggests that sequential births of deaf children are caused by the mother's fear of giving birth to another deaf child (Groce 1985, 119–120).

decides that my daughter should stop going to school, I will make a commotion; I will turn to everyone and not let this happen, whether she is deaf or not! [A year later, she married Said Al-Sayyid , then fifty years old, becoming his second wife.]

Sabriyah's situation raises the question of whether, and to what extent, a genetic characteristic will be permitted to override social factors in a woman's preferences of a potential marriage partners, and whether it will determine her identity and those of her future children. As a deaf woman in Al-Sayyid, Sabriyah has social resources that are based on a dense and accessible network. She perceives herself as an active and resourceful agent in the future of her children, deaf or hearing. Later in life, the future of her children and their status will influence her own status. What would Sabriyah's status be, and what social resources would be available to her as a foreign, deaf bride, if she married a stranger? How would his family members communicate with her? How would she and her children be treated, and what behaviors or characteristics would be attributed to her deafness? It appears that Sabriyah, like other women, even when aware of so-called genetic risk, were not interested in the social risk required to find the answers to these questions.

## CONCLUSION

I wish to conclude by returning to my initial remark on the multiplicity (and often seemingly contradictory) causality often present in local accounts of deafness and what might seem as incredible inconsistency. Faher initially criticized his parents for not understanding the simple principle of genetic inheritance. Willing to define the situation as a problem, he also argued strongly that heredity alone does not explain deafness. Faher altered what he perceived as strictly modern concepts with ones that might be seen as strikingly exotic. Abu Saalem was fascinated with the ability of doctors to check people's blood for congenital defects like retardation, but maintained this could not be relevant to deafness. Ikhsen related consanguinity to both deafness and heart disease. He resorted to genetic discourse to support the patriarchal practice of importing brides, but genetic considerations seemed to lose their relevance when it came to local women. At first glance, the use of different, sometimes contradictory, explanations by the same person may seem inconsistent. However, this is so only when an attempt is being made at drawing cultural cosmologies of conception. Rather than try and solve these

contradictions in an effort to formulate a unified theory of procreation, I have tried to demonstrate the way these explanations function in particular circumstances. In other words, I examine discourse as a practice and not merely as a key to cultural representations. Language and reasoning are not merely reflections of beliefs or ideas; they are modes of action. I do not wish to argue that Bedouins are more inconsistent than others. Rather, my working assumption was that social life and cultures are not consistent. Knowledge is situated, and people's statements in particular are highly situational. The consistency of the various accounts lies in their discursive value or subtext.

A range of deliberations mask or play down genetic considerations in matchmaking, and local speculations provide valuable insights into the range of competing considerations. People extract their explanations from the rich pool of perceptions and explanation patterns to which they are exposed. People modify the use of several explanations anchored in different dimensions of social life and discourse, and they sometimes choose conflicting ones. They make creative use of them in different contexts, while negotiating their contents. As a result of this, new subjects and contexts emerge. The discursive value of the explanations enables constant changing of the thematic frame in a particular conversation.

Medical discourse is translated and partially reproduced in local discourses but not fully embraced. Referrals to medical arguments or medical authority are highly situational and contextual. The genetic medical discourse is also subject to discursive interpretation, and therefore it does not easily impress its logic on local discourses.

The genetic explanation and prescription on procreation is partly represented in Al-Sayyid, but people in the community consider many factors other than the avoidance of one specific genetic risk in seeking a marriage partner.