Testing and empowerment

On the boundary between hearing and deafness

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Welk criterium van lidmaatschap moet een sociale beweging op het terrein van de gezondheidszorg hanteren? Is het gebruik van criteria ontwikkeld door de medische professie voor diagnostische doeleinden verenigbaar met het (politieke) programma van een beweging gericht op 'empowerment' en autonomie? In dit artikel maakt de auteur een vergelijking tussen de tests en criteria gebruikt door audiologen om gehoorverlies te bepalen, en de tests en criteria gebruikt door de dovengemeenschap om te bepalen 'wie doof is'. Aan de hand van dit voorbeeld wordt de voorlopige conclusie getrokken dat een politieke beweging die volledig collectief burgerschap van haar leden nastreeft, medische/diagnostische criteria voor lidmaatschap niet adekwaat zal vinden.

[gehoorverlies, meetprocessen, Dovengemeenschap, empowerment, sociale beweging]

Technologies of visualisation have transformed medical diagnostics over the past hundred years. It is clear that, most especially in relation to conditions thought to have an association with brain functioning, their radical transforming potential is far from exhausted (Dumit 1997). But it is another approach to diagnostics and screening, genetic testing, which now attracts the greatest attention from scholars in the social sciences and from society at large. Against the simple claim of tests' protagonists – that tests = knowledge = empowerment – social scientists are struggling to formulate a set of more complex questions around the emergence, introduction and social, cultural and ethical consequences of genetic (and other biomedical) tests. The claim that test results empower proceeds through the notion of choice. The knowledge that I have a genetic predisposition (that is, an above average chance of contracting) a certain disease means that I can choose to modify my behaviour accordingly. Or I can choose not to. I am empowered. This paper addresses not empowerment in this individualistic sense, but collective empowerment. And rather than focussing on a recent test, the social and cultural implications of which we are still trying to work out, I shall focus on a form of testing that has been familiar for decades.

Testing ‘hearing’ or testing ‘deafness’?

For hundreds of years the question of ‘who is deaf’ was a private one and a tragic one. The born-deaf, failing as they did to acquire spoken language, were almost universally excluded from human society and were seen as denied the word of god. The birth of a deaf child was a tragedy for any family. Such children were best hidden away, concealed, and sometimes, when they were older, driven from their homes. There had been remarkable examples of children of rich aristocratic families being taught to speak by dedicated teachers (sometimes to assure their inheritance), but this doesn’t affect the general picture. The attempt to educate deaf children, to reclaim them for human society, is a post-Enlightenment phenomenon (Lane 1984, Rée 1999). It is with the emergence of rehabilitative technologies – pedagogic and then acoustic – that the need for more appropriate tests emerged.

Nowadays a public health understanding of hearing loss has become commonplace. We all know that hearing loss is widespread in older people. The image of granny with her hearing aid is a familiar one. Surveys show, in fact, that hearing loss is by no means limited to the elderly

> More than 10 million Americans report that they have hearing loss, defined as difficulty hearing normal conversation. Hearing loss affects more than 4 million Americans age 65 and older, and almost 6 million Americans under age 65. Hearing loss can have a profound impact on an individual’s emotional, physical and social well being. People with hearing loss are more likely to report symptoms of depression, dissatisfaction with life, reduced functional health, and withdrawal from social activities. Although most people with hearing loss can be helped with hearing aids, four out of five Americans with hearing loss do not use a hearing aid (National Academy on an Aging Society 1999).

The message here is a familiar one. Hearing aid technology can help far more people than now profit from it; even though in the USA (and of course in poor countries) many people are unable to enjoy its benefits. Within this perspective deafness – which most people think of as ‘being able to hear nothing at all’ – has become simply the most extreme form of hearing loss.

In previous work I have tried to show how and why the Deaf community has turned the cochlear implant into a symbol of the abuse which deaf people have suffered at the hands of hearing society (Blume 1994, 1999). The Deaf community, it has frequently been pointed out, does not see deaf people as in need of correction by medicine or technology. It sees them as sharing a language and a culture, within which they are able to live as full lives as any one else. Here too a distinction is drawn between the hard of hearing, who with the help of hearing aids are likely to function fairly normally in hearing society, and the Deaf, dependent on sign language, who are not. The point of testing is now to offer appropriate help. People who have difficulty hearing should be provided with a hearing aid. The technology is getting better and better, and in a wealthy society there is no reason for anyone to be denied it. As for the extreme case, the deaf (or Deaf)…Hearing aids don’t help them very much, to be sure. But fortunately we now have the cochlear implant. Developed in the 1960s and 1970s, this device proved able to provide many people who'd lost their hearing with some kind of an artificial substitute (Blume 1995). For many, recovering their hearing is truly a wonder (Biderman 1997). A problem was that, surgically implanted into the inner ear, it did destroy any residual hearing that a person might have had. Learning to make use of it requires long periods of rehabilitative training. Appropriately deploying the battery of available technologies – including hearing aids and implants – thus requires that people be appropriately allocated to one group or another on the basis of tests of their hearing. This group needs hearing aids. That group should be implanted.… Granny-with-her-hearing aid is not part of the Deaf community. The Deaf don't want hearing aids. They have different needs and they want these needs to be recognized and accepted. As the Commissie Nederlandse Gebarentaal argued, they want their language – Sign Language – to be accorded the same status as other minority languages (Commissie Nederlandse Gebarentaal 1997). The Deaf community, from this perspective, is simply a cultural minority like any other. With the exception of course that 'recruitment' and socialisation do not take place within the family. 90% of deaf children are born of hearing parents. The Deaf community is thus well aware that its own reproduction depends upon what happens to children born into families that (often) know nothing of deafness. The future of the community also depends upon selecting out those who must become its future members. So here too testing is vital. What the Deaf community tries to establish is not how much a person hears…but whether or not he/she is deaf.

How can this be done? What are the implications of the testing procedures/criteria developed for rehabilitative (medical) purposes for the 'work of demarcation' to be done by the Deaf community? Put in very general terms, the central question that this paper will try to address is this: *Do health-related social movements need to develop their own criteria of membership, distinct from those developed in medicine, if they are to pursue what they take to be their collective interest?*

A little audiometric history

Attempts scientifically, 'objectively', to establish hearing loss emerged in the 19th century. Measurement of sound-intensity, and hearing-loss, in decibels is a tribute to the 19th century inventor Alexander Graham Bell, most famous for development of the telephone. Bell's father was a teacher of speech, as Bell himself was in his early years. With a deaf mother and a deaf wife, Bell was pre-occupied with issues relating to the deaf for the whole of his life. Bell was active in the establishment of educational programmes for deaf children, with an emphasis on teaching spoken language. In 1879 Bell devised a device he called an 'audiometer'. It consisted of two flat induction coils, one carrying an intermittent current of precise frequency, the other in circuit with a telephone receiver. As the coils were brought nearer on a graduated scale, the sound of an induced current grew louder in the receiver (Bruce 1973/1990: 394). Used to test hearing, the audiometer showed that many children regarded as deaf actually had significant amounts of hearing: useful in teaching articulation. It also showed that large numbers of children who had been regarded as mentally defective actually suffered from a hearing problem. Bell displayed his audiometer to the National Academy of Sciences in 1885. Despite the work of Bell and other 19th century pioneers audiometry is generally regarded as a relatively recent science. In order to measure hearing (loss) *reproducibly* it was necessary to generate pure tones across a range of known frequencies. Tuning forks and Bell's induction coils were a start, but it really only became possible with the advent of the electric valve tube just after the First World War. The first vacuum tube audiometers capable of making measurements across the whole range of human hearing were developed around 1920 (Blume & Regeer 1998: 39-40). Immediately a controversy arose regarding the calibration of the instruments. According to Noble (1992), when the first commercially produced audiometer was designed in the 1920s, the standardization of output was to have been based on acoustic zero (0dB). But E.P. Fowler, the otological consultant involved, was adamant that the instrument should fulfil a diagnostic assessment function and that zero output should therefore represent 'normal' hearing. The zero level on the early audiometer was accordingly fixed at the average threshold level of listeners at the Bell Telephone lab. In the meantime audiometric testing was carried out on a large scale on hard of hearing adults. The 'normal threshold' established by the American Standards Association in 1951 was based on a national survey conducted in the USA in the 1930s. It defined that 'normal threshold' as "the modal value of the value at threshold in normal ears of people aged 18-30 years"…although the survey had been done over a much broader age range. In the early 1950s two research teams in the UK set about measuring thresholds in groups of carefully selected young people. Their results agreed with each other, but differed markedly from the American results. Their data became the British standard. The attempt to reconcile the divergent findings led to years of discussion. Whilst some manufacturers used the ASA standard and others the British or some other, practice in general was to fix the zero output along these lines. It thus required the results of a large population survey to provide a standard.

What is 'the whole range of human hearing'? The 'young healthy normal ear' can perceive sounds in the frequency range 20Hz to something like 20,000Hz or (20kHz). By contrast a cat (young healthy normal?) hears in the range 60Hz to 60kHz and a bat 1Hz to 120kHz. Human speech takes place in the range 250Hz to 8kHz. Of course in testing no one has ever tried to measure at every single frequency. Conventions were developed regarding which frequencies to measure.

Thus, audiometric tests conventionally measure responses at frequencies of 125, 250, 500Hz, 1,2,4,8 kHz. This covers the speech range. The so-called pure tone audiogram is a plot of the threshold at which the listener can just hear sound at each of these frequencies. The tester (audiologist) tests at each of these frequencies, gradually raising the intensity of the sound until the person being tested signals that he/she can hear it. The audiogram is then a graphic representation of these intensities against frequency. It enables audiologists to assess the acuity of a person's hearing. Audiograms are usually not flat. Many people hear better at some frequencies than others. But a person with a hearing loss of around 30db averaged across the frequency range would have trouble hearing soft speech. He or she would be conventionally classified as mildly hard of hearing. A person with a hearing loss of 90db or more would be classified as deaf.

As the discussion regarding calibration suggested, audiometry has acquired a diagnostic function. By the 1950s electrical hearing aids were widely available. The test was thus intended to establish whether the individual being tested is in need of some kind of an amplification device (Newby 1958: 256). Audiometry in its classical form depends upon the subject indicating that a sound is – or is not – being heard. Testing very young children in general has required various adaptations. If a child is too young to understand the instruction then an alternative means is required of establishing if something is being heard. By the 1940s it was becoming clear that special techniques would be needed for testing children "below the age of 5-6 years" (Huizing 1959). For example, many testing procedures are based on noting whether the child turns to look at the source of the stimulus.

This dependency on the co-operation of the subject has long seemed a weakness in audiometric practice. Alternatives emerged from electrophysiological research. One of the most famous figures in electrophysiological studies of hearing, Hallowell Davis, writes:

> Electric response audiology (ERA) really began about 1962 with systematic clinically oriented studies of auditory evoked potentials in children. Two related audiological goals were defined. One was to make audiometry as 'objective' as possible. The electric response, substituted for the behavioral raising of a finger, immediately satisfies half of this goal. The subject does not participate actively: he/she/it merely cooperates passively. The recognition of the response, however, requires a subjective judgement by the audiologist (Davis 1981).

Why these continuing attempts at developing 'objective' tests? Why should tests depending on voluntary responses from the patient have been felt inadequate? Part of the answer to this question clearly reflects that growing faith in machine produced evidence, at the expense of the patient's own account, that marks all of medicine's recent history. But in addition to these well-known arguments that have been applied to medical practice as a whole, there is a different and more specific motive. That reflects the growing conviction that children have to be tested at very young ages. Intervention, to be successful, must start early. I am not yet able to document the history of this conviction, so that what follows is no more than indicative. Nevertheless I am convinced that the conviction precedes any strong evidence for the advantages of early intervention.

A recent report by Yoshinaga-Itano and Apuzzo (1998) reviews early studies from the United States focussing on the relations between early identification of hearing loss, early intervention, and the development of the deaf child. The literature, it is stated, is "scarce and often contradictory". Only 6 or 7 early studies – from the 1970s and 1980s – are regarded as worth discussing. Here are some of them.

> Greenstein (1975) found that children who began receiving intervention for hearing loss before age 16 months scored significantly higher on language tests as measured by the Receptive-Expressive Emergent Language (REEL) scale and the Lexington Preschool

> Oral Language Assessment or POLA … and in mother-child interaction when tested at 24, 30, 36, and 40 months of age, than infants who did not begin receiving intervention for hearing loss until after 16 months of age….
>
> Greenberg (1983) found that profoundly deaf infants and their families who received systematic family-centered intervention scored significantly better on measures of familial stress, developmental level, and communication ability than did members of a matched comparison who group…the group that received systematic attention was, incidentally, identified earlier than the other group, 8.3 months compared to 11.1 months.
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> White and White (1987) reported that, when tested at age 36 months, deaf children of hearing parents who were identified and began receiving intervention before age 18 months scored significantly higher on tests of preliminary and advanced receptive vocabulary, the reception of simple and complex requests, the reception of parts of speech, the reception of semantic categories, early vocal play….

On the other hand a study by Bess and Paradise concluded

> Extensive review of the literature revealed that there was inconclusive evidence that children identified early, defined in the literature as before 2.5 years of age, exhibited better outcomes in language, academic achievement, and other areas (Bess & Paradise 1994).

Yoshinaga-Itano and Apuzzo's study sets out to show that, in fact, early intervention is highly advantageous for both child and family. Taking this conviction as a starting point the fact that, in the USA, "the average age of diagnosis of hearing loss in the U.S. is currently 2½ to 3 years and does not generally occur until parents have become concerned that their child's speech and language development appear to be delayed"[1] becomes problematic.

Deafness as a social phenomenon

We have already come across Alexander Graham Bell as the inventor not only of the telephone but of an early audiometer. In 1883, inspired by notions of inheritance then much discussed, Bell wrote a paper entitled *Memoir upon the formation of a Deaf Variety of the Human Race.* (Bruce 1973/1990: 409-411). His paper was based on data collected from schools for the deaf. Bell's data seemed to show that deaf parents had a much higher proportion of deaf children than did the population at large; that 'congenital deaf-mutes' in his survey tended to have deaf relatives; and that "unlike those with other defects, the deaf strongly tended to marry the deaf. From these discoveries it followed that deafness could be inherited, and that it tended to propagate itself." According to his biographer Bell didn't want to *prohibit* deaf people marrying each other. He certainly wanted to discourage them. By obliging deaf young people to associate with hearing peers, and keeping them away from other deaf young people, the chances of their finding a deaf mate were reduced. Bell had long been against residential schools for the deaf. Bell's paper, reported in the press, came to be known among the deaf as arguing for a prohibition on intra-marriage. This account of Bell's views (whatever its accuracy) is the one that was picked up by the periodicals of the deaf and publicized. Deaf people were enraged at his having apparently implied that they were "forerunners of an inferior species" (Bruce 1973/1990: 411).

Neither Bell's precise views nor his understanding of genetics need concern us here. What is important here is its reference to deafness as a collective phenomenon. For Bell the notion of a deaf community was conceivable, but a dystopia to be avoided at all costs. Among the deaf there has long been another view. As early as the mid 19th century the deaf son of a wealthy Southern slave owner, John Jacobus Flournoy, had proposed that deaf people who so desired move to some part of the American west, to be granted them by the government, where they could establish a deaf state (Van Cleve & Crouch 1989: Chapter 6). Though his proposal received a cool reception, even from the better educated deaf, the 19th century saw the gradual organisation of the deaf community, not within a geographical space, but a social one. The historians Van Cleve and Crouch point out that dozens of organisations were founded from the mid 19th century onwards. In many large American cities deaf social, athletic, religious, literary and other associations were founded.

> The ubiquitousness of American deaf organisations is striking, but of more significance – because of its uniqueness – is the fact that these have been groups *of* rather than *for* deaf people. In the United States deaf people have created their own associations, funded them, and controlled them. In this respect the American deaf experience contrasts dramatically with the experience of deaf people in other nations, where historically most organisations were established for deaf people by hearing people. The paternalism of foreign deaf organisations, meant that, however well/meaning their administrators, their primary focus was on the expectations and needs of hearing people. American deaf organisations, on the other hand, most often grew from the self-perceived needs of their deaf members. Foremost among these was the association with individuals who shared similar communication methods, cultural values, and experiences.

There are a few recent studies that enable us – outsiders – to understand something of the criteria used here to establish membership in these institutions. The studies are recent because it is only relatively recently that scholars have recognized that Bell's nightmare – a deaf community – actually is the lived reality of deaf life in most of the industrialized world. How did scholars come to know this? Everything derives from a new understanding of the mode of communication generally used by deaf people which emerged in the 1960s.

In the late 1950s William Stokoe was appointed Professor of English at Gallaudet College (now University), still a unique higher educational institution for deaf (or hearing impaired) students in Washington DC. On joining Gallaudet, Stokoe recollects, he "began to learn how to produce signs, which were then presented to us as equivalents of specific English words" (Stokoe 1980: 265). Gradually he began to doubt that it was quite that simple. Stokoe began to interest himself in the possibility of applying tools of formal linguistic analysis to the signing he saw about him. Encouraged by linguists at the nearby Georgetown University School of Language and Linguistics, Stokoe obtained grants to start his work. Many at Gallaudet, including the Deaf students, thought the project ridiculous. With the help of Deaf assistants, signing for him before a camera, Stokoe persevered. In 1960 the first results of his project appeared: a monograph on the structure of American Sign Language. In it Stokoe argued, on the basis of formal linguistic analysis, that deaf people's signs had many of the formal properties of a full language. Though few were willing to be convinced Stokoe was not deterred. In 1965, together with colleagues, he published a Dictionary of American Sign Language. As more and more signs came to be recorded, and as more and more of the grammar of sign language became formalized, it became possible to teach sign languages like any other languages. Practical reality was different, however, as one of Stokoe's recruits, James Woodward, has explained. Deaf people preferred not to use American Sign Language (ASL) in interacting with hearing people, but a form of signing adapted to an hearing audience (Woodward 1980). In 1972 Stokoe started publication of a new journal, *Sign Language Studies.* A new area of research was opening in the field of linguistics. Not much later, the attention of scientists interested in the biological basis of language was drawn to sign language.

The work of Stokoe, Woodward, and their Gallaudet colleagues help make sense of another remarkable piece of scholarship, this time by a sociologist. In the introduction to the published version of his PhD dissertation (which was published in 1980) Paul Higgins (1980: 14) explains how he'd been trying to make sense of his own experience. 'Making sense' involved locating those experiences in a broader social context: thereby "transforming personal experiences into sociological issues". Higgins was the child of deaf parents. His wife taught deaf children. He himself had spent a year teaching in a school for the deaf before taking up graduate studies in sociology. His study, subtitled "A sociology of deafness", paints an unfamiliar picture of deafness. Though excluded from a hearing world in which they nevertheless live, the deaf are not the social isolates they have often been held to be. Higgins portrays a complex community, with which many of its members strongly identify. Despite unsurprising divisions based on age, ethnicity, educational level, religion and so on, deaf clubs provide their members with a place for free and easy social intercourse. Like the home, and for some perhaps more so, the deaf club provides a refuge from the grinding frustrations of the hearing world. Here they can communicate freely and easily with their friends. For most, though not for all, the basis of that free and easy communication is sign language. "Signing is not a sufficient condition, though it is a necessary condition, for membership in deaf communities", wrote Paul Higgins in 1980. "Signing," he went on, "is an indication of one's identity as a deaf person and one's commitment to the deaf world. It is perhaps the most obvious indication to hearing people that one is deaf' (Higgins 1980: 68).

For the Deaf community use of sign language rather than audiometric status is the crucial demarcation criterion. Where audiometric scales, implying courses of medical action, run from mild hearing loss (little problem, can be easily helped with a hearing aid) through profoundly deaf (hearing loss of 90, 100db or more – serious, possible candidate for an implant), the Deaf community assesses differently. Deaf children of deaf adults, brought up using sign language at home – 'Deaf of Deaf' – have a special status. Their natural ease with the language, and their knowledge of the folk ways of the Deaf community, give them their status. A remarkable study published a few years ago by two Deaf scholars provide fine insight into the complexities, but also the difficulties, in deploying a criterion of membership that diverges so considerably from that of the hearing world. Padden and Humphries (1988) show us the American Deaf community through the stories they recount. One theme concerns the place of hearing children of Deaf adults, brought up with sign language as a mother tongue. They recount a story concerning the hearing son of Deaf parents who wanted to play for a local Deaf basketball club. The club let him play.

> When the officers of the regional organisation learned that the club had a player who was not 'legally' Deaf, they pressed the club to act. Recognizing that the hearing player was in all other respects a member of the group, behaved as a Deaf person, and was virtually indistinguishable from his team mates, the club tried labeling him HARD OF HEARING. When the regional officers insisted on an audiological test, the club's officers knew they had played their last card and regretfully asked him to leave the team (Padden & Humphries 1988: 48-50).

The other story recounted by Padden and Humphries that I want to quote here concerns the way in which status within the group has been affected by opinion in society at large. There is a residual sense, surely much stronger in countries where emancipation is a more recent and weaker phenomenon, that hearing people are superior.

> The husband of a Deaf couple told us that for a long while he harbored feelings of superiority over his wife when he introduced himself as having lost his hearing in childhood. His wife, on the other hand, introduced herself as having Deaf parents. By explaining that he had lost his hearing, he could avoid the silent condemnation he believed hearing people directed towards his wife who had inherited her deafness.

Roughly, then, we can conclude that the Deaf community establishes 'Deafness' on the basis of communicative and social behaviour, not auditive competence. Sociality, not what Rabinow (1992) calls 'biosociality', is involved here. Oral deaf adults, who communicate via spoken language and cannot sign (of whom there are many) are at least as marginal – perhaps more so – than hearing children of Deaf parents (Preston 1995). The latter are typically allies in the struggle for emancipation in which the Deaf community has engaged since the late 1970's, whilst the former may not be. Those struggles, above all, were directed at the acceptance of sign language as equal to spoken language, to be used in the education and rearing of deaf children, and to acceptance of the Deaf as a cultural minority.

The challenge of technology

The Deaf community is well aware that its own future, its reproduction, depends upon children acquiring sign language and coming to see themselves, and behave, as Deaf. How does this occur? The first chapter of Padden and Humphries' book has the title

'Learning to be Deaf'. Part of this refers to acquisition of the language and folkways of the Deaf community. Part of it refers to a changed sense of self: of self-as-other. For deaf children in Deaf families, growing up with sign language as the normal medium of everyday communication, one can't speak of signing as an adjustment to not hearing, or as compensation. It's just the way they grow up. "Adjustments", Padden and Humphries explain, are what come later, when the child learns that the world outside has other beliefs and other practices. But for deaf children born into hearing families matters are very different. Whether or not the child is exposed to sign language will depend upon the choices its parents make and the advice they receive when its deafness is diagnosed. Here is an extract from an interview with the parents of a deaf child in Britain: [2]

> Myself and [wife], neither of us have been very enthusiastic about sending P along to these meetings [for deaf children]. And I think it's because we don't want him to identify himself as a deaf child. We want him to have this sort of consciousness that he is a child, a normal child, who happens to be deaf. And so if we group him together with other deaf children – I know it sounds as though they've got the plague or something, which obviously we know they haven't – we just thought it might sort of reinforce in him that this is a very, that he's a very definite type of child, do you know what I mean? We thought it might stereotype him in a way[...]it may be partly because neither of us wants to subconsciously accept that he's deaf, I don't know.

The cochlear implant has been widely presented as a way 'around' deafness: as offering hope that the child can, after all, be reclaimed for the hearing world. He may not hear but he need not be deaf.

However much parents may try not to let themselves be guided by the over-simplified picture painted by the mass media, refracted through the views of others that picture is unavoidably important. so refracted, it too can be a source of guilt or other forms of distress.

> [Mrs Donovan] Why did I think it would give him his hearing back? Well, because it's like a, it's made out to be like a miracle cure, isn't it?
> [Interviewer] Is that from the media?
> [Mrs Donovan] Yes, from the T.V, if you see it on telly that is exactly what it is really.
> [Interviewer] Do they just show the good sides of it?
> [Mrs Donovan] Yes, they didn't show any bad sides of it.

Here is another parent:

> One or two friends have said, you know, 'Has he not been able to have a cochlear implant?' They've worded it in such a way as we've been denied something. So I think the press do.. it is portrayed as 'this is a cure for deafness'...

As we have already seen, audiologists have long wanted techniques that could be used to screen very young children. With the emergence of cochlear implantation, and the sense that – by analogy with other forms of intervention 'the earlier the better' – the need seemed all the more pressing. In the early 1980s a procedure called auditory brainstem response (ABR) was developed. The baby is anesthetized and electrodes attached to its skull. By this means neural processing of sound stimuli can be assessed. The procedure is used in some hospitals but is regarded as expensive and invasive. In 1988 a less expensive and less invasive screening tool became available. The first tests of OAE (otoacoustic emissions) took place in 1990. In the Netherlands tests of OAE as a national screening tool took place a decade later. It seems likely that it will be introduced on a national scale in the near future.

If a child is deaf or hard of hearing it is good that this be discovered at an early age. Problems, frustrations can be avoided and language deficit minimized, in whatever modality the child is to be reared. Learning sign language too should start as early as possible. But how is the Deaf community to respond to the *combination* of the two technologies, diagnosis at the age of three or four months combined with the promise – or the threat – of routine implantation? The demarcation practices of the Deaf community have as it were been finessed by this development.

The most radical response to this challenge, indeed the only response that I know of, has come from the historian of the deaf and Professor of psychology, Harlan Lane. Lane's response involves a new and different interpretation of the social and cultural status of young deaf children. Lane argues that the child 'in the normal course of things' would become a member of the Deaf community and so have values different from its parents. Deaf children "have a DEAF heritage from birth" as a consequence of their physical constitution. The conventional view, reiterated by physicians (such as Cohen 1995), forced to defend themselves, is that "Deaf children of hearing parents are not members of the deaf community until they are either placed in that community by their parents or voluntarily decide to enter it." For physicians and for many parents, implantation is seen as offering the child the possibility of later choosing whether or not to enter the Deaf community. That isn't how Lane sees it. For Lane and Bahan the question is rather one of whether or not the child is allowed to take possession of its birthright.

> One does not say of, for example, Native American children that they start out in the mainstream society and only become members of the Native American minority culture when placed there by their parents or their own decision; rather, we would say that the child is Native American and has a Native American heritage at birth. Is that because Native American children normally have Native American parents? Is it the parents' culture that is critical in ascribing cultural membership to the infant? No, because a Native American child that is transracially adopted at any age is still considered a Native American child. *It seems that the cultural membership ascribed to the child is not based on his or her parents' culture, but rather on the culture the child would enter given his or her physical makeup*" (italics added)

There is another line that could be pursued here. A recent paper by a Finnish ICT expert deals with the implications of ICT for Deaf identity and Deaf culture. Raike (2001) points out that for the young generation of Deaf people Deaf clubs and schools aren't as important as they were for the older generation. People stay in touch with each other, exchange news and make dates, via SMS and 'chatting'. These technologies have made communication between Deaf and hearing people, and between the Deaf, far easier. Are they taking over the functions of the older institutions? I don't know. Raike argues that the Deaf community has to see Information Technology in terms of the possibilities it offers for rebuilding and reconstructing itself on a stronger less local basis. An alternative to Lane's *exclusive* attempt at redefining deafness would be *inclusively*, as a global community tied together not by any single criterion of membership, but by any one of a range of binding elements.

Implications of the analysis

There is no shortage of discussion of testing these days. The social and ethical implications of various rather new genetic tests are widely discussed, and the number of tests available is growing. Under what circumstances should testing be offered, and to whom? What risks of discrimination and exclusion do these tests bring with them? How does the (non)availability of therapy affect the issue? Following the overwhelmingly dominant tradition in bioethics, the focus of this discussion is largely on the potential gains and losses to the individual 'consumer'. There has been very little attention in bioethical discourse for the rights of 'collectivities'.[3] This paper is intended to shed light on some of the issues which testing health status brings with it. The case differs in a number of respects from current discussion of genetic testing. First, the testing of hearing has been around for much longer. We can look at what happens in a much longer time scale. Second, the Deaf focus precisely on those collective rights – rights as a linguistic and cultural minority – which bioethics tends to ignore.

The audiometric criterion of 'hearing loss >90db' does not correspond with the way in which Deaf people demarcate the community in which many of them choose to live much of their lives. As the Deaf community embarked on political struggles aimed at securing its own emancipation, from the late 1970s onwards, the distinction became all the more important. The struggle for the recognition of sign language did not unite people bound together by any audiometric criterion. Granny did not take to the barricades. Many people who could not hear, for example as a result of having lost their hearing in adult life, did not associate with this struggle. Some deaf people, including deaf law professor Bonny Poitras Tucker (1998), actively opposed it.

I suggest that a movement that had defined itself audiometrically, which had included the oral deaf and excluded non-deaf signers, would have embarked on different struggles. Not the struggle for sign language, but one more akin to the activism of other self-help groups would have resulted.[4]

Though the Deaf did not define their community in audiometric terms, nor has it been possible autonomously to impose their own social and behavioural criteria. The influence of norms and practices current in the broader society was too powerful. The example of the signing basketball player is indicative. Moreover, technological developments – the cochlear implant and 'objective' tests to be conducted on babies – can be seen as a 'finessing' of the Deaf community's position. Still more recent technologies – both genetic technologies and ICT – pose new challenges and offer new opportunities to the Deaf community.

My tentative conclusions are as follows. First, that the variety of tests and criteria for establishing 'who is deaf', reflect and derive from the variety of purposes which demarcation is intended to serve – from prosthetization to inclusion and participation. And second, that political activism directed at the achievement of full *collective* citizenship cannot rely on criteria developed by the medical profession for purposes that that activism almost certainly rejects.

Notes

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1 See Menzano 1999. In the Netherlands simple screening of the hearing of all infants at the age of 9 months has been conducted since the 1970s, via infant health centres.

2 These interviews come from an unpublished study conducted together with psychologist Lucy Yardley, University of Southampton. The names have been changed.

3 The Canadian ethicist Charles Weijer is trying to develop this approach. See for example Weijer 1999.

4 For a study showing how personal experience can be differently framed for distinctive political purposes see Maren Klawiter's study of breast cancer activism in the San Francisco Bay Area (Klawiter 2000).

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