"Making the deaf hear"

The cochlear implant as promise and as threat

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Al decennia lang hebben artsen gedroomd van een apparaat waarmee volledig dove mensen iets zouden kunnen horen. In de laatste twintig jaar is die droom werkelijkheid geworden. Maar, in tegenstelling tot de verwachtingen, is er grote weerstand in de dovengemeenschap. Deze vijandigheid heeft zijn wortels in het afkeuren door doven van het idee dat doofheid beschouwd moet worden als gebrek, als handicap. In dit artikel wordt een vergelijking gemaakt tussen de ontvangst van het zogenoemde 'Bionische Oor' in Groot-Britannie en in Zweden. Er wordt geconstateerd dat deze verschillen zijn te verklaren in termen van verschillen in de acceptatie van doven als taal- en culturele minderheid.

The commonsense understanding of deafness in western industrial society is as the absence of hearing. It is well known that as they age, many people find that their hearing declines in acuity. Hearing aids are often prescribed, though not always worn, and with them matters can be roughly corrected. Society is inclined to view those who become totally deaf as tragic victims: condemned to isolation and loneliness. Personal accounts of the process of becoming deaf reinforce this view of suffering and growing isolation. Lacking language – the principal characteristic of humanness – as they seemed to do, in many periods of history the born deaf were beyond even the sympathy of more than a few exceptional individuals. Ineducable, unable to share in the rituals of religious practice, they were in essence excluded from human society... In the past century what appear to be more enlightened, and certainly more charitable views have prevailed. We must do all in our power to integrate the deaf in human society. They can be given speech, and with it the power of thought and of belief, though the way may be long and arduous.

Though the medical profession has typically provided a legitimatory framework for these attempts to (re)habilitate the deaf, medicine's contribution in practice has been small. The practical burden has been born principally by various new professions, including audiology (which was to measure hearing and provide appropriate hearing aids) and speech therapy (*logopedia*), which largely speaking were made subordinate to medicine. The medical profession, and in particular the (sub)speciality of otology (which forms a part of ENT, or what in Dutch is called KNO), has used drugs and surgical procedures to correct identifiable pathologies of the organs of hearing. It has had little to contribute in the enhancement of hearing or speaking. But today at least, some doctors speak of having long dreamt of some kind of a "James Bond like gadget" with which they could offer hearing to the totally deaf. A new and heroic future seemed to beckon! With advances in the understanding of the physiology and psychology of hearing – in the 1930s, '40s and '50s – it began to seem that this dream could be realized. This paper deals with a technology which seems to be precisely the embod-iment of that dream. It is often referred to popularly as the "Bionic Ear".

Drawing as it does on two deeply rooted assumptions – that deafness is a tragic disability and that the healing power of modern technological medicine is potentially limitless – this is a satisfying story. That it is today questioned, indeed contested, may come as something of a surprise. The fact is that deaf people, because they view deafness differently, on the whole do not welcome the Bionic Ear. Indeed they fear it. In France they have recently taken to the streets to make their opposition clear. A British deaf organization has referred to it as an instrument of genocide.

This technology of hearing – to give it its medical name the cochlear implant – has very different significances for the medical and related professions on the one hand and for the deaf on the other (see Lane 1992). As the device was developed and knowledge of it spread, it became vested with these various significances. Thus, for example, it may have come to seem a 'new frontier' for the speciality of otology: a means of, finally, offering an heroic treatment like colleagues in other medical specialities were doing.

In recent sociological approaches to the study of technological change such 'ignificances' play an important part. They shape the engagement of different categories of actor in the career of the technology. Sociologists and historians try to understand the development of a technology in terms of its significance for different (categories of) actors, and the commitments they make to it. In some areas of technology potential users play an influential role, whilst in other areas they do not. Among the first category are devices used by medical professionals, among the second category are aids for the disabled (Blume 1992, 1994a). We can apply this perspective to the development and introduction of the cochlear implant. What influence, if any, have the deaf exercised on the processes by which the cochlear implant has become available? In what ways, if at all, have their understandings of deafness played a role in the development of a technology which, some claim, makes deafness a thing of the past?

In this paper I shall suggest that the deaf, and their understandings of deafness, have scarcely impacted on the history of the cochlear implant. In general, the medical world does not view the deaf as having anything significant to say about deafness or about provision for the deaf. However a comparative perspective suggests that this general conclusion needs to be made more nuanced. If we compare the debates that have taken place in different countries, a more complex picture emerges. The timing and the extent of the commitment which medical professionals made differs substantially from country to country. The involvement of the deaf also differs between countries, and it is this on which I shall focus. I shall argue that the involvement of the deaf community in the debate depends upon the extent to which it had gained acceptance and respect for its own perspective on deafness.

The conventional history: 'making the deaf hear'

A conventional history of the cochlear implant might begin with the Italian physicist Alessandro Volta, who is often credited with having discovered the electrical nature of hearing. In 1800, the story goes, Volta passed an electrical current through his head, by placing electrodes, connected to a battery, one in each ear. Completing the circuit led to a disagreable sensation and a noise said to have been like the boiling of thick soup. Although various subsequent attempts to replicate this finding failed, by the 1930s a number of investigators were investigating the phenomenon. Depending on the characteristics of the electrical circuit, and of the ear, various acoustic sensations could be induced in an experimental subject: a pure tone, a buzzing noise, both together, or (in some cases) nothing at all. By 1940 theoretical accounts of how the ear transforms sound waves into electrical (neural) currents, and of how electrical stimuli led to acoustic sensations, had been provided. All this was in the realm of science, even though in some of the research human volunteers (rather than animals) were used. No one was claiming that the research offered anything to deaf people, at least not in the short run.

At the end of the 1950s this began to change. In 1957 a totally deaf person about to be operated begged Paris otologist Eyries to try to give him some minimal hearing. Eyries approached Djourno, who was working on electrical stimulation of the auditory nerve in animals. After some deliberation they decided to try to implant the patient with an electrode, similar to that used in the animal research, which would stimulate his (functioning) auditory nerve. This was done in February and after a number of difficulties in July rehabilitation was started with a speech therapist. Very rapidly the patient's initial enthusiasm faded, as his expectations failed to be born out. It soon became apparent to the patient that different kinds of sounds could not be distinguished: speech, opening a door, dragging a chair: all sounded the same. After some months the patient decided that he wanted to terminate the rehabilitation. Nevertheless, despite many difficulties, the three cases which they had implanted led Eyries and Djourno to the conclusion that the technique had a future (Djourno & Eyries 1957, Albinhac 1978).

A Los Angeles otologist, William House, was one of those inspired by a report of this work.

> I remember that a patient brought me a little clipping from a newspaper about this particular work and about the results on the patient. That was in my first year of practice, which was 1956. I was very stimulated by that. I thought it was amazing that this might be done. I went ahead and got the article and had it translated because I don't read French very well. The amazing thing to me is that Djourno and Eyries never published any more on it, nor did they do more than, I think, two patients (House 1985).

In 1961 House implanted an electrode into the inner ear (the cochlea) of a man deaf from advanced otosclerosis. House's implant was different from that used in Paris. It was designed so as to stimulate the cochlea at five different positions along its length... The electrode was soon rejected. The wires were insulated with silicone rubber which at that time contained some toxic substances. The implanted patient began to develop symptoms which led Dr. House to explant the electrode after about 3 weeks.

What was new in the work of Eyries and House was not that they produced acoustic sensations by means of electrical stimulation of the inner ear. Others had done that long before. What was new was their purpose: their belief that they could provide hearing for deaf people in this way. The clinical context had previously been, as it were, *latent* (Blume 1994b). It could, however, be invoked where the constraints of scientific argumentation were removed: for example in newspaper accounts. The slightest suggestion of 'making the deaf hear' was enough. M.H. Lurie, in a 1973 discussion, refers to the influential work that he, Davis and Stevens had carried out at Harvard in the 1930s:

> I remember when Dr. Davis and I gave the first demonstration at the international meeting of the Physiologists. The newspapers obtained a report of the presentation. The first thing I knew I received letters from individuals all over the world asking when could they come and have their hearing restored and that is the great danger of this work appearing in the newspapers and the ensuing publicity...There will be people demanding that these procedures be done on them... (Lurie 1973).

In the period around 1960 the first attempts were made to make this clinical context manifest. However the time was not ripe. Both Eyries & Djourno and House stopped work after two or three attempts. Neither technology nor professional communities could support their ambitions. Within a few years House had started again however, though using a simpler device. His work was to inspire similar efforts in many other centres.

Part of the appeal of cochlear implantation for otologists lies in its probable implications for the status and jurisdiction of the speciality, as I have suggested. A pioneering 'bionic' technology, a treatment for a very large group who at present remained wholly without the speciality's jurisdiction: the appeal is not difficult to imagine. At the beginning of the 1970s surgeons working on cochlear implantation were convinced that the future was rosy: that of the 300.000 profoundly deaf individuals in the USA "as many as two thirds of these patients might derive some potential benefit from an implant device" (Merzenich & Sooy 1974). But there was a long way to go. Fellow professionals had not as yet been pursuaded, whilst within the basic research community there was outright opposition. Scientists working in the physiology and neurology of hearing took the view that present knowledge provided insufficient grounds for 'human experimentation'. Whatever clinicians' desire to 'oralise' the 'deaf and dumb', the basis on which to design an implant properly was simply lacking. Many felt that to proceed on the basis of what was then known was professionally and ethically unacceptable.

The beginnings of cochlear implantation in Britain: 1973-1978

Central figures in the origins of British work on cochlear implantation were the London ear surgeon Ellis Douek and the phoneticist Adrian Fourcin (at University College, University of London). The Department of Health, prompted by a deafened Member of Parliament active on behalf of the disabled (Jack Ashley, now Lord Ashley) suggested to Douek that his specialism was doing far too little on sensorineural deafness, and why didn't he do something in that area. It was suggested that he apply to the Medical

Research Council (MRC) for research support. Douek decided that, before going off to the US and seeing what House and the others were doing, he'd try it himself. This he did: sticking an electrode to the *outside* of a patient's cochlea. Surprised by the results – which seemed to show that you could get the same kind of results House was getting with an *implanted* electrode much less invasively – Douek went off to the MRC. Some discussion of artificial stimulation was already taking place in the MRC's Subcommittee on Sensorineural Deafness. The Council's basic scientists were not impressed by Douek's rudimentary experiment. Like their American colleagues MRC scientists were skeptical of the value of the approach: real language was far too complex. At this point the MRC put Douek in touch with Fourcin. Trained originally in physics, Fourcin worked in a department which had a long tradition of research in the technical-physical aspects of his discipline.

> We went to his department, which was like a magic cavern for me, with equipment that I'd never seen, and so on. He had an apparatus, which he had invented, called a Laryngograph. He said, "Look, if we put these electrodes on someone's neck it will record the changes in the pitch of the voice. Not speech. Speech is the mouth"... I'd thought of speech and voice as one thing... He said to me "Look at this." And there was an analysis of all the voice recordings with the Laryngograph. He said "What does that remind you of? Isn't it exactly the same pictures that you were able to produce by electrical stimulation?" (Interview with E. Douek, London, May 1992).

Fourcin demonstrated to Douek how an acoustic stimulus based on voice frequencies added to the information which could be read off from the lips.

In late 1974 the MRC set up a small Working Group, with the tasks of assessing existing research in the area of artificial auditory stimulation, and of recommending research to be carried out. Both Douek and Fourcin were members of this group. The Working Group concluded that whilst artificial stimulation was potentially useful "to the small number of patients who become totally deaf through a cochlear degenerative disorder", its practical achievements to date were limited (Thornton 1977). A simple approach was recommended, involving placing a single electrode *on* the round window. Avoiding the risks of implantation, and the complex electronics of other approaches, work along these lines had to yield a variety of information on pathology, physiology, psychoacoustics and surgical techniques. The Working Group's recommendations, presented in 1976, were accepted by the MRC. Douek and Fourcin, together with Cambridge psychologist Moore, presented a research proposal along the lines of the Working Groups report which was also accepted. In January 1977 the project formally began. First results were published in the course of that year.

The project differed from most implant projects abroad in two important respects, which were repeatedly stressed. First, deriving from Douek's initial experiment, was the view that a less invasive, and thereby less risky, extra-cochlear approach should be used. Second was Fourcin's important contribution: the idea that, at least at first, the implant should be used to supplement the information available from lip reading. The attempt to provide 'hearing' was not a realistic goal with the relatively simple (single channel) device being used:

> Our initial program of work was based on the expectation that the post-lingually totally deaf adult would depend on lip reading for speech communication, and be able to make use of any speech relevant sensation by reference to an earlier memory of speech patterns.

What was established here was a creative and productive research project, original in the questions it asked of its emerging implant designs. In the late '70s and early '80s this group made no claim whatever to have a prosthesis available for implantation on a substantial scale. Patients were restricted to adults who had had normal speech communication prior to total loss of hearing in both ears. This meant that patients could make use of their memory for sounds in describing sensations. The claims made, largely in the scientific and medical periodicals, were limited and technical, and did not lend themselves to newspaper headlines. Any clinical provision which might follow from their work lay in the future

The beginnings of clinical provision in Britain and Sweden

Between 1978 and 1982 not only did professional opinion begin to change, but industrial interest emerged. This change in opinion can be seen in both Britain and in Sweden (where discussion now began). The results of an independent assessment of House implantees, carried out in the USA, which showed modest but definite benefit, contributed significantly in this respect. These developments were such that one can speak of a new era in the history of cochlear implantation having begun around 1982.

In the USA House was continuing to claim that clinical provision of a useful prosthesis for the totally deaf was already possible. Indeed, together with 'co-investigators' based in various other centres, he was implanting on a significant scale. House's work was attracting considerable attention internationally among otologists. In France, it inspired C. Chouard to take up the work which his former teacher (Ch. Eyries) had begun years before. In Britain, despite Douek's claim to be developing a better implant than currently available, interest in clinical provision was growing. Here it was the Department of Health (DHSS) which took action. In October 1977 the DHSS invited a group of three experts (two ear surgeons and a neurophysiologist) to review current efforts in the area of electrical stimulation and to make recommendations. The three experts visited all active US centres in October 1977. In their report (Ballantyne, Evans & Morrison, 1978), these experts recommended a cautious approach in Britain, starting with a careful evaluation of the single channel implant. But that was not how it happened. Professional enthusiasm was not to be restrained in that way, at least not in Britain.

Ballantyne, Evans and Morrison also bear witness to the changes taking place in professional opinion in this period. In 1982 these British experts sought to revise the impression created by their earlier report (Ballantyne, Evans & Morrison 1982). In their new document (not commissioned by the DHSS), they argue that progress in the intervening period has been such as to lead them to revise their earlier emphasis on caution. Despite continuing uncertainty as to the relative utility of single and multichannel implants, the value of the technique has been proven. It would be advisable for the UK to establish a limited number of implant centres forthwith, concentrating on patients with whom success is to be expected, and working according to a common protocol. At the same time, states this report, further research on methods of transmission and stimulation should be carried out, and a working party should be set up to investigate the advisability of implanting prelingually deaf children.

A decline in professional opposition, official approval (by the US Food and Drug Administration) of the House single channel implant (now being manufactured by 3M) for implant in postlingually deafened adults, the activities of industrial firms,[1]... all these factors led to the beginnings of clinical provision in both Britain and Sweden in the early 1980s. There were however major differences in the way this occurred. In Britain, despite the recommendation of Ballantyne et al. in 1978, provision began in an unco-ordinated way, on the basis of various individual initiatives. In Sweden a decision was taken to implant a limited numher of deafened people and carefully to assess the results.

By the early 1980s there were a number of British otologists who wanted to begin clinical implantation. Some of them had visited House in Los Angeles, and had been impressed with the results he was obtaining. These surgeons did not share the views or the research interests of Douek and Fourcin. Public funds were not available, and surgeons interested in trying their hands at cochlear implantation (including Ballantyne and Morrison) had to find alternative funding.

One of the first to act was Fraser, a consultant ear surgeon at University College Hospital. Fraser did his first implant operation in March 1982, using a prototype multichannel device being developed in the University of California at San Francisco (Interview with G. Fraser, London, Febraruy 1992). Failing to obtain funds from either MRC or DHSS, Fraser's initial work was carried out 'on a shoestring'. He was, however, subsequently able to obtain five years funding from a charitable organisation (in 1983 or 4). Dissatisfied with the performance of the UCSF device, Fraser then started using a device being developed in Austria, before finally deciding that they should build their own implant. The objectives in this development work – which was carried out in collaboration with the Royal National Institute for the Deaf – were very different from those of Douek and Fourcin. Fraser's team wanted to develop a simple (single channel) device which, by virtue of low cost, could in principle be made widely available. Expansion of the work was restricted by lack of funding although gradually, as other groups managed to obtain small amounts of charitable funding work in other cities (Bradford, Cambridge, Manchester etc.) started.

Gradually pressure from the medical profession for public support of cochlear implant provision was building up. "I have a nightmare", wrote a nearby observer, the Director of the MRC Institute of Hearing Research,

> that a Health Minister, rather than accepting a policy of comprehensive rehabilitation for those who need it and can benefit, might in the future be pressurised into accepting 'cochlear implants' as policy simply because, like Everest, they are there and are famous (Haggard 1986).

In Sweden it was at the beginnings of the 1980s that discussion started. By this time there were one or two otologists who felt that the technology should be tried out in Sweden too. On the other hand, there was opposition among senior colleagues: a sense that the potential risks were too great. In 1983, the Swedish Medical Research Council convened a meeting, to which leading people working on cochlear implants abroad were invited. According to Goran Bredberg (the first Swedish surgeon to carry out an implant operation) foreign experts felt that Sweden was a good place for an implant programme. It is also apparent that Swedish doctors felt the need for foreign support in legitimating the beginnings of a Swedish project. At the end of that meeting it was decided to initiate a trial project in Stockholm. 10 people would be implanted between 1984 and 1987, and the results carefully evaluated. A year was scheduled for this assessment of what had been achieved before any further decisions would be made. No special funds were made available. However, whilst British surgeons had been obliged to raise funding from society-at-large, Bredberg was able to find funds through some reallocation within his hospital's existing budget. Finding patients, however, was more problematic. Of those who came forwards, some 4 out of 5 were not suitable.

> We also contacted patients who had been in our very hard of hearing programme... we also contacted young people (now about 20 years of age) who had been through the school for the hard of hearing... tried to pick up those who had progressed to deafness (Interview with Dr. G. Bredberg, Stockholm, March 1992).

Why were there problems in this respect? Professional opposition, Dr. Bredberg explained, had declined by this time, "though there was some debate going on". But there was opposition from the deaf organizations. In striking contrast to colleagues in other countries whom I have interviewed, Bredberg remembered well the arguments used by the deaf organizations

> They were negative and they said...you know in Sweden they have a very strong organization, the hard of hearing. They said, they should learn sign, they should learn the mouth-hand system where you give...[*cued speech*?]. Cued speech, that's right. And they wanted the organization to have as many members as possible. And they said also, this is artificial to have this kind of thing, this electric thing implanted: it's not natural. They said change the other things. And they said it's risky... They had a lot of arguments.

At this time, explained Dr. Bredberg, the deaf organizations limited themselves to spreading negative publicity among their members.

> I don't remember if it was in the newspapers. There was I think in the deaf newspapers...strong argument against it. But the tougher discussion has happened a little later, when we started operating children. There they have made an official stand. They said no child should be operated before the age of 18, when he himself can choose...They made an official statement and they tried to write to all politicians.

When I raised similar issues with Mr. Fraser, he painted a very different picture of the politics of implantation in Britain:

> *"Do you think part of the reason you were encountering resistance in MRC, in the DHSS, was to do with some sense of the objections of the deaf?"*
> "Not at all...except that they will pick on anything as an excuse for not giving money..."

When I asked Mr. Fraser (who was not implanting children)[2] about resistance he'd encountered from the British deaf community, he answered by describing demonstrations he had faced at lectures and meetings:

> Somebody came up with a picture of a head, with a bolt through it...

Apart from these symbolic protests, Mr. Fraser doubted whether any political pressure had been working against him.

Media presentation has been of great importance for the development of cochlear implantation. This is more obviously true for Britain, where funds had to be raised, but it is true for Sweden too.

> Some of the patients who had been operated on, they had gone to the local press. They had gone to the weekly magazines and so on...there were a number of interviews ... Which then built up pressure from the patients themselves... [...] ... if we didn't have that contact it would have taken a long time (Bredberg interview, *loc cit*).
> "*So the implanted patients themselves were a valuable resource...?*"
> "Absolutely. Absolutely."

Media presentation was typically encouraged. In all countries intending implant surgeons had a clear interest in publicity, and of course positive publicity, for their first efforts. This is to do with recruitment of patients (it was obviously important that there be a sufficient number of suitable applicants)...it has also to do with political influence, with the attempt to secure (public) funding for these costly devices. Implant surgeons' published accounts of their first experiences almost never make any reference to the problems involved in recruiting patients. Selection criteria are typically discussed in detail, but the difficult process by which a body of potential implantees (among whom a selection could be made) was built up, is passed over in silence. Why deaf people did not rush forwards in their hundreds at the first opportunity; why the expectation – which certainly played a role in the emergence of industrial interest – that the majority of the deaf would seek an implant proved wildly wrong are questions to which one will find no answer in conventional histories.

Deaf perspectives on cochlear implantation

Thirty years ago no alternative history of cochlear implantation could have been written. The cultural and intellectual resources necessary for a deaf history of the implant had not been gathered together. It is only in the last two decades or so, with the emergence of the notion of a collective identity and culture of the deaf (Lane 1988, Pos & Oderwald 1994) that it becomes possible to conceive of such an alternative rendering. How did the deaf became aware of the implant? What significance did it come to acquire for them?

In Britain the deaf community had not noticed the work which Douek and Fourcin had been conducting since the late '70s. Having no need actively to seek either patients or funding within society at large, this programme neither sought nor received widespread publicity. Cochlear implantation really came to the attention of the deaf community through the mass media: through media coverage of implant operations.

By 1984 controversy was developing, principally to do with the idea of implanting children, which (it will be recalled) had been put on the agenda by Ballantine et al. in their 1982 report. A major stimulus to controversy was the publicity surrounding an implant operation carried out by Morrison at the London Hospital in August 1984. Subject of the operation was a 21 year old Oxford undergraduate, Jessica Rees,[3] who was subsequently seen on television humming along to music. In Britain it was the organisation of parents of deaf children (NDCS), rather than the deaf community, which first tried to start a public discussion. Harry Cayton, the then director of the NDCS was quoted in 1984 as follows:

> Medically these operations are still experimental. Five or six operations on adults in Britain do not yet provide a basis for extending the programme to children. Nor do we know what the effect of having the implant for 10, 20, or 30 years is going to be. It might be very interesting for doctors and audiologists to study the reactions of a child with an implant but sometimes they seem to forget that deaf children are people, not just a set of non-functioning ears (O'Hagan 1984).

This suggestion that some doctors might be driven by their scientific interests to do things which are ethically questionahle has also been made in various sociological studies of medical innovation. A year later, in the *British Deaf News*, Paddy Ladd introduced a quite different argument, when he connected the emergence of the cochlear implant to the history of deaf oppression. Rumours were spreading and deaf people were becoming worried. Many of their fears (such as that the implant could provoke brain damage) now seem misplaced, but that is not the point. Ladd offered them a way of making sense of what appeared to be going on. His arguments were quite different from Cayton's (though he refers approvingly to the NDCS's stand). Under the headline *Oralism's 'Final Solution?'* Ladd interpreted the introduction of cochlear implantation as a further step in the medical (or as Lane now terms it the 'audist') establishment's attempt to keep the Deaf community in check. The media, he argued, have always been "hand in hand" with oralism. Within the BBC, Ladd tells us, "People at *See Hear!* and elsewhere have tried to get sense into the programme makers' heads. All to no avail." Ladd took the view that cochlear implantation, and its representation by the media threatened to create "a climate that will destroy all that we have built up in the last five years." Paddy Ladd called on members of the British Deaf Associaton (BDA) to protest strongly at the (then forthcoming) Manchester meeting on deaf education at which cochlear implantation was to be a major discussion point. They did: with banners and protest. But it is doubtful that their views were given much credence by those inside the meeting. "What had been built up", as Ladd put it, was only the beginning of any acceptance in Britain of the view of deafness which Deaf spokesmen espoused. Though research on British Sign Language, inspired by Stokoe's earlier work in the USA, was underway, the notion of the deaf as a distinctive linguistic and cultural community had made only limited advances in Britain.

In a recent Guest Editorial in the British Journal of Audiology Carlo Laurenzi (a sociologist working for the NDCS) refers to the role of the media: "In order to sell news", says Laurenzi, "they need either to sensationalise, dramatise or scandalise. Objective reporting rarely helps to sell newspapers" and to the role of charity fundraisers (who need to dramatise in order to appeal to potential contributors) (Laurenzi 1993). Out of all this, suggests Laurenzi, were born some of the 'myths' surrounding cochlear implantation.[4] This 'sensationalisation, dramatisation' and 'scandalisation' has provoked considerable concern among deaf people. It is only now, responding to the build up of concern among the membership, that the major organisation of the British deaf, the BDA, is engaged on formulating a policy on cochlear implants.

In Sweden things have been different. An alliance of deaf organizations, the organization of parents of deaf children, and sign language researchers at the University of Stockholm had succeeded in obtaining official recognition of Swedish Sign Language as a minority language in 1981. Major changes had taken place in the education of deaf children, in provision of interpreter services, in the use of Sign Language on television and so on. The deaf organisations were accepted as representatives of this minority, with a right to be heard on matters affecting the well-being of the community. In Sweden the deaf community did not first hear of cochlear implantation through sensationalist accounts in the daily press. Discussion of the technique began in the organizations of deaf and hard of hearing people, and in their periodicals, *before* Goran Bredberg carried out the first Swedish implant operation. In February 1982 *Auris*, the journal of the hard of hearing association (HfR),[5] carried an article on research going on abroad on the cochlear implant and pointing out that a Swedish working group has been established to follow developments abroad. In mid 1983, when the decision to do the 10 implants was taken, this fact was also announced. There was also an article about one of the first two Swedes implanted (in Vienna, paid for by her family). More information followed, on the possibilities and – clearly set out – the limitations of the implant. It will give perception of sounds, though language perception is unlikely. A long period of training is required. The organisations were preparing, and *before* the first operation was carried out in Sweden. The HfR discussed implants at their Congress in December 1983. A report on the congress in *Auris* says that HfR welcomes any aid that will improve communication possibilities for deafened adults who have no help from conventional hearing aids. They are not against an experimental series in Sweden, but prefer that the less invasive extra-cochlear device be used since the extra benefits of the more invasive and more costly intra-cochlear device have not been proven. HfR also demands to be involved in the evaluation of the first series of 10 before any decision regarding further implantation be taken. The deaf organisation (SDR) too began discussing cochlear implantation in advance – it seems roughly at the time the decision was taken to set up the experimental programme in Stockholm.

When Swedes began to be operated (in 1984) the operations received the same sort of coverage from the daily press as elsewhere. But though the headlines are comparable with those found in other countries, the texts are typically more restrained. Thus in December 1986 the wide-circulation daily *Aftonbladet* carried an article on 31 year old Asa Bergman-Blom, who had been deafened for 4 years ("I have got half of my life back and my husband"). The surgeon, Dr. Bredberg, also interviewed, stressed that though the implant gives a perception of sound, only some implantees are able to perceive parts of speech. Sound and hearing will never be the same as before the onset of deafness. By this time the deaf organisation SDR is beginning to consider the longer-term implications and risks of implantation – even though there has yet been no suggestion of operating on the born-deaf or on children. In 1985 SDR-Kontakt carried an article on the possible dangers implied by the device. "The greatest danger with these 'machines' is that you are cheated into believing that the deaf has become a hearing person. Oralism has once again got the wind in its sails, with false arguments." The article ends:

> Let us together, with united strength, prevent mechanical hearing operations in defenseless children and instead work for a good childhood and adolescence for them.

The points to be stressed are that discussion began in the organisations of the deaf and hard of hearing before implantation, and before coverage in the mass media. Readers of the periodicals of these organisations thus learned of cochlear implantation in a very different sort of way than did the British deaf.

Conclusions

The implantation of deaf people for therapeutic rather than purely research purposes began at roughly the same time in both Britain and Sweden. The devices principally used were imported from abroad, so that one can hardly expect deaf communities in either country to have exercised much influence on their development. Yet it is clear that these 'beginnings' were very different in the two countries. In Sweden, with its more consensual approach to public affairs, broad discussion preceded a collective decision to begin implantation on a cautious and experimental basis. It was agreed to start with a group for whom positive expectations were the clearest, and the deaf organizations were aware, in advance, of what was planned. They were able to begin formulating their own point of view. And note what they required: to be involved in the evaluation process. The question of the acceptance of sign language, the acceptance of the deaf as not a handicapped but a culturally and linguistically different group was no longer at issue. The Swedish deaf had reason to expect that they would be listened to: their views taken seriously. In Britain prior discussion was limited to professional circles. In the face of official unwillingness to provide funding (probably largely for financial reasons) surgeons went out into the community, seeking patients and funds. Media coverage was an important resource in their quest for both. It was through this coverage, not through prior consultation, that the deaf heard of cochlear implantation.

The British deaf community was not consulted, and professionals had little interest in, or respect for, their views. Deaf people learned of the technology through sensationalized accounts in the mass media, inspired by the (implicit) claim that medical science was on the point of eradicating deafness. It was a sense of threat which inspired the understanding of the cochlear implant which they developed. The device was interpreted in terms of the history of their oppression from which they had gradually begun to free themselves. The old enemy – oralism – and all that it stood for was once more flexing its muscles. The Swedish deaf community, respected, accorded the rights of a cultural minority, more secure in the gains it had made (which were also much greater), could and did react quite differently. It sought a voice in the collective view which would be reached regarding the benefits of implantation. Privately as well as publicly, doctors were obliged to take their views seriously and adopt a more cautious approach to implantation.

The Swedish deaf community had earned the right to be consulted. Subsequent events, outside the scope of this paper, make clear that even in Sweden the device has disturbed previous accommodations. The deaf organizations were not consulted to the extent to which they felt they were entitled: a matter about which they have protested. The technology has led to disagreements within the organisations of the deaf, notably regarding the age at which children might be considered candidates for implantation. Nevertheless policies were formulated and presented to politicians. In Britain this was not the case. Denied respect or serious attention, excluded from decision-making processes, the organisations of the deaf were not in any position to formulate a considered and 'reasonable' policy towards implantation. In order to give voice to their concerns they were forced into the symbolic protest characteristic of all excluded groups. Here too things have begun to change. In contrast to France symbolic protest has given way to the collection of information, to policy-making. This is not to say that the sense of threat has necessarily receded, or that deaf organisations now accept the value of implantation (except in deafened adults). It is rather that the British deaf organisations are beginning to express their concerns in other ways.

Noten

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1. By 1980 some five firms were involved in the development and production of cochlear implants. See Garud and Van der Ven 1989.
2. Differences in ethical perceptions are brought out by a newspaper account of the implantation of Michael Batt (then aged three) by surgeons at another leading implant centre. The child's mother said advisers at the Royal National Institute for the Deaf and on London University College Hospital's implant programme told her the operation was not ethical because of Michael's age. The caption under the photograph of Michael is: "Into the world of sound: Michael Batt, aged four, whose entire life was changed by an ear implant." (The Sunday Times November 19).
3. Jessica Rees had published an autobiography *Sing a Song of Silence*. For example, the *Daily Telegraph*, under the headline "Electrodes work for deaf girl" and a large photograph, reported that "twenty one year old Jessica Rees [is] hoping to hear again as she awaited the results of her operation yesterday."
4. In 1986 Professor Haggard, director of the MRC Institute of Hearing Research, had also been critical of media "overselling" of cochlear implantation (Haggard 1986). In his view the attempts made by the NDCS to "set the record straight", to re-adjust "the disturbed balance of acceptance and hope on the part of thousands of parents of deaf children", were well justified.
5. The HfR represents *deafened* people: distinguished from the deaf thus not by the extent but the timing of their loss of hearing.

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