

THE CONTRIBUTION OF SCIENCE AND TECHNOLOGY TO COMPENSATE HANDICAP

Report by Mrs Bérengère POLETTI, MP

Mrs Bérengère POLETTI, MP, first makes an inventory of the prospects of the improvement of assistive devices compensating for the consequence of handicaps, then she sets forth the obstacles hindering the take-up of these devices and presents the means to improve a situation that is not satisfactory.

Summary

Five million people (7.9% of the French population) should wear hearing aids and 1.8 million people use a wheelchair at home. The ageing of the population will lead to a 50% increase in the number of the dependent elderly in 2040. These few figures allow the importance of disability assistive devices to be measured.

HOPES AROUSED BY NEW TECHNOLOGIES

The development of new information and communication technologies has opened, in the handicap compensatory field, prospects regarded as science fiction twenty or so years ago. The disappearance of most cases of profound deafness and, in the relatively close future, the end of total blindness for a large number of the blind, can now be envisaged.



Robot

The multifaceted contribution of new technologies in combating handicaps

The increase in the power of computers and their miniaturisation are drastically changing the scope and the nature of tools combating handicaps.

This can be seen in a multitude of fields difficult to be determined with any precision as the frontier between products devoted to the handicapped and general public goods is permeable.

With the ever greater ageing of the population, **home automation** and **robotics** are likely to develop as they offer technical solutions adapted to the needs of the dependent.

Considerable progress has been accomplished in the field of the **interface between man and machines**. This progress completes that achieved in home automation and robotics, forming a genuine revolution. The possibility of operating a computer by head movements or even with the pupil, forms a breakthrough in compensating for the most serious handicaps.

Already successfully used in treating Parkinson's disease, **electrical stimulation is giving rise to great hope**.

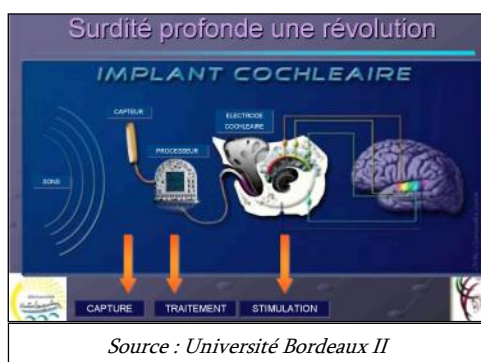
Sensory disabilities overcome ?

The greatest ongoing progress concerns the two main sensory disabilities: deafness and blindness. It is now possible to allow the profoundly deaf to hear and new processes allow envisaging sight being given back to the blind.

Ophthalmic surgery has already led to a considerable decrease in the number of the blind. Nevertheless, it is still powerless in the face of some diseases for which the use of assistive devices remains the sole solution.

It is estimated that in approximately ten years time a significant share of people having lost their sight will rediscover some visual perception thanks to retinal prostheses.

For diseases causing macular degeneration, the idea is to try to magnify the slight vision patients still have so that they can regain or keep their autonomy with **magnifying glasses**.



The new techniques combating deafness, especially cochlear implants, allow **profound deafness to be eliminated**. Acoustic prostheses, thanks to the improvement of digital techniques, are making remarkable progress. Admittedly, these devices do not give back normal hearing but nevertheless allow good integration in everyday life.

While the fitting of cochlear implants in the treatment of deafness is sometimes disputed, several arguments support their wider use in framed conditions:

- Cochlear implants are effective.
- Profound deafness is a handicap that should be screened as early as possible so that children do not fall behind in learning whatever language (oral language or sign language).
- Medical teams are responsible for screening deafness and informing parents.
- There is no valid reason to exclude deafness from systematic neonatal screening.
- A second examination must be performed before parents are told about a deafness diagnosis.
- In the event of deafness, parents must be objectively informed of all the possibilities of compensating for their child's handicap, such as the fitting of cochlear implants.
- By informing parents as early as possible about deafness in their children, the latter can master sign language more quickly.

In a close future, **the wheelchair of the most seriously handicapped will probably be designed**

as a genuine '**central control system**' allowing the handicapped to regain greater autonomy of movement and also accomplish, thanks to the installation of a robotised arm, a certain number of tasks, for example drinking, a simple activity for the able-bodied but difficult when it requires the presence of someone else.

Considerable progress has been achieved in the development of **artificial arms and legs**. 20% of American soldiers amputated following wounds in Iraq, can therefore become active servicemen again thanks to new prostheses.

Exoskeletons, which are articulated arms fixed on the limbs and moving the latter, are mainly used in physiotherapy. They could however form an interesting future pathway for some forms of paralysis.



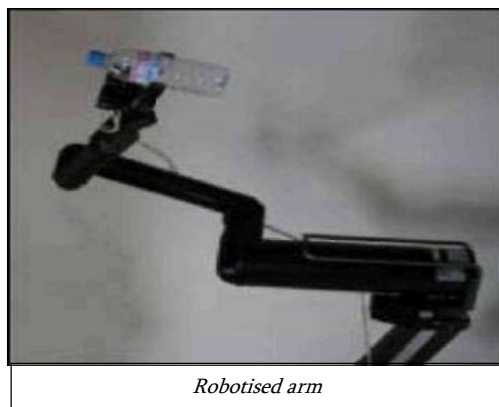
Exoskeleton

The fundamental contribution of assistive devices in the integration of the handicapped

The integration of the handicapped in everyday life implies greater use of assistive devices which must, if we do not want their cost to be prohibitive, be integrated from their design in public policies.

The idea must be dispelled according to which accommodations, such as access ramps, would be to the advantage of the handicapped alone. Urban public transport network managers who have conducted a global accessibility policy (i.e. taking into account all forms of disability, whether motor

were satisfied with this policy because, without being handicapped, they could board buses more easily with pushchairs and shopping trolleys. They also noted that public address systems fitted in buses considerably help tourists and the elderly alike.



The development of assistive devices requires an extremely pro-active policy as regards the accessibility of public areas and also private places.

TECHNICAL PROGRESS FOR ALL ?

Several obstacles are hindering the diffusion of technical progress.

Cultural factors must not be underestimated. For instance, a negative image is generally associated in France with wheelchairs and hearing aids.

The take-up of assistive devices often requires accompanying measures.

Many recent products are not included in the reimbursement policy.

Manufacturers do not always send in to the High public health authority the files to obtain acceptance for their reimbursement, in order to avoid the related constraints.

The sharing of roles between the National solidarity fund for autonomy (CNSA) and the health insurance authority is not always clear.

It is premature to attempt to assess the action of 'Maisons du handicap' (administrative structures in French departments dealing with the handicapped), in their first year of operation.

Prospective studies demonstrate that it is necessary to reason by technological segment, in terms of the sought goal and, in this field, support for research is insufficient.

Insufficiently valued research

While the traditional strengths and weaknesses of French research are to be found in the disability field, specific characteristics can also be identified, related to the applied nature of the research performed.

For more than twenty or so years the structuring of research in the disability field has been a recurrent question. Many reports have addressed this issue by denouncing primarily the weakness of the means, the absence of a structured organisation and the overly weak visibility of this sector.

There are many reasons for this shortcoming, the three main ones being:

- The very scant attention given to handicap issues in education in general, and especially in the fields of health and medical sciences.
- Handicaps are not openly prioritised by research bodies, but this situation is changing favourably.
- Lack of agreement over the perimeter of research coming under various disciplines - human and social sciences, education sciences, biomedical research, physiotherapy techniques, automated equipment, robotics.

A research field devoted to the issue of handicaps must be brought to the forefront in France.

Unsatisfactory market operation

The assistive devices market represents 19 billion euros, i.e. 12% of the market of medical goods, and more than 60,000 different products.

The narrowness of this market, characterised by the very low number of manufacturers in France, excludes any real competition. Therefore prices are very high, adversely affecting the actual level of reimbursement.

Some devices are correctly defrayed by the health insurance authority, for instance manual wheelchairs, while others (computer-aided reading devices) are not reimbursed at all or insignificantly with regard to the expense (hearing aids).

The complexity of coverage leads to undeniable difficulties for manufacturers and also for the handicapped.

Pathways to remedy the market shortcomings

- **Information:** Difficulty of access to information forms a recurrent complaint by all the players. Two regrets have been mainly expressed: insufficient contribution by the Information and advice centres on assistive devices (CICAT) and lack of knowledge about ergotherapists.

- **Standardisation:** The first requirement to lower prices is to integrate the taking into account of a handicap as soon as a product is designed.

- **Rental:** Its generalisation would allow wider distribution of assistive devices.

RECOMMENDATIONS

- A foundation for research on compensating for handicaps should be set in place. It would fund research on innovative products and would help SMEs to market them. This foundation would group all those funding assistive devices, including car insurance companies (by virtue of the indemnification of road accident victims). It would influence the cost of products by covering part of research costs.
- A 'biotechnologies' section must be created within the National council of universities (CNU). It would promote vocations of researchers in the field of assistive devices and the teaching of this field in faculties of medicine.
- Public research establishments and universities must pay thought together to how they can strengthen their cooperation, by drawing inspiration where required from the example of the 'Institut de la vision'.
- It is essential to promote early screening of all handicaps so that compensatory assistive devices are proposed as soon as possible.
- It is advisable that part of the funding of assistive devices to be paid by patients should be the subject of a tax credit (this provision would be limited to those with more than a 50% disability).
- The advice function should be clearly identified in the invoicing of ancillary costs related to devices; in particular, consumables should be the subject of reimbursement by the health insurance authority.
- A mechanism should be set in place guaranteeing independence between the consultant and supplier, especially for hearing aids.
- The encouragement of rentals of devices, where possible, (wheelchairs) and the development of a secondhand market, would be useful.
- By strengthening the Information and advice centres on assistive devices (CICAT), the development of independent advice and tests structures should be favoured.
- The marketing procedures should be simplified by substituting the analysis of benefits and risks for the precautionary principle that can delay excessively the marketing of new products.
- A request for an inquiry must be brought before the Conseil de la concurrence (Competition Council) to check whether anti-competitive practices exist in the disability assistive devices sector.
- The departmental disability allowance funds should limit the remainder to be paid to 10% of the amount of the expenditure; the absolute necessity to reach the goal set by the legislator should be recalled.
- It is necessary to ensure correct application of the Act of 11 February 2005 by the departmental 'Maisons du handicap'. These should reason in terms of the needs of the persons with disabilities and not on the basis of the acknowledged disability level.
- Thought should be paid to the ethical dimension of disability assistive devices.

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