Re-Inventing the Wheelchair;
Technology and People With Disabilities

by

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For

The Commission For The Future

"Despite the existence of numerous important problems relating to developing technologies, the more serious questions are social ones - of financing, of conflicting and ill defined goals, of hesitancy over the demands of distributive justice, and of isolated and uncoordinated programs"

Office of Technology Assessment, USA

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1. WHO ARE WE TALKING ABOUT?

SHANE

Shane Kelly is 28, thin, has a John Newcombe moustache and cerebral palsy. He cannot walk unaided or speak clearly. He needs help with dressing himself, eating, and using the bathroom. He lives in a group home -- owned and staffed by a charitable agency -- which he shares with two other men who use wheelchairs. He is a journalism student at a Technical and Further Education (TAFE) college and hopes to find work in the field after he graduates.

Shane's part of the interview that follows was spelled out on a communication board -- a board covering the tray of Shane's wheelchair which has the letters of the alphabet and several common words and sentences written on it in large squares which Shane can indicate with his fist.

What technology do you use?

I can't walk, so I rely on two wheelchairs to get around -- one manual, one electric; I can read perfectly welt but I can't turn the pages of a book, so I use an electric pageturner; I can't use a typewriter, but I can use an Apple lIe microcomputer with special switch attachments and a program called MacApple for word processing; I can't talk, but I have an Epson HX20 laptop computer with a scanning keyboard and a speech synthesiser (which isn't working right now).

The Epson has an extra scanning keyboard mounted in the lid of the briefcase. Scanner lights move in rows down the keyboard when I press a footswitch, and then the light moves along the row item by item until I press the switch again when it's on the item I want. I can retrieve pre-programmed sentences or paragraphs -- 'Hello, how are you?', that kind of thing -- or I can enter new material. I can either print out what I want on the built-in miniprinter or speak it directly through the synthesiser.

What's the most important one of those?

Word processing on the Apple. Getting stuff on paper has been a hassle ever since I was a kid. But now I can change what I write. I can shove the words around till I'm happy with them

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How does that help?

My marks at college have gone up about 10 per cent, for a start, and that makes the difference between passing and failing.

What about the Epson?

I think the speech synthesiser will give me a lot more acceptance in the community. Spelling boards like this one get the message across if you're talking to someone who knows how to use them, but the uninitiated have difficulties.

I remember one time when I'd taken the train into the city to catch a film and see the Moomba parade. That was OK, but after the parade I noticed that my electric wheelchair was slowing down. The power was running out, and it wasn't going to get me home.

I went down to Flinders Street Station to call a wheelchair-taxi. All I had to do was spell out on my board: '1 wants a maxi-taxi, could somebody please ring one for me?' I tried this on a couple of taxi drivers, but they didn't understand what I was doing. I asked a policeman, and that was no good either. I tried to get help from passers-by, but all they did was throw money on my tray, which meant that I couldn't even point to my commmunication board any more.

I finally found a young boy who could understand my spelling and ring up for me. I got home three hours late and $26 richer. People understand me better on the Epson.

What about electric wheelchairs?

I couldn't cope without one. Just getting around the house, going to the football or the cricket, going to films, visiting friends, getting to college .... There are drawbacks. They weigh so much that you can't put them in an ordinary car boot. That means you have to design a lot of your trips around getting a wheelchair taxi at each end, and the maxi-taxi system has too few cars and not enough flexibility.

What other problems are there?

Motorised wheelchairs break down a lot and it can take two months to get them fixed. I'm having similar problems with the Epson -- I keep hitting the wrong button and wiping the programming, and it's hard to find a programmer handy. Oh, and it's hard enough to use a communication board when you're drunk -- I can't imagine what using the Epson would be like.

Who paid for all this technology?

The Epson was paid for by the Lions Club. The Apple belongs to the Spastic Society. I've gone through three electric wheelchairs -~ my family bought the first one, the Spastic Society bought the second (with contributions from the Government and me), and the third one came through the PADP scheme (the government-funded Programme of Aids for Disabled People).

And summing up?

Technology has helped me to beat my disability. It allows me to show the community that I am a whole person.

We are moving into a world that is being altered by technology in ways that can appear unpredictable, uncontrollable, and inhuman. Every technological gain seems to bring with it an endless list of possible undesirable side-effects; increased productivity throws people out of work, word processors give people repetitive strain injury (RSI).

Technology for handicapped people is technology with an acceptable face. Giving handicapped people machines to overcome their handicaps seems to be an indisputable good.

Looking around after thirty years of promises we see a scattering of people like Shane using various devices, but no general distribution of the benefits of the technology and no basic change to the life of the average disabled person.

Many of the problems of disabled people can be removed wholly or in part by the use of technology. But that does not mean that they are basically technological problems, or even that technology is the best way to deal with them.

If you look through this book at the kinds of devices on offer you can see that they are mainly devices that replace human involvement. A computer-operated word-processor replaces an attendant who could read communication spelled out on an alphabet board; an electric wheelchair replaces a bathchair pusher; a mechanical text reader replaces a human text reader.

That is to say, these machines are like washing machines, not moon rockets or electron microscopes; they may make tasks easier, or do them faster or cheaper than if done by hand, but they do not enable people to do things that were not possible before. Putting it another way, we could do now, today, whatever we have projected technology doing this century for handicapped people, simply by paying more people to do it.

What kind of life people with severe disabilities are going to have -- whether they are going to have an education, or a home of their own, or a job -- is primarily a political decision. The significant developments that have occurred over the past decade in the opportunities for disabled people have been things like increased transport concessions, which permits greater mobility, and funding for attendant care, which allows people with disabilities to live at home rather than being forced into institutions. These innovations have been due to social and political changes, a shift in the culture; they have not been technology-driven.

WHO'S GOT WHAT

Every disabled person is disabled in his or her own way. This means, among other things, that working out how many people are disabled is rather like asking "How long is a piece of string?" The 1981 Australian census estimates that 13.2 per cent of the population was disabled, and 8.6 per cent were handicapped.

That means about 1.25 million Australians have handicaps. More than half of these were over 55 years old. Fewer than one in five were under 25. So if you are lucky enough to live to older than 70, you have

about an even chance of ending up with a disability. In fact, 45 per cent of 75-year-olds regarded themselves as handicapped.

Roughly 42 per cent of handicapped people have severe handicaps. This translates into about 514,000 people, and more than 92,000 of them would be under 25. But definitions of severe differ, and those raw figures cover all forms of handicap -- rheumatism, weak hearts, schizophrenia, asbestosis, intellectual disability. So it is not easy to calculate how many of them are likely to need special equipment, particularly as in 1981 only 38 per cent of handicapped people used any aids at all (spectacles were not counted, because most people with spectacles are not handicapped).

About 40 per cent of people who used aids had a low-tech walking-stick or walking-frame. Next most common were hearing-aids (29 per cent of aid users), washing aids -- a long wooden sponge holder to let you soap your back without stretching, for example -- at 26 per cent, and wheelchairs at nine per cent. Since then increased government funding has certainly led to greater use of aids, especially the more expensive items like motorised chairs. But those employing high technology accounts for a very small part of a small market.

All these figures are pretty arbitrary, because the census did not define disability, it just asked people if they thought they had one and recorded their response. Some of the figures seem low and others seem high. They stand as the best broad guesses available, however.

WHAT IT MEANS

The public image of disability is based on several factors. The three most important are what people fear most about disability, what they see in the streets, and what disability groups want them to think. How people with disabilities actually experience life comes well down the list. Many of the problems of the technology come from designing aids to fit the image and not the impairment.

Visual Impairment

If you try to simulate blindness by closing your eyes tightly you are probably overdoing it. Very few people are totally blind. Most 'blind' people can perceive light in some way. In Australia a person is regarded as legally blind if he or she has less than 15 per cent of normal vision. In fact, some legally blind people can read print using special spectacles or magnifiers. They do not need to learn Braille.

Visual impairment is the most widespread of all disabilities -- think of all the pe9ple who wear glasses -- and we can all close our eyes and think how awful it would be not to see. It is the disability which attracts most sympathy, the disability which has most community acceptance. To the understandable annoyance of people with more severe but less well-understood disabilities, it is the only disability which has specific legislative indulgence. For example, blind people are the only disabled people whose income is not taken into consideration in setting their pension.

Communication Impairment

Deafness is often referred to as the hidden disability. Unless people with impaired hearing wear large hearing aids their disability may not at first be obvious. This means, ironically, that people who are profoundly or totally deaf -- those for whom hearing aids are useless -- look unimpaired.

Most of us know older people with hearing loss. It isolates them, certainly, and irritates those about them, but it's important to recognise that it's quite a different disability from severe hearing loss in youth. An older person still has an intact language background. If all else fails you can pass a deaf adult a note; not so a deaf baby.

Children learn to speak and to understand speech by listening to other people talk. So children with severely impaired hearing have major problems with speaking. Often they also have problems understanding how language works. This makes learning to read and write difficult, and getting an adequate education very hard. Deaf children and their families have to learn sign language in order to communicate. It is very powerful, but useless

if you are trying to get something across to someone who does not understand it.

While some speech impairments are the result of hearing impairment, most people with severe speech impairments can hear perfectly well. Some people cannot control the movement of their mouth, tongue or throat -- people who have cerebral palsy often have this problem -- and some have lost their voices through surgery (for instance, having to have their larynx removed because of cancer). Others can speak clearly, but cannot get the right words out. This can happen after a stroke.

Physical Impairment

There are many types and degrees of physical impairment. Less sever impairments are very common. Most people have experienced one at least temporarily -- a sore arm in a sling, for instance, or having to use a crutch for a sprained ankle -- and found out how annoying and inconvenient it is. Nearly everything we do requires two good hands, and nearly everywhere we go requires two good legs. If you do not believe this, try having a shower with a sling on, or getting on a bus with crutches.

People with physical impairment include those born without limbs, those born with cerebral palsy who cannot control their body movements, those who have progressive neuro-muscular diseases such as muscular dystrophy, and those who suffer spinal cord damage -- some at birth through spina bifida, most through accidents -- and are to a greater or lesser extent paralysed. But the largest category, the one that makes musculo-skeletal diseases the largest single disability grouping, includes those who develop rheumatism and arthritis in old age.

The list is long and the potential disabilities widely varied, but the most common are inability to move unaided and the inability to pick things up. Of these, severe hand impairments are often more devastating than mobility impairments. It's true that someone whose hands do not work may still be able to walk, but paraplegics, who cannot walk, can push themselves in a wheelchair and in addition can feed and dress themselves, write, and drive. Furthermore, severe hand impairments are among the hardest things to fix with technology, because most of the things we do with our hands require such accurate movement and such fine discrimination.

Speech impairment is a special case of physical impairment. Some people cannot control the movement of their mouth, tongue, or throat -- people who have cerebral palsy often have this problem. Others have lost their voices through surgery -- having to have their larynx removed because of cancer, for instance. Still others can speak clearly but cannot get the right words out -- this sometimes happens after a stroke.

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Psychiatric Problems

Psychiatric disabilities are not usually amenable to technology. They generally affect the ability to choose behaviour that is acceptable to society, not the ability to carry out the behaviour that is chosen. Some psychiatric disabilities are short-term -- a "nervous breakdown" -- and some are able to be repressed by medication to the point where they no longer constitute a handicap.

Technology only comes in where there is a further complicating disability. For example, the best known (and least understood) childhood psychiatric disability is autism, where the child has great difficulty in relating to the people and world around him or her. These children, however, often have their behavioural disabilities compounded by speech and language problems, and here technology may help them.

Sally is now nine years old. She had encephalitis at the age of eighteen months and lost the ability to walk and talk. She soon learnt to walk again, but her speech did not come back. Her behaviour became hyperactive, uncontrollable, and appalling. She was assessed as being not only autistic but also severely retarded.

Sally eventually went to a communication centre. She ran round and round the room not talking to anyone until the therapist got out the speech synthesiser. With someone holding her arm she spelt D-A-D, then S-A-L-LY, and then answered some simple maths questions. Since then she has shown that arm support is not for communication, it's for reassurance. In fact she works just as well if you hold the arm with which she is not spelling.

Sally's behaviour has improved markedly since she has been able to communicate. She is now in a regular class in a regular school doing her schoolwork on a typewriter.

Intellectual disadvantage

Intellectual disadvantages are often confused with psychiatric problems. But people with intellectual disabilities are simply slower at learning how to do things; they have not lost touch with the everyday world. Most of them attend ordinary schools and work in ordinary jobs. They are just a little bit slower to catch on than the average, and their disadvantages only become noticeable when they are faced with a complex task like filling out an income tax form.

Those who find it more difficult to learn academic skills certainly can benefit from using computers with individually tailored programs.

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People who are assessed as more severely intellectually impaired often have difficulties with communication and movement. Technology can assist with both, and once their communication problems have been partially remedied, their intelligence can be reassessed in the same way Sally's was.

Aging

Disability is not necessarily a constant. It is a state into and out of which most of us will move at various times in our lives. Old age is not a disability in itself, but it is where a lot of the disabilities tend to collect. The incidence of most impairments rises steeply in old age. Many elderly people have more than one difficulty.

In her 80s my grandmother wore glasses, owned a hearing aid (but did not like it and would not wear it), walked with a stick for her stiff hip, was incontinent (which was remedied by surgery), and developed Alzheimer's Disease ~~ a gradual disorientation and intellectual deterioration that occurs in about 10 per cent of elderly people. The majority of people in care are elderly. They are people who cannot live at home without support, and the support services they would need do not exist.

Old people get less than their fair share of technological assistance, partly because they are not glamorous and partly because as a group they are not rich. Rehabilitation services tend to be geared to fixing up people who are going to re-enter the paid workforce, not those who have retired from the workforce. Money for wheelchairs is not made available to people who are going to stay in nursing homes till they die. Old age is incurable, so doctors are inclined to save their efforts for frantic bursts of intensive care in the last weeks of life.

Multiple Disabilities

A small number of people have two or more severe disabilities; they are both deaf and blind, for example. A depressingly high proportion of people in this group are "medical miracles". For instance, a very tiny, very premature baby who suffers brain damage and is kept alive in neonatal intensive care may become a blind spastic quadriplegic; the young man who arrives at hospital with massive head injuries may survive to face life with a body that does not work properly, without speech and fed by a tube.

The human body is a mechanism of enormous sophistication and complexity. The most complicated man-made machine is not remotely comparable to the intricacy of a cell or even a virus. Because the body is so complicated, there are an almost infinite number of things that can go wrong with it.

As a rough generalisation, everything in a normal human body is there because it has a function. If something does not work, and cannot be

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repaired by normal processes, the body's first response is to try and cover the loss. If you lose your right hand, you will quickly learn to feed yourself with your left. If you lose both hands, the best that can be expected is that familiarity will dull the irritation of having to use the botched patchup that is the best technology can provide. Often it does not; many of the children born armless as the result of thalidomide eventually rejected the ingenious artificial arms devised for them.

Remember, too, that in some ways any talk about how technology can help people with disabilities is premature. U we really wanted to help them, we would not be starting with technology. While we still have in this country large custodial institutions like Caloola or Peet Island, where people are treated, at

best, like white mice--fed, watered, kept clean and stopped from running away into danger-·a question of priorities arises. When old men with Alzheimer's disease are chivvied out of their beds and herded in front of the television at 5.30 am because that is when the shift changes; when the response to a disturbed child bashing his head against the wall out of sheer boredom is to fit him with a helmet, it is clear that state funding for new computers is little more than conscience money. If we are serious about the rights of people with disabilities, then we are going to have to alter a lot more than technology.

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2. IMPAIRMENT, DISABILITY AND HANDICAP

Impairment, disability and handicap are not fixed quantities. What they are and what they mean change as society changes, and as technology changes. Technology can cause disabilities, it can cure or compensate for them, and it can change the requirements for living in society in ways that turn some disabilities into handicaps and some handicaps back into mere disabilities.

One hundred years ago, with a different set of technologies, disabilities and handicaps were different things. Medical technology was rudimentary. Most serious illnesses and accidents led to a quick death and thus did not leave people with disabilities. People died younger. So there were fewer old people, and therefore fewer disabled people. On the other hand, there were a lot of occupational diseases we do not have any more in developed countries; people who made hats, for example, were poisoned by the mercury used in the manufacturing process, hence the phrase, as mad as a hatter..

One hundred years ago:

- Intellectual disadvantage was not as disabling. Literacy skills were almost unnecessary for everyday living. Most people did not have to pay income tax and so did not have to fill out income tax forms. There was no social security so people did not fill out dole forms. Shops had pictorial signs. There were few central services and so people did not have to pay electricity or gas bills.

- More people were employed in agriculture than in any other sector, and fanning always had a place for a strong back. A 'slow' boy would be put to work digging potatoes or picking peas. Similarly, mild intellectual disability would not stop a girl getting married and having a family.

- Braille had been invented but Braille books were rare and education for blind people even rarer; instead they might be put to weaving or broom-making.

- There was no radio, no television, and no telephones to put deaf people at a disadvantage. Nor were there any hearing aids. The most sophisticated aids were the speaking tubes and ear trumpets used by elderly people.

- The most sophisticated aid for severely physically disabled people (of whom there were probably fewer) was the bath chair. As now, trams were accessible, trams were not. Artificial legs ("peglegs") were used (e.g. Long John Silver) and hooks, then as now, were more useful than imitation hands (e.g. Captain Hook).

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- People with psychiatric disabilities either were regarded as eccentric, and possibly treated better than today, or mad, and treated worse. There were no effective treatments available for mental illness and they risked being locked away in institutions like Bedlam, an asylum in London.

- Elderly people were proportionately fewer. They accepted the discomfort of rheumatism and arthritis as a matter of course. Deteriorating sight and hearing were common problems. Many of them could not afford glasses, and prescription lenses did not exist -people simply tried on all the spectacles the pedlar carried and took the pair that fitted best. .

A hundred years later we live in an age of information. More than at any time in the past we receive processed information through television, radio, newspapers and magazines, books and computers, and give out information by answering questions, filling out forms, punching buttons on a computer, or writing essays. Our houses bulge with the floods of word-covered paper that come into them each week.

We are provided with a never-ending stream of information from radio and television, and if that is not enough we can link up with systems like VIATEL and have our television screens display such specialised information as the current floor prices in the Chicago hog belly futures market. We now even have disabilities which are information-based -- women workers in the Third World destroy their eyesight soldering the wiring to the silicon microchips for the microcomputers that give Australian keyboard operators repetitive strain injury (RSI).

As information becomes more important, anybody who has difficulty in receiving or sending information is correspondingly out of step, handicapped. A hundred years ago, most people worked at making things, doing things, or moving things from one place to another. These were practical, physical

things like cutting hay, throwing pots, scrubbing floors, or shovelling coal. Today, most work in developed countries consists of exchanging information or instructing machines. People with disabilities used to need to find a way to use whatever unimpaired bodily skills they had; now they need to find a way to use their unimpaired intellectual skills. In the bad old days blind people may have been taught no higher skills than making baskets or brooms, but making baskets and brooms were important industries. Nobody in Australia now could make a living making baskets by hand.

Deaf people are severely input-disadvantaged. They cannot hear radio or television or use a standard telephone. If they have been educated adequately they can read and write, but they cannot hear a lecturer or, come to that, a shop assistant. They may not have clear speech and may have to communicate by sign language.

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Blind or visually impaired people cannot read standard print and are thus cut off not only from most books and newspapers but also from standard computer displays. They can produce typed output but cannot review their work.

Physically disabled people, have less trouble with receiving information (unless they are so disabled as not to be able to turn pages). But they may not be able to type or write, and if they cannot talk they are cut off from active participation in most human activities, from running for parliament to ordering a· hamburger at McDonalds.

People with psychiatric disabilities are relatively well off in an information society, though most have problems putting information into context and acting on it as society expects, rather than in receiving it in the first place.

People with intellectual disabilities have no trouble with television and radio, provided that what is said or shown is within the range of their understanding. But many of them have poor literacy skills. Handling accOtll1ts or responding to official letters is often difficult or impossible.

People who have more than one disability are the worst off, as one disability can often rule out using aids suitable for another. For instance, people who are blind and very physically disabled cannot read Braille because they cannot control their finger movements sufficiently. They also cannot use a switch-operated computer-controlled typewriter because they cannot see the display screen.

The same impairments affected people's lives differently in the 1880s and the 1980s. This is not primarily because special technology had been developed over the century to help people with disabilities; rather it is because the interplay between technology and society has over that time changed the world they have to operate in.

This interplay works in both directions. Technology cannot change the lives of people with disabilities without changing the society in which they live. If cheap text-to-speech and speech-to-text devices are developed, for example, they will not simply make life easier for people with visual handicap or hearing loss, they will change the way society looks at literacy and the way information moves around society.

If fewer people feel they have to learn to read, and more information is given through sound rather than sight, these changes will be larger and more significant for everybody, handicapped people included, than the impact of text-to-speech devices by themselves.

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When the hearing aid replaced the ear trumpet it was as part of the whole wave of change that followed the discovery that speech could be turned into electromagnetism and back into sound. Did the hearing aid help people with hearing loss as much as the replacement of written correspondence by phone calls disadvantaged them?

Educational authorities spend considerable effort trying to predict where the winds of change will blow, so they can equip this generation of students for next generation's workplace and technology. They mayor may not be successful. But people with disabilities do not have the same options; they cannot tailor their impairments to suit society. A student whose education turns out to be irrelevant can be retrained. A blind person cannot switch to being deaf because there happen to be more jobs involving the use of video screens in unpleasantly noisy environments and fewer in basket-weaving.

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3. WHO CAN BE HELPED BY WHAT?

People with disabilities can expect technology to assist with:

- transferring them around
- transferring objects for them
- transferring information
- body maintenance and
- education and rehabilitation.

People Transfer

People need to travel from place to place, to move from one piece of furniture to another, and to change position.

Aids to help people with disabilities do this range from the simple walking stick to the stair-climbing wheelchair. Wheelchair design still lags behind general advances in technology. Hand-pushed wheelchairs are heavy, expensive, and hard to fold up to fit in a car. Battery powered wheelchairs run down quickly and take a long time to charge, though this will change as general-purpose batteries become more powerful.

Wheelchair controls need to improve to allow people with a wider range of disabilities to use them. Even so, travel itself is more easily mechanised than transfers are. A wheelchair may allow a you to move around, but you will not be independent unless you can get in and out of it without help. If you want a shower you will need to get from bed to wheelchair to shower-seat and back again. There are hydraulic and electric hoists, or even low-tech pulley arrangements, but they are clumsy and hard to use.

Object Transfer

Object transfer ranges from simple things like picking up a ball of wool from the floor (a difficult task if you cannot bend over) to the dangerous and difficult task of pouring boiling water into a teacup when you have weak hands.

This area is irredeemably low technology. You can protect yourself against boiling water by having a pouring cradle for your kettle or by running a rubber hose from the tap of an urn; you can pick up wool using a telescopic stick with a pincer on the end.

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Housework, which consists largely in shifting dirt, is fairly well provided for by mainstream machines such as washing machines and vacuum cleaners (though people with severe physical impairments cannot use even them). But for the foreseeable future those parts of housework that are not yet mechanised -- for instance, potato-peeling -- will be handled more easily by providing home help than by looking to new gadgets. And the most important object transfer, that of food to mouth, is not going to be easily (or desirably) mechanised.

Information Transfer

Taking a shower and all the other activities involving moving yourself or other things -- activities of daily living, in therapy jargon -- are a problem mainly for those with physical impairments. People with sensory impairments -- who cannot see and/ or hear, for example -- develop skills, such as walking with a white cane, to help them with movement. Their main problems, and hence their main needs for technology, are to do with the transfer of information.

Information transfer includes moving information from place to place by telephone, radio or television; changing information from one mode to another (from text to speech, for example); and, most commonly, passing information directly from one person to another by talking or writing. In writing this sentence I am moving my thoughts from brain to paper -- in reading it, I hope you are carrying out the reverse transfer.

The problem facing communication-handicapped people is others tend to think of language as almost the easiest skill they have acquired -- after all, a child of six can cope with it pretty well. This means that most people treat those who cannot communicate freely as if they understood less than a six year. Even better-informed people who ·can see that this does not follow still underestimate the immense difficulties of actually solving the problem.

Almost the only people who really appreciate the enormous complications involved in the simplest communication are the people who are trying to get a machine to do it. At present, only the human brain is capable of generating or understanding language, and nobody expects that to change in the next 20 years.

The problem is that without understanding a language at a sophisticated level it is very difficult to help somebody use it. The upshot of this is that machines can assist communication only at a fairly low level, not as well, for example, as a six-year-old child. So high technology at this stage is a good deal slower than using people. The job simply is not easy enough for the computers we now have.

Communication Input

People who are hearing impaired or visually impaired need a way to magnify and clarify incoming signals. Hearing aids cannot do what we do without thinking -- pick out the voice of the person to whom we are talking in a restaurant and ignore the chatter from other tables. Hearing aids simply magnify all sounds incoming equally rather than picking one relevant message out of the background noise as the brain can do.

A new system now under development can filter out everything that is not speech, allowing hearing impaired people to listen to a conversation even against a background of traffic noise. But while that is a step in the right direction, it will not help when several people are talking in a crowded room.

People who are totally blind or deaf are unable to receive information through the usual physical channels of sight or sound. For these people, information needs to be translated into a different channel; touch or hearing through Braille or synthesised speech for blind people, and sight through print or sign for deaf people.

There are continual advances in machines that read and speak text. But unfortunately this is another case where machines understand a good deal less than a six-year-old child. Enormous amounts of computing power have to go into persuading machines that w is the same letter as **w**, *w*, ***w***, and w̲, but progress is being made, and it's one of the things we can confidently expect to happen in the next ten years.

It will mean that books will not have to be translated into Braille. You will be able to pick up a book or a paper, run a digitiser over it, and listen to it being read out (through headphones, to avoid disturbing the other people on the tram). Alternatively, the text. could activate Braille signals on a hand-held tablet, the six dots of the Braille alphabet 'popping up and down under your finger as each letter is scanned.

But while having something read out is a great improvement on being faced with a sheet of typed paper, in many ways it is less efficient than reading Braille -- the maximum speed is slower, and it is much harder to skip-read. On the other hand, surprisingly, most people who cannot read print cannot read Braille either, and will not be concerned with a loss of speed and flexibility.

People who are deaf are waiting for the even more difficult development of speech-into-text machines that will hear' what someone is saying and automatically print it out. The problems of recognising a, **a**, *a*, and a̲ pale into insignificance besides the problem of recognising a in 'all', as spoken in a Scottish accent, an Australian accent, and an American accent, or even when said by three Australians, or when said by the same Australian on three different occasions.

People use inflections and emphases that do not occur in printed text. They do not separate their words properly when they talk, and they process speech by way of a' number of conventions that are not covered in the standard books on grammar. A computer that can deal with this as we do has to have an enormous memory store of background information.

On the other hand, while we are still a long way from anything that can make the common chatter of the street readable by deaf people, we are very close indeed to devising speech-to-text machines that can help blind people and quadriplegics to type -- that is, devices that can translate one person's speech into hard copy. The Kurtzweil voice writer, at about $15,000, can already recognise a 10,000 word vocabulary once it has been "trained" by its user.

Several other devices, none of them wildly successful as yet, have been made with the idea of translating vision into sound or sound into vision directly. For instances, radar pulses generators have been attached to spectacles to give blind people auditory feedback; symbols have been flashed up on to spectacles to give visual clues to sounds for deaf people.

The real problem is that the existing alternative channels are being used fairly thoroughly already. Blind people use their hearing quite a lot, and the buzzing of the radar can interfere with that; deaf people need to lip-read, and flashing symbols can be distracting. When systems become more intelligent we may have devices slotting into the modes that the person recognises and can cope with, such as speech. For instance, the radar could be made to trigger: "Look out, steps ahead" or "Person and dog approaching, watch out for the lead". But that kind of sophistication is several orders of magnitude above anything we have now.

Deaf people need substitutes for all the useful gadgets that rely on sound -- alarm clocks, doorbells, telephones, car horns, and whistling kettles, for example. At present, the move is to the low technology hearing-ear dog, who takes his master or mistress to the source of any noise. Even Lassie could not cope with doing all the voices on television, though, so television is of little value to deaf people without subtitling. The speech-to-text devices we earlier described should encourage more extensive subtitling (though if they are cheap enough, they may even supersede subtitling for deaf people altogether).

Communication Output

People who are so physically handicapped that they cannot communicate by speech or writing, even though they do not make up a large percentage of the disabled population, they face one of the most serious problems. They need other ways to get out messages.

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The low-tech way to handle this is to have the person point out a message on an alphabet or symbol board. High technology can tap into a muscle movement, use that to work a switch controlling the word processing function of a computer, and get a printout or have a speech synthesiser speak the message. As usual, there is a problem.

People can make a range of corrections to output to take account of obvious errors. For instance, if the context is there, they can fll in misng letrs, correct obmious misspelxings, expand telegraphese insert punctuation, finis wor whe th meani is cle, and interpret ambiguous movements. A computer finds this very difficult.

Synthesised speech is still fairly primitive; it sounds like the Daleks from the Dr Who television serial, it is mostly male and American, and it is not good at inflection. This is a problem that will take a considerable improvement in the programming capacity to fix. It is probably not even worth doing, because all will be solved by improvements in memory storage over the next few years.

A laser disc, for example, would be able to store a recording of male and female readings of every word in an extensive dictionary, which could be called up whenever the word is typed; all forms, all endings, and, if the person giving the message thinks it is worth it, with inflections and emotions. A different pronunciation could be produced for a word at the end of a message, or for words in a sentence ending in a question mark, or in a sentence where the 'anger' or 'affection' keys had been pressed.

Mind you, it is not easy to impress anybody by giving lists of the wonderful things high technology will be able to do for us in the future, because most people have the vague impression that most of it is already available. Most people seem to expect our most advanced computers to be something like HAL, the talking computer from the film 2001 -- able to carryon a conversation, operate robot arms, make difficult decisions, and even lip-read human' speech.

The reality is that what we have now, and what we will almost certainly have in 2001, are glorified pocket calculators. For what they are, they do better than we have any right to expect, and where a small

straightforward job can be isolated they can open up immense possibilities for many people, but that will have to be enough for us; we must not ask for our problems to be solved by a technological equivalent of the genie of the lamp.

Body maintenance

Body maintenance for people with disabilities can include both normal everyday maintenance -- washing the body, feeding it, covering it, and grooming it (brushing hair, for example) -- and sophisticated special maintenance made essential by certain physical disabilities. People who are

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immobilised for any reason, for instance, have great problems with pressure sores. They now use space cushions originally designed to keep the Apollo astronauts comfortable.

Mrs Costello has arthritis affecting her arms and legs. In her bathroom she has taps with levers instead of knobs so she can tum them easily, and the shower has a non-skid mat and a handrail so she will not slip. Mrs Costello puts her soap into an old stocking which she loops around her hand so she will not drop it, and she has a sponge on a handle to compensate for her limited range of movement. Drying and dressing are hardest; to dry her back she lies down on the towel she has laid out on the bed. She buys clothes that do not have buttons and wears loose slip-on shoes. Her daughter sews large rings on zip tabs for her. It all takes time, but she manages. The one thing she finds almost impossible is brushing her hair, and the meals-on-wheels lady usually gives it a final tidy.

By far the greater number of physically disabled people are like Mrs Costello. They can do most things with a little low technology help, and the things they cannot do are things like brushing their hair that technology cannot do either. The more severely physically impaired you are, the more things you cannot do without assistance. The more basic the activity with which you need help, the less chance there is that high technology can help you.

On the high technology side, anything that can be turned on and off can be operated through a computer interface. This means that a person with poor motor skills but with a properly organised system can sit in her wheelchair and turn on the television, send a message over a telephone hook-up, ring an alarm if she thinks she heard prowlers, and tum on the heating, all by blinking an eyelid. This, of course, will not make her independent -anybody who is that handicapped is going to need help with bodily care -- but things will be more convenient and comfortable, which is as much as we generally expect from appliances.

Education and Rehabilitation

Technology also has a role in helping people to overcome their disabilities through rehabilitation and education. A treadmill can help strengthen leg muscles, or a computer program may provide the motivation and repetition necessary for a child with intellectual disadvantages to learn to add up.

Cognitive rehabilitation, the painstaking process of recreating lost skills and memories in people who have suffered strokes or head injuries, can be carried out by a computer, providing that the patient is happy to receive therapy from a machine. In all treatment the computer's ability to keep detailed records of the patient's problems and progress is invaluable. For example, a quadriplegic may use a wheelchair driving simulation program to check out the various wheelchair controls available, and the computer

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will record the time taken to navigate the course, the number of accidents at various speeds, and whether performance at a particular control improves over a series of sessions.

Several studies have looked at the possibility of using computer education to improve people with impairments physically or neurologically. The results are ambiguous. For example, it is possible to show that over a period people show better reaction times at moving a joystick around to play Video games; it is not as easy to show examples where these skills have been generalised to improvements in the person's motor abilities in other fields as well. And the research papers seldom record any long-term assessment of the effectiveness of these methods. The average researcher sees a person twice and then records the improvement over the two sessions, a method which gives maximum scope for wishful

thinking. Any survey that does not recognise the influence on performance of expectations, motivations, experiences and disappointments can only mislead.

A large number of studies have shown that students with disabilities find working with computers highly motivating. All these studies are of short-term projects; some record only a few sessions, some take as long as a year over it all. But studies are lacking of whether not the motivation persists when students can see the whole situation in perspective, when the first flush of success has died down, when they have mastered the computer and can look around and see how much or how little difference it has made to their lives.

It is often hard for teachers who grew up without computers, and may have considerable resistance towards the glib machines, to value and reward students who do well on them. It is easier to reject the whole endeavour, to feel and say that performance on the machine is not indicative of any real talent, to treat it as if it was all Space Invaders. It is particularly easy to have this reaction if the person doing the things you cannot do is somebody of whom you did not expect much in the first place, someone with Down Syndrome, for example.

At present, computers do not make up a large part of classroom experience. There are enormous areas of the curriculum where the computer is little or no use. The proportion where students can benefit from computer assisted teaching, and therefore where people with handicaps can get the promised benefits, is limited. Unless it is abused grossly, high technology is not going to take the difficult students off the teacher's hands indefinitely. If the main advantage of computer learning is that it takes a handicapped child away from the teacher, the attendant disadvantage, of course, is that the child will eventually have to come back.

The reason computers get such good results from students with disabilities is that the school system has, until now, consistently and systematically underestimated the potential of students with disabilities. Any disabled students who are able to be observed by an impartial observer are almost

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bound to do better work than they had been thought capable of; but if the computer only alters the student's perception of herself, and not other people's perceptions of her, it is a trap. Here, as in other areas, technology can supplement efforts to bring handicapped people into the mainstream, it can make a contribution within a wider climate of tolerance, but it cannot act as a substitute for a change in attitude.

BUILT-IN AIDS

Most technology for people with disabilities looks at providing a free-standing machine to replace the missing function, as a wheelchair replaces walking. An alternative approach is to employ technology to enable the person's own body to carry out the function.

Some muscular disabilities occur because nerve commands to the muscle do not get through. Researchers are working on ways of correcting for this by stimulating the muscles directly and evading the problem. Someone who cannot control walking, for example, can either trigger the muscles through a switch or use the arm muscle to feed signals through wires to the thigh. The possibilities (and problems) of this kind of thing -- using a person's own limbs as prostheses - are just beginning to be explored.

Walking, for example, is such an extraordinarily difficult activity that we have not yet managed to get a computer to cope with it satisfactorily. But people already are thinking of a walk controlled by microprocessor, a chip that can instruct your legs to carry out all the subroutines of walking without your needing to think about it. It would just need to be instructed when to turn, start or stop, or walk down steps.

SHORTFALLS

Technology is most successful' in replacing the functions of impaired hands or feet or voices and in partially compensating for missing senses. If I cannot hold a pen to write, I may be able to use a typewriter, and if you cannot see my words, they could be printed in Braille for you. But the technology

cannot help me to organise my words or you to understand them, and if you have had a stroke, have memory problems, or are intellectually disadvantaged these are likely to be your main problems.

Equally, technology cannot help you to feel or show affection, a major problem for some. people with emotional or psychiatric disabilities as well as those with some severe physical disabilities. Facial paralysis is not uncommon and current technology has no help to offer. Imagine not being able to smile, not being able to express any emotion with your face. Similarly, we are better at remedying mechanical difficulties in reproduction than we are at restoring genital sensation in people who have spinal

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injuries. Thinking and feeling, the two most essential human activities, cannot be assisted by our current technologies.

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4. R&D: VERY LITTLE R AND HARDLY ANY D

Many will have seen Cedric on television or in newspaper supplements. Cedric was a computer operated by eye gaze--the user sat in front of a screen, looked at what he or she wanted to type, and the computer printed it or said it through a speech synthesiser.

Cedric was a very clever invention. It was fun, it was invented in Australia, and it looked good on television. None of the television reports were churlish enough to ask if it was of any use; but the research and development that went into producing Cedric cost about $400,000 of public money, money which could have been spent on other projects or on buying aids for people.

Cedric was a typing device, but it was not really portable enough to be a general-purpose communication device. At about $18,000 for a basic unit and $25,000 with peripherals, Cedric could be used by people, such as spinal quadriplegics, who can control their head movements but not their body. But these people could also use any number of simpler and cheaper devices for typing ranging from a mouthstick for typing ($10) to an eye blink switch linked to a microcomputer ($4000).

Many people--for example, people with cerebral palsy--cannot control their head movements enough to use mouthsticks or eyeblink. switches, but these people could not use Cedric, either. The only people who really have a use for it--who could not get by with anything less--are people with rare degenerative conditions such as motor neurone disease, where eye movement was· the only voluntary movement they could make.

In late 1987, four years after it became available, one Cedric had been sold in Australia. About the same time, a less glamorous but quite functional device, the Eyetalker, was developed in the US to fill the same needs as Cedric for about half the cost. If you were a disabled person desperately in need of a communication aid or adapted typewriter how enthusiastic would you have been about the "miracle" of Cedric?

In 1990 the company gave up. The chairman said that although it was altruistic to help people with disabilities, there was no. money in it. "Disabled people don't have the money to purchase this equipment, the technology is just too expensive. The main market was in hospital intensive care wards, but public hospitals simply did not have the resources to buy them."

The company now intends to sell the eye-gaze system as marketing research tool, to allow advertising executives to determine which part of a picture people look at, and thus the best place to put the trademark.

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The development of technology for people with disabilities is underfunded, lacks qualified researchers, and has no unions, business groups or other powerful lobby groups pressing for it.

If a computer company gets its new' release personal computer wrong, it makes very little difference to the potential consumers--there are plenty of other computer manufacturers around to take up the slack. But if something like Cedric turns out to be a dud, then it is likely to have used up a large part of the money and expertise for development of new aids in Australia for that year. So it is important that there be some kind of planning, some organisation, some communication to give us efficient division of responsibility. At present, we have instead a pervasive confusion that muffles and blunts most efforts. There is no way to build on the experience of others. From the design to distribution it seems' everything must be laboriously recreated for each successive project.

Stop that ego

Disabled people seldom design their own aids; even if they had access to the education, technology and funding required they would still have much less spare time than someone who did not have to cope with life with a disability .

The various forms of Australian technology for handicapped people have a characteristic history:

Somebody notices that a disabled person is handicapped by the lack of an ability to do something--to talk, for instance. The inventor then notices that there is a device in general use--a small computer, perhaps--that could be adapted to cope with this.

Sometimes the inventor will follow up this insight by asking the people who could be aided by a new device what they want. More often he or she does not. Sometimes the inventor investigates the size of the market. More often he or she does not. Generally the thrill of the chase after the solution is enough. Quite often the inventor simply goes away and works on it alone.

The inventor comes up with a fairly cheap prototype--a couple of silicon chips and a switch. It works pretty well when demonstrated by the inventor, less well when tried out by a person with a handicap, but well enough to be worth following up.

If people stick with the idea, we get to the production stage. The device will have a very small production run, because there are not many people with the particular handicap for which it is made. This makes the device expensive. So many of the people who could

benefit will not be able to afford it, and hence the potential market will become even smaller.

The device will work well for some people who buy it, and less well for others. People with disabilities 'are not a clearly-defined group with the same problem. They not only differ in their level of the handicap, but also can have varying severity of secondary or additional handicaps across three or four separate variables.' For instance, with a computer, some who cannot use their hands will be able to use a headpointer, others will need a foot switch, and still others will not be able to see a video display.

By the time all this has been sorted out the basic technology underlying the device has been superseded. Under the Christmas tree in 1986 many children found a toy talking computer costing $80 which shared some of the capacities of the recently released Vocriss speech synthesiser costing $2800 (see below).

Another inventor notices this, and sets to work to adapt the toy, and we are back to (1) again.

The Vocriss, a purpose-built speech synthesiser, is an Australian communications device that would have been very valuable had it been available in quantity in the early 80's. But when it came into production in 1986 after years on the drawing board it was already faced with competing devices that did the job better--they were lighter, more easily reprogrammable, and had better quality speech. Vocriss sales were helped by a minor price advantage and a connection with the Victorian Spastic Society, which helped to develop it.

Ironically, that very connection is the origin of one of its problems. It was developed for people with a specific diagnosis rather than to remedy a more general disability. In fact, it was made for people with severe physical impairments rather than for people who could not talk. So it has been designed to be carried on the tray of a wheelchair, and is too large and too heavy to be used by people who can walk-- that is, by the majority of people without speech.

The development of at least three other devices aimed at helping people in wheelchairs to communicate was being financed by different arms of government at the same time as the Vocriss. Meanwhile, nobody was producing anything to assist the largest group of people without speech, those who are diagnosed as having intellectual disadvantages but no major physical problems. This scenario is doomed to be repeated as long as there is no information exchange which enables the left hand to find out what the right is doing.

Devices built from scratch for a specific purpose inevitably are going to be much dearer and much less up-to-date than ad hoc adaptations of

mainstream equipment. But adapting off-the-shelf equipment is less fun than inventing a whole new gizmo. Everyone loves their baby.

Despite the problems which hamstring commercial research and development in Australia, a surprising amount of technical development goes on. Much of the best work is quite deliberately geared to providing one individual with a unique device.

In this Australia leads the way with an organisation of technically qualified volunteers called Technical Aid for the Disabled (TAD). They will take on almost anything and have made (taking a few examples from their journal):

- a sling to support a french horn for a player who has lost the use of one hand;

- a metal frame to seat two paraplegics in an inflatable raft for river trips;
- a needle guidance device so that a woman with severely impaired vision can inject insulin into a dialysis bag.

The problem which plagues TAD, and all people trying to develop new technology, is lack of information as to what has been done before.

In 1986 the DEAL Communication Centre wanted some small, cheap, speech synthesisers which just said the words "yes" and "no". After several frustrating and unproductive experiences DEAL found a small firm prepared to expend the considerable effort required to design and manufacture such devices.

Imagine the embarrassment and anger when, after several months work, it was discovered that six months previously an identical device had been made at a nearby college at the request of another disability service. It had been funded with public money, but its development had not been publicised. Adding injury to insult, as far as the DEAL manufacturer was concerned, a third agency thought it would like to join in, and went hunting for another college to invent the device over again with a view to having it made by students, benefiting the third agency's clients and nobody else. In fact, all hope of getting the yes / no box into production would have been lost.

Every second technician seemed to be making yet another one-off yes/no box, expending scarce resources which could be devoted to the multitude of unsolved problems in the disability field, while the DEAL manufacturer battled the problems of obtaining components for a small production run.

There is an international computer data base called Abledata which lists technical devices for handicapped people. It includes only commercially available devices, however, and that leaves the problem of finding out

about all the others--devices not marketed commercially, work in progress, and attempts that failed. Most failed inventions sink without trace, with the result that each technician faced with a given problem goes through a similar process of trial and error while their disabled clients experience unnecessary frustration and delay.

What is needed is a clearing-house for information. TAD, as you can imagine, is well aware of the risk of re-inventing the wheel, and maintains an index of work in progress and jobs completed at its Sydney headquarters. But to serve the wider need for such information this catalogue would have to be expanded to include commercial products and projects and be available on line. The closest approach to this comprehensive listing is the catalogue available on computer disc from the TRACE Centre at the University of Wisconsin.

It seems probable that funding for such technology will continue to be unplanned and decentralised. At a minimum, though, there should be more attempt to have the existing agencies working together. It should be possible, for example, to agree that no proposal for funding a new aid would be considered unless it was able to meet the following not particularly tough criteria;

- The target population would have to be defined, described, and consulted about its needs.
- Some sort of check would have to be made to ensure the device does not exist already, or, that it had not already been designed and had stalled before production.
- There would have to be a clear projection of how the device was going to fit in to its working environment. Where would it be used -- school, home, work, wheelchair? Would it need to be portable? Would it need a power outlet?
- There would have to be a clear projection of how the device was going to get into the hands of its intended users. Who would manufacture it? Would it be a commercial proposition? If not, how else could it be produced in quantity? Who would pay for it? Would it be within the economic range of its intended users? If it were to be bought by institutions or schools, how would they use it? How much peripheral equipment would it need?

Micro-processor-based projects would have to show that the idea would not be overtaken by improved software in the next three years or improved hardware in the next five years. (Any such project would take a minimum of a year to develop, a year to make, and a year to distribute. At the end of that time it

would find itself in competition with personal computers twice as powerful as the ones around when the project started, able to do much more, much

cheaper. If the device only promised to overcome the limitations of present-day technology it would almost certainly going to be knocked out by improved models.)

Taking all the above into account, is, the money to be spent on the project likely to help people more than spending it on what is presently available?

When the other inventors working on speech synthesisers found that the Vocriss was being developed to meet the communication needs of wheelchair users who could not talk, did they hand back their grants or look for another project? No, they went right on and re-invented the wheel, making it slightly oval so that people would know it was different. Survival of the fittest appears to have resulted in their inventions sinking without trace or being used for other purposes. Unfortunately, the combined cost, at least $600,000, would have paid for 200 Vocrisses or 1200 mini-typewriter communicators or 3000 yes / no boxes.

While this list of pitfalls may sound daunting, there are devices designed and manufactured in Australia that have been successful. The Eureka by Robotron is a portable wordprocessor / notetaker / diary / calendar / calculator / telephone directory that can play' back information from all these devices through a speech synthesiser for people with visual impairment. It has 300 pages of diskette storage, contains software for programming in BASIC and for composing music. The device can be connected to a printer, a braille printer, or other computers, and can be hooked up to a modem for distance work. The modem software even reformats incoming data from Telecom Viatel to make it more user-friendly. For instance, it erases graphics that the user would not be able to see. It retails at about $3000.

The designers of the Eureka began by taking another speech synthesiser to the Royal Victorian Institute for the Blind and asking for the institute's comments on its advantages and shortcomings. The makers, the institute, and the Australian Federation of Blind Citizens then set up a committee to work on the specifications for a new machine. The Australian Government gave an Industrial Research and Development Grant for 50% of the research and development costs.

The designers looked at other devices to see what they did not have, asked users in Australia and overseas what they really wanted, and then embodied the findings in the latest technology. They took surveys of the size of the blind population and of the percentage that were likely to use the Eureka. They ran trials of the prototype among users. They did most things right, and they produced a very useful device. Much of the production is exported, and Japanese, Spanish and Swedish versions have been produced.

It is a limited success, of course, to serve limited ends. Its standard input is through a Braille keyboard, and as only about a thousand people in Australia are fluent in Braille it is not going to make the manufacturers rich

or affect the lives of most Australians with visual impairments. The Eureka succeeds exactly because it fills a niche and has not tried to be a universal panacea. Equally, Robotron may have been' encouraged in its development by the relative affluence of its potential purchasers. Favoured by the provision of pensions, benefits and education, people who are legally blind are better off as a group than other people with severe disabilities.

It is not surprising that there have been more failures than successes in this area of technology. There are more failures than successes in every area of technology. History is littered with innovations that people did not want to buy, underfunded companies that went bankrupt, and bright ideas that did not work out. But the difference between standard consumer products and devices for disabled people is in the existence of a mass market--a threshold level of consumers with adequate discretionary income. When Henry Ford started the production line for his Model T he doubled the wages of his workers because he knew that the success of the project depended on people having money to pay for new cars. People with disabilities cannot support a production line while the disability pension is at the level it is now.

5. WHO GETS WHAT?

If you happen to be a disabled person the most significant technology issue for you is not what modem technology can do for you, but what access you have to it. It is scant comfort to know that someone somewhere. has invented a better gizmo when you have no chance of ever obtaining it. The main factors in the provision of aids are political and economic, not the needs of people with disabilities or the limitations of technology. It will be a long time before we are able to repair a disability--to make the blind see, for example--but we already have the capacity to make aids that would make blindness much less of a handicap.

Funding and Delivery Systems

At present in Australia there is no system for distributing appliances to the people who need them, and there is no indication that anyone in power notices this delivery system is missing. We have a patchwork--a haphazard and uncoordinated scattering of programs set up from time to time when particular groups manage to catch the ear of the government.

There is a general assumption, which politicians and bureaucrats do nothing to dispel, that all the health needs of all Australians are covered by Medicare--that aids such as wheelchairs, for example, are included in this cover. Most people would be appalled to think that they could be confined to one room in a nursing home in their old age because nursing home patients are not entitled to government-funded wheelchairs.

Provision of even the most basic disability aids is erratic and discriminatory. Two people of different age with the same disability, or of the same age and 'disability but stemming from different causes, or who have different diagnoses but the same equipment needs, will have to get their equipment from different agencies. One may be funded and the other not.

- Joe is 17 and at secondary school, so his speech synthesiser is paid for by the Schools Commission. But Jane is 20 and at university, and so she either begs the money from the local Lions' Club or goes without.

- Sam and Steve are both 25 and both quadriplegics. Sam drove into a tree when he was drunk. Because he lives in Victoria, a state with automatic cover for motorists, his motorised wheelchair is paid for by the Transport Accident Commission. Steve fell off a ladder while painting his house. He does not have a motorised wheelchair. Indeed, unless he manages to get out of the nursing home he is living in, he will not even get a manual one. The government aids system, PADP, does not give equipment to people in nursing homes,

    and the only money Steve has comes from the invalid pension, which goes towards his nursing home fees.

- Sue and Sally both have bladder problems. Sue has spina bifida and is an outpatient at a large teaching hospital which provides her with free catheters. Sally is elderly and has to pay for her own incontinence aids from her pension.

Even in those areas which are funded, finding out what your rights are and what is available is a chancy business. If you do not go and ask about equipment, nobody is likely to suggest it to you. If you miss out, few will know or care. To get anything you have to be knowledgeable, lucky, and persistent, or have family or friends who are.

At a conference on care for people with disabilities someone with cerebral palsy interrupted the speaker. "You talk about disabled people as the consumers of health care." she said. "There aren't any of us on the platform -- you're all therapists and nurses. There aren't many of us in the audience -- we weren't on your mailing list, were we? This isn't our system, it is yours. We aren't the consumers, we're the product."

The whole field of provision of aids to disabled people is notable for the absence of handicapped people at any level of the decision-making process. At the highest level, decisions on such vitally important

things as funding priorities among competing programs are made by politicians and public servants -- both professions where having a severe disability is an almost insuperable handicap. And the main bodies involved in research are tertiary institutions or big charities, such as the Spastic Society, not user groups.

As always, money or the lack of it is a major problem. People with severe disabilities generally are not rich. Without government assistance they are unable to afford more than the simplest aids. Manufacturers know this. They are not going to start an expensive research and development program in order to make equipment for people who will not be able to pay for it.

Australians with disabilities also are geographically disadvantaged. A long way from the rest of the world, they often do not hear of technological advances elsewhere. And when they do find out about a new aid they have problems obtaining it. If it is a sophisticated device the smallness of the Australian market means that the chances of it being duplicated by a local manufacturer are minimal. Despite this the cost of the device may be inflated by high tariffs protecting the non-existent local "industry·. These tariffs are as arbitrary as everything else to do with disability--only items for the use of "the blind and the deaf and dumb" are exempt. You may be, one of the very few unlucky Australians who have no arms and legs, but if you want equipment from overseas you will have to pay up to 20 per cent duty on the items you need.

Despite the protection given by the tariff barrier--or perhaps because of it-the manufacture of aids for people with disabilities in this country is largely Undertaken by small under-capitalised firms, backyard industries without the facilities or expertise to develop new or improved products.

There are about 17 firms making wheelchairs in Australia. France, with six times our population, has three. We all know how difficult it has been for Australia to maintain three car manufacturers. We all use cars, but only 50,000 Australians use wheelchairs.

There are other distribution problems. For example, CSIRO developed a microfiche reader for people who cannot tum the pages of books. "The device was licensed to an Adelaide company for manufacture but is no longer on sale. Sales were lower than expected, the manufacturer suffered losses, and the licensing arrangement with CSIRO was terminated by, mutual agreement." (Technology and Disabled People).

This failure was due in part to the difficulties of advertising a product to a small, widely scattered market who were unable to be reached by ordinary written material. Ironically, another reason for its failure could be that it was too advanced. If the non-disabled people responsible for buying the devices were themselves unfamiliar or uncomfortable with the use of microfiche readers, they would be unlikely to consider them an option for a person with a disability.

One Size Fits All

Most successful mass-market technology does not need adjusting to the particular needs of the purchaser. You do not have to have your measurements taken when you buy a television or a microwave, you just plug it in and that is that.

Technology for disabled people is not that kind of technology. Every disabled person is disabled in his or her own way, and so the manufacturer's job is not finished when the machine is packed into its cardboard box and taken down to the loading bay. Any equipment disabled people are going to use is going to have to be adjusted to individual specifications or they will not be able to use it.

Even if there were an affordable device that could do what a disabled person wanted--a one-finger single-switch computer-operated word processor, for instance--and even if he or she could afford it, it probably would be useless unless there were a team of specialists who could do such things as:

- work out how fast the computer should go to fit in with finger movement speed;

- adjust the stiffness of the switch until it was too stiff to trigger by accident, but soft enough to trigger when tired;

- decide if special support were needed in the wheelchair to prevent the finger from slipping off the switch.

These specialists are in short supply, and it is hard to get them on the job before you buy the device you want adjusted. This means a lot of expensive equipment ends up in cupboards. A workable system for getting technology to disabled people needs to provide for pre-purchase assessment and post-purchase training and adaptation. Any product marketed to severely disabled people without this pre- and post-sale service is not going to sell.

Does it do the job (and was the job worth doing)?

At the end of the day there is only one way to find out--ask the user. But as a nation, Australia has never been strong on evaluation. The general feeling seems to be that once a government has been generous enough to come up with money in a good cause, it is hardly gentlemanly to ask for proof that the money has been well spent.

But 21 per cent of handicapped people in a recent Australian Bureau of Statistics survey had difficulty using their main aid. In most of those cases it was painful, hard to get used to, or hard to use. An English survey topped this with the finding that about 30 per cent of elderly people who had eating, drinking and bath aids never used them.

Evaluation is often difficult, to be sure, but without some way of getting feedback from users a lot of effort goes into solving problems that do not need solving by providing devices that do not work very well to people who need something quite different.

If the community puts its mind to it, technology can be made that will genuinely help. The electric wheelchair is an example of a device that is just now beginning to work. It has been around for more than 20 years and taken for granted for about a decade, but only in the last five years have people begun to provide the ancillary. services--such as battery charge stations and ramps--that make it really useful.

There have to be funding schemes so you can get one, access regulations so that you can get through the doors using one, and maxi-taxis so you can get out beyond battery range. The pieces are starting to come together; even the kerbs are being ramped. But there is still no compulsion for theatres to provide lifts, even though we are getting to the stage where this seems odd rather than normal. And that is the point where political and social pressure can become effective.

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Communication aids, by contrast, are where electric wheelchairs were 25 years ago--the tec1mology is there, but the system is not, and their usefulness is limited to small and almost symbolic gains for a few individuals.

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6. BRINGING IN AND SHUTTING OUT

High technology for people with disabilities can be used to bring them into the community or to streamline their isolation.

Compare these two quotations.

> " ... the concept of handicaps as we know them today may well disappear during the next century, since AI (artificial intelligence) combined with robotics may remove dependence on primary caretakers. AI systems may be able to make the decisions necessary for daily living according to the physical and cognitive capacities of the individual. That is, the system may determine that the child is hungry and a robotic device will prepare a meal and, if necessary, feed the child without the necessity of a human interaction. The human interactions can then be directed more toward improving the quality of life for those individuals."
>
> Behrmann, p.263
>
> "A few years ago we considered making a device which is well within the state of the art; a black box, one side of which would be a refrigerator which could be loaded with seven television meals, while the other side would be a hot-air oven. Such a device could obviously produce a hot lunch every day, and moreover one which he (an elderly man living alone) liked or which coincided with a special diet, but we decided not to make it. We felt that to remove the meals-on-wheels lady, who might be the only visitor the person ever had, could well be against his real interests."
>
> H.S. Wolff, in Bray, p.116

Is being fed by a robot what quality of life is about? There are some levels of independence which are achievable but undesirable. We are a social species, and we need to interact with each other.

EDUCATION

The primary advantage of getting a computer to do the teaching is that it does not have prejudices about people with handicaps. It does not make assumptions about them, or treat them any differently from anybody else. These are negative virtues, but they account for a large part of the clear motivating effect computers are recorded as having on many disabled students.

Let us look at the way computer assisted learning is supposed to work. Students, whether disabled or not, learning mathematics, for example, sit

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down in front of the computer and work their way through a series of exercises. The exercises are designed to layout important concepts in a meaningful sequence. Mastering them gives the student the skills and knowledge necessary to go on to higher levels.

Students proceed at their own pace; if they do not succeed with one problem, the machine will give them another one at that level, and if they do not get that one right, the computer will be programmed to go back to easier examples. Once they succeed, the computer will move up to more difficult problems. If necessary, a suitably-programmed computer will note that the student does not seem to be coping, will analyse the area of the deficiency, and will direct the student back to the relevant portion of the course to do remedial or revision work. The computer records full details of how students coped at the various levels, and teachers can consult this record any time they need to.

It may not work that way, of course. It generally does not.

The quality of the software often is not up to it. There are always going to be problems with quantity and range--just compare the number of available programs in any particular area with the number of books in that section of the library shelves and you will notice a marked discrepancy.

The tasks may not be set at an appropriate level. Students may be forced to cover things that, with a good teacher they would be able to skip, and they may not be able to study areas that really interest them. The class may react unfavourably to the lack of human contact.

All these disadvantages, of course, apply to all students, whether disabled or riot. That is the advantage of the computer--it does not have to stream , students, divide them into groups, cull the sheep out from the goats. It can cope with the complexities of placing students on a continuum. A properly designed teaching program should be able to cope with slow students. There would be no need to have a special course for them--they would simply have more detours, more revision, and take longer getting to the end of the program. The computer would automatically place each child at the level where he or she would learn most effectively.

Used in this way, the computer can promote the integration of slow performing children into the ordinary classroom. Used in another way, it can cut them off. H disabled students are funnelled into computer assistance and other children are not--if the computer is allocated only on the basis of diagnosis--disabled children are going to have less time to mingle with able-bodied children. This will detract from one of the primary advantages of integration.

Many handicapped people suffer from the additional handicaps of shyness, social clumsiness, and lack of fit in social situations. This is because they do not go through the rough-and-tumble social relations of the playground or

get a chance to catch the jokes whispered from desk to desk in the classroom. School is as much about social conditioning, about instruction in the surrounding culture, as it is for teaching the, specific curriculum. And the children who miss out on this conditioning in order to catch up on their studies are socially handicapped. Integration into the normal classroom is important.

When Kurtzweil text readers cost $20,000, and blind people needed something like that to keep up with their education, then it would have made economic sense to have all the blind students in the same place, perhaps equipping one of the schools in a particular area for blind students or even creating special schools that took only people with visual disabilities.

By how many orders of magnitude would the price have to change before this ceased to be the case? Would a $10,000 device be issued at the rate of one to a classroom rather than one to a school? $5000? This is what about what computerised text reading costs now. $2000?

According to Australian Government figures about 60 per cent of disabled students now go to ordinary classes, about 23 per cent to special classes in ordinary schools, and only about 17 per cent to special schools. Will this change? Will the movement to give people with disabilities lives as similar as possible to their peers slow down in response to the introduction of new technology?

Whatever happens the classroom will remain among the least handicapping environments for people with disabilities, because all it is about is information. If you are physically handicapped, being ten times as slow at writing as your fellows can be a nuisance, but it does not compare with being ten times as slow at eating and having a shower and getting undressed and going to the toilet... The handicap is cumulative, involving simply having less time in your day to do things, to study, to work on your homework, to revise.

Even if, by some magic, disabled children could be relieved entirely of their handicap when they were working in the classroom, their marks would still reflect the problems they had with the activities of everyday 'life. Correspondingly, having a technology that reduces the writing handicap from ten times as slowly to three times as slowly still requires students to work five times as hard at everything else in their life to remain level with their classmates.

EMPLOYMENT

The latest Australian Government census found that only 34 per cent of disabled people of working age--and only 26 per cent of severely disabled

people--had jobs. It is not a high figure. Furthermore, more than half of the severely disabled people with jobs worked in sheltered workshops.

One of the more minor side-effects of the microchip is that it will cut increasingly far into the kind of undemanding repetitive work that has been the basic fare of these workshops. Even now, when 90 per cent of the costs of such workshops are met by government, they are struggling to survive.

This need not be regretted; the sheltered workshop has always been an anomaly. Under their roofs people with physical disabilities have been set mechanical tasks that they do badly, as opposed to mental tasks where they could be competitive; people with problems of adjusting to society have been given tasks that do not exist outside psychiatric hospitals; and people with intellectual disadvantages have been given mechanical tasks no less complicated than assembly-line work but worse paid.

Even with government subsidies and special tax breaks and sweatshop rates, the kind of low-level assembly work that they do--putting plastic spoons in plastic bags for Australian Airlines--can still be done more cheaply and efficiently by a smart machine. Is this sort of 'work' better than none?

Technology itself can sometimes be misused to manufacture "non-work' for people with disabilities. Recently, after hundreds of hours of development time, an electrically powered paper cutter of enormous complexity was produced to enable two people with physical impairments to take no more than five minutes to cut ONE sheet of paper into five centimetre squares for recycling. At the end of a standard six-hour workshop day the two workers could take pride in having chopped up 72 sheets of A4 paper between them, or roughly five minutes output of a government shredder.

Training should be for life and work in the community. But unfortunately this does not mean that work is going to be available.

People with disabilities have the highest unemployment rate of any group in the community. Part of the reason is prejudice, and we can hope this will diminish as people with disabilities become more visible in the community, are given more rights, and have a greater chance to show what they can do; part is due to the low level of the education people with disabilities often have been given, or to their lack of work experience; another factor is the problems disabled people have in getting to work on public transport. But the most telling reason is the fact that in a buyer's market for labor employers are not going to accept any limitation on performance unless obliged to by law and, unless fully reimbursed by government, are not going to ,spend any money on adapting the workplace, the equipment or the job specifications to suit even a highly qualified applicant with a disability.

In many jobs, people with disabilities work as well as able-bodied people. In some areas they actually do better, because they are more motivated by the

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work and therefore less likely to leave their job. Taken as a group, however, they are at a disadvantage; that is what handicap means.

Micro Power

Altair, the first personal computer, was marketed in 1975, and was quickly followed by other similar machines. Some of the first people to buy these machines had disabilities, and university computer schools were quick to realise their potential in this area.

At the time the sky seemed the limit. People with severe disabilities were not only able to compensate for their impairments-·and in some cases find a

means of communication for the first time--but many of them also learned to program the new devices and were able to find jobs in the rapidly expanding computer industry. At a time when few people knew what a computer did, and even fewer could program, quadriplegics who could were suddenly employable, even if they could not talk. People talked as if the problem of handicap could be removed by a brisk retraining program.

Times have changed. All secondary students now have computer experience and many are competent programmers. And although programming remains an area where the handicaps of physical disability are minimised, the disadvantages of being quadriplegic have re-asserted themselves in what is now a highly competitive area. While disabled people continue to find jobs as programmers, it is clear that this area is not a general solution to their unemployment problems. The highly skilled will find work--people who before the advent of computers might have had no chance at all--but for ordinary people with disabilities jobs are still hard to get.

Technology in the workplace

Technology can make life easier for workers with handicaps, but it can also make life harder. Blind people, for example, need continual advances in technology to help compensate for the stream of technological advances making life more difficult for them. The present trends are towards making life more, not less, dependent on vision. In particular, the replacement of the typewriter by screen-based systems and the trend towards the paperless office create difficulties for them.

Some, but not all, of these new problems can be corrected by other technology. For instance, slow but acceptable devices ate available that will read out what 'is on the screen or will print out the output in Braille. There are even touch-screen programs that give help with layout by telling you what words on the screen are under your finger. But blind people cannot use these devices at the automatic teller machine or at anyone else IS terminal. And interactive terminals will continue to invade new areas.

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Who Does the Service Sector Serve?

> "If we are to survive the next industrial revolution, which will remove a very large proportion of what at the moment we regard as work, we have to start now. We must orientate people towards jobs which will be concerned with rendering services to one another."
>
> Wolff, p.l07   '

It is generally considered cost-effective to substitute a machine for a person. But we have increasing unemployment, with the only growth areas being the service industries - hotels, hairdressing, escort agencies.

In the future, given that agricultural and industrial production is adequate to meet the community's needs without employing all those of working age, it may be socially desirable to redistribute income by paying people a wage to assist people with disabilities, rather than to subsidise enforced inactivity and boredom with unemployment benefits.

Many of the integration aides for schoolchildren with disabilities are trained teachers who would otherwise be unemployed. We may yet thank those people who are elderly, disabled or infirm for giving others something to do.

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7. THE MAGIC BULLET

The bionic ear, or cochlear implant, has been widely presented as a successful Australian development, but it is not without its critics.

Only a relatively small percentage on deaf people can benefit from.an implant. The implantation procedure is not like putting on a hearing aid--it causes irrevocable damage to the ear. So people who have had an implant may not be able to benefit from future advances in technology or treatment. Even with a successful implant, hearing is at a level comparable, in visual terms, with looking through the bottom of a dirty beer glass. The media has ignored these issues.

But for deaf people, the cochlear implant highlights social issues which are even more complex. In an article written for the Commission for the Future, Michael Uniake records one viewpoint:

"If you say to Brenda Carty the words 'cochlear implant' she immediately think~ of smiling deaf children in newspapers with headlines saying "Deaf Child Hears" when, as she puts it, "I know they can't." Carty is well known in the deaf community and is actively involved with service providers and consumer groups. She is also one of an extremely rare breed--a teacher of deaf children who is herself deaf. She describes the attitude of deaf people to the implant as one of anger and opposition. "I think it is a gut reaction to the implied lack of acceptance of deafness--the wish to change deaf people into hearing people." she says. "So many of these deaf people find their greatest satisfaction, enjoyment, and support through their identity as deaf people. They feel as if others want to take away their identity, and there is a lot of anger about that." There is also anger when predictions of extinction or major changes to the deaf community become known. Brenda Carty thinks that such predictions deny the validity of the deaf community as a cultural phenomenon and imply that deaf people only get together because of similar medical problems. "The deaf community," she maintains, "is a language group with an associated culture. It takes more than medical advances to eliminate that. The bionic ear, says Brenda Carty, "reinforces the idea that 'hearing' is the ideal state, and that differences should be eradicated rather than accepted and understood as a valuable diversity in society."

Technology can help people with disabilities, but do not expect it to cure them. Technology for disabled people is not a panacea. It can minimise the effects of the disability, but it is not going to remove the handicap. People with disabilities are always going to be marginal in economic terms--hired when there are labor shortages and laid off first when the labor market weakens.

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The economy, of course, does not move in response to what disabled people want. As in most areas, the problems of disabled people are the general problems of being poor, marginal, powerless, and irrelevant. What this means is that compared to general movements in society, policies and technology directed at the specific problems of handicapped people will have only marginal impact.

No new technology is going to make the entry of disabled people into the mainstream of education and employment easy. Among the reasons why so many of these people are prevented from going to school or working are (in no particular order):

- because their disability is not socially acceptable;
- because they need special toilets that are not available, or need help
- in going to the toilet;
- because they cannot get up the steps;
- because they are slow to learn;
- because they cannot see, or hear, the teacher or the supervisor;
- because they cannot read the set books or the manuals;
- because they cannot talk or write;
- because they need help with things like eating, drinking, or dressing;
- because they need extra services that are not usually provided-· physiotherapy, for example, or access to a Braille library.

Technology does not assist with many of these things, and there is little reason to believe that it will in the foreseeable future. This is not simply because the research is not being done (though little enough is), or that production of the technology would not be profitable (though it would not be), or even because it is not glamorous (though it certainly is not), but because present technology is very good at moving information but not very good at moving objects.

The real work in housekeeping and daily living needs technology to move objects, not information. The appliances developed to help out need more than turning on and off. A switch can turn on an oven, but not put a roast in it; set a dishwasher going, but not stack it; work a stereo, but not put a record on a record ,player. At school, computers will not change incontinence pads, and in the year 2001 that job will still have to be done by an aide.

Robotics is not going to be the answer, whatever the improvements in technology. Robots now work on factory production lines where tasks can be defined narrowly, the value added to a product is large, and the turnover considerable. None of those things applies in the average home or school. The number of different jobs a robotic system ,would have to do would require either 40 different special-purpose machines or a robot of awesome complexity, and in neither case is it possible to conceive of such a system

costing less than hiring a person to do the job. After 70 years of science fiction about robots with two legs, two arms, a vaguely humanoid face, and the ability to do any job a human can, it is something of a shock to realise that nobody--no corporation or government anywhere in the world--is seriously contemplating working towards anything like that. Just as jobs for people have been taken over by special-purpose machines, so have jobs for robots.

There are clear limitations in what we can expect special-purpose machines to do for people with disabilities. The smaller the job, the better the chances that technology will cope with it successfully--electric scissors, for example, are a perfectly adequate way of removing one small handicap for people with arthritis, but a wheelchair does not remove the handicap of lack of mobility. (You cannot play rugby in one.)

Some functions do not seem amenable to machines at all. It· has been suggested that people who cannot walk could be moved around the house by electrically powered hoists running along a metal track on the ceiling. One obvious drawback is that such a system would be immensely expensive (not so much because of the cost of the mechanical parts, as because of the necessity to make structural changes to the house). But less obvious is that anything that makes it less attractive for you to leave your house is going to have an effect on your social life.

At present, people with disabilities who can use computers have a temporary advantage in that computers are hot, sexy, and high in status. People whose speech is slurred or who use communication boards are commonly treated as retarded, and people with intellectual impairments are treated as if they were children. Though communicating using a board is no more difficult than through a computer, the computer is very much more socially acceptable.

This attitude is not acceptable; if we wish to remove the ill effects of discrimination, we should simply stop discriminating. And as computers become more widely distributed across the society--in particular, as they become widely used by people with disabilities--their status may fall.

ill our society, even hearing aids are seen as stigmatising (and anybody who doubts that should ask an adolescent to wear one to a dance). At present, the high-tech image of the, computer takes some of the curse off its use as a remedial tool, but will this survive its use by large numbers of people with handicaps?

The emphasis on technical solutions for individuals with disabilities takes the pressure off the rest of society to change its attitudes towards the disabled. When someone in a wheelchair goes to the movies, one method of getting them into the theatre is to have three ushers carry the chair up several flights of stairs--hard, inconvenient, stigmatising, and dangerous work for all concerned. There are several possible ways to avoid this. One is

to redefine the problem and say that since the invention of television and the videocassette recorder, there is no need to go to the cinema. Another is to develop a wheelchair that will go up stairs, and several inventors have done this. A third solution is to insist that all theatres install lifts or ramps.

A stair-climbing superchair allows disabled people more flexibility in many situations. It will let them climb the steps in the homes of friends, get them up and down kerbs, and help them travel in places that do not have laws about lifts. But this flexibility is gained at the cost of placing the responsibility for overcoming the problem onto' the shoulders of the individual disabled person, who has to find the right machine, pay for it, keep it serviced, and carry it around. Furthermore, people who have a lesser handicap, such as old people who do not like stairs or people who have had a heart attack, who may not want to invest $8000 in a superchair in order to see the latest movie sensation will still miss out.

Public provision benefits everybody in need and avoids asking people to identify themselves by handicap.

There are handicaps that can be handled most effectively by individual aids., For instance, it is easier for me to wear spectacles than for all newspapers to be printed in EXTRA LARGE CAPITALS. But many others can only be dealt with collectively. When newspapers are superseded by videotex systems, it will only take the press of a button to switch everything into VERY BIG LETTERS.

Public and private technologies need to be run in tandem. Even stair-climbing wheelchairs would be utterly useless without a system of railways or special taxis to get the chair into the city in the first place.

All public speaking venues··lecture theatres, churches, movie houses--can and should have a passive amplification system that broadcasts to hearing aids. It is relatively cheap and easy to install. On the other hand, lifts are major building items. Adapting all older buildings to meet present standards would run into hundreds of millions of dollars. It always costs a lot more to fix things afterwards than it does to get them right the ,first time. Which way does the balance of community benefit fall? And would another alternative be to require public buildings that did not have useable lifts to invest in a stair-climber? And would a third alternative be to raise disability benefits to the point where disabled people had enough disposable income for theatres to rush to install lifts and stair-climbers in the hope of getting a slice of it? The rich have just as many problems as the poor, but they also have many more people offering to help solve them.

All these questions become variations on the basic theme of how much the community is prepared to do for its handicapped members. One of the dangers in the way the media report technology for handicapped people is that there is such heavy emphasis on the successful cases, that the unthinking reader or audience could come to believe that all the problems had been solved, and people who insisted on behaving as if they were

handicapped must be being deliberately obstructionist. Technology can be used as a way of denying the reality of the need to make hard choices.

Some of those choices can be made for people with disabilities neither by society or professionals. Each individual situation is different, and each individual has his or her own priorities.

Anne

Anne is 30. She has cerebral palsy. She lives with friends and is studying humanities at Deakin University. She spelt out what follows on an alphabet board.

> "In 1965 I heard the doctor tell my mother: 'There is nothing we can do. She'll never walk or talk.'
>
> Twenty-five years later I still cannot walk and talk. I spent 12 of those years lying on the floor. I needed a special chair, and even though these were readily available I was living in an institution that did not buy such chairs for its residents. When I was old enough to get the pension I bought a simple child's folding pusher. This enabled me to sit upright. I could read books and watch TV, and people could take me outside the hospital. I've had more benefit from that pusher than I have from any of the sophisticated electronic aids I've bought since.

For severely disabled people who cannot ever achieve physical independence, the independence technology gives is spurious. It may allow me to move about, but I still cannot pick up a toothbrush or get myself a drink of water. I communicate by spelling on an alphabet board, on which I can reach a top speed of 400 words an hour. (You can probably talk at 200 words a minute, if you want to-- my friend Chris does.)

I own a Canon Communicator, a mini-typewriter which I use with a headpointer and which prints my message on a long, thin strip of paper; a speech synthesiser which strings together the phonemes I select with my headpointer to make words and sentences; a computer which has been adapted so I can use it as a word processor by pressing nine buttons instead of the complete keyboard. Every letter and function has a code--"a" is 11, "b" is 12--and it is the slowest to use of all my high-tech communication equipment, all of which is slower than using my alphabet board.

I can type at 10 words an hour, provided someone else sets up the computer (I cannot put a disk in the slot, let alone load a printer). The gadgets enable me to do things which I could not do without them, but they do not let me do them fast enough to make it

worthwhile. If technology made ,me normal, it would be great; as it is it makes me slower and less efficient and reduces the time I would otherwise spend with non-disabled people.

If I were to be independent I would have to have a motorised wheelchair, a hoist to lift me in to it, a robot to dress, wash and feed me, a computer and a phone modem to do my shopping, automatic doors and windows, and another robot to do the cooking, cleaning, and laundry. But at the end of the day I would be housebound with no-one to talk to. Manufacturing all that equipment might have created some jobs, but not as many as looking after me. I am fortunate enough to have attendants paid for by the government; I could not afford to pay for them myself, and I certainly could not afford the enormous sum. it would cost to set me up in high-tech independence.

Some aspects of the technological revolution have improved my life. Television, video and books on cassette all compensate to some extent for my inability to turn pages. They not only allow me to learn but allow me to enjoy the hours I spend waiting for other people to help me do things like eating or dressing.

Even so, I am not a fan of high technology. Laziness afflicts people with disabilities as much as people without them. The more severely disabled one is, the greater the effort involved in learning to use technology and the smaller the gains. I'm reluctant to make the effort until Jim certain the results will make the 'effort worthwhile. If using the computer means I write less and have less contact with people then it is not worthwhile. I do not like using a machine if there is a person available to help me. I can live a good life with no more technology than a wheelchair.

So why are other handicapped people so keen on technology? Perhaps because it gives them pleasure to be able to do anything for themselves. Of course, most people are not as severely disabled as I am, and many of my friends are able to make use of the technology now available (or would be if they could afford it). I think, though, that most use the technology either because they have been brainwashed into thinking that typing 10 words an hour is what life with a disability is all about or because they cannot find anyone to take dictation and have no alternative.

Yes, I would like to be able to type independently, but if I cannot get up to 400 words per hour it is not worthwhile setting up the technology. I have so little output for my efforts at the best of times that the thought of diminishing -it further simply in order to be independent has no attractions for me.

Having a disability is an individual experience. Not only is every person with the same disability affected slightly differently, but depending on their personalities they have different responses to their disability. Some see a disability as a challenge to be overcome. I see it as a nuisance to be endured. I see no reason to smile and pretend it is fine just to spare those who do not have a disability from the knowledge of what it is like.

Equally, I could protect others from having to come to grips with my disability by becoming independent or by restricting my life to those activities I can do without help, but I'm not going to.

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8. THE FUTURE

What the Future holds

People with disabilities are affected much more by changes in mainstream technology than they are by the development of new technologies for disabled people.

Automatic teller machines, for example, cannot be used by people in wheelchairs, people who do not see, and people with literacy or memory problems. This is not very important while such machines are used only for a small proportion of banking transactions, but by 2020 it is possible that nearly all banking will be carried out by automated tellers or through home computers, and that a bank with human tellers will be almost impossible to find. When this happens, anyone who cannot use automatic teller machines will acquire a disability (possibly sparking a new line of disability technology to counteract it). On the other hand, people who at present find human tellers difficult to work with, for instance people with hearing or psychiatric impairments, may welcome the automated system and find it lessens their disabilities.

While such changes in technology alter the nature of disabilities, more fill1damental changes will arise from developments in medical technology and the uses we decide to make of them. Some will be straightforward-cures for multiple sclerosis, Alzheimer's disease and schizophrenia may exist by 2020-- and will generate no debate. Others, such as foetal screening leading to the abortion of abnormal foetuses, are already in use and may be used more widely despite continuing debate.

Gene splicing--doctoring the foetus--adds another level of complexity, both to the technology and to the debate. In a simple form--if that is the right word for something intrinsically so complex--it is just around the corner. It could enable correction of a small percentage of disabilities. Equally, it could be abused by individuals and governments which prefer to have only certain types of people. Debate about its use certainly will be stormy. But gene splicing will not have any effect on the disabled population before 2020.

The numbers of disabled people will, however, reflect the use we make of the technology of resuscitation. Modem life support systems enable many people to be kept alive who would have died 40 years ago. Some go on to recover very well, but there are those who do not, and they constitute an increasing group of appallingly handicapped people, people who have disabilities so severe as to be unknown till recently. There is a higher percentage of people requiring continual high-powered medical intervention alive now than at any time previously. Do we wish this percentage to increase? Do we still want our doctors to keep us or our children alive at all costs?

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During the big polio epidemics of the 1950s, the iron lung was developed. It breathed for people suffering from respiratory paralysis. At the time it was assumed that its use was temporary, that a cure would be found. In fact, a vaccine was discovered and polio was eradicated from those countries which could afford it.

But no cure was found for the respiratory paralysis, and every old infectious diseases hospital has a respirator ward in which the survivors of the 50s live. While they pioneered the new respirator technology they were scarcely its beneficiaries. The same may be said of "the world's smallest ever premature baby to survive" who faces life as a blind spastic quadriplegic.

Technology, very costly technology, enables wealthy countries to provide care for 24-week-gestation foetuses, weighing less than 500 grams, whose chances of surviving unimpaired are around 10 per cent. Meanwhile polio, a major cause of disability, is endemic in many poor countries who feel they cannot afford the relatively minuscule cost of immunisation programs. Strangely both very rich and very poor countries are finding themselves responsible for swelling the numbers of people with avoidable, severe disabilities.

Whatever the advances in medical technology there are always going to be people with handicaps. There is no point putting off decisions on resources in the hope that science will make disability go away in the future.

While it is fairly easy to see how our present technologies might develop, it is much harder to foresee the development of technologies that do not exist at all now, and it is hardest of all to predict how a changed society and a changed technology will fit together.

A machine, however powerful, is not a technology. The technology of the car is not only, or even mainly, what the designers and workers produce in automobile factories. It is also the enormous infrastructure of road building, petrol refining, oil exploration, driver education, and police pursuit cars, in short everything that makes cars useable, an integrated system into which cars fit.

And while we may not be able to be entirely confident in our predictions of what is going to happen, we can be rather more sure what is not going to happen; we are not all going to wake up one morning and discover that the good fairy has brought together such an integrated system for people with disabilities. No great advances in the application of technology to the lives of handicapped people are going to happen unless we decide they should.

Eventually, people with handicaps will have technology to suit their needs because they will be making it themselves--setting their own requirements, applying their education to design solutions, and using their access to

money and power to have them built. But that is going to need deep changes in our society and will not come quickly or easily. In the meantime those of us who have had the education and the opportunities that people with handicaps have been denied will have to ask them what they need and then set up structures to develop the devices, get them to users and evaluate their success to feed into the next round of development. And we will have to do it all without creating an unresponsive bureaucracy that imposes its values, its prejudices, and its expectations on the population it is supposed to serve.

Unquestionably, people with disabilities need more than just gestures, but they need a gesture first--recognition, even if it is, at first, token recognition--that there is a gulf to be filled. It is too early to layout a detailed structure to monitor and direct national policies on technology for handicapped people. Not only is too little known of the needs--there has been too little consultation and too little research--but when it comes to applying policies suitable groups do not yet exist in the community for such a structure to plug in to.

In the past government has simplified the problem--indeed, it has avoided it entirely--by working through the large charitable institutions, such as the state Spastic Societies and Royal Institutes for the Blind, but it is now seen that the consequent dependence of disabled people on these monoliths is in itself undesirable. Too large, too paternalistic, and too all-encompassing to be truly responsive to the changing needs of their clients, they are still too parochial, being based on individual disability types, to have an overall perspective on the distribution of resources.

On the other hand, the independent self-help disability groups that enable handicapped people to speak for themselves are, where they exist, small, struggling, and not geared to take on the massive organisational and administrative effort that will be required.

We cannot move from where we are now to an ideal situation in one operation. We need a policy to bridge the gap, a policy to keep the issues at the forefront of the government's consideration, to press for change, to encourage and ease moves towards change by others, and to do quickly the things that can be done now, not just for the technological aspects of disability but for the whole field. We are looking, in fact, at something rather like the Office for the Status of Women; an Office for Empowering People with Disabilities.

One of the important tasks for such an office would be to work towards setting up a new system to develop and distribute the fruits of technology. Given that most of the finance for the present system comes from the public sector, it makes sense for there to be a central coordinating body. Such a body would have data-collection as a primary function. It would establish comprehensive databases of new technology, conventional technology, and work in progress' (or recently discarded). Any requests for research and

development funding would be vetted by the coordinating body to ensure that it did not duplicate other projects and that the necessary consumer consultation had been undertaken. This approval could easily

be made a condition of success in applying for money from any of the funding bodies in the area. In addition, each project should be required to have definite, goal-directed timelines supported by market surveys. The authority might say, for instance, that by a set time, 20 eye-gaze communicators will be in use by people with no other means of talking or typing. This should help avoid the Cedric situation, where the technical problems were solved, the awards were won and, years later, the potential users are as badly off as they were before the money was spent.

The coordinating body also would make rational decisions about which aids should be imported and which made here. For example, in the 1970s the availability of portable speech synthesisers and the decreasing price of microchips prompted the development of several different speaking communication aids in Australia and overseas. Unfortunately, none of the Australian devices is as compact, as easy to program, or as easy to understand as the commonly-used overseas models. The most successful Australian device, the Vocriss, had a price advantage (varying with the exchange rate) over comparable imported devices. Its research and initial development costs were funded by public institutions and hence did not have to be recouped in the sale price. If that cost was added, the Vocriss cost saving would disappear.

Would you be prepared to suffer an avoidable speech impairment in order to create Australian jobs? That is what those users who have to buy Vocriss "because it is cheaper" are being asked to do. Equally, the first portable speech-output communication aids became available in the US in 1978. The Vocriss project was finally able to supply those on its long-term waiting list only in 1986. Even if the only consideration were economic, the loss of educational and job opportunities caused by such a delay may well outweigh the creation of a small number of short-term jobs.

Because the Vocriss was outdated virtually before it went into production, moves are now afoot (in 1991) to update it. This will involve yet another injection of scarce public research and development funds. Once again it is proposed to spend money on a project without asking the client group what they want.

Australians with severe communication impairments would like voices with an Australian accent. A large US manufacturer of voice output equipment estimates that an Australian voice for incorporation into existing devices could be produced here for about $50,000. This is a small fraction of the cost of updating the Vocriss, would take only a fraction of the time, and would allow consumers the widest possible choice of devices.

The people involved in the original Vocriss project understandably are anxious to see it rehabilitated. But this is unlikely to do much to assist the

rehabilitation of people with severe communication impairment, particularly as there is no government funding now available to allow them to buy the new Vocriss or any other communication aid.

This is not to say that Australia should become totally dependent on imported technology for those with disabilities. High turnover, low cost aids such as walking sticks should obviously be made here. As their manufacturers are unlikely to be applying for research grants, the ordinary constraints of the market place will provide the only regulation needed.

The area which needs an overview is high technology, where public funds are sought for developing "new" devices. Here, there are a number of questions to be answered, including whether the planned device really is new or whether it parallels overseas developments without adding anything to them. H it is indeed a new invention, then is it really needed?

If it is not new, then we need to ask about comparative advantage. If manufacture in Australia is not going to produce significant time or cost savings, then it should not be undertaken unless the government intends to purchase the output for free distribution through a loans system. It is inappropriate that people with disabilities should be asked to suffer additional disadvantages in order to foster what is likely to be a short-lived local industry.

We also need to look at the question of tariff protection for local manufacturers. At present, devices to help people with disabilities attract varying levels of duty depending on what they are and who they are for. Customs regulations exempt from duty items for the use of the "blind, deaf and dumb"; these were obviously the only disabilities thought worthy of notice at the time the regulations were drawn up. As it happens, whatever the original intention of the regulations, communication aids are exempt because

their users are patently "dumb". But wheelchairs attract a duty several times as high as that on children's toys. It is debatable whether the public interest is served by that level of protection; people with severe, uncommon disabilities which necessitate the use of specialist imported chairs certainly suffer, as it is exceedingly difficult to win an exemption.

All this leads to the secondary function of the coordinating body, the development and monitoring of a distribution network for technology to assist disabled people. The great majority of aids are now in the personal possession of individuals. Some small agencies do operate loans systems, but the main purchasers of aids--the large public hospitals and the P ADP providers--are lending institutions in name only. They do not have the staff to follow up clients and check whether aids are being used, they do not have storage facilities for unused aids, and they are not generally able to provide repair or adaptation facilities. A dissatisfied client has no incentive to return unsuitable equipment, even if unused, as there is no guarantee that more appropriate equipment will be available. Because there is no system for recycling unused equipment, the homes of people with severe disabilities,

especially growing children, tend to accumulate stockpiles of unused aids, while at the same time somewhere else in Australia someone is suffering hardship through lack of funding for those same items. ,

If a loans system is to work, the first requisite is a computerised catalogue of all items held by all the providers. It could be based on the system used most successfully by print libraries. Then, when someone arrived at an aids library needing a wheelchair of a certain type with certain specifications, if one were not in stock, the staff could look up the complete listing for that type of chair throughout Australia, see who held appropriate chairs, whether they were out on loan, and which of those available was closest.

The computer system could also be used to reserve the chair and make the necessary freight arrangements. If the chair needed modification or repair this could be carried out by the library's maintenance staff, who provide or arrange servicing for all aids obtained through the library. (Probably the most common reason for high-tech equipment being left unused is that something minor has gone wrong which, due to the specialised nature of the equipment, no-one local has the parts or skills to fix. At present it is difficult to obtain information on aids servicing, and more so to transport the aid to a service centre which may be on the other side of Australia, as well as to pay the cost of servicing.)

Such an integrated library organisation would be able to get the advantages of bulk-purchasing, would speedily accumulate data on the effectiveness of aids and on unmet needs, and could be itself in the position to commission the development and/ or manufacture of new aids, giving the manufacturer the security of assured sales and an effective distribution network with professional back-up. This would help solve the common problem of the failure of manufacturers or distributors because their costing did not allow for the consultation and support that is needed to fit a complex aid to an individual.

Practical problems which need to be overcome in any new system for the provision of aids include servicing country areas, now appallingly disadvantaged, and removing the injustices of eligibility now rampant in the current P ADP system. Nursing home residents, for example, are at the moment excluded from any benefits. Equally, the categories of aids which are provided require revision and rationalisation.

The suggested computerised loan service could provide substantial benefits to country dwellers, eliminating the need for costly and frustrating trips to the capital cities in search of aids, which once gained cannot be reviewed, exchanged or repaired. Indeed, the most important advantage of a loans system would be the removal of guesswork from choosing aids. Many purchases of such complex aids as motorised wheelchairs now have to be made in hope--hope that the client will be able to learn to drive the chair, , hope that it will fit into his or her lifestyle (for instance, most motorised

chairs are lousy on unmade or steep roads, and many are difficult to manoeuvre in small houses or units).

If the wrong choice is made there is usually no redress. The client's money or PADP entitlement will be exhausted (the chair will have cost about $5,000), he or she will still need a chair, and the unsuitable

chair will sit in a back room, unused, while the waiting list for motorised wheelchairs grows. A loans system allows not just for mistakes, but for changing conditions.

If the most severely disabled--those people who cannot be served by off-the-shelf items--are not to be further disadvantaged, the charter of any loans system should include a requirement to develop one-off solutions, in conjunction with such organisations as Technical Aid for the Disabled.

There are enough wheelchairs out there; the problem is to get the right bums on the right seats.

Commitment to providing those who are handicapped with the tools they need to operate in the community will use resources that might otherwise be disposed elsewhere. This change in consumption patterns cannot be carried through simply by feelings of benevolence; if people with disabilities get more, people who do not yet have disabilities will get less.

People sometimes think technology is a way to get out of these difficult choices, a cheap option. It is not. The areas in which technology is appropriate are too limited, and the cost of developing, producing, servicing, and. providing backup for the technology is too great.

One reason for pressing ahead with technological development is that it will help us to do better at the task of improving the quality of life of everyone in our community. Another reason is that this will assist us in our search for knowledge about ourselves and increase our understanding and appreciation of the bodies which we all inhabit. More has been learnt about walking by those trying to replicate our bodies in robots than has been discovered by millennia of anatomical dissections. We only fully appreciate the complexity of our existence when we try to replace one of our missing or damaged functions with a machine. It is people with impairments who will eventually provide the answer to the question: "What does it mean to be human?" .

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9. AGENCIES INVOLVED IN THE PROVISION OF AIDS FOR PEOPLE WITH DISABILITIES

Technical Aid to the Disabled

Sydney - 227 Morrison Road

(P.O. Box 108) Ryde 2112

Melbourne - (TADVIC)

79 Buckhurst Street.

(P.O. Box 88) South Melbourne 3205

Independent Living Centres

New South Wales 600 Victoria Road (P.O. Box 351) Ryde 2112

Victoria 52 Thistlethwaite Street.

(P.O. Box 88) South Melbourne 3205

PADP Scheme

Abledata

Relevant Publications

Technology and Handicapped People, Office of Technology Assessment, Congress of the United States, Springer, N.Y., 1983