

WHY PREPARING FOR DISABILITY SHOULD BECOME PART OF EVERYONE'S EDUCATION

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Summary

This paper briefly explores some of the factors that affect individuals' ability to respond to rehabilitation. It is sug-

gested that general education could help to optimise such ability in individual people, and also help to ensure both that society's barriers to participation are minimised, and that rehabilitation goals are fully appropriate.

In this series of talks we have been asked to look ahead into the future and 'dream'. I shall be presenting a few ideas thrown up by my clinical experience over the last few years at Headley Court (a military rehabilitation unit 30 Km South of London) and Peartree House (a very slow stream residential rehabilitation unit in Southampton).

The ability to respond to rehabilitation varies greatly between individuals, probably reflecting their cognitive and physical capacities, their cultural background and personal philosophy, and the nature and appropriateness of the help offered to them. As life expectancy increases, more of us are likely to face disablement for longer periods of time. Could we improve our ability to respond (when the time comes) by preparing for this important life event? And given that the attitudes of other people around us (whether disabled or not) shape our environment and influence the objectives of our rehabilitation, can more be done to minimise the barriers that can impair our participation and fulfilment once we start to lose our physical or cognitive abilities?

Rehabilitation after traumatic brain injury is a fascinating process to witness, in turns inspiring and humbling. I imagine that we have all been struck by the contrasting progress made by different individuals who on the basis of their impairments might have been expected to follow similar trajectories. One of our major challenges is to help younger adults appreciate the nature of their cognitive impairments and the relevance of the necessary feedback, reflection and practice that is needed to move forward. This is particularly difficult for those who, prior to their injury, have naturally had an intuitive style of thinking, prioritising and decision making, and who were able to rely on rapid non-verbal communication in their interactions with other people. Such individuals are accustomed to being very engaged, active, and able to complete several activities concurrently without obvious cognitive effort. After an injury has impaired their attention, processing speed and 'memory sketch pad' their intuitive efforts rapidly fragment and the

simplest task appears suddenly and frustratingly difficult. Blame for these difficulties are often be laid on others or on our 'stupid' rehabilitation programme. By contrast, the systematic 'plodder', the person who habitually planned ahead and took one step at a time prior to the injury, seems to find a conventional rehabilitation approach much easier to accept.

Another surprising contrast is between the pattern of response I used to receive from young civilians treated in their local National Health Service Hospital in Southampton, and the injured combat troops of the Armed Forces whose rehabilitation starts in a special military rehabilitation unit at Headley Court, 40Km South of London. Having become used to the confused and irritable young adults from Southampton I was quite apprehensive at how the rehabilitation team at Headley Court would be able to contain a head injured and emotionally disinhibited paratrooper. To my great surprise, paratroopers appeared to be already attuned to the need to follow a programme of regular exercise to some kind of timetable, and their fellow patients in the programme could generally be relied upon to support each other in their tasks, rather than to try to escape from the hospital. This difference is could partly reflect the soldiers' identification with the Rehabilitation Unit as a part of the Armed Forces to which they belonged, in contrast to the young civilian's view of the local hospital as somewhere that old people go in order to survive a heart attack (provided MRSA doesn't get them first).

A different kind of contrast is seen after relatively minor head injuries. Some people take the injury in their stride and despite lingering symptoms of severe concussion, recover and achieve rehabilitation more or less by themselves. Yet other individuals, often (I would suggest) those who at the time of injury had been 'high achievers' operating near the limit of their abilities, suffer a catastrophic psychological response to the experience of being transiently out of control. Their ability to cope progressively fragments over the course

of the next 6 – 12 months, costing them their job and even their family relationships.

Why are such discrepancies so surprising to us? Hippocrates would probably have accepted such variability as part and parcel of medical practice, and used his knowledge of the patient as an individual to guide him or her on the path to recovery. In present times, all rehabilitation professions are educated and trained in rehabilitation in the expectation that we will become empathetic and effective practitioners. But in the process do we actually grow in our understanding of the patient's plight and our inventiveness in finding approaches that will be of optimal help to an individual? Or do we rather learn the role and rights of a rehabilitation professional and the rules a disabled person is expected to follow 'for their own good'? Some years ago now, a study by a disabled medical student in Southampton found that first year medical students were generally more interested in, and had a more positive attitude towards, disabled people than students of other disciplines. But by the fourth year of medical training, this difference had not only disappeared – it had reversed.

Among the unconscious needs of a health professional is likely to be a need to preserve a clear distinction between ourselves, as bringers of expertise and rehabilitation, and disabled individuals whose role is to receive it. Indeed, disabled people's organisations continue to comment unfavourably about this problem, despite our best efforts to rectify it. Another factor may be that current professional training emphasises regaining the physiological norm as the ultimate goal of the professional; 'participation in the life of society' or even 'the relief of suffering' are of subsidiary interest and importance. Does being a medical practitioner or a physiotherapist make us a better able to cope as patients, and better able to engage in and respond to a rehabilitation programme? I do not know of any clear evidence one way or the other about this, but what is certain is that we need to refine our understanding of the capacity to respond to rehabilitation. The 'capacity to respond' is self-evidently a crucial element in a person's rehabilitation potential.

In people with cognitive impairments, different patterns of impairment have been shown to be important determinants of behaviour. Thus a combination of impaired memory, higher level language disorder and impaired ability to control one's emotions is strongly associated with violence directed at family members and longer term outcomes in such people are, in general, improved by rehabilitation focussed on these difficulties. However, demonstrating that such relationships exist does not explain why some individuals respond while others do not. Concepts such as perceived

relevance, self-efficacy and locus of control take us closer to an understanding but it is doubtful whether, for example, an individual's scores on such scales can be improved by rehabilitation.

One factor worthy of further study is the tendency of some individuals to respond particularly well to certain therapists and less well to others. Sometimes these differences can be traced to conventional rules of skill acquisition, which tend to be better understood and observed by some therapists than by others. But cultural factors are also crucial. They affect the appropriateness of rehabilitation goals as well as the response to the therapy. For example, the head of a traditionally Indian household in the UK (and his close family members) may take great personal offence at his being offered training in how to make his own breakfast despite having had a stroke.

In an ideal world, we would all be brought up with an understanding of disablement and would acquire the attitudes and skills needed to promote rehabilitation in ourselves as well as in others. And such hopes are not of course confined to rehabilitation. Attempts have been made to shape children's education to promote better understanding of important concepts such as sexual relations, cultural diversity and citizenship. Can such understanding reliably be influenced by education or does it depend upon daily experience over many years and the unspoken assumptions and beliefs of a society? In the UK for example, the introduction of programmes of sexual education in schools has been accompanied by an increase rather than a decrease in the incidence of teenage pregnancies.

From a technical point of view, such education should probably not be delivered as a short programme at a particular age, but rather as a thread running throughout one's year of education, exploring the human condition, covering concepts of personal development, fairness, participation in society. We cannot fly like a bird or swim like a dolphin but there are other ways that we can explore and experience environments that pose difficulties for us. And the environment provided by society is something that we can all help to change - if we can see the need for it.

We human beings are much better at hearing what we want to hear than exploring aspects of life (such as disability) that make us anxious and against which we are psychologically defended. Preparing us better for this aspect of the human condition will therefore not be easy. That does not mean that progress is impossible. We can dream that one day, truculent head-injured young adults might be just as receptive to rehabilitation as Headley Court's paratroopers.