

The fragmented man

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Editor's note

To mark International Year of the Disabled Person the Journal asked Dr Blackwood, who is herself a sufferer from limb girdle muscular dystrophy and confined to a wheelchair, to give readers an 'insider's' account of the plight of disabled people and to discuss appropriate ways in which the able can help.

Every member of Society, from the moment he is born, has a vested interest in disability. Those who escape it early in life achieve it by old age which, in itself, is a social and physical handicap. Yet the man-in-the-street or woman on the Clapham omnibus has no constructive ideas, nor indeed thoughts, on the matter. A letter on disability published in the national press evokes no response. Yet, the person who is struck down by a handicapping disability finds it is the most devastating and shattering occurrence of his life – a life immediately distorted and intolerably away from the norm.

What are society's obligations in general? What are the medical profession's in particular?

1981 is International Year of the Disabled Person, a fact which, in itself, acknowledges that their number merits a whole year of thought and action.

Before the 1960s, apart from a few dedicated groups striving to help, there was little save an emotional wave of compassion for the war wounded. The 'civilian' disabled hid their disabilities and shame as best they might. Even their neighbours or relatives hardly knew the nature of their disability and, as far as income was concerned, it was vaguely assumed that the Government saw to all that!

This income, at first Parish Relief, then National Assistance, finally turned into Supplementary Benefit. It is still with us. It is supplementary to nothing as far as many cripples are concerned. Even the word 'cripple' is being phased out and the cumbersome but kinder 'disabled person' is being substituted. The conscience of society has been moving uneasily.

In 1965 Megan Du Boisson, a woman in the first stages of Multiple Sclerosis, founded DIG, (Disablement Income Group) a pressure group bent on changing legislation and obtaining for the severely disabled a State income in their own right. She uncovered undeniable poverty, ignorance and despair. She was emphatic in her arguments that

society must embrace its disabled members. She was equally emphatic in her insistence that the disabled must come out of their refuges and speak of their difficulties. She asked them to tell their local press; they had to speak of their poverty, their lack of basic and practical help. What they had sought to hide they must now expose. Pride was to be overcome and dignity take its place. This all called for real courage and it was their first painful step in the now continuing revolution, but it was utterly essential if there was to be a better world for the disabled to live in.

By 1970 the Government came up with the Attendance Allowance which covered some thousands of disabled people. In the main it was awarded to:

- a) those who, without attendance, might do themselves or others bodily harm or
- b) those who needed someone else's help for bodily functions day and night.

The criteria were narrow and severe though they were soon slightly relaxed to day or night attendance. The allowance was paid directly to the disabled.

Two more Allowances followed, the non-contributory Invalidity Pension – paid to those who were of working age but who hadn't paid their stamps, and the Mobility Allowance for those who were unable, or virtually unable to walk. It sounded too good to be true – and alas it was! Supplementary Benefit was removed by exactly the same amount, keeping the disabled person still at the lowest level.

A minimum allowance, the Invalid Care Allowance, was given to a prescribed relation who had given up a job to care for his or her relation.

1970 also saw the Chronically Sick and Disabled Persons Act¹ steered through Parliament by Alf Morris. This sought to make conditions easier for the disabled *viz.* new public buildings should be made accessible; hospitalised disabled people should be counted and their numbers presented to the Secretary of State; local authorities were urged to provide transport and houses.

Both in the allowances and conditions in the Chronically Sick and Disabled Persons Act 1970, there are, of course anomalies and gaps which become apparent as each individual case presents itself. Megan Du Boisson's all-embracing 'National Disability Pension for all disabled - regardless of how they came by their disability', has not, as yet, materialised.

Disability prevention

In the medical field there are highly organised routines to prevent or deal with disabilities. The first is genetic counselling. One goes on to ante- or post-natal clinics with community health visitors all watching out for malfunction and malformation. The Health Educationists produce posters advising against drinking, smoking or promiscuous sex. TV and radio programmes inform the public in a general way, and booklets and leaflets are obtainable from societies dealing with disability.

If and when bone deformity is established orthopaedic surgeons strive to correct it. Physicians attend the ailing and prescribe drugs.

The paramedical teams including bio-engineers, occupational therapists, physiotherapists and, before leaving hospital, the medical social worker, bridge the gap between medical and social problems.

At home the community nurses, the health visitor and the GP take over, together with the local authority occupational therapist who sees that the disabled person has the current mechanical appliances to facilitate ease of movement. She and the social worker cover a grey area of need.

If the patient is emotionally disturbed by his disability he may get psychiatric help.

Therefore, on the face of it, society in general and the medical profession in particular, cover all aspects of disabled living.

Yet, to the shattered man, now viewing the world from a wheelchair at the eye level of an eight year old child the aspect is daunting. Incredible problems present themselves. A staircase formerly admired for its elegance is now an insurmountable barrier; a bath an unobtainable luxury.

One's career is gone. Earning power is gone. Obligations have to be met. There are bank loans; mortgages cope with death but not disability; children's educational expenses have not been insured. The house is now unsuitable and the car is too small to hold a wheelchair in the boot. Possibly one's ability to drive is affected. The garden needs to be dug – holidays cancelled.

Added to these material complications there is the knowledge that one's body can actually repel or disgust one's fellow man and there is a growing chilling suspicion that one's acquaintances have attitudes which might include patronage, condescension, and a hint that one is now intellectually duller. One is an object for charity and compassionate supporters rally round while shaking their heads outside the door, holding consultations, concerning but excluding one. The 'them and us' situation is born. One is at everyone else's mercy because they have muscle power or no sensory impairment.

Unintended slights are often received by the oversensitive. In the disabled world they occur frequently. Thoughtlessness, or a lack of empathy, on the part of the non-disabled, leads to misunderstandings, while the disabled person, tired and in discomfort, can too easily get a distorted impression.

Notwithstanding these arguments there are many disabled people who are extremely rational and whose powers of reasoning, acceptance and humour are highly developed but who also feel the barbs of others. They can also see flaws in various declared motives.

A housebound patient waiting for months for physiotherapy is informed by telephone from the clinic at 11.30 am that a physiotherapist will call at 3.00 pm. The clinic is put out by the patient being unable to receive a 3.00 pm visit that very day. Indignant voice on telephone implies that housebound patient has no right to be involved in other activities. There was no suggestion of the 'would it be all right to come' approach.

Another recent example of downgrading happened to an almost totally disabled man dependent for turning twice nightly at a two hour interval on the community nursing service, while an 85 year old relative did it at midnight and 6.00 am. The gap was suddenly increased to four hours. Unable to endure the pain caused by lying on one side inert for so long he asked, 'why?' from each successive nurse. Neither he nor his GP had been consulted or told and the excuses or solutions did not ring true. 'The cuts' was one, or 'If one needs a turn in two hours one should be in hospital' and finally as a solution – 'take dope to alleviate pain'. This was after years of amiable and happy service. He was then transferred to the books of the next district and given to nurses who were not with his GP, so he lost contact and had to get others to write for prescriptions enclosing a sae for return by post. There was no geographical reason but he heard, *sub rosa*, that a similar patient had left and the nurses, anxious about their jobs, wanted to show a regular visit on their books. Whatever the reasons were in these two cases, none was offered to the patient.

Years of disability can stretch interminably in front of one and the fight to get back into society as an equal member a hard and painful one.

Once the initial shouting has stopped, the bravado and bonhomie has cooled down; once the treatment and facilities have been explored and put to use – when the decisions have been taken and actions carried out, who is responsible for seeing the fragments knit together making the man fulfilled and whole again?

Every man jack of us! There can be no opting out of responsibility. Disability may be five minutes away.