One World: the Disabled in Society

Bridget Nuttgens

Did you know that last December 5 was the Day of the Disabled. No? I'm not surprised. Possibly more people have heard that 1999 is the Year of the Elderly. A large proportion of our population is now over 60, and, frequently with old age comes some degree of disability, so perhaps our disabled citizens will get their share of attention this year. After all, the final part of the Disability Discrimination Act of 1955 (Part III) which requires service providers to review their procedures to make sure they do not exclude disabled people, comes into full force in October of this year. Then there is the new Human Rights Bill several of whose clauses cover the disabled, and the setting up by the government of a Disability Rights Commission which will mean that in future those suffering discrimination will have a body to whom they can bring complaints instead of being faced with the need to bring a private prosecution.

So all that remains is to change the attitude to disability in the general community. How do we do this?

First, (this sounds like a Delia Smith recipe) we must bury the Great Disability Debate as to whether it is personal physical limitations which constrict the lives of disabled people (the physical model) or the fact that society is not prepared to adapt itself to encompass the disabled (the social model). The basis for the first of these two approaches is that the disabled must accept that their life-situation *is* going to be different to that of the able-bodied ; for the second, that the disabled have a right to equal access and opportunities however difficult the circumstances.

Neither of these approaches is now valid. Both are polarities which we should by now have outgrown. What people of vision now recognise is that so-called minorities—whether ethnic groups, homosexuals or the disabled—are not problem groups which must be integrated into the community, but are already established and contributing members of that very community—certainly different, but *vive la différence*: you've got one arm, he's got red hair, she's a lawyer, I'm an epileptic.

So society must stop writing people off in a category labelled DISABLED. Oh yes, this still happens all the time. "I think you're

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wonderful," they say, "I don't know how you manage." But when it comes to looking at a disabled person as an ordinary member of the community, you find that they have been neatly filed in a MARVELLOUS DISABLED PERSON drawer. Before he became disabled, my husband did a lot of work on both TV and radio; when he retired from a top job in education, and went into a wheelchair, even radio work stopped almost immediately. The media perception appears to be that a disabled person is only usable on programmes about disability; a life's expertise seems suddenly of no account.

The Committee for the Employment of People with Disabilities will assess, train and supply equipment to employers and disabled employees so that they can work efficiently, and the rapid development of computerised facilities yearly extends possibilities for employment, yet it is the negative side of employing disabled people—the difficulties—which are still uppermost in many employers' minds. That disabled employees, having got a job, are frequently more conscientious and work harder than many of their able-bodied colleagues is often not recognised.

But there are all sorts of little practical ways in which this file of DISABLED PERSONS operates. For instance, adapted hotel rooms frequently remove the minibar. OK they want more space, but why should the bottle opener on the bathroom wall go too? And what about disabled ladies' toilets which have no sani-bin? Do they think all things stop together? Because the legs no longer work, does that mean the brain doesn't? Because the eyesight is faulty, does that mean one can't hear? We have all heard people shouting at somebody in a wheelchair: he's in a wheelchair, ergo: he must be deaf. Hath not a Jew eyes...? Does he take sugar? (My husband cherishes the occasion when a very decrepit old verger leaned across him in the pew to ask me in a loud hiss, "Do you think he wants to go to communion?" I had to stand on his toe very hard to stop him doing a pantomime of a maniac from a Hammer horror film.)

There is a third pitfall in response to disabled people—those that are so keen to show that they are *not* discriminating—that on the contrary they are so enormously understanding and keen to help—that they don't pause to appreciate the problem. I laughed when there was that fuss about the lack of disabled access to certain football grounds. Some self-righteous spokesman (and I mean spokes*man*) said how iniquitous it is that in many football grounds there were not two levels of counter at the bar so that wheelchairs can approach. Discounting the routine grumble at the lack of the hotel mini-bar, my experience is that most disabled people manage to get a drink if they want one. That is seldom their first

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priority. Get a group of disabled people together and what do they talk about? Lavatories. That, after all, is a problem that crops up every few hours of every day.

At the start of York University, the first building ready to be used had toilets only in the basement. The attitude was that 'it would do able-bodied young men no harm to have to help by lifting any wheelchair-bound fellow-student up and down the flight of stairs'. There was such a girl in the first intake; I think she lasted a term. People who have no personal experience of disability often fail to appreciate that most people with neurological injuries need to get to the lavatory in a hurry, and anyway, how embarrassing it is always to have to seek help for such everyday functions. And suppose, when they've just got you to the top of the stairs, you find you want to go back again....

There are the men who snatch the wheelchair from me saying, "Women! You go about it all the wrong way. Do it backwards and then you're using your stomach muscles, not your back !" Once, in ire, I snapped, "And how many babies have you delivered, Sir, with your pristine stomach muscles?"

Then (I've got a little list) there are people who will undertake an awkward manoeuvre, such as lifting my husband in at the narrow door of a coach, when they are not sure they can do it. Although with the very best intentions, they are so intent on proving themselves capable that they completely forget that they might be straining the back of the disabled person. (The ideal people to stop in the street and ask for help are skinheads or mohicans—the more studded dog-collars and tattoos the better. Because they are strong and young and are not going to hurt themselves; moreover they are often very pleased to be asked and allowed to show off their macho qualities. I owe many of them a debt of gratitude.)

I know it is a delicate question when to offer help to disabled people. My father, in old age , used to say: "The rule with geriatrics is to let them do as much for themselves as they find possible." So with the disabled. And people in the early stages of disability, in initial denial or during the long hard process of coming to terms with the changed life that is before them, can refuse help very brusquely. But anticipating the sensibilities of the disabled should not be used as an excuse for not thinking through practical situations. The hurry factor as regards lavatories is a case in point. While regular toilets in, for instance, motorway service stations are open all the time, disabled toilets tend to be locked, on the grounds that, being unsupervised, they are prey to vandals—"And you don't want to offer disabled people dirty toilets, do you?" So I have spent much time running around looking for a

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manager's office to get a key. This even occurred in the Royal Academy,—admittedly, some years ago. (It is possible to get a key which opens most public disabled toilets from RADAR, but many disabled people and their carers are not aware of this—nor, frequently, are their doctors.) If the authorities thought this through, we would not be faced with a choice between dirty toilets and a locked door.

Fire precautions are another such area. After we had been given a room on the 10th floor in a hotel in Denver, Colorado and had stood opposite the lift staring at the usual notice stating that in case of fire lifts must not be used, I asked the porter about fire. "Ma'am," he said, "don't even think of it." A new-built hotel in Edinburgh boasted a full floor of disabled rooms—and set them on the top floor. Some hotels scatter the disabled rooms around on different floors, on the grounds that disabled people dislike being 'ghettoed'. Frankly, I'd rather be ghettoed than burned.

What all this comes to, is that our society must learn a new attitude to a group of people who are an important working part of our community.

I can draw a parallel with another new viewpoint put to me by my daughter in her period as speaker for the Green Party. When people say to her, "Well of course you all lost your deposit" or "It looked a few years back that the Greens were going to make it politically—but that's all in the past", she explains that the aim of the Greens is not to become another top-scoring political party, but to change people's whole attitude to the world they live in—if, that is, they want to save the environment. What they are asking for is more like a religious conversion—a new approach to life. I am asking for a similar change of heart as regards the disabled.

Let me here describe my particular Damascus. Some years ago we attended a conference on accessible housing. The keynote speaker started in novel manner with a 'counting in' exercise—the opposite of an elimination exercise. Having identified those people in wheelchairs, she asked anybody to stand who had at any time used crutches or sticks or had a limb in plaster, anybody who wore glasses, was blind or partially sighted or wore a hearing-aid, anybody who had had heart problems, asthma, other breathing problems or was epileptic, anybody who had ever been pregnant or pushed around a pushchair. By this time, most of the room was standing, but for a row of men in smart suits in their twenties, thirties or forties who remained smugly seated—until, that is, she wiped the smile from their faces by pointing out that they almost exactly fulfilled the figure of 18% of the population who do not fall into any of her previous categories. She then went on to point out

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that by age-old custom, houses, shops, kitchens, bathrooms, cars are designed for that 18%. This situation has been canonised by the modules of great architects—one has only to think of Leonardo da Vinci's god-like male figure within the perfect Renaissance forms of the square and the circle and Le Corbusier's Modulor Man based on a London policeman. In other words, we have for generations got our thinking round the wrong way. Those with disabilities are not the minority; the minority are those smug men. Yet it is they who continue to set the rules.

Of course enormous strides have been made in recent years by the authorities, employers, service providers, and the general public. But there is a long way to go and the best way to improve things is to try and put oneself into the position of those with disabilities. Here is a run-down of some of the credits and debits.

The government's 'back to work and away from benefits' initiative will unquestionably make for a healthier society. Yet, incredibly, there are still job centres in this country which are totally inaccessible to wheelchairs. Even financially it pays society for all to be enabled to play a full part in the community. Every time a job opportunity is created for a disabled person, society benefits not only from his or her talents, qualifications and skills—social as well as technical—but also makes less likely depression or other ills which could eventually render the disabled person a full charge on the community. This was a point raised (but not fully explored) by the television programme "On the Sick". It pointed out the enormous increase in the numbers receiving sickness benefit in recent years. There was a suggestion that doctors were issuing sickness certificates to many who had been made redundant when properly speaking they should be listed as unemployed. (There may be a political advantage to the government in this practice in that it reduces the unemployment figures). But the programme only touched on the fact that the slight or moderate problems with which many people managed to cope while living a full life in work, often got the better of them when combined with a depression arising from being made redundant. They went downhill, and so went 'on the Sick'.

However there are improvements. Townscape is changing to accommodate the disabled. Although we are still at risk from enthusiastic councils which run out of money half-way through, leaving us marooned in the middle of streams of traffic, most pavements are dipped at crossings, and have warning studs underfoot for the visually impaired. Kneel-down buses have at last come here from the Continent (we have several now in York). I remember travelling on such a bus in Holland forty years ago, and we used the excellent Paris system last

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year. Making it possible (don't forget mothers with push-chairs) to get access to city centres without using cars is, of course, in line with the present government's traffic and anti-pollution measures.

Disabled accommodation is still very poor in some areas. Quite posh hotels, for instance, still may have no disabled toilet. There is one hotel room in the whole of the Borders of Scotland that declares itself in the Scottish Tourist brochure to have Category One provision—i.e. for a disabled person on their own.

Luckily, the Lottery are being very fussy in demanding disabled facilities including fire precautions before awarding grants. Most theatres and cinemas are making wheelchair provision, the better ones removing seats at the end of rows, so that a disabled person can sit alongside their party and not be banned to a 'disabled space' at the back of the stalls. Many have installed the Sennheiser infra-red system for deaf people which is an improvement on the Loop, and have regular signed performances.

Local authorities and disabled associations now supply handbooks for architects and builders on disabled needs. Yet frequently these are not consulted. One foundation whose job it is to cater for disabled people and has produced a superb manual, recently outfitted a new office with disabled toilets that were all wrong. Some large institutions like the National Trust employ special advisors. These are people trained to look at every form of disability, not simply to provide wheelchair access. For instance, somebody on two sticks is at risk from uneven surfaces underfoot, or surfaces slippery with, for instance, fallen leaves. Many country houses lead visitors around from room to room on a strip of carpet; but sticks or crutches will inevitably land on the highly polished floor beyond the carpet on either side. Beautifully turned doors may be a joy to see but too heavy for an impaired person to open. The accepted pattern of a door broken in the middle, is useless (somebody will always bolt one side top and bottom against draughts) unless the open side is wide enough for wheelchair passage. Really, there is no excuse if all this information is ignored. And there are signs that restaurants and even community halls are making an effort, although we are still foiled by the cleaner who spies the carefully designed turning or transfer space in the disabled toilet and decides it is a superb place in which to stack mops, spare chairs and paper towels.

As in all areas, manuals need to be updated as more information comes in, and disabled associations must get over their embarrassment about stating their needs. At one stage high toilets were recommended. Presumably somebody knew an arthritic woman who had difficulty bending her knees. This of course made it quite impossible for a man

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still upright on sticks to use the toilet. I understand that tiny washhand basins with spray taps are recommended by Building Regulations. Easier for arthritic hands? Possibly, but quite useless for anybody trying to rinse urine bottles or leg bags, or attempting to fill a disposable catheter with the water necessary to lubricate it for use. Hand dryers are often placed too high and of course cut out every time someone with little arm strength lets their hands fall away. Since carers are frequently of the opposite sex, unisex toilets are much preferable to the inclusion of a disabled compartment in each LADIES or GENTS. At a recent Disability Fair in Sheffield I saw people standing outside the lavatories, crying pathetically, "Are you all right, dear? Can you manage?" to their partners who were toiling along on sticks or crutches to reach the disabled compartment always placed (no doubt so that the able-bodied won't just bob into the first they come to) at the far end of the room.

We were once, along with Baroness Masham, in a group taken round Docklands by one of the Authority to inspect facilities for the disabled. Lady Masham, I was amused to see, was intent only on access considerations. My husband, as an architect and conservationist, was torn between access and the quality of the architecture. Old buildings are unquestionably difficult, as we experienced to our cost one year when my husband was lecturing first, at a conference in an Oxford college and the following week in a Cambridge college. But antiquity can be used as an excuse for bypassing simple and inexpensive measures—to employ a joiner half a day, perhaps, to make a removable wooden ramp and put support bars on the wall around toilets.

Housing trusts such as the Joseph Rowntree Trust are leading the way in building on the 'open access' principle. Their Lifetime Homes are from the outside indistinguishable from houses in any good housing scheme—until one looks closer. They have solved the age-old problem of needing front steps to carry one over the damp-proof course; instead there are ramped paths. They have taken on the problem posed for wheelchairs by the storm bar at the threshold with, immediately behind, a mat-well. The corridors inside are designed to be wide enough for wheelchair or push-chair access, and have turning space on the corners. Staircases are usually straight, and capable of taking a stair lift; if long, they will have a pausing-landing wide enough to take a chair half-way up where an elderly person may rest. The downstairs toilet is so plumbed and floored that a disabled shower can be fitted if required. The dining area can be easily turned into a bedroom. Window sills are low, so that one can see out from a wheelchair. All electric plugs are placed at an accessible height. These arrangements make it possible for people to stay on in the same house, right through bringing up a family

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and into old age. Yet most of these adaptations do not cost very much more as long as they are put in at the start when the houses are being built. Adding them later is of course much more costly.

I accept that it does require an exercise of the imagination if disability has not previously come within one's experience. The better architecture schools are giving students at least a day when they experience life in a wheelchair. Ideally, students should work in pairs, taking it in turn to be wheelchair passenger and carer (the other, often ignored, side of the equation). They should not only be given an assignment such as buying things from certain shops, having a pub lunch or going to the cinema, but should spend the entire day wheelchair bound, so as to appreciate the problems that crop up regularly, such as getting in and out of lavatories. (Gents' toilets can be particularly hazardous as a wheelchair user can be stuck between the doors in the tiny entrance hall required by bye-laws to shelter the urinals.)

Even now, as a seasoned carer, I sometimes fail to register difficulties, particularly as regards problems other than mobility. When we bought our one-floor cottage, we had only to build a tiny ramp (about 3") to the front door. It wasn't until we had a visitor on sticks, and later a partially sighted visitor that I realised just how lethal this ramp could be. I haven't seen it yet, but I understand that there is a problem for the partially sighted in the new British Library since there is no change in patterning between some level corridors and some steps.

The people at the sharp end of the exercise are the disabled themselves. Both they and their carers (for when disability strikes it may affect the lives and futures of the entire family) must be given time and leeway to sort themselves out. This often involves living vicariously. So when my husband says "Careful, it's a narrow turn" as I negotiate the gateway to the house we've lived in for twelve years, I must remind myself that, in his mind, he is still the driver.

This article is about changing our awareness. As David Puttnam pointed out in his Leonard Cheshire Lecture in January 1999, it goes beyond the practical pragmatic issues I have been outlining—"It's about instilling confidence, vitality and a sense of opportunity among those involved." And we are all involved—tall or short, black or white, cross-eyes or squint nose, chess champion or lowbrow, the future lies in all making our contribution to society. Let us set aside our categories and stereotypes along with shouting for our 'rights'. I once read a quote from Cardinal Hume which went something like this: "We are all disabled to some extent; only with some of us it shows more."

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Impenitent, Expatriate

Silence. Exile. Cunning.

Occasional words (exceptional)

prove the rule. Visibly.

Audibly.

An element

of choice? Not always driven,

but driving. Preferring.

The priest in his sixties
thirty-five years in an
obscure town in an
unimportant West African
country refusing to be
retired 'Home'. There
is *no* abiding resting
(or rotting) place
this side of Death.

Low cunning surely
helps. And high
intelligence. Meditation.
Creative verve. Sunset
glories of the senses.

While there is life

there is movement.

Later — no.

As any tropicalist fool

Know.

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Untitled

The dissent thing to do

to become

the only one

is to subvert all authoritarian

expertise

all professionals are prostitutes
all scientists technologists
are wrong

history always shows

not one of them knows

amateur thinking and loving

are free

intimately true

creatively you

let it be

Michael Kelly

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