

## 8 Learning the Role

**(From 'Disabled We Stand' (1981) Sutherland, A. T., London: Souvenir Press).**

None of us completely escapes the conditioning to accept a particular set of ideas about what we are and how we should behave as people with disabilities, because we are continually confronted with these expectations, from the moment our disabilities are first diagnosed, which for many of us means from birth or from early childhood.

The first influence for many of us is thus our parents. Most parents of children with disabilities are themselves able bodied, or at least ,do not have the same disability as their child, and therefore have little knowledge of what they are dealing with. They may well possess stereotypes of disability, or misinformation, either about disability in general or about the particular disability that their child has, which affects their attitude towards the child's condition. Obviously, if only because of a genuine concern for the child's welfare not many parents are going to react with total equanimity to the discovery that their child has a disability. This is perfectly reasonable, and not likely to do an exceptional amount of harm to the child if they are capable of overcoming their initial anxieties, accepting their child's disability and working to support her. Most of us who have had our disabilities since childhood and are now fighting our oppression owe a great deal to parents who have done this successfully.

But some parents do not manage to take this approach. I remember, for example, a person I once talked to who had had a single fit at the age of about ten. His parents reacted by becoming extremely over-protective, and for years they prevented him from taking part in any physical activity, such as playing football, in case he banged his head. I presume the reason for this was that they thought, quite wrongly, that this might cause him to have another fit. Inevitably, this constant fussing made him feel he was somehow different from other children. My impression was that he had probably suffered more psychological damage as a result of this one single fit (which, in view of the lack of any recurrence, may quite conceivably not have been a genuine epileptic fit at all) than I had done as a result of twenty years of epilepsy. He was perhaps lucky that he had no further fits; it would not have been easy to learn to live with them when he was being subjected to attitudes of that sort.

This kind of over-protectiveness, though not maliciously intended, is a damaging reaction to a child's disability. Another, particularly where the child has been born with the disability, is feelings of guilt, as if the parents were somehow responsible. Such feelings are irrational but not necessarily easily avoided,

particularly as they may be supported by cultural pressures: disability has often been seen as a punishment for the sins of the parents. Many people who have such feelings react by trying to find something else to pin the blame on, particularly if a possibility seems to exist of denying that the child was born with the disability, as one deaf person I spoke to, who was first diagnosed deaf at the age of three, but presumes he was born deaf, describes:

`I remember that my parents were pretty freaked out. They went round trying to find people to blame, cutting off relations with friends who had a dog that had knocked me over. The one that I really liked was that I kept walking into lamp posts when I was four and they said, "Oh, he's walked into so many lamp posts that it's made him deaf". Obviously, what was happening is that, you walk along the road looking at people, trying to lipread what they're saying and you don't look where you're going, so you bump into lamp posts. That's indicative of the general lack of knowledge about me.'

With certain disabilities parents may react- by refusing to accept the facts, exhibiting the kind of reaction that Chris Pearson encountered as an adult:

`My mother's reaction, when I left the army and was having blackouts, my mother was in fact told that they suspected epilepsy. And my mother never told me, because she wouldn't accept it. "My son is not epileptic", that sort of attitude. To this very day, my mother will not use the word, she'll ask me how's my illness, never ever use the word "epilepsy". She refuses to.

`That's the only sort of reaction I get in the family. My brothers and sisters, they are people who are quite ignorant about it as well. When I go back to Ireland on holiday, they' never ask about it, never talk about it. They won't talk about it. They know, they know what's wrong, they know the time I've had. They never mention it. They don't mention it to their friends either, wouldn't dream of saying that their brother's an epileptic, that's terrible in the family, that. I don't know if that sort of attitude does affect you, personally, because when you talk about it, for example about the question you brought to me about being isolated, about bringing things out into the open, you've got people putting pressure on you to hide it, not to bring it into the open. They are people who are close to you. *Unconsciously* they are putting pressure on you. If I went home tomorrow I wouldn't want to go round saying I'm an epileptic, because I know how my mother would feel.

`It has to be said: the word is they're ashamed. They are ashamed I am an epileptic. They're not bitter with me, I don't mean that, but they're ashamed. They're glad I'm living in England!'

If Chris's fits had started during childhood, it seems very unlikely that he would have been unaffected by such attitudes, even though familiarity with them might eventually have led to a greater acceptance. He would almost certainly have grown up with the feeling that his epilepsy was something to be ashamed of, and the knowledge that his family were ashamed of it, and learnt that he must not mention it. Subjected to such attitudes throughout his childhood, he would probably have internalised them strongly, and had to live with the consequences of that in adult life.

It is not easy to tell from the outside whether a refusal to recognise a child's disability springs from an inability to face up to it or a fear of other people's reactions. Often the two are closely interlinked, as seems to be the case with Chris's family. Whatever the cause, its results can sometimes be even more severe than conditioning to a role: I was told of one couple with a small daughter who had epilepsy who were so afraid of other people's possible reaction to the fact that they did not even tell their doctor about it; the child, receiving no medication for her fits, one night had one in her sleep and suffocated on the pillow.

But even the most accepting and supportive of parents are, if they are able bodied, unlikely to be able to avoid contributing to one aspect of our oppression, which is our lack of a cultural identity. The members of most other oppressed groups have parents who share their oppression and whatever factor, such as race or sex, leads to that oppression. They are surrounded by adult models of what people such as themselves can be. This does not apply to most people with disabilities. We do not normally, particularly as children, have any sense of a cultural identity. This leaves us isolated and less capable of resisting attempts to make us cooperate with things that we might reject if we felt stronger in our disability.

Paddy Ladd is now very aware of how this happened to him, as a deaf child at a hearing school who had then had no contact with the deaf world and saw his communication difficulties as something he had to put up with on his own. (He did not then draw a distinction between his hearing loss and his communication difficulties, which were largely due to other people's unwillingness to take account of his needs in that respect):

‘The thing is that if you haven't got an identity to locate it at this point, if you don't think of yourself as being deaf, you therefore swallow all the problems you're having with communication. That's a part of the process; you get verbal bullying, if you like. You accept it, so you can be miserable but it sort of rules out suicide as an option because you never have enough understanding of yourself to want to go that far. I don't use that phrase flippantly.

`At school, it's all verbal interaction, with a certain amount of physical interaction. Certainly as you go up the school it becomes more and more-verbal and you're very aware that you're losing out on it, you're very aware that you're not following it. I hadn't heard of the word "lipreading" then, the word "deaf" having been ruled out, and that left you with only one thing, that you must be a bit dire, a bit slow because you can't follow. What you effectively end up saying is, "I'm stupid". And you get just enough of that coming back from other people to corroborate that to a certain extent.

`And the only way out of that situation is in physical activity, in sport, so you can survive by every single moment of your school day you're out playing football in the playground. That may sound strange to you. I certainly spent literally every minute of every day from the age of eleven to seventeen doing just that to get out of that kind of situation. There are not many people who are going to do that, therefore there are going to be a lot of other people who have been even more freaked out, because they didn't like sport or something like that.'

Paddy sums up the situation he was in by drawing a parallel with racial integration:

`Essentially you end up very, very isolated when you're supposed to be integrated. I think the clearest example is to pretend that I was a black person brought up in a white home. I was very much afraid of deaf kids and also thought myself superior to them. In terms of integration, they didn't give a blind fuck whether you committed suicide or not - as long as it didn't show up on their records.'

The parallel with racial discrimination is by no means an arbitrary one; it is worth remembering that one reason why the struggle against discrimination has been taken further by people with disabilities in the United States than it has been in Britain is that much of the civil rights legislation of the 1960s, introduced primarily to end racial segregation, also gave access rights to people with disabilities. If we tend to draw parallels with the oppression of other groups such as blacks and women, it is precisely because many of the issues involved are almost identical.

Because able bodied parents have no personal experience of having a disability, and probably possess stereotypes of what we are like and what our capabilities are, they are likely to underestimate those capabilities and make false assumptions about what sort of life their child is likely to lead. Parents realise that they cannot simply use their own experience as a guide to what their child's experience and ability to handle the situations she encounters will be, so, out of

genuine concern based on lack of information, assume the difference to be greater than it actually is.

One result of this, indicated by Micheline Mason, can be that parents shelter their children too much:

`One thing which I think is still around a lot is the thing that we somehow have less emotional resources than most people, have to be protected from life, from the hurts and the ups and downs. It happens a lot to young people in their teens. Either their parents or people who are working with them, with the best intentions often, but completely illogically, protect the person from the normal things which people have to go through when they're growing up; having boyfriends and girlfriends and it not working and getting jilted and all sorts of normal things that people have to cope with, cope with the disappointments and things. They shelter and protect them from it, and so force the person to remain immature, just because of the deprivation, and then turn around and say, "Yes, but they're so immature that they couldn't cope with it", and use that as a reason for their sheltering. And that still goes on quite a lot. It makes me furious.

`Another part of it is the complete failure to see what that person has already coped with, which is probably ten times more than most able bodied people will have to in their lives. And that is somehow overlooked when it comes to those sort of questions.'

In her own childhood, Micheline did not initially have an image of her own future as an adult with a disability: `All through my childhood I think I thought that when I grew up I'd be able bodied. I'm pretty sure I had that idea in my head. Apparently that's a very common thing.' I have encountered this kind of belief elsewhere, and I am quite sure it is the result of the lack of adult models that I referred to earlier; I doubt if there are many black children who believe they are going to grow up white, or girls who believe they are going to grow up into men. But, as Micheline reached the age of about eleven or twelve, she started to become aware that other people's expectations for her were strictly limited ones:

`I just picked things up through not hearing things. It was more what people didn't say to me than what they did. Just the things they used to say to my sister which they didn't say to me. When you get married and when you have children of your own and all that sort of stuff' which was just never said to me.

`I remember on one occasion saying to my mother and my aunt something or other about, "When I leave home, I'll do such and such a thing", in a fit of temper. And my mother said, "You'd better face the fact, my dear, that you're pretty immobile".

`I remember my mother saying once about all my cousins, "Aren't they all growing up quickly?" And she said, "Funny that soon they'll all have left home -- except my Mich, of course". I remember that very distinctly.'

But it is by no means always the case that, where parents have formed unduly low expectations for their children, the children accept this evaluation. As they grow up, children tend to know their disabilities and are more aware of their capabilities than their parents are. As a result, parents find themselves learning from their children that they have been mistaken in their low expectations, and having to readjust their attitudes accordingly. Certainly this happened in Micheline's case:

`I think by the time I was nineteen, when I did leave home, I think my parents had realised that I was more or less going to do what I wanted to do. They'd realised then that a lot of their prognoses were just not right. I think they'd stood back really, I could sort of see the point where they did it. They were ever so good. I can never remember being pushed to do things, but I was always encouraged once I'd taken the initiative to do something. `When I was actually leaving home, I didn't mention the fact that I was going until I'd actually got the flat. I know why I did that; it was because I was nervous myself about doing it. And I knew my mother would panic and worry. And I didn't want to hear it, really, because I was worried enough myself. I didn't feel I had the reserves to put her at her ease. So I didn't tell them until I'd got the flat and I knew when I was going. I just dropped the bombshell over tea one day and mother went white ... I wasn't going far, that probably had quite a bit to do with it, about a mile down the road.

`They put a lot of trust in me by then. I think they pretty well knew that I knew what I could do.'

One particularly-interesting point that Micheline makes is that her parents' re-evaluation of their own attitudes, as a result of seeing how much greater her capabilities were than they had expected, led them to change their views more widely:

`I feel now that my parents have learnt a lot from watching me and realising how a great deal of what they were told was just not true. And I think it's made them question various aspects of a whole lot of other things too. It's made quite a big difference to their whole way of looking at life.

`I still feel there's a thing about marriage and all that stuff I expect they think won't happen. And now because I'm nearly thirty and it hasn't happened and they

don't know what has happened.... They daren't talk to me about it really. There's still a conspiracy of silence, but the reasons for it have changed.'

It is significant that Micheline refers to her parents as finding fault with 'what they were told'. Because able bodied parents usually know very little initially about their child's disability, they are very dependent on the information given them by 'experts' such as doctors and therapists. Unfortunately, such professionals tend not to fill this role very adequately. Though they do not necessarily provide false information, most of them tend to view their role in relatively narrow terms. Thus doctors, for example, generally confine themselves to medical information, and give parents little guidance on wider aspects of bringing up a child with a disability. (This is a fairly general failing of the medical profession, by no means confined to their dealings with disability.)

This is an adequate approach, even as far as strictly medical aspects of disability are concerned, since, while doctors can give general information about the nature of a particular disability, and some indication of how it affects a particular individual, there must always be a large area where the application of this information is dependent on the individual's knowledge of her own disability. One thing that doctors rarely do is to give any guidance as to how the medical information they are giving is to be related to the knowledge that one derives from living with a disability, or emphasise to parents that the greatest expert on the individual facts of one person's disability is the person herself.

Thus, in my case, my parents were given general information about things which tend to influence the frequency of occurrence of fits, such as leading a regular lifestyle and avoiding excessive consumption of liquids. I had to work out for myself, however, that these were general guidelines which did not necessarily apply to my particular case - I have never found, for example, that drinking leads me to have fits, though I have met other epileptics for whom this is true - and that, if I wanted to accept a slightly greater risk of having a fit as the price of keeping the hours I chose to keep, then it was my right to make that choice.

It strikes me as very significant that, in the one instance I am aware of where a doctor went out of his way to make a suggestion to my parents that went beyond the purely medical, the doctor in question had personal experience of living with a disability. When I was about fifteen, my parents visited the hospital (presumably with me accompanying them, though I do not myself remember the incident) to discuss how things were going, as they had been doing at regular intervals since I first developed epilepsy. The doctor they saw suggested that it was time that people started discussing my epilepsy with me, rather than with my parents. He told them that he was an asthmatic, and that he had had to learn to live with asthma and to cope with it himself, and that he thought it was now time

that I took control of my epilepsy and learned to handle it myself. It was not a question, he told my parents, of them telling me about my epilepsy; it was in my hands and the kind of life I led was up to me. Which, as my mother commented when reminding me of this incident, "was very sensible of him".

Parents, particularly parents whose child's disability has only relatively recently been diagnosed and who have therefore had little time to learn from observation, can be particularly vulnerable to misinformation. This is not hard to find; most people with disabilities can list a number of examples from their own personal experience. My parents were told by the first doctor they consulted about my 'twitches' that I'd probably got worms, and lots of children did that sort of thing and I'd grow out of it. He didn't suggest any treatment, or any' cause beyond the supposed worms. Which is why six months elapsed from the time my parents first noticed my epilepsy before it was correctly diagnosed and I started to receive medication.

But this piece of incompetence pales into insignificance beside the information given to Micheline Mason's mother after Micheline was born:

'My Mum's told me a bit about what they told her in hospital. When I was born I didn't look as if there was anything wrong. They didn't realise for a couple of days, but every time my mother touched me I screamed. She thought there was something wrong. And then they X-rayed me, and found that I'd got two broken legs or whatever through the birth. I don't quite understand the logic, but they then decided I wasn't going to live. And they said to my mother your child has got this, that and the other wrong with her, but don't worry, because she probably won't live. I was christened in hospital; I'm very proud of my birth certificate, which says "Pro mortis".

'That prognosis didn't work out. Then, I'm not sure exactly what they said, but they told her all the things I'd never be able to do. I'd never be able to walk. And I think they just instilled a lot of fears into her.'

Paddy Ladd remembers a subtler and more deliberate form of misinformation that occurred at the Centre for the Deaf that he was attending, when he was four or five years old:

'I do remember the most significant thing about being at the Centre, being partially deaf, not so deaf as I am now, being made to stand up in front of a whole row of parents and children and being told to show how well I could speak for the parents' benefit. The parents there, including the parents of children who were totally deaf, were being beaten by this big bootstrap which said, "Look how well I speak; your children will speak the same if you work hard and keep repeating



words", and all the rest of the litany that they have. It implied in brackets that if your child doesn't speak as well as that it's your fault for not having worked hard enough.

But if you're profoundly deaf, there's no way you'll speak like I was speaking then. You'll have a good deaf voice, but it won't go much beyond that. So they were being deliberately lied to, being beaten by that big strap, and therefore when their child failed to take that target, they either refused to see it, their whole picture of how the world was going to be for their child had nothing to do with reality, or were just driven back on themselves in the sense of guilt, of having it internalised as well: "It's our fault, we must take all this punishment".

I've seen a lot of repercussions over that in later work in terms of parents pretending that there are no problems at home. Instead of being supportive to each other, they're saying, "Oh, I don't have any problems with my child". They haven't been given an honest approach from the start, after which they can say, "Oh, yeah, the little fucker really misbehaved", or whatever. There's no solidarity between parents of deaf kids.'

Misinformation such as this and the appalling attitudes which Micheline's mother encountered play a significant part in conditioning us to accept a disabled role; our parents become unwitting carriers of oppressive expectations which have been presented to them as factual information and, coming from supposedly expert professionals, are likely to be accepted as such. Thus, when parents of profoundly deaf children are given false expectations of oralist methods, with no indication of the alternatives available from manual communication and the deaf culture, their children, failing to live up to these expectations and cut off from other deaf people, are likely to end up as poor imitations of hearing people, seeing themselves as too stupid or incompetent to achieve what was in fact an impossible goal, and inferior to real hearing people, rather than as the proud and articulate deaf people they could be.

And when a parent is, in effect, told that it would have been better for her daughter to die in infancy than survive to live the life that lies ahead of her, it would be surprising if she did not assume that the child was unlikely ever to take a full place in society and, with the child's best interests in mind, act accordingly. The child is therefore likely to grow up feeling that she is different from other people in more than her physical characteristics, and overconscious of her supposed disabilities.

Clearly, Micheline managed to , resist such conditioning relatively effectively; - but that she was not left untouched by it is indicated by her account of her announcement that she was going to leave home. I think this is typical of the way

conditioning works for a great many of us: though we refuse to accept it - or the aspects of it that we have identified as such - we have to fight it. This must inevitably limit us, because we are spending energy on overcoming our conditioning that could otherwise be used more productively. One important reason for learning to support each other is that, as we do so, we cut down the amount of energy we are dissipating in this way.

It was also as a result of misinformation that Derek McCarthy's mother agreed to let him be sent to a special school, an incident which he described in Chapter 5. As that chapter indicated, such schooling plays an important part in teaching many children with disabilities to accept the role of disabled person; the very fact of being at a special school accustoms children to seeing themselves as separate from society.

But the child with a disability who goes to an ordinary school may also be made to feel 'different'. In part this will come from other pupils; for Merry Cross, this occurred when she changed school at the age of fourteen:

'I don't think I registered that stuff' about difference until I moved to this new school. When I was twelve, and about the point in time where people might have started pulling away from me as they came into the teenage period and started getting interested in boys and stuff - I don't know whether they would, because I'd been friends with these people for such a long time, but they might have done. But a girl called Joan arrived at the school, and became my closest friend, and she always brought me totally into her world, which was very much a world of Elvis Presley and Pat Boone and boys and so on. And so I didn't feel different, but when I came to this new school people simply didn't assume I was in the boyfriend stakes or in the pop scene stakes at all.

'And I kind of wormed my way in every now and then, but I wasn't taken seriously. And I couldn't wear fashionable clothes and of course I did become self-conscious at that point, because pencil skirts, straight skirts came in for the first time and there was just no way I could wear those, because my caliper bulged out at the back. And so I became more aware of being different then.

'When I got my first boyfriend while I was there, he was very tall, good-looking feller, very beautiful feller. And I remember somebody saying, "How did you manage to get someone like that?" And people were just openly amazed.

'But again, he protected me from the worst of it, because he did fancy me and we went out together and.... He just didn't seem bothered by my leg at all. And we used to go swimming and play tennis together. But also sexually. He was the first person to make sexual advances to me, and in fact we had a sexual relationship in

the end. And so that also protected me from feelings of being totally unattractive, undesirable and so on. But he was the only one. Unlike most young people, I didn't have a succession of boyfriends. So I have this rather fragile sense that if he hadn't come along maybe there wouldn't have been anybody. I don't know.'

Such experiences are relatively common, -and not necessarily connected with schooling except insofar as school is the main place where children and adolescents meet other people of their own age. But they may be influenced by discrimination by the staff of the school; if, for example, Merry had been allowed to take her place on the tennis team, other pupils might have been a little less ready to write her off. In fact the staff of the school openly took the lead in treating her as different from the other pupils:

`Several teachers wouldn't ever let me forget about my leg, even though it was affecting virtually nothing at the time. My chemistry teacher used to say to me, "How are you today, dear?" - and I used to think back anxiously in case I'd been off ill.

`Apparently - I learnt this after I'd left the school - the headmistress had warned people that there was a cripple coming, and they weren't to laugh and they weren't to stare and they weren't to point. Now this was a secondary school, a grammar school ... I wouldn't even do that in a primary school. Even if it is likely that youngsters need the information that it's not nice to be stared at, there's still far better ways of doing it than making a proclamation before I turned up. I think people were expecting some monster, and I think they felt cheated when I turned up and was so agile and ordinary. And I couldn't make friends with people for ages. It was miserable.'

Obviously, people who acquire their disabilities in adult life do not experience discrimination while they are still children. They may however acquire stereotypes of disability as able bodied children and then fail to discard them when they acquire a disability. I have already quoted Chris Pearson's description of his difficulties caused by the stereotype of epilepsy and fits that he already held. That stereotype was undoubtedly partly due to childhood experience:

`People are afraid. People are genuinely afraid. I remember the very first time I ever heard the word "fits", as a kid in reformatory school. There was a boy there, they said to me be careful of him, don't pal around with him, because he gets fits. This was the attitude. No one mentioned epilepsy. Obviously I know now that this boy suffered from epilepsy. And the word in the school was, don't pal around with him, Ginger they called him, because he gets fits, he goes mad. Really all that was happening was that he was having epileptic fits. But the word was that he was mad, that he was a nutcase. We called him the Killer ... *He* didn't know he

was an epileptic, and he used to go round saying, "Watch it mate, cause I get fits and I go mad". Really!

Another-particularly important factor in maintaining the role of disabled person is the whole concept of `charity': both in the form of institutionalised charity and in everyday personal treatment of people with disabilities as passive recipients of other people's need to feel useful. (I am referring here to people who thrust help on us without consulting us, which implies that they know what is good for us better than we do ourselves; not to people who offer genuine assistance in a helpful way, so that we are free to indicate whether or not we want to accept it, and what particular form of help would be useful.)

Institutionalised charity continues to play a very significant role in relation to disability, performing a number of very necessary tasks such as the provision of various kinds of aids and facilities. This is an undesirable situation precisely because these tasks are so necessary; the provision of essential aids is too important a task to be allowed to remain dependent on the whims of public generosity. It is now generally recognised that the state has a responsibility to perform many of the tasks that were at one time left largely to charity, such as the alleviation of poverty or the care of sick and elderly people. But people with disabilities still have relatively few statutory rights; until these are very substantially extended, charities have to plug the gap in state provision.

However, charities dealing with disability tend to be run by people who do not have the disabilities in question. I know of no major charity dealing with disability which even employs a significant number of people with the disability they deal with, except in a strictly charitable way, through sheltered workshops and the like. Where a certain amount of positive discrimination does take place, it is normally in relation to the same menial jobs which are reserved for `the disabled' by other large organisations which do not totally disregard their legal responsibility to employ a minimum quota of people with disabilities: lift or car park attendant, switchboard operator, typist and so forth. This is not at charity, which is not necessarily those people who are most willing to give active support to people with disabilities) responds poorly to advertisements which present people with disabilities as strong and self-dependent. To raise the money they need, charities have to evoke sympathy rather than solidarity. They allow themselves to remain trapped in a vicious circle.

One memorable image of people with disabilities is a poster showing a single helpless-looking child in a wheelchair in the middle of a large open space. The caption reads, `He'd like to walk away from this poster, too'. I'm sure he would; I wouldn't care to be associated with it myself. To the customary presentation of us as hopelessly dependent - drawing attention to our

inabilities rather than to our abilities - it adds the implication that we are isolated and unhappy, none of which is calculated to encourage people to want to get to know us on the sort of terms that might give us the scope to behave as individuals. But the essential feature of the poster is that it is conceived entirely in able bodied terms. In actuality, no wheelchair-user I've ever met has wasted much of her energy in futile yearnings to be able to walk; what they do complain about is not being able to get where they want to go in their wheelchairs because of access discrimination.

This is how charitable appeals work; they play on the stereotypes that people already have of disability in general or of particular disabilities and, in doing so, create images and statements which reinforce those stereotypes. The degree of response they achieve is strongly related to able bodied ideas of how pitiable or tragic any given disability is. One very divisive force that hinders people with different disabilities from working together is the extraordinary discrepancy between the amounts of money donated to charities according to the degree of popular sympathy attached to the disabilities they represent - organisations for blind people, for example, receive a hundred times as much money as organisations for deaf people. The kind of hierarchy this creates inevitably breeds resentment and mistrust between people with different disabilities.

The second way in which organised charities affect us is in their direct dealings with us. Charities operate on a dependency model in which they are the bountiful providers (or the committed, responsible members of society, aware of the needs of those less privileged than themselves) and we are the passive, dependent recipients. They are also prone to see themselves as experts on the particular disabilities they concern themselves with, particularly if their work involves disseminating information about the disability in question and trying to bring about changes ('campaigning' would be too strong a word) in attitudes towards it; and hence to treat any criticism of their aims or methods by people who have the disability in question as a hostile attack rather than as information to be listened to and taken note of.

If we have any dealings with them, we are expected to approach them with due humility, accepting on their terms whatever they deign to give us. Consultation has no place in this process; though charities frequently claim to represent us, they do nothing of the sort: they merely act on our behalf, doing what *they* think is best for us. And we are expected to be grateful for it. If we criticise, we are seen as churlishly ungrateful, biting the hand that feeds us.

Though it is not easy to prove conclusively, I am sure that one reason why charities make little attempt to democratise their structures, to introduce people

with disabilities into their management or to increase consultation with the people they are supposedly representing, is that many of the people who work for large charities are so immersed in the dependency model on which they operate that they simply do not believe we would be capable of handling such a degree of responsibility. Such contact as they have with people with disabilities seems to bear this supposition out, since the people with any given disability who are the most able are also those who are least likely to be depending on such charities. (Whether their abilities are the reason for their lack of dependence, or vice-versa, is something I leave my readers to ponder over for themselves.)

Micheline Mason links the nature of charity to the class structure: 'I suppose charity originated when classism originated, inasmuch as there was an owning class and another class, and a little bit of guilt arose. That then made the owning class, who had no intention of giving up their power, prestige or property, feel they had to appease their consciences by giving away some of what they had to some of those who had not, in the Lady Bountiful thing. That's the basis of charity, the giving away of a little of one's wealth, to which one is entitled, to those who are somehow seen as not entitled or able to have it.

'The roles of the working class and the ruling class have been created by taking away from people what they once had and then giving back to them small portions of it, depending on their worth, judged by the people who've taken it to begin with. The same thing is happening with people who are now beneficiaries of charities; you find yourself in this position of being in need, having less than many others, often without knowing how you got to be there.

'It's very rarely looked at. It's seen as the way things are; something inherent in you has made you warrant that position in society and it's unchangeable, an intrinsic quality that by definition is something you cannot change and therefore is what puts you in that position. Disability is a very clear example of that, really. You're in a position because you have a disability, and the historical path is not seen. And that's a quality which is intrinsic and cannot be changed, other than by a miracle cure or whatever, which is also something people pay vast sums of money to try and get. It isn't seen in terms of social relationships between people, which can be changed, aren't intrinsic.'

Micheline emphasises the importance of distinguishing 'charity' in this sense from genuine kindness and helpfulness:

'I want to distinguish between that kind of charity, which is institutionalised, which is why I call it oppression, because it's certainly an institutionalised way of treating people, and doling out resources. I want to differentiate it a little bit from what people would call "Christian charity", which is a selfless giving,

which is really okay. I don't want to say I've no room for that, and it's all terrible and shouldn't happen, because I don't believe that.

`That word "charity" has got used to mean two quite separate things, or the same thing on very different levels, and I don't want to stop people from being kind. I really respect that a lot of people do do things out of pure niceness. I also think I have the right to do that too. I don't think we should be put in the position of always having it done to us, and not being in a position of being able to do it to other people. That's when it gets to be a question of power.'

Because charity is so intimately linked to dependence and power, anything that makes people with disabilities less dependent on the givers of charity tends to be distrusted or resented. At the simplest level, this is what is happening when would-be `helpers' take offence when a person with a disability points out that they don't need helping; the instrument of independence in such a case as this is simply free will, which is something that many givers of charity greatly resent finding in people with disabilities because it threatens to challenge their superiority.

The distrust is greatest when we are seen to be making ourselves more independent by using skills of our own which are not used by the able bodied and do not attempt to copy able bodied ways of doing things. The prime example of this is sign language. Not only is it an alternative to, rather than an attempt at, oral communication, but it is learnt by deaf people from other deaf people rather than from the able bodied. And because, like any other language, it is a very complex skill, a hearing person who uses it must, until she has spent a great deal of time learning and using it, show herself to be less competent in its use than its native speakers. (McCay Vernon also makes the very relevant point that physical gestures reveal a great deal more than does speech about the unconscious feelings of the user, which may prove very threatening to individuals who are emotionally repressed; this prospect is presumably particularly threatening to people who are communicating with others whom they regard as their inferiors, and whom they feel ought to respect them.)

Paddy Ladd points out that signing has in the past been more highly regarded than it is now, and suggests that charity has been partially responsible for this loss of status, in that its givers have resented the independence that signing gave to deaf people and therefore made attempts to suppress or denigrate it:

`People were just taught to use sign language, they weren't taught to speak, and so it was just silent signing, which was fairly highly regarded. There are a number of references to people like Bernard Shaw saying if I go deaf I would rather learn the sign language than wear a hearing aid. So people then didn't see

that as much of a stigma, perhaps, as they have over the past seventy or eighty years, when certain types of behaviouristic thinking have really become dominant.

'I think a lot of people were relatively fascinated by sign language, I don't think it's necessarily seen as that much of a stigma, except unfortunately by the do-gooders who then start to say oh you need helping and get angry if they can't help you, which leads to the thing of "I'm going to put you in the position where you're going to need help". There isn't necessarily a stigma, but there is a certain amount of resistance, but mostly by those who are in control, because those who are in control are more uptight physically than the other person who they've attempted to make like them.'

One can draw a certain parallel between the paternalism of charities and that of colonialism. Oppression commonly produces ideologies to justify itself, claiming that it is helping those whom it keeps in a state of dependence. The myth of the British Empire was that, far from being economic exploitation imposed and kept in existence by the use of force, it was of major benefit to humanity, bringing the benefits of civilisation to ignorant and heathen savages. Similarly, charities, while playing a major part in maintaining our dependent role, propagate the belief that we are helpless and, without their existence, would be even worse off than we already are.

By keeping in being organisational structures over which we have no control, attracting large amounts of money which are intended to be used for our benefit, and then using them in ways which serve our real needs very poorly, charities are diverting resources which, if administered by organisations run by people with disabilities, could be doing us a lot of good. And, though we are the logical people to be running the organisations that supposedly represent our interests, we are deprived of that employment, which is instead given to able bodied people. A considerable number of able bodied people earn substantial salaries as administrators of charities, while we have the greatest difficulty finding any employment at all. What, then, is that, if not exploitation?

The parallel may be taken a step further by observing the role of the church. The Christian religion has always gone hand in hand with colonialism of all types, winning colonised peoples away from their native customs and beliefs and instilling respect for Western values. Wherever there is Western colonialism, there is Western religion. In the case of disability, the church's genuine and praiseworthy concern with caring has very frequently slipped over into the kind of charity which creates dependency. Maggie Woolley gives one example:



`Way back in history, deaf people who were born deaf were just left to fend for themselves and so were regarded as imbeciles: they didn't speak, they didn't talk, they didn't have language or anything. They were just left and regarded as subhuman.

`That has very much stayed with us. In Victorian times there was this outcry that all these deaf people were not going to be saved, they were going to be condemned to hell because they knew nothing about God, and it was realised that they needed to have a language in order to take part in church and so on, in order that their souls might be saved. So the missionaries were the first people who looked to our education and so on, and of course it was a very paternalistic attitude which stayed with us right up until the present day, it's still there, there's still this element of looking on born-deaf people as very much inferior and so on.

`That does affect the way people see hard of hearing people as well. So much so that hard of hearing people don't call themselves deaf, they call themselves hard of hearing. They look on themselves as something quite different from that lot that sign and can't speak. Their attitude to the born-deaf is very similar to what I sense is the attitude of some hearing people to me.'

This strikes me as one of the saddest aspects of our conditioning; it leads us to reinforce the conditioning of other people with disabilities, whether they are, as in this example, people with more severe forms of our own disabilities, or people who have disabilities different from our own, which we may misunderstand just as much as our own disabilities are misunderstood by others. We must take great care to avoid letting such able bodied attitudes come between us any longer.