

9 The Professionals

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

Almost all of us have had a lot of experience of the professionals who deal with disability and the medical profession in particular, and few of us have found that experience entirely satisfactory. Our criticisms are not primarily about the medical aspects of the treatment we have been subjected to - though most of us can cite examples of medical incompetence - but about the degrading and dehumanising way in which we have been treated, which for many of us has been an important element in acquiring a view of ourselves as somehow less than human. This will be to some extent a chapter of horror stories; it is important to bear in mind that these are not examples of what would conventionally be considered bad or unethical treatment. They simply demonstrate the nastier side of normal acceptable medical practice. More particularly, they demonstrate the shortcomings of an approach to medicine that concerns itself with purely mechanical questions of the way the body functions, with little sensitivity to people as people.

Such dehumanising treatment is most strongly linked to institutionalised medicine; it's no coincidence that none of the major examples of such treatment quoted in this chapter refer to experiences with family doctors. Any family doctor knows that many of the people who come into her surgery come seeking reassurance rather than because they have anything seriously wrong with them medically; a good family doctor takes these worries seriously, realising that we live in a society where it is not necessarily easy to find people to turn to in distress, and that her function goes beyond the strictly medical in precisely the same way that a priest's function goes beyond the strictly religious.

But in a hospital one deals with specialists - not just doctors but a vast array of people who fulfil one particular function, and none of whom deal with the whole person: radiographers, physiotherapists, audiologists. Each ailment is split into a number of distinct tasks to be dealt with separately; even the doctor's role may be subdivided: when I am taken into hospital after dislocating my shoulder during a fit I am seen first by a doctor on casualty who diagnoses the dislocation and reduces the shoulder, then by an orthopaedic surgeon the next day, who considers what further treatment may be needed, and then, a week or two later, by a neurologist, who looks at the incident in the context of my epilepsy. Along the way I will also pass through the hands of (at minimum) one ambulance crew, three sets of receptionists (most of them more than once), one radiographer, one blood technician and

three or four nurses - and this is for a relatively simple injury. The end result of this, as with other production lines, is alienation.

Merry Cross points out how such specialisation affects the attitudes of its practitioners:

`The whole point is that the professionals who deal with us have - the numbers of them have just exploded, not just the number of doctors but all the different categories and sub-categories and subsub-categories of professionals. And what's happened, I think, is that the more specialised one gets, the less easy it is for them to remember they're dealing with human beings. They get to be dealing with speech; or mobility; or whatever it is; and not with human beings. And I think that's one of the things that permits them to lose sight of what is degrading and to perpetrate the most outrageous deeds.'

For most people time spent in hospital, or visits to a specialist, are isolated incidents in the course of a less generally alienating existence. This is less true for most people with disabilities for the reason that, as I have described, we also get subjected to a considerable amount of degrading and dehumanising treatment in the outside world. But for many people with congenital disabilities the situation is even worse, in that they spend the early years of their lives in hospital, so that their first impressions of the world are almost entirely formed by the hospitals in which they are living. This was Micheline Mason's experience:

`I spent most of the first four years of my life in hospital and the memories I've got are extremely ... horrible. And I can only piece them together. I just know things like that it was very very regimented. And that you woke at a certain time, and you ate at a time and you went back to sleep at a certain time and you sat on your potty at a certain time and got off at a certain time. It was all totally regimented. That went on for four years and I don't really know what effect it had on me, except that every memory I've got about it frightens the daylights out of me.

`I remember people not knowing what was wrong with me and feeling, very early on, that they didn't know, that I had to explain to people what was wrong, I had to explain to the nurses how to pick me up. I very quickly learned to mistrust them. I also learned that you're talked about as if you weren't there. I've got tons of memories of that, people with packets of X-rays standing showing them to medical students and all that sort of thing, pointing at this and pointing at that and they'd look at me and look up and look at me and look up again and they'd go on talking, as if I wasn't hearing what they were saying.

`It's very hard to explain what that feels like. It's like I, as a person, wasn't there. My body was there to be looked at, probed around, touched, X-rayed, seen inside out, upside down and whatever. It was not my property, it was theirs. Part of that is just because I happened to be a child as well. They do that to children anyway.' But though a child who is not living in hospital may be spared the day-to-day dehumanisation that Micheline describes, it is possible for a single incident to have a lasting traumatic effect. This happened to Merry Cross when at the age of eleven she was photographed in the nude:

`I used to wear a built-up shoe and suddenly I got this tremendous pain in my hip. I now know that a bit of cartilage had broken. Evidently the photograph was to help them assess what would and what wouldn't be helpful to me. But they didn't tell me that, they just said, "Oh, we'd like you to go and have your photograph taken". Just that.

`I went into this huge room, and a nurse said, "Come in this cubicle and undress, dear". No explanation. She shoved a box of green, skimpy G-strings at me, nothing to cover my breasts.

`My parents were there, and I can't remember whether I went out like that, or whether Mummy came in and brought me Daddy's coat. Anyway, I sat with Daddy's coat huddled round me, sat next to them wondering what was going to happen next. And they finally told me to go up on this stage. I had to stand on a stage all alone, while two men, one young one and one old one, photographed me with nothing on but this G-string and my parents were there as well. That in itself was probably the most humiliating experience I've ever had.

`And then they must have developed it quite quickly, and I had to go back in to see the surgeon, who had about fifteen students in there. And they passed this photograph round everybody, with me sat there, and I said, "Oh, can I see it?". I must just have thought, "Hang on, this has something to do with me", and I needed some sort of foothold in that whole situation. They showed it to me.

Now, years later, I've discovered how much distress that caused me, and how it affected me really quite severely in terms of my becoming self-conscious.

`I always recognised that there was a turning point, where I was at one time not self-conscious about, say, going swimming in a swimming pool and a time when I started to be. I don't actually know, looking back I can't make up my mind when it happened, but I'm damn sure that's got something to do with it.' Merry also discovered a more specific self-consciousness stemming from this incident, when she had been fitted with her present special shoe:

`There were lots of traumas for me about it. I found myself grossly self-conscious whenever I put it on. I couldn't understand it if I walked into a room and everyone didn't fall off their chairs with surprise, people who knew me. Eventually a situation came up where I walked into a big room full of people, who mostly knew me well. And nothing happened, nobody murmured, although it was the first time they'd ever seen it. I felt really upset and started to cry. It ended up with a huge, huge counselling session, which turned out to be all about when I was photographed in the nude. And that time is associated with the change from the "iron shoe" to my caliper. What I worked out eventually was that when I walked into a room wearing this thing I felt as if I was walking in in the nude and being just totally exposed and vulnerable. Ever since that session I've never felt bad about it, I've never felt so self-conscious. But that was all associated with enormous fear.'

Such treatment is outrageous, but it is not particularly unusual, as is indicated by the fact that Micheline Mason remembers a similar experience:

`I remember too having medical photographs taken. I remember being told I was going to have some photographs taken and I thought, "Oh, good!", thinking it was snapshots like my Dad used to take. And this man arriving with his equipment and cameras and things. Y was in hospital and I was in the children's ward and they just put the screens round me and told me to take everything off. I couldn't understand and just did it. I didn't know what was happening from that point onwards, really. I just knew that he was taking bits, he wasn't taking me, he was taking bits of me. It was horrid. I thought it was really rude.

`And I remember thinking what's he going to do with them, he'll put them in a book. And I think I asked him, I think I said, "What's he going to do with them?", and I think he said, "We're going to put them in a book". And that's really all that I can remember. I was disgusted by it.

`If they'd taken the trouble to explain what was going on, it still would not have been an okay experience, because they would have explained to me that what they were going to do was put them in a big book for medical students to stare at. It wouldn't have made it any better. They might have told me, actually. But you don't understand when you're nine ... or maybe you do understand, you know it's wrong.

`Nothing would have made it an okay experience, because I don't think it is an okay experience. And it's only one of a series of experiences, too, and they're all basically the same: Most of them are to do with men, the nurses are very different.

`My memory is basically of a whole series of experiences of being very coldly and formally mauled around, really. It's very alienating. It's as if you're a medical specimen. It's as if your humanness is of no interest, that all that is of interest is your medical condition. Even that's not right, because they're the ones that term it a medical condition.

`It's just very inhuman. Most people when they're touched, physical touching's a very important thing to people, and the way it's done is very important, it's a whole language. And to be touched that way is frightening. I was never told I was nice to look at or nice to touch, there was never any feeling of being nice, just of being odd, peculiar. It's horrible. It's taken me years and years to get over it.

`I think it's a violation. It's an absolute violation of somebody's private being.'

The knowledge that one's photograph is being used as an exhibit to be examined by total strangers is in itself a gross invasion of personal privacy. But, as if that were not bad enough, we are also required to perform live, as Merry describes:

`They gave me an artificial limb. And then they asked me to come for this special occasion. And there were about sixty or seventy nurses and doctors in this hall, and the surgeon took me up on stage and said, "Walk up and down, please".

`It wasn't permanent. It was only for cosmetic purposes. I wasn't wearing it all day every day, it was just something I could wear for dances or parties. I don't recall that this was ever my idea. I ended up ditching it because it was a terrible psychological strain.

`So they paraded me up and down on this stage, and the surgeon was saying, "Who can say what's wrong with this young lady?". And then I had to sit and watch a film of myself playing tennis, which they were showing to back up an argument that actually, no surgery would make me any more mobile than I already was. However, once again, they didn't tell me why they were doing it. I had no information at all until it was well in the past.

`And only the other day I found out that that also had left a huge pool of upset, which suddenly got triggered off by having like a small little audience sitting on the floor while I was sitting on a chair and suddenly it just got sparked off. Again, total humiliation.'

Micheline, comparing this experience of Merry's with her own memory of school medicals, suggests that the distress caused by experiences such as the one just described may be partly to do with the isolation of the situation:

`When we were at boarding school we used to have medicals at the beginning and end of every term. That consisted of going in in your underwear and walking up and down - the room and being probed around. And it was awful, there were people there who should never have been there. I mean, the headmistress was there. But it didn't have the effect on me that it did on Merry, because it was all of us, and we were all in it somehow and made jokes of it, used to wear knickers with all sorts of lewd things on and used to do all sorts of outrageous things. And at one point we all said we didn't want the headmistress in there and it was changed. It was different because there were a whole lot of us, I didn't have that terrible experience of when you're singled out to be the only one. But it was bad enough, it was still really humiliating.'

This aspect of our oppression is largely a case of our receiving an extra share of treatment which able bodied people also encounter; in the example just quoted, all schools give their pupils medicals from time to time, but special schools do so more frequently. As Merry says:

`When you talk to able bodied people who've been in hospital, they can all quote the same humiliating experiences. And obviously anyone who has to deal with doctors gets it, but we get it more of the time, because we're exposed to them more of the time.'

But even where we are not subjected to the particular humiliation of experiences such as I have just quoted, a more general dehumanisation arises from the unwillingness of medical specialists to concern themselves with personal problems. One might think it reasonable to assume that a doctor who specialises in the treatment of a particular area of disability would be particularly aware of the personal problems that might be associated with that type of disability. Such is not the case, as Maggie Woolley explains:

`My criticism of the majority of ear, nose and throat specialists I've had to deal with in the past is that their concern is with my faulty ears, and they have a very professional manner that sticks to that point of my faulty ears. So that if I, as in the early days I did, try to bring up far more important problems than the actual malfunction in my ears, like the effect that it was having on my life, then they would give very abrupt, pat answers which cut the conversation completely short. `For example, when I was very young, maybe eighteen, I said to my specialist that I was very worried about the effect that deafness was having on my life, and he said, "Oh, you mustn't worry, dear; worrying won't do you any good, you'll

eventually come to terms with it". Now that, to me, translated, was, "Shut up, don't worry me, dear". A more aware, considerate professional would have realised that that was an appeal for some kind of help. Now it may not have been within his role, but it wouldn't have taken too much time to refer me to another agency which could have helped me there.

`He said, "You'll eventually come to terms with it", but gave no indication of how that was to occur, because he had no idea, because he knew very little about deaf people and their experience of deafness. His subject is faulty ears; the human being and the life experience of deaf people was no concern of his. I say "he" because they've all been male, I haven't yet had a female ENT specialist.

`Often I've found it difficult to follow specialists. They tend to shout, they know very little about communication with deaf people.'

Such attitudes permeate downwards, if only for the reason that a specialist who is unaware of the needs of the patients he or she is dealing with is unlikely to realise when those needs are not being attended to:

`A visit to an ENT specialist begins at a reception desk. Now I've been to hospitals in Scotland and in London and receptionists have no idea how to deal with deaf people. I am not the only hard of hearing or deaf person who will say this to you, it's a common complaint.

`You will then be summoned by a lady in a white coat, and it's the same thing, there is this tendency to just shout. The language that is used is very simple, as if they were talking to a child, and the manner tends to be very patronising.'

People with disabilities have contact with a large number of professionals of various types. Yet this unwillingness to see their responsibilities in any but the narrowest terms seems to be quite specific to the medical profession (or, at least, manifests itself in a much more extreme version in medicine). Maggie points out that, in the case of deafness, many other professionals are much more willing to consider wider aspects of disability:

`As far as I know, there are no interdisciplinary professional groups that have yet managed to involve specialists much. I'm thinking of groups like the London Group of Workers with Deaf People, where there is a kind of liaison between different fields, between social workers, teachers and speech therapists. It tends to be difficult to get people working in the medical profession in clinical aspects to come along. You will probably get academics involving themselves - linguists, psychologists and so on, social workers,

some teachers and speech therapists. But the medical profession tends to be an elite, which is for and about itself and doesn't tend to integrate.

`Whatever you're talking about, whether it's deafness, gynaecology or whatever, there is this criticism of the medical profession that they don't want to understand people's experience of illness or disability, so that you get the most absurd assumptions about disability and illness.

`For example, thinking of women, all the misunderstandings about "women's problems" that the male medical profession have, and the female medical profession have because they're trained and conditioned in the same way. You get this with deafness too. They have no knowledge of our experience of deafness, and what they have is just based on assumptions, which tend to be rather negative; they tend to assume that we are "thick" and need to be spoken to in simple language, in the patronising way they have of talking.'

One reason for this insensitivity to the needs and experience of their patients may be that, in order to change their approach, doctors would need to learn from their patients precisely what their needs and experience were. And it is quite clear that many doctors feel such a strong need to maintain their authority that they have great resistance to admitting that a patient might have knowledge that they do not. This presents something of a problem to people with disabilities, because we do tend to get to know the facts about our disabilities pretty well, and so can easily find ourselves in the situation of knowing more about some aspect of them than the doctor we are dealing with.

For example, a couple of years ago, having been taken to hospital after a fit, I was asked by a doctor why I had one of my drugs in both fifty and hundred milligram capsules. I replied that the specialist who had determined my current dosage had explained that the drug in question, phenytoin (Epanutin, Dilantin), was not absorbed into the bloodstream in quantities that bore a constant relation to the dosage taken, the ratio varying with the dosage, so that above a certain dosage a small increase in the amount taken would produce a much larger proportional increase in the amount in the blood; the specialist had therefore decided to raise my dosage by only fifty milligrams per day rather than a full hundred. To my surprise, the doctor I was talking to denied that this was the case. He didn't say, "Oh, I didn't know that", which would have been a perfectly reasonable reaction, since there is absolutely no reason why a houseman on duty in casualty should be expected to have the knowledge of the specific action of one particular anticonvulsant that an experienced neurologist possesses, nor even, "I don't think that's correct". He simply told me flatly that what I said was not true.

These days, having read rather more about epilepsy than I had at the time, I could cite the details of a text book on the diagnosis and treatment of epilepsy in which such a doctor could find confirmation of my statement. I strongly doubt, however, that it would make a jot of difference, because he was clearly set against accepting the possibility that a patient might be better informed than he was.

This kind of attitude seems to occur at every level of medicine, even when it comes down to the very simple fact that we are, inevitably, the experts on the precise effects that our disabilities have on our bodies. Micheline Mason discovered that the same attitude can be found in nurses when she was still at a very early age:

`Quite often I would go into hospital with a broken something or other and the nurses were told that I had a broken leg, but not that I had brittle bones. On one occasion I was given a bath and I slipped in the bath and broke my arm. I said, "I've broken my arm", and the nurse said, "Don't be silly". And I said, "I *have*". I knew I had, and I was told for two days that I was telling lies and making a fuss about nothing. In the end I told my Dad, who then told them, "If she says she's broken it, she has", and they immediately took me to the X-ray department.... That was partly that they wouldn't accept my word because I was only seven. And because I was only a patient. Also, because I imagine the nurse was scared that she was going to get blamed. But it seems incredible to me that they didn't know enough to know.'

The particularly striking feature about this account is not that the nurse who was giving Micheline her bath would not believe her, but that *nobody* would believe her. It may seem extraordinary to some people that a seven-year-old should have the resignation to put up with a broken arm for two days without going into such panic that it would become apparent that something really *was* wrong. But, as we have seen, this particular seven-year-old already had a lot of experience of putting up with things she found unpleasant. One does become conditioned to a role:

`People feel they've got some right to you ... as if you become their property. It's such a series of humiliating experiences that you get used to being humiliated and it's like that is your place. It's somehow okay, nobody protests, nobody seems to think that it's wrong. And when nobody does, what in the end can you do except put up with it?'

Micheline describes her experience as `average to bad', and points out that it was partly a result of the particular disability that she had. `Because I had a particular disability that people knew very little about. And I think I was

experimented on a lot and I was of exceptional interest to medical students, because it was a very rare condition.'

She also suggests that some improvement may have taken place: 'That was twenty-odd years ago, and things have changed a bit. I remember writing to the Brittle Bones Association. I wrote a very impassioned letter about doctors and their attitude towards people and that a large number of the difficulties that I've grown up with are what doctors have done to me, and the attitude they've given me towards my own body, and things like that, which are very little to do with the disability itself. And I got a very nice letter back saying, yes, we're ashamed that these things have happened.

It was very much agreeing with me and saying that it is wrong.' So things are perhaps a little better than they have been, but I see no reason to suppose that any changes that may have taken place are anywhere near adequate. Though I have no immediate knowledge of any more recent incidents to match some of those described by Merry and Micheline, I am quite certain that they still happen, for the reason that the attitudes that lead to them are still clearly in evidence every time I go into a hospital.

But, though the medical profession has a particular brand of elitism that is all its own, the various other types of professionals still play a significant part in keeping people with disabilities disabled. This is partly the result of the very fact that they are professionals; as Merry Cross points out, their assumption of special knowledge about people with disabilities and their needs is in itself likely to increase dependence:

'They reduce our ability to function independently. Because they give you the impression that they're the only ones who know what's good for you, they reduce your belief that you can solve your own problems. They therefore reduce your motivation to get things sorted out in your own life. So then they produce somebody who'll come and deal with your lack of motivation.'

One particular way in which professionals reduce our ability to function independently is by cutting us out of decision-making processes, either by a simple rejection of consultation, a refusal to recognise our right to be involved in decisions being made on our behalf, or, more subtly, by conducting public discussion in ways that exclude us - by, for example, access discrimination, or conference fees that few of us can afford to pay. Maggie Woolley describes how such discrimination affects people who are prelingually deaf.

'There is a growing consciousness among the prelingually deaf which has been growing steadily over the past decade due to organisations like the National

Union of the Deaf, the Scottish Workshop for the Deaf and the Yorkshire Workshop for the Deaf. The consciousness involves the realisation that they represent a very definite ethnic group of their own, with their own culture, their own language and their own way of thinking.

`The problem is, that when there is some kind of discussion going on about this group, whether it's in the way of some kind of conference, seminar or meeting or decision-making process at local authority level, or whether it's a discussion that's taking place in a book, your book for example, the group itself is excluded, because these discussions take place in a different, language.

`The effect of this is twofold: a) they're excluded, full stop; the discussion's in a different language, b) those who do have enough English as a second language can take it in, given interpreters they can take it in, so they can be there when this discussion is taking place, they can read, but it's very difficult for them to express themselves in their second language.

`The most dangerous thing about that situation to me is that it creates a psychological oppression, an inferiority complex. They can follow that discussion if it is in their own language, they can follow it if they've got English as a second language, but that's very heavy going for them, so they might be confused by some idiomatic expression. They have this difficulty expressing themselves in their second language; they tend to equate that with inferiority and lack of intelligence, when the real question is one of different languages, not lack of intelligence. So on the one hand they can be excluded, on the other hand they can exclude themselves because of this psychological oppression.'

Merry Cross gets to the heart of the inadequacies of professional dealings with people with disabilities by drawing upon William Ryan's book *Blaming the Victim*¹:

`Ryan explains that there are two ways of approaching a social problem. You can analyse it in what he calls an exceptionalist framework, or a universalist framework. The exceptionalist one says, "What is it about this person that they have ended up in this situation? What particular thing has happened to them that they are this way?" The kind of solutions that are proposed are one-off, focused on the individual, and rarely tackle the real causes. A universalist analysis says, "What, about the way society runs things, causes people to end up like this person?" And the kind of solutions that are proposed are general social solutions, like making sure that single parents have enough bloody money to live on,

¹ Vintage Press (U.S.), 1976

instead of treating a single parent as an individual case and saying, "Why is she so depressed? We'd better give her antidepressants."

˘Most professional dealings with people with disabilities are based on the exceptionalist framework. Especially at the emotional level, it doesn't look to see what society's doing to us to make us feel apathetic, or feel depressed. It looks to what's going on in our family, or why haven't you got enough interests, or giving you drugs or whatever instead of what's going on out there. And so solutions are also focused in on particular individuals.

˘To some extent, for people with disabilities, there's an absolute necessity for an exceptionalist [approach](#). at one level. Each individual has got to work out exactly what their needs are at the level of aids and so on. But on the other hand, the whole professional intervention is a waste of time unless they start making a society which is going to be accessible to all of us, which treats us all with dignity and humanity, which provides us with the basic bloody money for living independently, which gives us places where we can live. When I say independently, I mean not in an institution and so on.

˘And to and behold! those would cut out most of the emotional problems that people with disabilities have, and cut out the need for thousands of these bloody professionals.

˘Ryan's book deals mainly with poor people and black people in America, but the parallels are extremely clear. The exceptionalist approach always ends up blaming the victim of the oppression. It ends up blaming the black person for not having a steady job and for being depressed and for being apathetic instead of blaming the society that is ensuring that they can't get a job, that they can't get decent housing.

˘In relation to us, it becomes clear in the kind of accusations that we're too independent, or we're too dependent, we're not motivated enough, we're unrealistic. All those accusations arise out of an approach that focuses on the individual and ignores what the environment, both social and physical, is doing to that person.'

One of the most extreme examples of the exceptionalist approach to disability, though it may not be immediately apparent as such, occurs in genetic counselling. It is positively obscene that one reaction to the fact that people with disabilities do not find life easy in our society should be to consider, not how to change that society, but how to prevent us being born. From there it is a short step to accepting disability as a ground for abortion (and it is accepted as such, even by many anti-abortionists) or to allowing babies who are born

with severe disabilities to die. The logical conclusion of such thinking was demonstrated in Nazi Germany, where a hundred thousand of us were sent to the gas chambers.

Many women find genetic counselling a very traumatic experience; this is hardly surprising, if one remembers that a woman who is told she should not have children because they might have her disability is, in effect, being told that it would have been better if she had not been born. It can be particularly so if the woman has acquired her disability relatively recently and has not yet adjusted to it fully. This was the case with Maggie Woolley, who saw a genetic counsellor three years after she started to go deaf at the age of eighteen:

‘I was asked to compile a family tree which gave indications as to which members of my family had been deaf. The geneticist looked at the family tree and went into another room. I'm not sure why, but I assumed that he used a computer. When he came back, he said that any child we had would have a fifty percent chance of being deaf. The subject of sterilisation was brought up. At that time I was very young, and very much in the middle of a traumatic period and I said if it seemed there was a strong chance of any children of mine being deaf then I would not have children. And I think I said something of that sort to the genetic counsellor. He suggested that one of us got sterilised, which was rather shocking, because sterilisation had never entered my head; I thought in terms of not having my own children but adopting children. And I think it was quite wrong of him to advise sterilisation to a woman of twenty-one who was in the middle of this very traumatic experience and who might have gone ahead and some years later really adjusted to her deafness and wanted children of her own.

‘As soon as I came out of that consultation room I was very angry and upset, and I wasn't sure why. In the days that followed it began to fall into place what the feeling had been that made me feel so humiliated, angry and very, very upset - I cried as soon as I came out of there. It was to do with the implication that I wasn't fit to be a mother, the implication that I should never have been born, and so on.’

There is nothing wrong with genetic counselling in itself; the information it provides can be of great value if the geneticist is prepared to accept the role of simply being a provider of the information that will enable a person to come to her own decision. When it comes to the question of bearing children who may have disabilities, however, many people do not see a choice as existing; it is taken for granted that that is undesirable. But there are geneticists who do not

hold that view, and who are capable of being supportive to the person who is making the decision. Micheline Mason met one of them:

`Nobody ever mentioned the issue of having children to me until I took part in a survey at Great Ormond Street. I went to Great Ormond Street Hospital when I was a baby, and they'd got all the records and things that were there. This woman was doing a particular piece of research into family trees and heredity and this, that and the other, of children with brittle bones. Somebody came to see me, and I was talking to her and she told me that this woman was a geneticist and that if I wanted to go and talk to her I could.

`So I went to see her and I walked in the door and she said, "Hello. You know if you want to have a baby you can, don't you?" Upon which I fell off my chair. She was wonderful. I've never met anybody like her in the medical profession, because she was completely positive about it. She was saying what the risks would be, but even when it came to the point of saying yes and you might have a child with a disability, "But so what, we treat them much better than we used to treat them in your day".

`She was incredibly positive about it in a way that nobody had ever been before or has been since.'