

Coming Out Disabled

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Approximately one person in fifty has some kind of epilepsy. I myself was diagnosed epileptic at the age of four. Yet it was not until I was in my early twenties that I met anybody else whom I knew to have epilepsy. For twenty years my disability was something I lived with on my own, with no knowledge of other people's experience of that disability. All my attitudes to my disability, all my feelings about how to respond to other people's reactions to my disability had to be worked out from scratch. Cut off from other epileptics, even though I must have been meeting them all the time, I had no opportunity to learn how they went about the business of living with fits, to draw upon their strength, or to come to appreciate and take pride in my own strength through the process of sharing it with other people who shared my disability. My epilepsy was a part of my identity, but a purely personal part. Unlike my colour, my class, my sex, it was not something that I had in common with anybody else I knew. This is one of the things that has in the past kept disabled people from starting to develop a shared radical consciousness: unlike most other oppressed groups, we, with certain notable exceptions such as the signing deaf, do not have a cultural identity of our own. We are exiles in an able-bodied world.

I can not honestly say that I took any particular pride in my identity as an epileptic - I use that term 'epileptic' deliberately, because I am not just a 'person with epilepsy'; my disability is an integral part of my identity, and those who wish to know me these days must accept that fact, not disregard it as if it were somehow separate from the 'real me'. And I certainly did not then have the anger that I now have at how other people with epilepsy are treated in this society: I hadn't yet learnt about the discrimination in employment and education, the ignorance and incompetence of much of the medical profession, the pressures that build up on some people in their own isolation, the nervous breakdowns, the unnecessary deaths...

I was lucky. I had sensible, supportive parents, who didn't fill me with unnecessary fears about my condition. My childhood fits were mild ones which, given my parents' attitude, didn't stop me from doing anything: I learnt to swim, I rode a bicycle. And they didn't attract the sort of attention that might have got me bullied or rejected at school. By the time I started having grand mal fits, losing consciousness, going into convulsions and

biting my tongue, sometimes dislocating my shoulder, the word 'epilepsy' held no mysterious fears for me, and I was able to take the transition in my stride. (I had more serious things to worry about; I was at university and doing my final examinations that year.) My middle-class background, education and articulacy have made it difficult for others to take my epilepsy as a sign of madness or mental subnormality, and enabled me to talk my way out of discrimination and soothe other people's frightened reactions to the possibility that they might have to cope with me having a fit. All these things have enabled me to be open about my epilepsy. On that level at least I haven't faced the problem of coming out as epileptic, because I was never really in in the first place. Because I was not worried about my epilepsy, my isolation from other epileptics did not do me any great damage.

That isolation is easily explained. Epilepsy is not a visible disability, and tends to be well-controlled by medication. People who have epilepsy are therefore faced with a choice as to whether or not they reveal their condition to other people. Epilepsy is one of the most stigmatised of disabilities, associated in many people's minds with mental illness, mental deficiency, irrational violence, sexual perversion or possession by demons. One British study has indicated that 'There is a significant correlation between a scale measuring racial prejudice, and one measuring attitudes to the handicapped (this scale being dominated by hostile attitudes to epilepsy). People with epilepsy are seen in hostile terms which are as great as, or greater than, those in which ethnic minorities are viewed.' As a result, the vast majority of people with epilepsy do not make their condition known to any but a small group of relatives and friends.

I don't agree with this. Though it's an understandable response, it's a poor way of bringing about change. Ignorance and fear breed hostile reactions, which lead people who have epilepsy to keep the fact secret, which leaves the ignorance and fear unchallenged. We have to break in to this vicious circle, and the only way we can do that is to come out into the open. We have to do this. The more visible we are, the more difficult it is for others to hold false beliefs about us. Epilepsy is one of the most common of disabilities, second only to mental handicap; it ought also to be one of the most familiar of disabilities. But it's not; to most people it's one of the most mysterious, and one of the most frightening. That fact is probably the single most significant factor supporting the continuation of prejudice against us. Every epileptic who comes out deals a powerful blow to such prejudice. If hundreds of thousands of us came out, we could simply bore people into a change of attitude.

But affecting the attitudes of non-epileptics is not the most important,

certainly not the most immediate, reason for coming out. As far as I'm concerned, the primary thing that disabled people need from the able-bodied is that we want them off our backs. Beyond that they can sort out their hangups for themselves. But in coming out, we do not simply make ourselves visible to non-epileptics. We also make ourselves visible to each other. In a world where large numbers of epileptics have come out, the person who has just been diagnosed epileptic will not, as now, have to worry about whether their whole life is going to be ruined. She'll be able to look around and see that other people with the same disability are getting on with leading perfectly reasonable lives (or, indeed, thoroughly unreasonable lives, according to taste). She won't have to rely on busy, unsympathetic doctors for practical information about the non-medical aspects of her condition; if she wants to find out what the diagnosis is going to mean in terms of how it will affect her life, she can go to an expert by asking one of the epileptics she knows. She'll be able to do that because she will know who they are. It might be a friend, or a friend of a friend, someone at her workplace, a local shopkeeper or a roadsweeper or her bank manager. It might even be her doctor.

It's not accidental that I've chosen a term, 'coming out', that is derived from the gay liberation movement. Gays and epileptics are, in this respect, in a very similar situation. Both groups have a choice about whether to make that aspect of their identity public knowledge, with very similar advantages and disadvantages to be gained if they do so. If gays have started to actually put the idea into practice widely before we have, I suspect it is largely because they are not as isolated from each other as we are; it has therefore been easier for them to develop a mutual strength and pride in their group identity.

There is one significant difference, however. Being gay is not a medical condition. I stress this because gays have had to fight against the view that homosexuality is a psychiatric disorder, and have suffered cruelly in the past as the result of such beliefs. As a result, I have known gays to reject the parallel I have just drawn, because they feel it threatens to reinforce their own oppression. We can not afford to have this happen. Epileptics can learn a great deal from the gay liberation movement, because gays have much more experience than we do of the practical difficulties of coming out.

We should recognise that we share a similar oppression, and need to be allies, not enemies to each other. In any case, if to have a 'medical condition' means that one has to give up control of one's own body, one's own life, then I would say that epilepsy is not in that sense a medical condition either. What I expect from a doctor is that she give me the

information that I need to be able to make my own decisions; what decisions I then make is purely my own affair. A lot of doctors find such an attitude difficult to accept. I could perhaps free myself from fits if I were prepared to live a 'regular' life, getting to bed by ten o'clock every night, always remembering to take my pills and perhaps accepting a higher dosage of medication, with a greater risk of side-effects. But I find it less inconvenient to lead the sort of life that suits me, and accept that from time to time I will have a fit as a result. To some doctors, such an attitude is utter heresy. It implies that there are more important things to life than medical cures; that the patient's wishes are more important than those of the doctor; that personal liberty is more important than medical science. Not all doctors find such views easy to accept. But I'm afraid that they'll have to sort that out for themselves, because I see no reason why I should let my liberty be reduced simply to soothe someone else's personal insecurity. In my experience, this is a problem that occurs with male doctors.

Coming out is not necessarily an easy process. Since I've got to know other epileptics, I've come to have greater sympathy with those who do not choose to do so, because I've learnt that some of them have very good reasons for their attitude. I have come to realise how much my own ability to be open about my own epilepsy is the result of privilege, as I described earlier. The person who has done most to open my eyes to this is Chris Pearson (not his real name), who is one of the people I interviewed for 'Disabled We Stand', where a lot of his experiences are described in detail. I knew Chris for two years before he told me he was epileptic himself; if I hadn't talked openly to him about my own epilepsy we should probably never have learnt that we had that in common.

When his epilepsy was less well controlled than it is now, Chris experienced a great deal of discrimination in employment, as he describes here:

'Because of my epilepsy it was difficult to get a job, because I had jobs where I had fits on the job. I was working in a builder's once, we were building these houses and I had a fit on the top floor. The boss came in, saw me while I was having a fit, and told me to get out of the yard. He got rid of me quick. He told me to clear off. He told me I was a nutcase, those were the words he used. He said, "You're a bleeding nutcase"...just told me to clear out.'

Chris also has a lot more to lose by coming out than I have; he is married, with four children, and would be risking his family's livelihood. But his decision to avoid mentioning his epilepsy to potential employers is not

purely negative; it is partly a matter of pride:

'I don't really want to feel I'm being carried by people in a job. If you're an epileptic and you take a job and you tell these people and they take you on, they also make it a condition of taking you on that your colleagues who work with you must know...And because all your colleagues are told about you, they're not just told "Chris Pearson's an epileptic", so watch in case he has a fit, if you see him have a fit you know what it is. They don't say that, they say keep an eye on him, because that's what people tend to do. And before you now it they end up carrying you, or else they find you a nuisance and they resent it. It's always one or the other. Nine times out of ten if you get on with them it's always the way where they tend to carry you or make a fuss over you. You'd better not do this, Chris, I'll do it. Don't climb up that ladder. Or you may get a foreman shouting at you for climbing up the ladder. He may not be saying so in so many words, but he's getting across indirectly that you've no right to be climbing that ladder, you're disabled. So once you've told an employer you've got epilepsy, you're telling an employer you're disabled, that's what you're really telling them. And your employer's telling the rest of the staff you're disabled and you're known as disabled. And that's what I resent.'

This is a problem familiar to most disabled people, whatever their disability: we get assumed to be less capable than we actually are. In a very real sense, we are disabled less by our disabilities than by other people's discriminatory treatment of us. People with visible disabilities do not have the option of avoiding that discrimination, and might be inclined to envy those of us who do. But secrecy has its disadvantages. The epileptic who has not come out has to live with the fear of discovery, and of possible loss of their job. Even the epileptic whose fits are well under control with medication has to live with the fear of a relapse. That can obviously be a very stressful situation to be in; the irony is that stress is one of the factors that can help to induce fits. That in itself is a very good reason for coming out. Of course, if this country had adequate legislation against discrimination, such stress would be much less of a problem for people who have not told their employers about their epilepsy.

One of the questions I asked Chris when I was interviewing him for the book was how he would like things to be in an ideal world. He replied,

'I can answer that very briefly. I'd like to be able to walk out into the street and scream I'm an epileptic and the hell with yez and walk back in again and sit down. I'd love to be able to shout it to the world:

“Hey man I’m an epileptic. Big deal.” And someone to say, okay, Chris, and turn round and say are you coming for a pint? Something like that, you know. I think that’s a fantasy. I think so anyway. It’d be lovely to do that, and get no reaction, like what you get now, just get someone laugh their head off at you: is he crazy or something? Of course you’re frustrated. All the things I’ve been saying now about I can cope with this...But in an ideal world of course I’d like to come out, fall in line so to speak. I would love to do it. I really, really would. It’s not an ideal world, never will be, and I will never do that. No way.’

A very great many epileptics are in the same position as Chris. They would like to be able to be more open about their epilepsy, because they know what a strain it is to live in secret, but coming out is simply not a realistic possibility for them as things stand at the moment. I think that places a particular responsibility on people like myself, for whom coming out is a practical possibility. Though I have always been fairly open about my epilepsy, these days I am quite aggressively determined to make sure that all the people I come into contact with know about it; I think I owe that to people like Chris, people whom I care about very much.

I am quite certain that this openness is not merely a gesture; it does actually have an effect on people’s lives. Other epileptics I meet get to know they’re not alone, and see that coming out doesn’t necessarily lead to total disaster. Non-epileptics are forced to question some of their stereotypes. And somewhere along the line my openness is going to make a really big difference to someone’s life. Somebody who starts to have fits, or whose child is diagnosed epileptic, will have a positive image that will enable them to say, ‘Oh well, it’s not the end of the world’. Or somebody will be saved from losing their job when they have a fit at work because their employer has given up the stereotype of epileptics as ‘nutters’. Or somebody who has asked me what they should do if I have a fit, and remembered what I’ve told them about turning me on my side after the convulsions stop, will save the life of someone who vomits while they’re still unconscious and would otherwise have choked to death. For all I know, one or more of these things may have happened already. And the more of us there are who decide to come out, the more these things will happen, and the easier it will be for other epileptics to decide to come out themselves.

So far, I have discussed coming out as if it were simply a matter of admitting openly to one’s disability. Certainly that is an important element in coming out, but it’s by no means all that’s involved. Because if coming out is partly about changing one’s relationship with the outside world, it is even more about changing one’s relationship with oneself. The most

important part of coming out is learning to take pride in one's own identity, and ceasing to feel ashamed of one's disability. That means rejecting a great deal of conditioning, which one may have absorbed very thoroughly - so thoroughly that it's not always easy to recognise it for what it is. If one has been taught from childhood to think of oneself as someone whose capabilities are severely limited by their disability, it's not easy to change that belief overnight. But once it does start to change, the new confidence that arises as a result is remarkable. I have seen extraordinary changes take place in people with all sorts of disabilities as they have come to realise that they can lead much fuller lives than they had previously assumed.

This can be a very politicising experience. Because once you start to realise that much of what you have previously believed was wrong, you tend to start to think about where those wrong ideas came from. And that leads to much larger questions about what our society does to people with disabilities, what is expected of us to save inconveniencing the able-bodied. We start to realise how we have been discriminated against in education or employment. We start to think about the false or misleading expectations our parents may have been given by the medical profession. (One woman I know describes in 'Disabled We Stand' how, when, shortly after her birth, it was discovered that she had a severe congenital disability, her mother was told by a doctor, 'Don't worry, she probably won't live'. Is it any wonder that Micheline's mother assumed that her daughter would never be able to leave home and live an independent life?)

Coming out is a continuing process, and one that can perhaps never be entirely completed until the oppression of people with disabilities is entirely eradicated. I have certainly not yet completed it myself. One important step forward was when I first started to think of my disability as being a political matter, and to use terms like 'oppression', 'discrimination' and 'coming out'. Another, and probably the most significant yet, was when I started to describe myself as disabled, and to align myself with people with disabilities other than epilepsy: polio, deafness, spinal injury, blindness, cerebral palsy and so forth. That hasn't been as easy as it might sound. The term 'disability' tends to be used to refer only to people with a quite limited range of visible disabilities, particularly those which limit mobility: one hears such phrases as 'the blind and the disabled', as if blindness were not itself a disability. When I first came to the conclusion that epileptics shared a common oppression with people who had other kinds of disability, I was not at all sure that this conclusion would be accepted by people with other disabilities, or that I myself would be accepted as disabled by such people. Once I got to know other people with disabilities such as I have described, I found that I had no cause for worry; in coming

out as a disabled person rather than just an epileptic I have had a lot of support from other people with disabilities.

This is, in my experience, a common difficulty for people with epilepsy, a feeling that one does not have a right to call oneself disabled, feeling somehow fraudulent if one uses the term.

Such feelings are reinforced by able-bodied people who say, 'But you're not disabled!'. That can mean one of several things. The speaker may be indicating that they don't want to know about your experience of disability; they'll accept you as long as you leave them room to disregard that aspect of your identity. Coming from people you know well, it may mean that they're prepared to accept you, because they know and like you as an individual, but that doesn't mean they're prepared to accept every cripple on the street. Or - and this is probably the most frequent meaning - it means that they are unwilling to abandon the stereotypes of disability that they hold. Many of the able-bodied think of disabled people as being helpless, passive and pathetic, incapable of running their own lives or even speaking on their own behalf. Faced with someone who is demonstrably none of these things, and yet claims to be disabled, they are threatened with the possibility of having to abandon some very deep-rooted beliefs. It is much easier to refuse to admit that the person they are dealing with falls into that category. I used to think that this reaction, 'But you're not really disabled', was one that I got because my disability was not visible. But I've asked other disabled people about it, and discovered that everyone I've asked has experienced that reaction. To be fully accepted as disabled, it appears that one has to be a helpless vegetable. (And it's noticeable that when able-bodied people tell a disabled person, 'But you're disabled', they are almost always trying to persuade them not to do something, telling them what they can't do, as if they somehow have a superior knowledge of that person's capabilities, pushing them towards vegetabledom.)

As I said, I now reject the idea that I do not have a right to call myself disabled. I have a disability, epilepsy. I am a disabled person. I and other epileptics are subjected to the oppression of disabled people. I know these things to be true. And yet I have not completely accepted them. There is still a part of me that whispers insidiously, 'You're not really disabled.' In my heart of hearts I am still not entirely confident that I have a right to refer to myself as disabled in the same way that someone in a wheelchair has a right to refer to herself as disabled. I know that that is garbage, but the society I live in divides disabled people from each other very successfully and, like other disabled people, I have internalised a lot of that divisive teaching. Getting rid of those doubts, becoming really confident in my identity as a disabled person, is a continuing part of my coming out

process. And when I label myself disabled, and share that with other disabled people, those doubts recede a little further each time.

So far, I have discussed coming out mainly in relation to epilepsy. There are, of course, other non-visible disabilities that bring similar problems. But the most important form of coming out is one that is applicable to every type of disability, visible or not. To have a disability is one thing. To be a strong, proud and determined disabled person is quite another. All of us have to come out as disabled people, to recognise that we share a common oppression, to take a pride in sharing a common identity as disabled people, to develop solidarity with each other. We have to start refusing to be treated as second-class citizens. We have to recognise that we have a right to be very, very angry at the way we have been treated in the past. We have to stop being grateful for every minute concession condescendingly given to us, and start demanding what should be ours by right: adequate access for people with limited mobility on the streets, on public transport, in all public buildings. Access to communication for deaf and blind people. Comprehensive and powerful legislation to outlaw discrimination, carrying penalties that are severe enough to make sure that that legislation is complied with.

Coming out disabled will mean different things to different people with different disabilities. But for all it will mean taking a pride in maintaining an identity as disabled people. I would particularly like to see an end to the divisive classifications that separate people with differing degrees of the same disability: partially sighted and blind; partially hearing and deaf. I have one partially sighted friend who has taken to carrying a white stick, the traditional badge of blind people, which he uses whenever he wants to make it clear that he has a visual disability. That is an important form of coming out for him. I know an increasing number of people who could possibly describe themselves as partially hearing, but choose instead to describe themselves as deaf and demand that those around them learn the manual alphabet and fingerspell the first letters of words as an aid to lipreading. That's a form of coming out that brings particularly immediate advantages.

That example illustrates one particularly strong reason for coming out. People with disabilities are generally expected to strive to appear as able-bodied as possible, even though it is not at all in our best interests for us to do so. It is absolutely criminal that many deaf people, for example, live lives of appalling loneliness, because they have been led to believe that there is somehow something demeaning about using any form of manual communication. Almost all disabled people have strong experience of isolation, which comes from trying to live as bad imitations of the able-

bodied in a society which makes few concessions to disabled people. Yet that is particularly easily dealt with, by recognising our group identity as disabled people and supporting each other. We have far more to gain by being successful disabled people than unsuccessful able-bodied. All it takes is self-respect.

Once that self-respect is present, extraordinary changes can take place. One of the most powerful and moving sections of 'Disabled We Stand' is a description by Maggie Woolley, a deaf woman, of how this happened for her. The passage follows on from a section in a previous chapter which describes how she and her husband had been to see a genetic counsellor, and she, a young woman of twenty-one who had started to go deaf three years previously and was still in the middle of a very traumatic period of adjustment, was advised to have herself sterilised:

'Gradually, all by myself I began to appreciate that I had a right to be a mother, I had a right to experience birth and motherhood if I wanted to, because I was a woman. That if my children were going to become deaf in childhood or adult life - I knew they wouldn't be born deaf - then they were going to have the best person around to help them, because I knew a lot about the experience, and that there was going to be an end to the kind of ignorance I met with all the time about deaf people.

'That was in fact a turning-point in my life, because it represented the first positive thinking I had about being a deaf person. I had rights as a woman, I had rights as a deaf woman, I could be a fantastic deaf person. I thought right, if they're going to have a deaf mother, they're going to have a fantastic deaf mother. And if my children had this chance of going deaf, I was going to get it right now. So that there was going to be this tremendous change of attitude in other people towards deaf people. It was a very crucial point in my life, this decision to have children, because it led to this positive thinking which took some time to...It took some time for that positive thinking to lead into action and confidence and soon. That process is still going on. But it was the beginning of self-respect. It stemmed from, I think, that anger and humiliation after the genetic counselling.

'Of course I don't want either of my children to go deaf. But it's a possibility that's beyond my control. And of course it will be painful if it does happen. But since so much of my life since the children were born has been about raising my own consciousness about deaf people, struggling for change in attitude, both towards myself and deaf people as a whole, I am sure they will not have to go through what I went through in complete isolation for so many years. That is

one of the drives behind my commitment to people with disabilities, this commitment to my children. Neither of them may become deaf. Even so, it's all-important because they as hearing people are experiencing - I hope! - how to get it right.

'It's not something that worries me, this possibility of my children going deaf. All my thoughts, all my actions on that topic are positive and were before I even conceived my children. So that if I get depressed about being deaf for some particular reason at some point in my life, there's always this feeling that we've got to get this particular thing right here and now, because it's not going to happen to me again, it's not going to happen to any deaf person again, it's not going to happen to any people who become deaf in future.'

More and more of us are coming to feel like this. We know what has happened to us. We know what has happened, and is still happening, to other disabled people. And we are not prepared to let it go on happening. Maggie will not tolerate a society where young women are told that they should be sterilised because their children might be like them - that, in effect, they should not have been allowed to be born themselves, a society where she spent years in isolation because of simple ignorance about deaf people. I am not prepared to tolerate a society where a man as fine as Chris Pearson can be tormented by a straightforward lack of knowledge about his own disability so extreme that he thought he posed a danger to his own children, driven to the brink of suicide by isolation and discrimination and unnecessary fear of what was happening to him. It's the same struggle, against the same oppression, the same ignorance and callousness, the same systematic discrimination against people with disabilities. And increasing numbers of us are realising this, coming out together as people with disabilities and saying that these things are not going to happen to any of us again.

There aren't as yet many of us who have come quite this far, partly because a lot of disabled people feel too dependent upon the able-bodied to take quite such a bold and angry step forward. But our numbers are swelling rapidly. One thing that's happening is that isolated individuals who have reached this point on their own are finding each other, and realising that it's possible to work with people with other disabilities. We've hardly started to show what we can achieve together. Our anger is too great to be easily stopped. The disability movement is growing rapidly, and it's going to go on growing, as more and more people come out and start identifying themselves as proud, determined angry disabled people.