

## **10 Working for Change**

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

If we are to overcome our oppression as people with disabilities, we need to start by getting rid of our internalised oppression, the conditioning that tells us that, because we have disabilities, we must think of ourselves in a particular way, prescribed by the able bodied, and act out a particular role; either becoming one of The Disabled or denying our disability and thus our entitlement to certain rights, which we would not claim as 'normal' people.

I think this has to be our starting point, because that conditioning has held us back from recognising our oppression for what it is, something that is imposed on us from outside rather than an inherent part of disability. That is why it has taken us much longer than many oppressed groups, such as women, blacks or gays, to recognise our right to control our own lives. It is only now that we are starting to break out of our isolation and join with each other to start working for change.

Attacking our internalised oppression also makes a logical starting point because, as we start to overcome it and see ourselves fully as people, people with disabilities and with full human rights (including some, such as the right to mobility and the right to communication, which have not hitherto been widely recognised as such), so we start to become aware of how much is being denied us and how much is being imposed upon us. Anger and a desire to take action follow automatically, particularly once we recognise our individual and collective strength and realise that we are capable of bringing about change.

The key to all of this is self-respect; as we come to believe in ourselves as individuals, to take pride in who we are as people with disabilities, remarkable changes can take place, sometimes very rapidly. For Maggie Woolley, such a process was triggered off by the interview with a genetic counsellor described in the last chapter:

'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, then 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 so on. 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.'

An important part of this development of self-respect consists in recognising the importance and validity of our own needs. We are subjected to so much pressure to become helpless, dependent beings that many of us react by trying to reject all assistance whatsoever. But the refusal of helpful assistance (whether that to which we are legally entitled or that which is offered by individuals) is not independence but stupidity, into which we can easily be pushed by a combination of a dependent role and our other conditioning to be `brave' and not make a nuisance of ourselves to the able bodied. What makes the issue a difficult one is the fact that most of us are to some extent genuinely dependent on other people. Some of us with limited mobility need help with such tasks as getting dressed; some of us need patience and co-operation in

communication; we need various forms of special facilities. This dependence has been defined for us as a one-way process, so that we become the recipients of other people's charity, and we have become afraid to demand too much. We ask for too little and usually get less than we ask for.

This is a habit that all of us have to unlearn. We need to develop confidence in the fact that we are interdependent with other members of society and have a right to receive as well as to give. And because we each know best what our own needs are, we must acquire the habit of making those needs clear to other people and demanding that they be fulfilled. We do not necessarily need to be aggressive about this (for purely tactical reasons - self-assured persistence gets better results) but we do need to be completely clear in our own minds that we are not merely asking favours. Our rights having been redefined for us as charity, *we* are simply reclaiming them.

This is not a completely straightforward task, because, in order to attach a proper importance to our own needs, we need to rid ourselves of the habit of constantly reassuring the able bodied. To suddenly start leaving them to sort out their problems for themselves, and expect *them* to pay attention to our needs, requires a considerable change of attitude. But they'll survive; as Micheline Mason points out, it's time we started putting ourselves first for a change:

`We take on as our responsibility everybody's fears, worries and everything about us before we worry about ourselves and it becomes of paramount importance. And that feels like a big part of why it's taken us so long to start getting things sorted out, because it requires a reversal of that role of putting people at their ease and making it seem that it's not that bad. It's taken a tremendous amount of energy from us, it's constantly done.

`What I'm saying is that we do have to stop worrying about putting people at their ease, but it's very hard to do it. I'm not even sure that it's possible, because there is some, there must be a reason why we do it. I know I've been doing it since I was as young as I can remember, so there must be a real reason, a real gut reaction to the reaction to us that makes it so important.

`I remember this thing of breaking bones and pretending that I hadn't. I'd try and pretend that I hadn't, because I couldn't stand to see my mother's face when she knew. And that was more important to me than having a broken leg. I couldn't hide it for long, but I would try, that's the point of it.

`I don't think people realise what an intolerable burden their prejudices put on us.'

But the good news is that once we do develop confidence in ourselves and make our needs clear, we get results, as Maggie Woolley discovered:

‘Once you've reached the point where you have to tell people you're deaf, the next stage in the coming-out process for people like me is to quit saying, "I'm sorry, I'm deaf", and to give more information, because people don't reject you because they think you're saying "I'm the Devil" or "I've got an infectious disease", they reject you because they don't know what to do, they don't know how to communicate with you, they don't know what you need-and they are incredibly embarrassed and flustered.

‘You have to really stop being sorry you're deaf and stop feeling that you are expecting too much of people or that you're being a nuisance or whatever and you develop ways of giving little bits of information. Straightaway, whatever you think you need. It varies, it depends on the person you're talking to. And giving that information in a relaxed, confident, unaggressive, non-passive manner is the next. It's very much to do with understanding what's going on for hearing people when they realise that you're deaf.

‘The latest stage in my coming-out process is quite incredible. It's to stop saying oh I can't join this group or that group or the other group because I'm deaf and I'm the only deaf person. It's to stop saying I'm the only one, there are more of them, therefore I can't expect everybody to communicate for me, and to realise that I'm important enough to be included and that I have something very valuable to offer these groups I want to be a part of. And to go into these groups, to say now in order to be a member of this group I need this, this and this. The thing I need where people have to make the most effort is to ask them to fingerspell. In the beginning I didn't do very well with this, because I expected people to believe it was too much trouble and too difficult. I didn't expect that people would do it, and so I had a lot of failures. Then I changed and started to believe that people would do it. And now they do. It's amazing!

‘So that I feel I really am coming out as a deaf woman. I'm really defeating this isolation.’

Isolation is a major factor in our oppression. It is not merely a result of our situation, but positively reinforces it: the more isolated we are from each other and from the rest of society, the more difficult it is for us to counteract the discrimination and conditioning that affect us. One of our primary tactics must therefore be to come together, breaking each other's isolation and learning to support each other and to work together.

As part of this process, we must learn to provide for each other's needs, because talk of working together is meaningless if we ourselves continue to discriminate against each other. Every one of us who seriously intends to change his or her situation should know how to push a wheelchair, fingerspell, guide a blind person, cope with a grand mal epileptic fit, and be working at acquiring more complex skills such as Braille and signing. But the most important element in provision for each other is of course an ability to listen, to let each person define her needs for herself in the knowledge that her statement will be taken seriously and acted upon. So long as that ability is present, most specific skills do not need to be known in advance; the point of learning them in advance is more to do with solidarity and being able to combat feelings some people may have about being an imposition on others. What is important is simply that we should be able to feel that when we are with other people with disabilities we will not need to question whether or not our needs will be met. As we learn to take this for granted from each other, it becomes much easier to expect the same thing from individuals or groups of people who do not have disabilities, and demand it with the confidence that gets results.

(Of the simpler skills listed above, the one that does need to be learnt in advance is fingerspelling. While it is possible for a group that is meeting regularly or for an extended period - at a conference, for example - to spend time acquiring this skill, this is less practicable for one-off meetings such as a planning meeting before a demonstration. Which is why the manual alphabet can be found in an appendix at the back of this book.)

Learning skills such as those mentioned above is something to be done in case they are needed; we must not thrust them on people who don't want them, simply because we have learned them. Most of us have quite enough experience-of other people assuming they know what we need better than we do ourselves; it still remains essential to let other people define their own needs. But in doing so, it's important to recognise the difference between offering support and unloading personal worries. I have already explained why I do not welcome the question, 'What should I do if you have a fit?' The person in whom I have confidence, on the other hand, is the one who asks me something along the lines of 'Is there anything you'd like me to know about what to do?', which leaves me free to determine whether it would be helpful or not, and does not burden me with responsibility for the speaker's personal neuroses.

At the same time, we should not be afraid to *offer* skills that we do have. This may seem a very obvious point, but I make it because I remember that when I first met Maggie Woolley, at a workshop on disability, it took me the best part of two days to get around to asking if it would be helpful if I fingerspelled. I'd

learned the skill out of curiosity about ten years previously, from a hearing friend, and didn't at first offer to use it because I was afraid I might just be indulging a personal desire to show off. When I reminded Maggie of that incident while interviewing her for this book, she commented: 'That's just an example of the hang-ups people have about it. If you met a French person and decided to use some of your very limited French vocabulary, you would probably explain, "I don't know much French, tell me if you don't understand", and you would try. But because manual communication is different, there seem to be more hang-ups about it.' More generally, it's important not to be worried about making mistakes. Meeting each other's needs is not some kind of examination that has to be passed; making mistakes is part of the process of learning, and it's a willingness to learn that's important; so long as that's clearly there, no one's going to worry about anybody not getting it exactly right the first time.

Because conditioning and internalised oppression play such an important part in holding us back, we need to find strategies for supporting each other personally and dealing with the accumulation of emotional distress that lies behind self-oppression and the acceptance of the roles we have been conditioned into. This needs to some extent to take place separately from any more specific political action that we take. First because we need something that will play a role similar to that which has been played in the women's movement by consciousness raising groups, where we can deal with our personal experience of disability and give each other the kind of personal support from which we can draw strength, which will then be fed back into our other activities together. Second, because many of us have too much internalised oppression to be ready to see disability in directly political terms. It is crucially important that we do not merely write such people off. We must, therefore, create space for people who are still preoccupied with their own personal difficulties so that they can receive support without being expected to commit themselves to any more general stance until such time as they themselves wish to do so; if adequate support is given most of them will come to such a position in due course.

I, together with most of the people I've interviewed for this book, am a member of a support group for people with disabilities, which provides one model of how we can deal with the personal and emotional aspects of our oppression. This group sprang out of a weekend workshop organised by three people with disabilities who were experienced in the techniques of Re-evaluation Counselling, in which people learn to counsel each other as equals. (These techniques have remained the most important tool we use in the group, their value increasing as the rest of us have learned to use them.) The main

purpose of this workshop was to bring together a group of people with disabilities and to work towards overcoming our isolation.

That was a very remarkable weekend. There were about fifteen people there, and most of us did not know many of the others. Some of us had doubts about whether we belonged there; I was not sure when I went whether my epilepsy would be accepted as a 'real' disability by other people there. And yet a strong feeling of security and trust was very rapidly established, partly because the people who were running the workshop were working hard to establish such a feeling and partly because their efforts were supplemented by a strong general feeling of trust and caring about each other. This may also have been an example of turning our conditioning to positive ends. I suspect that people with disabilities tend to be more than averagely skilled at being supportive to others, because we have so much experience of reassuring the able-bodied. It makes a pleasant change to be using that skill willingly and for each other.

Such security is very important. If a support group is to work successfully, it is essential that everybody in it should feel absolutely safe: a person who is feeling threatened or insecure cannot be expected to start dealing with the experiences which have proved painful to her. For this reason, one of the most fundamental rules observed in this type of counselling is that what people say is strictly confidential; when talking about personal emotions and private feelings one needs to know that what one says will not be repeated to anybody else.

This sense of security having been established, people started to lower the protective barriers they were used to maintaining against the world, and to admit to their personal pain and fears and distress. In some cases people were admitting these things to themselves for the first time; it was during that weekend that I first realised that I had been hiding from myself the distress that living with my epilepsy had sometimes caused me, and in particular the feelings of isolation from having to cope with my grand mal seizures by myself - feelings which have been most acutely provoked by these occasions in the street late at night when I've approached a passer-by after I've had a fit and they've just walked straight past.

I can remember crying my eyes out as I described this experience to someone. I could remember crying like that once before, after one of these incidents, when I sat on a wall in a deserted street with tears flowing down my face for about half an hour, until a police patrol came along and gave me a certain amount of somewhat embarrassed support. The important difference was that on this occasion there was someone else with me, listening attentively and not getting embarrassed by my display of emotion. Crying on one's own may

provide a temporary release, but ultimately it reinforces one's feelings of isolation, which, if that's what one is basically crying about in the first place, does not do much good in the long term. In a support group one can discharge accumulated distress without causing further distress to build up; in this way one gradually gets rid of the fears that cause self-oppression.

Most of us cried at some point during that weekend; it was a very intense and emotional two days. And yet the general mood was not a depressing one; a feeling of euphoria sprang up as we all came to realise that we were no longer alone. To go from isolation to having fifteen allies in less than forty-eight hours is a very remarkable experience; the fact that so much had happened so quickly gave us all a sudden surge of confidence that change really was possible. Something had been created that weekend that none of us wanted to lose, and the idea of meeting regularly as a group followed automatically.

We did start meeting regularly, and at the first of these meetings we set aside time for the whole group to learn to fingerspell, so that what was said in the group would be more fully accessible to Maggie. Now everybody in the group fingerspells first letters of words as an aid to lipreading whenever Maggie is present. (Except while being counselled, when people need to be able to devote all their attention to themselves; if this is happening in a group situation, someone else acts as interpreter; when we break up into pairs for one-to-one counselling, Maggie relies on lipreading alone, which is easier in such a situation than it would be in a larger group.) And that has already given several of us the confidence to start to learn to sign.

We've come to attach a lot of importance to this fingerspelling, I think partly because it has a symbolic significance as the most obvious and concrete manifestation of the seriousness with which the needs of everybody in the group are treated. If the truth be told, there is a slight danger of our becoming smug about our fingerspelling.

The group meets about once every six weeks, though most of us have a lot of contact with other members of the group between meetings. (The exceptions are people who live out of London, where the group is based.) As with most groups, of whatever sort, a few people have dropped out and others have joined. We have taken a decision to limit the numbers of the group to around twenty. (Actual meetings are smaller than this, because in practice not everybody comes to each meeting.) There are two main reasons for this decision. The first is that a group much larger than this would become too unwieldy to give adequate support to all its members, and would also be likely to be more anonymous,, and thus less safe. The second is that a support group is dependent on a continuing build-up of trust and feelings of security, so that people can come to feel safe to deal with more

threatening worries which they may at first have been afraid to expose. Occasional new members can be introduced to a group without unduly damaging this feeling of security, but a constant stream of new additions would prevent it from developing any further. Our hope is that in time members of the, present group will be able to lead further groups, so that this will eventually be just one of many such support groups.

We have used the confidence and solidarity we have drawn from the group to start working together politically: making contact with other people with disabilities in order to share support and information with each other; initiating and providing support for campaigns which fit in with our views on disability; publicising those views by such means as providing speakers, writing, giving interviews to journalists and making careful use of television and radio. We decided to keep these activities separate from the support group. Such a decision was inevitable, because the organising that goes into political activity takes up a lot of time, and would cut very heavily into the relatively infrequent meetings of the group, leaving too little time for its basic function. But even were this not so, such a decision would have been necessary. Not every member of a support group necessarily wants to become involved in political activity, and it is important that those who do not should not feel pressured to do so.

We formalised our political activity by setting up a group entitled the Liberation Network of People with Disabilities. Originally composed purely of members of the support group, the Network has now started to acquire an impetus of its own, attracting new members who did not necessarily know of the existence of the support group when they joined. So far, we have been able to incorporate any new members of the Network who wished it into the existing support group, but we are rapidly nearing the point where we shall have to face the problem of what to do about Network members who need personal support for whom the existing group does not have room. Support groups need leaders - the security that exists in the present group would not have been achieved without the counselling skills of the three people who set up the workshop from which it sprang - and most of us in the existing group are not yet skilled enough as counsellors to be able to lead a new group.

I am confident that we will find a solution to that problem, but I don't yet know what that solution will be. Certainly it is essential that we do find it. As I pointed out at the beginning of this chapter, dealing with the internalised results of our oppression has to be the starting point of our liberation, and there is little point in letting the Network expand if it does so in a way that fails to help most of its members do this. At least a third of the people who write asking for information about the Network specifically mention the fact that they feel isolated, and we have no intention of letting this isolation continue. It would

also be very damaging to the Network in another way if this problem were not solved: those of us who are in the existing support group would inevitably come to form an informal elite within the Network, if we shared the trust in each other and personal friendship that can arise from the support group and the rest of the people in the Network did not.

The support group includes several able bodied people. These as people with counselling experience whom we have invited to join the group, because we feel it is helpful to have some members who are able to stand outside our oppression to some extent. For instance, when one of us is counselling somebody else about an aspect of the oppression by which we are both affected, what one person says may evoke the other's own experiences, bringing to the surface feelings of distress which get in the way of giving satisfactory support. It is useful to be able to draw upon the strength of someone who is less directly affected. But one difficulty we have discovered is that people who join the group as able bodied allies, thinking of themselves as able bodied, frequently turn out to have disabilities which they've avoided recognising or thought of as 'not important enough' to make a fuss about (and it's quite remarkable what some people have come to see as not important).

More generally, we need to recognise the role that able bodied people can play in our liberation. At its simplest, this is just a question of realising that we do not necessarily jeopardise our independence if we ask for or accept help from the able bodied, as Micheline Mason realised when planning a visit to the United States:

'There's no way that accessibility is going to make me able to pick up and carry a suitcase myself. There are still always going to be limitations to what I can do and what I can't do. If I had to work it out, which airport I was going to, how I was going to travel from one to the other so that I could do it without help, it would take an incredible computer-like brain. I'd have to work every single detail out. And it suddenly dawned on me at some point that there is nothing I can't do as long as I'm okay about asking for the help that I need. My limitations are not my limitations, they're as far as other people are willing to help, really. Able bodied people are another resource to make things accessible, that should not be dismissed. And what is happening is that we are dismissing it, we're trying to do it in a way that makes them unnecessary out of a feeling that it is better not to make that contact with another person.

'What makes us feel that independence is a better thing is that the help is so often incompetent. Another thing I remember about the States is that, before people took hold of my chair, they would come round, look at me, and say, "What do I need to know about pushing this chair before I start?" Oh, was it a

relief! That just made so much difference compared to the usual thing of people saying, "I know how to do this" behind you, where you can't talk to them and they can't hear what you're saying unless you shout your head off, and laughing while they push you head first down a flight of stone steps. It happens all the time. People won't ask, they won't assume that you know, they feel that they ought to know - and they don't. And when you're actually putting yourself in their hands, it can be really frightening.

`The few experiences I've had where the help has been competent, or at least has taken the time to learn or to listen to what is needed, have been infinitely more rewarding, more fun for both people concerned.'

What is important, therefore, is that the able bodied be prepared to recognise our expertise. On the simplest level, we know best what our individual needs are; and when it comes to working for change, we are the people who know best what our oppression consists of, because it is we who experience it. The extent to which we can work with the able bodied is entirely dependent on how far that recognition is present. We have all had quite enough of able bodied `helpers' doing things for us (whether it be pushing a wheelchair or trying to influence legislation and social attitudes) in a way that reduces us to unnecessary dependence and fails to do those things in the way we want them done. But when the able bodied recognise our right to control our lives and determine our future for ourselves, they can be valuable allies.

They can also be educated into becoming a better resource. One important reason for not trying to be more independent than we need is that, in making demands upon the able bodied, we encourage them to change their thinking about disability and people with disabilities. (Indeed, it is to some extent irrelevant what demand is being made; to many of the able bodied it is an educative experience to discover that people with disabilities can be forceful and articulate - or that people who are forceful and articulate can identify themselves as people with disabilities.) When I and the independent film-maker Steve Dwoskin organised a series of films dealing with disablement, "Carry On Cripple", at the National Film Theatre, we insisted that the season be made as accessible as possible to people with disabilities. We had to argue this fairly forcefully, particularly when we announced that we wanted sign language interpreters to be provided for all the English-language sound films in the season. Eventually we got our way: the NFT constructed ramps, installed an induction loop system for hearing-aid users, paid and provided facilities for interpreters (whom we nominated) and issued a detailed leaflet about access and facilities written by Steve and myself. Somewhat to their surprise, if not to ours, the NFT discovered that people with disabilities made use of this improved access to go to films in other NFT seasons that were taking place at the same time. And, having

discovered that sign-language translation was not difficult to provide and caused little inconvenience to hearing members of the audience, the NFT suggested that they might be able to make translation a permanently available facility for groups of deaf people who book in advance.

Micheline Mason suggests that children should learn about disability as part of their education:

‘There’s no reason why people shouldn’t learn as part of their general education how to deal with different things that might come up in life. There’s no reason why children shouldn’t learn - in fact sometimes they do - shouldn’t get into a wheelchair for a day and go out and see what it’s like, or go round with a blindfold on, or go round with earplugs so they can’t hear. There’s no reason why children shouldn’t learn basic sign language and things like that as part of the skills of life. I think that should be a part of our general education, the education for life as opposed to the education for passing exams.

‘It seems that the more we ourselves struggle to not need them and not put any of those demands on people, the less likely they are to learn. So I think we have to be really careful about what we’re doing.’

Chris Pearson made a similar point in relation to epilepsy: ‘All my children know about my epilepsy, only because I sit there and explain to them about it. And then I explain why I don’t want them to go around telling all their schoolmates. Once you’ve explained the dangers of telling people, kids are very clever, they understand. They’re very careful, but they talk freely about it in the house.

‘If you talk to kids and explain about it, that’s where epilepsy should be attacked. There’s a saying, “The former is more easy to deal with than the latter”, and I think it’s true. If you tell kids at school, teach them about it at school, school age, about disablement in general, explain it to them, they’ll understand it. There won’t be so much prejudice.’<sup>1</sup>

The question of the role of the able bodied in our liberation deserves particularly careful thought in the case of the organisations which work on our behalf. As I pointed out when discussing charities in Chapter 8, such organisations tend to be run by people who see us as dependent beneficiaries of their bountiful endeavours and are particularly resistant to any suggestion that it might be in our interests to have a voice in, or control over, the way their organisations are run. Frankly, I think it would be a waste of energy for us to spend much time trying to

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<sup>1</sup> An interesting example of an attempt to explain to young children about epilepsy is provided by *Benjamin*, a short American animated film distributed in Britain for the British Epilepsy Association by Concord Films, Ipswich.

divert these juggernauts from their chosen courses while we are at our present stage of organisation. It's not worth going out of our way to gain a voice in these organisations; though if concrete opportunities do arise it would be foolish to neglect them, unless we're obviously being used purely as window-dressing. It is far more productive for us to set up organisations of our own over which we have full control right from the start. (This does not mean that we shouldn't take advantage of such resources as the facilities for transcribing written material into Braille offered by the R.N.I.B.).

One area where we particularly need to be able to work well with the able bodied is in using, the media - something we need to learn to do as efficiently as possible. Effective use of press, television and radio can enable us to make our views known to large numbers of people, a sizeable proportion of whom will have disabilities themselves to counteract the stereotyped images of us that appear elsewhere; to get people used to the idea that disability can be a fit subject for politics as well as charity; and to reach people who are isolated from contact with other people with disabilities.

A lot can be accomplished by articles that we ourselves write, but that can be difficult for those of us who do not have the skills or confidence to write for professional publication. That's something we need to work on, particularly as the problem is often simply one of lack of confidence rather than lack of ability, and can be overcome by giving each other support. A useful technique is for two or more people to work together on an article. Collaboration can be appropriate even when writing separate pieces, such as contributions to a collection of individually-written articles: one thing that makes writing difficult for many people is that it is normally done in isolation; being with someone else who is doing the same thing can make the task much lighter.

We can also use the skills of able bodied journalists, by inviting people whom we know to be planning to write about disability to discuss the subject with us, so that we can suggest aspects of the subject that may not have occurred to them, or by giving interviews to journalists who we feel can be trusted not to misrepresent us. Journalists and programme makers are continually on the lookout for potential copy, and the very unfamiliarity of our politics makes us an attractive subject.

We have found in the Liberation Network that we do not really need to approach journalists offering to be interviewed; they come to us and ask. This is useful, in that someone who's interested enough by what we're doing to seek us out is likely to be willing to try to represent us and our ideas accurately and fairly, and we are in a stronger position to negotiate conditions than if we had made the original approach. The way we have handled such interviews has been

to insist that they be conducted with a group of us, which gives us all confidence, ensures that we are shown to be a group rather than isolated individuals, and avoids the danger of any of us being turned into media figures. Even when an interview is to be carried out with a single person, for example for a news story about something that has happened to her, it's very valuable for her to have somebody else there to give support. But this is flexible; on the few occasions where it has been appropriate, the trust we've developed in the support group has enabled us to delegate responsibility to an individual with full confidence that she will represent us well. The task for which we most frequently delegate people in this way is participation in decisions that are made after a group interview has been carried out - the editing of a television programme, discussion of photographs that have been taken to illustrate an article.

We always make it a condition of agreeing to be interviewed that we be allowed to see what is written before it goes to press, so that we can check factual statements and ensure that we have been quoted accurately and that what we have said has not been used in a way which misrepresents us. It is not practicable to demand a complete power of veto, but this has not proved to be necessary in practice. On one occasion we went to a lot of trouble after having been approached by the makers of a television documentary, meeting both the researcher and the producer to discuss the programme and delegating someone to be interviewed, only to have the producer decide that she was not prepared to include her in the programme on the terms we were stipulating. It is important to realise that such an incident is not a defeat; we took pains to avoid being exploited by the programme makers and were successful in that. Though disappointed, we were not disheartened by what was their loss rather than ours.

What we have found most difficult is controlling how we are represented in photographs. We can control what goes into an interview by being careful about what we say and checking the article after it is written, but it's difficult to do the same thing with photographs. We have learnt to watch for signs that the photographer is emphasising our disabilities unduly, to show us as some of The Disabled, rather than as people with disabilities. Sometimes these attempts are easy to spot, as when a photographer set up a group shot and carefully arranged someone's crutches on the floor in the foreground; but at other times it may simply be a matter of the choice of camera angle or - what we have no hope whatsoever of recognising at the time - the use of a particular lens. Even in the case of the artfully positioned crutches, none of us stopped the picture being taken, because that was the first occasion on which we'd dealt with a photographer and we hadn't yet learnt to consider carefully how we were being used and refuse where necessary to cooperate.

We did, however, later prevent the picture from being used by getting in touch with the journalist who'd interviewed us. We also managed to get an assurance from the photographer that the picture would not be used elsewhere. For such reasons as this, it is essential to arrange, wherever possible, to be involved in the selection of photographs and, particularly if the photographer is working freelance, to get her agreement (preferably in writing) that she will not use any of the photographs elsewhere without consulting the people who appear in them. One possible partial solution to such difficulties is to build contacts with freelance photographers, discuss with them the issues involved and then suggest their names to journalists who are trying to set up interviews; freelancers are likely to be cooperative about this, because it means extra work for them.

The kind of newspaper articles I've been discussing are fairly lengthy feature articles; news stories pose a different set of problems. It's not so straightforward to control the accuracy of articles that are being written to a strict deadline; it is still possible, however, to arrange for reports to be read back over the phone so that factual accuracy can be checked. In such cases, well written press releases may make an invaluable difference; if they are well written enough, journalists may well incorporate sections of them wholesale into their articles, or even write the whole story from the release.<sup>2</sup> A further reason for agreeing to be interviewed for feature articles and television programmes is that they give us experience of dealing with the media, and contacts with the media, that can prove very valuable when we are campaigning over specific issues and want to attract news coverage. And, in case anyone is still in doubt about the value of press interviews, I should point out that this book was commissioned after the publishers had read and liked the views expressed by a group of us in a magazine article written by a sympathetic able bodied journalist.

The stage beyond enrolling able bodied people as allies in our struggle against our oppression as people with disabilities is to have them take catering for our needs for granted as a necessary part of other activities which are not primarily to do with disability. Maggie Woolley achieved this in the women's group she belongs to:

‘At the first meeting I asked a friend who could fingerspell to come along, because I felt it would be better if I could explain what I wanted of the group and have somebody there who was doing what I wanted so they could see it was possible. This friend was only able to come to one meeting, she was too busy to take up the group as a regular thing. So I taught the alphabet to the women who were there and my friend interpreted for the first meeting.

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<sup>2</sup> A whole chapter on writing and using press releases may be found in Denis MacShane's *Using the Media: How to deal with the press, radio and television*, Pluto Press, 1979

`At the end of the first evening, one woman suggested that everybody there should learn before the meeting the following week and that we should spend the first hour of the next meeting fingerspelling. The next meeting came and there were three new women there, who weren't at the first meeting. So I said to them, "Well, look, here's a fingerspelling card, try and learn it for the next meeting, and tonight people can interpret for you". These women insisted on fingerspelling straight after they'd learnt, which meant they were speaking very slowly, but they insisted on doing it then, so I was very pleased about that. And somehow or other, the idea about fingerspelling for the first hour was forgotten. They fingerspelled for the whole evening.

`Since then, when new people have come along, the same thing has happened, they've insisted on doing it straightaway. Whether it was the pressure of the crowd, I don't know. Maybe I've been lucky that they're super women. But it's been marvellous. And after three or four meetings, people were doing it as easily as they type. It's not something they're stumbling over or getting frustrated about, it's really marvellous.'

I don't find it coincidental that this should have happened in a women's group rather than any other kind of radical group: `Sisterhood is powerful' embodies a much more concerned, mutually supportive ethic than, for example, `Workers of the world, unite!' But the point is that we are not on our own; the idea that we are, and that the whole of the able bodied world is either ranged against us or completely unconcerned about us is just another piece of our conditioning - the idea that we are isolated and powerless transferred from an individual to a group level. Not only do we have each other, but we are surrounded by potential allies. We are not weak; we are not powerless; we are not alone. Control of our future is ours for the taking.