

THE HANDICAPPED PERSON A NEW PERSPECTIVE FOR SOCIAL WORKERS?

Proceedings of a Conference held at the Royal National Hospital for Rheumatic Diseases, Bath on 17 September 1981. This Conference was the joint contribution of the British Association of Social Workers and the Central Council for Education and Training in Social Work to the International Year of Disabled People in the South West. It was sponsored out of the C.C.E.T.S.W Wales and South West Region Short Course Budget.

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EDITOR'S INTRODUCTION

When I was asked first to organise a Conference on Social Work and Physical Handicap I refused. I have attended too many such conferences over the years where all the speakers have been able bodied and where the contributions, although well intentioned, often well informed, have seemed to me to be inappropriate, sometimes irrelevant and occasionally patronising in the extreme. I was conscious of my own changing attitudes, of my 'education' begun painfully with 'Better Lives for Disabled Women' (Virago 1979), continued in 'Images of Ourselves' (Routledge and Kegan Paul 1981) and still far from complete. As a professional I was confused by my role as an enabler, an ally, and I was concerned about the social work task in relation to physical disability. As Ann Shearer points out in her excellent book,* people can be handicapped by professional perceptions of their disability, yet social workers by their response and attitudes, for example, can play an important part in determining how easy or difficult it is to live with a disability.

I had second thoughts and accepted. I asked my friends, mainly professionals themselves, and all with physical impairments, to join me in preparing a conference which would take a new look at the social work role in relation to physical handicap. Frankie Raiher looked back over almost twenty-five years of living with disability and her relationship with social workers during that time. Pat Rock examined the extra costs of disability and the ways in which social workers would co-operate with Rights' Workers in information giving and advocacy. Merry Cross introduced the idea that disability is not about industrial misfortune but rather about oppression. She discussed the concept of 'blaming the victim' and looked at how social workers can avoid this trap. Micheline spoke about the liberation movement of people with disabilities and explored the role of able-bodied allies. Finally Mike Oliver brought together these themes when he considered the impact of new perspectives on disability in social work, offering a social, rather than an individual, model, for professionals to consider. We hope these papers will provoke comment and discussion. Patrick Phelan reviewing the Ann Shearer book recently in *Social Work Today* said, 'It asks us how prepared ; we are as workers to remove the handicaps which as a society we impose, and it puts our responsibility in the matter unequivocally in partnership... This is not to diminish the contributions which social workers have to make to the lives of people with disabilities but it is to emphasise the supreme significance of social work as a working partnership.'

We would like to thank Gwen Russell and Catherine Cox of the British Association of Social Workers and Pamela Morley of the Central Council for Education and Training in Social Work for their excellent organisation and hospitality in Bath and also George Wilson and RADAR for their generous help in this publication.

Jo Campling
October 1981

* Disability: Whose Handicap? Ann Shearer, Basil Blackwell 1981

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A PERSONAL PERSPECTIVE ON DISABILITY

Frankie had polio when she was 27 years old. She was married with a little girl of 5. She gave evidence to the Snowden Committee on the Integration of the Disabled and her evidence is published in Volume 2, 'Evidence to the Snowden Working Party'. (National Fund for Research into Crippling Diseases, 1979). She is a contributor to 'Images of Ourselves', (Routledge & Kegan Paul, 1981)

I am speaking to you from a purely personal point of view. When I was asked, my first reaction was to refuse and that was because I felt it was all rather a waste of time. I spoke to a large group of social workers some years ago in Glasgow and then later in Newcastle, in the hope of creating a greater understanding of physical disability. It wasn't very difficult because I found at that time they knew next to nothing about the needs of the handicapped and I was pleased to think I was helping. However, I have seen very little change in the situation since then and it had makes me feel it is all rather futile. I also know very little about social workers although I have been disabled for 24 years. This is because I don't think I have had contact with any for more than about 6 times in those 24 years. Finally the and reason I did agree to come was because of my affection for Jo Campling and I like the idea of seeing Bath again!

I will tell you my story in the hope that this time there will really be some changes that will breach the gap between us. I caught polio in 1957 at the age of 27. It left me severely disabled and very dependent on other people. All four limbs, body and trunk were affected and I could not sit up from a lying position or stand up from a sitting position. I could not dress myself and was totally dependent upon others for getting out of the house. I was unable to use public transport. This was my situation when I was discharged from hospital after the first eighteen months. I had no support from anyone except my family. No one suggested doing any alterations to the house and the treatment at the hospital ceased altogether in one fell swoop.

My husband was a very highly strung man who had always been subject to great changes of mood. He immediately began to worry about what would happen to me should anything happen to him. He did not find it easy to talk to anyone about our problems, because in those days people generally found disability an embarrassment and, as I have said, there was no one professional to whom I could talk anyway. These moods soon developed into long periods of depression and I worried myself silly about the constant pressure on him. I wondered if I would be able to keep our marriage together and what kind of mother I would be if I couldn't physically handle my child. It depressed me terribly the first time I saw someone else doing her hair. How I would have liked to have had someone outside the family to whom I could talk about it all. There was no one.

We struggled on like this for some years and eventually I found a philosophy that helped carry me through, although it took an awful lot of painful soul-searching over a very long period, to do it. I decided that the amount of help a severely disabled person needs is enormous and an ordinary family could never

cope with it. The fact that it is all long-term, permanent in fact, doesn't help either. I was lucky enough to have some voluntary helpers and as many paid ones as I could afford. So I set about weighing up carefully how much pressure each person could take so that no one was overloaded. I tried to accept graciously what each person wanted to give me, although frequently it had nothing to do with what I required. I was constantly trying to spread the load between all the helpers so as to avoid confrontation at all costs. I also tried to keep myself fully occupied by developing an interest in cooking and painting and later on I tried to earn some money doing telephone canvassing. I found it soul destroying but I did enjoy the financial independence and I must have carried on with it for about 5 years. All this was designed to make me more independent of people for company and outings, etc. Time flew and I barely had time to breathe so I felt much less of a burden on everyone. I was more contented and much easier to live with but I was obsessed with guilt for the way my family had to suffer and always tried to over-compensate for it.

We carried on like this for 10 years or so until I suffered an enormous setback. It had been having a lot of trouble with my back due to constantly overdoing things and ignoring all the warning signs. Eventually I collapsed with degeneration in two discs. Unfortunately this coincided with my husband having a nervous breakdown and so neither of us could really do anything for the other and my daughter, aged 15, and to cope with it all. This was a desperate situation and I must say here that the right kind of social worker to give each of us a little support, would have been a great improvement on what we had, which was nothing. I cannot stress the fact enough that my husband and daughter needed equally as much support as I did and they very much resented the fact that no one seemed to be aware of how the situation affected them. I remained upstairs in bed, hardly able to move without on bringing on enormous pain, for a whole year and it was only because I was then considering transferring my bedroom downstairs that I approached the social services for financial help towards putting in some washing facilities. A gentlemen came to see me to discuss it all and he brought with him, would you believe it, the first social worker with whom I ever had contact. She seemed very nice, though I never really got to know her, because after her next visit she left, and no one else ever came from her department. As a matter of fact I was completely forgotten - my case got pushed to the back of a drawer for some eighteen months. Naturally I did not wait for them and moved downstairs with no proper washing facilities. All the time I was desperately trying to rehabilitate myself. The doctors had given me up as hopeless. There was nothing they could do and I felt them to be altogether disinterested. I had no guidance as to how to get back to sitting up for a few hours, let alone back on my feet because I wasn't really expected to do either and there was no one who could help me with how to live with the whole situation.

About this time my mother came to live with us. She had had a stroke some months before from which she was recovering very slowly. She had been living with my sister who was now in the throes of a divorce and was no longer able to look after her. Not long after she came to us, we received a visit from a young social worker. My mother had been a very active, smart, modern, attractive woman and she was finding it

terribly hard being confined and filling her time. The social worker immediately asked her if she would like to make baskets or join in some community singing somewhere locally. My mother was horrified to think that this was what she had come to and she cried for days afterwards. I could never mention the word social worker again.

I now thought I had better take stock of the situation once again. I decided that if we were to have any future at all then I must look into things much more deeply. In order to relieve pressure wherever possible, I planned some alterations to the kitchen. I made sure that my new shower room which was eventually being built, would make me completely independent. This was much to the disgust of the council architect and the people dealing with it - they couldn't understand why I wanted to be so independent. I then did a sort of business management survey on my home and the way we lived. The utmost efficiency was essential for all our sakes, but particularly if the helpers were to keep coming. I cut down on wasted time and made sure that everything got attended to in the right order of importance. I spread my load as far as I could among the paid and voluntary the helpers and even recruited a few more. Life gradually became much more bearable. Of course it would have all been that much easier had I been able to discuss it with a regular social worker. In those days I did feel very much alone with my problems. I think that one of the reasons that the social services never considered that I needed help, was because I live in a rather nice house which is, by hook or by crook, always reasonably clean and tidy. The same thing applies to my own appearance and I have always felt that these two facts were very much against me. With my new efficiency I now found that I began to make considerable improvement physically. The system definitely worked. Life was easier all round and we began to enjoy life once again.

We had a few years of reasonable peace until I had the biggest blow of all time. My husband had a heart attack and died. I was completely devastated and found bereavement the hardest thing I have ever had to deal with. The struggle this time to make a new life was like climbing Mount Everest and I found it so hard. I had no incentive. In the past it had always been for my husband and daughter but now she was married and he was gone and I couldn't see anything to struggle for. Once again I felt completely let down by the social services. I saw no one although I think someone phoned to say they were sorry. I found all the dozens of official papers terribly hard to deal with and as for dealing with social security - which I had to do for a period, well, that would make a book on its own. If I saw an envelope had arrived from them I had hysterics on sight. A social worker could have probably helped a lot with all that. As it was I felt that the system was quite impersonal and uncaring. After all, I had had nineteen years experience of it by then.

My daughter and son-in-law happened to be living with me when my husband died, because they were selling one home and were not quite ready to buy another and the whole situation had a disastrous effect on them psychologically. They felt completely trapped and as I had not the slightest idea as to how I was going to live, physically or financially, I couldn't do very much to make them feel any better. At this time I was desperate for the help of someone not emotionally involved. Both my

daughter and son-in-law felt that the whole world was looking at the problem from my point of view and no one could see it from theirs. If anyone could see it from their points of view, it was probably me but I was in such a state that I was totally unable to communicate.

Eventually, of course, things did sort themselves out. I decided to let the rooms in my house and lucky enough to be approached by people I knew to take their sons to live with me for one reason or another and this has worked incredibly well. I also started to give cookery lessons to 10 ladies at a time in my own kitchen one day a week. This too has been very successful. It is of course, a very big responsibility and I couldn't do it without the generous support of my family, friends and helpers. My daughter and son-in-law moved to their own home and they have a beautiful baby who has given me unbelievable joy and we have a really on good relationship now. Of course I am delighted with my independence.

After my last talk to social workers I came home fired with enthusiasm and tried to offer my help in the training of social workers. I thought that as I had worked out a successful way of living with severe disability, it could be of use to them but no one was interested. Just recently I have had occasion to look more kindly on social workers. Actually I don't think I looked on them unkindly. I never had any thing to do with them. During the summer my whole system falls apart due to holidays and having read about a disabled woman in Jo Campling's book 'Images of Ourselves', who is maintained by community service volunteers, I set about trying to get one to come to me for July and August. This had to be done in conjunction with the social services and of course it wasn't long before a social worker came to see me. There was quite a large fee to be paid to the community service volunteers, organisation for getting me the volunteer and I had been told that the social services should pay that. The social worker's name was Hazel and, of course, I had my little but somewhat forceful speech all ready for her. Before I could open my mouth, Hazel told me how pleased she was that I could have the volunteer and that it would be paid for by them. I was quite speechless. My, how times have changed. She followed on saying that she had never heard of the organisation and what a great idea it was and after going into a bit more detail, she said she thought the volunteer would have a really good couple of months with me. She then admired my dogs and promised to come and take them out for me which she did and that clinched it. Hazel and I are now firm friends. I found her to be a really caring person with a deep understanding and I could talk to her about anything.

At the moment everything is running peacefully and smoothly, but when I think back to some of those horrendous times in 24 years when my husband and daughter suffered so much, to say nothing of my mother and myself, where was Hazel or whoever, when we needed her?

THE EXTRA AND HIDDEN COSTS OF DISABILITY

Pat had polio when she was 2 which left her paralysed from the waist downwards. She walked with the aid of calipers and crutches until comparatively recently but is now in a wheelchair because of spinal problems. She worked as a secretary for a number of years with the Civil Service until she obtained a place at College, and later at University. After University she worked for the Royal Free Hospital as Co-ordinator for a research project in diseases of the heart, as a secretary for the National Bureau for Handicapped Students and then as Advisory and Information Officer for the Disablement Income Group (DIG). Last year she was awarded a Winston Churchill Travelling Fellowship to study self-help housing schemes in Alberta, Canada. Based on the Alberta experience, she has become Director of the Islington Community Aide Programme, which trains mildly mentally handicapped people to become full time aides for severely physically handicapped people. Pat is the author of 'Compass: the direction-finder for disabled people'. (DIG 1981) and a contributor to 'Images of Ourselves' (Routledge and Kegan Paul 1981).

'People who are not disabled tend to think that if disability strikes them down, the Welfare State will pick them up and put them back alongside their non-disabled peers. Unfortunately this seldom happens. Disability can reduce or extinguish earnings and, in addition, cause heavy extra expense in daily living. The Welfare State is an inadequate provider when it comes to replacing the lost income of a disabled person or offsetting the extra expenses he or she needs to incur because of disability'. (DIG's National Disability Income 1979).

During my time as Advisory and Information Officer for the Disablement Income Group Charitable Trust, I was struck many times by the stark truth of this quotation. Disabled people undoubtedly do have greater problem than their able-bodied peers finding suitable and lucrative employment - that if they are able to work at all. And disability itself imposes a multitude of extra and hidden costs both exceptional and in daily living, so that the disabled person is doubly penalised, and as a consequence may easily fall into severe financial deprivation and despair. And it is not only the disabled individual him or herself who suffers, but indeed the whole family. I hope below to present some details of these hidden and extra costs and show their effect of disabled people, and then with the help of some cases from DIG's files, indicate the many ways in which social workers can and do help alleviate the problems caused by poverty and disability.

Despite the quota scheme, unemployment is an immense problem for disabled people. Some - those disabled during the course of their working lives - are unable to continue with their previous job. At best they must be content with more menial and poorly paid work; at worst they must exist on Invalidity Benefit. Those disabled at birth, or in their childhood or teens may never get the chance to work at all and so must survive on Non-Contributory Invalidity Pension which is only a fraction of the contributory rate and so must be topped up with Supplementary Benefit. Disabled housewives can also now claim a Non-Contributory Invalidity Pension, but to do so they must undergo a degrading and arduous test of their ability to perform household duties. Even if they

have courage and handicap enough to pass this, the amount of their new benefit will be deducted from a husband's Invalidity, Unemployment or Supplementary Benefit, so the family will be no better off. The Invalid Care Allowance is available for those who stay at home to care for a severely disabled person, but not only is the amount derisory compared to any full-time income, also it cannot be paid to a married woman, presumably since she should be at home anyway -says the DHSS. And just to make certain the disabled person doesn't do any part-time work to ease him or herself back into the employment field, the therapeutic earnings limit ensures that any Invalidity Pensioner earning more than £15 per week (current rate) loses all his or her benefit. So it does seem that the State is a less than adequate provider when it comes to replacing the lost income of a disabled person.

As if this were not enough, a disabled person will then find his/her meagre income stretched to the limit by innumerable additional costs. Just a few of the most common are given below, but there are many, many more:-

costs of extra heating for longer periods during the day and night and for more months during the year. Disabled people are more likely to be at home all day and to need extra heat for poor circulation. With steeply rising fuel charges, this problem is becoming more acute than ever before.

costs of extra laundry arising from incontinence.

costs of having to buy convenience foods because cheaper forms are difficult to buy (problems with access) and to prepare.

costs of buying small quantities of food because large quantities cannot be carried.

costs of buying clothes and household goods by mail order because of being housebound or unable to get into shops.

costs of paying for an adult baby-sitter for a mentally handicapped son or daughter.

costs of paying for a reader for a blind person.

costs of telephone and letters which are often the only means of regular contact with the outside world for housebound disabled people.

costs of paying for gardening, painting and other small jobs to be done in the home because disabled people cannot do themselves.

costs of special diets.

costs of having one's hair cut at home.

costs of replacing clothes worn out by braces or calipers or by frequent washing needed if someone is incontinent.

costs of essential mobility: taking taxis or keeping a car on the road. A disabled person's car is often his or her lifeline.

The Social Security system does in fact recognise certain of these extra costs: the Mobility Allowance helps those who are unable or virtually unable to walk, though it ceases at age 65 whilst the need for mobility does not, and for those unable to drive, it does little more than subsidise taxi fares. Those in need of help with personal care can get the Attendance Allowance - payable at two different rates according to degree of care needed. However, obtaining these allowances towards the extra expenses of one's disability can involve multiple medical examinations and form-filling and more than one client who was clearly eligible for one of these refused to apply because it meant 'More tests, and I can't take it'. In addition to these two allowances, there are SB Additional Requirements for heating, laundry and diet, but the amounts are often derisory and they are rarely paid unless proof absolute of need by virtue of disability is established. Single payments (the old ENPs) for extra costs due to disability are particularly hard to come by since the regulations changed. Indeed someone has said that one should be destitute and at death's door to qualify for a single payment these days. Let us just say that such payments are cautiously administered.

As DIG's Advisory Officer I worked closely with social workers to help our clients (with their permission, naturally) and I will illustrate what I see to be three basic types of interaction with Social Services Departments which an organisation like DIG can have. Firstly, there are the many instances where a social worker will approach the appropriate body for specialist information - in case of DIG, about benefits and services available. Earlier this year an Assistant Director of Social Services in the South of England wrote to DIG about a 42 year old MS woman who had given up work to care for her elderly mother but who had been refused Supplementary Benefit under the new Regulations because her mother had savings of just over £2,000. He felt this was quite unjust and decided to seek DIG's advice about the advisability of taking the case to the Commissioner; he was advised to do so and, as with many such appeals which take an age to be resolved, the case is still under consideration. Just before this, another social worker came to DIG about the withholding of Attendance Allowance during a period of hospitalisation of a severely mentally and physically handicapped boy. Clearly there had been some misunderstanding, since AA can be paid for up to 4 weeks in hospital; I explained the position of the regulations and advised an appeal which was duly won. Another victory for co-operation.

Almost as frequent are the instances where DIG refers a disabled person or family to a social worker for long-term help and support. These will most often be people without young children at home and below retirement age, since youngsters and pensioners are more likely to receive regular visits and attention from Social Services Departments where there is evidence of need or deprivation. Mr E is a 64 year chronic bronchitic with a diabetic wife receiving psychiatric treatment and 3 adult unemployed children, two of whom are mentally handicapped. Mr E received Invalidity Benefit, his sons Supplementary Benefit, and over several years they ran up an electricity bill of over

£500 and were threatened with imminent disconnection, despite written affirmation from Mr E's GP that it was essential for his health to have sufficient heat in the home. DIG obtained a short stay of execution from the Electricity Board and thought it wisest to refer the entire case to the family's very sympathetic social worker since they were clearly in need of long-term support and supervision to clear their debts and prevent a recurrence.

Mrs A aged 56, was badly injured in a hit and run accident and returned home from hospital on crutches, virtually housebound. Her husband walked out threatening divorce proceedings and leaving her with no money and no income, confused and frightened, and she telephoned DIG in despair. I quickly contacted her Social Services Department, and within no time a social worker had organised her various applications for state benefits and helped calm her down considerably. She is now recovering slowly.

The third type of interaction with the Social Services which I encouraged whilst at DIG was close collaboration with social workers on Benefit Appeals, whether for Mobility Allowance, Attendance Allowance or Supplementary Benefit; I found from experience that as a general rule Appeal Tribunals put considerable store by the opinion and support of a claimant's social worker, and that their very presence at a tribunal can sway the case in the disabled person's favour. And the help need not stop at appeals - a letter from the SW in support of a claim for a SB single payment or a request for financial help from a charitable trust, can be extremely effective as the following cases demonstrate.

Mr G aged 65, was on dialysis 3 days a week following complete renal failure in 1975. His wife gave up work to look after him and they lived on Invalidity Benefit, partial Attendance Allowance and a small occupational pension. This was just before the new SB regulations came in in November 1980. and I was able to enlist his social worker's help in applying for ECA's for diet and heating. Once again I left matters in the capable hands for the social worker as long-term care and support was indicated.

Miss B aged 59, and severely disabled with osteomyelitis since age 11, had lived with her brother in the family home, but had to be rehoused by the Council because of his continual cruelty to her. She earned a small wage at Remploy factory, but had been on Sickness Benefit for three months following a hip replacement operation. She had to furnish and equip her council flat and was falling behind on the HP payments so she returned to work against her doctor's advice. She was shortly due to retire and was most anxious to clear her debts by then if possible. Between myself and her social worker we managed to raise a total of £85 from 3 different charitable trusts. One particular charity in fact preferred to liaise with the social worker, partly because she knew the woman and her circumstances at first hand, and partly because her authority was recognised and respected - whilst I was something of an unknown quantity.

Mrs B, disabled by heart disease, arthritis, and a double amputation, and confined to a wheelchair, in her late fifties, lives in a council house with her divorced daughter and grandson, her sole income being NCIP, and Supplementary Benefit. DIG collaborated

with her social worker to get her numerous single payments for a bed, bedding, clothing, removal expenses, carpet, curtains, gas reconnection charges; we also obtained the higher rate heating addition for her and a diet allowance - all this in the space of a few months. Which just goes to show that it can be done. I have mentioned several ways in which the social worker can be instrumental in alleviating the disabled person's problems, but there are also other kinds of help he or she can offer: visiting the client regularly particularly if the disabled person is housebound or has limited mobility - this should lessen feelings of isolation and abandonment; or the social worker could find a local voluntary group prepared to visit on a regular basis. Moreover, a housebound disabled person may not have access to current information relating to benefits, aids and services available in the community; in such cases the social worker could provide leaflets, explain claim forms and translate letters from the DHSS into plain English. The client could be encouraged to apply for additional benefits if he/she fits the criteria and told how to go about this. I have already indicated the importance of moral support and practical assistance at tribunals and medical interviews - a role for which the social worker is admirably fitted.

Finally, the social worker can help implement the much maligned Chronically Sick and Disabled Person's Act, 1970, by seeking out those disabled people in need of aids or adaptations in the home so they can live as normal a life as possible, or who need a telephone to be installed for the safety of their health, or who require meals on wheels as they cannot manage to cook for themselves - and no one is at home to do it for them. Those in need of a home-help must be identified and provided with one, and those who have been living under stress for some time should be helped with a holiday - this may to some seem like a luxury, but to a family coping with one or more disabled members and struggling to make ends meet on a weekly pittance, it may be the one means of retaining sanity. These various services will of course be very familiar to most social workers, but I feel that cannot be repeated too often. They are all part and parcel of the problem of disability, and in a way cannot be separated from the financial problems outlined earlier. If money were no object, then attendants, cooks and domestics could be paid for; the installation of a telephone would present no difficulty, and a holiday would be a regular expense rather than a major problem.

Most, if not all, of the social daily difficulties associated with disability stem from financial hardship. DIG has identified the causes and effects of the problem and the social worker can play a major role in helping avoid the causes and softening the effects. I believe that the social worker can and should help disabled people receive all benefits they are entitled to, and thereby assist them to live as independently as possible in the community.

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A NEW PERSPECTIVE ON DISABILITY

Merry was born with her left hip-joint missing and the femur short. She was able to attend ordinary schools and went on to study psychology at university. She trained as a teacher and taught for 2 years before training and qualifying as an educational psychologist. During her first job in a schools psychological service she had back trouble which kept her in bed for about 7 months. It was during this period that she first realised that people who are disabled are oppressed and began to identify on this basis. She later began research that questions the current psychology of disability and actively engaged herself in national and local groups of people who are disabled, campaigning for their rights. She now runs training courses for social workers and other working in the field of disability and is also starting work as a psychotherapist. Merry is a contributor to 'Images of Ourselves' (Routledge and Kegan Paul 1981).

It seems important to me that people who are disabled should be asked to talk about their lives and be listened to with complete respect and without interruption, as with Frankie today. People so severely lack information about us that they are usually astonished by what they hear, and learn a tremendous amount. How is it then, that despite a growing trend towards asking people who are disabled to come and talk about themselves, professionals seem to have changed little in their approach and understanding of what disability really means? I believe that the answer is that there is a hidden danger in listening to individuals. The danger lies precisely in the fact that they ARE individuals speaking as such. Listening to their personal stories your attention is diverted from what happens to us as a group.

Social workers have had their attention diverted in this way for several reasons. In the first place social workers were once children! They too grew up hearing, through the media, from families and teachers, highly distorted information about us, information that suggested that if we have enough courage and personality it is always possible to adjust to disability - that is information that conveys that disability is a personal tragedy.

This kind of misinformation continues in professional life and Mike Oliver will enlarge on that. I would like to use the concept of Blaming the Victim (introduced in a book of that name) to illustrate how this comes about. Blaming the Victim is about people who are poor and/or black in the United States. By 'victims' Ryan meant people who are oppressed, i.e. people who suffer as a group mistreatment that is enshrined in the institutions of the land. Ryan describes how for people who are black this means that they have poor job opportunities and get second rate education, second rate health services, second rate housing and a raw deal as far as the law goes. And so on.

I am saying that people who are disabled are also victims; we are also oppressed in just these kind of ways. We are segregated at the earliest possible opportunity into special schools where we receive sub-standard education based throughout primary school models (see Thomas); it is extremely difficult to find work, though we may end up in a work-centre working for a pittance; we are kept separated from the rest of the

community by lack of access to meetings, buildings and information; worst of all we are institutionalised.

People should be under no illusions about what this means. Firstly it is automatically segregation: in many cases institutions are miles away from anywhere, in the country. Secondly, in most cases it means being deprived of decision-making power over one's own life (choosing clothes, staff, friends: choosing to have sexual relationships, marry or have children). Thirdly, all too often it means frequent theft of one's property. I could continue.

Oppression is a much more profound concept than that used by most sociologists and social workers, i.e., the concept of being members of a minority group. The latter merely suggests there are not many of us and that the only real problem is people's attitudes. Micheline will be saying more about this.

Basically, Victim Blaming is the art of trampling on people and then blaming them for getting squashed. An example of professional Victim Blaming described by Ryan is the conclusion that the reason for the break up of so many black families is their sub-cultural value system, rather than their bad housing, lack of employment, harassment etc. When it comes to us, oppression and apathy are blamed on our lack of courage, lack of adjustment and lack of motivation, rather than on the fact that we have been denied work, separated from our friends and families and been led to believe we are incapable. Micheline will also be saying more about how we end up in these depressed and apathetic states.

Ryan points out that there are two possible ways to explore social problems, and that Victim Blaming can only arise out of one of them; it arises out of an exceptionalistic method of analysis which explores why this individual rather than that one is failing to cope. On the other hand a universalistic analysis explores what it is about the social environment (where this includes people, the physical environment, institutions etc.,) that may be causing the problem.

Clearly these two types of analysis must lead to proposals for solutions of a very different nature. The first, having isolated the individual as the problem, produces solutions that are private, voluntary, remedial, special, local and exclusive. (These words are very familiar, aren't they, in the world of disability). The universalistic approach leads to solutions that are public, legislated, promotive or preventive, general, national and inclusive. The two methods and their types of solution are relevant to the caseworker versus community worker controversy. Whilst I think there is a place for limited casework, my vote would fall heavily on the side of community work.

So, having said that we are an oppressed group, I am also saying that an exceptionalistic approach to our problems can only result in a perpetuation of that oppression by its continuing emphasis on separating us through special provision. A universalistic approach, however, can only lead to national and permanent change in the direction of our liberation.

The very nature of the social work system, locked as it is within other institutional structures, pressurises social workers into adopting an exceptionalistic approach. Nevertheless it is possible for social workers to begin to sway the balance, and I do sense that you are fed up with your role as plumbers, sealing off leaks in an increasingly rusty pipe.

At the general level you can look at how you spend your time in relation to disability. It is possible to firmly resist the pull to individual casework and use the time thereby freed to study exactly what happens to people who are disabled in your area in particular, as well as in the country as a whole. You can very usefully take steps to ensure that the disabled population has access to ALL the information available about their rights. (My experience is that this information is as hard to obtain as gold dust). This alone would be a big task but have a very liberating effect. You could make it your job to see that people get whatever help they need in claiming these rights, as Pat has pointed out. If you are called upon to work in institutions you could devote much time to working with staff to convince them of the absolute necessity for residents having major decision-making powers. You could keep your eyes and ears open for efforts being made to create schemes that would allow people to live in the community and back these up in whatever way the people who are disabled say is necessary.

At a more detailed level you could re-examine such things as the forms you use to register people as disabled. If the forms Blame the Victim, i.e., if they ask 'What can't you do?' change them so that they ask 'What does your environment/local transport service/employment situation prevent you from doing? Small things like this can make an enormous difference to people who have been led to believe all their lives that their situation is their fault.

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LIBERATION OF PEOPLE WITH DISABILITIES -The Role of Allies

Micheline was born with a congenital disability called fragile bones. Her childhood was constantly interrupted by periods in hospital recovering from fractures. She had a home tutor until the age of 14 when she went to Florence Treloar Grammar School for Girls with Disabilities. She left there and went to Art College where she trained to be a graphic illustrator. On leaving art college she had a strong sense of needing to find something more meaningful to do with her life. She worked for a charity for people with disabilities and then left to found an organisation called the Greater London Association for Initiatives in Disablement (GLAD). She has since learnt to be a peer counsellor and has used the knowledge thus gained to help found the Liberation Network of People with Disabilities. She is also a freelance writer and illustrator, the author of 'Creating Your Own Work' (Gresham Press 1980) and a contributor to 'Images of and Ourselves' (Routledge & Kegan Paul 1981)

A lot has been said about the way in which society uses able-bodied people to continue our oppression. I am going to speak about how we see able-bodied people becoming allies in our liberation.

First of all I want to challenge the rather simplistic idea that we have to change attitudes towards disability. We are not born with attitudes about disability. We are given our attitudes by all the means of communication and propaganda that society has at its disposal. It is obvious that the attitudes thus given are falsely created by misinformation. Misinformation comes at us about all people in the form of generalisations and stereotyping. Whilst it is true that all people are stereotyped in some way (vicars are 'good', teenagers are 'irresponsible', the British are 'reserved'), there is a fundamental difference between the way people such as judges or doctors are stereotyped, and the way black people, for example, or women or people with disabilities are stereotyped, because people who are considered useful for our particular social system are given positive stereotypes, e.g., judges are 'entirely trustworthy', whilst others who are seen as less valuable are given negative stereotypes, e.g. blacks are 'lazy'. This is because we live in a society in which the power is held by a minority of people who rely on such misinformation in order to convince people that this system is just. People are seen as unequal, and this inequality appears 'natural' rather than just created. Therefore we need to change the society which creates peoples' attitudes, not simply attempt to change attitudes by changing individual people.

People with disabilities are primarily seen as dependents upon society, are not considered useful, and are therefore devalued enormously by society. In the past people with disabilities have been shut away in back rooms, ostracised, regarded as evil, forced to beg, even used as fodder for medical experiments in Hitler's camps and then murdered in large numbers. Nowadays this mistreatment is cloaked in apparent sympathy and kindness, but nevertheless exists almost as strongly as ever. You may ask 'If you all know so clearly what the problem is, then why don't you just get up and do something about it, take control of your own destinies?'. It is because we have a hidden enemy which we call 'Internalised Oppression'. This is the process whereby

disvalued groups of people hear what is said about them, explicitly and implicitly, believe it, and act as though it were true. 'The person is pushed to 'agree' or 'accept' being oppressed, to accept the invalidating feelings, to be defeated in the attempt to remain human. Thus a person with a disability will believe that she/he is inferior, has forfeited her/his right to a full life, cannot make decisions for her/himself, is the victim of malevolent fate (not a malevolent social system), is unattractive, a burden to society. She/he believes her/his needs are only filled by the kindness of people, based on their compassion and not their respect. She/he will smile constantly, being careful to reassure everyone that life is good. She/he will always try to be as little trouble as possible, expressing gratitude for every small service. Or she/he will get angry at 'fate' who has chosen her/him for unjust punishment. But as 'fate' is supernatural and all-powerful, the anger must necessarily be impotent and is very likely to be turned upon her/himself. Or she/he will act out as nearly as possible the 'able-bodied' role, at whatever personal cost, denying the disability, and often denying all solidarity with other people with disabilities. People are not to blame for these reactions. They are inevitable.

Oppression also relies on divisiveness for its perpetuation. 'The crucial social means for the perpetuation of oppression is dividing the oppressed and pitting them against each other so that different groups of oppressed people co-operate in oppressing each other to the benefit of the oppressive society'². People with disabilities have been divided up into groups on the basis of their differences. The biggest division is between people with visible disabilities, usually called 'The Severely Disabled' and people with invisible or milder disabilities, usually called 'The Able-Bodied'. What is important in relation to our oppression is that the result is that a false idea that we are a tiny minority of people is fostered and encouraged. If we believe that we are a small bunch of disunited freaks then we will not demand our rights as normal members of society who have been overlooked.

The fact is that we constitute at least 10% of the population. There are more people with disabilities in the world than there are citizens of the USA. It is estimated that our numbers are 500 million world-wide, 5.5 million of whom live in Britain. It is also true to say that anyone who lives a normal life-span will become a person with a disability at some time in her/his life. The division between able-bodied is fluid, arbitrary and defined by the oppressive society. I have not yet met a physically perfect and totally able person. However, in practice there are very clear divisions of role. Able-bodied people are also conditioned to accept a role - the role of oppressor. In professional social work this role is disguised as 'helper' and its true nature is hidden both from the client and from the social worker whose intentions are usually completely honourable. This can only happen because most people who consider themselves able-bodied have been oppressed too, as children, as women, as workers, as immigrants etc. Therefore we are proposing that because it is in the interests of everyone to end oppression, that we, as people with disabilities, separate in our minds the role (of social worker) from the person, and reach out to the person as a potential ally in the real struggle to create a new society, in which oppression does not exist.

We, ask of you that you separate in your minds the real effects of our disabilities from the effects of our oppression, in order to become true allies to us. This analysis of our situation has come largely through the sharing of ideas, experiences and knowledge of a number of people who have founded the Liberation Network of People with Disabilities. We came together on the basis of a common understanding that disability is a political issue and that like all minority groups we need to organise ourselves in order to clarify our thinking and demand our rights.

We spent our first year meeting regularly in order to 'put our own house in of order'. We had to learn about each individual's needs and strengths, what each person needed in order to be able to contribute fully to the meetings, and to the movement, about disabilities with which we were not familiar, and about each person's personal experiences and thinking. We began with an attitude of complete respect for each other. For many of us that has turned into pride, affection and loyalty of an intensity we had never before known. We encouraged each other to openly express our feelings and emotions knowing that this would leave us free to think more clearly afterwards.

Our Network has produced a draft policy of liberation in which there are many statements on intent, covering the abolition of institutions, the right of self-determination, the ending of additional economic oppression, and much more. One statement is to 'Seek allies amongst able-bodied people (i.e. people who will help be us fight for ourselves, not on our behalf)'³. There is no blue print as to how we should do this. It seems clear that it will firstly and foremostly involve a lot of listening to our life-stories, our thinking, our viewpoint and our definitions of the problems that need solving, as we have barely begun to speak for ourselves. It will involve not agreeing with, or colluding with our internalised oppression, and particularly when it shows itself as self-blame or hatred, lack of confidence, discouragement, hopelessness or picking on each other. At these times your intervention can be invaluable. It will involve looking at your own fears and feelings about disability, and exploring your own experiences of being oppressed. It will involve giving over information which you, as professionals, have been given and which we need. It will involve practical support for initiatives which we take, and it will involve re-designing your role as 'helper' into one of 'enabler'. Most of all it will involve making friends with us on our terms. This may feel painful, frightening, difficult, or even humiliating to you, as it sometimes does to us, but we are certain that it is necessary for all of us to get through this period of fundamental change in order to live together and to enjoy each other as equals.

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A NEW MODEL OF THE SOCIAL WORK ROLE IN RELATION TO DISABILITY

Mike became tetraplegic at the age of 17 after a diving accident but eventually found his way into a job as an unqualified teacher in a borstal. After taking his first degree in Sociology at the University of Kent, he went on to gain his doctorate. He is now the only lecturer in the country in social work and physical handicap and is in charge of the post-qualifying course at the University of Kent. He is the author of the forthcoming book 'Social Work with the Disabled' in the BASW/MacMillan series 'Practical Social Work'.

1. Introduction

This paper will consider the likely impact of new perspectives on disability on social work. In order to do this the development of services for the physically disabled since Seebohm will be discussed before going on to consider the specific contribution of social work. It will then be suggested that the new perspectives on disability arise from what might be called a social model of disability, but before describing such a model a critical overview of the individual model of disability will be undertaken. Finally an attempt will be made to draw out some of the implications of this new perspective - the social model for social work practice. In the past the bulk of work done and help given to handicapped people and their families was really only available through the health service (medical social workers) or voluntary organizations such as the Invalid Children's Aid Association and the Spastics Society. A few local authority health departments set up professional social work services in the 1950's, staffed by mainly medical social workers, and in some cases occupational therapists as well. Welfare Departments in the pre-Seebohm days also offered services to the physically handicapped, but as most departments did not employ trained social workers little was done beyond material help, information giving and residential care.

2. The Role of Social Services Departments

In considering the development of services for the physically handicapped, the Seebohm Report will be taken as the starting point. While some, notably Brewer and Lait (1980) would argue that this is the wrong place to start, their proposed framework does highlight a number of areas of concern that can be usefully considered. The Seebohm Report recommended the development of services for the physically handicapped in seven directions as follows:

- "1. Services for the physically handicapped are in urgent need of development.
2. A reasonably accurate definition of the size and nature of the multiple and complex problems of physical disability will require extensive research.
3. The social service department should be responsible for social work with physically handicapped people and their families, the provision of occupational therapy, residential and day centres for them, holidays, home helps, meals on wheels, sitters-in service, help with adaptations to houses and flats.

4. Substantial development is particularly required in the services for handicapped school leavers, and more thought and experiment is required to determine the best timing and methods of giving guidance on careers to physically handicapped children and young people.
5. Co-ordination of services for physically handicapped people requires a major effort in teamwork. It is impracticable at present to specify a particular form of organisation designed to achieve this everywhere.
6. The emphasis from the point of view of the social service department must be on helping the handicapped individual in the context of his family and community, and for this purpose a broadly based training and approach will be required.
7. It will be quite impossible for local authorities to run effective services for physically handicapped people without help from voluntary bodies.”

Based on this report, the Local Authority Social Services Act 1970 established Social Services Departments in their present form and the seven recommendations on physical handicap were incorporated into an Act of Parliament, the Chronically Sick and Disabled Persons Act 1970.

Unfortunately, this Act came at a time when other legislation was being passed which laid a great deal of additional duties on the new Social Services Departments for demands were increasing in all directions, and only limited resources were made available. This has continued to be the case and understandably, as work with children and the elderly has increased, so the work with the younger physically handicapped has had to be neglected somewhat. In my view there never has been a generic service - just a specialist child care one with other bits tacked on.

At present it appears to be a matter of local organisation and resources available within each department as to which members of staff are working with the handicapped. Senior social workers, social workers and social work assistants may all be involved, as well as occupational therapists, craft instructors, craft assistants, and technical officers. Many handicapped clients never see a social worker, and occupational therapists are often 'holding' and supporting families who should be dealt with by a social worker, or other supervised team member.

If consideration is given to each of the Seebohm recommendations separately, it is possible to make some reasonable estimate of progress in the last few years. Certainly in terms of recommendation 1., services have been developed in recent years though there is still a long way to go. As one recent study (Knight and Warren 1978.70) has noted

“Despite the substantial development of services for handicapped people and the considerable increase of expenditure on these services ... there were widespread indications ... that even the most active departments could develop their services further.”

Recommendation 2. suggested a reasonably accurate picture of the size and nature of the problem and this was built into the Chronically Sick and Disabled Persons Act as a legal requirement. While all local authorities have conducted their own surveys, the question of accuracy remains. Most of these surveys only located approximately 50% of the people that the Government's own survey (Harris 1971) suggested there might be. In addition many of the surveys are now out of date and this obviously affects their accuracy also. Warren, Knight and Warren (1979) in following up their original survey in Canterbury found that 13.4% of the cohort had died, 4.9% had left the district and 5.1% were in hospital or residential care on a permanent basis. In addition they found considerable changes in the needs of people in their cohort, some needing more help and others needing less. And of course, this study did not consider people who had become disabled in the meantime. It is obvious, therefore, that it is an extremely complex and time consuming business maintaining an accurate picture of the needs of disabled people in a particular area and some have questioned the allocation of resources in this way, arguing it would be more productive to spend money on direct services.

With recommendation 3. the Seebohm Committee placed the onus on Social Service Departments to provide a wide range of services, foremost among these being a social work service for the physically handicapped and their families. Few, if any, departments would claim to provide such a service. Other services such as residential and day care are often criticised, not on grounds of the failure to provide but rather in terms of what is actually provided - often 'segregated warehouses'. Durrant (Brechin, Liddiard and Swain Ed. 1981) suggests that this is a defensive approach and that

“That large gymnasial-like buildings masquerading as day centres, and the purpose-built hostels which advertise the differentness from the rest of the street, typify this approach.”

Yet other services such as occupational therapy, holidays, meals on wheels, aids and adaptations, are usually criticised on the grounds of the failure of departments to allocate adequate resources to them and not in terms of the kinds of services they provide.

Recommendation 4. suggested the development of services for handicapped school-leavers. This is usually left to the Careers Service and at present every education authority in England and Wales employs a specialist careers officer for the handicapped. However, according to Rowan (1980.71)

“In July 1978, 6 per cent of young people under 18 registered as unemployed had been out of work for over 26 weeks, and 2½ per cent for over a year; the equivalent figures for registered disabled young people were 30 per cent and 13 per cent.”

Most social service departments are reluctant to attempt to identify the non-vocational needs of disabled young people for fear of the expectations and increased demands

that might be created. To my knowledge there are only two such projects in hand at present, and one of those is being carried out by the voluntary sector.

Improved co-ordination between services was identified as the 5th Seebohm recommendation. This remains a major problem as Blaxter (1980) clearly identified and Phelan (Cypher Ed. 1979.56) in his review of Seebohm unequivocally states.

"Effective co-ordination is as elusive as perpetual motion and if truly achieved verges on acquiring that very characteristic but frequently social provisions are either organised without acknowledgement of it or administered within a scope which endeavours to eliminate the need for it. In services for people with handicaps, where generally co-ordination is required more than anywhere else, paradoxically it is to be found the least "

The issue of training which forms the basis of recommendation 6. was taken up by a Working Party convened by the Central Council for Education and Training in Social Work, whose major finding was encapsulated in its title (CCETSW 1975)

"People with handicaps need better trained workers". Their major recommendations were for improved training at in-service, basic and post-qualifying levels and while a few post-qualifying courses are eking out a precarious existence at present, the general impression of in-service and basic training about disability is little better now than when CCETSW produced its report. Of course the introduction of the special option on handicap as part of CSS courses and the considerable number of professionals from Social Service Departments who have taken the Open University Course "The Handicapped Person in the Community" may have improved matters somewhat.

The final Seebohm recommendation was for close-co-operation between the statutory and the voluntary sector. There have been few, if any, studies of this relationship at local level, though voluntary sector provision extends from residential and day care services to providing individual volunteers for gardening, driving people to appointments and so on. Hatch, (1980.105) in his study of voluntary organizations in three towns found.

"At the local level most of the organizations for the handicapped worked quite closely with the statutory services. Where they did not do so it seemed in the three towns more a result of statutory neglect than antagonism on the part of the voluntary organization. Within this kind of relationship the voluntary organizations were able to communicate needs, but seldom did they openly challenge the adequacy of existing provision by taking up an active pressure-group role".

Any attempts to accurately assess progress since Seebohm are obviously difficult, but in the light of what has been said, it is not unreasonable to conclude that we have come some way, but still have far to go. It is in the area of social work services specifically that least progress has been made and in the rest of this paper some of the reasons why this should be so will be considered before going on to outline some of the existing

possibilities that lie ahead for social work intervention with the physically handicapped.

3. Social Work Services for the Handicapped

Specifically with regard to social work services, the CCETSW Working Party concluded that professionally trained social workers should be used:

- (a) to provide personal social work help to the handicapped and their families on an individual, group or residential basis where, in addition to or arising from handicapping conditions, clients experience difficulties of a special nature (e.g. additional internal or external or environmental stress).
- (b) to assess, with or without members of relevant other professions, the overall situation and specific needs of handicapped clients and their families.
- (c) to provide, with or without the assistance of the remedial professionals and vocational guidance staff, care, support, advice and guidance; and to assist whenever possible in the process of rehabilitating those with handicaps.
- (d) to advise, supervise and contribute to the training of social service staff on the social work aspects of services for those with handicaps and whenever possible to involve the client in the process.
- (e) to plan and co-ordinate services either alone or with members of other disciplines, initiating plans based on where the client is living, include the domiciliary supportive services and take into account all relevant community aspects.

While this sounds fine in theory, in practice social workers (and especially qualified ones) have had a much more limited role.

There have been a number of studies which have discussed social work in relation to the physically handicapped -none of which are very complimentary to social work. For example Parsloe and Stevenson (1978) found that the level and extent of social work intervention with the physically handicapped is relatively low. Occupational therapists or social work assistants in the main provide most input to the handicapped and their families. Goldberg and Warburton (1979.86) found that social work intervention both lacked depth and fared badly in comparison with work with other client groups.

"We see that problems of physical disability, excluding visual handicaps (which were dealt with by specialists), were tackled in 30 per cent of the intake population and in 47 per cent of the long-term cases. But these problems are largely confined to agency review and constituted 80 per cent of all agency review cases. In other words, of the 659 physically disabled and elderly clients looked after by the long-term teams, 495 received occasional surveillance and only 164 were allocated to individual social workers.

Cases presenting child-care, delinquency and family problems constituted 29 per cent

of the intake population and 22 per cent of the long-term population ... Most of these cases - in contrast to the elderly and disabled - were on allocated caseloads."

Not only that but social workers also failed to recognise the potential of working with the physically handicapped (Goldberg and Warburton 1979.93)

"What aims did social workers pursue? In just under three quarters of all the cases that were to remain open the preservation of the status quo was all the social workers hoped for. "

Some social work intervention was even positively harmful, for as Phillips and Glendinning (1981.43) found in a welfare rights project

"... it was clear during the course of the project that information about other benefits had not been sent in any systematic way to the disabled people involved, and that although they all known to their Social Services Department they had not received advice and encouragement to apply for benefits to which they were entitled. Indeed some people had even been given inaccurate information from social workers which had deterred them from making applications for benefits and caused subsequent financial losses. "

As a consequence of this disabled people have been critical of social workers and the CCETSW Report (1974) identified a number of dimensions of this including

- lack of status granted them by workers
- inadequate information
- ignorance about handicapping conditions
- lack of continuity of worker involvement
- failure to involve handicapped people in training process
- failure to recognise need for practical assistance as well as verbal advice.

While disabled people have therefore been critical of social workers, social workers have often been reluctant to throw themselves wholeheartedly into work with this particular group. There may be a number of reasons for this which may include the following. Firstly, low priority given to work with this group and hence low career prospects. Secondly, lack of understanding of potential of working with this group, for as Trieschmann (1980.XI) puts it

"Many people believe that work in the field of physical disability must be depressing because they have a vision of custodial care and of crippled lives filled with sadness and lost dreams. In actuality, rehabilitation of the physically disabled is especially rewarding because of the potential that exists in human beings in the face of stress, a potential that has seriously been underestimated"

and Thirdly, as has already been said, poor teaching about handicap on training courses may mean that workers feel inadequate or incompetent with this group. Finally, personal fears about handicap may mean that workers may be reluctant to get involved.

BUT the major criticism is that social workers, like all other professionals, have operated with inappropriate models or theories of disability, and it is in a sense perhaps fortunate that social work intervention has been so limited up to now. Before going on to consider an appropriate model of social work intervention it is necessary to discuss why the current model is inappropriate. For this purpose the inadequate model will be referred to as the 'individual model' of disability and this can be taken to include the medical model.

4. The Individual Model of Disability

This individual model sees the problems that disabled people experience as being directly related to that disability. The major task of the professional is therefore to adjust the individual to his own particular disability. There are two aspects of this; firstly there is physical adjustment through rehabilitation programmes designed to return the individual to as near normal a state as possible: and secondly there is psychological adjustment which helps the individual to come to terms with his physical limitations. It is possible to be critical of both of these aspects of adjustment and though I propose to concentrate on the latter, as it is of most relevance to social work, there has recently been a critique of the former also (Brechin and Liddiard 1981). In order to criticise the psychological adjustment the assumptions based on the individual model of disability, spinal cord injury and blindness will be the disabilities from which evidence will be drawn, though similar points can also be made about other disabilities.

Starting from this assumption that something happens to the mind as well as to the body, a number of psychological mechanisms of adjustment have been identified, or more appropriately borrowed from other areas such as death and dying. Disabled individuals are assumed to have undergone a significant loss and as a result depression may set in. In order to come to terms with this loss, a process of grieving or mourning will have to be worked through, in similar manner to those who must mourn or grieve for the loss of loved ones. Only when such processes have been worked through can individuals cope with death or disability. Some writers have seen these mechanisms as a series of stages or steps which have to be worked through. A recent study (Weller & Miller 1977) in New York University Hospital identified a four-stage process by which newly disabled paraplegics come to terms with their disability.

Stage 1 - Shock - the immediate reaction to the physical and psychic assault of spinal cord injury often characterised by weeping, hysteria, and occasionally psychosis with hallucinations.

Stage 2 - Denial - a refusal to accept that complete recovery will not take place.

Stage 3 - Anger - often projected towards those physically active around them, who serve as constant reminders of what has been lost.

Stage 4 - Depression - a realistic and most appropriate response to a condition of a severe and permanent disability and a necessary stage if adjustment, rehabilitation and integration are to be achieved.

Albrecht (1976) characterises this and various other schemes as developmental models and argues that they all, at least partially, assume that:

- (1) an individual must move sequentially through all of these stages to become fully socialised;
- (2) there is but one path through the stages;
- (3) an individual can be placed clearly in one stage by operational criteria;
- (4) there is an acceptable time frame for each stage and the entire process;
- (5) movement through the system is one way, that is, the system is recursive.

In case you think that spinal cord injury is somehow a special case and that such models are appropriate in respect of this particular disability only, there are certainly similar ideas in the area of blindness for example. According to Carroll (1961.11)

"Loss of sight is dying: When in the full current of sighted life blindness comes on a man, it is the end, the death, of that sighted life."

In order to come to terms with this death Fitzgerald (1970) identified four distinct phases in the typical reaction to the onset of blindness: disbelief, protest, depression and recovery.

There are a number of general criticisms that can be levelled at these theories or explanations. Firstly, the model of man which these theories implicitly draw upon is one where man is determined by the things that happen to him - the adjustment to disability can only be achieved by experiencing a number of these psychological mechanisms or by working through a number of fixed stages. Secondly, adjustment is seen as largely an individual phenomena, a problem for the disabled person, and as a consequence, the family context and the wider social situation are neglected. Finally, such explanations fail to accord with the personal reality of many disabled people, particularly those with traumatic spinal cord injury, who may not grieve or mourn or pass through a series of adjustment to stages.

Further it is not just those with spinal cord injury who question such models. Clark (1961.11-12) who lost his sight as a result of a war injury states

"... the loss of sight need not and usually does not touch the core of a man's intellect and emotional being. What has changed is his relationship with the external world, a relationship with which he had grown so familiar that he scarcely thought of it. At this stage the very words we use about blindness become a little dubious. It is of course right to describe a war casualty as having been 'blinded: because the word conveys the idea of the violence of the event. Thereafter, however, he simply thinks of

himself as lacking the visual sense images to which he had formerly been accustomed. It is something negative that has to be allowed for. He may at times refer to himself as being 'blind' so as to conform with verbal habits of the rest of the public. But privately he does not think of it in that way. Only when he falls into the pattern of ideas that others have of him, does he feel of himself as being 'in darkness'

Despite these criticisms, it would be true to say that these theories have made up the dominant, individual model of disability and this in itself needs to be explained. A major factor in this is that these theories are in accord with 'the psychological imagination' in that theorists have imagined what it would be like to become disabled, assumed that it would be a tragedy and hence decided that such an occurrence would require difficult psychological mechanisms of adjustment. However, the psychological imagination may not be an appropriate starting point for such theorising or research - it is surely a value judgement to assume that disability is a tragedy rather than that it is a phenomena which may be explained in a number of ways. Another factor is that these explanations are individualistic and thereby politically convenient. When a disabled person fails to internalise the rehabilitation goals set by the professionals or persistently pesters his local Social Services Dept., he can be characterised as having problems in adjusting to his disability. This conveniently leaves the existing social world unchallenged; the goals of the rehabilitator remain unquestioned and the failure of the welfare department to provide the right assistance can be ignored.

While these and other factors may explain the adherence to these psychological theories, they do not explain why these theories have been empirically validated by a number of studies. In fact these theories may become self-fulfilling in at least two ways. At a methodological level, having conditioned research in the sense that they posit adjustment to disability as a problem, researchers then ask questions relevant to that problem and get answers which are then presented as findings, valid social facts. To my knowledge, there have been no studies which started out with the assumption that disability was not a problem. The following quote nicely illustrates the point: (Ibbotson 1975)

"Reflection on the many problems to which the cord injured person must make an adjustment impresses one with the gravity of the psychological, processes which occur following a cord injury.

Such an individual is confronted with grieving over his loss, coping with pain and phantom sensations, alterations in sexual functioning, loss of bladder and bowel control, the frustrations of immobilization, loss of vocational goals and earning capacity, feelings of uselessness, role reversals in the family and the attendant loss of self-esteem and the social stigma, of being 'different' in the public eye. It is an amazing tribute to the flexibility and magnificence of the human spirit that so many people whose lives are thus devastated survive and function at the level of physical and social independence which most cord injured people achieve."

This quote accurately reflects the process of 'sanctification' of disabled people which is deeply embedded in our social consciousness and reinforced through stereotyped media presentations. There is a polar opposite of this image which presents disability as a tragedy and personal disaster. As Shearer (1981:21) suggests

"The 'norm' demands that people whose disabilities are obvious and severe must be at least 'sad' and even 'tragic: And if that defence breaks down in the face of individual reality, it is ready with its own flip-side. The reaction of people who break out of the mould becomes: 'Aren't they wonderful?'"

In view of these images the scope for professional intervention with heroes or tragic victims must appear rather constrained and it is perhaps not surprising that social workers are reluctant to get involved.

But as so many paraplegics and blind people are able to function at a reasonable level, it is surely more logical to assume that this is a normal everyday reaction and need not be described in such glowing terms. To put the matter simply, adjustment may be normal and not a problem at all. And yet with the honourable exception of Ann Shearer's book, I know of no study which starts from the assumption of disability as normality.

There is a second way in which these theories may become self-fulfilling in that they may actually create the reality they purport to explain. In the case of mental illness it has been shown that psychiatrists impose their definitions of the reality of particular problems upon their patients. Similarly in the study of criminal behaviour it has been shown that criminals will often verbalise theoretical explanations as excuses for their behaviour even in compulsive crimes like pyromania, kleptomania and child molesting. With regard to disability, many disabled people will have contact with the theories described above, not through meeting academic psychologists or participating in research projects, but through the everyday contact with professional workers who are also internalising these by theories. Professional journals are beginning to disseminate these theories widely. An article in Occupational Therapy argues not only that individuals must experience the following phases of shock, denial, turbulent aggression and working through, but also that there are a number of adaptations that patients must make including adaptations in body-image, adaption in role-image, loss of security and loss of self-esteem, A recent article by a practising social worker (Dickinson 1977) expressed the following sentiments:

"Patients must be allowed to come to terms, they must grieve and mourn for their lost limbs, lost abilities or lost looks and be helped to adjust their lost body-image. Personally, I doubt if anyone who has not experienced the onset of irreversible disability can fully understand the horror of the situation."

What is being suggested is that the psychological mechanisms and processes that research has identified and described are themselves the product of that research activity both as a result of its methodological predispositions and the spread of this knowledge to professionals who are then able to impose this definition of reality

upon their clients. This is beautifully captured by Trieschmann (1980.47) who asks

"Is it possible that some of the publications that professionals have written reflect the requirement of mourning? Have professionals seen more stress and psychological difficulty than actually is present? Have professionals uncritically applied terms and theoretical concepts from the field of 'mental illness' to describe the 'normal reaction to an abnormal situation' which the onset of spinal injury represents? Have professionals been describing phenomena that do not exist? Have professionals in clinical interactions, placed disabled persons in a 'Catch 22' position? If you have a disability, you must have psychological problems: if you state you have no psychological problems, then this is denial and that is a psychological problem. And because this is so, have psychologists, psychiatrists, social workers and rehabilitation counsellors lost credibility with other rehabilitation personnel and with persons who or have spinal injury, and rightly so?"

And it is not just a matter of losing faith but as she (Trieschmann 1980.xii) points out

"They (disabled people) have felt victimized by professionals who write articles about the reactions to spinal cord injury that are based more on theory than fact".

Despite these criticisms, it is clear that the individual model remains the dominant one with regard to disability and it has perhaps taken on the attributes of what one writer (Kuhn 1962) has called a 'paradigm' - that is, a body of knowledge to which all those working in the field adhere. However, the same writer has shown that paradigms are sometimes replaced or overthrown by 'revolution' and this revolutionary process is often sparked by one or two critiques of the existing paradigm, before a new paradigm can develop to replace the old. Having provided one such critique, it is now worth considering what a new paradigm - a 'social model' of disability might look like.

5. A Social Model of Disability

This new paradigm involves nothing more or less fundamental than a switch away from focusing on the physical limitations of particular individuals to the way the physical and social environments impose limitations upon certain groups or categories of people. Shearer (1981.10) captures the need for this change in paradigm in her criticism of International Year of Disabled People.

"The first official aim of the International Year of Disabled People in 1981 was 'helping disabled people in their physical and psychological adjustment to society.' The real question is a different one. How far is society willing to adjust its patterns and expectations to include its members who have disabilities, and to remove the handicaps that are now imposed on their inevitable limitations?"

Adjustment within the social model then, is a problem for society, not for disabled individuals. For some, however, it is not just a matter of society's willingness to adjust its patterns and expectations but to remove the social oppression which stems from this

failure to adjust. One statement of this comes from the Union of Physically Impaired Against Segregation (1976) who state

"In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. To understand this it is necessary to grasp the distinction between the physical impairment and the social situation, called 'disability' of people with such impairment. Thus we define impairment as lacking part of or all of a limb, or having a defective limb, organism or mechanism of the body: and disability as the disadvantage or restriction of activity caused by a set contemporary social organization which takes no or little account of people who have physical impairments and thus excludes them in the mainstream of social activities. Physical disability is therefore a particular form of social oppression.

This social model of disability, like all paradigms, fundamentally affects our world view and within that, the way we see particular problems. If we take the problem of housing for disabled people as an example, the individual model focuses on the problems that disabled people encounter in terms of getting in and out, bathing, access to the kitchen, bedroom and so on. However, the social model sees disability as being created by the way housing is unsuited to the needs of particular individuals. We thus have 'housing disability'. A research project in Rochdale has recently attempted to operationalise the concept (Finlay 1978.15)

"The research team has attempted to investigate the housing needs of people prone to reduced performance capabilities by taking their own physical attributes as given, and measuring against them the various physical attributes of their environment which restricts their ability to function to an extent that they themselves regard as unacceptable and yet believe to be avoidable. "

The implications of this approach for the provision of housing suitable for the handicapped centres on (Finlay 1978)

"Whether the policies most suited to their needs should adopt a preventative approach, in the form of more suitable housing provided in the community, or a remedial approach in the form of para-medical support provided either in the home or special institutions by people whose very intervention, if made unnecessarily, is by itself a disabling factor in the lives of physically handicapped people "

The same perspective can provide important insights in other areas, as with Davis and Woodward (1981.) who develop the concept of 'information disability' , and suggest that

"The Physically impaired person who vitally needs open access to specialist information frequently finds mystification instead of matter-of-factness; complexity instead of clarity; secrecy instead of salience or ignorance where there should be knowledge. These facts are deeply embedded in our social relations!.

They go on to argue that it is not just the physically impaired who suffer from information disability but

"for those such as people who are physically impaired, where access to specialist information is crucial to meaningful participation, there is a significant distinction. Information disability is a specific form of social oppression. In practice it results in the disadvantage or restriction of activity caused - not by the impairment of the individual - but by the way in our society we present, or withhold, information and prevent opportunity for full participation in the mainstream of social life".

When applied to the world of work the social model of disability provides equally 1 Valuable insights (Swain 1981.11-12)

The world of work (buildings, plant, machinery, processes and jobs, practices, rules, even social hierarchies) is geared to able-bodied people, with the objective of maximising profits. The growth of large-scale industry has isolated and excluded disabled people from the processes of production, in a society which is work centred "

This is crucial in present day society where the individual is judged upon what he does and appropriate social status thereby accorded. Hence it is not difficult to see that the dominant social perception of disabled people as dependent stems not from their inability to work because of their physical limitations but because of the way in which production is organised.

According to Finkelstein (1980) this social model of disability may be most an appropriately applied to physical impairments but it can also take in sensory impairments. For example, deaf people may be disabled by the way we communicate in that increasing use of the telephone may restrict people who can communicate perfectly adequately at a face to face level or meetings may not be organised in well lit rooms where the hearing impaired can adequately see other participants and follow their lips. Similarly mental handicap can be seen as less the problem of the intellectual impairment of certain individuals but more related to general expectations about levels of social competence. As Dexter (Boswell and Wingrove 1974.294) wrote many years ago

"In our society, mental defect is more likely to create a serious problem than it is in most societies because we make demonstration of formal skill at co-ordinating meanings (reading; writing and arithmetic) a requirement for initiation into adult social status, although such skills are not necessarily related to the capacity for effective survival or economic contribution. "

The importance of this social model of disability is that it no longer sees disabled people as having something wrong with them - it rejects the individual pathology model. Hence when disabled people are no longer able to perform certain tasks, the reasons are seen as poor design of buildings, unrealistic expectations of others, but the

organization of production and so on. This inability does not stem therefore from deficiencies in the disabled individual. Now as Finkelstein (1980.25) points out

"The shift in focus from the disabled person to the environment implies a shift in the practical orientation of workers in the field "

What does this mean for social work? It is this question that I now propose to consider briefly.

6. The Social Model and its Implications for Social Work

The social work profession has failed to give sustained consideration to physical disability either in terms of theory or practice and evidence for this view can be sustained by comparing the number of books that have been written about the subject with say, the number written about children. To my knowledge there have been no books solely devoted to the topic of social work and physical disability at all, and while this is only one example of social work's lack of sustained interest, it is nonetheless a pretty powerful one when one considers that in recent years social workers have been very keen to write about a whole range of other topics from sex therapy to community work, from children and families to death and dying, from juvenile delinquents to the mentally ill and so on.

However, as was suggested earlier, it is perhaps fortunate that there has been this lack of sustained interest for social work has adopted the wrong model of disability any case. In attempting to outline a social model of disability before going on to now discuss some of the implications of this for social work practice, this goes against the current conventional wisdom which suggests the theory should be practice based rather than the other way round. Nevertheless to rely on practice to inform theory when practitioners may have already internalised an inappropriate model is to invite disaster, for it would merely result in reinforcement of the individual model of disability at a theoretical level. Therefore an attempt has been made to lay the theoretical base before going on to consider some of the practice implications. This discussion will inevitably be brief for it is for practitioners themselves to work out, in conjunction with their disabled clients, the full implications and not for academics to extract practice blueprints from their theories.

If consideration is given to the three main social work methods, it is nonetheless possible to make a number of statements relevant to practice. The switch from an individual to a social model of disability does not signify the death of casework for example. Rather it sees casework as one of a range of options for skilled intervention. It does not either deny that some people may grieve or mourn for their lost able-body but suggests that such a view should not dominate the social worker's assessment of what the problem may be. Shearer (1981.113) cites one such example of

"a man who contacted his local social services office to seek help with getting his

ceiling painted was treated instead to a lengthy visit which has to do with the need the social worker saw for him to come to terms with the fact that he had, some years ago, broken his spine."

Thus grief work or bereavement counselling may be appropriate in some cases but not all or even a significant number. Some disabled people, particularly those suffering from progressive diseases, may need long term support of the kind that only a casework relationship can provide and building upon Alf Morris's idea of the disabled family, the whole family may indeed become the target for casework intervention.

Similarly groupwork need not focus solely on the need to create a therapeutic environment in which individuals or families can come to terms with disability. Groups can also be used to pool information on particular benefits, knowledge on where and how to get particular services and even on a self-help basis to give individuals the confidence to assert that their disability does not stem from their physical impairments but from the way society often excludes them from everyday life. In addition the group can be used as the major means of giving disabled people back responsibility for their own lives as is described in a recent discussion on residential care (Dartington, Miller & Gwynne 1981:52-3)

"Meetings in the small residential groups were a forum for staff and residents to plan their activities and to determine priorities. They gave the opportunity for residents to take responsibility for themselves and also for the staff to do 'social work'"

The potential for intervention using community work methods is also exciting. There have already been a number of local access groups which focus on the way the physical environment disables people and numerous access reports and guides have been produced. A few community workers have organised 'forum' meetings of all organizations of and for disabled people in a particular locality and these have proved useful in confronting local authorities about cut-backs, in ensuring that the needs of disabled people are taken into account in pedestrianisation schemes and so on. And if the definition of 'community' is expanded beyond its strictly geographical meaning to take in the idea of moral communities (Abrams 1978) or psychic communities (Inkeles 1964) then it is possible to see community work methods being used in disability organizations. For example, the Spinal Injuries Association is currently employing a welfare officer whose job is one of enabling its members to work out their own problems and solutions by utilizing the collective wisdom and experience of its 3,000 paraplegic members through mutual support, peer counselling and the provision of information and advice.

In suggesting that theory should inform practice with regard to physical disability rather than vice versa a number of developments in social work practice compatible with the social model of disability have obviously been ignored. There have undoubtedly been initiatives by individual social workers or departments which are not based on the individual but social work as a profession has not given systematic attention to developing a theoretical perspective on disability, that is being developed

elsewhere. As a consequence theory and practice have proceeded separately and have not merged into what was earlier called a 'paradigm' in respect of the individual model. It is crucial however that over the next few years there is a merger between theory and practice in order to create an alternative paradigm to the present one based on the individual model. Only then, following Kuhn's (1962) argument will the social model replace the individual one which has proved so ineffective in meeting the needs of disabled people and so unattractive to professionals working in the field.

7. Conclusions

In this paper it has been suggested that social work as a profession has paid little attention to the physically disabled up to the present time, but that this has perhaps been fortunate for social work, like all other professions, has adopted the wrong model of disability. There are indications now of a shift from an individual to a social model of disability and an attempt has been made to explore some of the implications of this. This shift has thus far been effected largely by disabled people individually and collectively with some help from individual professionals. The time has now come for the professionals themselves to take part and in this social work is ideally placed to play a crucial part. It is less tied to the individual model of disability than the medical, paramedical professions and it has a range of methods of work, skills and techniques which are well suited for working within the social model of disability. The rewards for social workers will stem from enhanced professional and personal satisfaction that will stem from both the increased range of tasks in which to exercise professional skills and the greater potential for achieving change. In working with disabled people the social work task is no longer one of adjusting the individual to a personal disaster but rather helping him to locate the personal, social, economic and community resources to enable him to live life to the full.

In discussing the implications of a switch to a social model for social work the focus has been on general issues at present; the two areas requiring further development are obviously firstly the kinds of social work skills that will be required and secondly, the organizational context in which such work might take place. Let us hope that social work as a profession will give them some attention over the next few years.

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