

Employed, Self-Employed or Un-Employed?

by Alan Martin

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When I wrote my abstract for this presentation some months ago, I had hoped to have some good news about my job hunting. I am sorry to report that this paper should have been titled, 'Going around in ever decreasing circles'.

I have done my best, and followed all the advice given to me that I was capable of following, but I am still an unemployed person who finds himself actually working full time. Why is this? I will try to summarise the barriers still in my way.

The welfare benefits trap

First, the welfare benefits trap. It is still there, maybe a little smaller than before, but as anyone who uses a wheelchair knows well, one big step makes a building as inaccessible as 20 steps! Everyone's circumstances are different, obviously, but the system is simply not flexible enough to allow for this. In my case, I do not have a family or spouse to fall back on if I get into a financial mess. I live on my own independently and my income is all from welfare benefits. To make the huge jump from the way I am now to earning my living is still too risky for me. The trap seems to me to be that I am basically on income support benefit, rather than invalidity benefit. I have spoken to welfare benefits advisors again and again, and they have all agreed with me that I am stuck in a trap.

The next barrier, which I can't get over, is my dealings with MPs (Members of Parliament) and government departments. I have asked questions, through my own MP and also other MPs. They always answer questions which I never asked, and fail to grasp the actual problem.

The most practical thing I was offered was that my MP got in touch with my local job centre, and put me in touch with the disability employment advisor. She agreed that I was in a trap but had to refer me to a job broker. After trying to find a wheelchair accessible job broker, (you may imagine that people who have disabled jobseekers referred to them would be accessible -not so!) I went to see one, who also said (off the record!) that I was in a trap too. He still sends me job advertisements -for jobs which are completely unsuitable, but then that is all he can do.

Lack of understanding about disability

Another barrier is lack of understanding about some disabilities. In my own case, I have tried working full time, six days on the run. Afterwards, I was so exhausted that I needed a week's break. I am not being lazy. I think people do not realise how much effort I have to put into working. To get ready, I have to get up very early because it takes me a long time to wash and dress. I am often tired before I start work. The level of stress is extremely high because of things like worrying about access in buildings. It's very stressful to think that you may not be able to get into a toilet all day. How many able

bodied people would happily work all day knowing that they were not able to go to the toilet? I have done this quite a few times, and, believe me, it is stressful to know that, although dying of thirst, you aren't drink, just in case! Also, I worry about my equipment letting me down. If my electric wheelchair goes wrong, I am in a mess. If my communication equipment fails for some reason, I am in an even bigger hole. Then I have to make sure I have a supportive personal assistant working for me who is not always clock watching. I have to put in a lot of time preparing for work too. If I am asked to give a talk about services for people with disabilities, I can't just write it on the back of an envelope while having a coffee! I have to spend days working on it, and programming my communication aid. These are all inequalities which are not faced by the non-disabled worker.

I am very glad to say that one big barrier to employment has now gone. From April 2002 any money I earn will not now be deducted from my care money. Before, if I earned more than £40 a week, I had money taken off my Independent Living Fund money. What a massive disincentive to work was that?

Why bother working?

People often say, "Why bother to try to get into work?" I answer that I want to work for my money for the same reasons that anybody else does. I want the self-esteem of knowing that I am a productive member of society. I do realise that working voluntarily as I am doing now is a way of paying society back for my social security benefits, but I have able-bodied ambitions. I do not want to be always stuck on a low income, and able to 'just get by'. I want to increase the quality of my life. I want to be able to afford to travel. I want to be able to buy all the equipment that could help me, which I can't get from statutory bodies. I want to go to the theatre and do all the things that everyone else aspires to.

I know that what I do is wanted and valuable. It is something which I have developed for myself and is not fitting into a job which already exists, so I am not really looking to be employed by an employer. I need to be able to work freelance and selfemployed. If an employer took me on, he would have to pay me a full wage to replace my benefits and give me a little extra, for just two or three days a week's work. Although he could take me on for one year and pay me £60 a week under the permissible earnings rule, and I could still keep my benefits, he would then have to pay me a salary of around £ 15,000 plus expenses take home pay, for a half-time worker. I would be very lucky to get an employer to do this! Employers can claim some of the cost of taking on a disabled worker through the Access to Work scheme. Many employers don't know about this. I wonder why there isn't more publicity about it?

Has anyone truly worked out the cost to the country of keeping someone like me on welfare benefits compared to enabling me

to do a job where I would be paying taxes and being productive. Is it all just down to money?

Going round in circles

Up until when I got my first communication aid about eight years ago, all I was offered was voluntary work for parks and gardens, picking up rubbish with a stick. I have spent five years getting qualified and experienced in what I want to do for work. I have attended performing arts, computer, and business management courses. I have done the work voluntarily for expenses only for about four years. My work is giving inclusive dance workshops and performances, and working with dance projects. Also, I give presentations on disability issues. I have worked for many organisations, education and health services, charities and arts groups among others. I am often offered a fee for my work. I have to say, "Thanks, but, no thanks." I could only give workshops or presentations for about two days a week because it takes me another two days at least to prepare individual presentations and program my aid with what I need to say. My work is unpredictable and varies from week to week. One week I may be asked to work, then I may not have anything for a month. I cannot say how much I could earn in anyone week. It could be £300 one week, then nothing for a month.

I've seen benefits advisors, disability employment advisors, and told them of my dilemma. They have all said to me that the system is not flexible enough to allow me to do what I want, and that the law has to change before I can do that. I've been told about the New Deal scheme, Access to Work scheme and tax credits -I have heaps of leaflets about them. They are all very difficult to understand, but I think that none of them help in my case. I have been told that I could be in trouble for what I am doing now, that is, turning down pay, in order to stay on benefit. I feel very frustrated.

Does anyone see what I meant by going round in circles?

I've been told to set up as a charity or as a company, and claim expenses, but not a wage. This is a dodge that some disabled people use, but I am not happy to do it. I want to be honest and open about what I do, and not worry about getting caught. I am not particularly unusual in this conflict. I know very many other disabled people who could work freelance like me but who have the same problems. It is particularly difficult for disabled artists. I would like to be able to earn perhaps £2,000 a year without coming off benefits. If my work developed in future and I earned more, I would then come off benefits. I can only just now manage on my money. I was told by a benefits advisor that if I needed something like a new washing machine, I could get an emergency payment from social security. It seems crazy when I could earn that money for myself.

Many people do not realise the hidden costs of living with a disability. Just things like the cost of specialist transport or buying equipment which seems very expensive because it is sold to a relatively small market. Do you know what it costs to replace wheelchair batteries, tyres and an annual service? At least as much as it costs to do the same to your car! Then there is the insurance of your wheelchair. My NHS wheelchair is covered for repairs by the NHS, but then I have to insure it for third part: and theft. With my private electric chair I have

to insure for all risks. I have less choice when shopping, because many shops are still not wheelchair accessible, so my choice is limited, often to the more pricey shops. Another hidden cost is the cost of keeping warm. I have cerebral palsy, which gets considerably worse when I am cold, and as I do not move a lot I quickly get very cold feet. There is no automatic heating allowance for people with disabilities until the temperature falls below freezing. I estimate that my heating bill is double what it would be if I was not disabled. I could go on about hidden costs, and that is not what this paper is about, but it is all part of the bigger picture.

Why employ a person with a disability?

I have said why I want to work. Now I would like to consider this from the employers' point of view. Why would anyone want to employ, either permanently or just for one day, a person with a disability? There are many good reasons why it is in the best interests of an employer to use disabled employees. One reason, which I disagree with most strongly, is that it makes the employer look good in the competitive world. If it makes the employer look good, well then that is just a bonus for him. The real benefits are far more far reaching than such a cynical and exploitative one.

The benefits in employing disabled people, as far as I can see, are, firstly, that they are extremely motivated to succeed and prove themselves, and so will perform far better than their non-disabled counterpart. I have seen this in many disabled employees. They get to work early, put in extra time unpaid and are loyal and supportive to their employer. I feel that to try to prove themselves equal to non disabled employees, they feel they have to be not just equal but better. If employed in a business which has disabled clients the disabled employee will have more empathy and understanding than the best intentioned able-bodied worker.

Many employers would find physical barriers to taking on disabled staff, and here the Access to Work scheme can help. Access to Work can pay for such things as making a building accessible, and any reasonable adjustments to the work place. It can pay for the cost of personal assistants, sign language interpreters, special equipment such as adapted computer equipment or communication aids. Access to Work, as far as I understand, will not pay for communication aids to help a person find work. But all these financial incentives should encourage employers to take on people with disabilities.

Why is it, then, that, with all these incentives, more disabled people are not in work? Is there any point raising disabled children's expectations about getting a job, putting them through an increasingly inclusive education system, and then letting them face the reality of being jobless when they are adults. I get the impression that many employers still think 'disabled' always means the same as 'sick', and that if they take on a disabled person, then he will always be absent through illness. Employers whom I have met have told me that their disabled employees are a genuine asset to the firm.

Is there a typical 'disabled person'?

I believe that within the group labelled as 'disabled people' there are as many or more variations and differences as

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between the non-disabled and disabled category. There is no such thing as a typical disabled person. What suits one does not necessarily suit another. It is most important that all people with disabilities do not feel under pressure to get work. For some it will not be right, and that is fine for them. For those who choose and want to work, then the barriers that I have told you about should not be allowed to prevent them getting work. But what should and does happen are two different things.

What should and does happen are two different things...

In my case, I have not been able to break through yet and get into employment and off benefits. I feel very frustrated. Let me tell you about a good friend of mine, also with cerebral palsy, who has always worked for her living, has never been on benefits, and at the age of 40 has risen as high in her job as she could go without changing jobs. She then went through the examinations and tests to work for MI5 (government security services) in London, got the job, but had to refuse it in the end because there was no accessible affordable housing in the area. A very different case from mine, but how very sad for my friend, and also for MI5!

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Conclusion

Yet again, while I have been writing this paper, the phone has rung with the offer of work leading dance workshops with a group of severely disabled people, one hour drive away, one day a week for a year. The job is paid, but I had to say that I would do it for my expenses only.

I really feel as if I am just going round in circles still. If I took the fee offered, it would be less than my benefits, but I would have to come off them and then re-apply next year. The red tape and paperwork involved would then give me a full time job for another year.

I know that the social security system is designed to prevent fraud and abuse. In my case, it is keeping me in my place. I have heard that in some other countries it is not like that. Perhaps I need to move to Denmark to do what I want...

I'd love to hear from anyone with any suggestions to keep me in Britain, because at present the system is not enabling me to go forward with my life.

Alan Martin