

Carrots and Sticks
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I do a lot of voluntary work, I've been doing it for more than ten years now. I do it for a variety of reasons: I love doing it, I find it satisfying, and I can't handle anything resembling normal employment. A close shave many years ago brought home to me that I need to look after myself. I really need to look after myself, because no-one else will save me. And so now I will fight with whatever strength I have to make sure I have a life that I feel is worth living, because it's too risky for me not to.

But if I don't do any paid work I get harassed by the state. For years this was the main cause of stress in my life. I've always found the Disability Employment Advisers at the Jobcentres I've had to deal with great. I never felt pressured by them if I didn't feel ready for work, they always took what I said at face value and worked with me to best meet my needs as a person, and didn't try to push me down some route that wasn't right for me. But centralisation took away a lot of the protection I had. When I say centralisation, I'm talking about a whole host of changes over the last few years, or maybe ten years, including the change to the Jobcentre Plus and things like that. Also, if I haven't been paid, why does the system not deal with that automatically? Why do I have to chase it up, making lots of phone calls? Does the system hope I'll think "I'll just leave it, I didn't need any money to live on anyway?" Because that's not going to happen, however unpleasant the process is made. Now, with centralisation, one has to chase one's paperwork around the country.

One time I was told by Paisley, or Greenock, that my paperwork was missing, and that I would have to phone Inverness, which is where I live, to get them to send them again. I phoned Inverness, and they said they could print them out down there! So I rang back, and the man said "well, I could try..." Success! But why was I having to do all that anyway? Another time my money stopped and it turned out they'd closed my claim because they thought I'd left the area! I hadn't. I hadn't moved at all. I can't begin to understand how the system can think I've left the area without my address changing. The last time I saw a DEA was to set up my supported permitted work. Supported permitted work means I can keep my benefits and earn twenty pounds a week, which is what I still do now. You can, if you meet certain criteria, which I didn't, earn a lot more for up to a year. The higher rate gets inflated, the lower rate never does. The main help I needed was for someone to deal with the benefits agency for me, because I find dealing with them so stressful.

A few years ago, I lost my benefits, due to an unfair medical assessment, faced with the prospect of the stress of signing on I panicked and went into a job I shouldn't have, and wasted my time and theirs for over a year. With hindsight I could have just gone to my GP and got another sick note, but I wasn't thinking straight. So when I finally got the confidence to leave that job I worked out what I could do to protect myself, partly I was just lucky that I had opportunities available to me that most people don't.

And so they leave me alone now. Not because of all the voluntary work I happily do for nothing, but because of the little job that is a tiny part of what I do. I should be angry and bitter about that, maybe I am. They don't hassle me to get back to work because as far as they are concerned I am working. But I would be working anyway without the job, just as much as I am now. I said earlier that I need a job to be very few hours. In truth even the job I have, makes me wonder if I am worth the money, and so on. And sometimes I have to say no to some bit of voluntary work I'd rather do because I have to do something to do with my job that day. But it's less of a drag than being unprotected would be.

Enough about me. Sort of.

The help that is available to help people get back to work - is it really fit to meet people's individual needs, or is it just fit to meet the needs of those whose needs happen to fit it? It's not all bad news - just as HUG have a lot of members who feel intolerable pressure from welfare reform, we also have quite a few who feel that they would like to go back to work in the medium-term, and who feel that the help they will need is available for them when they're ready. But what about people with different sorts of needs?

How do they decide who's capable of work? Are they applying guidelines fairly, equally and carefully?

We need time to be ill, and time to stay well. We may have some time left over for work. But this may be variable. This doesn't fit neatly into the system, which doesn't really do flexible. It doesn't really understand 'part-time'. It's more like it sees sixteen hours plus as full-time, and can't comprehend that anyone would only be able to do less than sixteen. The last job I had, which as I said was too much for me, was seven and a half hours a week. No-one was paying my national insurance contributions. I was left with about as much money as I would have had on benefit. I was just doing it so I didn't have the stress of signing on.

There's lots of things I haven't got time to go into. The paucity of psychological services, and access to them. The expectation that GPs will have the expertise to advise employers on what adaptations they need to make for someone returning to work. But I'll leave you with three case studies from Rag Tag 'n' Textile, a social enterprise working with people recovering from mental health problems in Skye and Wester Ross. The biggest issue that people have there is the fear that if they go back to work/volunteering that they will lose benefits and may never be able to get back into the system.

Case study 1, is someone who came to work for us, she had been unemployed for ten years and was very isolated and lonely. When she joined us she struggled with concentration and was very lacking in confidence. She has now been with us for nearly two years and is very much a member of the team. She has moved (with our support) and managed to pay off debts (again with our support), however when she first came to us she was not actually better off, at least not initially. Now, she is not only working, she is volunteering as well (for another organisation). She recently had a milestone birthday and said 'I feel my life has finally started.'

Case study 2 is a volunteer, she has a disabled child and is physically disabled herself, she also has a diagnosed, long term and enduring, mental health problem. She does volunteer when she can, but we support her to do so. She was told by her doctor, when she was 35, that she would never work again and became very depressed, however she is a very talented lady and has been very involved in a number of creative projects, supporting and teaching others. She is sometimes unwell, for weeks at a time, but contributes loads. She is very unlikely to ever 'work' in the traditional way, but that does not mean that she can't contribute.

Case study 3 is a women who has been very active and busy throughout her life until about three years ago she had a stroke which completely destroyed her life, however she has been working with us, she now makes jewellery and toys, which we sell for her (sale or return, she gets two thirds) she also helps out with our e-bay sales and is helping to generate enough that we can pay her a proportion of sales. She has a small income from this and is way below the tax thresh-hold, but we also offer support so that she doesn't have any problems with tax – we've supported her to become self-employed.

These people have been supported to make what progress they can in a safe way, according to their own abilities and health. Some of them have, or will in time, find themselves in a situation where the system will be satisfied and leave them alone. Some of them won't. But they're all doing what they can, and making a contribution. Shouldn't that be what matters? I can't depend on having my job forever, or on finding another one that encroaches on my voluntary work in such a minimal way afterwards.

And so I live in the shadow of the very real prospect that one day I will be once again faced with a system that doesn't care about all the voluntary work I do, and would rather I went to stack shelves and become ill. Next time I won't even have the protection of a sick note. What do you expect me to do about things that are not in my power to change? Much of what is wrong with me is that I'm bad at dealing with things I shouldn't have to deal with in the first place.

Why can't I write a sicknote for society? When you're fit, then we can talk about what you want from me. But then, if you were fit you'd be happy with what I'm doing now.

Thank you.



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