

## **WELFARE REFORM COMMITTEE**

### **THE FUTURE DELIVERY OF SOCIAL SECURITY IN SCOTLAND**

#### **WRITTEN SUBMISSION RECEIVED FROM JENNIE KERMODE**

My personal circumstances mean that I have been in constant contact with the social security system as an end user for twenty one years. I spent a decade as a carer for my partner, who had leukaemia and was left with chronic health problems by the treatment he received for it. I have subsequently become seriously ill myself, with mixed connective tissue disease, which means that my partner now has to care for me full time and is unable to work, whilst I work but am only able to do so from home, severely limiting my earning potential. At various times my partner or I have been in receipt of Income Support, Housing Benefit, Council Tax Benefit, Sickness Benefit, Incapacity Benefit, Disability Living Allowance and Carers' Benefit. The system has not run smoothly for us and we have experienced homelessness, inability to afford sufficient food and significant difficulty with inflexible processes failing to accommodate our access needs. We have been told directly by DSS staff that this would be less of a problem if I simply chose not to work.

Further to the above, my charity work and academic work have brought me into contact with significant numbers of people who have fallen through gaps in the system. In particular, I have worked with young LGBTI people and child abuse victims who have found themselves socially and financially vulnerable due to family estrangement. I have also worked with people with a variety of disabilities who have at times found themselves without adequate support.

#### **Personal Independence Payments, Disability Living Allowance Attendance Allowance and Carer's Allowance**

I have no experience of PIP but have supported my partner when he was in receipt of DLA and am now in receipt of DLA myself, at the high rate for both mobility and care. I have generally had a positive experience with this benefit on a personal level, and it has been important in enabling me to work, enabling me to access hospital treatment and enabling me to meet the extra costs of being housebound. Working to support individuals with mental health problems, however, I have found the same system to be highly problematic. I have assisted people who were unable to fill out the form at all without help (but received no offer of help automatically), people who were intimidated by the form and by DSS communication requirements to the point of having panic attacks, and people whose low self esteem or state of confusion meant they had failed to identify problems described on the form which severely impacted them. For instance, when asked about mobility, people frequently fail to realise that being terrified of leaving the house, to the point of collapsing when trying to, is disabling.

In order to cater to people with difficulties like this, the system needs to direct applicants to specific, up to date sources of support, and to do so in a prominent manner. These sources must be ones which applicants can clearly identify as neutral, because many fear that they cannot discuss uncertainties with DSS staff because this would lead to them being denied benefit. In addition to this, it would be very helpful to offer applicants the option of communicating by email, as phone

phobias are common among sufferers of anxiety related illness. It is vital that the system not depend on access to a computer as this is impossible for some disabled people, who may have difficulty using computers (including smartphones) at all, may not have felt they could afford to have one at home, and may be unable to access public facilities in, for instance, libraries or job centres.

As a disabled person I have experienced significant physical difficulty in accessing DSS premises, compounded by the inability to have any say in which centre I use (so, for instance, I have been sent to one that is further away and more difficult to get to because of the catchment area I fall into). It is frustrating in the extreme to see a sign that says 'the work you want, the help you need' in a building where there is no parking available (at all – not just for wheelchair users), no option to sit whilst waiting, and a policy of having security staff attempt to throw out carers who not part of the claim (this has happened even when said carers have been physically holding me upright). Simple, obvious changes here could make a huge difference.

The single biggest change that would liberate me from poverty traps and enable me to be in control of my life would be if I were no longer expected to be financially responsible for my partner. Technically I am the breadwinner because I work, but my partner is not choosing to be unemployed – he is doing a vital job of work as my full time carer. Because I am expected to support him as well as myself, despite my earnings being severely limited by my illness (I have been headhunted for jobs offering three times my current annual income which have been unable to work around me being housebound), I am effectively in a financial trap. Were I in employment with regular, predictable wages, the situation would be even worse, because his Carer's Benefit would be reduced in accordance with that wage – even though he would still be doing the same job of work (for which he is already paid well below minimum wage even before taking into account antisocial hours and very long shifts). Needless to say, if he were to walk out it would cost the state a huge amount more in order to provide for me.

### **Universal Credit (housing element and administrative arrangements arrangements) and Discretionary Housing Payments**

When the notion of protecting disabled people from cuts is raised at Westminster, it is frequently elided that more than half the UK's disabled population is reliant on Housing Benefit. This means that cuts to housing support have a serious impact on those least able to alter their financial circumstances. Disabled people are also more likely to find moving difficult because it can be seriously detrimental to their health, they often need a lot of help to pack and organise their belongings (which can be expensive), and they may be unable to maintain support networks vital to their wellbeing.

It is widely understood that there is a problem with a shortage of smaller properties, so linking benefit to property size is not helpful. I live in a spacious flat, as a result of which I receive only partial Housing Benefit, but my rent is really low because I knew my landlord when I moved in; by phoning around letting agents I have established that it would cost me the same amount to rent a place half the size, reducing my living space without any saving to the taxpayer, whilst the poor condition of my home means that it would not be suitable for family accommodation. When it comes to living space, I would note that this means something very different to those of us who

are severely disabled from what it means to the average person. Not only is it very difficult for me to share a bed with my partner (we both experience chronic pain), but I have been outside this flat five times in the past three and a half years, when I have been carried out for medical or dental treatment. This is not just a shelter to return to at night – it is my entire world.

I am particularly concerned about Westminster moves to restrict the availability of Housing Benefit to persons under the age of twenty five, and hope this is an area where the Scottish Government would do things differently. I left my parents' home at the age of eighteen, at which point I was suffering frequent panic attacks and hardly sleeping as a consequence of sexual abuse. Being a student gave me some financial security but I really struggled during the summer months because I would have killed myself rather than go 'home', and I weighed less than seven stone by the autumn, leading to medical complications. A year later I became a carer and at that point Housing Benefit was made available to me. I write this by way of illustrating that not everybody has the option of return to the parental home (I have worked with several other abuse victims who have had similar experiences, one feeling that her life would be at risk if she went back; I have also worked with young LGBTI people rejected by their parents); and to demonstrate that people under the age of twenty five can have significant responsibilities even if they have not become parents. I appreciate that discretionary payments are supposed to be available to help in cases like these but in my experience any discretionary DSS payment is exceedingly difficult to access (or even for the average service user to find out about) and applications take months to be processed when need is immediate – one either gets the money or one is out on the street. Emergency housing providers say they can't help couples (seriously problematic if a care relationship is involved; applicants are not necessarily made aware of, or directed to, council support for the disabled homeless); and hostels are frequently unsafe for LGBTI people and for people with mental health problems such as post traumatic stress disorder. Furthermore, victims of child abuse often feel unable to articulate their experiences until years after the fact, so can very easily be dismissed as not in need of help. Both these groups are also likely to suffer from low self esteem, meaning that (as I did) they may not consider themselves to be deserving of discretionary support and may assume such assistance is intended for others in greater need.

### **The Work Programme and Work Choice**

As a person who is fortunate enough to be able to work (albeit in restricted circumstances), these matters have not affected me much on a personal level. I was, however, recently sent a letter insisting that I attend a work capability assessment. When I wrote back explaining that this would be impossible because I'm housebound, that it would be nonsensical because I already work, and that the request itself was nonsensical because the DSS already possessed all this information, I was contacted by a manager who told me that (a) "they made us send those letters to everyone" – something many inappropriate targets doubtless found distressing – and (b) "I don't have access to your data on the system. It's all over the place" – you can imagine my concern about the DSS being fit for purpose. This highlights the kind of bureaucracy that wastes taxpayer money and makes life difficult for claimants, and it illustrates why the whole system is in urgent need of review. It needs to stop being treated as a political football and be streamlined in a practical manner.

I have worked with, and in some cases know personally, literally dozens of disabled people who have expressed acute distress at being called in for work assessments. Those who have 'passed' have been relieved; those who have 'failed' have been left terrified, not knowing how they would cope until the end of the week – some of them with children to worry about as well as themselves. In several cases this has had a serious aggravating effect on illness.

I have spoken with numerous disabled people who have told me that they want the freedom to work part time, to do a few hours as and when they feel well enough (sourcing the work themselves), or to try working full time, but often they feel unable to actualise this for fear of falling into poverty traps or being left destitute if things don't work out. In this regard, the current system is actively mitigating against a positive choice to work. One practical measure that might be taken is the provision of a guarantee that any person finding themselves unable to remain in a job within two months of taking it on could return to the same level of benefit-based income they previously received, with no need to re-apply. Another helpful measure would be an acknowledgement at all levels of the benefits system that being able to work part time does not equate to being well enough to work part time. There must also be a guarantee that all work-related training courses authorised by the state be fully accessible to disabled people and take the health needs of disabled subscribers (including the need to take breaks) seriously in accordance with prevailing medical opinion.

### **The Regulated Social Fund, new benefits, top-ups and delivery of benefits overall**

There is a tendency for people at the administrative level, most of whom have functioning social support networks, good credit records and at least small amounts of savings, to underestimate the precariousness of existence for many persons in need of benefits. In a context where people do not have enough money for food or shelter, delays of months before benefits are provided are simply unacceptable. Even crisis loans, where they are provided at all, can take days or weeks to come through, during which some people simply have no food. A lot of landlords will simply throw out tenants who can't pay the rent, assuming them to be in ignorance of their legal rights or intimidating them into going. This is the real world in which the vulnerable live and it is imperative that government make real, effective provision for them – they are just as much its citizens as anyone else.