Scottish Parliament Social Justice and Social Security Committee

Budget scrutiny 2026-27, Future Social Security Spending in Scotland

Written submission by the Department of Physiotherapy, School of Health and Life Sciences, Glasgow Caledonian University

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Dear Social Justice and Social Security Committee

Regarding: consultation on future social security spending in Scotland

I am responding from my perspectives as a physiotherapist and having recently completed PhD research where social security featured as an area for improvement in the lives of people with chronic pain in Scotland. As a physiotherapist I work (part time) in a chronic pain service where I assess and treat people who need healthcare input to live with their long-term, severe, chronic pain (mainly a process of rehabilitation). I recently completed my PhD research where social security operations (and the discourses around it) arose as a major feature of living with severe chronic pain that could impact on: health outcomes including mental health and pain, and engagement with care. In this submission I enclose: extracts from my thesis research; relevant literature sources; recommendations that I drew from my thesis, and anecdotal experiences from my clinical role as relevant to your consultation.

My experience as a physiotherapist suggests that in the last year, my patient group report less problems with ADP (compared with previous PIP), allowing more peace of mind, and focus on rehabilitation goals. Remaining problems are that people have had such a poor experience of previous applications and interactions with DWP that they are reluctant to experience this again, thus avoid engaging with the system and struggle for some time leading to detrimental effects on health and various aspects of life. People also continue to struggle to make ends meet, and have difficulty remaining in certain work roles with chronic pain and multiple long-term conditions. There are limits to what can be achieved through healthcare regarding work goals where limited adaptations can be made, proving a barrier to outcomes. Furthermore, people with pain can internalise stigmatising discourses about what it means to receive benefits and be unable to continue as before in paid work. Connected to these experiences, I wrote a short piece which I include as a potentially useful summary and can be found here: https://painconcern.org.uk/social-security-and-chronic-pain/

Social security is an important health resource in itself. The main points that I wish to raise are:

- The current scope to improve awareness and accommodation for chronic pain within social security processes, utilising contemporary knowledge and categorisation systems.

- Improving the interface between social security and paid work for those with chronic pain and illness.

- Improving the interface between healthcare and social security.

- Issues of political and societal discourses that marginalise disabled people and those with health conditions including chronic pain.

- Fairer funding, centring health and wellbeing across all policies, and reducing inequalities.

I address these points in the pages that follow. I am happy to discuss any of this with you, and am aware that there are others willing to support actions on any of these points. I also wish to remind the committee that the Scottish Governments own survey data shows that almost half of respondents thought the government should increase taxes and spend more on health, education, and social benefits, and 50% agreed that Government should redistribute income from the better-off to those who are less well-off, while 23% disagreed, (Scottish Government, 2024). I am also supportive of growth in devolved spending on social security, however, there are many other factors to consider and limits to what the Scottish Government can achieve alone. I believe there is, never-the-less, scope for improvement in social security for people with chronic pain and illness, enabling a sense of security that I believe would be beneficial to pain, life and health for this group.

Yours Sincerely

Cassandra Macgregor

Improving awareness and accommodation for chronic pain within social security processes

Introduction to chronic pain and pain care

Pain is a common personal experience and can vary in meaning from an indicator of injury, or potential damage to the body, associated with secondary disease, to a primary, long-term condition (LTC) in itself, and involves different explanatory mechanisms across these possibilities (Raja et al., 2020; Tracey et al., 2019). The context of interpretation plays a role in pain perception, influenced by biological and psychological factors, socioeconomic and cultural environments (Gatchel et al., 2007; Mills et al., 2019; Zajacova et al., 2021). While painful conditions often resolve in the short term, trajectories for people with longer term pain are more variable with any reductions in pain smaller, leading to significant disease burden and socioeconomic cost (Breivik et al., 2013; Vos, 2020; Wallwork et al., 2024).

'Chronic pain' refers to the heterogeneous and broad category of conditions and pain states where the pain has persisted for over three months (Treede et al., 2019). Like many other health conditions, chronic pain is socially patterned, ranging from 29% prevalence in the least socioeconomically deprived areas in Scotland, to 50% prevalence in the most (Scottish Government, 2023b). The condition is experienced severely by a smaller number of people impacted by the pain emotionally, financially and in terms of daily function (Dahlhamer et al., 2018; Morgan et al., 2011; Nicholas et al., 2019). Furthermore, there are higher levels of chronic pain among women and other groups marginalised by historic, economic and social conditions (Craig et al., 2019; Macgregor et al., 2023).

Living with chronic pain can involve an impact on identity or sense of self, and can limit engagement in work and social roles – some people describe a sense of loss, or struggle to maintain normalcy, which can cause distress and suffering (Smith & Osborn, 2007; Stilwell et al., 2022; Toye et al., 2017, 2013; Zajacova et al., 2021). A sense of shame and stigma can occur, exacerbated by the invisible and subjective nature of chronic pain and exacerbated by systems that do not account for chronic pain (Scott et al., 2024; Smith & Osborn, 2007; Toye et al., 2013; Webster et al., 2023). Trauma, sleep and mental health disturbances are also associated with chronic pain (Mills et al., 2019; Nicolson et al., 2023).

Similar to living with other Long-term conditions (LTC), daily life for people with chronic pain involves the work of managing the condition which may involve implementing treatment advice such as taking medications, practising exercise and using strategies such as 'pacing' or goal setting (National Institute for Health and Care Excellence, 2021). The journey through healthcare can bring emotional and cognitive burden for the person with pain and their network (Doebl et al., 2020; Healthcare Improvement Scotland, 2023; Toye et al., 2013).

Scientific understanding of chronic pain has progressed over recent decades. Advancement in imaging techniques for the central nervous system improved understanding of the neurobiological changes associated with chronic pain, leading to the framing of a disease state in some instances (Tracey & Bushnell, 2009). The scientific progression enabled the Scottish Government to recognise chronic pain as an LTC in its own right (NHS Quality Improvement Scotland, 2008); an important step towards promotion of long-term management that continues today (Scottish Government, 2022).

The eleventh revision of the International Classification of Diseases (ICD-11) introduced in 2022 expanded the classification of chronic pain conditions, recognising ‘chronic pain’ as a distinct clinical entity (or diagnosis), rather than a symptom or subset of other conditions (reflecting updated scientific knowledge) (Treede et al., 2019). The ICD-11 now contains chronic primary pain: the disease state/LTC, for example, fibromyalgia associated with disability and/or distress (Korwisi et al., 2021; Nicholas et al., 2019), and chronic secondary pain: associated with another disease such as arthritis or cancer (Treede et al., 2019). An individual’s pain may be coded as both, and may also change as new information comes to light (Korwisi et al., 2021). This marks a significant departure from earlier coding systems including ICD-10 which did not reflect more recent developments in pain research, particularly around the primary chronic pain concept, that seeks to remove the outdated dichotomy of physical and psychological pain (Nicholas et al., 2019).

Improving how chronic pain is accounted for in social security processes

My research showed harm to participants’ health that occurred related to the (UK-wide) benefits system and the wider discourses surrounding it, causing stress, anxiety, and self-stigmatisation. Stress and psychological factors are well known to influence pain perception, with increased distress associated with chronicity and severity of chronic pain (Chapman et al., 2008; Nicholas et al., 2019; Pincus et al., 2002). My research was in the context of a discussion about coming to terms with chronic pain, and situations where individuals are required to accept limits and pain, it is therefore clearly paradoxical that basic societal structures are unaccepting, poorly fit people with severe, long-term pain, and can lead to further health difficulties.

My participants experienced that their chronic pain (and therefore themselves) did not fit well with the systems – they did not match the ‘tick boxes’ that they described. While factors involved in these experiences may be multiple, on a practical note there may be scope to improve processing and recording of claims primarily based on chronic pain. Social Security Scotland currently use codes for ‘primary disability category’ based on ICD-10 classifications (Official Statistics, 2025), and show the two most populous categories are mental health/behavioural disorders, and musculoskeletal/connective system disorders (Official statistics, 2025). On closer examination (of available Excel files), there is no category of ‘chronic pain’ (Official statistics, 2025). It is possible that my participants could be assigned either musculoskeletal or mental health categories, or the next largest - ‘disease of the nervous system’ (Official statistics, 2025). Given the degree of impact that can occur, particularly with the smaller number of people with severe chronic pain, improved categorisation may raise awareness, and better demonstrate the need to provide adequate care and adaptation for chronic pain.

Social Security systems could improve awareness and categorisation of chronic pain (while acknowledging the individual, subjective nature of the condition), which could include education, training, improved data collection and recognition of chronic pain as a primary disability category in itself. Institutions for the study of pain are keen to improve awareness, utilisation and uptake of the improved knowledge, and to maximise any potential for more accurate and appropriate coding, and data utilisation, for example: https://europeanpainfederation.eu/sip/icd-11/

Interface between social security and paid work

Social situations for those living with chronic pain include key features of the social security/benefits system itself, workplace adaptation, and social capital. Experiences, journeys and outcomes for the individual with chronic pain relate to these structures, concepts and institutions. My participants living with chronic pain rated the need for improvements to social security as their top priority. I found the dehumanising nature of experiences, and ways that social security could be improved to be key themes. Some participants from a staff group thought the social security system didn't function as intended and could act as a barrier to positive patient outcomes, '*perpetuating the patient role*,' putting people in a '*work v benefits'* situation. Adequate financial support was also a feature of my literature review on coming to terms with chronic pain successfully. My data showed that workplace adaptation and supportive employers were key features of positively accepting and adapting to chronic pain. Difficulties with work, including no longer being able to manage previous work roles, subsequent loss of finances, worries about expectations to work and relief at no expectations to work featured in my data, providing further insight into social *insecurity*.

Both the nature of population health challenges, and social security systems have changed markedly over recent decades (Bambra & Smith, 2010; Global Burden of Disease Collaborators, 2018; Zajacova et al., 2021). Life expectancy increased during this period with chronic illness burden, including chronic pain, recognised as a major health and socioeconomic challenge (Breivik et al., 2013; Global Burden of Disease Collaborators, 2018). Social security in the UK, similar to but not the same as other high- income countries, has moved from passive welfare, to active welfare - including support for disabled people and health conditions to remain in work, to conditional, 'workfare' approaches (Bambra & Smith, 2010). Recent reforms to the UK system include introduction of Universal Credit: a move that purported to simplify social security, but has been criticised for worsening the situation for those with complex needs and disabilities (Cheetham et al., 2019). Higher loss of social security payments across local authority areas in recent years is associated with earlier deaths in the areas most affected (Seaman et al., 2023).

Success in helping disabled people and those with chronic illness to uptake paid work is limited by the supply side focus of any interventions in the UK, with limited options for any manageable work - often poorly paid and lacking the supportive conditions needed for those with disabilities and health conditions (Atay et al., 2024; Bambra & Smith, 2010). Recent evidence shows that people with health conditions are more likely to leave the workplace without flexibility and control over roles and tasks (Atay et al., 2024). Both people with chronic pain and employers identify that any capacity to adapt the workplace and offer flexibility is important for successful return to work, but that the characteristics of chronic pain including unpredictability, limited mobility and poor sleep can bring challenges (Grant et al., 2019). Characteristics of successful and sustainable return to work for people with low back pain, across high-income countries, includes adaptation of workplaces, job redesign and less strict social security criteria that offers flexibility (Anema et al., 2009). Unlike many other high- income countries, the UK has not taken a pro-active approach to worker health (Atay et al., 2024), and at the same time is experiencing a decline in health amongst poorest communities (Walsh et al., 2022).

Earlier improvements were made to legislation and social security systems to enable workplace access for people with chronic illness and disabilities (Bambra & Smith, 2010). However, both my data and the wider literature suggest that the current situation in the UK with regard to social security is suboptimal, and requires systemic change both for wider economic gain, and to improve the situation for individuals with chronic pain, illness and disabilities (Atay et al., 2024; Cheetham et al., 2019; Garthwaite, 2014; Heap, 2024). While prevalence of chronic pain is high, the issues facing the smaller percentage of people with severe chronic pain could be better recognised - a group more likely to interact with the benefits system (Morgan et al., 2011).

The need for a society-wide response to address and adapt to the realities of chronic illness including chronic pain is clear. The importance of optimising both environmental and personal factors is key to reducing disability (where possible) caused by chronic illness, injuries or otherwise (Cerniauskaite et al., 2010; World Health Organisation, 2024). Social Security Scotland promote inclusive rhetoric of benefits seen as ‘an investment in people’, offer choice and flexibility where possible, showing positive direction (Heap, 2024; Official Statistics, 2025). These positions better meet the idea of *security* and could counter some of the stigmatising attitudes that inhibit wellbeing for people who live with chronic pain. Devolution is limited, however, in legislation affecting social security, industrial policy, workplace regulation, capacity to raise taxes, and therefore the extent to which the parliament can protect rights of disabled people, and sufficiently modify the situation for those with chronic illness and pain to remain in paid work.

Interface between social security and healthcare

In my clinical role, between Summer 2022 to Spring 2023, we introduced a poverty screening question with categorical response to patients referred to a specific interface service within physiotherapy and recorded responses. The questions was: ‘do you ever have difficulty making ends meet at the end of the month?’ (Brcic et al., 2011), and accompanied by signposting to financial resources developed by Health Improvement in NHS Lanarkshire, who were promoting ‘Routine Enquiry’ about money worries at the time. The responses are shown in the table below.

Making ends meet responses	Number of people (n=90)
Never	20
Rarely	8
Sometimes	20
Frequently	8
Always	10
Not asked	24

The responses show that a majority of patients (who were asked the screening question) referred to the interface physiotherapy service with chronic pain reported that they sometimes, frequently or always struggled to make ends meet at the end of the month. At this time, we also found that patients were not aware of sources of financial support and the question also led to some people bringing up difficulties at work. This enabled us to provide support and also to begin conversations about rehabilitation goals.

My patients often discuss benefits with me during the process of navigating their adaption to living with chronic pain and illness. Concerns with regards to the benefits system include that participating in exercise may give the perception to others that they are completely able, and therefore not eligible for benefits. Exercise and activity are common recommendations in pain rehabilitation, and concerns about implications of participation should be factored in to social security staff awareness.

In my research, participants described the degrading visits to 'Cadogan Street' (DWP office in Glasgow), and of the mandatory reconsideration process. These aspects of the claim process are different under Scottish Social Security with a choice of mode of attendance (Heap, 2024; Official Statistics, 2025). Applicants can provide supporting documentation from healthcare professionals (Official Statistics, 2025), perhaps showing scope for the connection desired by participants who thought that the benefits system need to obtain accurate information on the health and disabilities of individuals. Connection between the healthcare team of the patient and social security could improve this process; perhaps agreed routes of patients having access to letters and coding could be established. Caution should however be applied to sanctioning of benefits entirely by healthcare staff.

Marginalising discourses

The individual with chronic pain and illness may be required to negotiate challenges to their own capacity, identity and the legitimacy of their illness and pain, further complicated by moral judgements about self-worth (Garthwaite, 2014; Pryma, 2017; Varul, 2010). With regard to the benefits situation in the UK, the language and policies promoted by the UK government and politicians in recent years has been criticised for including sick and disabled people in an active process of marginalisation (Bambra & Smith, 2010; Cheetham et al., 2019; Garthwaite, 2014).

I found that some research participants struggled with a disabled identity, where the question, '*do you identify as disabled*?' provoked uncertainty. One participant stated '*no, but for practical purposes yes*,' and another changed their position from no to yes within the answer. The data showed dilemmas of negotiating a disabled identity, difficulties and emotional work of proving disability and ill health for the purposes of gaining social security benefits. My patients in clinical practice and experience these complex processes that can inhibit positive adaptation to their condition.

My data collection showed examples of marginalising discourses, and took place from March to May 2024 when the UK Prime Minister (at the time) made high profile announcements about benefits cut backs, suggesting that some benefits recipients were 'undeserving', as relayed to the group by a participant: '*…sick lines will be over and it's just like….universally, 'people are basically at it, with their symptoms' and you know, 'it's back to work' so ….they're doing away with sick lines*.' There was evidence that participants internalised stigmatising attitudes as shown by another participant: '*If anyone asks me what I dae for work I just say 'I'm a bum', like I mean I don't work so that's just how people will see you anyway…you just belittle yourself so that other people don't do it*.'

I extracted the following passage from my thesis to illustrate the nature of the previous system. It shows participants discussing how they may be expected to prove their incapacity for work, and be successful in claiming benefits, by degrading themselves: P1-2 '*I had to go for an assessment at Cadogan street [DWP office] in Glasgow and he [GP] said, 'even if you're feeling good on that day, don't look as if you're feeling good because they'll be watching you*.'' P4-2 '*aye, because you dae have days when you feel good, and* *you want to feel good on your good days, so it's like you can't win, can you?*' P7-2 '*aye, you have that as well, people saying like dress like as a tramp, and like you were on the streets, and like covered in like urine, like disgusting looking*.' P4-2 '*but that's what I mean…you feel as if you're degrading yourself to get… to live*.'

The staff group in my research thought that patients who belonged to certain groups may be at a disadvantage, including younger (working age) people. Coming to terms may involve a change in career – not necessarily stopping work, but doing things differently (new role) or with less intensity (reduced hours). Many people with chronic pain are women and these additional [caring] responsibilities bring feelings of guilt, such that their pain is often low down the list of priorities.

Fairer funding, centring health and wellbeing across all policies, and reducing inequalities.

At a population level, Scotland has lower life expectancy than the rest of the UK, and worse health outcomes compared with other European countries (Miall et al., 2022; OECD/European Commission, 2024). Scotland has high levels of health inequalities (worse than the rest of the UK) that have increased over the last decade (Miall et al., 2022), with poorer areas recently experiencing worsening health, an issue now understood as connected to austerity policies (Seaman et al., 2023; Walsh et al., 2022). The health of Scotland's most deprived communities is becoming more 'detached' from the general population, with drivers including severe forms of multiple disadvantage which include homelessness, opioid dependence, imprisonment and psychosis (Finch et al., 2023). The detachment is shown through increasing differences between the two most deprived deciles in all causes of mortality for young adults, and drug related hospital admissions (Scottish Government, 2023a). An important point for consideration is the known relationship between high levels of socioeconomic inequalities and below-average population health; reducing socioeconomic inequalities is likely to improve population health as a whole (Pickett & Wilkinson, 2015).

I outlined inequalities in chronic pain prevalence figures in the first section and expand on that here. In areas of relative socioeconomic deprivation, there is a higher disease burden and severity, higher levels of prescribing, higher prevalence of MLTC, poorer mental health, and more people experience more severe pain with onset of ill health occurring at a younger age (Brekke et al., 2002; Jordan et al., 2008; Miall et al., 2022; Morgan et al., 2011). In Scotland data from 2003 to 2012 shows that people living in the most deprived SIMD quintile were between three and four times more likely to be prescribed opioids than those living in the least deprived (Torrance et al., 2018). People living in areas of deprivation may also feel less able to participate in consultations, less in control and engaged in chronic disease management (Brekke et al., 2002; Dixon-Woods et al., 2006; Protheroe et al., 2012).

Where individual socioeconomic data has been collected, chronic pain is associated most clearly with lower levels of formal education and income (Prego-Domínguez et al., 2021). Furthermore, without adequate prevention, chronic pain prevalence is predicted to increase in coming years, and to continue to disproportionately affect socioeconomically deprived groups (Raymond et al., 2024). Therefore, understanding and addressing mechanisms of inequalities is relevant to pain research and prevention of disease.

The fundamental 'causes of causes' of health inequalities are unequal distribution of income, power and wealth reflecting wider socioeconomic inequality, which can influence policy and also, for example, access to education, social security and housing, which in turn can influence individual behaviours and biology (Lucyk & McLaren, 2017; McCartney et al., 2020).

Pain is a political, and economic issue; the individual continually engages with institutions, discourses, norms and pressures (Wailoo, 2014; Zajacova et al., 2021). I outlined in my thesis research (that will soon be available) and some published work (Macgregor et al., 2024) how economic models influence the health of individuals with chronic illness and pain. Those who are unable to meet the ideals of independent, active and productive citizens can experience stigma, shame and marginalisation, exacerbated in systems in which health status is tied to access to social security, requiring moral boundary work (Pryma, 2017; Walker et al., 1999) with societal discourse framing those out of work as ‘scroungers’ and ‘shirkers’ (Garthwaite, 2011). Without addressing these wider systems around the person in pain, there is a limit to the extent to which they can experience improved health.

My research findings echo calls for caring and inclusive societal narratives that are accepting of individuals with chronic pain and their needs, and counter any marginalising or stigmatising narratives. Alternative societal and economic models could facilitate a shift in our thinking and approaches to prevention, where possible, and adaptation to the realities of chronic illness in ways that work for all (Ayo, 2012; Shipton et al., 2021). A shift towards social and economic models that centre inclusion and health offers better alignment with my findings. Different societal priorities are needed to foster accepting and caring systems for the participants across the studies. Alternative models include concepts of an inclusive economy where equity is deliberately fostered and different types of work accounted for (Shipton et al., 2021). Addressing prevention of ill health may further benefit from the ‘wellbeing economy’ model that places priority on human and ecological wellbeing over economic growth with increasing recognition of the link between the systems that perpetuate poor health, inequities, and climate change (Fioramonti et al., 2022).

The staff group in my research raised cultural ideas of pain and a person’s worth, and wondered if education played a role in improving societal understanding of holism with respect to health, and ideologies of capitalism in ‘*driving people,’* and thought society should enable a sense of purpose for all - ‘*people with pain want to show their worth in society*’. My research findings show that it is important to both change narratives on health, disability and chronic illness, and also change the structures to promote health and inclusion.

Conclusion

I conclude that the Scottish Government should continue with its approach to ADP, promoting flexibility and inclusion, connected to trauma-informed policies which will also be important to understand previous experiences of the DWP, PIP and other benefits assessments. Wellbeing economy policies should be further adopted. Social security needs to be adequately funded and delivered in a flexible, supportive manner for those both unable, and partially able to undertake paid work. The Scottish Government should be bolder on wealth redistribution, reform and investment in public services and universal provisions, using whatever levers possible to improve the social determinants of health. For example, fairer solutions for the local taxation system has been long been called for. I note many patients and participants are disaffected with government and I fear frustration and anger may be misdirected – reforms and bolder actions are needed. Improving awareness of chronic pain, updating coding systems and staff knowledge could be beneficial. Connected to this , adequate capacity for pain care also needs to be delivered by the Scottish NHS.

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