

Social Security Committee Consultation on Social Security Bill 2017

Summary of evidence:

- A specific claimant right to access advocacy services throughout the claimant journey should be added as a key principle as set out in Section 1 of the Bill.
- Specific provision for co-production of the Social Security Charter should be added to Section 3 of the Bill.
- An independent statutory body should be established to oversee and scrutinise the creation, implementation and practices of the new Social Security system.
- The Scottish Government should use the definition of disability as set out under the United Nations Convention on the Rights of Persons with Disabilities, within Section 14 of the Bill.
- The Bill should be consistent and make specific provision for all key words/criteria within Schedule 4 to be used when determining disability assistance, to be set out in Regulations.

Q1 - Benefit rules in Regulations

1. Crohn's and Colitis UK welcome the process as set out by the Scottish Government to place the majority of the rules governing the new Social Security system within subordinate legislation rather than in the Bill itself in primary legislation.
2. It is foreseeable that when introducing legislation in a brand new area of competency, that inaccuracies or misinterpretations will occur when drafting new primary legislation. By setting out the detail of the new devolved benefits within subordinate legislation, this will enable amendments or additions to be made to Regulations easily and more speedily than changing primary legislation. This will ensure swift changes can be made to the Social Security system as and when it will be needed.

Q2 - The Seven Principles

3. Crohn's and Colitis UK warmly support the establishment of key principles of the new Social Security System in law. This not only demonstrates the commitment to these principles but it provides a legislative mechanism for these key principles to be the consciousness of the new Social Security system, guiding and driving its development.
4. Ensuring that key principles are set out in legislation will ensure that suitable duties fall onto all within the social security process. This will help change the culture around claiming for benefits to fit in with the key principles of fairness, dignity and respect that the Scottish Government have outlined as crucial within its vision for any future Social Security system.
5. Crohn's and Colitis UK also support the inclusion of a specific principle on co-production, ensuring that claimants are put at the heart of the new Social Security system.
6. We welcome the Scottish Government's view that social security is an investment in people and, whilst it is in itself a human right, it also contributes to achieving other human rights.
7. Claimants often believe that the benefits system is designed in such a way as to put people off from claiming some or all the support they need. Therefore, it is extremely welcome that a specific principle, number 4, (Section 1(d)) has been added to ensure the Scottish Government has a role to play in ensuring people claim what they are entitled to.

8. However, Crohn's and Colitis UK believe that this principle should be extended to give a specific right for claimants to access independent advocacy services within the claimant journey. Given the evidence around the important role advocacy plays in maximising successful benefit claims, it is clear that advocacy has a fundamental role to play in seeing that the goals of principle 4 can be realised within the new system.
9. Crohn's and Colitis UK has experience that when a claimant has access to independent support and information within the application and claimant process, they are more likely to be successfully in getting the care and support they need. This both ensures the wellbeing of the applicant and ultimately reduces appeal costs to the Government, delivering a right first time approach.
10. Whilst we note that access to advocacy services seems to be part of the current Government's plans, this may not be true for all future governments. Therefore, Crohn's and Colitis UK believe that a specific and fundamental right to access advocacy services within the claimant journey should be added to the seven principles within the Bill.
11. A point that the Committee may note that is absent from the Bill as a whole is that whilst Section 2 states the principles which are to be reflected within the Charter, the Bill does not outline specific redress mechanisms if these principles are not adhered to, either through the charter or within the application process. To ensure the Bill has real teeth, this may require whether enquiry by the Committee, should it wish.

Q3 - The Social Security Charter

12. Crohn's and Colitis UK believe it is noteworthy that the Scottish Government listened to feedback from constituents and stakeholders and ensured that the key principles and existence of a charter were set out in legislation. This not only fully legitimises and gives strength to the Charter and the seven key principles, but it allows revisions to the more detailed Charter without the need to amend primary legislation.
13. The Social Security Charter would be a useful way of ensuring that the stated principles of the Social Security system are well understood, both by people using the system and those administering it. As a patient organisation, we feel it is imperative that any Charter is co-produced and built upon active and constructive dialogue with people who use the social security system, creating a discourse which encourages respect and dignity within a human rights-based framework. Co-production approaches help to create a discourse that encourages respect and dignity within a human rights-based framework and, in itself, is an example of taking a rights-based approach.
14. Whilst Section 3 of the Bill talks of consultation with claimants of the devolved benefits, it falls short of expectations around genuine co-production as set out in the seven principles. Crohn's and Colitis UK would therefore welcome a clear commitment within the Bill for the Social Security Charter to be prepared and reviewed using a genuine co-production method with a range of stakeholders such as claimants, patient and voluntary organisations and academics.
15. Accountability must be the main principle guiding the development and application of the Charter. As previously highlighted, we believe that any charter should set out what happens if the state does not comply with the Charter and, beyond that, how the general public can hold the Scottish Government to account on the implementation and application of the Charter.

16. Crohn's and Colitis UK believe that an independent body should be set up to scrutinise the Scottish Social Security arrangements and this requirement should be included within the Bill, establishing this organisation on a statutory footing. It would be important for any independent body that is established to follow a co-produced model, with diverse governance arrangements with representation from service users, voluntary and charity organisations, political parties, as well as from academics.
17. The role of this new statutory body could include: mandatory scrutiny of social security regulations, safeguarding equality of access to the Social Security system ensuring that those that need access to the system can receive it, informal scrutiny of other regulations where there is an overlap between another policy area and social security and providing advice and assistance to Ministers in the management and possible changes to the system.
18. Crohn's and Colitis UK believe that the timescales for the preparation and review of the Social Security Charter seem to be reasonable and in keeping with the Parliamentary cycle.
19. We welcome the establishment of the Social Security Charter annual review in legislation. However, it is unclear which body within the Scottish Parliament will be scrutinising this annual report and whether such scrutiny could be undertaken by establishing an independent body to oversee the scrutiny of the system as a whole. Parliamentary bodies such as the Social Security Committee could then oversee the running of this independent body.

Q4 - The rules for Social Security

20. We warmly welcome the proposed changes in how the Social Security system will operate, from a system where claimants have to prove entitlement, to a right's based approach where Ministers' only determine those claimants that are not eligible and do not meet the selected criteria.
21. The Bill introduces a duty on Ministers to "give assistance" as determined by entitlement processes, as set out in future regulations relating to each of the devolved social security payments. Section 14 states that the Scottish Government will have a duty to provide *Disability Assistance* which will be given to people who have "a disability arising from a physical or mental impairment" or "a terminal illness".
22. Crohn's and Colitis UK have grave reservations around the limitations of this wording in Section 14, due to the misrepresentation of someone not defining themselves as being disabled or having a disability despite claiming PIP or DLA. Many people with long term, fluctuating and incurable diseases like Inflammatory Bowel Disease may not view themselves as having a disability, despite the immensely incapacitating nature of the condition.
23. The Scottish Government should consider amending the face of the legislation to include reference to "long term conditions" or relate this to the definition of disability under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). This states "Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others."

Q5 - Benefit Schedules

24. Crohn's and Colitis UK are concerned that whilst Section 1(2) of Schedule 4 makes provision for the regulations to define "terminal illness" for the purpose of determining entitlement to

disability assistance, the Bill does not make provision for the terms “significant” or “short-term” to also be outlined in Regulations. Inflammatory Bowel Disease (IBD) is a long term, fluctuating condition and to ensure that those with IBD can access the disability assistance they need, and prevent any inconsistency or unfairness in the application of this benefit, it is important that these terms are also outlined specifically in Regulations. Crohn’s and Colitis UK would therefore like to see specific mention of these important definitions within the Bill to be laid out in Regulations.

Inflammatory Bowel Disease

25. Every 30 minutes someone in the UK is diagnosed with Crohn’s Disease or Ulcerative Colitis, the two main forms of Inflammatory Bowel Disease (IBD). At least 26,000 people or 1 in 210 people in Scotland have been diagnosed with IBD. Scotland has the highest prevalence of IBD of any country in the UK. IBD is a lifelong condition that most commonly first presents in the teens and early twenties (mean age of diagnosis is 29.5 years) but it can be diagnosed at any age of a person’s life from childhood to old age.
26. In IBD the intestines become swollen, ulcerated and inflamed. Symptoms include acute abdominal pain, weight loss, diarrhoea (often with blood and mucus), tenesmus (constant urge to have a bowel movement), and severe fatigue.
27. People living with IBD view Social Security, particularly access to Personal Independence Payments (PIP) as important in maintaining their independence and social inclusion, supporting their participation in work and social activities and contributing to the extra costs incurred by their condition due to its disabling impact.
28. People with IBD face challenges and restrictions in their lives, arising from their condition, which impact on their ability to engage in activities of daily living, restrict their mobility and ability for self-care. For example, fatigue is a common symptom of IBD. Studies have demonstrated that fatigue measurement scores in those with IBD are comparable to scores reported in cancer patients. Joint problems are also associated with Inflammatory Bowel Disease, meaning that some people experience mobility issues affecting their ability to walk.
29. IBD may have a significant effect on hobbies, work and social interaction due to the need to be close to toilet facilities and the need to plan journeys accordingly. People with stomas may also experience these restrictions due to the need to access toilets to prevent or manage leakages. Psychological symptoms due to the chronic nature of the condition may also affect overall function and the ability to work or take part in social interactions.

Crohn’s and Colitis UK

Crohn’s and Colitis UK is a national charity leading the battle against Crohn’s Disease and Ulcerative Colitis. We provide high quality information and services, support life-changing research and campaign to raise awareness and improve care and support for those affected by Inflammatory Bowel Disease (IBD).

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