

Social Security Committee consultation on the Social Security (Scotland) Bill – CLIC Sargent submission

Introduction

1. Every year in the UK around 4,000 children and young people under 25 are diagnosed with cancer. In Scotland, around 300 children and young people are diagnosed with cancer each year. CLIC Sargent is the UK's leading cancer charity for children, young people and their families. We fight tirelessly for young cancer patients – individually, locally and nationally.
2. When cancer strikes young lives CLIC Sargent helps families limit the damage cancer causes beyond their health. We do this by providing nurses, social workers, financial grants and via our Homes from Homes. We also fight tirelessly alongside young cancer patients and their families to create change in health, benefits and wider systems around young cancer patients and their families, so that they get the support they need. Last year we provided services to over 7,200 young cancer patients and their families across the UK.
3. CLIC Sargent welcomes the opportunity to respond to the Social Security Committee's consultation on this Bill. We know that benefits are an area of concern for young cancer patients and their families, as identified in our 2016 report #Cancercosts. The report identified that applying for benefits could often be challenging and we would like to see changes made that ensures young cancer patients get the support to which they are entitled as quickly as possible. We hope the new Scottish social security system can address some of the current issues with the Westminster system and better support young cancer patients.

Response to consultation questions

1. The Bill aims to provide a framework for the creation of the Scottish social security system. In addition the Scottish Government has chosen to put most of the rules about the new benefits in Regulations. It believes that putting the rules in Regulations will make things clearer and less confusing. Parliament cannot change Regulations, only approve or reject them. The Scottish Government intends to develop Regulations with external help.

Q. Do you have any views on this approach?

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4. This seems like a sensible approach, particularly if it will ensure the rules about the new benefits will make things clearer and less confusing. CLIC Sargent would welcome the opportunity to act as part of the external help for the Scottish Government to develop Regulations to ensure that young cancer patients and their families are appropriately supported by the Scottish social security system.

2. The Bill proposes that the Scottish social security system will be based on the following seven principles:

- **Social security is an investment in the people of Scotland.**
- **Social security is a human right. It is essential to accessing other human rights.**
- **Respect for the dignity of individuals is at the heart of the Scottish social security system.**
- **The Scottish Government has a role in making sure that people are given the social security assistance they are eligible for.**
- **The Scottish social security system will be designed with the people of Scotland, and based on evidence.**
- **The Scottish social security system should always be trying to improve. Any changes should put the needs of those who require social security first.**
- **The Scottish social security system is efficient and delivers value for money.**

Q. What are your views on these principles and this approach? Please explain the reason for your answer.

Q. Are there other principles you would like to see included?

5. CLIC Sargent would agree with these principles, as they would seem to create a fair and accountable welfare system. We would like to see something about ensuring that the social security system also provides social security promptly. We are aware that there can often be delays in administering benefits to individuals and young cancer patients are no exception. We know that the costs start to mount up as soon as the doctor says cancer and we would like to see young cancer patients and their families receive any benefits to which they are entitled as quickly as possible.

3. The Bill proposes that there will be a publicly available social security ‘charter’. This will say how the Scottish Government will put the seven principles above into practice. It will also say what is expected from people claiming benefits. A report on the charter will be produced by the Scottish Government each year.

Q. Do you agree with the idea of the charter? Please explain the reason for your answer.

Q. Is there anything specific you would like to see in this charter?

6. CLIC Sargent would support the idea of the charter to ensure greater transparency and accountability in the system.

4. The Bill proposes rules for social security which say:

- **how decisions are made and when they can be changed**
- **how to apply and what information people have to provide**
- **how decisions can be challenged**
- **when overpayments must be repaid**
- **what criminal offences will be created relating to benefits.**

Q. Do you have any comments on these rules?

7. CLIC Sargent welcomes these rules, but would also like to suggest rules around timescales for social security to be paid. We are aware of the delays to the current social security system and would like to see the Scottish Government take steps to ensure eligible applications are processed in a timely manner to ensure individuals receive social security as quickly as possible.

5. The Scottish Government will take over responsibility for some current benefits. The Bill does not explain how they will work in detail. This will be set out in Regulations at a later date. The current benefits which will be run by the Scottish Government are:

- **disability assistance (including disability living allowance, personal independence payment, attendance allowance and severe disablement allowance)**
- **carer's allowance**
- **winter fuel payments**
- **industrial injuries disablement benefit**
- **cold weather payments**
- **funeral payments**
- **sure start maternity grants**

Q. What are your thoughts on the schedules in the bill in regard to these benefits?

8. With regard to Schedule 4 on disability assistance, we would like further detail on the sections which suggest eligibility and value of assistance being dependent on age. We would be concerned, for example, if children and young people were to be considered less eligible or eligible for a lower value of disability assistance. We would welcome clarification on this matter.
9. With regard to Schedule 4 on carer's allowance, we are similarly concerned about the conditionality around age and would seek the same clarification. With regard to eligibility being dependent on whether the individual is in employment or education, we would also welcome clarification to ensure that young cancer patients and their families are not unfairly penalised.
10. With regard to Schedule 7 on funeral payments, we are deeply concerned about the sections which suggest assistance will be reduced for those who receive additional assistance towards the cost of a funeral. We know that the current Westminster system for help with funeral costs does not go far enough. In 2015, we carried out a small survey and asked our care professionals (nurses and social workers) about Funeral Payments. Many had helped families claim for support for funeral costs from the Social Fund, and almost 90% reported that successful Funeral Payments never or rarely covered the full cost of a funeral, suggesting that additional contributions toward funeral costs can be a necessity for some families who are struggling to meet the costs.
11. This is one of the hardest things any parent will ever have to deal with. For parents dealing with this devastating loss, trying to pay for their child's funeral, when they may already be struggling financially, is enormously stressful. This year, CLIC Sargent provided just over 400 compassionate grants totalling £120,450 to help reduce this emotional stress. Our grants are funded entirely by voluntary donations and we don't think it's fair that families are unable to access the government support that they are entitled to as a result of accepting our compassionate grants.

12. We know that the DWP is currently consulting on proposals that would allow recipients of Funeral Payments to receive additional payments towards the cost of a funeral from other parties without deducting these contributions from the value of Funeral Payments. While we currently do not know how much the Scottish Ministers will allocate to Funeral Payments, unless it is significantly higher than those offered under the Westminster system, it will not cover the cost of a funeral. We would strongly urge that the Scottish Ministers ensure bereaved families are not penalised for receiving additional assistance for the cost of a funeral.

6. The Bill proposes that a new type of short-term assistance will be introduced. This will be for someone who is challenging a decision to stop or reduce a Scottish benefit.

Q. What are your views on this proposal?

13. CLIC Sargent would support the introduction of this proposal.

7. The Bill includes the power for the Scottish Government to be able to top up 'reserved' benefits (ones controlled by the UK Government), but does not say how these will be used. The Scottish Government also has the power to create new benefits. This is not included in the bill.

Q. Do you agree with these proposals?

14. Yes

8. The Bill proposes that carer's allowance should be increased as soon as possible to the level of jobseeker's allowance (from £62.10 to £73.10 a week).

Q. What are your thoughts on this proposal?

15. CLIC Sargent would support an increase in the rate of carer's allowance. We know that many families struggle with mounting costs when a child is diagnosed with cancer and any additional support for them at this time would be very welcome.

9. The Bill proposes that discretionary housing payments continue as they are. They will still be paid by local authorities. The Bill does not require any local authority to have a discretionary housing payments scheme but if they do, they must follow Scottish Government guidance on running it.

Q. Do you agree that discretionary housing payments should continue largely as they are?

Q. Do you have any other views on the proposals for discretionary housing payments?

16. We have no view on this question.

10. Q. Is there anything else you want to tell us about this Bill?

17. We have no further comments at this time, but will continue to follow the progress of the Bill to ensure that young cancer patients will get the support to which they are entitled under the new Scottish social security system.

18. At CLIC Sargent we know that #Cancercosts young people and their families and can plunge them into debt. We don't think this is right or fair. We believe that any social security system should include and provide timely support for young cancer patients and their families for as long as they need it.

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