



DWP Department for
Work and Pensions

Public consultation

The future of the Independent Living Fund

Presented to Parliament by the Secretary of State
for Work and Pensions by Command of Her Majesty
July 2012

Cm 8366

£6.25



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Ministerial foreword

Over the last two decades the social care system across the UK has fundamentally changed. In England, the development of personal budgets, building on the experiences of disabled people using direct payments, has put choice and control in the hands of service users. Building on this progress, and as set out in the Care and Support White Paper ‘Caring for our future: reforming care and support’, the forthcoming Social Care and Health Bill will put personal budgets on a statutory footing, and require all local authorities to offer personal budgets to all disabled people who are eligible for social care services. Moves towards greater choice and control for disabled people are also a feature of social care reform in Scotland, Wales and Northern Ireland.

The Independent Living Fund (ILF) has played an important role, providing support for some disabled people in the form of direct cash payments since the fund was established in 1988. But it has been clear for some time that the changes we have seen in the wider care and support system have called into question the efficacy of a separate funding stream operating in parallel to, but outside of the mainstream care and support system administered by local authorities. Furthermore, while the ILF has applied national eligibility criteria in a consistent way, there is considerable geographical variation in ILF take-up rates. These were the conclusions of an independent review of the fund in 2007, but no decision on the strategic future of the fund was taken at that time.

The Government believes that the care and support needs of existing ILF users can and should be met within one cohesive social care system, in a way that is consistent with our commitment to localism, with funding and services integrated around individuals’ need through personal budgets. Our preferred approach is that from 2015 ILF funding is devolved to local government in England and to the devolved administrations in Scotland and Wales. The Government’s approach to the ILF is driven by the clear need to reform the system. I want to reassure users that we remain fully committed to maintaining their care packages up to April 2015. The purpose of this consultation is to seek views on how they are supported from 2015 and beyond.

This consultation seeks the views of disabled people, their carers, families, local authorities and other interested parties on the proposed approach, and the potential implications for ILF users and for the wider care and support system. I hope we can get the views of as wide a range of interested individuals and organisations as possible.



Maria Miller MP

Parliamentary Under Secretary of State and Minister for Disabled People

Purpose of the consultation document

This consultation document seeks your views on the impact that devolving funding to local authorities and Devolved Administrations, meaning the closure of the Independent Living Fund (ILF) in 2015, would have on users, local authorities and the wider care and support systems across the UK. The Government would also like your views on how closure could be managed in a way which would minimise disruption to the care and support needs of existing ILF users.

This document was published on 12 July 2012. We need you to respond to the questions by 10 October 2012. Details of how to respond are in Chapter 7.

If you have any queries about this consultation, or would like to receive the consultation document in a particular format, for example, large print, Braille, audio, or Easy Read, please contact:

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The devolved administrations

The ILF currently operates across the United Kingdom, so this consultation applies to England, Scotland, Wales and Northern Ireland¹. However, responsibility for care and support is a devolved matter. While this document seeks views on how the needs of ILF users can be best met within the mainstream social care system, specific policy responses resulting from the closure of the fund will be the responsibility of the relevant Governments in each part of the United Kingdom.

The UK Government is committed to working closely with the Governments of Scotland, Wales and Northern Ireland.

¹ Funding for ILF users in Northern Ireland is currently the responsibility of the Northern Ireland Department for Social Development, not the Department for Work and Pensions.

Introduction

1

1. The Government is committed to removing the barriers disabled people face in fulfilling their potential and playing a full role in society. As set out in our discussion document *Fulfilling Potential*, ensuring disabled people have maximum choice and control over the services they depend on is crucial if we are to realise the aim of independent living. Significant progress has been made in the personalisation of care and support over the last two decades, with only 23 per cent of disabled people in 2010 reporting that they did not have choice and control over their lives.² The Independent Living Fund (ILF) has played an important role in achieving that, proving that disabled people, including those with very high support needs, could significantly increase their quality of life if given direct control over funding for their care and support.
2. While recognising the historical contribution that the ILF has made, including the personal contribution of the fund's trustees, the Government concluded in December 2010 that, given the very different policy context to when the ILF was established in 1988, administering an increasing amount of social care funding outside the mainstream care and support system was no longer appropriate or sustainable. Therefore, it was announced that the fund would be permanently closed to new users, that funding for existing users would be maintained until the end of this parliament in 2015, and that there would be a consultation on how the then 20,000 existing users would be supported beyond 2015.
3. There are currently 19,373 ILF users and the Government believes that the care and support needs of those users now can and should be met within a single cohesive care and support system, administered by local authorities. This consultation seeks the views of users, their carers, local authorities and other interested organisations on that proposed option.

² Office for National Statistics, ONS Opinions Survey, 2010.

The Policy Context

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History of the ILF

4. The Independent Living Fund was created in 1988 to mitigate the impact of the end of domestic assistance allowances when Supplementary Benefit was replaced with Income Support which included flat rate disability premiums. Following discussions with disability groups, the Government established the ILF as a charitable trust to make payments to people on low incomes who had to pay for personal care. The fund was originally established for a maximum of 5 years and was expected to support around 300 people.
5. The ILF proved to be popular and applications were much higher than expected, providing evidence of a real demand for direct cash payments for care as a means of enhancing choice and control. At this time there was no clear legal provision for local authorities to make such payments. In 1992 the ILF was closed to new users and a new fund was created in 1993 to receive new applicants. Taking account of new responsibilities of local government in the National Health Service and Community Care Act 1990, the new fund required applications to be made by local authorities, and required a minimum local authority contribution of £200 per week to each user's care package, the approximate cost of a place in residential care at that time.
6. Alongside the operation of the ILF in the early 1990s, the case for granting local authorities the power to make direct payments to service users continued to build, resulting in the 1996 Community Care Act which made such payments possible. Access to direct payments was extended to a range of groups of services users over the following years, and legislation in 2001 created a legal duty on local authorities to offer a direct payment to anyone eligible for community care services.
7. Meanwhile the ILF caseload continued to grow, and by 2006 there were 22,000 users, supported by an annual budget of £250m. Key factors in the growing caseload were an increased demand from disabled people to live independently, the related growth in take up of direct payments and greater local authority awareness of this funding stream. However, growth varied significantly across the country with local authorities engaging with the funding stream in different ways.

8. In 2005 the ILF was listed as an executive non-departmental public body under the sponsorship of the Department for Work and Pensions, and in 2007 the two funds were amalgamated, with a new single Trust deed governing how the fund operated.
9. In light of policy developments across the social care landscape, and in line with Cabinet Office guidance, DWP commissioned an independent strategic review of the ILF in 2007.³ The review noted that the ILF had played a significant role in the history of independent living and that its achievements over the previous 18 years had been important. But it concluded that, in the long run it would be highly anomalous to continue to administer a large amount of social care funding through a cash limited, discretionary fund administered by a board of trustees under a different set of rules and remits from the mainstream care and support system. The previous Government noted the recommendation that there should be a smooth transition towards full integration within a system of personalised budgets, but no strategic decision was taken at that point.

The closure of the fund to new users in 2010

10. On a number of occasions since the ILF was created the eligibility criteria have been changed to match changing demand and funding allocations. In 2008, in the face of increasing applications and costs, funding was changed from a demand led to a cash limited basis, and the eligibility criteria were changed to focus support on applicants with the greatest needs. Further changes to the eligibility criteria were required when the budget allocation for 2010/11 was reduced by the previous Government. However, ahead of, and in anticipation of the new rules, a very sharp increase in applications put the ILF budget under significant pressure, and in June 2010 the trustees had to take the decision that the fund would be temporarily closed to new users. At this point, it was clear that a strategic decision was needed on the role of the ILF from 2010/11, taking account of changes in the wider care and support system, in particular the roll-out of direct payments across the UK, personal budgets in England and other models of self-directed support in Scotland, Wales and Northern Ireland.
11. Unlike direct payments which are a payment of the cash equivalent of commissioned services, personal budgets let users know up front what funding they are eligible for and give them maximum flexibility over how that funding is used to meet agreed outcomes. Funding can be taken as a direct cash payment, in the form of services or a combination of both. This model of self-directed support incorporates many of the features which made the ILF approach popular, but supports much greater flexibility in how funding can be used to deliver independent living outcomes. The social care white paper, 'Caring for our future: reforming care and support', published this week sets out the Government's plans to reform care and support, which includes the intention to put personal budgets on a proper legal footing, and to create a new legal right to receiving care and support through a personal budget. This will be supported by the improved availability of high quality information and advice, enabling people to exercise genuine choice and control over the care and support they need.
12. It was against this policy backdrop that the Government concluded that it was no longer appropriate for a NDPB operating as a trust to administer an increasing amount of social care funding in parallel to the mainstream social care system. The objectives of the ILF could be met within the care system administered by local authorities, in a way that is more responsive to the needs of, and accountable to local people. Alongside that decision the Government committed to fully protecting care packages of existing users until 2015.

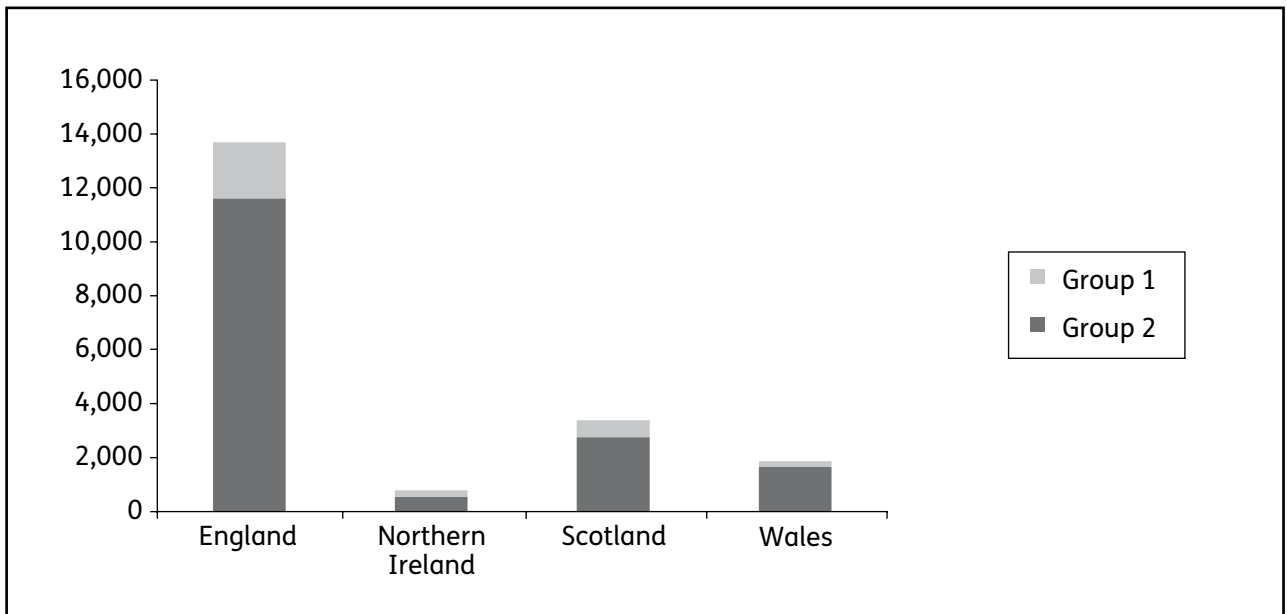
³ Henwood & Hudson (2007) Review of the Independent Living Funds.

Existing ILF users 3

The ILF caseload and user care packages

13. At the launch of this consultation there are 19,373 ILF users across the UK. Within this there are two distinct groups of users, those who started receiving ILF support pre-March 1993 and those who applied to the fund created in 1993, referred to in this document as Group 1 and Group 2 users respectively. The key difference is that Group 2 users have care packages which include a minimum of £200 per week contributed by their local authority. While many Group 1 users receive some support from their local authority, this input is not part of their ILF eligibility criteria.

Figure 1: Distribution of ILF users across the UK (Source ILF administrative data)



14. For all users the gross care package represents their total assessed need. For all Group 2 and 45 per cent of Group 1 users, this is made up of the local authority payment and any charge they require plus the ILF payment and any 'available income' charge they levy. Gross figures are used throughout this document unless stated otherwise.
15. **Group 1** users fit into three categories, (a) those who have a known local authority contribution to their care packages, (b) those who have a local authority contribution but the ILF do not know the amount, and (c) users who the ILF have not been able to confirm whether they have a local authority contribution or not. Where the level or existence of local authority funding is unknown, it can be because the users have not consented to the ILF contacting their local authority.
16. **Group 2** users make up 84 per cent of the caseload and have average local authority and ILF weekly contributions of £536 and £368 respectively.
17. Across the ILF caseload and between different local authorities there is considerable variation in user awards and differences in the balance between local authority and ILF contributions to care packages. In the majority of local authorities the ILF contributes between 40 per cent and 50 per cent of funding to Group 2 users, but there are a small number where the ILF contributes over 50 per cent to user care packages. Where local authorities do contribute to the care packages of Group 1 users the ILF contribution ranges from around 20 per cent to 75 per cent of funding.

The geographical distribution of ILF users

18. While it is very difficult to estimate the take-up of ILF funding, the distribution of users across the country does not appear to be strongly related to the distribution of the potential users⁴. Though the ILF treated applications in a consistent way on the basis of national eligibility criteria, local authorities have engaged with this funding stream in varying degrees since it was established. The 2007 review found that local authorities and different social workers varied in the knowledge of the ILF and the extent to which they actively encouraged people to apply for it. This variation must also partly reflect the historical variation in the pattern of take-up of direct payments and the focus on delivering independent living outcomes through self-directed support.

Age of ILF users and award duration

19. The original fund had no age restrictions so 20 per cent, a sizeable proportion of Group 1 users, are over 65 years old. The fund set up in 1993 (Group 2 users) restricted applications to people aged 16 to 65. The relationship between age and duration is generally as might be expected with those with the shortest durations in the younger age groups.

⁴ A full breakdown of ILF user numbers by Local Authority, including as a proportion of the local population and as proportion of people receiving the higher rate of the Disability Living Allowance (DLA) is published by the ILF at: <http://www.dwp.gov.uk/docs/user-profiles-1211.pdf>

Figure 2: Award duration of ILF caseload (Source ILF administrative data)

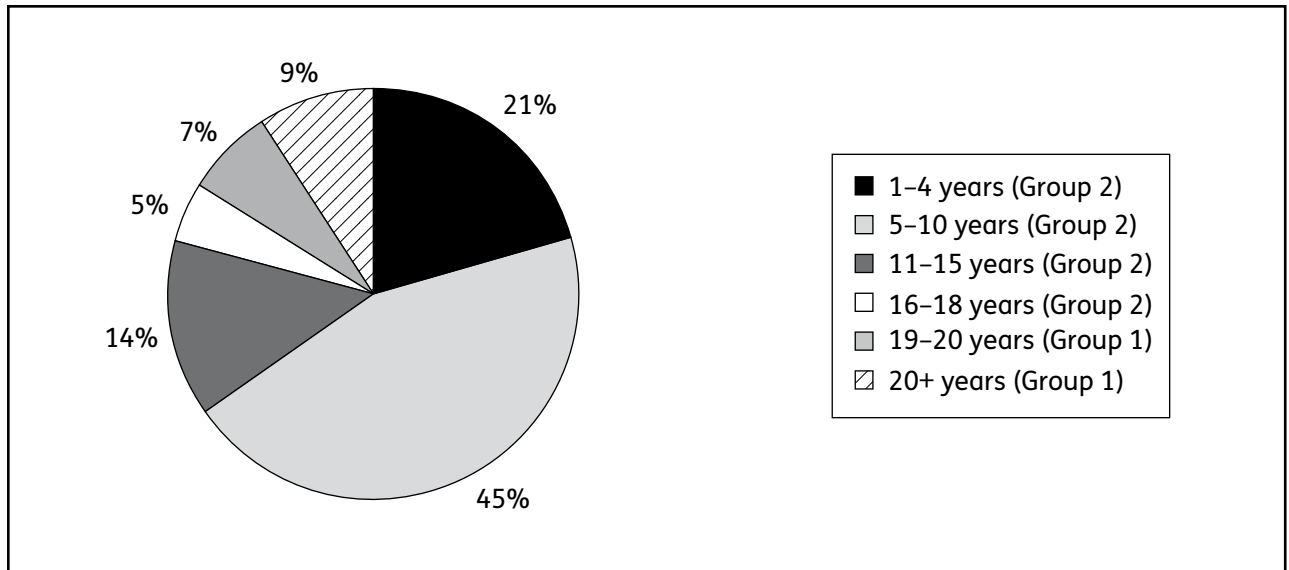
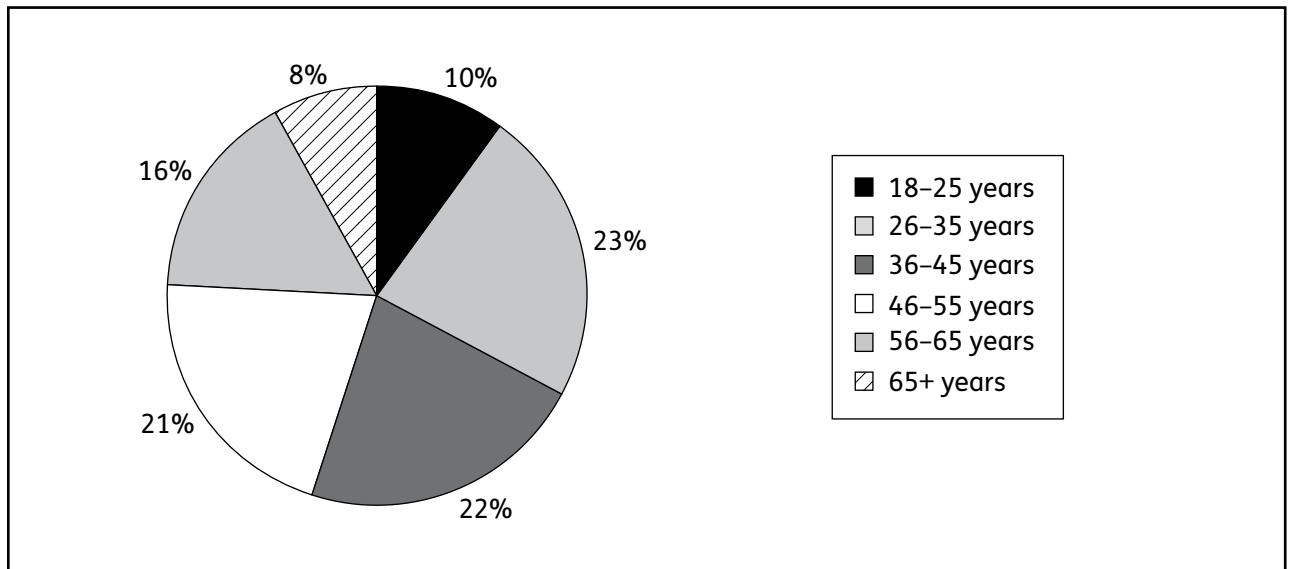


Figure 3: Age composition of ILF caseload (Source ILF administrative data)



Support for ILF users from 2015

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20. The purpose of this consultation is to seek views on the Government's proposal as to how the 19,373 existing users of the ILF should have their care and support needs met from 2015. While the Government is fully committed to funding users' care package up to 2015, we do not believe that the continued operation of the ILF as a legacy fund would be sustainable or justifiable. Around 94 per cent of ILF users are already part of the mainstream care and support system, with around 41 per cent⁵ of this group receiving direct payments from both the ILF and their local authority, but under different eligibility and charging regimes. This has led to some duplication of functions, unnecessary bureaucracy, and has made efforts to integrate the funding streams around user needs more difficult.
21. The ongoing reform of the care and support system, including the planned historic overhaul of the social care statute provides an opportunity for the integration of ILF funding within the mainstream care and support system.⁶ The Government's preferred option for the future support of existing ILF users is that the ILF is closed in 2015, and that ILF funding is devolved to local government in England and to the devolved administrations in Scotland and Wales. This will allow existing users to have their eligible care and support needs met within the statutory system through personalised budgets and direct payments, ensuring ILF users are engaged with their local authority and so are accessing the full range of services available, in line with local priorities. However, it will be for the Government's in Scotland, Wales and Northern Ireland to determine their individual policy responses if the ILF is closed in 2015.
22. We know that the process for implementing the Government's proposed transfer to sole local authority support will take time, requiring the reassessment of users by their local authority and the ILF ahead of the closure of the ILF. This consultation seeks the views of users, their families and carers, local authorities, and all other interested individuals and organisations on our proposal and how we can best meet the future needs of ILF users in a way that minimises anxiety and disruption to their lives, and mitigates the impact on the adult social care system more widely. The consultation questions set out in the next section of this document provide a structured way of thinking about the challenges and submitting views through the various channels we have established.

⁵ Based on analysis of 5 per cent sample carried out in November 2010.

⁶ <http://caringforourfuture.dh.gov.uk>

Consultation questions

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23. If the ILF is closed in 2015, Local Authorities will continue to have a duty to assess the care and support needs of those disabled 16,309 Group 2 users who are already jointly funded by local authorities and the 1,737 Group 1 users who receive some local authority care and support; and will be required to assess the needs of those ILF users who do not currently have a relationship with their local authority.

Question 1

Do you agree with the Government's proposal that the care and support needs of current ILF users should be met within the mainstream care and support system, with funding devolved to local government in England and the devolved administrations in Scotland and Wales?⁷ This would mean the closure of the ILF in 2015.

Question 2

What are the key challenges that ILF users would face in moving from joint ILF/Local Authority to sole Local Authority funding of their care and support needs? How can any impacts be mitigated?

Question 3

What impact would the closure of the ILF have on Local Authorities and the provision of care and support services more widely? How could any impacts be mitigated?

⁷ Funding for ILF users in Northern Ireland is currently the responsibility of the Northern Ireland Department for Social Development, not the Department for Work and Pensions.

24. We know that the closure of the ILF would be more difficult for those Group 1 users who are not currently receiving any Local Authority funding, and who in some cases have little experience of the mainstream care and support system. It is important that those users engage with the local authority care and support services for which they are eligible.

Question 4

What are the specific challenges in relation to Group 1 users? How can the Government ensure this group are able to access the full range of Local Authority care and support services for which they are eligible?

25. The Government remains committed to funding current ILF care packages until 2015. But we know that it will take some time to manage the move to sole local authority funding. It would be necessary to start such a process well in advance of 2015. This consultation is only the start of a process of working with users, Local Authorities and the Governments of Scotland, Wales and Northern Ireland.

Question 5

How can DWP, the ILF and Local Authorities best continue to work with ILF users between now and 2015? How can the ILF best work with individual Local Authorities if the decision to close the ILF is taken?

Impact and Equality Impact Assessment

6

26. The purpose of this consultation is to set out our position on how the care and support needs of the current users of the ILF might be met from 2015, and to seek views on our preferred option, the closure of the ILF on the grounds that users should now be supported by the mainstream care and support system in from 2015.
27. We will publish our response to this consultation in Autumn 2012. Alongside that response, which will set out the detail of our decision, we will publish a full Impact and Equality Impact Assessment. It would be premature to attempt to conduct a full Impact and Equality impact assessment at this stage because the details of our proposal have not yet been developed. The overview below is our initial assessment of the potential impacts for the different equality groups, as far as we are able to tell at this stage.
28. During the consultation process we would welcome views on the impact of our preferred option on the people covered by equality legislation in order to help inform the equality impact assessment.

Equality Area	Impact
Disability	In general, ILF payments are not paid on the basis of a particular impairment or health condition, but according to support needs. Nonetheless we know that current users have a range of primary and secondary disabilities and we will be assessing how the closure of the ILF would impact particular groups of users on the basis of their impairments.
Age	Applicants to the ILF since 1993 had to be at least 16 years old to apply for ILF payments and, due to the Fund being closed to new applications from June 2010; the youngest recipients are 17 years old. People are able to continue to receive ILF payments after they reach 65 years old, so long as their application was made before they reach this age. This means that there are around 1,500 pensioners who are ILF recipients.
Race	Administrative data on the ethnic background of ILF recipients is held when a person chooses to disclose this information. As a result, while the information on the ethnicity of ILF recipients is reliable, there are a large number of people who have chosen not to disclose their ethnic background. However, the available data suggests that the ethnic background of ILF recipients broadly reflects the ethnic diversity in the UK. Therefore, there is no evidence to suggest that the policy would impact disproportionately on any ethnic minority group.
Gender	Overall, the number of men and women receiving discretionary payments from the ILF is almost equal. As the numbers of men and women in receipt of payments from the ILF is broadly similar there is no reason to suggest that either men or women are more likely to be affected by the proposed changes.
Sexual orientation	No data is collected on the sexual orientation of Independent Living Fund recipients. However, we believe that there are no grounds to suggest this policy is more likely to have an impact on ILF recipients based on their sexual orientation.

How to respond to this public consultation

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Duration of the public consultation

29. The consultation period begins on 12 July 2012 and runs until 10 October 2012.

Scotland, Wales and Northern Ireland

30. While social care is a devolved responsibility, there are ILF users in all parts of the UK. The Government is therefore seeking views from all ILF users. The relevant government departments in Scotland, Wales and Northern Ireland may additionally choose to engage specifically with existing users, local authorities or other interested organisations in each of those parts of the UK.

Consultation arrangements

31. The best way to respond to the consultation is through the online consultation tool as this will ensure that your contribution is received and recorded straight away. You can find the online tool on the DWP website at: www.dwp.gov.uk/future-of-ilf
32. Alternatively, you can email your response to the consultation to: ilf.consultation@dwp.gsi.gov.uk
33. You can also post responses to:

ILF Consultation Team
Ground floor
Caxton House
Tothill Street
London SW1A 9NA

34. If you would like to discuss alternative accessible ways of responding to the consultation or would like to receive this document in an alternative format you can contact DWP using the email address above, by telephone on 0207 449 7999 or by textphone on 18001 0207 449 7999.
35. When responding please say whether you are responding as an individual, or on behalf of an organisation.
 - If you are responding as an individual, please let us know whether you live in England, Scotland, Wales or Northern Ireland.
 - If responding on behalf of an organisation, please make clear who the organisation represents, whether your organisation is specific to England, Scotland, Wales, Northern Ireland or the United Kingdom as a whole and how the views of members were obtained.

The consultation criteria

36. The consultation is being conducted in line with the Government Code of Practice on Consultation and its seven criteria.
 - **When to consult.** Formal consultation should take place at a stage when there is scope to influence the outcome.
 - **Duration of consultation exercises.** Consultations should normally last for at least 12 weeks, with consideration given to longer timescales where feasible and sensible.
 - **Clarity of scope and impact.** Consultation documents should be clear about the consultation process, what is being proposed, the scope to influence, and the expected costs and benefits of the proposals.
 - **Accessibility of consultation exercises.** Consultation exercises should be designed to be accessible to, and clearly targeted at, those people the exercise is designed to reach.
 - **The burden of consultation.** Keeping the burden of consultation to a minimum is essential if consultations are to be effective and if consultees' buy-in to the process is to be obtained.
 - **Responsiveness of consultation exercises.** Consultation responses should be analysed carefully and clear feedback should be provided to participants following the consultation.
 - **Capacity to consult.** Officials running consultation exercises should seek guidance in how to run an effective consultation exercise, and share what they have learned from the experience.

Freedom of Information

37. Please make sure your response reaches us by 10 October.
38. We have given notification about this consultation to a large number of people and organisations who have already been involved in this work or who have expressed an interest in it. Please share this document with anyone you think will want to be involved in this consultation.
39. We will publish a summary of the responses to the consultation and the action that we will take as a result of them in Autumn 2012. A PDF of the responses publication will be available online on the consultations section of our website: <http://www.dwp.gov.uk/consultations>

Feedback on this consultation

40. We value your feedback on how well we consult. If you have any comments on the process of this consultation, for example, how it could be improved, but not about the issues raised, please contact our Consultation Coordinator:

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elias.koufou@dwp.gsi.gov.uk

41. In particular, please tell us if you feel that the consultation does not satisfy the Government Code of Practice on Consultation, or if you have any suggestions about how our consultation process could be improved further.



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