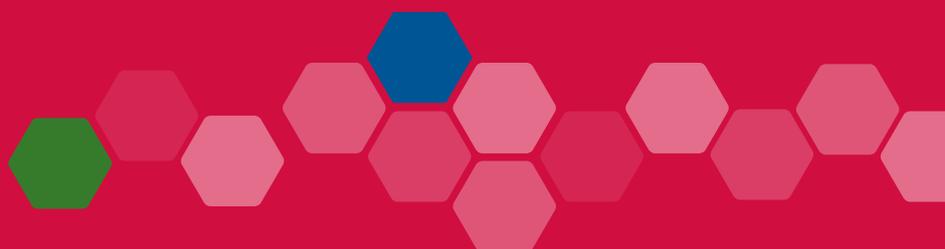


The Impact of Welfare Reform in Scotland - Tracking Study - Sweep 4 Report



EQUALITY, POVERTY AND SOCIAL SECURITY

THE IMPACT OF WELFARE REFORM IN SCOTLAND – TRACKING STUDY

Sweep 4 report to the Scottish Government

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Scottish Government Social Research
June 2016



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ACKNOWLEDGMENTS

The research team would like to thank all the participants who have given their time to make this study possible.

We would also like to thank staff at the Scottish Government and members of the Research Advisory Group (RAG) for their support and guidance:

Marion Davies, One Parent Families Scotland

Anthony Glendinning, University of Aberdeen

Ade Kearns, Glasgow University

Gerry McCartney, NHS Health Scotland

Andrew McGuire, Improvement Service

Fiona McHardy, Poverty Alliance

Bill Scott, Inclusion Scotland

Alison Stout, Scottish Government

Martin Taulbut, NHS Health Scotland

GLOSSARY

| Acronym | Term |
|---------|---|
| CB-ESA | Contribution-based Employment and Support Allowance |
| CTB | Council Tax Benefit |
| CTC | Child Tax Credit |
| CTR | Council Tax Reduction |
| DHP | Discretionary Housing Payment |
| DLA | Disability Living Allowance |
| DWP | Department for Work and Pensions |
| ESA | Employment and Support Allowance |
| HB | Housing Benefit |
| HMRC | Her Majesty's Revenue and Customs |
| IB | Incapacity Benefit |
| IR-ESA | Income-related Employment and Support Allowance |
| IS | Income Support |
| JSA | Jobseeker's Allowance |
| LHA | Local Housing Allowance |
| PIP | Personal Independence Payment |
| SDA | Severe Disablement Allowance |
| SMP | Statutory Maternity Pay |
| SWF | Scottish Welfare Fund |
| UC | Universal Credit |
| WRAG | Work Related Activity Group |
| WTC | Working Tax Credit |

EXECUTIVE SUMMARY

The aim of this study was to explore the impact of ongoing welfare changes on a range of working age households in Scotland. The study consisted of four interview sweeps over a three year period (2013-16), and was carried out by the Employment Research Institute at Edinburgh Napier University and the University of Stirling. This report presents the findings from the final sweep of the study, and reflects on the study findings as a whole.

The study used a longitudinal qualitative methodology to explore participants' perspectives on how welfare reform affected them, and to follow their experiences over time. The study drew on the real life experiences of those in receipt of working age benefits to provide rich, in-depth insights into the impact of welfare reform. Forty-three individuals took part in Sweep 1 of the study, thirty-five in Sweep 2, twenty-eight in Sweep 3, and twenty-four in Sweep 4. The sample design sought to represent the experiences of working age benefit recipients across a range of locations and socio-demographic characteristics, including lone parent and low income families, disabled claimants, and those in rural areas.

Interviews in Sweep 4 sought to establish any changes in participants' circumstances since the previous sweep. Participants were also asked to reflect on how their situation had changed since the first interview around three years earlier, and on how they felt benefits issues could be handled differently in the future.

The policy implications of the findings from Sweep 4 and across the study are grouped together under two main headings: mitigating actions that the Scottish Government could take to reduce the impact of welfare reforms that sit outside its jurisdiction; and issues to consider in the design and implementation of new devolved benefits. It should be noted that these recommendations are not definitive suggestions, but they reflect the experiences of the participants in this study.

Improving the implementation of existing policies

Information, advice and support

The findings of this study show that those affected by welfare reform are not always aware of how changes to benefits will affect them, and that there are a range of situations in which people might seek advice. It also shows that there is no ideal or 'one stop shop' solution; support and advice need to come from a range of services.

Policy implications: Efforts should be made to raise awareness, via a range of media, of entitlements to different benefits. There should also be a centralised opportunity to check all entitlements.

It might be helpful if those potentially affected by changes were able to find out how proposed changes might affect them personally, and also to know about what support is available to them if they were to be negatively affected.

Key third party information and advice agencies play an important role across a range of benefits issues and should continue to be supported by the Scottish Government.

Frontline health and social care services could play a role in supporting benefit recipients to access support. Referral mechanisms between such frontline services, and advice services, should be developed.

Families with children

Childcare costs posed an issue for some participants, due to them no longer receiving a contribution if both partners were not working over 16 hours per week, or having to pay the 30% contribution towards childcare, which may represent a substantial proportion of the household's weekly income. Throughout the study, the need to increase the amount of childcare that parents can access cheaply or free of charge has been stressed. This could make a considerable difference to how low income families cope with intensified work requirements, and cuts to their financial support, as a result of welfare reform.

Policy implications: Plans to extend free childcare provision are welcome, although a particular gap still needs to be addressed; that is to improve provision outside standard hours, including pre- and after- school and holiday care.

An issue was identified around the loss of entitlement to certain forms of assistance (e.g. Warm Homes Discount, free school meals) after a small increase in income, with the net result of a loss for families already struggling to get by on a low income. Some families may actually be worse off in work for this reason.

Policy implications: Family circumstances should be reviewed holistically before entitlements are removed. The criteria for receiving these should be reviewed, particularly in relation to whether they have a perverse impact on work incentives.

It could be beneficial to low income families for policy makers to consider more broadly the costs incurred by families with children – such as school uniform, and other costs associated with attending school – and ways to offset these, in order to leave more room in the family budget.

Carers

Participants caring for disabled children and adults have themselves remained relatively unaffected by welfare reform, but they have played a key role in managing the benefit changes of those they care for.

Policy implications: The devolution of Carers Allowance to the Scottish Government provides an opportunity to ease the financial strain on carers, by considering increasing the level at which it is paid.

The Scottish Government should consider the needs of those caring for more than one person, perhaps offering help with their transport costs.

Stigma

The considerable dislike and distrust that participants have developed of the benefits system is in part a result of the UK Government and media rhetoric around the delivery of welfare reform. The language used has made them feel stigmatised, and fearful that they will lose their entitlements, and this has contributed to the stress they have experienced as a result of welfare reform. Participants have also reported feeling stigmatised by some of the officials they deal with in the process of claiming benefits.

Policy implications: Language and tone matters. 'Talking tough' on welfare reform instils fear and distrust. The Scottish Government should seek to use terms and statements that help foster good relations between the system and claimants, and do not stigmatise those receiving benefits.

Stigmatising messages from the media need to be countered by public education campaigns about those on benefits and of the true (limited) nature of benefit fraud.

It is important that those in client facing roles in the benefits system deliver services in a non-prejudiced way.

Employment support

The findings of this study suggest that, according to the views of participants, stronger conditionality is unlikely to get more people into work. However, there are a number of interventions that can help, by addressing barriers to work, in the areas of education, skills, employability services, childcare, and health.

There is a gap between being deemed 'fit-to-work', or undertake work related activity, and the opportunities available in the labour market. Participants with less severe or fluctuating conditions have often found themselves trapped or moving between different states; into and out of work, and/or between ESA and JSA.

Policy implications: This gap could be partly bridged with better, more targeted training and employability support for those with mental and/or physical health conditions and disabilities.

Issues in benefits system design

Reducing unnecessary pressure and stress

Many participants experienced a range of life stressors that constrained their ability to tackle the process of applying for benefits, and had few resources to fall back on, which meant that even temporary delay or loss of benefit could have a substantial negative impact. The length and repetitiveness of forms, and the amount of information required, was also cited as being burdensome. The devolution of the

Personal Independence Payment (PIP) provides an opportunity for the Scottish Government to implement an application process that imposes less of a strain on claimants.

Policy implications: The application and appeals process should be founded on the initial assumption that the applicant is genuinely in need, and take into account the potential complexity of their situation.

When determining what information should be sought during the application, the benefit of additional information should be set against the increased strain on the applicant, and in the context of the overall burden of the form.

Life or long-term awards could be considered for those whose conditions are permanent, and some may not need to go through an assessment at all if their needs are clear cut. Repeat assessments could be limited only to those whose condition is expected to improve.

Building in feedback from clients

Participants did not find the process of claiming benefits very user friendly. They appreciated being listened to about their needs, and wanted to be involved in the design process of any future changes to the system.

Policy implications: Reflexivity and responsiveness to feedback from claimants regarding the appropriateness of the application process and assessment criteria should be built into the welfare benefit system.

The Scottish Government could consider opportunities for some form of co-production in the development and implementation of a devolved PIP.

Application forms should be reviewed by a panel of applicants, in order to test the accessibility of the language, the clarity of the requirements, and the appropriateness of the questions. Policymakers should demonstrate clearly how they have responded to feedback.

User experience should be embedded in the targets that providers are expected to meet. The system should be evaluated (among other things) on whether claimants feel they are being treated fairly, and with dignity. Claimants should have the opportunity to provide feedback on their experiences, either online, by phone, or in person.

Improving client assessment

Participants who considered themselves to have fluctuating conditions or 'hidden' disabilities felt that the assessment process for disability benefits did not adequately capture the impact of these on their lives. They found it difficult to quantify or predict the effect of a fluctuating condition in the straightforward way required by the polar questions in the assessment.

Policy implications: The suitability of polar questions in particular needs to be reviewed. The impact of the disruption and uncertainty created by a fluctuating condition could itself be taken into account as a limiting factor.

Improving the way in which benefits are administered

Participants often found official communication about benefits and benefit changes – not only by DWP, but also by Local Authorities – to be confusing and poorly or negatively worded.

Policy implications: Those who will be affected by changes need to receive clearer information about what will happen, and when. Communication of decisions should be clear and unambiguous.

A number of participants had been caused problems not (or not solely) by the welfare changes themselves, but due to errors and delays on the part of the agencies responsible for their claims.

Policy implications: How the relevant agencies respond to mistakes is important; they should be efficient, and should give claimants a reasonable benefit of the doubt. In the event of a loss or delay of a benefit, it is important that claimants have recourse to a well-funded crisis support service that can respond quickly to financial emergencies.

INTRODUCTION

- The aim of the study was to explore the impact of ongoing welfare changes on a range of working age households in Scotland over a three year period (2013-2016), with four interviews held during this time. This report covers the fourth and final sweep of interviews.
- Chapter 1 outlines the objectives of the study and sets out the policy and economic context in which sweep 4 of data collection took place.
- Changes in policy since the previous report published in May 2015 are briefly outlined.

Background and research objectives

The study was carried out for the Scottish Government by the Employment Research Institute at Edinburgh Napier University and the University of Stirling. This is the fourth and final report from the project, following on from the three previous reports (Graham et al., 2015; Graham et al., 2014; Lister et al., 2014).

The aim of the study was to explore the impact of ongoing welfare changes on a range of working age households in Scotland over a three year period (2013-16). It was intended to increase understanding of the impact of the welfare changes in Scotland as they occurred over time, and assist the Scottish Government in making decisions related to those areas within its devolved responsibility.

The research objectives of the study were:

- **To obtain baseline information about a sample of 30 Scottish working age households with direct experience of welfare changes:** The baseline stage of the study involved the selection and recruitment of an appropriate sample of households, and the collection of information from them. The sample selected was of households with common direct experience of welfare changes, but also reflecting some of their diversity with respect to characteristics such as family type, family circumstances, the types of benefit received, and geographic location.
- **To obtain follow up evidence on the sample of households about relevant changes to their lives since the first interview:** This ongoing aspect of the study involved re-interviewing original participants about their household situation, with particular interest in any changes that had occurred and the impacts of these.
- To analyse the differences between time points, and potential reasons for these differences, and the implications of the findings for understanding the impact of welfare reform and appropriate responses from the Scottish Government. The study has contemporaneously informed the Scottish Government about significant or emerging problems encountered by households, to assist the Scottish Government in framing their response to these.

This report covers the fourth and final sweep of interviews, and provides an overview of the research findings from the study as a whole.

Policy and economic context

The Welfare Reform Act 2012 introduced major reforms to the UK welfare system. The aim of the Act was to improve work incentives and simplify the benefits system. The main elements of the Act that were of particular interest in this research were (Department for Work and Pensions, 2012a; Graham et al., 2015; Lister et al., 2014; Scottish Government, 2014 UK Government, 2012):

- **Abolishment of certain discretionary elements of the Social Fund at the UK level**

The elements which were abolished included Crisis Loans for Living Expenses and Community Care Grants. These elements were replaced in Scotland by the Scottish Welfare Fund (SWF). The Welfare Funds (Scotland) Act 2015, which places the SWF into law, was passed and received Royal Assent in spring 2015. Permanent regulations and statutory guidance will be in place from April 2016.¹

- **The introduction of a cap on the total amount of benefit that working-age people can receive**

Households on out of work benefits no longer receive more in welfare payments than the average weekly wage for working households (Department for Work and Pensions, 2012a). The cap applies to the combined income from benefits, although some benefits are exempt from the cap, e.g. certain disability benefits.

- **Introduction of the Personal Independence Payment (PIP) to replace Disability Living Allowance (DLA)**

The key differences with the new benefit are: the absence of an equivalent to the lowest care component of DLA; a stricter mobility test; and the introduction of a face-to-face medical assessment in some cases.

- **Changes to the entitlement for the contributory element of Employment and Support Allowance (ESA)**

Under this change people can now only receive contributory ESA for up to one year if they are in the Work Related Activity Group (WRAG)² or assessment phase. Provisions allowing young people to qualify for contributory ESA without meeting the standard National Insurance conditions have also been abolished.

- **Abolishing Council Tax Benefit (CTB) at UK level**

The nationally devised CTB has been replaced by locally administered Council Tax Reduction (CTR) schemes, and subject to a 10 per cent cut in UK Government funding.³ The scheme provides help for people on low incomes or

¹ www.gov.scot/Topics/People/welfarereform/scottishwelfarefund (Accessed 02 February 2016)

² Following a Work Capability Assessment, ESA claimants are placed in one of two groups: those in the WRAG are required to attend interviews with a Jobcentre Plus advisor to discuss job seeking activities and may be required to participate in the Work Programme; while those whose disability severely limits what they can do are placed in the Support Group, and are not required to attend interviews.

³ www.gov.scot/Topics/Government/local-government/17999/counciltax/CTR (Accessed 29 January 2016)

claiming benefits towards their Council Tax bill. In Scotland the Scottish Government fully mitigates the 10 per cent funding cut from the UK Government.

- **The introduction of the ‘bedroom tax’**

Through this element of the Act there has been a percentage reduction in Housing Benefit (HB) for working age households judged to be under-occupying their property in the social rented sector. This is fully mitigated in Scotland through Discretionary Housing Payments (DHP) to affected tenants.

- **Changes to Local Housing Allowance (LHA)**

Changes to LHA have included new caps in the amount of HB that can be paid, and younger single claimants without dependents can only claim HB for private sector accommodation based on the cost of living in shared accommodation.

- **Changes to the uprating of working age benefits and tax credits**

Child Benefit and certain tax credit elements were initially frozen, and thereafter the uprating of working age benefits and tax credits was restricted to 1 per cent for three years.

- **Changes to procedures in the event of a disputed benefit decision by the DWP**

In the event of a disputed decision, the claimant must request a ‘mandatory reconsideration’ before submitting an appeal. Those wishing to appeal after a mandatory reconsideration must submit their appeal directly to the tribunals service.

- **A new sanctions regime for those on Jobseeker’s Allowance (JSA) and ESA**

The new regime: introduced escalating fixed term penalties for repeated failures; extended the maximum duration of a sanction for JSA clients from 26 weeks to 156 weeks; and increased the benefit withdrawn from ESA claimants in the first four weeks of a sanction from 50 to 100 per cent.⁴

- **New conditionality for lone parents**

Lone parents whose youngest child has reached the age of five are no longer entitled to Income Support (IS) solely as a lone parent, but could be entitled to JSA, which would require them to look for work. Lone parents receiving IS who have a youngest child aged three or four may be required to undertake mandatory work-related activity.

- **The introduction of a new Claimant Commitment related to jobseeker activities**

From October 2013 new claimants of JSA, ESA and Universal Credit have had to sign a ‘Claimant Commitment’ that sets out the job readiness and job searching activities which they will undertake as condition of receiving their benefits. Claimants may be sanctioned if they are considered to not have fulfilled their commitment.

- **The introduction of Universal Credit (UC)**

A number of key means tested benefits such as IS, Income Based Jobseekers

⁴ www.gov.uk/government/uploads/system/uploads/attachment_data/file/238839/jsa-overview-of-revised-sanctions-regime.pdf

Allowance (IB-JSA), ESA, HB and Tax Credits have been combined into one single entitlement called Universal Credit. Problems with the development of the IT system have meant that the roll out of UC has been delayed. It has been projected that the majority of claimants will be transferred by December 2019, although this will not include those claiming ESA or tax credits only (National Audit Office, 2014).

The timetable by which the above changes have been implemented is shown in Figure A1.1 in Appendix 1, which also presents data on the number of claimants affected by the changes in Scotland.

The roll out and direction of current reforms to the welfare system are likely to change in future as more powers are devolved to the Scottish Parliament. Following the 'No Vote' in the September 2014 Scottish Independence referendum Prime Minister David Cameron announced that Lord Smith of Kelvin would oversee a process to take forward devolution commitments on further powers for the Scottish Parliament. The Smith Commission published its report in November 2014. The report detailed Heads of Agreement on further devolution of powers to the Scottish Parliament (Smith Commission, 2014).

The Commission outlined the following in relation to working age welfare benefits (Smith Commission 2014; Sandford 2015):

- UC would remain a reserved benefit administered and delivered by the Department for Work and Pensions (DWP), although the Scottish Government will have the administrative power to change the frequency of UC payments, vary plans for single household payments, pay landlords directly for housing costs, and vary the housing cost elements of UC.
- Powers would be devolved to the Scottish Parliament for: Attendance Allowance, Carer's Allowance, DLA, PIP, Industrial Injuries Disablement Allowance and Severe Disablement Allowance, Cold Weather Payment, Funeral Payment, Sure Start Maternity Grant, Winter Fuel Payment, DHPs.
- Responsibility for the following benefits would remain reserved: Bereavement Allowance, Bereavement Payment, Child Benefit, Guardian's Allowance, Maternity Allowance, Statutory Maternity Pay, Statutory Sick Pay and Widowed Parent's Allowance.
- The Scottish Parliament will have powers to create new benefits in devolved policy areas; and make discretionary payments in any area of welfare without prior permission from DWP.
- The Scottish Parliament would have (on expiry of the current commercial arrangements) all powers over support for unemployed people through currently DWP contracted employment programmes e.g. the Work Programme and Work Choice.

The Scotland Bill 2015-2016 has been proposed to put into effect the recommendations made by the Smith Commission. As of February 2016 the Bill was undergoing the Committee stage and Report stage in the House of Lords.

Structure of the report

The remainder of this report:

- outlines the study's methodology and presents key statistics on the sample size and characteristics
- presents changes since the previous sweep
- looks at participants' trajectories over the course of the study
- and finally, summarises the key findings, from this sweep and the study as a whole, and their implications for policy.

Appendices to the report are contained in a separate document. Appendix 1 provides further information about welfare reform and the number of claimants affected in Scotland. Appendix 2 provides an overview of eligibility for and rates of key working age benefits. Appendix 3 contains the interview schedule used in sweep 4⁵, and Appendix 4 summarises all the policy implications across all the reports from this study.

⁵ Interview schedules for previous sweeps can be found in Lister et al. (2014), Graham et al. (2014) and Graham et al. (2015).

METHODOLOGY AND DATA

- Chapter 2 outlines the study's methodology and presents the size and key characteristics of the sample.
- The study utilised a qualitative longitudinal approach in order to best track participants' experiences over time, as the welfare changes were introduced.
- In-depth, semi-structured interviews were carried out with 24 participants in sweep 4.
- All participants interviewed were currently in receipt of working age welfare benefits, and were selected using a purposive sampling strategy which was designed to reach those in receipt of benefits from across Scotland, and cover a diverse set of household circumstances.

Methodology

The study takes a qualitative longitudinal approach, covering approximately two and a half years (September 2013-January 2016).⁶ This report covers the fourth and final sweep of interviews.⁷

In-depth, semi-structured interviews were carried out with participants in all four sweeps. Interviews in sweep 1 were used to gather baseline information. In sweeps 2 and 3, the questions centred on the changes since the last interview. Together with the background information collected in sweep 1, questions were tailored to participants' circumstances, focussing on areas most relevant to them. In sweep 3 an additional module of questions on the support networks of participants was also included. The focus of these questions was on how services, organisations and individuals support people, and to identify lessons for how services can better meet the requirements of those who need support. In sweep 4, as well as asking questions about the changes since the last interview, participants were asked to reflect on the past and think about the future. For example, participants were asked to think back to the time they were first interviewed (in most cases around two years previously) and reflect on whether they felt that since then their overall situation had improved, got worse, or stayed about the same.

In conducting the interviews, the research team used a topic guide to give a clear idea of the issues to cover. The interview schedule used in sweep 4 is shown in Appendix 3. Most questions focused on open responses, providing the opportunity for participants to give rich, personal and in-depth accounts of their experiences and to raise other issues. For sweeps 1 to 3, all interviews were conducted face to face (bar one interview in sweep 3). This allowed the researchers to build a rapport with participants (this was especially important in helping to minimise sample

⁶ The rationale for using a qualitative longitudinal approach has been outlined in previous reports.

⁷ Sweep 1 took place September 2013 – February 2014; Sweep 2 took place April – June 2014; Sweep 3 took place November 2014 – Feb 2015.

attrition between sweeps). In sweep 4, having established a rapport with participants, all but two of the interviews were conducted over the telephone. Both face-to-face and telephone interviews lasted between 45 and 90 minutes.

Participants were given an information sheet before participating in the study in sweep 1. Interviewers reiterated this information prior to subsequent interviews and answered any questions that the participant had. Consent was obtained (either written or orally) before proceeding with all interviews in each sweep. Interviews were audio recorded where permission was given, and partially transcribed (i.e. relevant content from interviews, such as the households' accounts of their experiences, but not incidental conversation or 'warm up' questions).

No payment for time provided by participants was given. However, participants were given a voucher (sent by post in the case of telephone interviews) to compensate for out of pocket expenses, at a rate of £10 per household per meeting.

This study received research ethics approval from Edinburgh Napier Business School's Research Integrity Committee.

Sample characteristics

Twenty-four participants were interviewed at sweep 4 of the study. Interviews took place between November 2015 and February 2016.

Table 2.1: Sample attrition

| Sweep | Sample | Reasons for non-participation |
|----------------------------------|--------|--|
| Sweep 1 (Sep 2013 – Feb 2014) | 43 | N/A |
| Sweep 2 (Apr – June 2014) | 35 | 41 to contact (2 did not meet inclusion criteria) 2 not available this sweep 4 could not be contacted |
| Sweep 3 (Nov 2014 – Feb 2015) | 28 | 37 to contact (previous sample + 2 unavailable at previous sweep) 4 not available this sweep 5 could not be contacted |
| Sweep 4 (Nov 2015 – Feb 2016) | 24 | 32 to contact (previous sample + 4 unavailable at previous sweep) 2 did not wish to participate 1 not available this sweep 5 could not be contacted |

Forty-three participants were interviewed at sweep 1. Participants were initially selected at sweep 1 using a purposive sampling strategy. The main criterion for inclusion in the sample was that the participant was of working age, and in receipt of at least one of the benefits subject to reform. Consideration was also given to obtaining representation across a variety of characteristics such as type of benefit, age, gender, disability, household composition and urban-rural dwelling. The sample is neither large nor 'representative' enough to draw firm generalisations across all people in Scotland. However, the study provides valuable insights into the experiences of those in receipt of benefits and highlights some of the issues

faced by specific groups which could be followed up in more depth in other research.

Table 2.2: Overview of sample characteristics

| Household characteristic | Requirements for diverse sample | Sweep 1 | Sweep 2 | Sweep 3 | Sweep 4 | Change between sweeps 1 and 4 |
|---------------------------|---|---------|---------|---------|---------|-------------------------------|
| Children | with dependent children under the age of five years | 5 | 2 | 1 | 1 | -4 |
| | with dependent children over the age of five years | 16 | 13 | 8 | 5 | -11 |
| | with two or fewer dependent children | 16 | 11 | 7 | 5 | -11 |
| | with more than two dependent children | 3 | 3 | 1 | 0 | -3 |
| | without dependent children | 24 | 21 | 20 | 19 | -5 |
| | lone parent households | 10 | 7 | 3 | 3 | -7 |
| | where both parents/carers present | 9 | 7 | 5 | 2 | -7 |
| Employment | where members are employed full-time | 2 | 3 | 3 | 3 | 1 |
| | where members are employed part-time | 2 | 4 | 3 | 2 | 0 |
| | where some members are employed and others unemployed | 6 | 6 | 5 | 4 | -2 |
| | where all adults are unemployed | 33 | 22 | 17 | 15 | -18 |
| Protected characteristics | households with disabled adults | 27 | 24 | 20 | 17 | -10 |
| | households with disabled children | 3 | 2 | 2 | 0 | -3 |
| | household with both men and women | 19 | 16 | 14 | 10 | -9 |
| | households with working age adults of different ages | 19 | 16 | 14 | 10 | -9 |
| | households with ethnic minority adults | 1 | 1 | 1 | 1 | 0 |
| Location | rural areas | 6 | 6 | 4 | 3 | -3 |
| | urban areas (but not cities) | 18 | 15 | 12 | 11 | -7 |
| | cities | 19 | 14 | 12 | 10 | -9 |
| Gender | Male | 17 | 15 | 15 | 12 | -5 |
| | Female | 26 | 20 | 13 | 12 | -14 |
| Total sample | | 43 | 35 | 28 | 24 | -19 |

Note: Overlapping categories mean that totals within categories may not sum to total sample. Reported change between sweeps reflects changes in circumstances as well as drop out (e.g. moving into work, children turning five, etc.).

Over the course of the study there has been some 'drop out', as can be expected, due to health reasons, changing address, non-response to interview requests, etc.

Participants either could not be contacted, or a suitable time to interview them could not be arranged during the relevant fieldwork period. Table 2.2 shows the characteristics of the sample over the four sweeps, and highlights that the attrition was concentrated amongst certain households.

Figure 2.1: Longitudinal participation

| Participant | Sweep | | | | Participant | Sweep | | | |
|-------------|-------|---|---|---|-------------|-------|---|---|---|
| | 1 | 2 | 3 | 4 | | 1 | 2 | 3 | 4 |
| 1 | | | | | 23 | | | | |
| 2 | | | | | 24 | | | | |
| 3 | | | | | 25 | | | | |
| 4 | | | | | 26 | | | | |
| 5 | | | | | 27 | | | | |
| 6 | | | | | 28 | | | | |
| 7 | | | | | 29 | | | | |
| 8 | | | | | 30 | | | | |
| 9 | | | | | 31 | | | | |
| 10 | | | | | 32 | | | | |
| 11 | | | | | 33 | | | | |
| 12 | | | | | 34 | | | | |
| 13 | | | | | 35 | | | | |
| 14 | | | | | 36 | | | | |
| 15 | | | | | 37 | | | | |
| 16 | | | | | 38 | | | | |
| 17 | | | | | 39 | | | | |
| 18 | | | | | 40 | | | | |
| 19 | | | | | 41 | | | | |
| 20 | | | | | 42 | | | | |
| 21 | | | | | 43 | | | | |
| 22 | | | | | | | | | |

Grey shaded cells indicate participation.

Although the total sample size has fallen over the course of the study, this has not simply been the case of participants permanently dropping out between sweeps; some participants have moved in and out of the study (Figure 2.1). The result of this is that there is some degree of longitudinal information on 37 participants.

CHANGES IN THE PARTICIPANTS' SITUATIONS SINCE THE PREVIOUS SWEEP AND THE IMPACT OF THESE CHANGES

- Chapter 3 presents the changes in participants' situations since the previous sweep, and the impact of these, as well as expectations about future changes.
- There were few changes to benefits, or other income sources, since the previous sweep.
- Four participants had been assessed for PIP since the previous sweep; of these, one decision was pending, one had been awarded it, but at a lower rate than DLA, and the other two had been turned down due to a failure to provide enough supporting evidence (both were in the process of appealing). Another participant had undergone an appeal against a previously rejected PIP application, which had also been unsuccessful. Participants' views of these experiences are discussed below.
- There were few changes in employment status since the previous sweep. One participant had moved into work, one had received a promotion, one had been made permanent, and one had received a small pay rise. However, in two of these cases, the increase in income was offset by a loss of benefit entitlements that meant the net income effect was negative.
- The postponement of ESA reassessments, and of the rolling out of PIP to existing DLA claimants, meant that many participants had not had any changes to their benefits, although these were now imminent. Few felt confident that this process would run smoothly.
- Those affected by PIP reform questioned the need to assess those with unambiguous limitations, and to reassess those with permanent conditions. Listening to disabled people and involving them in the design process was considered key to implementing a system that met their needs.
- Some participants faced the prospect of changes to tax credits or the move to UC, although they were not clear how this would affect their individual situations.

This chapter presents the changes in participants' situations and experiences since the previous sweep, and the impact of these changes, as well as expectations about future changes.

Income changes and managing financially

Changes to benefits

Just under half of the sample had experienced a change to the benefits they received that had affected their income since their previous interview for the study, approximately a year before (Table 3.1). Thirteen participants had seen no change. Some of these had expected to have been reassessed for ESA in the period between the sweep 3 and 4 interviews, but these had not occurred because reassessments had been suspended during this time. One participant had experienced a change in the benefits they received due to temporarily moving into work between the interviews, but was receiving the same benefits at sweep 4 as they had at Sweep 3.

Table 3.1: Changes to benefits in the sweep 4 sample in the last year

| Type of change | N |
|--------------------------------|----|
| No change | 13 |
| Interim change | 1 |
| Change – receive more | 2 |
| Change – receive less | 6 |
| Change – unclear income effect | 2 |

Two participants reported receiving slightly more; one now qualified for a Winter Fuel Payment due to their age, and the other had moved from the ESA WRAG to the Support Group.

Two participants reported relatively recent transitions, of which they were not yet sure of the impact, although neither expected that they would be worse off in the longer term. One had moved from JSA to UC, and the other had moved from out of work to in-work benefits. In both cases, the non-financial impact of this change was considered to be positive. The move to in-work benefits was precipitated by the participant's partner moving into work, which they considered a positive transition. The participant moving onto UC was the first in this study sample to do so, and they reported that so far they had found the benefit somewhat more flexible and user friendly.

“It actually encourages intermittent earnings, whereas [with JSA] there’s a cap... In terms of in-house, the coaches are actually focusing on the job side of things. They don’t have disability advisors any more... but if you do have an illness or something, the coaches are all trained to deal with that, and they have someone to go to for training or advice. And so far they’ve been really, really helpful with me, and they’ve spent a lot of time explaining things... I’ve seen a side to the Jobcentre I’ve never seen, a helpful side, because previously they were busy chasing money and dealing with that side of things.”

Six participants experienced some loss of benefits. In two cases, an increase in income from employment had resulted in a loss of entitlement to the Warm Home Discount, and to free school meals and the school uniform grant. These losses were not offset by the additional income, and the net impact was a financial loss, despite receiving a higher income from employment.

One participant had lost entitlement to the childcare element of the Working Tax Credit (WTC), because their partner, although still in work, was no longer working at least 16 hours per week. Childcare was still required on the days that they both worked, but they were no longer receiving any help with this.

Losses had also been incurred in the transition from DLA to PIP. One participant had moved from DLA to PIP but was now receiving less money because they had gone from the middle rate of DLA to the lower rate of PIP. They were currently in the process of appealing this decision, on the basis that their Mandatory Reconsideration had taken place without reference to the medical evidence they had provided. They felt that the scale of the loss was on a par with proposed cuts to tax credits for low income families, but that it was not viewed as sympathetically.

“I’m in the process of trying to appeal... I’m sitting at 11 points and you need 12 points for the higher level [of Daily Living], and at the moment they’re saying I’m not entitled to any Mobility component... It’s frustrating because everyone’s up in arms at the moment because tax credits are changing and they’re going to lose £1,000 a year, and all the disabled people who have lost at least £1,000 a year moving to PIP, we’ve just to accept that because we’re ‘scroungers’, or that’s how we’re perceived.”

Similarly, another participant had lost money through moving from the higher rate of both DLA components to the standard rate of both PIP components. They had narrowly missed out on being awarded the enhanced rate for Daily Living, and felt that the result of the assessment did not reflect the discussion that had taken place during it. They were left wondering whether they should have said more or gone

into greater detail. The assessment process also occurred while the participant was waiting for a tribunal to appeal an ESA overpayment – a situation that has been ongoing for some time – and having both to deal with at once was creating a great deal of stress, to the extent that they felt their mental health was being affected.

“[The PIP assessor] didn’t come across as trying to catch me out, you usually get the feeling they’re trying to do that, she seemed nice and she seemed to get it, and when I was talking she was nodding and smiling. So maybe I didn’t say enough... So pretty much feeling it from all angles, with ESA as well, quite a lot of uncertainty at the moment. I’m trying not to let it affect me too much but it’s difficult... It’s not so much [the income aspect], well it is that obviously, but... it’s having things hanging over me. I can deal with a decision; I just want to know... The waiting around bit makes me think about it too much, and I feel a change in my mood.”

Another participant who had been on DLA had failed to be awarded PIP altogether. This participant was one of three in the sample who had applied unsuccessfully for PIP. In their case, and in the case of one other participant, the problem had been a lack of medical evidence, and both were currently appealing the decision. The other participant had already had their appeal, which had been unsuccessful, and the process of applying and appealing had taken a considerable toll on their mental health.

“It was a horrible process, it actually in terms of my progress it pushed me back, and I spent a lot of towards the end of last year really struggling with depression and anxiety, because of a lot of the things this process has brought up... Being made to relive [traumatic events] is horrific... It’s a horrible, horrible assessment... It’s harrowing.”

Changes in employment status and income

There was little change in employment status, or income from employment, in the sample (Table 3.2). Fifteen participants were out of work, and had been continuously so since their last interview. None of these participants were actively seeking work, although they varied in the extent to which they expected to return to work at some point in the future, with some hoping that this would happen, and others not expecting to ever work in the future.

One participant, who was receiving ESA, had started working three hours per week, which was considered permitted work for the purposes of their benefit entitlement. They had found that this was consuming most of their energy, and had had to cut back on other voluntary work and their distance learning course as a result. However, they felt positive about the transition:

“I really enjoy it. It’s not really that different from some of the volunteer stuff I’ve done in the past, but it’s really nice having that paid element, in terms of feeling a bit more valued, feeling like I’ve got a job.”

Table 3.2: Employment transitions since previous interview

| Status | N |
|--------------------------------------|----|
| Continuously employed between sweeps | 6 |
| JSA to employment | 1 |
| ESA with permitted employment | 1 |
| Interim employment | 2 |
| Out of work at both time points | 15 |

Six participants had been in employment at the previous sweep, and had been continuously employed since then. Of these, one had received a promotion, one had been made permanent, and one had received a small pay rise.

One participant had been on JSA at sweep 3, but had moved into work by sweep 4. Although they felt that this had been the right decision overall, there were a number of downsides; they did not feel any better off financially, and had much less time to spend with their children. They questioned whether it had been worth it, as their quality of life had deteriorated. Although they hoped to progress in their job, they expected any salary increase to be offset by reductions in their tax credits, and did not expect to ever be in a position where they were not struggling financially to some extent.

“You start examining the quality of your own life, and is it worth it? ... I find myself struggling, and I shouldn’t be struggling... I don’t think I’ll ever get out of the rut that I’m in [because any extra money will be subtracted from benefits], so I’m always going to be in this rut, I’m never going to have money to take the children away on holiday or anything like that.”

The majority of the sample had seen no change in how they were managing financially; 14 said there was no change. Six said they felt better off, although none felt substantially better off; they reported small changes that had made a slight difference to their household budget, such as paying off a debt. One person said they felt worse off, and two were in the midst of a transition and found it difficult to say.

Expected changes

Most participants expected some change to their benefits in the next year (Table 3.3). Only two said they did not expect any change, although both still held a general perception that benefits are always likely to change. Four participants were expecting some changes to their benefits, but due to likely changes in their circumstances rather than changes to the benefits themselves. Two were expecting a change, pending an appeal against a change that had reduced the amount they received.

Table 3.3: Expectation of changes to benefits in the next year

| Expectation | N |
|---------------------------------------|----|
| No specific change | 2 |
| Expecting change due to circumstances | 4 |
| Pending appeals | 2 |
| Transition to PIP | 13 |
| Changes to tax credits | 3 |

Three participants expected that their tax credits would be reduced, either due to proposed cuts to tax credits, or as a result of the move to UC. This was a source of concern, although there was considerable uncertainty about exactly how it would affect them:

“I know there’s an ongoing issue with the tax credits. I should be fine in the meantime, but that will be a factor whenever they do decide they’re going to reduce that, that’s a big worrying factor. If that does come into force I will struggle.”

“I’m unsure how this Universal Credit is going to work, or if I’m going to be affected by it. I don’t really understand it if I’m honest. So I’ll just wait. I’ve not heard anything as yet, but I don’t think as a single parent in my circumstances, from what I’ve heard, I don’t think it’s going to change dramatically for me. I’m hoping not! I mean if I receive less I will be absolutely snookered.”

Fourteen participants were receiving DLA and expecting to be assessed for PIP. Of these, one was expecting to lose their entitlement, three were relatively confident that they would continue to receive at least as much as they did at present, and the remainder were unsure or not confident.

The participant who expected a loss felt that they would no longer qualify under the more stringent criteria for PIP. None were certain that they would be successful, but those who said they were quite confident all felt that they had quite a good understanding of how the criteria applied to them specifically, and believed that they met the criteria in a fairly unambiguous way, and could provide the relevant evidence for this.

Those who were less confident, but still hopeful, were relatively sure they would meet the criteria, but because they knew of others who had lost their entitlement, and due to distrust of the system generally, this meant their confidence was low:

“I think that I’m a fair candidate, or I should be a fair candidate for getting PIP, but the fact that blind people have lost their contribution, and people with [the same condition as me] as well, I’m just going to be like the rest of the people that get reviewed, and we know it’s not equitably assessed, so I can’t say at this point in time what the outcome will be.”

“Having seen some of my friends, who are wheelchair bound and need help to get up in the morning, get their benefits stopped completely, I see them taking one look at me and the fact I can dress myself and actually walk, although not a great distance, I’d need an arm to go any distance, I can see them taking mine away instantly, I can, honestly.”

Concerns centred around two main issues. The first was the assessment questions, which were perceived not to capture the full extent of the way that conditions can impact day to day life. Many of those with an illness or disability felt that their condition fluctuated a great deal and that it was difficult to say whether they could do something or not, as their abilities varied day to day. This was true both of those with mental health issues and those with physical conditions.

“I think it’ll be quite hard. I think the points system they use... doesn’t take a holistic view of people’s needs or the expenses they have in their life due to their disability... It’s hard to say [what my outcome will be]; it depends who you get to see. Also my situation, my condition changes a lot.”

“To be honest I think they should just abandon these assessments completely and go on what the doctors say, regardless of seeing a person and asking them if they can pick something up off the floor or something stupid like that.”

“I don’t think they’re looking at individual cases, I think it’s all a tick box exercise, and they have so many quotas they need to fit into, that I don’t think they really look at it on a case by case basis.”

The other issue was a perception of inconsistency between assessors and decision makers, and the suspicion that many of these were under pressure to reject claimants. Perhaps unsurprisingly, given that a stated aim of PIP was to reduce the total caseload, participants perceived that the aim of the reassessment was ultimately to reject as many claimants as possible.

“The form is to strip you from your benefits, that’s it.”

“I’m a little bit sceptical nowadays, the decision makers may have some political pressure on them to cut costs, and that’s their priority rather than making the right decision for the right reasons... In my own experience in the past the person was given the benefit of the doubt.”

“I’m quite convinced that they will discover that my eyesight is 20/20 and I can run and walk and charge about without the assistance of a guide dog or a cane.”

“I think they’ll try everything to get me off it.”

Those with additional income sources, such as a pension, or income from work or a partner who worked, were less concerned about the potential loss of their present DLA income, although none felt they would cope with the loss without problems.

PIP in Scotland

Those currently receiving DLA were asked about their thoughts on how the system might best operate after it has been devolved to the Scottish Parliament as part of the Scotland Bill 2015-2016.

The first issue raised was where the starting point should be. Rather than design something from scratch, most were fairly satisfied with DLA and felt that this was a reasonable point of departure; however, it was also seen as an opportunity to reform it for the better, without taking the same route as PIP. Some felt that changes to DLA were necessary in order to reduce fraud and make sure it was helping those who needed it:

“I think DLA is a reasonable assessment as far as myself goes. But I do know obviously some people have taken advantage of the system and beaten the system, and these people shouldn't be on DLA. So for every instance it's not necessarily appropriate.”

“There were a lot of repetitive questions that were there to try and catch you out or ask things in other ways, which to an extent I can understand because they don't want people claiming it fraudulently. We don't want people, oh I've got a sore back, you know what I mean, because there was abuse in the past, and we have to make sure that doesn't happen again. But we're not wanting people who are in genuine need of it being automatically turned down.”

“I think the need for a closer eye on long term conditions was fair, but to go about it the way they did [with the new assessment process] just exacerbated things and made people's health even worse... I think DLA needed tweaking, it didn't need a whole new system. It was sold as something it wasn't, and I don't think it was necessary.”

Participants perceived a number of design pitfalls with PIP that should be avoided. It was felt that the PIP criteria were too abstract, and that it should not be simply a case of whether a person can do an activity, but in what context; under what conditions, in what environment, and in conjunction with what? One participant gave the example that a person may be able to meet the mobility criteria somewhere where there was a smooth walking surface and that was accessible (e.g. a shopping centre), but not on an uneven pavement with roads to cross.

Another participant stressed the importance of a residual category, for those who do not quite fit the criteria but are demonstrably in need. There was also a widespread demand for transparency, as there was a lot of confusion about the new criteria and the implications of using aids and assistive technologies.

“I’m concerned about the mobility part, I don’t know how it’s working out, this twenty metres thing, if you can manage to go twenty metres in your chair, you’re mobile basically. That’s assuming there’s pavements, no roads to negotiate. I couldn’t cross the road safely by myself... And [my local] streets are absolutely terrible.”

There was some debate over whether the life or indefinite awards that were available under DLA should be reinstated. Some felt that there was no point in reassessing those with permanent conditions:

“Why waste money reassessing people? I’d love to believe in miracles, but people don’t regrow a lost limb, sight doesn’t come back. Reassessment is there to irritate and frighten people, and it’s not saving the government any money, because most serious conditions, once you’ve got them, you’ve got them.”

“The whole process is so unfair, it’s just continually assessing and reassessing, which is not helpful for anyone. If you know you’re not going to get better, the last thing you need is soul destroying forms every two years, to continually put it all in again and remind yourself you’re not going to get any better.”

Others welcomed a move towards a system that does not ‘abandon’ people on DLA for life. However, it was suggested that perhaps revisiting claimants could be less about reassessment, and more about helping people to access the services that they need.

“I think there was an issue with Disability Living Allowance that people were getting left alone for years and years. I think there should be an element where people are at least invited into Jobcentres or something to see what their situation was or how the government could help them, not necessarily to paid work, but just to live a more inclusive life.”

Some participants suggested that perhaps, in the presence of medical certification, some conditions should be considered as automatically entitling people to the benefit. Assessment efforts could then be targeted on the more ambiguous cases.

There was perceived to be a lot of duplication in the process of applying for benefits. Some were not clear why they were required to fill in a form when the same information would be sought from their doctor in any case. Others noted the stress of making multiple applications for different benefits, often submitting very similar information and accompanying evidence; for example those applying for both ESA and DLA, and perhaps for social care at the same time. These issues raised the question of whether a more joined up system between health and benefits agencies might reduce stress and required workload for those claiming benefits.

“I’d have thought it would be fairer for people with quite complex disabilities that don’t necessarily present as a disability you can see, I think it’s more beneficial to take the information from a GP or a hospital consultant, rather than continually run them through assessment processes... A bit like they do with driving licences, where every three years if you have a medical renewal, they send you some paperwork to sign for them to look in your medical files and speak to your consultant, and then that goes back to the driving licence authority and they make decisions. Something like that, a joined up approach.”

The introduction of another face-to-face assessment process with PIP was almost universally perceived as negative by participants. Few saw a benefit to insisting on a face-to-face interview in every case, especially given the difficulty of capturing the impact of a fluctuating condition during a brief meeting with a stranger. Assessments have been a source of considerable stress to many participants in recent years, and they hoped that the devolved approach could at least be a more approachable and user-friendly process. It was felt that, if there are to be face-to-face assessments, ill and disabled people should not be expected to make long journeys to attend appointments.

Many stressed the importance, in designing a suitable system of support, of listening to disabled people about how their conditions affect their daily life, and making sure the criteria reflect and are able to capture this impact. Several mentioned some form of co-production, feeling that disabled people should be involved in the design and assessment process. Indeed, listening emerged as an issue more generally, with many participants feeling that politicians do not understand their needs, and could perhaps benefit from some experience of their situation.

“They’re really sticking to their guns; they’re not listening to other people with conditions. I just feel it’s as if they don’t care, they’re not bothering to look at all the recommendations that have been provided to them.”

“They need to experience it; they need to do it themselves. It really annoys me; they’ve no concept of how hard it is.”

Most participants said that taking part in this study had made them feel listened to, and appreciated the chance to share their experiences.

“The research you’re doing is really valuable, because you’re actually taking a pragmatic position on it and actually talking to disabled people about their experiences and what we’re finding.”

“It’s quite good that you’re actually doing something like that, because it does help when you do these research things and give it to government and say this is what is happening and this is how people are feeling about it. It is useful, and helpful.”

“[Politicians] are on a different planet, they have no idea, and that’s why I like what you’re doing, that somebody is listening... [This research is] something that needed to be done, and hopefully people listen to what you guys put together.”

PARTICIPANTS' TRAJECTORIES OVER THE COURSE OF THE STUDY

- Chapter 4 considers participants' trajectories over the course of the two and a half year study as a whole, and attempts to identify the factors that have ameliorated or exacerbated their experiences.
- The experiences of the participants in this study suggest a gap between what the benefits system would consider 'fit to work', or to undertake work related activities, and the opportunities available in the labour market.
- Those who have moved into work have found that the net impact of can be positive, but that health and caring responsibilities may pose challenges to sustaining employment.
- Participants' ability to deal with the benefits system, and the adequacy of the amount they receive for meeting their needs, has been highly dependent on their individual situations. Often changes to the system and the need to apply for new types of benefits have caused considerable stress to participants.
- Transitions were more difficult to cope with for those who are socially or geographically isolated.
- A lack of stability and security has been a feature of participants' trajectories over the course of the study.

This chapter considers participants' trajectories over the course of the study, and attempts to identify the factors that have ameliorated or exacerbated their experiences.

The long-term impacts of welfare reform

Within the 37 participants for whom longitudinal data is available, three groups can be distinguished.⁸ The first group (containing 13 participants) is comprised of those who are the most seriously ill or disabled, who considered that their conditions made it unlikely or impossible that they would ever work in the future. The second group (10 participants) comprises those with less severe or intermittent conditions, who felt that they could potentially work (either now or in the future), but who faced considerable barriers to sustained labour market attachment due to their health. The final group (12 participants) are those whose caring responsibilities inhibited or obviated their participation in the labour market.

⁸ 35 participants fall into one of these groups – the other two participants did not fall into any of these groups.

Far from the labour market

This group are those with the most serious health conditions, who are the furthest from the labour market. Most were previously on Incapacity Benefit (IB), and have been reassessed for ESA. This group experienced the least turbulence over the course of the study. However, that is not to say their experiences have been without problems.

Only in one case did a participant fail to receive any ESA, even after appeal, because they were deemed unable to prove that their pain and fatigue, which severely limited their day-to-day activities, existed. This highlights the potential difficulties with the WCA for those that consider themselves to suffer from an 'invisible' condition.

Some had managed to move from IB to ESA successfully on the first attempt, and in some cases without the need for a face-to-face assessment. However, none had done this without considerable help in preparing their applications, for example from organisations that specialise in helping those with their particular condition.

Others had initially failed to be awarded ESA, or had been placed in the WRAG, but had been placed in the Support Group after an appeal, in most cases by the time the sweep 1 interviews took place. Some had waited a considerable length of time for their appeal, only to have the decision reversed very quickly and easily once their case was finally dealt with.

By the time of the first interview, most of this group were already on ESA, and they have largely experienced little change since then, particularly as ESA reassessments were suspended for much of this time. Most were also still waiting to be reassessed for PIP by the time of the final interview. This group is the least able to generate income from employment, and is therefore most dependent on continued receipt of income replacement benefits. Any loss of entitlement could be particularly catastrophic for them.

Case study: From an ESA appeal to getting by OK

At the first interview, the participant had recently been placed in the ESA WRAG, but was awaiting an appeal that they hoped would put them in the Support Group. Although the person conducting their assessment had stated that they were unlikely to be able to work, the DWP decision maker had ultimately placed them in the WRAG. They were obliged to attend interviews at the Jobcentre, which caused them considerable distress. However, by the time of the sweep 2 interview, they had successfully appealed the decision, and had been placed in the Support Group. Although retaining some residual fear of reassessment, the participant's situation was largely stable after this point, and they felt that the amount they received was enough to meet their needs. They stressed the importance of the help they had received from an advocacy organisation in successfully appealing the decision, and also in claiming the backdated monies they were owed.

Closer to the labour market but with barriers

A second group of participants are those with health conditions that limit their ability to work, but who could work, or would like to. However, their needs and capabilities fluctuate in a way that the benefits system struggles to deal with.

This group have had a more turbulent experience. Their benefit income was far from secure, and there was considerable trepidation about what would happen at the next round of reassessments. Some had failed to qualify for ESA; others had been awarded it on appeal. Perhaps the most challenging experiences were those who moved between JSA and ESA and back again, because they struggled to show that they were ill enough for ESA or well enough for JSA.

Case study: Caught between ESA and JSA

The participant was assessed for ESA but it was not awarded, and an appeal was unsuccessful, so they were placed on JSA. When they attended their first meeting at the Jobcentre, their advisor said they were too ill to seek work. They reapplied for ESA and were eventually awarded it. At this point in time, the participant felt that they were not capable of work, as their mental health condition had a serious impact on their day to day functioning. However, once they were back on ESA, their mental health improved, to the point that they felt well enough to embark on a college course (at this point their ESA was stopped and they received a student bursary). By the final interview, they were still in college, and their partner, who had also suffered from mental health issues, had also improved and had moved into part-time work. Reflecting on the previous two years, the participant felt that the family had moved in a very positive direction. They stressed the central role of a third sector organisation that supports parents, both with their mental health issues and helping them move towards work.

Most of the participants in this group aspired to work, and some did so over the course of the study. However, the extent to which they were able to contemplate work depended on their health status, and even if they felt able to work in theory, their ability to do so in practice was hampered by a lack of employment opportunities that they could reconcile with their health issues. This was particularly problematic for those whose condition varied (most of the participants in this group), who had a fear of being unable to sustain work, or being an unreliable employee. None felt that the support available for them to move into work took account of the gap between their abilities on the one hand, and the opportunities available in the labour market and the expectations of employers on the other.

Care responsibilities as a barrier to labour market engagement

A third group can be distinguished, of those who are themselves able to work, but for whom this is balanced against caring responsibilities, for a child or disabled person.

Previous reports in this study have documented how lone parents have been particularly affected by intensified requirements to seek work, which have resulted

in negative experiences with the Jobcentre, and feeling pushed to seek work whether they feel this is the best thing for their children or not (Graham et al. 2015; Graham et al. 2014; Lister et al., 2014). Most of the lone parent participants did manage to move into work, although this was not without some associated stress and guilt. Even in work, freezes to WTC and cuts to the assistance available for childcare have made it difficult for low income families to make ends meet.

Case study: From depression to anxiety

At the first interview, the participant, a lone parent, was receiving JSA and desperately seeking work; they felt depressed about not being in work, and found the job seeking requirements on JSA stressful and sometimes unreasonable. By sweep 2, they had moved into work, although the position was for more hours than they had wanted to work, and was a temporary role. Their job was eventually made permanent, and issues around working hours eased as their child got older. Moving into work had made the family slightly better off, and the participant was delighted to be in work and felt less depressed. However, the challenges of juggling work and domestic responsibilities made them anxious, and they worried that their anxiety was making their child anxious as well. They felt that they struggled to cope sometimes:

“My self-esteem is a lot better, but sometimes I do still feel quite worthless. I’m trying to make an effort but it’s an uphill struggle sometimes, and it’s tiring.”

Participants who are full-time carers have borne much of the stress of the impact of welfare reform on the people they care for. They have assumed the practical and emotional burden of benefit changes on behalf of those who are unable to cope with these things themselves, often at the expense of their own health, other relationships, and labour market and other ambitions. Thus, although there have been no changes to Carer’s Allowance, they have been affected by changes such as the reassessment of IB claimants, and await the move to PIP with possibly as much trepidation as DLA recipients. One thing that is notable from their experiences over the study is the way in which they may have been affected several times over, either by a number of different changes, or because they care for more than one person.

Case study: It never stops

At the first interview the participant, who cares full-time for their partner, had recently gone through some difficulty in obtaining a DHP to mitigate their bedroom tax liability. Over the course of the study their partner was reassessed for moving from IB to ESA. By the final interview the participant was still awaiting news about their partner’s reassessment for PIP, which was a source of stress for them. The participant was struggling to make ends meet due to the high costs imposed by

their partner's condition, and the prospect of losing entitlement in the transition to PIP was frightening. The participant's own health deteriorated during this time, and they were temporarily hospitalised:

“It's been a constant battle with no stability whatsoever; it's just lurching from one crisis to another... And with the health issues on top of that and PIP looming, they've continually moved the goalposts which is no help at all; it's just made it worse.”

Barriers and enablers to managing change

Looking across these trajectories, it is perhaps possible to distinguish some factors associated with how successfully participants managed change. This section considers what made it harder for participants to cope, or helped them to do so.

Individual needs

The impact of welfare reform depends very much on the context of an individual's life. For example, a person's ability to navigate the benefits system depends on their health at that point in time. Health is the primary focus and determinant of well-being, and can pose an absolute barrier to tackling the complexity of the benefits system.

The financial impact of change, and the ability to manage financially on benefit income, was also highly dependent on the presence or absence of other costs in their lives. In some cases, participants found they had enough income to meet their needs comfortably. In other cases, participants found this income fell short due to additional costs: these included transport to medical appointments, housing costs, childcare costs, the expenses associated with children attending school, debt repayments, and household emergencies.

Some felt that the system should do better at recognising individual needs. This was particularly true of those with mental health conditions, many of whom felt that the benefits system did not take into account the way their condition affected their life. This sentiment was also felt particularly strongly among those who had lost entitlement to free school meals because their income was too high or their child became too old. They stressed that there may still be a need for these things among people who do not quite fit the criteria.

“These things, the limits of that could be a bit more negotiable, because everybody’s an individual. I’m missing out on these things that are beneficial to me, by £20, which is nothing if you look at that over a year. So these things, I think they’re a bit die hard, I realise there have to be rules, but there has got to be some kind of give and take somewhere.”

Support

A key factor in managing change is loneliness and isolation. The experiences of those with partners, good networks, and access to transport were generally easier than those who were isolated socially and/or geographically. It is difficult to understate the importance of practical and moral support in navigating the benefits system.

“I would be massively panicking and be even more stuffed if I didn’t have [third sector organisation].”

“Massively important. If it wasn’t for [third sector organisation] I don’t know if I’d be here today.”

The presence of support and advice for those applying for benefits was considered crucial by most participants. One participant argued that there should be a requirement upon those administering benefits to fund independent advice for everyone who requires it. Several flagged the issue of better advertising of entitlements, and the need for a centralised, ‘one-stop-shop’ to check entitlements.

A lack of financial security

For those on tight budgets, there was support for being able to alter particular aspects of UC, such as being able to increase the payment frequency, split the payment between adults in the household, and pay rent directly to landlords. One participant commented that getting weekly tax credits alongside their monthly salary really helped them to budget. Others felt that a single monthly payment of all benefit income to one person was not necessarily beneficial:

“I’d probably end up in rent arrears, so it is a bit scary... the DWP say oh we just want to give people responsibility, but when you’re struggling and you get your rent money in your account, people are going to spend that, the temptation is there to spend it.”

“Two years ago I wouldn’t have seen a lot of that money, and we’d have been in an even worse pickle. And I think that’s something they’ve not considered that there can be situations where for reasons of mental health or choice or whatever, it is not safe, particularly when there’s kids, to give all the money in a single payment to one person, who may just choose to go out and spend it. And I think they need to consider that.”

Several participants mentioned that they wanted to see more social housing. They were keen to move, as this would be of considerable help financially, perhaps even obviating the need for benefits altogether, but they had been unable to get a social housing property.

In essence, what participants were looking for was some element of stability and consistency; to not be constantly subject to assessments and reassessment, and to not constantly feel that their income is about to be taken from them. There was also a strong feeling that the system lacked compassion, made assumptions about the negative motives of claimants and denied them the benefit of the doubt. Participants simply wanted to be treated humanely, by a system that makes some allowance for the battles people are facing; whether this is living with a health condition or disability, or trying to meet a family’s needs on a very low income.

“It’s just the fear factor, that everyone seems to have, the stress of that certainly doesn’t help people medically, it’s a huge concern.”

“Consistency. Not having the fear that it could be taken away, not consistently worrying about that.”

“It’s exhausting. You cannot relax for a minute. Every decision has to be weighed up, is it more important to buy toothpaste or toilet roll this week, which one can I do without? There’s no downtime... And I think that’s something they don’t allow for; you don’t actually have the breathing space to change things, because your thought processes are taken up with simple survival... And then when you add mental health issues into that, it becomes incredibly difficult.”

CONCLUSIONS

- This chapter presents the key findings from sweep 4 of the study, and their implications for policy, as well as policy implications from across the study.
- Based on the findings of the study to date, there are a number of steps that could be taken to mitigate the impact of reserved welfare reforms:

Increased access to free or cheap childcare, to help parents cope with intensified work requirements and cuts to family support.

Improved support for carers: financial support, such as help with transport costs; practical support, such as advice about benefits changes; and emotional support.

Improved targeted employability support to help those expected to seek work move closer to the labour market.

Comprehensively available advice services to offer both practical (information) and emotional support. It could also be made easier for people to check their entitlements and find out about how proposed changes would specifically affect them.

- There are also a number of issues to consider in designing and implementing the benefits that are expected to be devolved to the Scottish Government as part of the Scotland Bill 2015-2016:

Consider the overall impact of the assessment process across a number of benefits that a person may be claiming, and the stress it can cause.

More or better use could be made in the process of medical supporting evidence, and previous benefit applications.

Consider the possibility of lifetime and/or automatic awards for those with serious and/or permanent conditions.

Improve the assessment process to better capture the impact of invisible and fluctuating conditions.

Ensure that the language used to communicate with claimants is clear and non-stigmatising.

- In summary, based on the experiences of the participants in this study, policy areas where improvements should be considered include:

Improving the implementation of existing policies around information, advice and support, caring and childcare, stigmatisation, and employment support.

Issues in benefits system design; reducing unnecessary pressure and stress, building in feedback from clients, improving client assessment, and improving the way in which benefits are administered.

This chapter presents the key findings from sweep 4 of the study, and their implications for policy, based on the experiences of our participants. It then sets out the recommendations from across the study to date, under a number of key headings.

Sweep 4: Conclusions and policy implications

An issue was identified around the loss of entitlement to certain forms of assistance (e.g. Warm Homes Discount, free school meals) after a small increase in income, with the net result of a loss for families already struggling to get by on a low income. Some families may actually be worse off in work for this reason.

Policy implications

Family circumstances should be reviewed holistically before entitlements are removed. The criteria for receiving these should be reviewed, particularly in relation to whether they have a perverse impact on work incentives.

It could be beneficial to low income families for policy makers to consider more broadly the costs incurred by families with children – such as school uniform, and other costs associated with attending school – and ways to offset these, in order to leave more room in the family budget.

Childcare costs have posed an issue for some participants, whether this is due to no longer receiving a contribution if both partners were not working over 16 hours per week, or having to pay the 30% contribution towards childcare, which may represent a substantial proportion of the household's weekly income.

Policy implications

Increase the amount of childcare that parents can access cheaply or free of charge, including pre- and after- school and holiday care.

Carer's Allowance has been untouched by welfare reform, but its low level means that participants who are carers have experienced financial hardship.

Policy implications

The devolution of Carers Allowance to the Scottish Government provides an opportunity to ease the financial strain on carers, by considering increasing the level at which it is paid.

The Scottish Government should consider the needs of those caring for more than one person. This does not necessarily imply awarding multiple allowances, but perhaps offering help with their transport costs.

There is a gap between being deemed 'fit-to-work', or undertake work related activity, and the opportunities available in the labour market. Participants with less severe or fluctuating conditions have often found themselves trapped or moving between different states; into and out of work, and/or between ESA and JSA.

Policy implications

This gap could be partly bridged with better, more targeted training and employability support for those with mental and/or physical health conditions and disabilities.

Participants facing the prospect of being assessed for PIP have already been subject to many challenges as a result of welfare reform, and as a result of the impact of their condition generally. They are approaching the assessment with some trepidation.

Policy implications

The devolution of this benefit provides an opportunity for the Scottish Government to implement a scheme that could better meet claimants' needs, and impose less of a burden on them.

User experience could be embedded in the targets that providers are expected to meet. The system could be evaluated (among other things) on whether claimants feel they are being treated fairly, and with dignity.

In designing the assessment process, the impact on claimants should be a key consideration. Life or long-term awards could be considered for those whose conditions are permanent, and some may not need to go through an assessment at all if their needs are clear cut. The burden of assessment should lie with the assessors; the requirement upon ill or disabled people to make long journeys to assessment centres should be minimised.

Future cuts to tax credits and disability benefits were found to be a source of stress and concern for participants.

Policy implications

It might be helpful if those potentially affected by changes were able to quickly find out how proposed changes might affect them personally, and also to know about what support is available to them if they were to lose entitlements.

The considerable dislike and distrust that participants have developed of the benefits system is in part a result of the UK Government and media rhetoric around the delivery of welfare reform. The language used has made them feel stigmatised, and fearful that they will lose their entitlements, and this has contributed to the stress they have experienced as a result of welfare reform.

Policy implications

Language and tone matters. 'Talking tough' on welfare reform instils fear and distrust. The Scottish Government should seek to use terms and statements that help foster good relations between the system and claimants, and does not stigmatise those receiving benefits.

Participants appreciated being listened to about their needs, and wanted to be involved in the design process of any future changes to the system.

Policy implications

Consider opportunities for some form of co-production in the development and implementation of the devolved version of DLA/PIP.

Previous rounds of the survey have found, and this final round has confirmed, the importance of support and advice in shaping participants' experiences of welfare reform.

Policy implications

Offer a centralised opportunity to check all entitlements, so that anyone can make sure they are receiving everything they are entitled to.

Offer support and advice at all stages of the application process.

Reviewing the policy implications from across the study

Across the four sweeps of the study, a series of policy recommendations and implications have been outlined (see Graham et al., 2015; Graham et al., 2014; Lister et al., 2014). In this section, these policy recommendations and implications are drawn together in order to highlight the key messages for policy from this study. A full list of the policy recommendations and implications from each sweep is provided in Appendix 4.

The Scotland Bill 2015-2016 has been proposed to put into effect the recommendations made by the Smith Commission – which includes the devolution of a range working age welfare benefits such as Carer's Allowance, DLA, PIP and DHPs (Smith Commission 2014; Sandford 2015). The devolution of these benefits provides an opportunity for the Scottish Government to implement a scheme that could better meet claimants' needs, and impose less of a burden on them. The Scottish Parliament will also have powers to create new benefits in devolved policy areas; and make discretionary payments in any area of welfare without prior permission from DWP.

The policy implications of the findings from across the study can be grouped together under two main headings: mitigating actions that the Scottish Government could take to reduce the impact of welfare reforms that sit outside its jurisdiction; and issues to consider in the design and implementation of new devolved benefits. It should be noted that these recommendations are not definitive suggestions, but they reflect the experiences of the participants in this study.

Improving the implementation of existing policies

Information, advice and support

Efforts should be made to raise awareness, via a range of media, of entitlements to different benefits. There should also be a centralised opportunity to check all entitlements, so that anyone can make sure they are receiving everything they are entitled to. It might be helpful if those potentially affected by changes were able to find out how proposed changes might affect them personally, and also to know about what support is available to them if they were to lose entitlements.

The findings of this study demonstrate a range of situations in which people might seek advice. It also shows that there is no ideal or 'one stop shop' solution; support and advice need to come from a range of services. Key third party information and advice agencies play an important role across a range of benefits issues and should continue to be supported by the Scottish Government.

These findings can help to identify best practice for those providing advice, and what is very important to get right. Advice should be timely and accurate, provided by well-trained and approachable staff, with whom users can have some continuity, where this is helpful and appropriate to the situation. Best practice is also to provide support in multiple formats - in person, by telephone, on paper and online - in order to reach those who may not be able to access one or more of these formats. Online information can provide a useful source of support, but it cannot replace other delivery modes completely.

The findings suggested that frontline services could play a role in supporting benefit recipients to access support, but that in places their involvement could be stronger and more joined up. It is particularly necessary to recognise the role of GPs in providing information to support an application for disability benefits. Health and social care professionals, and other frontline services, do not have to be experts, but should at least be aware of the kind of support that people might be entitled to.

Referral mechanisms between frontline services, and advice services, should be developed.

Caring and childcare

Throughout the study, the need to increase the amount of childcare that parents can access cheaply or free of charge has been stressed. This could make a considerable difference to how low income families cope with intensified work requirements, and cuts to their financial support, as a result of welfare reform. The plans to extend free childcare provision are welcome but a particular gap still needs to be addressed; that is to improve provision outside standard hours, including pre- and after- school and holiday care. This would enable parents, particularly lone parents, to compete for jobs that do not fit around school opening and closing times.

Carers could be better supported in their role, through the provision of practical advice, emotional support, and help with expenses such as travel costs.

Stigma

Stigmatising messages from the media need to be countered by public education campaigns about those on benefits and of the true (limited) nature of benefit fraud. Participants have also reported feeling stigmatised by some of the officials they deal with in the process of claiming benefits, therefore it is also important that those in client facing roles in the benefits system are able to deliver services in a non-prejudiced way.

Employment support

The findings of this study suggest that, according to the views of participants, stronger conditionality is unlikely to get more people into work. However, there are a number of interventions that can help, by addressing barriers to work, in the areas of education, skills, employability services, childcare, and health. There also appears to be a need for specialist employment services and staff who more fully understand the employment barriers facing specific groups, such as lone parent advisors in Jobcentres.

Issues in benefits system design

Reducing unnecessary pressure and stress

The application and appeals process should be founded on the initial assumption that the applicant is genuinely in need, and potentially experiencing a range of life stressors that might constrain their ability to tackle the process of applying for benefits. It should be acknowledged that applicants might have few resources to fall back on, and that even temporary delay or loss of benefit could have a substantial negative impact.

When determining what information should be sought during the application, the benefit of additional information should be set against the increased strain on the

applicant, and in the context of the overall burden of the form. Supporting information should be provided alongside forms, or at least clearly signposted, rather than left to the applicant to obtain for themselves.

Building in feedback from clients

Reflexivity and responsiveness to feedback from claimants regarding the appropriateness of the application process and assessment criteria should be built into the welfare benefit system. Application forms should be reviewed by a panel of applicants, in order to test the accessibility of the language, the clarity of the requirements, and the appropriateness of the questions. Although the current system ostensibly does so, via its regime of regular independent reviews, policymakers should demonstrate clearly how they have responded to this feedback.

Improving client assessment

There should be more sophistication in the assessment process for disability benefits, especially in relation to fluctuating conditions and 'hidden' disabilities. Entitlement to a disability benefit should not be predicated on the applicant being able to quantify a fluctuating condition (the suitability of polar questions in particular needs to be reviewed), or attempt to predict its future course. Rather, the impact of the disruption and uncertainty created by a fluctuating condition should itself be taken into account as a limiting factor.

Life or long-term awards should be considered for those whose conditions are permanent, and some may not need to go through an assessment at all if their needs are clear cut. Repeat assessments should be limited only to those whose condition is expected to improve. Even for those in this category, frequency of assessment should be balanced against the cognitive and emotional toll of assessment on respondents.

Improving the way in which benefits are administered

The findings from across the study suggest a need to improve the administration of benefits, including more sensitive service provision by departments and better administration of benefit changes. The study has found that there is a need for much improved official communication, not only by DWP, but also by Local Authorities, about benefits and benefit changes. Those who will be affected by benefit changes need to receive clearer information about what will happen, and when. Communication of decisions should be clear and unambiguous. Further research could identify examples of good practice in this respect.

Language and policy rhetoric should be carefully considered, as it may affect the degree of fear with which change is viewed by those affected. The Scottish Government should seek to foster good relations between the system and claimants, and set out to provide a service to those who need it, not deny one to those who do.

Mistakes should be minimised, but are inevitable to some extent; so how the relevant agencies respond to these situations is important. Their response needs to be efficient, and should give claimants a reasonable benefit of the doubt. The impact on those who fall foul of new rules - or who are affected by a mistake on the part of a benefits agency that is not their fault - can be severe. When things go wrong, it is important that there is recourse to a well-funded crisis support service that can respond quickly to financial emergencies.

User experience should be embedded in the targets that providers are expected to meet. The system should be evaluated (among other things) on whether claimants feel they are being treated fairly, and with dignity. Claimants should have the opportunity to provide feedback on their experiences, either online, by phone, or in person.

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How to access background or source data

The data collected for this social research publication cannot be made available by Scottish Government for further analysis because this qualitative data is not held by the Scottish Government.



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This document is also available from our website at www.gov.scot.
ISBN: 978-1-78652-287-0

The Scottish Government
St Andrew's House
Edinburgh
EH1 3DG

Produced for
the Scottish Government
by APS Group Scotland
PPDAS72612 (05/16)
Published by
the Scottish Government,
May 2016



Social Research series
ISSN 2045 6964
ISBN 978-1-78652-287-0

Web and Print Publication
www.gov.scot/socialresearch

PPDAS72612 (05/16)