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ALLIANCE
HEALTH AND SOCIAL CARE
ALLIANCE SCOTLAND
people at the centre

Evaluation of Welfare Advocacy Support Project

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Section 1: Introduction

In March 2015 the Scottish Government awarded the ALLIANCE £192,000 to deliver a one year pilot benefits advocacy service targeted at people going through assessments for PIP and ESA in four pilot areas; Dundee, Falkirk, Glasgow and Midlothian. The project was to be delivered through local partners, and to focus on people with mental health problems, learning disabilities, and neurological conditions.

For the Scottish Government, this investment formed part of a wider suite of interventions seeking to mitigate the impact of welfare reform initiated by the UK Government, and also provided an opportunity to explore strategic questions in advance of the transfer of new powers over welfare following the Smith Commission.

For the ALLIANCE, the project offered the opportunity to test a model of a potentially replicable project in a field, anti poverty work and welfare reform, in which it had developed a considerable interest responding to issues raised by members. The project also offered the opportunity for the ALLIANCE to influence the development of the Scottish Government's thinking about its use of current and future powers.

The Scottish Independent Advocacy Alliance, the SIAA, were also a key partner in the development of the project idea. Their involvement stemmed from awareness of the pressure on their members' services occasioned by welfare reform, and the opportunity presented to explore whether advocacy for benefit claimants could become a greater area of activity in the future as an effective way of supporting claimants' rights within the process.

For the four delivery partners, Dundee Independent Advocacy Support, DIAS, Forth Valley Advocacy, The Advocacy Project and VOCAL, involvement in the pilot promised a means of dealing more effectively with the demands they were already facing to support clients through benefit assessments, and of opening the door to real investment in this area of work. FVA's proposal identified their commitment to explore the delivery of the project partially through volunteers, VOCAL's proposal their commitment to explore the value of the project to carers as well as claimants.

This evaluation explores six key questions relating to what became the Welfare Advocacy Support Project, WASP:

- Has the project been targeted at a real need?
- Has the project been effectively delivered?
- Has the project been delivered by the right people?
- What impact has the project had?
- Has the project added value to the support available to people going through the assessment process?
- Has the service identified key lessons for future policy and practice on welfare reform?

The evaluation is divided into six main sections.

Section 2 looks at UK Government policy towards welfare reform, the numbers of people affected by changes to disability benefits in the pilot project areas, the Scottish Government's mitigation response to welfare reform, and the devolution of further powers under the Scotland Bill.

Section 3 looks at how the project was developed, the model for its delivery, and the project budget.

Section 4 analyses statistics for the project, including outputs, source of referrals, the characteristics of clients, the results of assessments, financial and qualitative outcomes for clients.

Section 5 looks at clients' experience of and views on; starting their claim for benefit, referral to and initial contact with the project; perceptions of the impact of the advocate on their experience and the result of the assessment; the financial and psychological impact of successful claims; how the assessment process might be improved; and the future of the project.

Section 6 discusses feedback from those involved in project delivery; advocates, their managers, and organisations referring to the service. It explores in turn their experience of and views on; how the project has changed the nature of the support available; the issues facing clients; referral relationships; the impact of the project; how the project has met the challenges it faces; and the additionality the project offers.

Section 7 sets out the evaluation's conclusions, returning to the six key questions this evaluation has sought to answer.

Section 2: Policy Context

The project has been delivered in the context of:

- Almost a decade of welfare reform, bringing significant changes to the benefit system that have affected disabled people/ people with long term physical or mental health conditions.
- Work by the Scottish Government to mitigate the impact of these changes.
- The potential for the transfer of power over some benefits for disabled people under the terms of the Scotland Act 2015.

This section of the report looks at each of these aspects in turn, plus an analysis of the numbers of people affected by the two most relevant elements of welfare reform in Scotland and each of the four pilot areas.

Section 2.1 Welfare Reform.

The current period of significant change to the benefits system can be dated back to the last Labour Government's third term in office, and the introduction of Employment and Support Allowance to replace Incapacity Benefit.

The process of reform picked up pace under the Conservative/ Liberal Democrat Coalition government. During this period, the rationales offered for reform included a much more explicit focus on saving money as a key part of the UK Government's austerity programme.

Three broad types of change could be observed across the whole period:

- Transitions; with existing claimants moving from one benefit, or set of benefits, to a new replacement benefit, and new claimants applying for the replacement benefit.
- The 'salami slicing' of benefits in cash and real terms, through freezes, small changes to entitlements, the tightening of eligibility criteria and the application of stricter sanctions in relation to conditional benefits.
- The localisation of control over particular benefits.

The key transitions to a new benefit have been:

- The move from Incapacity Benefit to Employment and Support Allowance.
- The move from Disability Living Allowance to Personal Independence Payment.
- The move from key income related benefits and tax credits to Universal Credit.

This project has focused on people affected by the first two transitions, though if the project continues, clients will also include people making the third transition.

Section 2.1.1. The Introduction of Employment and Support Allowance

Employment and Support Allowance (ESA) was introduced to replace Incapacity Benefit (IB) as the benefit for people unable to work due to ill health.

- Since October 2008 all new claimants have claimed ESA rather than Incapacity Benefit.

- In April 2011 the migration began of all existing claimants in receipt of IB and Severe Disablement Allowance (SDA) to the new benefit. This element of the process has now effectively concluded.
- In April 2012, claimants in the Work Related Activity Group have only been entitled to contribution-based ESA for a maximum of 365 days. After that point they must claim income-based ESA, to qualify for which their household income must be below a certain threshold.
- A further change is proposed in The Welfare Reform and Work Bill proposes a further change to the entitlement of claimants. From April 2017, all new claimants placed in the Work Related Activity Group will be paid at the same rate as Job Seekers Allowance claimants.

Issues with Employment and Support Allowance

At the heart of the process of applying for ESA is the Work Capability Assessment, WCA. The WCA has been subject to substantial criticism by claimants, voluntary organisations working with disabled people, by the House of Commons Work and Pensions Select Committee, and within the Harrington and Litchfield Reviews set up by the DWP to review and assess implementation of the new system.

Criticisms, which have not disappeared after the implementation of the recommendations of some of the reviews outlined above, include that the WCA:

- Fails to take proper account of the variability in people's conditions, the impact of pain and fatigue and medication and effect of compounding conditions.
- Is ineffective in recognising the impact of mental health problems.
- Does not properly consider the social model of disability.
- Is based on inaccurate assumptions, inaccurate recordings and use of unsophisticated tools.
- Too often involves unprofessional conduct by staff carrying out assessments.

Section 2.1.2: ESA Statistics

Figures are from May 2015 at <http://tabulation-tool.dwp.gov.uk/100pc/tabtool.html>

Current ESA Claimants in Scotland.

	Total	Proportion of Scottish Claimants	Total Annual Claim
Dundee	9,090	3.6%	£53,691,721
Falkirk	7,340	2.9%	£42,301,594
Glasgow	47,730	18.8%	£289,947,531
Midlothian	3,710	1.5%	£20,980,821
Scotland	254,500	100.00%	£1,483,796,080

This table makes clear:

- The very significant numbers of people claiming ESA in Scotland; 7.3% of people aged 16-64 in Scotland are claiming ESA.
- The importance of ESA to the Scottish economy.
- The extent of the claiming of ESA in Glasgow, nearly 1 in 5 Scottish claimants of ESA live in the city.

Gender of ESA Claimants

	Total	Male	Percentage Male	Female	Percentage Female
Dundee	9,090	4,820	53.03%	4,270	46.97%
Falkirk	7,340	3,740	50.95%	3,590	48.91%
Glasgow	47,730	25,560	53.55%	22,170	46.45%
Midlothian	3,710	1,860	50.13%	1,850	49.87%
Scotland	254,500	132,970	52.25%	121,530	47.75%

Claimants of ESA are fairly evenly split between men and women, although there the split in each area is slightly in favour of men, particularly in the more disadvantaged areas of Dundee and Glasgow.

Phase of Claim/ Group of Claimant

	Total	Assessment Rate	WRAG	Support Group	Unknown
Dundee	9,090	1,610	2,760	4,580	140
Falkirk	7,340	950	1,840	4,270	280
Glasgow	47,730	7,380	14,640	24,930	770
Midlothian	3,710	650	1,010	1,950	100
Scotland	254,500	43,110	66,460	138,430	6,500

These figures highlight:

- The continuing use (in fact the use is growing) by decision makers of the Support Group rather than the Work Related Activity Group.
- The fact that a very clear majority of those claiming ESA who have passed through the assessment will not be able to work in the immediate future, and will be financially reliant on claiming benefits, and/ or support from other household members
- The numbers of people at any one time who are at some point within the assessment process for ESA, one in six of those claiming the benefit.

Age of ESA Claimants

	Total	18-25	25-34	35-44
Dundee	9,090	680	1,520	1,810
Falkirk	7,340	530	980	1,400
Glasgow	47,730	2,810	6,350	9,300
Midlothian	3,710	340	590	680
Scotland	254,500	18,290	37,040	48,560

	45-54	45-49	50-54	55 plus	55-59	60 plus
Dundee	2,610	1,150	1,460	2,440	1,530	910
Falkirk	2,230	990	1,240	2,170	1,260	910
Glasgow	15,540	7,180	8,360	13,640	8,420	5,220
Midlothian	1,040	480	560	10,40	580	460
Scotland	76,100	35,320	40,780	73,880	43,220	30,660

The pattern of age distribution of ESA claimants has some similarity to the distribution for DLA and PIP claimants, with the peak of claimants arising in the 55-59 category.

Reasons for Claiming

Figures are available for the whole of Scotland for the number of people claiming ESA for reasons in the categories identified:

- 50.2% of claimants have 'mental and behavioural disorders'.
- 6.1% of claimants have 'diseases of the nervous system'.
- 12.0% have diseases of the musculo- skeletal system.
- 6.3% have diseases of the circulatory/ respiratory system.
- 4.4% have been affected by injury/ poisoning.

These figures have been used to generate estimates (actual statistics on reasons for claiming ESA are not available at a local authority level) of the numbers of people claiming for different reasons in each of the pilot areas.

	Total	Mental and Behav- ioural Disorders	Diseases of the Nervous System	Diseases of the Musculo-Skeletal System	Diseases of the Circulatory Respiratory System	Injury Poisoning etc	Other
Dundee	9,090	4,562	558	1,092	575	401	1,902
Falkirk	7,340	3,684	451	881	464	324	1,536
Glasgow	47,730	23,955	2,931	5,731	3,019	2,104	9,989
Midlothian	3,710	1,862	228	445	235	164	776
Scotland	254,500	127,730	15,630	30,560	16,100	11,220	53,260

The statistics in the table indicate the extent of potential demand for the pilot project, which focuses on people who are likely to face particular psychological and cognitive barriers to receiving an appropriate decision at a benefit assessment.

They also indicate, taken with the statistics previous presented that ESA is not, as perhaps Incapacity Benefit was once assumed to be, a benefit primarily for former manual workers in heavy industry, whose bodies have been broken by their work, or who have lost a job in such an industry and been 'put on the sick'.

Section 2.1.3: Disability Living Allowance to Personal Independence Payment

Disability Living Allowance is paid to people under the age of 16, people of working age, and some people over the age of 65 to help them cope with the extra costs of living with a disability.

In the Welfare Reform Act 2012, the Government set out details of the creation of Personal Independence Payment (PIP) to replace Disability Living Allowance (DLA) for eligible working age people aged 16 to 64.

The Government's intention was that Personal Independence Payment would: *'focus support on those individuals of working age who experience the greatest challenges to remaining independent and leading full, active and independent lives'*.

Like DLA, PIP:

- Has two components, a daily living component and a mobility component, both paid at standard or enhanced rates (there is no lower rate).
- Is available to people who are either in or out of work, and will not be means tested.

Unlike DLA, there are no life awards for PIP. The DWP expect most people to be awarded PIP for 2 years with the maximum award to be for 10 years. At the end of this period, claimants will have to go through a new assessment.

Access to PIP is through an assessment carried out by an independent health professional. For the majority of applicants this will include a face to face assessment as well as a review of their PIP application form, and additional information such as doctors' reports.

All new claims by people of working age for financial support with the extra costs of living with a disability have been for PIP rather than DLA since June 2013.

More recently, the transition of existing DLA claimants of working age to PIP has begun in all areas of Scotland, with the process due to finish between December 2017 and March 2018. The former date is the estimate from the DWP of the time by which all existing claimants have been called for assessment, the latter date is the consultant's estimate of the time, on this basis, by which all DLA claimants making the transition will have to have sought advice on their claim.

Potential Impact and Outcomes of the Change.

Claimants use Disability Living Allowance in a variety of ways including to:

- Purchase personal care, or pay for a variety of less intensive household task related support, or meet expenses incurred by informal carers in delivering care.
- Travel, including paying for taxis or accompaniment on journeys by a carer.
- Pay for equipment or other additional costs experienced as a result of disability, for example increased laundry bills due to continence issues, or increased heating bills due to lack of mobility.
- Cover work related costs related to having a disability.

Some claimants will also use DLA to cover general household expenditure or as a guaranteed source of income if their broader income is less stable.

A loss of, or reduction in, support to cover the costs of living with a disability may leave people:

- Struggling to manage financially.
- More isolated, and less able to engage in social activities.
- Less able to engage in any activities outside the home.
- Less able to maintain themselves in employment.

Those going through the transition from DLA to PIP may fear that these constraints on their lives will have a severely negative impact on their health and wellbeing, some that they will be forced to seek extra support that might not be there in the context of cuts, others that they may no longer be able to live independently, or that they will be forced to give up work.

Section 2.1.4: Statistics on Scottish Claimants of DLA and PIP

This next subsection gives an overview of the characteristics of working age claimants of DLA, and claimants of PIP.

Figures used are:

- For DLA, those relating to May 2015, the latest available and the month when the pilots began available at <http://tabulation-tool.dwp.gov.uk/100pc/tabtool.html>.
- For PIP, those relating to October 2015, again the latest available at <https://stat-explore.dwp.gov.uk>.

Number of DLA Claimants, Amounts Claimed

	16-64	Proportion of Scottish Claimants	Average Amount	Total Amount Claimed
Dundee	6,460	3.6%	£79.67	£26,762,746
Falkirk	5,310	3.0%	£82.06	£22,658,407
Glasgow	31,590	17.6%	£80.78	£132,695,690
Midlothian	2,660	1.5%	£82.27	£11,379,586
Scotland	179,100		£82.38	£767,221,416

This table indicates the number of people of working age in Scotland claiming DLA in May 2015, when few had made the transition to PIP. A very significant number of people will have made that transition over the course of the project up to this point, or will have to make that transition over the next two years to December 2017- March 2018.

The average amounts claimed, and the total amounts claimed, are a reminder of the extent of the money at stake for people making the transition.

DLA Claimants by Gender

	Total	Male	Percentage Male	Female	Percentage Female
Dundee City	6,460	3,240	50.2%	3,210	49.7%
Falkirk	5,310	2,630	49.5%	2,690	50.7%
Glasgow City	31,590	16,110	51.0%	15,480	49.0%
Midlothian	2,660	1,340	50.4%	1,330	50.0%
Scotland	179,100	90,280	50.4%	88,820	49.6%

There is a very even split of DLA claimants between men and women, with no particular pattern discernible between the different areas.

DLA Claimants by Age

	16 - 17	18 - 24	25 - 29	30 - 34	35 - 39
Dundee City	150	470	360	450	470
Falkirk	160	420	250	300	370
Glasgow City	690	1,960	1,530	1,580	2,010
Midlothian	60	220	170	130	170
Scotland	4,300	13,410	9,800	10,310	11,870

	40 - 44	45 - 49	50 - 54	55 - 59	60 - 64	Total
Dundee City	670	810	1070	1160	830	6,460
Falkirk	500	690	890	960	780	5,310
Glasgow City	3,070	4,480	5,740	6,070	4,450	31,590
Midlothian	260	340	450	450	420	2,660
Scotland	17,200	24,250	29,620	32,610	25,730	179,100

There is a clear pattern in the age distribution of DLA claimants, with number of claimants per age category rising from 16 onwards and peaking between the ages of 55 and 59. There are still a significant number of claimants below the age of 40, at a Scottish level 27.7% of claimants are below this age; this is not just a benefit for people of middle to late working age.

DLA Claimants by Disabling Condition

The consultant has developed a series of broad categories of main disabling condition to enable analysis of the reasons why people claim Disability Living Allowance.

At a Scotland level:

- 27.0% of DLA claimants claim because of a mental health primary condition.
- 22.3% of DLA claimants claim because of a learning disability.
- 12.0% of DLA claimants claim because of a neurological primary condition.
- 14.4% of DLA claimants claim because of a musculo skeletal primary condition.

- 3.3.% of DLA claimants claim because of a cardio/ respiratory/ cerebro-vascular primary condition.
- 8.6% of DLA claimants claim because of a sensory primary condition.

The table below uses these percentages to estimate the number of people in each pilot area claiming DLA for each of these reasons.

	Total	Mental Health Conditions	Learning Disabilities	Neurol. Conditions	Musculo Skeletal Conditions	Cardio-Respirat// Cerebro Vascular Conditions	Sensory
Dundee	6,460	1,747	1,442	775	930	215	552
Falkirk	5,310	1,436	1,186	4,428	765	177	454
Glasgow	31,590	8,541	7,053	3,791	XXXXX	1051	2699
Midlothian	2,660	719	5,94	319	383	88	227
Scotland	179,100	48,421	39,986	21,494	25,794	5,957	15,304

DLA Claimants to Lose or Gain Post Transition to PIP

Before PIP was introduced, the DWP released estimates of the impact of the transition from DLA to PIP, including estimates of the number of people who would actually start the transition process, and of those who would gain, lose, see their entitlement unchanged in value, or lose entitlement entirely.

	Total Number at May 2015	Total Number to Make Transition	Estimated Number to Gain	Estimated Number to Lose	Estimate Number Unchanged	Estimated Number Lose Completely
Dundee	6,460	6,191	1,802	1,802	953	1,591
Falkirk	5,310	5,089	1,481	1,481	784	1,308
Glasgow	31,590	30,276	8,810	8,810	4,662	7,781
Midlothian	2,660	2,549	742	742	393	655
Scotland	179,100	171,649	49,950	49,950	26,434	44,114

Based on the DWP's estimates, over 94,000 people in Scotland claiming DLA might expect to lose their existing support in part or in its totality after being assessed for their entitlement to PIP.

The tables below set out what using the DWP estimates might mean for people with the three different types of condition that are the focus of this project. These figures are very much conjectural, different types of condition might fare systematically differently under the DLA to PIP transition.

Financial Impact of Transition to PIP on People with Mental Health Problems

	Total Numbers	Total Number to Transition	Estimated Number to Gain	Estimated Number to Lose	Estimate Number Unchanged	Estimated Number Lose Completely
Dundee	1,747	1,674	487	487	258	430
Falkirk	1,436	1,376	400	400	212	354
Glasgow	8,541	8,185	2,382	2,382	1,261	2,104
Midlothian	719	689	201	201	106	177
Scotland	48,421	46,407	13,504	13,504	7,147	11,927

Financial Impact of Transition to PIP on People with Learning Disabilities

	Total Numbers	Total Number to Transition	Estimated Number to Gain	Estimated Number to Lose	Estimate Number Unchanged	Estimated Number Lose Completely
Dundee	1,442	1,382	402	402	213	355
Falkirk	1,186	1,136	331	331	175	292
Glasgow	7,053	6,759	1,967	1,967	1,041	1,737
Midlothian	594	569	166	166	88	146
Scotland	39,986	38,322	11,152	11,152	5,902	9,849

Financial Impact of Transition to PIP on People with Neurological Conditions

	Total Numbers	Total Number to Transition	Estimated Number to Gain	Estimated Number to Lose	Estimate Number Unchanged	Estimated Number Lose Completely
Dundee	775	743	216	216	114	191
Falkirk	4,428	4,244	1,235	1,235	654	1,091
Glasgow	3,791	3,633	1,057	1,057	560	934
Midlothian	319	306	89	89	47	79
Scotland	21,494	20,600	5,994	5,994	3,172	5,294

PIP Claimants: Reassessments Versus New Claims

	Reassessment	New Claims	Total
Dundee	307	1,744	2,053
Falkirk	274	1,585	1,859
Glasgow	1,750	8,310	10,066
Midlothian	538	828	1,366
Scotland	15,072	49,521	64,597

The table above reflects that the transition from DLA to PIP began on a phased basis. Differences in the characteristics of DLA and PIP claimants are more likely to reflect differences between the characteristics of new claimants than between those who have made the transition between DLA and PIP and remaining DLA claimants.

Total Numbers and Gender

	Male	Percentage Male	Female	Percentage Female	Total Claimants
Dundee	895	43.6%	1,158	56.4%	2,053
Falkirk	813	43.7%	1,049	56.4%	1,859
Glasgow	4,607	45.8%	5,457	54.2%	10,066
Midlothian	620	45.5%	742	54.4%	1,363
Scotland	28,947	44.8%	35,649	55.2%	64,597

There is a significantly higher proportion of female claimants of PIP than male claimants. There is no immediately obvious explanation for this difference.

The Age of Claimants

	16 to 17	18 to 24	25 to 29	30 to 34	35 to 39	40 to 44
Dundee	59	140	118	158	156	225
Falkirk	64	129	80	122	132	206
Glasgow	261	501	502	642	718	1,050
Midlothian	82	113	58	80	109	151
Scotland	2,371	3,861	3,142	4,124	4,661	6,683

	40 to 44	45 to 49	50 to 54	55 to 59	60 to 64	65 and over
Dundee	225	253	296	346	264	28
Falkirk	206	247	314	273	261	24
Glasgow	1,050	1,465	1,732	1,747	1,299	137
Midlothian	151	170	200	206	183	19
Scotland	6,683	8,498	10,113	10,555	9,494	1,111

The pattern of the age of current PIP claimants broadly reflects that of current DLA claimants, with the peak age for claims again being 55 to 59. 28.1% of claimants are under the age of 40.

Reasons for Claiming

	Psychiatric Disorders	Proportion with Psychiatric Disorders	Neurological Disease	Proportion with Neurological Disease	Learning Disability	Proportion with Learning Disability
Dundee	701	34.15%	185	9.01%	95	4.63%
Falkirk	556	29.91%	212	11.40%	102	5.49%
Glasgow	3671	36.47%	881	8.75%	487	4.84%
Midlothian	422	30.96%	156	11.45%	119	8.73%
Scotland	19726	30.54%	6,855	10.61%	4015	6.22%

There are differences between the proportions of people claiming PIP on the grounds of the conditions which are the focus of this project, and those claiming DLA on those grounds:

- People with mental health problems make up a slightly larger proportion of PIP claimants.
- People with neurological conditions make up a slightly smaller proportion of PIP claimants.
- People with learning disabilities make up a much lower proportion of PIP claimants.
- This suggests that there will be fewer new applicants for PIP with learning disabilities in any given period, perhaps not surprising given the lifelong nature of learning disabilities. Most of the demand for any future versions of this service from people with learning disabilities will come from people making the transition from DLA to PIP, or being reassessed for PIP after the expiry of their initial award.

	Daily Living Enhanced	Daily Living Standard	Daily Living Nil	Total Positive Awards	Proportion of PIP Claimants Claiming Daily Living	Total
Dundee	916	987	150	1,903	92.7%	2,053
Falkirk	908	800	153	1,708	91.9%	1,859
Glasgow	4,634	4,647	784	9,281	92.2%	10,066
Midlothian	729	554	80	1,283	94.1%	1,363
Scotland	31,897	28,114	4,574	60,011	92.9%	64,590

	Mobility Enhanced	Mobility Standard	Daily Living Nil	Total Positive Awards	Proportion of PIP Claimants Claiming Mobility	Total
Dundee	479	679	892	1,158	56.4%	2,053
Falkirk	590	630	643	1,220	65.6%	1,859
Glasgow	2,688	3,265	4,108	5,953	59.1%	10,066
Midlothian	425	445	500	870	63.8%	1,363
Scotland	19,638	21,010	23,940	40,648	62.9%	64,590

Daily Living remains the more significant element of PIP, as the care element is for DLA. Around 24,000 people claiming PIP are not claiming the mobility element, only 4,600 are not claiming the daily living element.

Section 2.2: The Welfare Reform Mitigation Response in Scotland

The Scottish Government has sought to mitigate the impact of welfare reform on Scottish households through the investment of additional resources between 2013/14 and 2015/16 in direct income transfers as follows:

- £90m in Discretionary Housing Payments to protect social rented tenants who would otherwise be affected by the underoccupation penalty/ Bedroom Tax.
- £69m, complemented by £51m from local authorities, in the Council Tax Reduction Scheme.
- £114m in the Scottish Social Welfare Fund which replaced crisis loans and Community Care Grants in 2013.

The Scottish Government has also made significant investments in the capacity of the advice and other sectors to mitigate welfare reform, £23.4m over the same period, alongside support from other sources, primarily local authorities, but also including NHS Boards, housing providers, the Big Lottery and charitable trusts.

This has included:

- Providing £5.1m of a £7.45m total pot for the Making Advice Work fund. This has been routed through the Scottish Legal Aid Board, split between the advice organisations, social landlords, and innovative projects targeting overindebtedness.
- Investing in the Welfare Reform Resilience Fund (WRRF) in April 2014, with projects taking a variety of often assets based co-production approaches.
- Investing £2.4 million in the 'Tackling Money Worries Fund' administered by SLAB and focused on work with low-income families between October 2014 and October 2016.
- Providing £2.5 million between 2013-14 and 2014-15 to Citizens Advice Scotland (CAS) to fund a range of services, including the provision of support for online claims, within bureaux across Scotland, followed by an additional £1.46 million for 2015-2016 to support CAS's welfare reform mitigation efforts.

- Supporting partnership working with NHS Boards in line with a plan developed in conjunction with NHS Board representatives, COSLA and third sector organisations, which sets a framework for local action targeting working-age people and their dependents who are most likely to be directly affected by Welfare Reform, and is backed by a Health and Welfare Reform Development Fund.
- Investment in a £1m Emergency Food Aid Action Plan over 2014/15 and 2015/16, split between FareShare, and local emergency food providers, including foodbanks.

New Powers in the Scotland Bill.

The Scotland Bill is continuing its passage through the UK parliament at the time of writing.

The Bill sets out the new powers over the social security system to be devolved to Scotland:

- Powers over benefits for carers, disabled people, and those who are ill (currently Attendance Allowance, Carer's Allowance, Disability Living Allowance, Personal Independence Payment and a range of others).
- Devolution of the Regulated Social Fund (Winter Fuel Payments, Cold Weather Payments, Sure Start Maternity Grants, and Funeral Payments).
- Powers to vary housing cost elements of Universal Credit.
- Administrative powers to change payment arrangements for Universal Credit.
- Power to create new benefits and to top up benefits in reserved areas; and
- Powers over Discretionary Housing Payments.

The Scottish Government has set out some of the key principles that will guide future reform/ replacement of PIP as being:

- Better use of medical evidence/ data sharing.
- Respect and dignity to guide the treatment of all those within the system.
- A simpler, more effective system.
- The availability of appropriate advice and support.
- Alignment with provision of health and social care.

WASP directly focuses on Personal Independence Payment, and the generation of insights into how the system for assessing people for ESA and PIP might be improved was one of the initial strategic aims for the project. Prior to the 2014 referendum it was also felt that findings from the project might inform the development of a new welfare system if Scotland voted for independence.

Both the Scottish Government and the ALLIANCE are clear that the project now offers a substantial body of evidence to assist the Scottish Government to develop its thinking on how it might reform or replace Personal Independence Payment once the relevant powers have been devolved.

Section 3: About the Project

This section looks at:

- How the project idea was developed.
- The model for delivery of the project.
- The cost of the project.

Section 3.1: Development of the Project Idea.

Initial Discussions

The ALLIANCE has been aware for a number of years of the impact of welfare reform on its members' patients/ service users. In particular, it has been aware of the range of challenges associated with the assessment process for ESA, and the potential for the assessment process for PIP to replicate similar problems.

In 2013 it began to explore the idea for a project aimed at tackling some of these challenges, which it felt would add value to the existing substantial investment from the Scottish Government and other funders in advice services targeted at people affected by welfare reform.

It convened a well attended members' meeting in July 2013, at which the Scottish Independent Advocacy Alliance were present. This meeting identified a significant interest in the seeing work taken forward in this area, and an appetite for the ALLIANCE to seek support from the Scottish Government to see the work progress.

Discussions with the Scottish Government followed. Capacity issues delayed the ALLIANCE's ability to progress the work as quickly as it would have liked. However, in late 2014, the Scottish Government gave the ALLIANCE the indication that they would welcome a proposal to run the project on a pilot basis for financial year 2015/16.

'Bidding Process'

Shortly before Christmas 2014, the ALLIANCE and SIAA circulated an invitation to SIAA's members to submit a brief project proposal by mid January 2015 to deliver the project on a one year pilot basis.

The invitation set out the aims and objectives for the pilot projects and described the rationale on which the idea had been developed. It made clear that the projects would target people with mental health problems, people with neurological conditions and people with learning disabilities.

The invitation indicated that:

- The ALLIANCE was prepared to work with up to four projects from anywhere in Scotland.
- The working assumptions, shared with SIAA members, were that:
 - One of the projects would be run in Glasgow.
 - Projects would seek to focus on individual local authority areas, though with the potential to cover more than one area if appropriate.

- As a pilot project, those delivering the work would be expected to engage in comprehensive monitoring of the project, and support the delivery of a robust evaluation.
- Those involved would also be expected to attend meetings of a national project steering group.

SIAA members were:

- Given a basic model for the delivery of the service, outlining the key tasks that would be delivered at every stage from referral to a post decision meeting.
- Asked for their plans to develop referral relationships with other local organisations, and with local advice organisations where clients need support with form filling and appeals.
- Asked to describe their current range of work, the extent of current adhoc work being undertaken to support clients within benefit assessment processes, the number of advocates and volunteers working for them.
- Asked to provide costs for delivery of the project on the basis of employment of a single worker.

Identification of Delivery Partners

Responses to the invitation to submit proposals were received by the ALLIANCE from 6 organisations:

- The Advocacy Project to deliver to people in Glasgow.
- Ceartas to deliver to people in East Dunbartonshire.
- Central Advocacy Partners to deliver to people in Falkirk.
- Dundee Independent Advocacy Support, to deliver to people in Dundee.
- Forth Valley Advocacy to deliver to people in Falkirk and the wider Forth Valley.
- VOCAL to deliver to carers in Midlothian.

The ALLIANCE then identified four organisations as preferred delivery partners; The Advocacy Project, Dundee Independent Advocacy Support, Forth Valley Advocacy, and VOCAL. Further discussion with VOCAL clarified the ALLIANCE's expectation that the service would work with both ESA/ PIP claimants and carers of claimants.

A final proposal was sent to the Scottish Government at this point, outlining the budget required to deliver the project.

Award of Funding and Project Set Up

The Scottish Government confirmed the award of funding for the four proposed pilot projects at the end of March 2015.

The ALLIANCE appointed a consultant who had worked with them on the development of the proposals to manage the process of project delivery, and carry out this internal evaluation of the project.

The consultant met with each of the projects to:

- Clarify aims and objectives.
- Identify any points arising from the proposals they had submitted.
- Confirm how they intended to deliver the project.
- Discuss plans for generating project referrals and timescale for recruitment.

These initial discussions also enabled discussions, which guided the development of the reporting template for the project, ensuring that it was fit for purpose in terms of collecting the necessary information, whilst not being an excessive burden on project staff.

Partner agreements were then developed and issued to each of the delivery partners, setting out expectations of both the ALLIANCE and the delivery partners, and schedules for the provision of monitoring reports and payments.

The project's national steering group was established. This involved:

- Representatives from the ALLIANCE.
- Representatives from the Scottish Government, meetings have been attended by staff from both the Social Justice Team, and the team working on disability benefits.
- Managers and, from the second meeting onwards, advocates from each of the referral partner.
- A representative from the SIAA.
- Representatives from the Scottish Association for Mental Health, and the Scottish Consortium for Learning Disability.

The first national project steering group meeting took place on May 18th 2015. There have been three further meetings, in August, October and December. Further meetings are planned in February, April and June.

Three of the projects, in Dundee, Glasgow and Midlothian, began in the middle of May 2015. The project in Falkirk began at the start of June 2015.

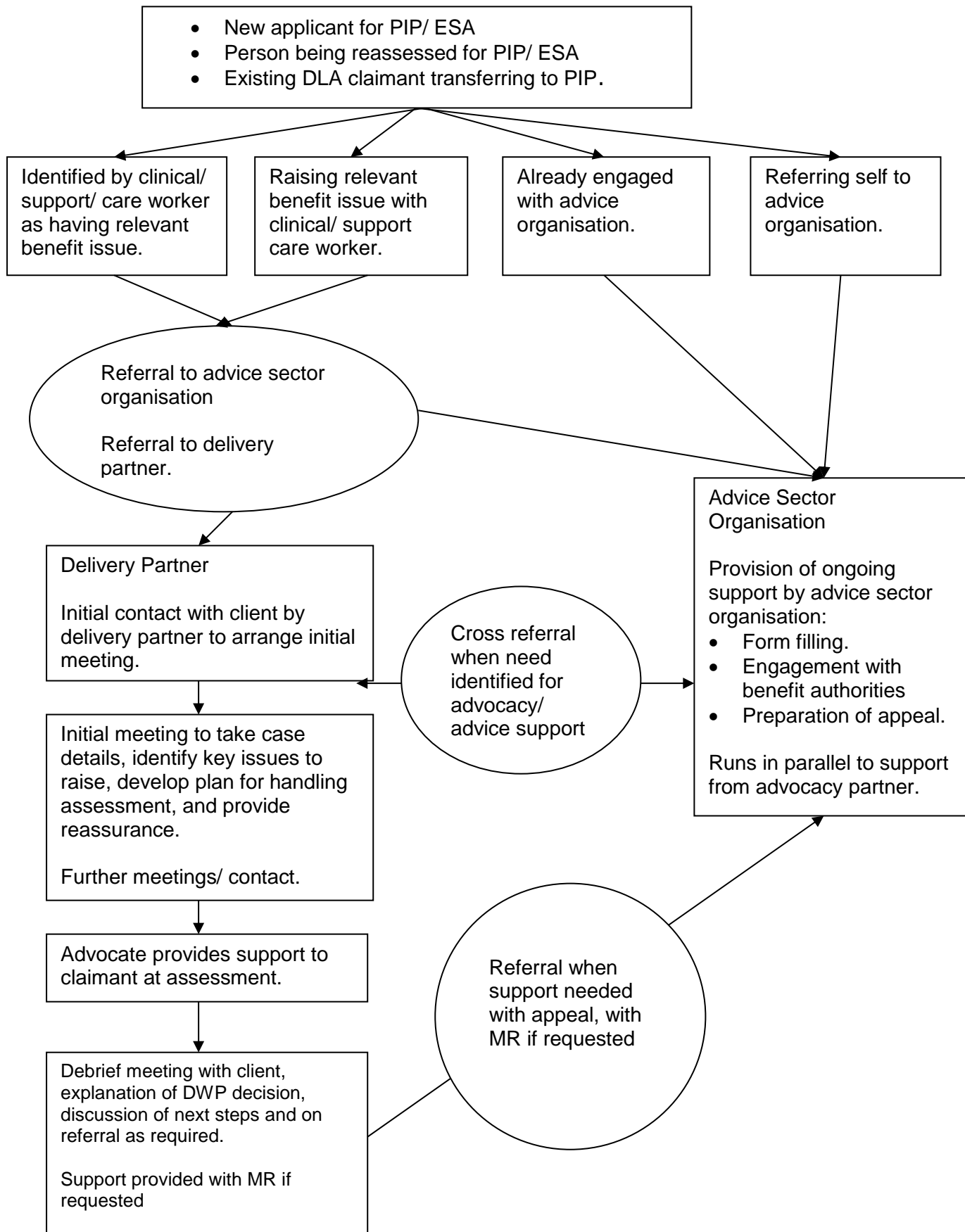
Section 3.2: Project Model and Budget

Each of the projects has operated using the same basic model, set out on in the flow chart on the following page which captures the client journey.

The budget for the project is set out below:

Pilot Projects – total costs	
Staffing costs (including travel/training)	£129,197.00
Project management	£16,395.47
Admin support	£2,900.00
Running/office costs	£19,212.73
Capital costs	£2,850.00
Carer travel/alternative care costs	£1,300.00
Sub-total	£171,855.20
Central ALLIANCE costs	
ALLIANCE Management Fee and Marketing	£7,050.00
Consultancy Support (incl. VAT)	£6,480.00
Evaluation (incl. VAT)	£7,480.00
Sub-total	£21,010.00
TOTAL	£192,865.20

Client Journey Flow Chart



Section 4: Project Statistics

Section 4 looks at the following sets of project statistics:

- Project outputs; the total number of referrals and clients worked with.
- Source of referrals.
- Client Demographics.
- Assessment and financial Outcomes.
- Qualitative Outcomes

Section 4.1: Project Outputs

	Dundee	Falkirk	Glasgow and West	Midlothian	TOTAL	Percentage
Total Number of Referrals Received	112	70	111	44 (57 people supported-includes carers)	337	
Number of Referrals Received-ESA	46	24	40	8	118	35.0%
Number of Referrals Received- PIP	66	46	71	36	219	65.0%
Number of clients supported at assessment	53	43	74	25	195	59.5%

Key Points:

- After slightly more than six months the projects have collectively received 337 referrals.
- The total project target was to reach 575 clients.
- At the current rate of referral, the project will reach around 640-650 clients, substantially exceeding its target.
- In terms of the individual projects:
 - Dundee, after 6 ½ months, has worked with 112 referrals against a target for the year of 120.
 - Falkirk, after 5 ½ months, has worked with 70 referrals against a target for the year of 180.
 - Glasgow and West after 6 ½ months has worked with 111 referrals against a target for the year of 175.
 - Lothian, after 6 ½ months has worked with 44 referrals and 57 people against a target of 100.
- Dundee and Glasgow will substantially surpass their targets, Falkirk looks set to fall a little short of its target, Lothian will about hit its target.

- Falkirk referrals have leapt in the last 2 months, as have Lothian referrals.
- Falkirk's target of 180 was always ambitious if the volunteers they intended to recruit did not come through.
- There are substantially more people being referred for support with PIP than ESA 65% of referrals being for the former benefit.
- This will to some extent reflect the comparative numbers of current applicants for the benefits, including the recent commencement of the transfer from DLA to PIP.
- Nearly 60% of clients have now been supported at an assessment, giving a sense of the throughput of clients, and the large number of live cases.

Section 4.2: Source of Referrals

Source of Referrals	Dundee	Falkirk	Glasgow and West	Mid-Lothian	TOTAL	Percentage
Self Referral	14	13	54	14	95	29.0%
CAB/ Specialist Advice Organisation	42	19	6	7	74	22.6%
Local Authority Welfare Rights	17	10	3	7	37	11.3%
Housing Provider	1	9	24		34	10.4%
Other Voluntary Organisation	8	2	4	5	19	5.8%
Internal	2	4	1	11	18	5.5%
Local Authority Social Work	3	4	4	0	11	3.4%
Voluntary Organisation-mental health	6	3	2	0	11	3.4%
Links Worker (for Glasgow and West)	0	0	7	0	7	2.1%
NHS Mental Health Service	2	1	2	0	5	1.5%
Voluntary organisation-learning disability	1	1	2	0	4	1.2%
Other NHS Specialist Service	0	2	0	0	2	0.6%
Other NHS Primary Care Service	1	0	1	0	2	0.6%
Voluntary organisation-neurological condition	1	1	0	0	2	0.6%
Other Local Authority Service	0	1	0	0	1	0.3%
Voluntary organisation-general social care	0	0	1	0	1	0.3%
GP	0	0	0	0	0	0.0%

Key Points:

- Self referrals are the most important route into the project, nearly three in ten referrals coming about this way, though some clients may be recorded as self referring when they have in fact been signposted rather than referred by a partner agency.
- Advice agencies from the voluntary and local authority sectors account for about a third of referrals.
- Over 44% of referrals come from advice workers, once referrals from housing providers which are largely from welfare rights services, have been added.
- There have been far fewer referrals from; the rest of the voluntary sector, 11.3%; from other LA sources, 3.7%; and from NHS provision, 2.7%.
- Some referrals from the voluntary sector may be from staff working on advice and welfare rights issues as part of broader support.
- The lack of referrals from the voluntary sector, NHS and local authorities might be slightly deceptive, some clients will have been referred from such organisations to advice specialists, before being referred on again to the service, whilst being recorded as an advice sector referral.
- However, it might also suggest that some people, who are not in contact with the advice sector, are potentially missing out on a service that could assist them.
- Conversely, reliance on the advice sector for referrals may be one indication that the delivery partners are receiving most of their referrals at the right point in the process, once initial support has been provided with form filling.
- The referral statistics paint a picture of services working closely in tandem with advice colleagues, slotting in nicely alongside existing advice provision, one of the initial requirements of the pilot.

Section 4.3: Client Demographics

This section looks in turn at the age and gender of clients, their ethnic origin, their employment status, and the health conditions impacting on them.

Age and Gender

	Dundee	Falkirk	Glasgow and West	Mid-Lothian	TOTAL	Percentage
Age						
16-24	6	9	21	4	40	12.2%
25-34	20	8	9	2	39	11.9%
35-44	17	14	12	7	50	15.2%
45-54	27	18	43	12	100	30.5%
55-64	30	21	23	10	84	25.6%
65 plus	2	0	3	0	5	1.5%
Gender						
Male	58	38	49	13	158	48.2%
Female	45	32	62	31	170	51.8%

Key Points:

- The largest number of clients are to be found in the 45-54 and 55-64 age groups.
- There is a spread across the remainder of the age groups, with a significant spike in the numbers of 16-24 year olds receiving support, largely due to some specific referral relationships established by The Advocacy Project in Glasgow and Lanarkshire.
- There are marginally more female than male clients overall, with the disparity particularly clear in relation to Midlothian clients, but also present in relation to Glasgow clients. There is something of a disparity in the opposite direction in Dundee and Falkirk.
- Overall, the gender split amongst project clients reasonably reflects the likely gender split between ESA and PIP claimants in Scotland.

Ethnic Origin of Client

	Dundee	Falkirk	Glasgow and West	Mid-Lothian	TOTAL	Percentage
White British/ Scottish/Irish	99	69	102	34	304	92.7%
White- Other	0	0	2	3	5	1.5%
Mixed Race	0	0	1	0	1	0.3%
Asian	1	0	5	0	6	1.8%
Chinese	1	0	0	0	1	0.3%
Black African	0	0	0	0	0	0.0%
Black Caribbean	0	0	1	1	2	0.6%
Other	2	1	0	1	4	1.2%

Key Points.

- Clients are predominantly of white British/ Scottish/ Irish origin.
- Numbers of people from BME communities within the client base are broadly at the level that would be expected.

Employment Status of Clients

	Dundee	Falkirk	Glasgow and West	Mid-Lothian	TOTAL	Percentage
Employed	1	1	2	5	9	2.7%
Unemployed	102	65	106	30	303	92.4%
In training/ education	0	4	3	4	11	3.4%

Key Points

- The vast majority of clients are out of work.
- This is partly a function of the fact that ESA is an out of work benefit.
- However, it also reflects the level of disability/ high impact of conditions on those clients supported with PIP, which can be claimed by people in work.
- It is a clear reminder that the project will have a substantial impact on the poverty faced by its clients, particularly when clients live in a single adult household with no alternative source of income to benefits.

Health Conditions

<i>Primary Health Care Condition</i>	Dundee	Falkirk	Glasgow and West	Mid-Lothian	TOTAL	Percentage
Mental health problems.	83	49	90	21	243	74.1%
Neurological condition	1	9	8	7	25	7.6%
Learning disability	9	1	10	2	22	6.7%
Other	10	11	3	12	36	11.0%
<i>Secondary Health Care Condition</i>	Dundee	Falkirk	Glasgow and West	Lothian	TOTAL	Percentage
Mental health problems.	7	13	6	9	35	10.7%
Neurological condition	0	1	4	2	7	2.1%
Learning disability	8	1		1	10	3.0%
Physical disability	36	16	37	25	114	34.8%
Other	2					

Key Points

- By the far the most common, 74.1%, of the primary health conditions amongst clients relate to their mental health.
- The majority of clients with primary conditions in the 'other category' have physical impairments/ health problems or sensory impairments.
- The percentage of clients with learning disabilities is lower than had been expected.
- This may be partly explained by the fact that there are fewer new applications for PIP from people with learning disabilities, unsurprising given their learning impairment will not, generally, have been subject to deterioration triggering a new application (though there will always be some new applications for PIP from people whose learning disabilities have not previously been recognised as potentially triggering entitlement).
- However, projects are now seeking to respond to may still be an imbalance in referrals with efforts to generate greater numbers of referrals from clients with neurological conditions and learning disabilities.
- Just over half the clients have significant compounding conditions, which are likely to have a further impact on their entitlement to PIP/ ESA.

Section 4.4: Assessment and Financial Outcomes

ESA Awards/ Comparison to Predicted Awards

Actual Awards	Dundee	Falkirk	Glasgow and West	Mid-Lothian	Total	Percentage
Total number of clients in receipt of decision on ESA application	13	13	16	7	49	
Total number of clients placed in Work Related Activity Group After Assessment	3	0	2	1	6	12.2%
Total number of clients placed in Support Group	9	11	13	6	39	79.6%
Total number of clients receiving no award	1	2	1	0	4	8.2%
Predictions						
Number of clients with accurate advocate's prediction	2	8	6	6	22	45.8%
Number of clients with worse than advocate's predicted outcome	4	2	2	0	8	16.7%
Number of clients with better than advocate's predicted outcome	8	3	8	0	19	39.6%

Key Points

- 79.6% of total clients, 86.7% of those with a positive result are placed in the support group.
- 12.2% of total clients, 13.3% of those with a positive result, are placed in the WRAG.
- Current UK figures for placement in:
 - The Support Group are running at 56.2%.
 - The WRAG Group are running at 13.9%.

- The 'Fit for Work' group are running at 29.8%.
- These statistics suggest that the project, alongside others helping clients with claims, has a significant impact on the results of clients' ESA assessments.
- This comparison could also be a simple function of the service targeting more vulnerable clients who are more likely to receive a positive result on their claim.
- Set against this, however, are two elements of the testimony from clients' interviews:
 - A significant proportion of interviewees had failed in a recent claim for ESA.
 - A significant proportion of clients reported that they were better able to cope with, and communicate within, assessments as a result of the advocate's support.
- If advocates' predictions of results are regarded as being close to objective assessments of entitlement, the nearly 40% doing better than predicted might be regarded as further evidence of the service's impact.
- This might suggest that clients are being helped to get more than they are due by advocates, which could be seen as problematic.
- However, assessment and prediction are subjective arts. It seems reasonable to regard at least some of the difference between prediction and outcome as an indication of some capriciousness within the Work Capability Assessment.
- Only 'some of the difference', because the pattern of difference does not seem to be random; the proportion of better than expected outcomes is significantly higher than the proportion of worse than expected outcomes.
- That pattern may, of course, also be impacted by excessive pessimism in advocates' predictions.

ESA Financial Gains: Annualised Income

Actual Awards	Dundee	Falkirk	Glasgow and West	Mid-Lothian	Total
Total annualised income	£83,023.20	£19,476.00	£98,117.76	£44,939	£245,555.96
Annualised Income for clients placed in Work Related Activity Group	£15,935.40	£0.00	£13,000	£5,311	£34,246.40
Annualised Income for clients placed in Support Group	£67,087.80	£19,476.00	£85,117.76	£39,627	£211,318.56

Key Points

- On the usual measure of success in advice projects, annualised income received by clients, the project has achieved substantial financial gains for clients claiming ESA.
- Not all of these client financial gains will be wholly additional, some clients would have received awards without support, or only with the support of advice or other support organisations, but the discussion in the foregoing section suggests that a substantial proportion of the £245,000 is money that the client would not have received without the support of the advocate.

PIP Awards / Comparison to Predicted Awards

	Dunde	Falkirk	Glasgow and West	Mid-Lothian	Total	Percentage
Total Numbers						
Total Number of clients supported through PIP assessment	39	25	51	21	136	
Total number of clients in receipt of decision on PIP application	28	15	43	14	100	
Total number of clients receiving Daily Living Component	27	15	30	12	79	84%
<i>At enhanced rate</i>	11	11	20	7	47	47%
<i>At standard rate</i>	16	4	10	5	32	32%
<i>No award</i>	1	0	13	2	21	21%
Total number of clients receiving Mobility Component	19	9	23	10	61	61%
<i>At enhanced rate</i>	7	5	14	6	32	32%
<i>At standard rate</i>	12	4	9	4	29	29%
<i>No award</i>	9	6	20	4	39	39%
Predictions						
Number of clients with accurate prediction	1	6	23	8	38	38%
Number of clients with worse than predicted outcome	12	3	9	3	27	27%
Number of clients with better than predicted outcome	15	6	11	3	37	35%

Key Points

- Given the way that PIP is structured, and the way the statistics have been collated, it is not possible to identify the total number of clients who have received some sort of PIP award.
- 79% of clients with a decision have received an award of the Daily Living Component, 61% have received an award of the Mobility Component.
- The difference in award rates between the components reflects the client group targeted, made up largely of people with mental health problems, and the significant number of people with physical disabilities/ health conditions.
- For both components, more awards are made at the enhanced rate than at the standard rate.

- The percentage of positively determined awards for Dundee currently sits at 44%, for Falkirk at 57%, Glasgow at 48% and Midlothian at 55%.
- This suggests a significant impact of the service, and others helping clients with claims, on the results of PIP assessments for clients.
- The caveats and qualifications in relation to the ESA figures apply to PIP.
- There is even more variation against prediction for PIP than for ESA; 62% as against 55% of results not being as predicted.
- There is less of a difference between the proportion of clients receiving a worse than predicted result and a better than predicted result than for ESA, there being slightly more of the latter.
- The last two points suggest that the assessment for advocates is harder to call, and there is greater capriciousness of the assessment than with ESA.

Financial Gains: Annualised Income

	Dundee	Falkirk	Glasgow and West	Midlothian	Total
Annualised Income Total	£123,312.80	£89,343.80	£162,271	£63,034	£437,961.80
Annualised Income Daily Living Component	£92,918.80	£58,536.40	£111,379	£44,283	£307,117.00
Annualised Income Mobility Component	£30,394.00	£30,807.00	£50,892	£18,752	£130,845.40

Key Points

- On the usual measure of success in advice projects, annualised income received by clients, the project has achieved substantial financial gains for clients claiming PIP.
- As argued above in relation to ESA, not all of these client financial gains will be additional, but a substantial proportion will be.

Total Outcomes

The tables below set out the figures across ESA and PIP:

- The accuracy of prediction.
- Total client financial gains.

	Dundee	Falkirk	Glasgow and West	Lothian	Total	Percentage s
Number of clients with accurate prediction	3	14	29	14	60	40.0%
Number of clients with worse than predicted outcome	18	5	11	3	37	24.7%
Number of clients with better than predicted outcome	22	9	19	3	53	35.3%

	Dundee	Falkirk	Glasgow and West	Midlothian	Total
Annualised Income Total	£206,336	£108,820	£260,389	£107,973	£683,518

Key Points

- The project has achieved very substantial Client Financial Gains in 6½ months, with gains being 3½ times the cost of the project.
- Given that the slowness with which decisions are made creates a time lag in recording financial gains, this figure is likely to rise to beyond 9 times the initial investment by the end of the project.
- Whilst it is difficult to identify the precise level of additionality in these figures, evidence from client feedback suggests it will be substantial.
- Furthermore, large majorities of the successful claims made with the support of the project will continue for more than a year.

Section 4.5: Qualitative Outcomes

Clients completed an outcome star at the start of their engagement with the project , and at its end/ after the assessment.

The star looks at a six key dimensions of the way people feel about the assessment:

- Their preparedness.
- Their ability to communicate.
- Their confidence in communicating.
- Their understanding of the process.
- Their stress/ worry about the assessment.
- Their general mood and wellbeing.

	Falkirk Before	Falkirk After	Changes	Glasgow and West Before	Glasgow and West After	Changes
Responses						
Preparation	1.89	3.39	1.5	1.45	3.57	2.12
Communication	1.45	3.21	1.76	1.59	3.71	2.12
Confidence	1.26	2.53	1.27	1.57	3.57	2
Understanding	1.81	3.34	1.53	1.79	3.64	1.85
Stress/ Worry	1.1	1.92	0.82	1.57	3.25	1.68
General Mood	1.39	2.66	1.27	1.9	2.96	1.06
	Mid-Lothian Before	Mid-Lothian After	Changes	Mid-Lothian Carers Before	Mid-Lothian Carers After	Changes
Preparation	1.7	3.1	1.4	1.8	3.3	1.5
Communication	1.7	2.6	0.9	1.9	3	1.1
Confidence	1.7	2.4	0.7	1.8	2.8	1
Understanding	1.3	3.3	2.0	1	3.2	2.2
Stress/ Worry	1.3	1.9	0.6	1.3	2.2	0.9
General Mood	1.7	2.5	0.8	2.2	2.5	0.3

Key Points

- The largest impacts are seen on clients' understanding of the process, their ability to communicate and preparation.
- There are significant impacts on clients' confidence about communicating.
- The lowest, though still significant, impacts of the project are on clients' general mood and their levels of stress and worry about the assessment.
- These findings broadly reflect the client feedback discussed in Part 3 of the evaluation.

Section 5: Client Feedback

This part of the report sets out the feedback from the 38 client interviews. It is ordered in a largely sequential fashion, following clients' feedback on the experience from becoming aware of their possible entitlement through to the impact of the decision received on

Section 5 is divided as follows:

- Section 5.1 looks at clients' experiences prior to beginning the application process, how they became aware of potential entitlement, how they made their decision to claim, and their initial feelings when contemplating the prospect of the assessment.
- Section 5.2 looks at clients' experiences of referral, their prior understanding of advocacy, initial contact with the project, the support provided at initial contact, and the impact of that support.
- Section 5.3 looks at clients' experience of the assessment, and the nature of the support provided by the assessor.
- Section 5.4 looks at clients' perceptions of the impact of the advocate on their experience of the assessment.
- Section 5.5 looks at the financial and psychological impacts on clients of successful assessments.
- Section 5.6 looks at the views of clients on how the assessment might be improved in the future.
- Section 5.7 looks at recommendations for changing the service, clients' experience of recommending the service, and clients' overall views of the service.

Details of Interviews

- 38 interviews were carried out in a semi structured format.
- 10 interviews were carried out with clients from the Glasgow/ Lanarkshire and Dundee services respectively, 9 interviews with clients from the Falkirk and Lothian services.
- 24 women were interviewed, 14 men were interviewed.
- In terms of age:
 - 1 interviewee was aged 16-24.
 - 2 interviewees were aged 25-34.
 - 3 interviewees were aged 35-44.
 - 7 interviewees were aged 45-49
 - 12 interviewees were aged 50-54.
 - 8 interviewees were aged 55-59
 - 4 interviewees were aged 60-64
 - 1 interviewee was aged over 65.
- 4 interviewees were not the benefit applicant, but the carer for the applicant.
- 4 interviewees were in work, of whom two were carers, and two applicants.

All interviewees' names have been changed.

Section 5.1: Prior to Engagement

Section 5.1.1 Awareness of Entitlement

Interviews explored how clients who had not previously been claiming PIP or ESA had become aware of their entitlement to benefit.

For a number of ESA claimants, their claim had been a follow on from a claim for Statutory Sick Pay. Noticeably, those in this situation had not been aware of ESA previously, and their GPs had played the key role in signposting them towards entitlement:

'I got sick pay when I went off work. I didn't know anything about benefits. In 38 years I've never asked for anything. My doctor told me to claim ESA and that I wasn't fit to go back to work physically or mentally.'
(Emma, 56, Glasgow)

'I went to see my doctor for sick pay. I was working for an agency so that didn't happen. The doctor said that I should go onto ESA' (Claire, 53, Glasgow)

Some clients had been told about the availability of PIP or ESA by organisations that were supporting them on issues other than benefits:

'It was the Carers' Centre that encouraged me to apply, they put me onto it'
(Phil, 45, Dundee)

'I went to the Carers Centre to ask them if I would be entitled to Carers Allowance, they told me about PIP' (Margaret, 61, Dundee)

In one instance, Job Centre Plus had made a client aware of his entitlement to a higher level of support:

'The girl at Job Centre Plus thought I should be in the Support Group. I was in the WRAG, she [disability advisor at JCP] thought that this was wrong and said I should be in the Support Group' (Neil, 59, Falkirk)

Some had learnt about the availability of benefits informally from friends or acquaintances:

'I was sort of told by one of my customers about the benefit. I didn't know that I could claim it.' (Parveen, 32, Dundee)

Several clients held beliefs about their entitlement, sometimes erroneous, which put them off applying:

'I didn't think I could get the care component of DLA because I thought my husband was helping me so I couldn't claim.' (Nicola, 47, Glasgow)

'I didn't really think I was entitled to any benefits [the interviewee had been refused DLA on a couple of occasions previously], but Kirstie at Grapevine encouraged me' (Nadia, 34, Midlothian)

'I generally think I'm not as bad as that' (Claire, 53, Glasgow)

For others, their general life situation acted as a deterrent to applying:

'I heard about DLA from a friend who claimed it. So much was going on that it never crossed my mind to claim it.' (Claire, 53, Glasgow)

Even clients who were aware of the system professionally did not always realise their own potential entitlement to support:

'I work as a support worker, and I help people with benefits sometimes. But it's one thing applying for a benefit for someone else, it's another thing to apply for it yourself... I thought I wouldn't qualify but someone told me to go and see Jane' (Sandra, 49, Carer, Midlothian)

Section 5.1.2 Reasons for Applying

For the vast majority of clients the decision to apply for ESA or PIP was either not really a decision, because they were responding to contact from the DWP transferring them to a new benefit, or, in the cases below, because they felt compelled to apply by their life or more particularly their financial circumstances:

'I really only applied at the point I did because I was really not coping. I was not getting anywhere with the pain clinic. I just felt totally lost and in deep depression. I was missing appointments because I didn't know where I was.....

My friend gave me a push to apply, she said if I didn't she would phone up for me' (Parveen, 32, Dundee)

'We'd reached the stage of being homeless within a month'
(Nadia, 34, Midlothian)

'I was told to go for ESA. I'd been suspended from work and things were very difficult' (Lorraine, 58, Midlothian).

'I went for PIP mainly out of desperation [despite previous experiences of being knocked back for DLA]. The condition is the worst thing, but living on a low income is also bad, is also stressful and I get in a guddle with money.....

My daughter has a muscular condition which is deteriorating. We support each other, but I can't rely on my daughter to help in the same way, particularly as she's also struggling with her young child. There is a limit to how much I can ask my daughter to do. I needed help, and I thought I might be able to get someone in' (Sarah, 50, Midlothian)

Other clients had decided to apply for more positive reasons, encouraged by organisations that were supporting them:

'The Carers' Centre suggested that PIP would give me the chance to do my own thing and get some proper support for myself. I care for my partner 24/7 and I don't get the chance to do much myself.' (Phil, 45, Dundee)

A small number of clients had applied in the context of their condition worsening, some weighing up carefully whether they wished to pre-empt their transfer from DLA to PIP:

'I'd been on the lower rate of DLA previously, but my condition was worsening, so I thought I would go for it' (Laura, 43, Midlothian)

'I'd been claiming DLA for a good while. I got into contact with welfare rights at the Council. We had a long chat about my health getting worse. They suggested that if I wanted to, I could go for PIP, I might get more.....

I had a long think about it. I didn't want to lose my [motability] car and then get stuck at home. It was a big question for me, what was the right thing to do? It was stressful thing to think about, I was really worried about it.'
(Gerry, 66, Dundee)

'I got a letter through saying we're going to move you over from October. I thought it's July and I may as well get it done anyway, it was going to happen'
(Sheila, 50, Falkirk)

Section 5.1.3 Clients' Initial Feelings about the Assessment

Interviews explored in detail how clients felt when they became aware that applying for PIP or ESA would probably involve a face to face assessment.

Response to Letters.

Some clients related how they had responded when they received contact from the DWP informing them that they were being called to an assessment.

For those who raised this as an issue, the letters had clearly occasioned a significant degree of panic:

'I was really worried when I got the letter. I thought they were going to take my money off me, I was really nervous' (Robert, 38, Dundee)

'I was getting letters telling me to go to Edinburgh and I was terrified because I didn't think that I would be able to get there' (Kathryn, 50, Falkirk).

Significant Stress in Anticipation

Anticipation of the assessment was very clearly the source of substantial stress for clients:

'I was worried about the assessment. Just the actual fact of having to go there, the outcome. The idea of seeing someone that didn't understand what you were going through. How would I be able to explain myself?' (Joanne, 46, Glasgow).

'I was really, really anxious. It was horrible. I ran away from everything. I lost my memory because of this. I couldn't even remember my own name. If someone asked me something, I couldn't answer.' (Emma, 56, Glasgow)

'When they told me about the assessment, I had a panic attack. It was partly the thought of going to Edinburgh, having to go out of the house without someone with me. Total panic set in.....

When they postponed the assessment it almost felt like a relief, but I knew it was something that I had to go through' (Lorraine, 58, Midlothian)

One carer reported how she had seen the anticipation of the assessment impact upon her husband:

'There was definitely a drop in his health. Both physical and mental, for him the two are really intertwined, the anxiety impacts on his pain levels.'
(Sandra, 49, Carer, Midlothian)

For one client, with previous very negative experiences of the benefit system, that stress reached the level of contemplating suicide:

'Before VOCAL, I was worried about the assessment. Of course I was, I've got mental health problems and severe anxiety. ATOS don't care about anything, they aren't nice people.....

It was making me very anxious, the thought of the assessment. I said that if I didn't get through the assessment this time, I would kill myself. I had plans to do it. I had been pushed to the brink and I had had enough. I was stressed out to the max.

I told Jane this. If I didn't get it, I'm going to end it, I couldn't take any more of this crap' (William, 52, Midlothian)

The impact of the stress could have physical manifestations:

'I was making myself physically sick, just the actual thing of talking to people'
(Nicola, 47, Glasgow)

'It was impacting on my health. I get asthma and this was triggering attacks'
(Robert, 38, Dundee)

'I was very nervous about the prospect. I was panicking, not sleeping, getting agitated' (Gail, 60, Falkirk)

'He was worried about me, my stress levels were going up and this was impacting on my blood pressure and my eyesight' (Laura, 43, Midlothian)

Two clients used variants of phrase that was revealing about attitudes towards mental and physical health, one is quoted below:

'It's not really my health, that was getting affected, it was my nerves'
(Gail, 60, Falkirk)

Sources of Worry

People's previous negative experiences of assessments or appeals where they had not received appropriate outcomes were clearly one of the drivers of their stress:

'The last assessment was all lies. They wrote down the opposite of what I said, it was a complete bunch of lies.... I thought this is going to be the same, I won't be able to get over what I want to say.... I'm not good at meeting people on my own' (Stephanie, 52, Glasgow)

'I was worried about the assessment itself, the impact it would have on his [her husband who was the applicant] and my health....It was already beginning to impact on his health....

I was worried about the outcome because I know there are assessors who don't have a mental health background. They focus on the physical stuff, and don't want to know about mental health' (Frances, 51, Carer, Dundee)

Two clients had had particularly negative experiences of previous appeal tribunals which had left them worried:

'I was extremely stressed about the assessment. I had been to appeal before, that was such a process. I turned about and walked out, I really struggled.' (Barbara, 53, Glasgow)

'It [the appeal tribunal] was just like being in court. It was very intimidating. I thought if that's what they do for ESA, what will they do for PIP? It will be like going to Barlinnie or something.' (Andrew, 43, Falkirk)

For one client, previous negative experience had been piled upon negative experience with serious consequences:

'I've tried to take my life five times because of these assessments. I took co-codamol and Bacardi, two and half litres and I survived that.' (William, 52, Midlothian)

For other clients, the source of their worry had been media reports about the way that assessments are carried out, or feedback from friends and family:

'I was worried that the person wouldn't know about my illness. I was hoping that I would get someone who understood. You read all these things in the papers and you worry' (Gerry, 66, Dundee)

'When I got the letter it was a lot of stress. I'd just heard from friends how bad it was, just through the grapevine' (Kathryn, 50, Falkirk)

Clients were concerned about their ability to cope emotionally within assessments, and their ability to communicate to ensure success.

'I was panicking. I was thinking, how am I going to get my point across in half an hour or forty five minutes? I was worried about answering the questions wrong' (Barbara, 53, Glasgow)

'I wasn't looking forward to the assessment at all. I was really scared about the idea of doing it alone. When I get nervous, I clam up and go quiet. I was nervous about getting the chance to say what I needed to say on my terms.'
(Phil, 45, Dundee)

'I found the idea absolutely terrifying. I get so anxious and I was getting more and more worked up about it, and finding it difficult to cope with the idea.

[what worried her was] trying to explain the ins and outs. I'm always worried about being taken seriously, about things not being interpreted as serious.'
(Laura, 43, Midlothian)

For some clients this concern had grown in the context of their illness not being taken seriously more generally:

'I thought I'd be treated like a number, that no-one would believe me. People look at me and they think I am young and well. I don't have a walking stick or anything. They don't see that I'm ill. They don't see the support that my mum has to give me 24/7, that she's there with me all the time, that I sometimes have to crawl to the toilet if she's not there' (Parveen, 32, Dundee).

Other clients were concerned about being able to cope emotionally:

'Hearing yourself say those things is very difficult, particularly when you have been pretending that everything is OK. You can live in the past, when [her son whose death four years ago had triggered the problems] was here and everything was great, or you can live in the future when you think how things are going to be, but living in the now and hearing yourself say those things is very difficult.' (Tracey, 47, Falkirk)

One client, a carer for her teenage son with a learning disability was concerned about his ability both to communicate with the assessor, and to cope emotionally in the process:

'I was very worried about the interview, more particularly what it would be like for my son. I thought that he would struggle to answer the questions with it. He would not quite understand it.....

I didn't feel confident about it. You read about these things on the TV and in conversation and you worry. There are no go areas with him, and he is not very good at explaining anything on a touchy subject.' (Caroline, 47, Carer, Falkirk)

The simple prospect of being faced with someone unfamiliar was a source of nervousness for some:

'It was just the thought of going into a room with someone I didn't know and getting asked lots of questions' (Gail, 60, Falkirk).

Anger about Assessments

The stress people were experiencing could manifest itself in a degree of anger about the situation that they found themselves in, and the way that the system was treating them:

'I was really depressed and stressed about the assessment. It's something that you don't expect, that you have to explain yourself to a doctor, and then go and explain something to another health professional, so that they can make sure that you are telling the truth.....

It's like me telling you that I'm 23 and you getting someone else to check that. Proving things once should be enough. It's just the whole idea of having to go through it all again with someone.

I was worried about my benefits getting cut, worrying about that happening and that they'd tell me that I was lying.' (Lee, 23, Glasgow)

Relaxed/ Ambivalent Attitudes towards Assessments

A small minority of the clients interviewed appeared to be able to take a more relaxed attitude to the assessment that lay ahead:

'I wasn't nervous at all. I'm just me, I don't tell lies, so there was nothing to worry about, I wasn't bothered at all.' (Gary, 59, Dundee)

Others felt ambivalent at the prospect, or felt that other worries were more pressing:

'I wasn't really worried about the assessment. I do get a bit anxious before I get talking to people to people but I thought I could cope'
(Grant, 53, Midlothian)

'I wasn't really worried about the assessment, I don't tend to worry about those things. I know what's wrong with me. Compared to worrying about being able to walk the assessment wasn't bothering me. Perhaps I was a wee bit apprehensive, having someone in your home and thinking about what they would say. But I always say if you tell the truth then it can't go wrong. Yeah, you do have to talk to people you've never met before. But if it doesn't go right, doesn't go your way, you can always appeal.' (Thomas, 59, Midlothian)

Section 5.1: Key Points

- **Organisations already supporting clients have a key role in telling people about their entitlement to ESA and PIP.**
- **A lack of knowledge of entitlement, even from those who might have been expected to have better knowledge, and, often erroneous, beliefs about entitlement are barriers to claiming.**
- **People are often pushed to claim ESA or PIP by the worsening of financial circumstances.**
- **Deciding to submit a new claim is not an easy process where there is a risk of losing existing benefits.**
- **Clients face significant stress in advance of face to face assessments, notification letters can act as a specific trigger.**

- **This stress can even result in attempted suicide.**
- **Stress may also be physically manifested negatively, impacting on physical health.**
- **Previous negative experience of face to face assessments and tribunals is a major trigger for stress.**
- **Clients worry about their ability to communicate at face to face assessments, and their ability to cope emotionally. Carers may have particular concerns about relatives they support.**
- **A minority of clients were relaxed or ambivalent at the prospect of assessments.**

Section 5.2: Referral and Initial Engagement

Section 5.2.1 Experience of Referral

Interviews explored the means by which clients had been referred to their respective delivery partner, and their experience of referral.

Two stage referral

A number of clients had gone through a two stage referral process; being advised to seek support with a benefit claim from a referral partner, or from another section within a delivery partner, and then referred on to the delivery partner for advocacy support:

‘The Carers Centre passed me on to the CAB. The CAB said that there was someone they could put me in touch with if I needed someone to go with if I was uncomfortable with going by myself, and they sent me down to FVA.’
(Caroline, 47, Carer, Falkirk)

‘Job Centre Plus told me about VOCAL. I go in for a carer’s assessment every few months and they sent me down. I went into Johnstone Terrace [one of the VOCAL offices] then they passed me on to Jane’ (Janet, 56, Carer, Midlothian)

For some clients, arrival at the service came from them making use of their already existing relationship:

‘VOCAL have been helping me for a bit. I went to see the CAB adviser who comes in. They helped me with the forms then passed me on to Jane’
(Lorraine, 58, Midlothian)

One client had come a circuitous route to the service, through a number of experiences with other organisations that had been less than satisfactory:

‘I went to the CAB. They messed things up, told me things that weren’t true, that the Scottish Government was taking over benefits in October 2015.....

I got in contact with Nicola Sturgeon’s office, and they put me in contact with Jane’ (William, 52, Midlothian).

Offer of Support and Seeking Support

Some clients had proactively sought support to accompany them to their assessment from an organisation they were already engaging with, and had then been referred on because the organisation working with them could not offer that type of support, or could not on this occasion. Some of these clients had also initially looked to family members for support:

‘The people at the Carers Centre didn’t mention Vonnie at first, but then they couldn’t attend and they passed me on’ (Nicola, 47, Glasgow)

‘I was going to ask my son to come with me. When he couldn’t make it, I asked the CAB, but they couldn’t, it’s not their remit, and they put me on to Adam’
(Claire, 53, Glasgow)

'Initially I hoped that my cousin would go with me, she's a social worker in Aberdeen. She couldn't make it. I asked welfare rights who were doing my form, and they passed me on to Vonnie' (Patricia, 62, Dundee)

One client had sought help from one organisation and not been able to get it, coming to the project through a more roundabout route- through a different organisation who helped her with her application to the service:

'I got help with the forms but I still felt I needed support. I did speak to the RNIB, but they didn't have anyone available to do it. They didn't have the staff to do it' (Laura, 43, Midlothian)

One client had sought advocacy help in something approach desperation, having not been able to get help from anywhere else, and having an existing relationship with the organisation:

'They had helped me with my daughter. I didn't know anything about the benefits service. I'd gone to the council's welfare rights, but no joy, they said they couldn't help me.....

I phoned up The Advocacy Project and said that I'd tried other places and no one had got back to me. I was really tearful and I told them that I didn't know what to do. They sent someone straight away. Gail came out to see me, but when she did she realised it was help from the project that I needed. She phoned the manager and checked that it was all right that Adam could come and see me.' (Emma, 56, Glasgow)

Some referrals from referral partners were based on proactive offering of the service:

'We were talking about Jane's service when Grapevine were helping me out. When the letter came back with my assessment date, they put me in touch.' (Nadia, 34, Midlothian)

'I got a letter through from DIAS. I was an existing client, they had been helping us with something else.' (Frances, 51, Carer, Dundee).

This could be in response to referrals partners' observations of a client:

'They saw me walking with sticks and said I might be able to claim PIP. Shona at the Carer's Centre helped me fill out the form and then told me about the service' (Margaret, 61, Dundee)

Others seemed based on a joint conversation about what lay ahead:

'Craig and I thought that I couldn't express myself very well, and Craig said that there was someone who could help with that. We thought I needed help to talk about the things that I couldn't get down on paper very well.' (Malcolm, 62, Dundee)

'I just said I can't do this alone. I can't go in there by myself'
(Kirsty, 52, Dundee)

That process of referral could take a degree of reassurance from the referring partner about the service the delivery partner would offer:

'Craig at the CAB was giving me a lot of help. He explained about the service, that it was there if I really wasn't able to manage. He made clear that they were really nice there, he reassured me about that' (Parveen, 32, Dundee)

'They said FVA would send someone in with me. I was very stressed before I met Ian. He gave me someone else to contact, someone who could confirm that on the basis of what I had told him, I would be entitled to ESA. That helped me. It also helped me that he gave me a named person to contact. It meant that I wasn't having to find someone and chase them up, I wasn't having to wait to get a call back, missing them, calling back.' (Tracey, 47, Falkirk)

The Role of Happenstance/ Informal Referral

Feedback from some clients illustrated both the importance of happenstance in people finding a route to the service, and its limitations.

One client worked for one of the delivery partners but had not immediately considered claiming benefits, or seeking support with her claim, until a chance conversation with her colleague:

'I was having a chat with someone at work about things at home with my husband, and she just said, why not go and have a chat with Jane'
(Sandra, 49, Carer, Midlothian)

Some clients had been told about the project informally:

'It was my mum who told me about the service. She had heard about it from a few people and she said if I wasn't comfortable going by myself, I should give them a shout and they'd help me' (Lee, 23, Glasgow)

Another client was familiar with the advocacy field through her previous employment, but not with the specific delivery partner, happenstance does not always work:

'I knew of advocacy because of my work. You would see advocates come into the Job Centre with clients. But I wasn't familiar with VOCAL'
(Laura, 43, Midlothian).

One client had been aware of her local delivery partner through another source, though as she remarked herself, she had actually ended up being referred by another organisation, rather than using that knowledge to go and seek support for herself:

'DIAS were looking at renting an office in the place I was managing. I'd even thought of retraining for advocacy myself at some point. But I didn't have any idea that help like this was available' (Patricia, 62, Dundee)

Section 5.2.2 Prior Understanding of Advocacy

Clients were asked if they had heard of advocacy before they were referred to support from one of the partner projects.

Most interviewees had not heard of advocacy services before:

'I didn't know what advocacy was, it was all new to me.' (Grant, 53, Midlothian)

However, once the concept was explained it was perfectly understandable:

'I'd never heard of advocacy before, it made sense once they explained'
(Andrew, 43, Falkirk)

'I didn't know what advocacy was. I'd never heard of them. They told me that someone would help me at the assessment, and it made sense then'
(Joanne, 46, Glasgow)

One client was clear at this point of the interview about the need for advocacy services to raise awareness of what they could offer people:

'I'd never heard of advocacy before. I don't think a lot of people know about it. It was such a huge help for me, and I think it should be a well known thing.'
(Nicola, 47, Glasgow)

For some clients their understanding of advocacy was hazy or had been lost, rather than being straightforwardly absent:

'I'd heard of advocacy before, but I'd forgotten about it. I couldn't have said what it was about' (Barbara, 53, Glasgow)

Others had previous experience of using advocacy services before, or had relatives who had such experience, whether provided by the delivery partner or not. Those who had such experience had still not been aware that support within benefit assessments might be available to them:

'I had heard of it before, I've used CAPS [a Midlothian based mental health organisation]' (William, 52, Midlothian)

'I'd heard of advocacy before. My niece is in [local psychiatric hospital] and she has been getting help from FVA. I didn't know [before I was referred] that something like what Ian does was available' (Neil, 59, Falkirk)

'I knew about the organisation. They helped me when I was looking for a diagnosis for my daughter' (Emma, 56, Glasgow)

Section 5.2.3 Support Received at the Initial Meeting.

Interviews discussed what support advocates provided at the initial meeting with clients.

The tasks undertaken by the advocates with clients were:

- Making time to get to know the client.
- Drawing out information from clients that is not present on application forms.
- Working through the forms to understand the basis for their claim.
- Discussing in detail the impact of conditions on clients' day to day lives.
- Discussing how capable they felt of dealing with the assessment.
- Discussing their past experiences of assessments.
- Highlighting how they could make the test more comfortable, that they could ask for a break, that they could ask for a glass of water, that they could get up and move around if they are uncomfortable.
- Clarifying the situation in respect of carers/ family members also being present within the assessment.
- Familiarising clients with the process.
- Talking through the practical aspects of the test and what to expect, what the room would be like, how long the test might last.
- Going over the questions that would be asked at the interview.
- Going through in detail key answers to questions.
- Agreeing strategies for responding if they find certain questions emotionally difficult, or are in some way not coping with the test.
- Drawing up a list of key points that would get covered in the test.
- Agreeing information and documents that they should bring along with them.

In Depth Exploration

The initial meeting with the advocate is often a very in-depth exploration of their situation for clients, and sometimes their carers.

'We talked about absolutely everything, all the physical and mental health problems that I have' (Nicola, 47, Glasgow)

That in-depth exploration could still be quite an informal process:

'We talked about all my past experiences and how my health conditions have been ignored. She was trying to get all my background information from me, but really it was just like sitting down with a cup of coffee and having a blether' (William, 52, Midlothian)

Being prepared to deliver this in client's homes has been a key part of successful engagement:

'The first time they met, Jane came out to see me. That was incredibly helpful, I don't go out and about much to do things, it depends on the state of my body. It's not always possible for me to go and see someone.

I spent a couple of hours answering questions. I was scared, I have had a lot of experience of people who were meant to help not really helping. Jane made me feel better about the whole thing.....

She talked about the assessment, and talked through my medical history and form. She made time to get to know me and my situation. She also met my husband and clarified that he could come too and that he could ask questions too' (Nadia, 34, Midlothian)

Preparation and Reassurance

Talking through clients' answers to key questions, advocates had focused on the need for them to give sufficiently detailed answers:

'They talked things through openly and honestly. Ian went through the questions, explaining everything, explaining that I should say on how many days I felt like that, how often I felt like that' (Lisa, 53, Falkirk)

'He told me what not to say. He said that if you just said that you could do something, without explaining that it was difficult, you would fail straight away. He gave the example of making a pot of stew. I might say that I could do it, but could I do it every day, was it difficult for me? He made clear that I needed to tell them how it was' (George, 60, Falkirk)

The provision of reassurance was described over and over again by clients as a central part of the support provided by their advocate:

'We talked through the questions that would be in the assessment, and Ian told me not to panic about any of them. He would be there to make sure that I would answer right.' (Gail, 60, Falkirk)

Preparation not Coaching

A number of clients were keen to stress that they didn't feel they had been coached to give the answers:

'We really got into the detail of what my condition means for me.....We didn't so much plan what we were going to say, she was explaining what I might expect-though obviously you can't know exactly what they are going to say in advance.' (Sarah, 50, Midlothian)

'Jane explained what to expect, and how to conduct myself. She wasn't telling me to lie, she made clear that I should only say something if it applied.

At one point my husband said, 'should I say that?' And she came back straight away and said 'only if it's true' (Lorraine, 58, Midlothian)

Discussion of Previous Assessments

Advocates took the opportunity to explore clients' past experiences of assessments, identifying where issues may have arisen which led to inappropriate outcomes.

For some clients, issues of embarrassment and pride had been an issue at a previous assessment, and they needed reassurance to ensure that they were prepared to talk openly about their experience:

'He told me that my pride might have got in the way. There were some things that were personal and I didn't want to talk about them the last time.....

He made it clear that I should say everything. He suggested that if I told them everything I would probably be entitled. He wasn't coaching me, he was just understanding what the problem had been.

I have IBS so I can't go far from a toilet, I have to wear Tena pads and I hadn't told them about that. Ian said that I had to tell them everything, but I was not to worry as he was there to support me.' (Lisa, 53, Falkirk)

'Ian highlighted that I said I had turned up at the first assessment with my hair done and my make up on and looking presentable. But you have no idea how much effort that took.....

He said that how I presented was something that would be being looked at. He said you don't need to make a massive effort to turn up all presentable, it's your illness that they are looking at. You are not there to pretend that everything is OK, you are there to let them know how bad things are.' (Tracey, 47, Falkirk)

Other Issues

Advocates had also used the initial meeting to communicate some basic information about the benefits that people were applying for:

'He had this big folder full of leaflets. That was all about explaining the benefits, telling me about the money I could get and the different types of ESA.'
(Michael, 58, Glasgow)

One of the carers interviewed reported that even sitting with the advocate talking about the assessment had proved too difficult for her son, and that most of the initial meeting had taken place without his involvement:

'I told him someone was coming, and he was there at the start, but after a minute it got too much, and he left.

In some ways it was easier without him, it meant we could go right through the questions' (Caroline, 47, Carer, Falkirk)

A number of clients had been in contact with the advocate more than once before the assessment. For some, this was because the advocate was providing some form-filling support alongside preparation for the assessment. For others, it involved the provision of a degree of emotional support:

'I did phone up a few times, including the night before. I was so stressed, I needed that bit of reassurance that things were going to be OK.'
(Parveen, 32, Dundee)

Section 5.2.4 Views on the Initial Experience of the Service.

Interviewees were asked about their initial experience of the service from the delivery partners, essentially to explore the ability of advocates to establish a rapport with them.

Without exception, experiences of initial engagement were positive. Some clients simply expressed an overall judgement on that initial contact:

‘It was a brilliant meeting, excellent, really clear’ (Stephanie, 52, Glasgow).

‘We sat down and talked about it all. It was fantastic.’ (Sarah, 50, Midlothian)

Clients returned over and over again to the personal characteristics of the advocate and the impact that had on their experience of initial contact.

Advocates were seen as being able to establish a sense of trust with clients allowing them to relax and open up:

‘A lot of the way the service is, is to do with Jane, and who she is, just a lovely, lovely person. I felt really safe with her, and that’s the key to being around people for me’ (Sarah, 50, Midlothian)

‘Everything, her professionalism, the way she came across’
(William, 52, Midlothian).

The way in which the service managed quite delicate situations was highlighted:

‘In terms of her help, I don’t know where to begin. I was up to high do when I met her. She was so calm and reassuring and patient. I get overloaded so easily by questions, I get so stressed by them, and she really took her time.’
(Sarah, 50, Midlothian)

Other personal characteristics were also apparent to clients:

‘She was amazing, so patient and understanding. She completely understood the situation when she was asking questions, and she wasn’t patronising at all’
(Nadia, 34, Midlothian)

‘He’s so easy going, it’s unreal. He’s very pleasant and down to earth.’
(Neil, 59, Falkirk)

Clients appreciated the professionalism and understanding of the advocates. That was the case across the projects, with the abilities of the youngest of the four advocates still securing the appreciation of clients despite his relative youth:

‘She was really good at explaining questions and what would actually happen. She was pretty much right on everything she said’ (Lorraine, 58, Midlothian)

'I felt very at ease with Ian. Though he's younger than me, he's very professional, I just felt very much at ease with him. He was just very understanding' (Lisa, 53, Falkirk)

'I felt comfortable very quickly. He's a young man who knows his stuff' (Andrew, 43, Falkirk)

One client was very explicit about what he saw as the contrast between his advocate and other professionals who had delivered other services to him in the past:

'I feel like he actually got to know me. I think he got to know the actual me. They treated me like a human being not like dog shit.....

Sometimes I've felt that for other people who have been meant to help me it's just a nine to five thing, but Adam really cares.' (John, 46, Glasgow)

One client had been left with a much stronger impression of his advocate than the actual content of that initial meeting:

'That first meeting was very helpful, Jane is a very helpful person. I can't remember the specifics, but I know she went out of her way to help' (Thomas, 59, Midlothian).

Section 5.2.5 Impact of Preparation on Client's Pre-Assessment Experience.

Interviews explored the impact that preparation work with the advocate had on the experience of clients.

Some of this feedback, relating to the impact of the preparation work on the ability of clients to communicate and cope with the psychological challenge within the assessment is explored in more detail below. This section focuses on the impact of preparation on the *feelings* of clients going into the assessment.

A number of clients reported that the initial/ preparatory meeting had a significant positive impact on their feelings going into the assessment:

'After the meeting I felt very different. I felt that I could go through it. Before I thought, I can't face this, I can't get through. Afterwards I felt that I had back up from someone who knew the system. Something that could have been very difficult was something that I thought I could get through. I felt better because I knew what to expect.....

I had been self harming, but I stopped cutting myself after I saw Jane.' (Nadia, 34, Midlothian)

'She reassured me, and I was feeling petrified and terrified' (Laura, 43, Midlothian)

'She was a really calming influence. I was cool as a cucumber walking in [to the assessment]. I didn't have to worry' (Patricia, 62, Dundee)

That impact could be seen in terms of increasing people's confidence that they would be listened to:

'We went through all the questions. It gave me just that little bit more confidence that they were going to listen to me.' (Malcolm, 62, Dundee)

For others, the preparatory meeting might be best seen as taking the edge off their nervousness and anxiety about the assessment, rather than transforming their feelings about it:

'I didn't feel confident, that would be pushing it. But I did feel better than I had before the meeting.' (Sandra, 49, Carer, Midlothian)

One client seemed to draw a revealing distinction between her different feelings prior to the assessment, between natural nervousness, and feeling prepared:

'She calmed me down really.... But I still felt I was going in blind. She'd talked me through it but I was panicking about the decision. I was worried that I was going to say something wrong, what was going to happen to me, would it go for or against me...

I would have been nothing like as prepared if it hadn't been for Jane. I don't think I would have got to that point' (Janet, 56, Carer, Midlothian)

One client stated that engagement with the advocate had given her permission to seek help and support, something she hadn't felt the first time she had applied for ESA:

'He managed to make me feel that my claim was genuine, that I wasn't just at it.....

I was made to feel that it's OK, it's just about where I am right now, it's not who I am, or who I am going to be. I just need someone to help, and someone to support me, and somebody there with me.' (Tracey, 47, Falkirk)

One client reported a more negative experience with the advocate, feeling that his advice had actually led to her being more stressed:

'It did seem a little OTT, having to get together all these documents. It got me really stressed about the whole thing, I didn't sleep the night before.'
(Sheila, 50, Falkirk)

Section 5.2: Key Points

- **Clients take a variety of routes, of varying complexity, to the service.**
- **Some come through organisations they have an existing relationship with, some pass through referral partners first, and some come from elsewhere within the delivery partners.**
- **Clients may have been offered referral by referral partners who felt they needed it, or may have initially proactively sought advocacy type support from referral partners. Some may have initially sought emotional support from family members.**

- **Some clients require a degree of reassurance about the service before accepting referral.**
- **Informal referrals and chance still play a significant role in people accessing the service.**
- **Advocacy is not well understood by people who have not used advocacy services before. It is however, a concept easily grasped once explained.**
- **Advocates undertake a variety of tasks at initial meetings centring on familiarising themselves with the client's case, building a rapport with clients, and preparing for, and strategizing in relation to, the assessment. Advocates are clear that they do not coach clients for the assessment.**
- **This preparation work is in depth, and throughout contact advocates will seek to provide clients with reassurance.**
- **Meetings are often carried out in an informal way, in a clients' home or local meeting place.**
- **Initial contact is also an opportunity to talk through previous experience of assessments.**
- **Clients are very positive about initial contact.**
 - **Advocates are seen as patient, kind, calm, reassuring, caring and capable of building up a relationship of trust.**
 - **Experience of the way advocates work is sometimes contrasted with experience of other support services.**
- **The initial meeting is often successful in providing reassurance to clients and reducing their stress, though this might extend only to 'taking the edge off' a stressful situation.**

Section 5.3: Client Experience of the Assessment

Section 5.3.1: Clients' Overall Experience of the Assessment.

Clients were asked to describe their overall experience at the assessment.

Stress throughout the process

For many clients, the experience immediately prior to the assessment remained one of substantial stress, and of feeling that, despite the input of the advocate, they remained unprepared for what lay ahead. This could sometimes be the result of previous negative experiences of assessments, or for the simple reason that their assessment had been delayed:

'I wasn't confident and prepared at all. I was worried about getting my point across. The assessor [at an earlier ESA assessment] spoke over me and I don't think I got the chance to say what I needed to' (Claire, 53, Glasgow)

'I was so tearful at the assessment, I got myself into a huge state, because I'd been waiting for so long.' (Emma, 56, Glasgow)

That stress continued into the assessment for some clients, something that was often seen as an inevitable response from their condition to a difficult situation:

'I did find it very stressful. I was shaking in the taxi going there, and on my way into the building.....

That's my condition, to feel like that. To get a bad reaction. I get very nervous, that's what I struggle with' (Laura, 43, Midlothian)

For some clients, the stress experienced at the assessment was just part of a period of worry stretching from the making of the initial application to the receipt of a decision on their claim:

'He didn't cope well. At the test perhaps he wasn't as bad, but afterwards the problem started. He was really down for the next 2 or 3 weeks, whilst we waited for the result' (Sandra, 49, Carer, Midlothian)

'It was 10 out of 10 for stress, or maybe 8 or 9. Then just not knowing the result and how you were going to feel. The waiting was tough, waiting on an answer' (Janet, 56, Carer, Midlothian)

Triggers for Stress within Assessments

Some clients identified specific aspects of the assessments which triggered negative emotions, including the invasion of privacy and personal nature of the questioning:

'The assessment was awful. The young man who was asking the questions was pleasant enough, but you are being asked about things that you wouldn't tell your family.....

I felt very exposed by it, I felt left wide open by it. It's a horrible thought that it's written down about you, that it's out there somewhere in the ether, all my

personal details are there for someone to read through. I was really despondent for a couple of days afterwards.' (Sarah, 50, Midlothian)

Others saw stress as inevitable given their own personality:

'I was terrified in the interview. The tears did come, I'm quite an emotional person anyway' (Sarah, 50, Midlothian)

The Extent of Stress or Discomfort

That stress could have physical manifestations:

'At the assessment I was really panicking. I just kept missing breaths. I felt I was in there to be judged' (Parveen, 32, Dundee)

'I was really nervous, I was scratching myself all the time. I was really upset, I didn't feel confident, didn't feel prepared, I didn't know what I was getting into' (Robert, 38, Dundee)

Others reported a high degree of physical discomfort in the test, either for them or for their partner:

'It was difficult for [her husband]. He had to get up and walk about a fair bit because of his back, he needs to stretch it a lot. He was physically really uncomfortable, it was a cramped wee room with hard chairs' (Sandra, 49, Carer, Midlothian)

Some clients remained angry at the experience of being in a face to face assessment:

'I felt awful and couldn't get out quick enough. What they are putting people through to get benefits is disgusting.' (Lorraine, 58, Midlothian)

One client had tablets to try to calm him before the assessment. This had ended up negatively impacting on its outcome:

'I took a lot of tablets the first interview I went for [for ESA]. I was completely out of it, I don't remember being there. Ian thinks it hit my chances....

The next time I didn't take anything, but I couldn't sleep at night, couldn't even concentrate on the TV, nothing' (George, 60, Falkirk)

Mixed Experience

Other clients reported a more mixed experience, suggesting in one breath that they had felt very stressed, whilst explaining earlier or later in their interview aspects of it that had gone well:

'The assessment was nerve wracking.....

I was able to say everything that I wanted to.' (Joanne, 46, Glasgow).

'I was mostly at ease in the assessment.....

I wasn't really able to say all that I wanted to, I didn't get everything out. I did start to get emotional. You are sitting there and she is typing whilst she's talking to you' (Kirsty, 52, Dundee)

'I can't remember the assessment that well, it was a bit of a blur. But I think I got across everything I wanted to say.....

The overall experience was very stressful. My anxiety levels went through the roof.....

I felt very confident and prepared for the assessment.'
(William, 52, Midlothian)

As well as some judging different aspects of their experience within the assessment positively and negatively, some clients reported that they had felt less stressed as the experience had gone on:

'At the start I was really stressed, but once I got into it, it was OK'
(Kathryn, 50, Falkirk)

Positive Experiences

Some clients reported a more positive overall experience. This could be as a result of feeling that they had been able to communicate all they wished to within the assessment, or because of the way they were treated by the assessor.

The first person quoted below had indicated that they had initially not felt at all confident or prepared because of past negative experience:

'It was a very easy assessment. The assessor seemed to realise what was wrong and leave it at that. It was surprisingly easy. The assessor didn't ask me to do anything that I would have difficulty doing' (Claire, 53, Glasgow)

'I walked out [of the assessment] feeling that I'd said everything.'
(Patricia, 62, Dundee)

Some clients appeared to take a fairly phlegmatic attitude towards the test, generally the same ones who had been less stressed going into the test:

'I didn't find the experience that stressful. I've had people shooting at me, so talking to a woman in a room wasn't going to bother me' (Gary, 59, Dundee).

A number of clients identified that their condition had manifested itself within the assessment, something they felt had been to their advantage:

'I had a coughing fit which showed how difficult things were with that'
(Patricia, 62, Dundee)

'The phone went during the interview and I got up to get it, the assessor could see how difficult it was, how I look as if I'm going to fall on my head when I stand up, even though I'm not' (Thomas, 59, Midlothian)

Reflections on Questions

Clients reflected on the questions they had been asked within the assessment.

Some had found the questions difficult to understand:

'There were a few questions that I didn't understand. That's when Gail stepped in' (Emma, 56, Glasgow)

Some found it strange that they were being asked the same set of questions that were covered on the application form:

'The assessment was OK. They just asked me about my health. I answered the questions OK. They were the same things that social work were asking me when I filled out the form. Perhaps it was a little bit strange that I was asked twice.' (Miriam, 53 Glasgow)

Others found the questions reasonable, or at least experienced nothing perturbing about answering them. Noticeably the client below had a very short assessment, which might be best described as 'no nonsense':

'I answered the questions. The assessor then popped out to check with his colleague and that was it. I think I must have answered them right because it was so quick' (Gail, 60, Falkirk).

Section 5.3.2 Conduct of the Assessor

Unsurprisingly, the conduct of the assessor has a major impact on clients' experience of the assessment. Interviews explored what clients felt about the assessor's conduct of their assessment.

Positive Experience

Most clients were positive about the assessor. Generally key to this was their sense that the assessor was understanding of their situation and their condition, that they *got* the issues involved, often without having to unpick them with unnecessary repetition or in unnecessary detail:

'I was very well treated by the assessor. He was very understanding. He understood about the aids and adaptations and things I have in the house to help me. He never asked me to repeat anything ' (Emma, 56, Glasgow)

'The assessor was great. She didn't question what I was telling her, she listened basically, she was wearing it.' (Lee, 23, Glasgow)

'The assessor was very nice. He understood my situation and wanted to listen to me' (Nicola, 47, Glasgow)

Carers felt similarly positive when they had been able to have their say in the process:
'The assessor treated me OK. He let me speak, and he let Michael speak, and he was happy for Jane to prompt when required' (Janet, 56, Carer, Midlothian)

The thoroughness of assessors could also be appreciated in this context:

'The assessment did it in a thorough way. I didn't have the chance to miss anything out, I had the opportunity to talking about things.

She was familiar with the condition, so I didn't have to explain anything in too much detail' (Laura, 43, Midlothian).

Feeling that they were believed by the assessor made a huge difference to clients' experience:

'I can't do anything but praise the assessor. Perhaps she realised that I wasn't putting anything on, she must have read the reports about me too'
(Gary, 59, Dundee)

Similarly people felt positively when their wishes had been accommodated, and/ or when they had been shown sympathy and consideration:

'The assessor was really nice. She allowed Vonnie and my wife in, even though he wasn't supposed to. She saw I was upset and nervous, that's why'
(Robert, 38, Dundee).

'The PIP assessor was very nice. She knew I was having a very, very bad day. I got really quite upset, more than I have been during this phone call [the client had cried during the phone interview]. The assessor was considerate and said not a problem, take your time.' (Lorraine, 58, Midlothian)

'The assessor was OK. She was happy to continue when [her son] walked out of the interview, she could see for herself how he was'
(Caroline, 47, Carer, Falkirk)

That sympathy and consideration could also be manifest simply and practically:

'The woman at the assessment was very friendly. She offered to open the window because I was hot and offered me a cushion because I was fidgeting and not feeling comfortable.

She was interested if you know what I mean. In other assessments I've just been a ticket, just a number, We don't like the look of him, nothing wrong with him he's fine. The other times I've felt like I'm getting judged.'
(Andrew, 43, Falkirk)

It also extended in at least once case to the assessor terminating the assessment early, on the grounds that all the information required had been gathered:

'The woman could see I was in such a state. She stopped the interview and said, I've seen enough. She was very nice, she treated me well and was sympathetic, I think it's because she had a background in mental health' (Neil, 59, Falkirk)

This positive reaction to the conduct of the assessor was sometimes present even when the client was finding the overall experience difficult, largely because of clear efforts by the assessor to reduce the level of stress involved:

'The assessor was quite nice, but she had a job to do, so some of the questions were quite difficult. They weren't very nice, but they had to be asked.....

She [the assessor] could understand how disturbing some of the questions were and she made that clear to me that she understood. I was worrying about being judged, but she also told me not to worry, that she was not there to judge me.' (Parveen, 32, Dundee)

The reaction of other clients to their assessor could most accurately be seen as 'pleasantly surprised':

'The assessor was not as snooty as I thought.' (Joanne, 46, Glasgow)

Genuinely positive?

Some had had a positive experience of the assessor, but remained suspicious about that. In the first case this suspicion may have been triggered by receiving a negative outcome on their claim, in the second the client seemed to be generally uncertain:

'She was very nice. But I think at the end of the day they were trying to lull me into a false sense of security' (Patricia, 62, Dundee)

'She was very nice, but I wasn't in that long that she could show me a different face. She was good at what she did. She just asked me the questions and that was it' (Gail, 60, Falkirk)

Even where assessors were seen by clients as treating them well, this could not always compensate for the stress inherent in the situation:

'The young woman who asked the questions was pleasant enough. But you are being asked very personal questions, I felt very exposed.....She was OK, I just felt very raw about the whole thing, it was horrible.' (Sarah, 50, Midlothian)

More Mixed or Negative Experiences

Some clients reported more mixed experiences of the assessor, two Midlothian clients reported dealing with pleasant but inexperienced or disorganised assessors:

'The assessor was inexperienced. It may even have been his first one, we weren't sure. He was struggling a bit, and he just went on and on. He kept asking questions about information that he already had..... He wasn't unpleasant though, he was perfectly pleasant' (Sandra, 49, Carer, Midlothian)

'The assessor was very nice. At first we thought he was a bit hopeless, he got my name wrong and in the assessment he didn't seem to have read things. Jane had to point out a couple of things, for example that the form had been sent in.....

He was quite jokey at first. He was quite thorough, he asked me to do exercises. I felt that he seemed to take on board what I was saying, I thought he was very nice.' (Lorraine, 58, Midlothian)

Others felt that generally positive experiences with an assessor had been at least partially soured by not being believed on key aspects of their testimony:

'Even then there was an issue with my back [which had been injured doing heavy manual work.] She said there was nothing wrong with my back. I've had that from other people too. She said there's nothing in your back to cause pain. But my back seizes up if I sit for too long.....

I felt like I was being told that I was a liar and I didn't like it.'
(Malcolm, 62, Dundee)

Two clients reported that there had been negativity between the assessor and the advocate, in one case this had impacted on the assessment, in the second the overall experience of the assessment had remained positive:

'The assessor kept cutting him off. I felt terrible for him. She just cut him off and wouldn't allow him to speak. I never actually got to talk properly about my ankle'
(Lisa, 53, Falkirk)

'The assessor didn't seem think she needed the documents that I'd brought in. She was quite dismissive of the advocate about that...

The assessor was excellent. She was commonsensical, she asked about the back, I felt that I could tell her straight. ...

She was asking me about my use of a stick. She drew out about how I could use the stick, and how I couldn't do much without it. I didn't get asked anything inappropriate, I didn't have to prove that I was ill.'
(Sheila, 50, Falkirk)

Excessive Formality

A number of clients reported that they had not been able to establish a rapport with assessors who were formal or quite cold towards them.

Some took that in their stride, as if it was to be expected or as if it was understandable:

'The assessor was a bit cold. I know he has a job to do, but he was a bit cold to me' (Phil, 45, Dundee)

'The assessor just sat there and typed. He asked question after question and didn't seem to be listening to the answers.....

I guess it must have gone OK, I got it. But I don't really think he was taking a broad view. It was more like a conveyor belt, chop-chop and then you were out of the door' (George, 60, Falkirk)

For others this was more distressing (although in both cases of the clients quoted below, they received the expected outcome, and the advocate reported that the assessor concerned was one of the better ones in terms of client outcomes):

'The assessor was OK. He was reading from a script. The questions made you feel like a pile of crap' (William, 52, Midlothian)

'The assessor was robotic. He was reading off his screen and typing the whole time. He made no eye contact. He was quite abrupt, Jane had said about the lack of eye contact.....

He didn't put me at ease, even he could see that I was angry and shaking, he could have asked if everything was fine.....

I don't think he did anything wrong, it's really difficult to do his job. I didn't have a problem with him personally but with the system itself.'
(Nadia, 34, Midlothian)

Highly Negative Experience

One client had had an extremely negative experience at the hands of an assessor, who had pursued an intrusive line of questioning way beyond what she felt was reasonable.

Even more insultingly in the eyes of the client, this had unfairly affected the result of the assessment through the assessor's misjudgement and misreporting of her husband's response to the questioning, and the non reporting of the information gained through the questioning:

'My husband didn't want to speak at all at the assessment. It was primarily me that spoke, with some input from Vonnie. The assessor wasn't happy with this. She wanted to speak to him and made that clear to us.....

The assessor then pressed and pressed my husband to speak about his suicide attempt, although it was really clear that he was in considerable distress because of this.....

She then wrote down that he was speaking at a normal pace and pitch in response to her questions. She did not actually mention the suicide attempt in her report, despite having pushed so hard on it. That's the sort of tactics that assessors use. I was really shocked by it.....

It was one of the last questions my husband was asked, and it was the most upsetting. It was a very stressful experience, particularly at the end. My husband was hugely upset and I was too.' (Frances, 51, Carer, Dundee)

Section 5.3.3 Previous Experience of Assessments.

A significant minority of clients had had negative past experiences of face to face assessments.

At the heart of such negative experiences was the sense amongst some clients that their situation had not been properly considered:

‘The first assessment, I found it so upsetting just going through it because of the situation that I was in.

It didn’t take anything about my mental health into consideration at all, though I think the physical issues should have been enough. I told them about the constant pain I was in and still the benefit got cut off.’ (Nicola, 47, Glasgow

‘The guy sat there and didn’t have a clue what I was talking about. I got zero points despite my colostomy and depression. The stoma itself should have got me points. When I got to the tribunal the doctor thought it was ridiculous and said I shouldn’t have been there.

In other assessments I’ve just been a number, just a ticket. We don’t like the look of him, there’s nothing wrong with him, he’s just fine’ (Andrew, 43, Falkirk)
Clients reported that they had previous experience of assessments not accurately reflecting what they had said:

‘The first time I went, the report came back and it was different from what I’d said’ (Malcolm, 62, Dundee)

Clients also reflected on how difficulties they had experienced communicating at a previous assessment or an appeal tribunal had negatively affected its outcome:

‘The first time, the experience was nerve-wracking. I didn’t let them know everything. They asked me how often I bathed and I said every second day because I didn’t want them to think that I was dirty. I didn’t want to say that I need my mum to prompt me and to actually bathe me.

At the appeal the doctor was asking me when things started. They made the point that I was not consistent. But my head was pickled, I was all over the place, who remembers dates? I just know that things were getting worse.’ (Lisa, 53, Falkirk)

On a similar theme, one client suggested that her own desire to appear in a reasonable fashion taken with the incuriosity and manner of the assessor had led to problems, both in terms of outcome and the nature of the experience:

‘The other assessment was awful. The assessor at that one asked to be excused because he couldn’t type and look at me at the same time. He was just asking questions and staring at the screen. I felt so insignificant, not like I was a person. It was like I was being referred to in the third person, it was horrible....

Everything I said was being taken at face value. I'd turned up with my hair done and my make up on and looking presentable. But you have no idea how much effort that took. If you'd seen me the day before or the day after. I couldn't get out of bed for four days and I just lay there and wanted to die.'
(Tracey, 47, Falkirk)

Where past experiences had been negative, the lack of qualification and skill of the people carrying out the assessment was often identified as the cause. The extent of the impact on clients of negative assessments could also be severe:

'The issue at the previous assessment was the doctor. They had no understanding of osteoporosis. They didn't understand what it meant for pain once you'd had a break' (Patricia, 62, Dundee)

'The other assessments have been 20-23 year olds, if you are lucky, no doctors, no nothing, no absolute clue.....The young person doing the assessment didn't have a clue and I scored zero. If you met me you would wonder why.....

I have tried to take my own life, that's how bad it got, and it was at the back of my mind this time round' (Nicola, 47, Glasgow)

'I've tried to take my life five times because of this. I took co-codamol plus 2 ½ litres of Bacardi and survived that' (William, 52, Midlothian)

For one client, negative past experiences at assessments, associated with both the outcomes and his emotional state during the process were part of a history of negative experiences of the benefit system:

'I've gone to Cadogan Street for my assessment 18 times. I failed every single one of them. I've been to 6 for PIP, I never even got one point. Totally zilch.....

I've walked out of an interview with women previously. I expected to lose the head with this guy [the assessor] this time.....

I've been sanctioned about 8 times. It's made me really angry. I've been sanctioned because when I made a phone call to a warehouse company about a job I told them about my forgetfulness and so I didn't get the job. But I was just being truthful....

I was also sanctioned because I forgot an appointment at Cadogan Street. I still got sanctioned for that. Of course I forgot, I've got memory loss.'
(John, 46, Glasgow)

Section 5.3.4 Support from the Advocate

Clients described the support they had received from advocates at the assessment:

- Staying with them when there was a delay to the assessment.
- Clarifying with staff at the assessment centre when an issue arose in advance of the assessment.
- Explanation of questions asked by the assessor.

- Interrupting an assessment/ calling for a break when they were upset/ under pressure.
- Calming them down when they became agitated or angry within the assessment.
- Verbally encouraging them at points of stress within the assessment.
- Prompting them to give a deeper explanation/ more detailed explanation of an answer, or if they had forgotten to raise a specific issue or concern.
- Speaking on their behalf when they were unable to explain something, unable to speak, had forgotten something, or when a more detailed explanation was required.
- Referring them back to the written statement drawn up in preparation for the interview.
- Keeping them aware of the progress they were making in relation to the points they wanted to get across.
- Maintaining a reassuring presence within the assessment, including eye contact, even when they were largely 'keeping a watching brief'.
- Asking them to check what was being written by the assessor and questioning what was being written by the assessor.

Engagement Prior to the Assessment.

A number of clients touched upon the engagement they had with the advocate prior to the assessment.

For many, it was a brief opportunity to go through what they were going to say at the assessment, and get a final bit of reassurance:

'We spoke before we went in. It was just for reassurance and that bit more confidence.' (Barbara, 53, Glasgow)

'We had a little chat in the waiting room, Adam reminded me what to say' (Michael, 58, Glasgow)

'She took me to get a coffee to calm me down' (William, 52, Midlothian)

That provision of reassurance and assistance could be at an even more basic level:

'He took my arm because I was struggling to walk' (Barbara, 53, Glasgow)

'He carried my bag for me' (Peter, 43, Falkirk)

For a couple of clients, there was a sense of their stepping from the support of their family to the support of the advocate prior to the assessment:

'We met just before the assessment. I went there with my brother, I brought him with me in the taxi. I didn't want him with me in the assessment, he was just there to help me get there' (Margaret, 61, Dundee).

'Ian met me there. My family came to support me, my niece and nephew, but I didn't want them in the assessment itself' (Neil, 59, Falkirk)

Occasionally, issues with the timing of the referral/ assessment meant that advocates had met with clients for the first time immediately before assessments:

'Yvonne was away when the assessment was called. She phoned on the day of the assessment.

We met at the assessment place and planned things for the interview. Yvonne never really got to see the case. Yvonne talked about how to calm down, and what to do if she got stuck. That was good.' (Robert, 38, Dundee)

Advocates also helped people deal with delays to being called into the assessment:

'I got there at 10.30. Adam was on holiday so it was one of his colleagues who was helping. She had to go over and say that I had not been seen. It was 5 ½ hours, it was absolutely appalling, I didn't want to go home, she knew that she couldn't have done it again.

I stuck it out for 5 ½ hours. Gail stayed with me, and said she would get someone else up if necessary. I didn't realise it was going to be that long. It was very kind of her to do that.' (Emma, 56, Glasgow)

Prompting

Clients gave a sense of the issues on which they had been prompted by the advocate:

'I have a problem with my vision. I can't see depth at all well, which makes me vulnerable to falls. She reminded me of that' (Emma, 56, Glasgow).

'He did prompt me about the morphine that I was taking' (Sheila, 50, Falkirk)

'Jane reminded me to say that I work from home. That was the sort of thing that I'd forgotten because I was so anxious.' (Nadia, 34, Midlothian)

Some made more general reference to interventions on their behalf, and to the use of a written statement as the basis for the advocate prompting:

'All the detailed things that I couldn't explain, he stepped in then. He had to help me explain them' (Barbara, 53, Glasgow)

'If I forgot to mention that I took tablets, or wasn't able to do something, she prompted me' (Kathryn, 50, Falkirk)

'Anytime that I was struggling, she'd remind me of what was written down' (Gerry, 66, Dundee)

The prompting appears to have been quite a subtle process, in terms of not slipping into coaching answers from clients:

'When I couldn't say something properly, Jane would not prompt exactly, that doesn't seem like the right word, she wasn't training me what to say, but she would stop and say to take my time' (Nadia, 34, Midlothian)

Some clients referred to actually asking for prompts during the assessment:

'I would turn to Jane and ask for help. She didn't answer for me, but she did help me clarify what I was going to say, she could do that because she knew the background.' (Sarah, 50, Midlothian)

Frequency of Interventions

The frequency of interventions from advocates varied. For some, interventions were frequent:

'She did talk for me quite a lot....she kept making references to the report, I struggled quite a lot, and she came in to help me' (Parveen, 32, Dundee)

'Vonnie did a lot of prompting. Those places where I would just have said, Yeah, she pushed me to give more detail' (Gary, 59, Dundee)

For others, the interventions weren't constant, many clients reported that they took the lead in speaking:

'At one stage he intervened and filled the gap when I left something out. Otherwise it was me that spoke.' (Claire, 53, Glasgow)

The advocates speaking on behalf of clients sometimes did so in conjunction with family members:

'A couple times I just closed off on myself. Vonnie spoke then, and so did my wife' (Robert, 38, Dundee)

Some of the carers who had been supported at the assessment alongside their family member reported that they had done a significant amount of talking on their relative's behalf, with support from the advocates. For the first carer below, the majority of the interview had been carried out without the client's son, who was the applicant, being present:

'He said I can't deal with this and left the room. I went outside and checked he was OK in the car and then started the interview again.....

It was so much easier to cope without him there, I could talk properly about what it was like. Even when he was in ([her son] had said very little, the assessor had got very little from him.' (Caroline, 47, Carer, Falkirk)

Many clients referred to the advocate remaining quieter than had been planned for within the assessment:

'She kind of stayed silent. We'd talked before about when she would come in, but she didn't need to.' (Patricia, 62, Dundee)

'She took a back seat in the assessment. That helped me, I was happy with that' (Lorraine, 58, Midlothian)

'During the assessment Jane just sat there and didn't say much, she was there for the support' (Thomas, 59, Midlothian)

An advocate had on one occasion intervened to challenge the assessor on the client's behalf:

'Jane was mostly quiet at the assessment, she didn't say much. But she did pick up on things that were being typed into the screen. I couldn't read them, I don't read well at distance, but she noticed them and asked me to take a look because they weren't what I said. I took a look and she was right, so we got them changed.' (Sandra, 49, Carer, Midlothian)

Provision of Reassurance

Clients highlighted the role of advocates in intervening when they became upset:

'When I started getting upset, she'd come in with questions. She'd help whenever she saw that start happening.' (Nicola, 47, Glasgow)

'I got really upset when the assessor asked if I lacked the motivation to do things. I got really angry at that. I don't suffer from lack of motivation. If it was about motivation I would be well. Jane calmed me down after that' (Nadia, 34, Midlothian)

'I've helped a couple of times when I got upset. There were a few moments...I can find that difficult, talking about the past, talking about how it has been with [her son]. I bottle it up, and then it boils over, often I don't realise I am going to get upset' (Caroline, 47, Carer, Falkirk)

A number of clients had become angry during the assessment. This was often something that had been discussed in the preparation meeting:

'He'd come in when I got flustered and angry. We knew this might happen, I've got anger management issues.' (Lee, 23, Glasgow).

'When I started to feel emotional, he stepped in. He knew all about this, he stepped in whenever I was getting wound up, he'd answer on my behalf.

As soon as I was asked about personal things, he was watching out for the signs' (John, 46, Glasgow)

Communication to reassure about progress could come in different non verbal guises:

'Every time I said something, he'd put a tick on the paper, just to let me know that we'd covered it' (Lee, 23, Glasgow)

Section 5.3: Key Points

- The process of the face to face assessment is stressful for many clients from start to finish.
- Stress can be triggered by the nature of the situation itself, or the personal and intrusive nature of questioning.
- Again, this stress can be physically manifested.
- People can experience physical discomfort within assessments as a result of their length and the venue in which they are held.
- Negative feelings about the assessment can extend to anger.
- Some clients felt positive about some aspects of their experience, whilst being negative about others, for example feeling stressed but still able to get across their point.
- For some clients, their experience of the assessment improved as it went on.
- Some clients were largely relaxed throughout the experience, before and during the assessment.
- Clients had differing views on the questions asked. Some found them reasonable, others repetitive, others struggled to understand them.
- Most clients were broadly positive about the attitude of the assessor towards them, though a minority expressed a degree of cynicism.
- Positive views centred on assessors being responsive to their needs, listening to them, being sympathetic and aware when they were finding the experience tough, and displaying an understanding of their condition.
- Some mixed experiences were reported, with some clients highlighting assessors being disorganised.
- Three clients reported some conflict between assessor and advocate.
- Most negative comments focused on assessors displaying too little sympathy and excessive formality, with some clients accepting this, and others finding it off putting.
- One client had an extremely negative experience with an assessor involving highly intrusive and insensitive questioning and misreporting.
- Previous negative experiences of assessments centred on a lack of consideration by assessors, misreporting, and difficulties communicating.
- Some clients had also experienced barriers that related to pride and embarrassment to communicating the full extent of their difficulties relating to their condition.
- Key tasks carried out by advocates in assessments centred on:
 - Prompting clients at varying degrees of frequency.
 - Providing reassurance, verbally, non verbally or by their presence.
 - Calming clients down, including prior to assessments and when there were delays.
 - On one occasion challenging assessors, on another challenging the behaviour and decisions of assessment centre staff.
- Advocates had often been quieter than clients had expected.

Section 5.4: The Impact of the Advocate on the Assessment

Clients were asked about the impact of the advocate on:

- Their feelings during the assessment, which included, where the interview led in that direction, exploration of the advocate's impact on their ability to get through the assessment.
- Their ability to communicate in relation to their condition.
- The behaviour of the assessor.
- The result that they achieved.

Discussions also touched on the issue of how the support provided by the advocate compared to the support given to them in assessment situations by family members or by other support workers.

Section 5.4.1 Advocate Impact on Client Experience

Reassurance and Confidence

The most consistent message from clients was that the presence of the advocate in the assessment had acted to give them reassurance or reduce the stress they were experiencing.

'I knew that someone was there if I got tearful who would help as best they could.....It was less stressful to have him there, I was still nervous though'
(Joanne, 46, Glasgow)

'Having Vonnie there was a comfort, someone who understood that things might not be clear to me, that there could be a situation in which I didn't know what they were asking and they were trying to trip me up.'
(Patricia, 62, Dundee)

'At first I was really nervous, I was scratching myself a lot. By the end of the assessment I had calmed down a bit. That was Yvonne that calmed me down, I would not have been able to manage if she wasn't there.'
(Robert, 38, Dundee)

Giving that reassurance often did not require much more than the simple presence of the advocate:

'It just felt better, even when she wasn't saying things, to have her there'
(Lorraine, 58, Midlothian)

Alongside reassurance had come confidence, in both cases clients spoke of the value of having someone 'on their side':

'Having someone there to keep you right actually works wonders. It gives you confidence that you can speak properly.'
(Barbara, 53, Glasgow)

'Vonnie was looking over to me to say that I was doing all right. That gave me a lot of confidence. It made a real difference her being there'
(Parveen, 32, Dundee)

'It was quite a support having Ian there by my side. It was much better having someone who could come in when needed' (Neil, 59, Falkirk)

Again that confidence did not necessarily require more than the presence of the advocate in the assessment, and the understanding that they had someone knowledgeable on their side:

'It was helpful to have someone who kept in the background, but was there when you needed them' (Lorraine, 58, Midlothian)

Some clients felt that the presence of the advocate, and the preparation work done with them had enabled them to avoid potential conflict:

'I was worried I was going to get violent. I would have lost the head if Adam hadn't been there, I expected to, to be honest. Adam being there helped calm me down. He was watching me for the signs, and every time I started to get wound up he'd come in and answer the question. He picked up on every little sign, and would butt in, just to break things up.' (John, 46, Glasgow)

'Jane would calm me down at certain points. It helped her being there. I'm a bit like a volcano. I just build up and build up. That [the presence of the advocate] put me at ease. You sometimes feel when you are answering questions that you are being treated like you are subhuman. You get treated by the assessor so badly, terrible. Jane calmed me down' (William, 52, Midlothian)

Emotional Impact of Preparation

The preparation that people had experienced as part of the service had an impact on their levels of stress within the assessment:

'At least I knew what I was going into. That made a big difference' (Emma, 56, Glasgow).

Similarly, the preparation work gave clients greater confidence and reassurance. Often the reassurance stemmed from simple explanation of how the process would go, and their rights within the process:

'It was that having it explained to you that it will be fine. He would listen to you very patiently, would explain why things would happen. I had confidence that I would not have had without him.' (Barbara, 53, Glasgow)

'She had said that I could call for a break at any point if it got too much. The fact that she said that meant that I didn't need to. It was reassurance enough to know that I could...

It was reassuring to know that I wouldn't be forced to anything that I didn't want to, anything painful or excruciating' (Sarah, 50, Midlothian)

Limits to the Impact

Some clients were clear that the impact of the advocate on the experience of the assessment could only go so far. Sometimes that was seen as inherent in the nature of the situation, sometimes it was seen as being a result of their condition:

'I got a little bit less stressed because he was there, but you're bound to get a little stressed in situations like that. He put me at ease quite a bit, but I was still stressed.' (Claire, 53, Glasgow)

'I was stressed, but not as much as I would have been if Vonnie hadn't been there' (Patricia, 62, Dundee)

It was helpful to have Vonny there. Was I less stressed because she was there? Yes, but it's kind of hard to explain. I feel stressed speaking about myself. That's when everything gets on top of me.' (Robert, 38, Dundee)

Even with the support of the advocate, some clients remained very dubious that they would be successful in their claim:

'I was glad I had him in my corner, but I wasn't looking forward to it, I still thought I was wasting my time' (Andrew, 43, Falkirk)

One of the carers interviewed gave a sense of how nervousness was impacting on both her and her husband:

'It made me more comfortable, but I was still anxious. It's a new situation here, so I was wary about what to believe.

It was probably my husband who was more worried. It was the fear of the unknown that was bothering him. He struggles with new situations.'
(Sandra, 49, Carer, Midlothian)

'I wouldn't have went, I wouldn't have got through

Time and again, clients indicated that they felt that they would not have seen through the assessment process had it not been for the support of the advocate.

In this context, the end to end support offered by the service was seen as critical:

'I would just not have got through it. I wouldn't have been able to get through any stage of it' (Janet, 56, Carer, Midlothian)

'I got very stressed waiting to go in to the assessment. If I had managed to get there [to the assessment], I'm not sure I'd have stuck it out. I would have struggled. I would just not have completed it, just gone and left the room'
(Barbara, 53, Glasgow)

'I don't think I would have got to the assessment without help, I would have just packed it in' (Sarah, 50, Midlothian)

'I wouldn't have went in without him. I just wouldn't have went in'
(Gail, 60, Falkirk)

That ability to see things through could be a function of greater confidence as a result of the service laying out what would be involved:

'Without Adam I don't think I'd have got through. I was more confident because I knew what I was going in for.' (Stephanie, 52, Glasgow)

'Without him I don't think I'd have had the confidence to do it. I don't think I'd have been prepared for it at all. I wouldn't have been able to get through with it' (Lee, 23, Glasgow)

'I was far more prepared for the assessment with Adam than I had been without him there. I would have just collapsed without him there.'
(Barbara, 53, Glasgow)

It could also be a matter of the provision of emotional support at critical points in the test:

'I was crying and he comforted me. It would have been very different if he hadn't been there. I might not have managed, I might not have got through the interview' (Miriam, 53, Glasgow)

One client emphasised the extent to which her ability to get through the test was the result of the joint effort of the advocate, and her husband who had also accompanied her:

'I don't know how I would have got through. My husband did a lot of the talking. I don't know how I would have got through without both of them there, it was lovely to have them both there for support' (Nadia, 34, Midlothian)

Section 5.4.2: Advocate Impact on the Behaviour of the Assessor

A number of clients believed, or viewed it as possible that their advocate had had an impact on the behaviour of the assessor.

One client, who had experienced a hugely negative assessment for ESA when she had been supporting her husband, felt there was clear evidence of the assessor modifying his behaviour in the presence of the advocate:

'I think the assessor was different because Vonnie was there. He questioned us about how we were finding things. He asked about how we had found it compared to our expectations. He was probing a bit about whether we had expected that the assessment would be confrontational, and that's why Vonnie was there.....

He pitched it at the most reasonable end of things. I've never seen an ESA assessment that has been so reasonable, and I've seen quite a few over the years.' (Frances, 51, Carer, Dundee)

Another drew a clear contrast between the behaviour of assessors at previous assessments, and their behaviour at the most recent one where he had the support of the advocate:

‘The 3rd time was when Vonny was there. It seemed like she [the assessor] was listening to us. Before they didn’t seem to be paying attention to what I said, this time they did. The assessor did treat us better, she was listening to us.....

I think I got the result because of Vonny, because it made them pay attention to me. There is another person in the room and that makes a difference.’
(Malcolm, 62, Dundee)

One client noted the behaviour of the assessor change when it became clear who the advocate was, and the contrast between this and previous assessments:

‘It was so different from assessments I’ve had before, so, so different.....

At first the assessor treated me quite poorly, he was quite a crabbit chap. When Jane said who she was and what she was there for, he seemed to panic a bit.’
(William, 52, Midlothian)

Many were not quite sure, but suspected that there was at least some impact of the advocate’s presence on assessor behaviour:

‘It was a surprisingly easy assessment. I don’t know if it was because Adam was there that it was like this. Perhaps because he was there it put a stop to this.’ (Claire, 53, Glasgow)

‘The assessor was very nice. He’s probably have been like that anyway, but the fact that Adam was there, I think that helped a little bit’
(Barbara, 53, Glasgow).

Section 5.4.3: Impact of Advocates on Communication.

Clients felt that being prompted by advocates had a significant impact on their ability to communicate with the assessor:

‘During the assessment, I forgot things. He reminded me about them. He picked up on things I’d told him about the illness. Things I was forgetting, he helped me remember’ (Stephanie, 52, Glasgow)

Advocates also had an important role in explaining aspects of the assessment which were not clear:

‘There were lots of questions that I didn’t understand. Adam made those clear for me. It was really helpful.’ (Stephanie, 52, Glasgow)

The emotional impact of the service discussed above could have a major impact on clients’ ability to communicate:

'Getting past the whole talking to a stranger thing was a big thing for me'
(Laura, 43, Midlothian)

'It makes a difference having them there and knowing that they could step in. I didn't need that in the end, but it was good to know it could happen'
(Margaret, 61, Dundee)

More generally, clients could still find it hard to communicate about their situation, whether because of its complexity, the nature of their condition or because they were struggling to remember things, and therefore welcomed the support provided:

'Trying to communicate about your symptoms is difficult. Yvonne managed to get across a few things for me' (Kirsty, 52, Dundee)

'I was forgetting things, my head isn't my own at the moment. There would have been things I would have forgotten to say and I just wouldn't have answered....'

One example- She reminded me that my husband came with me to the first meeting, it was an example of me not going out on my own'
(Lorraine, 58, Midlothian)

'Because the discussion was so embarrassing we would not have gone into detail without Jane. I would have lost points and wouldn't have got the benefit....'

I think that Jane thinks I should have got more, but ME is very difficult, and PIP's harder to get than ESA. It's only your word against theirs, there is no test, no physical evidence. People who cheat make it difficult for people like me to get the help they need.' (Sarah, 50, Midlothian)

One client pointed to a very specific impact of the service, which had dealt with an objection from staff at the centre to her exercising power of attorney for her husband:

'Without the service I would not have been able to do Power of Attorney. My daughter would have had to do it and she is only 20. I didn't want to put my daughter in that position, she also has mental health problems.'
(Frances, 51, Carer, Dundee)

Impact of Preparation Work on Communication

The preparation work that had been done with clients proved critical in enabling them to communicate at the assessment:

'I seriously don't think I'd have got it [the benefit] without advocacy. The main thing was that we'd talked through everything, so I better understood what was happening. I had a better idea of the questions that were going to be asked, and how I was going to answer them' (Nicola, 47, Glasgow)

'I was able to get it all across OK because he'd done that, he'd spoken to me before' (Stephanie, 52, Glasgow)

'I gave better answers than I did before. They were better because I'd talked about them before' (Grant, 53, Midlothian)

This could be to the extent that clients felt they did not need the advocate to prompt them within the assessment:

'Everything that I could have forgotten, I could remember because we'd talked about it before. That preparation went through everything, everything that could be said.' (John, 46, Glasgow)

For some clients, the reassurance provided by the simple presence of the advocate in conjunction with the preparation work gave them the confidence to communicate fully, to the extent that some felt that they hardly needed the advocate to make an intervention in the assessment:

'Adam's presence made me more confident, so yes, it probably made a difference. He explained a few things so I knew what to say about certain things.' (Claire, 53, Glasgow)

'I was not quite as nervous. Jane acted as positive reinforcement. I knew what I would talk about. I knew that if I failed to get it across, Jane would step in, that she was back up....

It meant in actual fact that I didn't forget, because Jane was there, I didn't need her to [step in] because I wasn't worrying about it.'
(Laura, 43, Midlothian)

Clients were also clear that the preparation work had enabled them to talk about things that were embarrassing or emotionally difficult:

'There may have been some things that I was embarrassed to say. I said that to him, and he said, no, you must tell them everything'
(Stephanie, 52, Glasgow)

'It's not just the questions, but it's the emotions that bubble up when you are discussing these things. Because the discussion was so embarrassing, I wouldn't have gone into detail without Jane. I'd have lost points and not have got it [PIP]' (Sarah, 50, Midlothian)

Contrast with Previous Experience of Communication

Clients did draw explicit contrasts between their experience of communication at previous assessments and at their most recent assessment, and drew the connection between their ability to communicate at the assessment, the report that was produced at the end of the assessment, and the result that they obtained:

'The first time, the report came back and it was different from what I'd said. It was much better. That's because she [the assessor] was listening and I could explain things better.' (Malcolm, 62, Dundee)

'He jotted down what I was telling him, he'd explained he was using it so that I would know what I needed to say. When I went to my last assessment I came out thinking that I wished I had said this, or I wished I had said that.... This one couldn't have been more different' (Tracey, 47, Falkirk)

'At the PIP [assessment] I felt I could get everything across. It was a huge difference having Ian there. I don't think I'd have had the confidence without Ian there. I don't think I'd have had the confidence, and I wouldn't have done half as well' (George, 60, Falkirk).

Section 5.4.4 Contrast with Other Support

A number of clients discussed how the support they had received from the advocate differed from that which would have been available from other people, or that they had received from other people.

The difference was often couched in terms of the specific knowledge that the advocate brought to the situation:

'It helps to have someone who knows the system rather than your husband, wife or son. It's so much better.' (Stephanie, 52, Glasgow)

'The key is, Vonnie knows the system, she understands the process and what comes next' (Patricia, 62, Dundee)

'I brought my sister along too, but I didn't want her to speak. Vonnie knows what she is talking about.' (Parveen, 32, Dundee)

Family members were seen as less likely to be able to cope emotionally with what could be a fraught situation:

'I don't think they would have dealt with it as well as Vonnie' (Patricia, 62, Dundee)

The independence of the advocate also appeared to be part of what clients valued:

'I would take my sister, but I think she would just say the same things as me. I think it's important to have someone independent with you, that's what's helpful and reassuring, thank you.' (Kathryn, 50, Falkirk).

It could also relate to the potential awkwardness of discussing personal matters in front of family members:

'It's not something I could ask my father about. He didn't know the extent of my problems' (Michael, 58, Glasgow)

One client contrasted the support he had received from the service with support from a social worker in the past:

'The social worker wasn't much help. He should have said more, I'm the one with memory loss' (John, 46, Glasgow)

Some people did not have suitable family members available to help them:

'If it had been a family member, it would have had to have been my brother. But we've been out of touch for a few years, we aren't really speaking.'
(Michael, 58, Glasgow)

The vast majority of clients interviewed were very positive about the service that they had received from other advice agencies in support of their claim. However, one client drew a contrast between the support they had received from the advocate, and what they felt was less than ideal support from a local welfare rights service:

'The person from the council was just terrible, completely different to Ian who I can't thank enough. I felt like I was being grilled, like I was going through the assessment again. It wasn't helpful' (Kathryn, 50, Falkirk).

Section 5.4.5: Advocate's Impact on the Result

The feedback in the previous sections of this guide builds an implicit and sometimes explicit case for the advocate having an impact on the result of an assessment. Clients who feel better and are more confident about the assessment, who have a better experience engaging with the assessor, and who feel better able to communicate are more likely to get an appropriate result. Clients who get through an assessment process from which they would otherwise have dropped out preserve at the most basic level their opportunity to get an appropriate result.

Where it had not become clear from discussions about the impacts of the advocate discussed above, clients, were asked explicitly about whether they felt the support of the advocate had made a difference to the result they obtained. The consistent response from clients was that advocacy had had such an impact, their response to this question going on to touch on the range of issues picked up in the previous sections:

'I think the support did make a difference to the result. It made a difference because having her with me in the waiting room calmed me down. Someone was there for me, checking everything. It made me feel a lot more human.'
(Emma, 56, Glasgow)

'Perhaps I would have got the result by myself? But I don't think I'd have been able to get them to understand. I wouldn't have been confident to ask the questions....'

The result was a lot better than I expected. I thought it would be a case of- We have the forms and yes, you have a problem, but here's a pat on the head, there's not much wrong with you basically. Stay the way you are'
(Thomas, 59, Midlothian)

'I often think about whether it made a difference to the result. I think so, it made them pay attention to me. Another person in the room, that makes a difference'
(Malcolm, 62, Dundee)

'I don't know if it made a difference Ian being there. Probably it did..... Yes, I do know that I wouldn't have got it without him, let's put it that way'
(Andrew, 43, Falkirk)

Key Points

- **The presence of an advocate provides reassurance to clients and builds their confidence.**
- **The feeling of having someone on their side is central to this.**
- **Preparation work with clients can have a key role in promoting client confidence.**
- **The assessment is still a stressful experience for many, despite the presence of an advocate.**
- **Many clients are clear that they would not have gone to the face to face assessment, or not have completed the face to face assessment, without the support of an advocate.**
- **Clients believe, backed by their experience of assessors at previous assessments, or the changing behaviour of assessors during their most recent assessment, that advocates impact positively on the behaviour of assessors.**
- **Clients are clear that advocates enable them to communicate better at assessments, through preparation, prompting and their reassuring presence.**
- **Preparation builds clients' confidence, understanding, and ability to respond appropriately to emotionally difficult questions.**
- **Communicating at assessments is still a challenging experience for clients.**
- **Clients comparing current with past experience are clear that communication at assessments when they are supported by an advocate is substantially better for them than communication when they are not.**
- **Clients believe that the professionalism, knowledge and independence of advocates makes them a better option for providing support at assessment than family members.**
- **Clients explicitly and implicitly identify a positive impact on their assessment result because of the support from an advocate.**

Section 5.5: The Financial and Psychological Impact of A Successful Claim

The interviews explored the impact that making a successful claim for ESA or PIP had on the lives of clients. It is clear that a successful claim leaves no-one's lives untouched.

The financial impact of a claim could be seen on clients in several ways:

- Increasing the money available to spend to help them cope with the impact of their condition.
- Increasing the money available to spend on basic household goods.
- Increasing the money available to spend on transport.
- Enabling them to cope with financial crisis.

Clients also stressed the importance of a positive result in:

- Giving them financial peace of mind.
- Giving them the financial resources to preserve their sense of self respect and independence.
- Giving them the opportunity to make appropriate choices in respect of work.
- Validating their sense that they were genuinely ill and in need of support.

With a number of clients, the interviews also explored the limits of the impact of an improvement in their finances on their quality of life.

This section begins with a brief discussion of the work of advocates with clients once the assessment process has been concluded.

Section 5.5.1: Clients' Post Assessment Engagement with Advocates.

Clients reported a variety of engagement with advocates once they had received a decision.

Some clients proactively contacted the advocate to let them know the result of their claim, others were contacted by the advocate.

For some, this was an opportunity to thank the advocate personally, and bring a degree of closure to their engagement:

'We just had a chat on the phone after I got the award. I was really pleased. It was quite important to have that chat, she did so much for me and I didn't think I would get that far. It felt like phoning a friend, and I got the chance to say thanks.' (Gerry, 66, Dundee)

'It's really helpful to have that chat at the end. To be able to say that she had made a difference. I wanted to show her that, to let her know that, and thank her.' (Parveen, 32, Dundee)

'We talked about things on the phone. He came back out to me to close the case off. That was really helpful, just to know that it was all sorted, and make sure everything was in order. It helped put my mind at ease'
(Stephanie, 52. Glasgow)

'We've spoken a couple of times on the phone. He was pleased that it's all sorted for me. I was glad to say thank you, and happy to be interviewed for this' (Nicola, 47, Glasgow)

Some clients had needed a either explanation or reassurance in relation to the outcome of their claim:

'There was backdated money as well. Adam went through it all and explained it.

That meant I could go out and spend. Before that I was actually feart, I thought they had made a mistake, they've made mistakes before' (John, 46, Glasgow)

'I felt overwhelmed when the letter came in. Getting the disabled badge, even that overwhelmed me. I was still getting some anxiety' (Parveen, 32, Glasgow)

One client reported that the advocate had contacted her to check if she had received a result on her claim, and when she indicated that she had not, he had chased this up on her behalf.

Some clients had not received the decision they had hoped for in relation to the claim.

Some had therefore received or were receiving further support from the advocate to take forward a mandatory reconsideration:

'I phoned when I got the letter through and Jane has been down to see me and help with an MR.... I've put in an MR with her help and am waiting to hear back. She helped me by talking me through it, and batting stuff back and forth

I got awarded both at standard rate. I want to have a look at the mobility test again. I'm not ungrateful, but there were a couple of discrepancies in the health professional's report, and I want them re-examined, I can't go to a new place by myself. There are also couple of points that could have been taken into consideration which could have got me the enhanced rate [for Daily Living]. There was an issue about them looking at the way I use a magnifying glass, when it's good for some things but not for others.' (Laura, 43, Midlothian)

Other clients were considering their options in relation to their claim:

'Vonnie was helping me with a reconsideration. I just got word back to say that it wasn't successful. I'm meeting with Vonnie tomorrow to talk about an appeal, she'll give me advice.

I know there were issues with the report [from the PIP assessment], they made errors which we picked up in the MR' (Frances, 51, Carer, Dundee)

Others had sat/ were sitting down with the advocate to look at the broader range of issues that they faced, including other benefit support that was available:

'I am meeting with Jane next week, to talk about future opportunities, and about how I am feeling. Jane said to me earlier that we could meet up to chat about

what I would do with the money if I got it. You don't really get that chance with anyone [else].' (Nadia, 34, Midlothian)

I phoned Jane up to say that I had got the award. We talked about what doors that opened to me, PIP means I can get other support. We talked a little about what I could spend the money on.

We met up to talk, I got a form for the blue badge for instance, and info about other things, to get that little bit extra financial support. She told me about the gas and electricity help that I can get, I'm worrying about Winter and keeping warm, I'm glad I can sort that.' (Sarah, 50, Midlothian)

Making clear that clients could get access to the service if they needed support with another claim in the future was also a part of the post decision engagement:

'Adam said that I could get in touch when I went for PIP. He said to get in touch with him if I didn't think I would be able to get through by myself'
(Emma, 56, Glasgow)

Section 5.5.2 Financial Impact on Spending to Cope with their Condition.

Equipment, Gadgets, Household Goods

A number of clients identified specific spending on equipment, gadgets or household items that they had been able to undertake because of the additional money that they had received:

Some of these items were small:

'We were able to get a walking stick with a seat for him [her husband], so when we're out and about he can have a rest' (Sandra, 49, Carer, Midlothian)

'I've bought a large magnifier' (Laura, 43, Midlothian)

'I've bought myself a raised toilet seat' (Margaret, 61, Dundee)

Some were larger and more expensive:

'I'll get a new couch, that will help with my back. Some of the other new bits and bobs I get for my flat will help me with my back, they'll help me manage the pain better. That's all I can do, it can't be cured.'
(Claire, 53, Glasgow)

'The walker I've got is too heavy to lift into the car. The one I want to get is much lighter. £200 is a lot of money, and I couldn't afford it. But now I can'
(Gerry, 66, Dundee)

Additional Costs

One client spoke in some detail about being able to cope with the range of extra costs that resulted from her condition:

'I've managed to buy little gadgets for the house. I've been able to get stuff with grips on them to help myself. I can afford to buy these things now when I couldn't before.....

I have to buy [incontinence] pads for myself, I want to be able to do that, not have to rely on others. My shoes get damaged and my trousers get ripped because I fall over, it all adds up. I have had some really bad accidents and needs to replace my trousers.' (Parveen, 32, Dundee)

Others were able to spend more on household utilities to cope with aspects of their condition:

'It pays for us to use more electricity, I can't see at night very well, we've more lights on' (Laura, 43, Midlothian)

Additional Help and Treatment

Some clients were pondering the possibility of getting extra help around their home to help with household tasks that they found difficult:

'I haven't got someone in yet, but it's an option I'm thinking about. I worry about my immune system so cleaning is really important. It's horrendous if I get ill, it really affects me. I can be a wreck for two weeks or more.'
(Sarah, 50, Midlothian)

'I will use the extra money to get people to help me with the ironing and messages etcetera. I can't do it all by myself, I need help with it.....

I can't rely on my family, my sister is busy, and my parents are elderly, my dad's in hospital at the moment.' (Nicola, 47, Glasgow)

Clients were also looking at purchasing alternative treatments that enabled them to cope better with their situation:

'One of the things that I want to do is to go to aromatherapy. I know it seems like a bit of an indulgence, but it makes my symptoms better, even if it's just for a couple of days. I get a lot of pain and a massage really helps, I get a good sleep.' (Sarah, 50, Midlothian)

Section 5.5.3 Financial Impact on General Household Spending.

For many clients, the primary impact of a successful claim was a reduction of pressure on their household budgets. Consistently, alongside this reduced financial pressure, came reduced worry and concern.

A large number of clients focused on the basic areas of expenditure of heating and eating:

'I don't have to worry about where the next loaf of bread is coming from. It's a great weight off my mind.' (Joanne, 46, Glasgow)

'It's extra pounds in the meter. It's being able to keep warm in Winter'
(Lee, 23, Glasgow)

'I'm eating better, and keeping my house warmer. I can put money in the gas and electric OK. I'm definitely not worrying about gas and bills and stuff.'
(Kirsty, 52, Dundee)

Some referred to having an extra buffer against problems:

'When I'm out I can get things without having to think hard about it all the time.

If a bill comes in suddenly, I can pay it, the money's there' (Gail, 60, Falkirk)

'I can keep the heating on all the time when I need it. I've got that extra money for the electric. I can pay Council tax and everyday things for myself. I can put that bit extra on the keycard, top it up when I need to. It means I've got a cushion and am prepared if I get a bit short.' (George, 60, Falkirk)

Others saw themselves as no longer facing financial choices of the same difficulty they had faced before:

'I'm not worrying about the gas meter anymore, I don't need to put pounds aside to make sure I've still got money on Friday' (Andrew, 43, Falkirk)

'I'm more relaxed when I put the heating on, I can do that more. I can get better things to eat.' (William, 52, Midlothian).

For one client, the ability to spend more may have been something of a mixed blessing, given his problems with alcohol abuse:

'The extra money has made a difference. I've been able to get my messages, pay my electric and get more booze [laughs]' (Grant, 53, Midlothian).

One client reported reduced pressure in the context of expensive housing:

'It was huge help to get the cash. I work part time, he can't get any benefit because of that. We rent in the private sector, it's really expensive and we don't get any help with it.' (Sandra, 49, Carer, Midlothian)

Two clients intended to use the additional money to help them equip new homes or buy clothes:

'I am getting a new house. I'm going to get the painters and decorators in. Get everything looking nice.' (Sheila, 50, Falkirk)

'I don't have words to describe the difference it made to me. I'm living in furnished accommodation with very little.....

They gave me an inadequate starter pack, just one fork, one knife, one spoon. I had a mattress on the floor, no carpet, no cooker and a microwave that didn't work.....

I was walking round in the same clothes for a year. I can actually buy things, go to the shop and buy things. I have been able to get a carpet for the floor. I can actually afford to do that.' (John, 46, Glasgow)

Some clients were clear that they only had modest desires in relation to their spending:

'I'm not spending the money on anything in particular. I haven't really thought about buying anything with it. I'd like a TV, but I can't afford it. I just do what I want, I don't need much more. I don't drink or smoke so I don't need to worry about that' (Malcolm, 62, Dundee).

'I'm saving for a rainy day and so my family will get it. The way I see it I need nothing. I know that my life won't change in any other way, it's just my family that are important to me, not myself.' (Margaret, 61, Dundee)

Section 5.5.4 Financial Impact on Ability to Travel

Unsurprisingly, given the focus of PIP on mobility issues, many clients reported increasing spending on travel as a result of a successful claim.

Taxis and (Motability) Cars

For a number of clients, this meant extra spending on taxis, particularly important for some in the context of being unable to use public transport for reasons associated with their condition:

'I was stuck in the house. My partner had to go everywhere for me, I couldn't get the bus. Now I can get taxis, I don't have to walk.' (Kathryn, 50, Falkirk)

For one client, use of public transport appeared to be impossible for another reason:

'I can get taxis places now. I've been banned from public transport for years, so I have to get taxis when I'm out. I can't always get a lift' (Gary, 59, Dundee).

One carer reported using taxis because her disabled son was reluctant to use public transport:

'Next week is an example, I'm working two days and he has two orthodontist appointments on successive days. It means we can get him taxis to them, and then taxis can get him back to school, he won't always use public transport. Sometimes I can get him a taxi to school, if he's having a bad day and something is bothering him and he won't walk.' (Caroline, 47, Carer, Falkirk)

Others had been able to keep a car running, or purchase a new car:

'I've been able to get a motability car. On public transport I feel every bump. I get panicky when it's busy. My car is my own environment'
(William, 52, Midlothian)

'I've got a car now. Yes it's old and second hand, but it means that I can get up and down and round about and not have to walk everywhere.....

I can go and meet people when before I had to go by bus. That was always a bit difficult and the bus always seemed to keep breaking down.'
(George, 60, Falkirk)

'I've been able to keep dad's old car going [the client's father had died recently] I've got the insurance and kept it on the road' (Michael, 58, Glasgow)

Travel and Social Activities

The ability to travel was explicitly linked by a number of clients to their ability to stay engaged with other people or engage in activities that they liked:

'I can drive down to North Berwick and I'm not stuck staring at the four walls.'
(William, 52, Midlothian)

'I was starting to become a bit of a recluse. I can go out with my daughter now. I can get a taxi and feel more comfortable in my own skin.'
(Emma, 56, Glasgow)

'I can get a taxi to go places and not mooch about at home. I can't travel by bus, and now I can get a taxi and not worry about the expense.'
(Stephanie, 52, Glasgow)

Meeting Expenses

Meeting friends' or family's travel expenses was also something highlighted by clients. In the second case below, the major importance that this could have was brought out clearly:

'The money helps. I can get taxis places. I can give some petrol money to my brother' (Kirsty, 52, Dundee)

'I have a friend who comes and stays when I'm down, when I'm feeling suicidal. I can pay for his taxi to come over and see me' (Neil, 59, Falkirk)

One carer was clear about the way in which the extra money helped her deal with some of the transport related challenges of having a disabled son, through the making of contributions to a family member:

'I can also get some petrol money to my sister to pick him up.'
(Caroline, 47, Carer, Falkirk)

Section 5.5.5 Impact on Dealing with a Financial Crisis.

For a significant number of clients, a successful benefit application had enabled them to deal with a financial crisis that had been building up. Clients consistently linked such crises to negative impacts on their wellbeing and quality of life.

Dealing with Financial Shock

Some clients had suffered a financial shock when the onset or worsening of their condition, or that of their partner, had left them unable to work:

'It's been a big drop in income, from me being employed to this. I've much less money to run the house. The cash helps compensate for that a bit.'
(Laura, 43, Midlothian)

'I managed to get him medically retired, so we've got our mortgage cleared. We were expecting him to work till he was 60 and then retire on a good pension. We've got a big house, and my daughter has a condition which means she gets cold, and our energy bills would have been unmanageable, [without the money] we'd have been in financial difficulties.'
(Frances, 51, Carer, Dundee)

One client had been left vulnerable because of the loss of Carers Allowance. The additional money was effectively tiding him over until an occupational pension kicked in:

'After my father died I was worried, I lost the Carers Allowance. I was worried about not being able to pay the Council Tax or other bills. Now it's OK. I'm just waiting for my Civil Service pension when I'm 60, it's not much more than I'm on now' (Michael, 58, Glasgow)

Clearing Debts

Some clients were now in a position to clear debts:

'It's £75 per week. I also got a backdated payment. I could pay off my debts, I'd been living off my overdraft and getting hit by bank charges. I owed about £500 in total, that includes money to my daughter, which made me feel awful'
(Sarah, 50, Midlothian)

'I got into debt because I was signed off and put onto JSA. I had a mortgage to pay and lots of debts, and I'd got behind. The money helped clear some of that- the PIP and ESA were backdated, I have a lot less stress than before'
(Stephanie, 52, Glasgow)

'I was under a lot of stress about money that I couldn't pay back. With the backdated money I could pay some of it back.' (Parveen, 32, Dundee)

One client was particularly clear on the impact of increased income in giving them a sense that they had turned a corner:

'I'd cashed my endowment. I'd sold my BMW, I had sold everything that I could sell, I'd cashed everything and what could I do now?

My quality of life is definitely better than it was a couple of weeks ago. I am much more optimistic. This result that has been part of that.’
(Tracey, 47, Falkirk)

One client was clear about the consequences for him if he hadn’t been successful in his benefit claim:

‘I wouldn’t have been able to pay all my bills. I think I would have had a nervous breakdown. I’d have worried about the bills and coping with the kids.’
(Robert, 38, Dundee)

Dealing with Housing Difficulties/ Threatened Homelessness

Many of these clients were facing difficulties with their housing situation, finding themselves in arrears, and under threat of action or homelessness:

‘We were stressed to the max, we didn’t have any more money. The council were on at us about the rent, and because he wasn’t getting PIP we couldn’t get it paid. It was affecting our health, we didn’t know whether we were kicked or punched, or where the rent was coming from.....

We haven’t sorted it out yet, but we’ve got an appointment for Thursday with the council, and the backdated money will clear the arrears’
(Janet, 56, Carer, Midlothian).

The emotional relief of dealing with a situation of threatened homelessness could be profound:

‘It stopped me being homeless. Our financial problems began four years ago. I wasn’t able to work and my husband lost his job at the same time. I had to leave my part time job, and the zero hours contract job he had stopped giving him as many hours.....

We hit rock bottom again and we’ve had to rely on friends and family to keep a roof over our head. I have never had enough money until this. The backdated money means we have been able to pay rent

I now wake up in the morning and I’m not scared. I wonder if this is how other people feel? I couldn’t remember what that feels like, not to have a huge black cloud covering my life, that’s how life has been. There are no words for how dark and scary it has been.....

I have actually had a moment of happiness not just distraction, genuine joy. I couldn’t remember what that was like.’ (Nadia, 34, Midlothian)

For one client, who had lost her son, the emotional impact of losing her home would have been extremely severe:

‘The sheriff officers were coming round because of Council Tax, and I couldn’t get any help with my mortgage.....

We've been 17 years there, we moved in just after he [her son who had died] was born. All his memories are there, and his tree is in the garden. That extra money has just been a weight off my shoulders.' (Tracey, 47, Falkirk)

Section 5.5.6 Financial Impact on Quality of Life

The foregoing section has given a strong sense of the emotional impact of clients being able to deal with a crisis. The impact of a successful claim on clients' experience of their quality of life was also visible in less dramatic ways. Even small amounts of money could make a difference:

'It's not a huge amount of money but it will make a big difference. We aren't struggling at the end of the month anymore, we can pick up stuff we lack'
(Sandra, 49, Carer, Midlothian)

'It's helped my quality of life, it's settled everything down'
(Thomas, 59, Midlothian)

Increased Social/ Leisure Activities

Sometimes improvements in quality of life were associated with the ability to engage in social activities:

'I'd like the odd day out. I like poking around 2nd hand shops, getting myself a little treat' (Barbara, 53, Glasgow).

'He's got into snowboarding which doesn't come cheap so this means that he can keep doing that. We can go out on trips together and that's important for his quality of life.' (Caroline, 47, Carer, Falkirk)

'It makes a huge difference, I feel like a part of society again, rather than being stuck at home. I've been able to get bits and pieces for my house, and spend some money on myself. I basically feel that life is now easier, that I'm not being made to feel subhuman.

I can go out to the pictures, I'm going to see the new Bond film, I can go in the morning when it's not busy. Things like that make me feel I am not a drain on society and I am getting myself back together. It takes time, I've been fighting with this claim for six or seven years. It destroyed my self esteem.'
(William, 52, Midlothian)

One client planned to use the extra income for holidays:

'I want to go on holiday. I can't go by myself so I've put down a deposit on that, and I'll go with my daughter, her partner and my granddaughter. Then I'm going to go to Mexico in 2017 with my youngest sister...Every month I'm putting away money for this now.' (Sheila, 50, Falkirk)

Increased Choice

Sometimes the impact of improved finances on quality of life was a result of a simple increase in the change of expenditure choices that clients have:

'My quality of life is definitely better. It took me a couple of weeks to realise the subtle differences. Things like when I go to the local shop to get bits and bobs, I can have a bit of indulgence with food. Nothing that expensive, but I used to have to get things that were heading up to their sell by date and now I can just buy them. I can tell myself I can afford them.' (Sarah, 50, Midlothian)

Section 5.5.7: Financial Impact on Self Esteem/ Sense of Independence and Work Choices

Clients identified a range of other impacts of increased or maintained income associated with people maintaining or increasing their independence, their sense of self esteem, and the choices they can make in relation to work.

Self Esteem and Family

A number of clients spoke of issues connected with self esteem in the context of their family. This could relate to something quite simple:

'I've got the money for my daughter's Christmas' (Lee, 23, Glasgow)

It could also relate to deeper and more complex feelings alongside simpler issues:

'I'll use the extra cash to put aside for my funeral. I don't want my daughter to get stressed or find it a burden..... I rarely go out or anything..... I can also help her when she needs something for college' (Barbara, 53, Glasgow)

'I was embarrassed to have my daughter come and see me. I was living in this undersized flat with just a mattress on my floor' (John, 46, Glasgow).

Financial Independence

Two clients identified that they felt more financially independent, or more able to make a contribution to their family, as a result of their claim:

'I can now make a contribution to my house bills. Before I was only getting £60 for Carers Allowance. I've been able to help in the house and get things in. We can take it in turns to pay bills. I can say to my partner, No, let me do that.....

I can go up to Perth to see my pals, I don't have to plan away in advance, I can just decide to do it' (Phil, 45, Dundee)

'I'm getting significantly more money. I was getting £146 a fortnight, £100 of that was going on direct debits, which left me £46 to live on. My mum was having to buy me dinner every day. She is 81 and I didn't want her to have to do that.....

I'm now getting £250 per fortnight. That gives me £150 left. My mum comes down and cooks, we can go shopping together and go halves.....

We lost my dad in February and I felt guilty asking her to help me out. I feel better now that I can pay my own way, now I am not sponging off her. I've always been independent, at 53 it's terrible to rely on your 81 year old mum.'

(Lisa, 53, Falkirk)

Work Choices

Three clients focused on how additional income facilitated different choices in relation to their work. For two of these clients, additional income meant that they could fulfil their caring responsibilities:

‘The extra money helps because I need to be at home to look after my [elderly] parents. I don’t have to work so many hours’ (Thomas, 59, Midlothian).

‘I work part time because I can afford to. I spread my hours over three days, and this [PIP] means that I can make sure I am home when he comes home from school.....

If I hadn’t got it, I might have had to look at extra hours. My employer has been really good to me but I don’t know if they’d be available.’
(Caroline, 47, Carer, Falkirk)

For the other client, the success of her claim had meant financial breathing space whilst she sought help for the problems that were affecting her, and the opportunity to start again in the future:

‘I want to go back into business or take a job. At the moment I can’t do that, I’m doing a lot of stuff with my therapist. This means six months breathing space and it will help me along the way’ (Tracey, 47, Falkirk).

One client, a carer, anticipated the difference to quality of life in the future that would be made by the income from the successful application:

‘I hope in the future that he makes it to college or university. It will help towards that.’ (Caroline, 47, Carer, Falkirk)

Section 5.5.8: Successful Claims and Validation

The interviews picked up one more way in which a successful claim could have a positive psychological impact on clients; giving them a sense of validation that their condition, and its impact on their lives, had been recognised by someone.

For some clients, validation was explicitly in the context of a broader lack of support, or lack of belief from professionals and others in their experience of illness:

‘The recognition was important. Getting better isn’t about wanting to be well. If it was, I’d have been better ten years ago. I’ve had so little support and this has given me recognition’ (Nadia, 34, Midlothian)

‘It did feel good to be believed. I don’t feel like they believed things in black and white from my consultant, not even my GP does’ (Barbara, 53, Glasgow)

‘Having an acknowledgement is quite important. It’s a good thing that people have actually believed me and understood. I thought that the only person who understood me was the doctor, it’s been good to know that others do too.’
(Emma, 56, Glasgow)

Simply being listened to made a difference to one client:

'I'm not spending much of the money at the moment. It wasn't really about the money, I feel better that someone has listened for a change, and that I have something in return.....

I'm quite a deep person anyway, I find it hard to open up, but it's good that someone listened.' (Margaret, 61, Dundee)

Validation had come as something of a pleasant surprise to some clients:

'It was good to get that acknowledged. If I hadn't been successful, and I had got nothing it would have been, Christ look at the state of me and I don't get anything.' (Gary, 59, Dundee)

One client went from expressing a degree of cynicism at the start of this section of her interview, to a position more accepting of the importance of validation:

'Of course it's about the cash. You wouldn't put yourself through it otherwise. You aren't doing it for the good of your health, but because you need help with the extra costs of being disabled.....

Do I think it's about validation as well? Perhaps there is something about recognition. I don't qualify for benefits, and he can't work because of his health, and some people may be looking at us and thinking- What's wrong with them? There may be a bit of validation there' (Sandra, 49, Carer, Midlothian)

Section 5.5.9: Limits to the Financial Impact on Quality of Life

Several clients noted that, whilst a successful claim had made a difference to their quality of life, there were limits to how far this could go:

For one client, the extent of his illness since receiving a positive decision had simply meant a lack of opportunity to actually use his extra money in any way:

'I've not been right since the assessment. I haven't been able to go out and spend, I've been really ill from day one and I've had the doctors out. The money can't make everything better' (Andrew, 43, Falkirk)

Others saw things continuing for them as they had been doing, with concerns other than money pressing on them. Some clients with with mental health problems also remained doubtful about the impact of treatment that they were receiving:

'I don't have a great quality of life, the life I'm living isn't great. I don't get help anymore, my last psychiatrist left. I don't want to see people, I tried hard to make myself do it and I can't. I find it quite to talk and I bury my thoughts. I can't cope with groups' (Neil, 59, Falkirk)

'I'm still not ready to be happy or anything like that. Everything is still the same, I still take everything as it comes.... I haven't jumped over the moon. The money is good to have but life is still the same.' (Lee, 23, Glasgow)

'Unfortunately a lot of my problems are about other issues beyond [money], Money can't solve everything, no. Only the doctor and health centre can do that, and they aren't doing to well- I don't think that alcohol is really an issue that they deal with. I don't think the people that I deal with understand the problems that I have.' (Michael, 58, Glasgow)

Clients with physical health problems were also sometimes not optimistic about their quality of life improving across the board:

'The difference to my quality of life is that I am not worried about spending. I can spend a bit of extra money without worrying. It can't change everything, I have lots of pain coming from different places in my body and I take lots of tablets and painkillers. This makes me sleepy, zombified, but the pain in my back is bad, like someone is stabbing me. I am a little bit trapped in my home.' (Kathryn, 50, Falkirk)

Some clients were not really seeking or expecting major changes to their quality of life as a result of the service:

'My quality of life still isn't good. I still don't go out much, but that's my choice. I'm quite happy in my cocoon. Everything would be much better if my health was better' (Claire, 53, Glasgow)

One client felt that even though the service gave her a chance for a new start, she would still miss her old life, and regretted that going fully back would not be possible:

'You know that you've been a single parent of four, that you've run businesses and started a charity and it's difficult to admit you can't cope. I know that dynamic woman is never coming back' (Tracey, 47, Falkirk)

One client also saw the help received from the project as the springboard to doing much more to sort out areas of his life that he was unhappy with:

'It's opened my eyes to a lot of things. I now know what crap care is. There is someone gets paid to help me get dressed, and I want better support from them, and from other people, my psychiatrist and GP. Even my back is getting slightly better. I feels that people are now changing the way they are to me because I have my eyes open. I am getting them to look at my treatment, I hope I am on the right road.' (John, 46, Glasgow)

Section 5.5: Key Points

- **Engagement with the advocate after the decision letter has been received offers the opportunity for:**
 - **Closure, and for clients to thank advocates, something many feel is important.**
 - **Advocates to explain decisions to clients, and reassure them that the money is theirs to spend.**
 - **Clients to consider future options with advocates if they have received an inappropriate negative decision on their claim.**
 - **To begin work on a mandatory reconsideration if required.**

- To refer to other support, and point towards/ provide basic assistance with applications for passported benefits.
- Clients use ESA and PIP on a variety of goods and services to help them cope better with their condition including; gadgets, new furniture, equipment, help around the home, and treatment; and to meet extra costs resulting from their disability such as purchase of sanitary product and additional clothes, and higher heating bills.
- ESA and PIP are also used by clients as a boost to household budgets that can be spent on food, heating, clothes and items for their home.
- Many clients' material aspirations can only be described as modest.
- Boosting household budgets reduces psychological as well as financial pressure on clients, stopping them from regularly running out of money, and helps them build buffers against problems.
- ESA and PIP may also be used to purchase cars, often Motability cars, or keep existing cars running.
- They may also be used to pay for use of taxis, particularly where clients face barriers to the use of public transport.
- Clients also use ESA and PIP to pay relatives or friends to give lifts or travel to see them when they need help.
- Spending money on travel helps some clients maintain or restart engagement with social or leisure activities.
- ESA and PIP can help clients deal with an income shock associated with a loss of employment or cessation of caring responsibilities.
- ESA and PIP, particularly backdated payments, can be used to clear debts, including to family members.
- Two clients were able to escape the threat of homelessness as the result of successful claims, one was able to deal with a growing arrears situation.
- Dealing with financial crises brings enormous emotional relief to clients.
- Successful claims boost clients' quality of life, engagement in social activities, financial independence, self esteem and ability to make appropriate choices about the balance between their work and caring responsibilities.
- Some clients experience a positive psychological impact as a result of a successful claim, as it provides a degree of validation, particularly in a context where others have not recognised their situation fully.
- The boost of a successful claim can only change some things in clients' lives. It cannot deal with the totality of their condition or wholly transform their lives.

Section 5.6 Recommendations for Changing the System.

To stimulate further reflection on their experience, and in the light of the transfer of powers over PIP to the Scottish Government and ongoing controversy over the efficacy and impact of existing assessment processes, clients were asked what they would change about the benefit and assessment process that they had been through. More specifically they were sometimes asked to place themselves in the position of the Government at Westminster and/ or Holyrood, and say what they would change about the system, from the application to the assessment and beyond.

Two broad categories of response emerged, although the boundaries between the two were blurred. Between a quarter and a third of the clients wanted to see the face to face assessment scrapped entirely, or scrapped for particular groups of claimants. The remainder felt the assessment was necessary and/ or fair, with a minority of this second group suggesting it was an important opportunity for applicants.

People in the second group were, without exception, clear that the assessment process still needed to change significantly. The changes that they identified generally echoed the factors that led those who wanted the assessment scrapped to hold that view.

It should be reflected that the vast majority of feedback in both categories was coming from people who had received positive outcomes on their claim.

Section 5.6.1: Support for Scrapping Face to Face Assessments.

Reasons given for scrapping face to face assessments were based on two contentions, that they:

- Were not necessary and added nothing to the process.
- Were excessively stressful or unfair for some groups of clients.

A number of clients felt that the information provided on application forms, by GPs and other medical professionals should be enough for a judgement to be made:

‘At the face to face [assessment] they seem to ask questions that are already on the form, and that you’ve already covered in letters etc. I’ve got a medical history of ten years behind me, it’s all there on the form. The GP should be able to give them it all.....

They got nothing from my interview that wasn’t there in the medical notes. The only thing that was different was they asked me to squeeze my fingers and point my toes.....

I don’t really understand the point of the assessment. Perhaps for some conditions, but the experience puts people down and makes them feel small.’
(Nadia, 34, Midlothian)

One of these clients felt that the supporting letters that she had provided had not mattered in comparison to the face to face assessment, something she thought was the wrong way round:

'I don't think it's fair going through the assessment. You get doctors' letters and things that tell how your condition affects you, but they don't matter. It just feels unfair' (Barbara, 53, Glasgow)

Two clients felt that a more joined up system would mean the assessors seeking out key information for themselves:

'They should try and find out for themselves. They should do the research themselves into your medical history, you shouldn't have to meet face to face' (Lee, 23, Glasgow)

'Things should be more automatic for people. You should get the benefit without filling in forms, they have your medical history.....

I've even had a blue badge before, so they should know my situation without me having to fill in forms. How could they not know about it by now? Nobody administers these things, if you are in that situation, why should you have to fill in forms to get help?' (Thomas, 59, Midlothian)

One client made this point in a particular way, stressing that the assessors could simply not understand his condition in the same way as people familiar with his case who had been working with him for years:

'They should contact the doctors. My GP knows my background better than anybody, certainly better than someone who's seen me at a 20 minute assessment. You feel as if you have to sell yourself and convince them of your problems, but a GP knows what those problems are.' (George, 60, Falkirk)

Part of the stress affecting people results from the reputation that the face to face assessments carry before them, suggesting that for some clients, the Work Capability Assessment is a brand damaged beyond repair:

'It was really stressful. You see it on the news, you see stuff and you think you haven't got a hope in hell. If a doctor says you need help, why can't they listen to the doctor' (Claire, 53, Glasgow)

Another client captured his disagreement with face to face assessments in a particularly resonant phrase:

'I don't think assessments are fair. You have to go to someone you don't know and tell them about your life. It's not fair then when they turn round and say you haven't got anything wrong with you, when you have.....

It's like the assessments in World War One. That's where assessments began, when they were sending you back to the front' (Malcolm, 62, Dundee).

People with mental health problems were seen as particularly prone to experiencing stress and anxiety as a result of the test:

'Is sitting down and telling people about your condition too stressful? Maybe. It's certainly very, very daunting for people. It's a scary, scary thing to have to go to.....

Perhaps people with other conditions are OK, but if you have mental health problems it's scary. It could be different for people with physical conditions, I'm not sure.....

There is potentially a place for face to face assessments, I don't know, but for someone like me going through things it's a lot of stress on my mental health. The assessors have a lot of power, it feels quite an unnecessary thing to put people through.' (Lorraine, 58, Midlothian)

One client expressed very strong views, not about the situations specific to her and her husband, who were both claiming ESA, but about the situations facing some people with learning disabilities or mental health problems:

'I would not have people with that level of disability go through the face to face assessment. The assessors should be able to read the form and make a decision.....

A lot of people I've seen in Cadogan Street shouldn't have to go through this.... I've seen people with mental health problems who can't look at other people and sit there facing the wall because they have such anxiety about being in public places. They are clearly unfit for work.....

I see elderly parents in their 70s and 80s of someone in their mid 40s with Downs Syndrome who should not be sitting there. A generation of people with Downs have not been treated as full members of society and are now be tested to see if they are fit for work. They are being provided with no support, and they should not be called in and be sitting there.....

People should have their cases sifted out at the assessment stage and doctors should be listened to. It's an unspeakable ordeal for some people to be put through when it's clear that they shouldn't have to.'

(Frances, 51, Carer, Dundee)

Section 5.6.2: Reform not Scrap Face to Face Assessments/ Areas for Reform

As indicated above, the majority of clients felt that face to face assessments were fair. However, without exception this was qualified by the identification of changes that were seen as needed if fairness was to be achieved.

'The face to face is fair enough. It's how you go about things. I can see the value in it, it's how you go about it. There must be a better way to deliver it'

(Sandra, 49, Carer, Midlothian)

Assessments as Necessary and/or Fair

Face to Face assessments were seen by many clients as necessary to make sure that sure that people did not receive benefits to which they were not entitled:

'There is a place for them. You could say anything on a form with nothing to back it up' (Janet, 56, Carer, Midlothian)

This sense of the assessments being necessary could be shared by people whose experience of the assessment was quite negative:

'I'm not saying that there shouldn't be [face to face assessments] There are people who are getting benefits who don't need them. I understand why they are tightening it up, the way things are.....

When you are 100% genuine, you can feel like you are begging and have to justify yourself, but I can understand why' (Caroline, 47, Carer, Falkirk)

'I think it's fair to have a face to face assessment. There are people who want to get something for nothing.' (Gary, 59, Dundee)

Some clients were quite torn on the issue:

'I think that the process shouldn't exist. You shouldn't have to go through it. I wish that what you put down on the page could just be accepted.....I know that's a bit idealistic, I understand it's necessary, that's just the way it is' (Sarah, 50, Midlothian)

'I didn't think that this was needed at the start. I think there was a lot of detail given in the forms. I couldn't get information from the GP because they had stopped doing that, but they had the detail. I suppose you have to have the face to face assessment, anyone could be wanting anything done' (Neil, 59, Falkirk)

Even in the context of views that the *existence* of the assessment was fair, some clients felt that the *actual experience* was difficult for some people, and that the results it produced were currently not always fair:

'There are genuine people as well. It's not easy for them. They get refused whilst other people get it.' (Gary, 59, Dundee)

'There are people who lack self confidence. They find it difficult to be heard and hard to answer questions. Some don't have any problem' (Phil, 45, Dundee).

Assessments as an Opportunity

They were also seen by some clients as an opportunity for the assessor to pick up additional information, and thus an opportunity for the claimant as well:

'There is information that you can't put on a paper form.' (Sandra, 49, Carer, Midlothian)

'Yes, it is fair [to go through the assessment]. People can actually see the person and see how you are. They know then that you are not just some number on a form, and realise that you need help' (Joanne, 46, Glasgow)

'The assessor could see I was struggling to speak, so she knew how my condition affected me. She could see it' (Gerry, 66, Dundee).

Section 5.6.3: Suggestions for Changes to the Assessment.

Clients came up with a range of suggestions for improving the face to face assessment, and other parts of the process.

Several clients were clear that the process should be amended to ensure that the information collected within the assessment was genuinely additional:

'You shouldn't have to answer stuff that's already on the form. There is specific medical information on the form and you are being asked again about that. It's not appropriate, it's not necessary, it's a waste of time.....

They ask technical things, why are they asking when it's in the paperwork. It seems that they are trying to catch you out, it [the repetition] is part of what makes it seem like that. Why ask again?' (Sandra, 49, Carer, Midlothian)

Other clients suggested that assessors did more research into cases before assessments, to make them less onerous:

'The system should look more at people's backgrounds. There are people who are not entitled who are playing the system. I'm not here to sponge, I want to get back to work when I'm ready' (Lisa, 53, Falkirk)

Clients felt that the process could be made more genuinely user friendly, with some specific suggestions for how this could be done;

'The process could definitely be made more user friendly. Perhaps the austerity of it is for a reason, but they could soften it' (Sandra, 49, Carer, Midlothian)

'It could be less formal. Perhaps they could have the assessment in people's homes. It wouldn't seem as frightening then' (Janet, 56, Carer, Midlothian)

The changes suggested could be quite simple, just involving basic customer service:

'I tried to rearrange the appointment because I was in hospital. I gave them a call and they were a bit brash about it. Their telephone manner could be improved' (Gary, 59, Dundee)

Some clients focused recommendations on the needs of people with mental health problems:

'The questions at the moment are really tedious, boring rubbish' (Andrew, 43, Falkirk)

'There should be more questions about mental health. That would make them understand better how I feel. I was made to feel inadequate.' (Neil, 59, Falkirk)

The length of time taken by the whole process was seen as something that should be dealt with to reduce the stress experienced by claimants:

'It should be changed so that you don't have to wait so long before assessments. You shouldn't have to wait as long as 13 weeks. You should only have to wait a couple of weeks to get the results' (Joanne, 46, Glasgow).

Qualifications of Staff

The most frequent suggestions for changes related to the need for those delivering the assessment to be properly qualified to do so:

'There are changes I would make to the system. It should be people who know about disability and mental health that do the test. I don't want someone who has just done a course, and is asking questions about whether you can reach something or put your arms out from your side' (Andrew, 43, Falkirk)

'Perhaps the assessment should be done by a psychologist' (Neil, 59, Falkirk).

'The lady in Dundee was a nurse, the people that carry this out should be nurses or doctors.' (Patricia, 62, Dundee)

There was particular concern that the assessment should not be done by physiotherapists who were seen as lacking a full understanding of the conditions with which people were presenting:

'I think physios don't really know what people are talking about. You need people with a better understanding of what you are telling them' (Claire, 53, Glasgow)

'The so called independent professionals, some don't have the qualifications. You have physios working on this. You can't teach physios about mental health. That's not an insult to them, it's a recognition of the complexity of the conditions' (Frances, 51, Carer, Dundee)

There was also concern that staff without sufficient qualifications would not understand how conditions fluctuate:

'I'd change the system so that it was done by a doctor. The woman [who assessed her] probably didn't even understand what the symptoms were. Every day is different for me, I can be OK for a few days and then not' (Kirsty, 52, Dundee)

A further priority was seen as being to deal with the complexity of the forms, or the way they were phrased:

'They should get rid of all the jargon. I write professionally and I am struggling to understand them and what they are after and fill them in' (Nadia, 34, Midlothian)

'The assessment is making a lot of people miserable. I think they should change the paperwork. It should be more realistic. They ask you if you can walk 50 metres, I don't know what 50 metres is, do you?' (Patricia, 62, Dundee)

Section 5.6: Key Points

- **A significant minority of clients believe that face to face assessments should be scrapped, at least for some client groups such as people with mental health problems or learning disabilities.**
- **The majority see face to face assessments as necessary and as fair, subject to certain adjustments being made.**
- **A minority believe that face to face assessments provide an essential opportunity to clients to make their case in a way that is not possible through application forms or medical reports alone.**
- **Key suggestions for improvement to assessments focus on:**
 - **The need to ensure that assessors are appropriately qualified, particularly when assessing people with mental health problems.**
 - **The need for assessments to genuinely seek additional information, rather than simply going over the ground covered in forms.**
- **Further suggestions for improvement to assessments include;**
 - **Making the assessments more user friendly and improving basic customer service.**
 - **Better tailoring of the questions to reflect the issues facing people with mental health problems.**
 - **The simplifying of application forms.**

Section 5.7: Changing/ Recommending the Service and Overall Views

Section 5.7.1: Recommendations for Changes to the Service

Clients were asked to recommend changes that they thought should be made to the advocacy service.

The vast majority of clients indicated that they did not have changes to recommend. Where recommendations were made, they tended to focus on the need for better publicity for/ advertising of the service, or on the need for the service to be sustained or expanded. The exceptions proposed a change to service practice relating to initial engagement, and suggested a slightly different model for the service.

Clients were clear that the service should be sustained or expanded:

‘It has helped so many people, it should be continued. It would be madness not to continue it.’ (Sandra, 49, Carer, Midlothian)

‘I think the service should be extended to anyone with mental health problems who needs it. That would be wonderful.’ (Frances, 51, Carer, Dundee)

Clients were clear about the need for better, wider project public publicity, a failing that was seen to be common to support services in general:

‘It’s difficult to know where to get help. I was aware of Grapevine [the organisation who had referred them to the project] though my work, but there are a lot of disability organisations out there that I’d never heard of like VOCAL, and I’d only heard of Grapevine because of my work’ (Laura, 43, Midlothian).

‘It’s a fantastic service. The only thing is that it’s not publicised enough. There must be thousands who could do with the service.’ (Claire, 53, Glasgow)

‘The service should be better known. There should be notices in doctors’ surgeries, things like that, that make clear that there is someone that you can go and see’ (Gerry, 66, Dundee)

The model of the client journey within the service typically involves people receiving support from an advice agency as well as an advocate. One client, who had instead been supported all the way through the process, from form filling onwards by their advocacy worker suggested that they preferred this model:

‘I’d prefer to see just the one person. If I’d seen the CAB worker as well, it wouldn’t have been as good. Dealing with two people isn’t as good.’
(Sandra, 49, Carer, Midlothian)

One client felt that the initial engagement with the service should be looked at again in the light of their experience. They were very clear about placing this in the context of an overall positive message:

‘One thing though. When you phone up, they ask you if you have mental health problems, because the service is restricted to people with mental health

problems. There is a stigma around that. It's quite difficult, when you've been a businesswoman, a Rotarian, when you have set up charities, to admit to that.

Perhaps there is another way that the question can be asked. It might make it easier to pick up the phone if you didn't have to admit that life is pretty crap right now. That feeds into the grief that you feel. There are times when you struggle to put one foot in front of another. To categorise yourself is difficult....

Get some funding. It is an invaluable, fabulous service' (Tracey, 47, Falkirk)

Section 5.7.2: Recommending the Service

Clients were asked if they would recommend the service to other people. Without exception, they responded positively.

This section therefore focuses on the feedback from clients who indicated that they had already recommended the service to others, to capture a sense of how word of mouth gets generated about the service, and how it might be helped along:

'I've already recommended the service. I've handed out the cards that Jane gave me' (William, 52, Midlothian)

'The taxi driver who brought me in [to the assessment], his wife was having the assessment the next day. So I told him about Jane's service.

'I've told customers about it when we get chatting' (Parveen, 32, Dundee)

One client was consciously mentioning the advocacy service whenever she spoke to friends or acquaintances about benefits:

'If I speak to someone about benefits, I always mention the advocacy service to them. I tell them what a great help the service was to me' (Nicola, 47, Glasgow)

Clients saw the service as potentially helping out friends in difficulties:

'I've told someone I know. She's got really bad health, but she's been knocked back for ESA and she's only getting a wee bit from PIP' (Lisa, 53, Falkirk)

Section 5.7.3: Overall Judgement on the Project

Clients were asked to give their overall view on the project and the service they had received.

Without exception the comments were positive.

Some clients picked out the value of the service to particular people:

'I think it's a good service. There are people who could benefit greatly from it. There are people who could sail through assessments without any problems, there are others who don't know how it all works, and I think it's a really good thing for them.' (Lorraine, 58, Midlothian)

'It's a brilliant service. It's really, really good for people who don't know the system, it's very supportive' (Lisa, 53, Falkirk)

The characteristics of the advocates were again picked up at this point:

'Ian's not that old. I've been helped by people that age before, I've not been patronised exactly, that's not the right word, but I have felt uncomfortable talking to them. I didn't feel that way with Ian, he was so easy to talk to.'

'The people there [at the assessment centre] treat you like idiots. With you [The Advocacy Project] it's very different. Adam treated me like a real person' (Miriam, 53, Glasgow).

'She was brilliant, very professional, and she didn't speak out of turn. She didn't try and take over, it was really great.' (Malcolm, 62, Dundee)

'It must have been difficult for Vonnie to hear about his [Frances' husband's suicide attempt]. Her example helped me hold myself together, I think it's actually a very special person who can do that, you can't train someone to be like that, they are either like that or they are not.'

'She's a totie wee woman too, I'm five foot and she's smaller than me.'

(Frances, 51, Carer, Dundee)

The service and advocates were sometimes seen in stark contrast to other staff./services:

'Adam is passionate about his job. I've only met him three times, and he's done more for me in those three times than anyone else. Others have been shit, I'd rather be sanctioned than see them again' (John, 46, Glasgow)

'It's a fantastic service. I've had bad experiences in London where I've had no help at all. The CAB there didn't help me prepare properly. The situation is 100% better here' (Patricia, 62, Dundee)

'It's been better than social work or welfare rights. They speak to you as if you are a person, not just doing a tick box exercise. Welfare rights are only doing their job, but they sometimes seem like they are reading from a text book. The Advocacy Project doesn't do that, it treats you like a human being.'

(Emma, 56, Glasgow)

Finally, the following four comments capture effectively and vividly the responses of clients when asked to sum up the service:

'Thank you for Jane. Whoever taught her thank you. There is nothing to change about the service, 20 out of 10' (Janet, 56, Carer, Midlothian)

'I'd change nothing about the service, it was absolutely everything you would want it to be' (Nadia, 34, Midlothian)

'It was bang on. If it hadn't been, I wouldn't have been able to go through with it.' (Lee, 23, Glasgow)

'She did a fantastic job. If it wasn't for her I wouldn't have got anywhere. She was my rock. I feel very sorry for anyone who doesn't have someone with them. A hundred out of a hundred. I dread to think what people do when they haven't got access to an Yvonne.' (Kirsty, 52, Dundee)

Section 6: Project and Partner Perspectives.

Section 6 of the report presents the findings from interviews conducted with each of the advocates and project managers, and six external referral partners.

It looks in turn at:

- The situation facing delivery and referral partners prior to the setting up of the project.
- How the projects developed partnership and referral relationships, and the effectiveness of those referral relationships.
- How the service model has been delivered at initial meetings, assessments and debriefing meetings and the context of client experience at those points.
- The impact of the service, its additionality and the way in which it complements other services.
- How the project had dealt with organisational issues such as capacity management, training and professional support.
- Key remaining research questions; how the service fits with other activities, the value of using volunteers, and whether the service has engaged with the right groups.

Section 6.1: Prior Situation

The pilot projects were not set up in a vacuum. Each of the delivery partners was already trying to manage demand to support clients with their attendance at PIP and ESA assessments.

That demand was not as great as the current demand for the pilot services, coming largely, though not entirely, from amongst existing clients, with delivery partners deliberately not publicising the potential availability of support to other organisations.

Each delivery partner was responding to requests for support at assessments in slightly different ways:

- DIAS would:
 - Receive a significant number of last minute requests for support from Dundee City Council Welfare Rights, and Dundee CAB.
 - Try to accommodate such requests in the context of contracting arrangements that already did not reflect the extent of their work.
 - Sometimes have to turn people away.
- Forth Valley Advocacy would:
 - Try to find volunteers to provide the support.
 - Largely confine the provision of this type of support to existing clients to avoid raising expectations they couldn't fulfil.
 - Sometime be unable to offer support where it was needed.
 - Refer clients with learning disabilities in Stirling to another local project.
- The Advocacy Project:
 - Had stepped back from their previous practice of supporting clients to access advice services, on the grounds that those services themselves offered a sufficiently high level of support. This had not been a comfortable decision for them, but it was one dictated by the tight focus of their contracts.
 - Would attend assessments with existing clients if this was possible, but could not guarantee it.
- VOCAL:
 - Would look to signpost people on to other local organisations.
 - Was clear that there was a lack of organisations available to help people on benefit issues.

Referral partners reported similar previous struggles:

- Having, sometimes with reluctance, to encourage people to go into assessments with a family member for moral support.
- Trying, and sometimes failing, to find a support worker to accompany people, whilst acknowledging the risk that the support worker might feel too close to the situation and too emotionally involved with the client.
- Where it was possible, some advice agencies had even accompanied clients to assessments themselves, reasoning that this was more effective and efficient a way of proceeding than having to deal with an appeal further down the line.

One organisation did report making a limited number of referrals from his welfare rights service to another local advocacy organisation prior to the setting up of the project.

One organisation reported that in the week that they were first able to get support from the project, six clients had approached them looking for support at an assessment, even higher than the still significant one per week that was more normal.

Section 6.2: Partnership and Referral.

Section 6.2.1: Partnership Building

For each of the delivery partners, an initial focus of the project was to build up partnership links with a range of referral partners.

There appears to have been a broadly similar pattern to the process of partnership building in each area:

- Identification of potential referral partners by project managers, advocates and their colleagues, often based on existing links.
- Advocates then taking the lead engaging with potential referral partners, concentrating their efforts on building personal relationships.
- The use of local advice and information/ financial inclusion forums as a mechanism for communicating with potential referral partners.
- Follow up work with key referral partners including speaking at staff meetings.

DIAS had had one key advantage in its partnership engagement work; recruitment of a CAB advisor had guaranteed a high volume of referrals from her ex-colleagues right from the start.

The process of partnership building has not stopped, and in each area it has been set against the need to control the volume of referrals. Each of the delivery partners identified partners they were in the process of engaging with to expand the range of clients; for example DIAS is engaging with SAMH, Forth Valley Advocacy is expanding engagement beyond Falkirk, The Advocacy Project is engaging with the Scottish Huntington's Association and care providers for people with learning disabilities, and VOCAL is engaging with disability charities in Edinburgh.

Partnership engagement had been a time consuming activity for most of the delivery partners. Advocates noted the need in the early stages to establish their bona fides with referral partners, who would want to know that they were referring their own clients to an effective and professional service. This process could take some time, but once success was achieved with initial referrals, it would pay dividends.

Partnership building work has been successful in building links with some referral partners who had not hitherto had a relationship with the delivery partner, who had engaged with the advocate at one of their outreach sessions, and have gone on to make a substantial number of referrals. Effort at partnership building could be pushing at an open door, one advice worker described his organisation as 'biting the hand off' the advocate when they heard the service was available.

For most partners, maintaining an effective referral relationship did not require specific efforts to keep engaging once trust had been established, with the relationship being kept warm by positive feedback on client progress, and the normal requirements of referral and information sharing. One advice worker did indicate, however, that he felt that advocacy was not well understood amongst his colleagues and volunteers in his organisation, and that a more formal referral protocol, and more awareness raising might help deal with this.

Section 6.2.2: Success of Partnership Working.

Partner engagement had thrown up both unexpected successes, and situations where relationships had not yet developed as had been hoped.

On the positive unexpected side:

- Forth Valley Advocacy had established an effective working relationship with a supported housing provider.
- The Advocacy Project had established effective working relationships with welfare rights staff at a supported housing project in North Lanarkshire, and a Glasgow housing association.

More disappointing for projects have been:

- The general lack of referrals from primary health care providers, though both DIAS and VOCAL noted the extent of ongoing reluctance from GPs in their area to get involved in the benefit assessment process in any way.
- The lack of referrals from one of the local money advice projects to The Advocacy Project, despite the highly positive reception for the service from senior staff, with project suspecting that the message has not percolated down to the frontline.
- Some 'turf issues' in Lothian, with some potential referral partners and a local advocacy provider feeling that VOCAL were interloping into this area of work, meaning referrals had not come as hoped from some parts of the health or advice sectors.
- Issues in Dundee with one local advice provider seeing the project as a potential threat, although these have largely been resolved and referrals are beginning to come through.

Delivery partners have a degree of concern about the lack of referrals from the health and social work sectors, suspecting that this means the service is still largely reaching those who are already in contact with advice services, whilst potential clients who are not miss out.

Section 6.2.3: Appropriateness of Referrals.

Each delivery partner presented a positive picture of the appropriateness of referrals to the project. The pilot is being used by people who need the service.

The Advocacy Project has found that some 'gatekeeping' has been required. Internal referrals to the service were initially not always wholly appropriate, and one referral partner initially sought to make a significant number of referrals of clients who are solely affected by physical disabilities. The project is clear that both issues have now been resolved, and were no more than teething problems.

VOCAL were clear that the extent of the appropriateness of a referral is not always immediately apparent. A case that at first sight looks relatively simple can become something much more complex on further exploration. The VOCAL advocate reported one such case, where a client initially presenting with fairly low level problems was sectioned under the Mental Health Act during the period leading up to her assessment.

Conversely, projects report occasional cases which have prompted them to question whether a client needs their support.

Discussion around the appropriateness of referrals opened up a broader discussion with referral partners about who the project should target.

Projects are clear that they have been prepared to work with people whose primary condition has been a physical disability. This has been on the simple grounds that people in this situation often face a significant level of compounding mental health problems or high levels of stress when contemplating the prospect of the assessment, thus placing them within the target group for the project. For carers, the level of care burden alone can be enough to justify their receipt of the service.

Section 6.2.4: Timing of Referral.

Each of the advocates highlighted issues with the timing of referral. In a significant minority of cases referrals are received close to the assessment itself. In some cases advocates had received a referral within a couple of days of the assessment date.

Advocates' immediate response will be to try to get clients to rearrange assessments, but this will not always be possible, with some clients already having asked for one rearrangement.

Advocates report trying to be as flexible as possible in terms of accommodating late referrals. Some clients have been met with the day before an assessment, others have been accompanied to assessments with no preparation, with advocates clear about the limits of what they can offer under such circumstances, they can give moral support and nothing else. Only rarely have referrals been turned down.

Section 6.2.5: Referral Process- Referral Partner Perspective.

Practice within referral partners varies:

- Some referral partners, particularly those engaging with a predominantly vulnerable clientele, will make a proactive offer of the service to the majority of the clients they are supporting with ESA or PIP.
- These partners will usually only not make an offer of referral where it is clear that the client has an other source of support, although their preference is for this not to be a family member; people are seen as not always being 100% honest about their condition if a family member is present.
- Other referral partners will place more emphasis on triage, looking to identify people who may have a particular need for support in the assessment and lack alternative means of accessing it, exploring how confident they feel about the assessment, and being happier to accept that people can be adequately supported by family members.
- One referral partner also uses printed information in which they highlight the value of being supported by someone at the assessment, and the potential for people to access the project.
- Some referral partners report not having to do too much to proactively identify people in need of support, with clients often asking for it themselves.
- One partner reported adapting their criteria for referral in the light of feedback that they were referring too many people with physical conditions as their primary condition.

Referral is usually by means of the referring partner contacting the advocate (using an online referral tool used to access any of the organisation's services in the case of DIAS) and, with permission, providing the contact details of the client, and information such as application forms relevant to the case.

Section 6.3: Delivering the Service Model

The range of support provided by advocates at the assessment has been covered in Part 3 of the report containing client feedback.

This section focuses on advocates' understanding of what they are trying to achieve at the different stages of their engagement with clients, and the issues that they are trying to deal with in terms of client feelings and experience.

Section 6.3.1 Initial Contact

Client Initial Feelings.

Advocates report that:

- Clients are often apprehensive about meeting them for the first time. They need a degree of reassurance that they are dealing with someone who is effective and understanding.
- Making the step to coming into their premises can be difficult for some clients, necessitating home visits or meetings in venues in the community such as cafes.
- Clients have a high degree of anxiety at the prospect of the assessment; fearing losing their entitlement, having the details of their life looked at, and facing an assessor.
- This anxiety is almost universal whatever their prevailing state of mental health.
- Some clients are anxious to the extent of 'shaking from head to foot'.

One advocate observed that there does not appear to be less nervousness on the part of clients who have received support from advice partners. Those clients will sometimes have received basic explanation of the assessment process that lies ahead, but the incompleteness of that explanation will have left some of them still concerned about their situation, and perhaps facing an even greater level of worry.

Focus of the Initial Meeting.

Advocates have clear aims at the initial meeting. These are to:

- Establish a rapport with clients.
- Draw out from clients the information that they need.
- Prepare clients appropriately for the assessment.

Establishing a rapport is essential, without it the service cannot be delivered, without someone trusting the advocate or being at ease, the service cannot function. Once they have explained about the service they offer, advocates use a number of techniques:

- One advocate highlights the need to avoid appearing too formal, or too professional (though her professionalism was much praised by her clients).
- Another advocate describes himself as aiming to be as light hearted as possible.
- Another identifies the importance of being prepared to share information about herself with clients as a way of breaking down the power differential between them.

Whatever techniques are used to establish a rapport, understanding client perceptions of their situation and the world is essential.

Advocates are clear that they are able to draw more information out of clients than will have been provided on the relevant application form. The review of application forms is an essential part of the process, but in the adapted words of one advocate 'they are standard forms, which ask standard questions, which produce standard answers'.

The objectives of preparation are to:

- Ensure that clients have all the practical information about the test that they might require.
- Get clients clear about key points that they must communicate at the assessment.
- Develop a clear strategy for dealing with challenging situations within the assessment, in particular where people might get upset or angry.
- Review past experience with clients, and make clear potential pitfalls within the assessment, stressing the need for clients to give sufficient detail, making clear when things are difficult for them.

The process of preparation and drawing information out of people can be quite subtle. Advocates talk about the way they structure the conversation around the way that the assessment itself is structured. They will both explicitly discuss the descriptors with clients, and seek to get them familiar with the underpinning ideas, getting them thinking in terms of the descriptors and how they can explain their condition in those terms.

Three of the advocates pull together a list of key points/ summary document for clients. In two of the projects, DIAS and Forth Valley Advocacy, there is a significant focus on getting clear approval of the document from clients which is formally shared with them. VOCAL specifically took the decision not to do this with clients, feeling that it takes responsibility away from the client, and that, given that the advocacy organisation signs off the document with information gathered from their perspective, its accuracy cannot be relied upon.

Projects take slightly different lines on the offer of more than a single meeting:

- DIAS will have a second meeting, and sometimes a third, focusing on getting the written statement agreed.
- Forth Valley Advocacy will meet for a second time with clients where they feel it is needed. This has sometimes been a task carried out by the project's volunteers.
- The Advocacy Project has moved away from offering clients two meetings as one of the ways in which they have sought to manage capacity. They acknowledge that some clients do still require support at more than one meeting.
- VOCAL, based on the vulnerability of many of the clients that they work with, has regularly had two or more pre meetings with clients.

Advocates do make themselves available to discuss further issues, or provide further reassurance in the period between the initial meeting or further meeting and the assessment.

Section 6.3.2 Assessment

Client Feelings at the Assessment

Levels of stress amongst clients when they meet the advocate at the assessment are described by advocates as sometimes being even higher than they were at their initial meeting; one advocate described the moments before the assessment as invariably the worst for clients. For some people this can extend to having panic attacks. One advocate highlighted another issue. People with substance abuse issues generally try to go into an assessment sober. That can leave them particularly anxious and shaky.

Clients going into an assessment are right before the crucial moment when their entitlement will be decided. They are facing having to engage with someone they don't know, who will look at the intimate details of their life, who they see as having the power to determine their quality of life by making a decision about the money they will receive.

People's past negative experience of assessments, and particularly tribunals, in which they have faced a panel of three people, can have a particularly heavy bearing at this point.

The advocate from The Advocacy Project suggests that the situation is exacerbated for ESA claimants in Glasgow by the nature of the place in which the assessment is held, incidents have occurred involving threats being made towards security guards, and people have been caught using drugs in the toilets.

Advocates suggest that this feeling of nervousness does not always last. Once people are inside the assessment they often find that their worst fears are not borne out.

Focus of Support at the Assessment.

The aim of the advocates within the assessments is simple; to provide whatever support is necessary to clients to enable effective communication to the assessor of the detail of the impact of their condition.

Advocates are clear that assessments, as well as a potential ordeal, are an opportunity to bring to life the information that is set out in the form, and to give a fuller picture of the way that they are impacted by their condition. They are also clear about the risks to the client if they do not communicate that clearly.

Advocates are also clear that much of their work within assessments, to an extent that surprises them, has simply been to be a reassuring presence. Many have found themselves keeping much more of a watching brief than they had expected, as clients who have been well prepared are able to do most of the speaking for themselves.

There is some prompting that is done by advocates, although there is some debate about the use of that term. Advocates will remind clients of what was said during initial meetings, or make explicit references to what is contained within the written statement that they have drawn up.

Speaking on behalf of clients has been less common still. Some advocates report that they view this as a last resort, partly because they do not expect their input to be reflected in the report.

Advocates report that it can be particularly difficult for clients with mental health problems to fully explain how their conditions impact on them, particularly when faced with questions that ostensibly have more relevance to physical health. There can also be issues for people with autism and Aspergers Syndrome, who may answer questions without fully understanding the reasoning behind them, or in order to please the assessor, rather than to communicate accurate information.

At other points advocates will interrupt at a point when a client is feeling emotional to ensure that a client can take a breath. One advocate noted how such a break can shift the attitude within assessments, with assessors feeling as if they are given permission at that point to be more sympathetic to clients.

Relationships with Assessors.

Advocates noted a considerable amount of variation between assessors, and between assessors' attitudes towards their presence. Some are welcoming and good at relaxing clients, some appear to be more abrupt, and focused on doing their job and simply getting through the questions.

Problems can arise for clients when assessors are abrupt. This is not in the sense of there being a simple equation that abrupt assessors mean that a negative result is more likely, but clients with depression and anxiety who are in need of reassurance can find abrupt assessors difficult to deal with.

Assessors are generally consistent in their own approaches, advocates do not report that they are subject to 'having bad days'.

Most assessors appear to have been positive about the presence of the advocates. They welcome the additional information that can get brought out within assessments as a result of their input, and they generally respect and understand what the advocate is trying to do.

Conflict has arisen between assessors and advocates:

- One advocate suggests that the attitude of one assessor has consistently been problematic, showing resentment at her presence, and that her raising of a complaint about the issue has led to a degree of frostiness between her and other assessors.
- Another advocate reports being threatened with expulsion from an assessment if they continued to speak. He reports that the assessor was of the view that his attempts to explain questions to his client were in fact coaching. Subsequent engagements with this assessor have not seen a repetition of the conflict.
- One advocate has had to interrupt an assessment when an assessor was tutting and rolling their eyes at the answers of his client, and to ask for more respect to be shown. Although the immediate situation was resolved, they have pursued a complaint on the issue. The same advocate reports developing an attitude that any rudeness by an assessor towards him is irrelevant, it is the way they treat the client that matters.

One advocate also notes that the latest wave of PIP assessors appointed to cope with the increasing number of people passing through the system had not been interested in the service, or curious about what it was trying to achieve. Another suggests that there has been a deterioration in the quality of newly appointed assessors, particularly in the way they handle mental health issues.

Further issues with assessors are noted:

- Advocates do not wholly trust assessors, there remain occasions when reports do not fully reflect discussions within assessments.
- Some assessors are seen as pushing to hard on particular topics, or leading clients down particular pathways in a deceptive manner.
- Despite the commitments given by contractors, it is clear that some clients with mental health problems are still being assessed by physios or other people whose expertise lies in physical health. Attempts to raise this with the contractor have not been successful.

Advocates and project managers made two further comments about how they have sought to manage the relationship with assessors:

- Advocates have introduced themselves as being part of a Scottish Government funded pilot project, making assessors aware that they are part of a process which involves the collation and submission of feedback to the Scottish Government.
- One advocate wished that there had been formal communication with assessment contractors at the start, so that they were aware of the project, and could communicate its intentions to front line staff.

Section 6.3.3: Closing/ Debriefing Meeting

Advocates believe that the closing debriefing meeting is an important part of the service offered to clients.

The objectives of the meeting are to:

- Ensure that there is closure on the case for clients.
- Explain decision letters to clients, whether they are positive or negative.
- Help clients think through their options if they are not happy with the decision that they have received, or even if they have received a positive result.
- Identify further support that can be of benefit to clients.

Closing meetings may be carried out face to face or over the phone, and often do not last for very long, sometimes for only 15-30 minutes. Where clients are less vulnerable, and/ or are in receipt of a positive decision on their claim, they are less likely to be proactive in seeking contact with advocates, and more likely to see the client face to face.

Advocates believe that the meeting is valuable in providing an opportunity for clients to thank them for the service they have provided, and to tie up any emotional loose ends. It also enables advocates to communicate a clear message about the availability of further support if they are called for another assessment during the project period.

For many clients, the information contained in decision letters from the DWP is not easily understood. Advocates may need to explain what the letter means and the

thinking behind it, and clarify basic practical matters such as the period that will elapse before they are called for reassessment.

Advocates report that clients may greet a positive result with a degree of disbelief. They may find that they have to give clients 'permission' to start spending the money, or accept that they have been successful.

Where clients have received a decision that they disagree with, advocates play an immediate critical role. They are in a position to identify where the decision, and the report on which it is based, might be inaccurate and may provide grounds for a mandatory reconsideration (MR). Advocates have on occasion helped clients to draw up a letter setting out the grounds for an MR, particularly where clients have learning disabilities, or have drawn up a list of points on which an MR can be built.

Advocates will not support an appeal themselves, although they will make a referral for support, where possible back to the organisation that helped their client with their application, and will provide background information to those providing support with the appeal. As one advocate puts it, the key objective is to avoid leaving people in the lurch at this point, but to talk through their options.

A number of clients will be applying for ESA or PIP in the near future. Advocates make clear that the project can offer them help, and where necessary will refer them to an advice partner for form filling support.

Many of the clients they deal with are vulnerable, and a significant number are not in contact with other organisations and experience a high degree of social isolation. Advocates will therefore identify where clients need further support and make referrals, both to other support organisations and to colleagues. This can often include referral to occupational therapists for help with aids and adaptations.

Section 6.4: Impact, Additionality and Complementarity

Section 6.4.1: Issues and Trends within Assessments.

Referral partners, advocates and project managers identified a number of issues and trends in assessments which set the context in which the service is delivered:

Issues with the Assessment

- Some suggest that PIP has not proved the horror story that was expected in terms of decisions, others identify major issues.
- Some referral partners are observing a reduction in the care with which PIP decisions are made, with assessments seemingly done mechanically, and poor quality, general explanations given of the reasons for a determination.
- PIP and ESA assessors often seem to lack real understanding of mental health issues. One client highlighted what she felt were particular difficulties getting clients with mental health problems onto ESA.
- Demand for support with PIP is growing, some people are already being called for reassessments, which appear to be going worse for people even if their condition has not changed.
- On occasion clients' ability to converse with the advocate is inappropriately being used by decision makers as evidence that the client can talk to anyone.

Systemic Issues

- The switch between ESA and PIP from a focus on being diagnosed as having a condition to the impact of that condition may particularly disadvantage people with Autism Spectrum Disorders or epilepsy.
- The transition from DLA to PIP is seeing some people lose access to Motability cars as they lose mobility higher rate, whilst others gain as they move from DLA lower rate care, to PIP daily living at standard or enhanced rate.
- The Mandatory Reconsideration process is viewed as a mechanism for discouraging appeals, with success rates proving low, and the introduction of more delay into the system. Appeals remain formal and off-putting.
- The Mandatory Reconsideration and Appeal system remains ridden with jargon.
- Getting the assessment right first time is critically important.
- All the advocates see the assessments as difficult to call.
- There may be a growing reluctance to offer clients assessments in their home.
- There has been a growth for advice agencies in the amount of supersession work that they undertake, particularly in relation to people seeking to move from the Work Related Activity Group to the Support Group.

Issues for Clients

- Clients often put on a front when they meet people for the first time, trying to present their best face and keeping some personal information private.
- People always carry with them previous negative experiences of assessments, the experience and influence of friends and family, the media and the power of their own imagination.
- Young people, who may have issues with engaging with authority, may struggle to articulate the impact of their condition on their lives. One partner reports having some young people who should have been successful in the

assessment receiving zero points because they were not able to make their case effectively.

- Young people may be reluctant to ask their families for support at the assessment, or be unable to call on such help.
- For many young people, applications for benefit may be only one of a number of events in their lives contributing to upheaval, alongside issues such as homelessness, family contact etc.
- Questions on the application form and in assessments are often not effective at drawing information out of people.
- People may be confused about the different entitlements attached to the WRAG and Support Group, and not realise the importance of being in the Support Group to avoid the potential time limiting of their benefit.

Section 6.4.2 Impact of the Service

The Impact of Preparation and Initial Contact

Preparation work is seen as laying the ground the service's impact. It is the essential to them being able to draw out from clients the extra information that can make a difference to their application, by giving a more rounded perspective.

The initial meeting is seen as being successful in allaying some of the fears that clients have, and taking at least some of the stress from them. This is the first element in making sure that they make it to the assessment.

The Advocacy Project reports that they have had cases when they have submitted extra information to complement the form prior to the assessment, which has been sufficiently detailed to avoid the need for the client to attend a face to face assessment.

Reduced Stress, Increased Ability to Communicate.

Advocates are clear that they have an impact reducing the stress faced by many of the clients. This is backed up by referral partners who see them as really good at providing reassurance and allaying fears amongst clients.

It is this reduced stress that they see as lying behind their less than expected need to communicate on behalf of their clients at assessment. Their presence, and their preparation work, empowers clients and makes them confident enough to speak on their own behalf. People who were convinced that they would not be able to communicate on their own behalf, find themselves able to do so.

Influencing the Course of the Assessment.

Advocates and referral partners see themselves as influencing the course of the assessment in a number of simple ways, for example by asking for a break when someone is getting anxious. This is something backed up referral partners who report client feedback suggesting that advocates can slow down an assessment that may be progressing too quickly for a client, whilst not giving them the opportunity to explain their situation fully or emotionally pressurising them in away that inhibits their ability to communicate.

Guaranteeing Presence at the Assessment.

From both referral partners and advocates there is a strong sense that the presence of an advocate gives a much stronger guarantee that clients will attend an assessment. Referral partners reporting sometimes having to make substantial, and not always effective, efforts to persuade clients to attend, something made much easier when advocacy support is in place. Advocates may, given the nature of their role, actually be better placed to encourage attendance.

Some clients would rather drop out of the process, with all the attendant problems that causes than face an assessment. One referral partner quotes the example of a young person they work with who failed to get on a train to his assessment on three separate occasions before finally managing it in the knowledge that he was being supported by an advocate.

Impact on the Result.

Advocates are convinced that they impact on the result of clients' assessments. They evidence this through:

- Pointing out the number of people they assist to attend the assessment who would not have managed without them.
- Comparing the success rates for those they support through the process with the success rates for people in their area more generally.
- Reporting anecdotal evidence from advice partners about reductions in the number of appeals they are seeing because people are getting an appropriate outcome first time.
- Turning round local perceptions that few people are successful in getting PIP without going through MR and appeal first.

Clients qualify their comments on their impact on results in one critical way, they do not aim for their client to be successful in their application, but for them to be able to express themselves effectively and get an appropriate result. That difference matters.

One referral partner makes a further suggestion, proposing that the actual presence of the advocate in an assessment acts as an indication to the assessor that someone is potentially in need of support. Conversely, one advocate was clear that she would not generally expect the fact of her own prompting of clients to appear within an assessor's report.

Section 6.4.3: Additionality and Complementarity.

Project staff are clear in their belief that the service has a positive impact and fits alongside advice sector provision. The more acid test is perhaps in the views of referral partners, what added value do they think the project brings?

Project partners:

- Believe that both they and clients would miss the project were it not there, and that its presence helps them deliver their objectives and reduces their workload.
- Do not believe that the resources would be there for them to provide the sort of support delivered by the project.
- Do not believe that there are adequate alternatives to the project from which their clients currently benefit.

It is also clear that many advice organisations do not consider it appropriate for them to provide support at assessments, because they see it as problematic in a context in which they may be asked to provide support with an appeal. In this sense, advocacy provides something that not only are they not resourced to do, but they should not do. Even put less strongly than that, advice organisations see their role as being more on the mechanics of the process, the technical side of applications, the role of advocacy being more about providing emotional and moral support.

One referral partner, a welfare rights officer cum financial inclusion worker, captured his sense of the additionality of the project, and the complementarity between his work and the project in this way:

'It's definitely a team effort. The move through the assessment process is about a journey, and advocacy helps with another part of the journey. The two aspects, advice and advocacy do something different, and it's important to make people understand that.'

Section 6.5: Organisational Issues

Section 6.5.1: Managing Capacity

Managing capacity is a challenge that has faced DIAS and The Advocacy Project from the start, and is increasingly an issue for Forth Valley Advocacy and VOCAL.

None of the projects would be able to cope comfortably with a further spike in referrals, each is now pretty much at capacity. Advocates have experienced being required at three different assessments in a single day, and the taking of holidays has consistently led to a backlog of cases.

The lower numbers seen by VOCAL do reflect a slower start to the project, but also what appears to be a greater vulnerability of clients who require more preparatory meetings, and possibly the specific challenges of working with high numbers of carers. This need for more meetings may also reflect the greater preponderance of PIP claimants within their client base.

The challenge has been met in different ways:

- DIAS have identified tasks that can be undertaken by administrative staff to reduce the burden on their advocate.
- FVA have used volunteers to carry out some of the advocate's roles, in particular delivery of the second visit.
- Not all existing clients of The Advocacy Project needing support within assessments have been referred to the specialist advocate. Some clients have been supported by other advocates within the organisation, with the specialist advocate using his own knowledge and experience to give his colleagues 'second tier' support in that role.
- Each of the advocates has had to be highly flexible in the management of their diary.

Section 6.5.2: Training and Professional Support

Advocates and managers made a number of key points in respect of training and professional support:

- The emotional challenges of dealing with people who are vulnerable, and in some cases in crisis, mean that debriefing support from management has been critical for advocates. That support has been forthcoming, and the ability to speak honestly about situations has been valued.
- There has been a degree of isolation inherent in participating in the pilot; advocates have been the only people working within their organisations who are solely focused on benefit issues, and (in perception at least) one of only four people across Scotland doing so.
- In this context, the steering group has been important as a vehicle for advocates to communicate with each other and interested parties, although there would still be value in a more specific meeting solely for advocates.
- The Dundee and Glasgow projects have also found value in further conversations with each other about how they manage the challenges of dealing with high demand.
- The initial training delivered to FVA, The Advocacy Project, and VOCAL staff was appreciated as an introduction. One advocate was clear that the

complexity of ESA as a benefit meant that further training on this specific benefit would have value.

Section 6.5.3: Organisational Fit.

There are differences between this project and the way that much advocacy is generally delivered:

- There is a very tight focus on a specific issue rather than more general support.
- The 'arc of engagement' with clients follows a similar path every time through an externally defined process.
- There are fewer meetings with clients, but more advocate time is spent in face to face engagement with clients.

Those differences acknowledged, delivery partners do not feel that there is a conflict between the delivery of this pilot project and their other work. They take a clear view that the advocacy service fits alongside the broader range of services that they offer in terms both the principles that guide it and the skills that it makes use of.

Section 6.5.4: Use of Volunteers

Funding for Forth Valley Advocacy was used to support two posts, a 0.8 FTE advocate's post and 0.2 FTE increased hours for the organisation's volunteer co-ordinator.

The initial hope of the project was to recruit and train volunteers sufficient to ensure that two were always involved in the project.

This has thus far proved more difficult than had been expected. Some of the difficulties recruiting volunteers are common to projects across the voluntary sector, but there have also been specific challenges in relation to this specific project.

One volunteer that was recruited stepped back from work after finding aspects of it emotionally difficult. The project manager suggests that volunteers have to be prepared to work on some upsetting issues, a number of clients have disclosed issues relating to historic abuse. There are also situations in which volunteers cannot be placed, one client with mental health problems threatened, albeit 'jokingly' to stab the project advocate. The project advocate believes that the nature of the task at the assessment means that it is essential that it is carried out by someone with sufficient experience, something difficult for volunteers to acquire.

Whilst volunteers have proved useful to FVA's delivery of the project, in particular in relation to taking the second visit burden, the project manager is clear that were she to run the project again, she would increase the hours of the project advocate to 1.0 x FTE rather than keep the investment in the volunteer co-ordinator.

Section 6.6: Working with the Right Groups?

Section 6.6.1: Reaching the Right People

Project managers and advocates are clear that the groups targeted by the project; people with mental health problems, learning disabilities and neurological conditions, are the right ones.

There is a general acknowledgment that there has been less success targeting people in the latter two groups in the first half of the project, and steps are now being taken to rectify that.

Each of the projects has, with the permission of the project national co-ordinator, used a degree of flexibility to work with people whose primary health condition relates to a physical impairment, sensory- usually visual impairment- or long term physical health condition. This has been justified in terms of the stress through which the assessment puts clients, and more critically, the high incidence of co-morbidity between long term physical health conditions/ impairments and mental health problems.

Projects are clear that this flexibility should be maintained, and possibly expanded, subject to the availability of resources in any future iteration of the project.

Two further indications of the extent of the vulnerability of clients also suggest that the project has targeted people from the right groups:

- Two projects highlighted the number of clients disclosing incidents of historic or recent sexual abuse, assault or rape. Two disclosures were made to the project national co-ordinator when he was carrying out the client interviews.
- A number of clients have made previous suicide attempts, some of which have been associated with stress relating to benefit assessments. Again, two disclosures of such attempts were made to the project national co-ordinator when he was carrying out the interviews.

Section 6.6.2 Working with Carers.

The VOCAL project has explored the delivery of the project to clients who are carers for people who are claiming ESA or PIP. The advocate and project manager are clear that the project has been successful both in reaching carers, and in making a difference to their lives.

Amongst the key findings from VOCAL are:

- Carers and other clients engaging with the project do not wish for their information to be shared with the broader organisation, something VOCAL has dealt with by maintaining the database for the project separately.
- One referral partner believes that basing the project within a carers' organisation acts as a deterrent to service access for a small number of clients. This has been exacerbated by difficulties accessing the centre for those without their own transport, and a perception amongst some in the community that VOCAL only focus on older people.
- A number of carers have sufficiently significant support needs that they may be entitled to disability related benefits themselves, nearly four in ten of the carers

worked with so far have been involved in claiming PIP themselves. Many of those support needs will previously scarcely have been recognised.

- Many clients, referred as claimants, have significant caring responsibilities, usually for partners or parents, but do not actually recognise themselves as carers.
- The potential this causes for exclusion is exacerbated by the fact that some carers worry that if they apply for disability related benefits, it will be assumed that they cannot provide adequate care themselves. Recent changes, with it now being impossible to be placed in the ESA Support Group and receive Carers Allowance, have complicated matters further.
- Within the assessment there is a clear partnership between claimants and carers, differences of perspective between them have not been as wide as expected, but a key task prior to any assessment remains the identification of any areas of potential disagreement. Procedures have been developed to ensure that there are no conflicts of interest, but have not been used to date.
- Work with carers to make sure they are clear about the assessment process, and working through issues jointly has been an important part of the success of this work.
- The project has been successful in providing advocacy to a new client group. Only one of VOCAL's clients has used an advocacy service, other than services provided by VOCAL, prior to this project, this despite the potential for advocacy to provide support to the often vulnerable client group.
- Many carers have no knowledge or understanding that they can be involved in supporting their partner/ other person through the assessment process, including at the face to face assessment, and are very surprised about this.
- Carers may themselves be generally stressed, anxious and depressed, and face additional challenges if they are to provide useful support to the person they care for in an assessment. On those grounds, any future iteration of the project should allow that a high level of carer burden alone should qualify people for support from the project, even if the claimant has a physical primary condition, and any carer applying for PIP or ESA being able to access the service.
- Not all carers wish to be actively involved in the assessment process, particularly in situations where the person being assessed is in the 45 – 60 age group and lives on their own, with care coming from non resident family members and friends.

Section 7: Conclusions

This final section returns to the six key questions set out in the introduction:

- Has the project been targeted at a real need?
- Has the project been effectively delivered?
- Has the project been delivered by the right people?
- What impact has the project had?
- Has the project added value to the support available to people going through the assessment process?
- Has the service identified key lessons for future policy towards welfare reform for the Scottish Government?

Has the Project Been Targeted at a Real Need?

By the end of the pilot period, over 600 people going through the benefits system will have been identified, or will have identified themselves, as needing support to get through the assessment processes for DLA or PIP. This will exceed the target set at the start of the project. At this most basic level of proof, the project has demonstrated that the demand exists for the service.

The initial needs analysis guiding the project targeted two key issues within the literature; the stress of the experience of going through assessments for claimants with mental health problems, neurological conditions and learning disabilities; and the risk of claimants not getting an appropriate decision on their claim.

The project has borne out the truth of that initial analysis. Clients consistently report huge stress going through the assessment process, from the point of considering starting an application through to receipt of the decision and beyond. Many report previous highly negative experiences of assessments and inappropriate outcomes, as a result not only of that stress, but also the conduct of assessors, their own struggle to communicate the impact of their health/ conditions on their lives, and decisions and reports not accurately reflecting their situation and the content of assessments.

The project has also identified further areas of need. Originally focused on supporting people with mental health problems, neurological conditions, and learning disabilities, the project has also worked with significant numbers of people with secondary, and even primary, physical health conditions. The co-morbidity between mental and physical health conditions means that many people with primary physical health conditions face sufficient mental health difficulties going through the assessment process that they also need advocacy support. The targeting of carers through one of the projects has identified the need for carers of claimants to receive a degree of support in the process, that carer burden is a justifiable trigger for access to support, and that carers themselves may have unrecognised support needs, and entitlement to benefits.

Finally, the socio economic characteristics of clients, with only 2.7% in work, mean that the project is, perhaps to an extent not fully appreciated prior to delivery, an anti poverty intervention.

Has the Project Been Delivered Effectively?

The project appears to have been delivered effectively:

- Referral relationships have operated effectively, and delivery partners have been active and successful in building and maintaining new referral relationships.
- The basic service model has worked, and has been delivered as intended.
- Delivery partners have been prepared to tweak the model, for example some have placed more emphasis on generating a written statement than had originally been expected. They have been flexible in responding to, and learning from, the challenges they have encountered.
- Advocates have been well supported within the project by their management, and have established a degree of linkage with each other.
- The project's national steering group has functioned effectively as a place to discuss issues in delivery, and of wider policy and practice interest.

There have been some challenges:

- The extent of demand for the project, and its limited capacity have meant that three of the delivery partners have had to reduce the amount of work done to build relationships with new partners.
- Partly connected with this, the project has not engaged with as many people with neurological conditions and learning disabilities as had been hoped.
- The vast majority of referrals to the project have been appropriate, but work has sometimes been necessary with referral partners to ensure that this remains the case.
- A key task now is to communicate key lessons from the project to stakeholders.

Has the Project Been Delivered by the Right People?

The feedback from clients about the advocates who supported them has been overwhelmingly positive. Advocates' commitment, care and compassion, and professional competence have been hugely appreciated by clients.

Delivery partners have been fully committed to playing their part in the project as a pilot, supporting ongoing monitoring and the delivery of this evaluation with prompt provision of statistics, and other assistance and engagement as required.

It is also clear that the referral partners bring a specific set of skills and values to the delivery of this work, because they operate in accordance with the key principles of advocacy.

Most specifically, their commitment to being clear with clients about what the service offers, their independence, their commitment to empowering clients and being client led, mean they are perfectly placed to offer trusted and appropriate support to clients within the assessment process.

What Impact has the Project Had?

The project has helped people through what can be a traumatic experience for those who are most vulnerable. People have entered assessments better prepared, more understanding of the process, more able to communicate and more confident in their ability to communicate.

There is a limit to what the project has been able to do to reduce the stress people face during the assessment process, particularly in the period leading up to face to face assessment when negative anticipation is a significant problem. For some, that anticipatory stress carries over into the test, for others, the presence of the advocate means their experience was better than they had expected. Success in reducing the stress involved has also partly been a function of the positive impact of the project on the behaviour of assessors.

One of the most significant findings about the project is the extent to which the preparation work done with clients by advocates, alongside their presence within assessments, has empowered many clients to speak on their own behalf to a much greater extent than they or the advocate had expected.

The project appears to support clients to achieve appropriate outcomes on their claims through:

- Impacting on the behaviour of assessors.
- Ensuring that clients communicate fully to assessors about the issues that they face, preparing them to do so and empowering them to speak on their own behalf, by prompting, reassuring and encouraging them during assessments, and by ensuring that any problems with their physical and mental comfort during assessments are responded to.
- Ensuring that they stay engaged, and appropriately engaged, with the process.

The emphasis at all times on client empowerment, and on being client led, and the commitment of advocates to avoid coaching answers, or encouraging clients to present a falsely negative picture of their situation, mean that the impact of the project should be interpreted as achieving more appropriate outcomes rather than more generous financial outcomes for clients. It should be seen as enabling clients to access their rights within the benefit system.

The service cannot wholly change clients' life circumstances, or cure the conditions that affect them. However, for clients who received a positive financial outcome, newly received benefits may be spent in a whole range of ways that have positive consequences for their physical and mental health, with increased spending on care, aids, adaptations, gadgets, better food, more consistent heating, travel and leisure, and resolution of financial crisis. For some clients, a positive decision on a benefit application also brings a sense of validation.

Has the project added value to the support available to people going through the assessment process?

The project has clearly had a positive impact on clients' experiences of and outcomes from the assessment process. That impact establishes its additionality in one sense; without the support of the service, many clients would have had significantly worse experiences of the assessment, and would not have achieved an appropriate outcome on their assessment.

The impact of the project appears to be additional in the stronger sense that the delivery partners are providing a service that they are better placed, given their skills and values, to provide than anyone else.

- Clients do not see the support they are offered by advocates as being appropriately delivered by relatives.
- Advice organisations do not see themselves as having a role representing clients within assessments.

The project has therefore proved complementary and additional to existing provision.

Has the service identified key lessons for future policy and practice on welfare reform?

The project has identified a number of key lessons for future policy and practice on welfare reform.

In relation to advocacy:

- Advocacy is an important part of the suite of support services that should be available to people claiming disability benefits, having a clearly additional and complementary role alongside that of the advice sector in tackling poverty.
- The need for advocacy for some clients will persist for as long as face to face assessments exist. No system involving face to face assessments seems likely to be able to design out the need for advocacy support, any more than any benefit system can completely design out the need for welfare rights support.
- The Scottish and UK Governments, and partners in the NHS and local government should consider the need for longer term investment in advocacy support for benefit claimants.

In relation to the Scottish Government's use of its future powers to replace or reform PIP, and to the DWP's current responsibility for PIP, and continuing responsibility for ESA:

- There may be a justification for the continued use of face to face assessments, in order to maintain the credibility of assessments, and provide an opportunity for people to better explain their circumstances.
- If face to face assessments continue to be used, the process must become more user friendly, with forms clarified, better use of input from claimants' medical and social support, and assessors taking a more human, less interrogatory approach to their conduct of assessments. All assessors should be properly qualified and experienced enough to make accurate determinations.
- Consideration might be given to a system in which claimants could opt to have a face to face assessment, if they wish to have the opportunity to explain their situation.
- Investment in advocacy should be planned for as an essential element of the assessment system.

Any reform of/ replacement to PIP must take into account that the process of engaging claimants as part of that change will be highly stressful for many.

About the ALLIANCE

The Health and Social Care Alliance Scotland (the ALLIANCE) vision is for a Scotland where people of all ages who are disabled or living with long term conditions, and unpaid carers, have a strong voice and enjoy their right to live well, as equal and active citizens, free from discrimination, with support and services that put them at the centre.

The ALLIANCE is the national third sector intermediary for a range of health and social care organisations. It brings together over 1500 members, including a large network of national and local third sector organisations, associates in the statutory and private sectors and individuals.

The ALLIANCE has three core aims; we seek to:

- Ensure people are at the centre, that their voices, expertise and rights drive policy and sit at the heart of design, delivery and improvement of support and services.
- Support transformational change, towards approaches that work with individual and community assets, helping people to stay well, supporting human rights, self management, co-production and independent living.
- Champion and support the third sector as a vital strategic and delivery partner and foster better cross-sector understanding and partnership.

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