

Citizens Advice Scotland

**Evaluation of IASS
(the Independent Advice and Support Service)**

Final Report

October 2008

**ROCK SOLID SOCIAL RESEARCH
& TLWORKS**

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Executive Summary

Purpose of Study

1. Citizens Advice Scotland (CAS) commissioned Rock Solid Social Research and TLWorks to undertake an evaluation of the Independent Advice and Support Service (IASS). This service came about as a result of a strategic agreement in 2005 between CAS and the previous Scottish Government. It is delivered by individual or Consortia of Citizens Advice Bureaux (CABx) through individual partnerships with the fourteen territorial Health Boards in Scotland, and is supported by the Health Support Unit (HSU) funded by the Scottish Government.
2. The report describes the policy background to IASS, how it was established, and what the expectations are of this service. It describes the approach taken to mapping and assessing the main outcomes achieved, the challenges addressed, and the learning points identified by research participants. Finally it sets out some recommendations based on this learning for the future development of IASS in partnership with its key partners.
3. A range of stakeholders' interests and perspectives were considered - IASS clients, IASS workers, Health Boards who funded local delivery of IASS and frontline health care staff, The Scottish Public Services Ombudsman, The Scottish Health Council, and the Scottish Government who funded the Health Support Unit.

Core focus on health service users	Secondary focus on health service providers	Focus on other stakeholders e.g. referral agencies, SPSO, Scottish Government
Extending knowledge of NHS complaints procedures and support for raising issues about NHS care	Extending access and informed advice on NHS complaints procedures and support for effective resolution of health care issues	Extending access and informed advice on NHS complaints procedures and support for effective resolution of health care issues
Raising awareness of CAB services - advice/information on issues impacting on health	Raising awareness of CAB holistic services within NHS, and of impact of non-health issues on health outcomes	
	Promoting operational and strategic partnership working	Promoting operational and strategic partnership working
Maximising CAB, Health Board and Scottish Government funding to support those in most need	Maximising efficiency savings through problem resolution and informed use of complaints procedures	Maximising efficiency savings through problem resolution and informed use of complaints procedures
	Feedback on patients' views in order to inform service redesign	Feedback on patients' views in order to inform service redesign

Table 1: Range of outcomes agreed with stakeholders

Key Findings

4. A number of challenges have been identified in delivering the service. The key themes are:
 - Developing a nationally recognisable service, delivered by CABx as a specialist service.
 - Balancing the needs and expectations of clients, CABx, and Health Board partners.
 - Promoting organisational and service learning between IASS workers, across CABs, Health Boards, and NHS Scotland, which can contribute to improving the patients experience and inform consultations such as 'Patients Rights'.
 - Reassuring Health Board funders of additional benefits of the service to patients and carers by clarifying reporting requirements i.e. presenting client data in a way that is meaningful to health service providers, to the Scottish Government and to other interested partners.
 - Continuing the development of working relationships and shared understanding of 'how things are done', and of how NHS and IASS services might complement each other by impacting on improvements to 'the patient experience' and that of carers.

5. The Health Support Unit in CAS has built a comprehensive resource to support the establishment and delivery of IASS services and is developing its role in developing the strategic direction of the service with other stakeholders. The establishment of local IASS projects has happened in phases - the first starting in Sep 2006 in Lanarkshire and the last in May 2008 in Ayrshire and Arran. This has been challenging for the Health Support Unit in terms of developing a national brand and of a national perspective on the service. There have also been challenges around agreeing reporting arrangements which meet the strategic planning needs of Health Boards, and provide for Health Board colleagues meaningful information around patient needs and system failures. The input of individual IASS workers is valued by clients interviewed for this study and informal contacts with Health Board personnel appear to be working. NHS staff are supportive of the role of IASS and see that provision of this type of independent service can assist them to deal more effectively with NHS users, in a range of different ways. However there is a low level of awareness generally within the Health Service about IASS and of the management role of the CABx in delivering IASS.

Recommendations

- ◀ CABx in conjunction with HSU to explore ways in which to promote partnership working with Health Board and NHS colleagues including convening joint workshops and events
- ◀ As a matter of urgency a review of reporting frameworks and satisfaction with information sharing to be undertaken by HSU in conjunction with CABx managers and funding partners.
- ◀ That the HSU and IASS workers in conjunction with Health Board partners develop opportunities for joint in-service training at a local and national level in each other's respective approaches to dealing with complaints.
- ◀ That the HSU in conjunction with CABx and Health Board partners develop a joint marketing and communications strategy including a review of national versus tailored publicity materials
- ◀ That IASS workers and Health Board colleagues explore innovative approaches to rapid feedback and resolution of health concerns.

SECTION 1 INTRODUCTION

Remit & Scope of the Report

- 1.1 Citizens Advice Scotland (CAS) commissioned Rock Solid Social Research and TLWorks to undertake an evaluation of the Independent Advice and Support Service (IASS). This service came about as a result of a strategic agreement in 2005 between CAS and the previous Scottish Government. It is delivered by Consortia of Citizens Advice Bureaux (CABx) through individual partnerships with the fourteen territorial Health Boards in Scotland, and is supported by the Health Support Unit (HSU) funded by the Scottish Government.
- 1.2 This report describes the policy background to IASS, how it was established, and what the expectations are of this service. It describes the approach taken to mapping and assessing the main outcomes achieved, the challenges addressed, and the learning points identified by research participants. Finally it sets out some recommendations based on this learning for the future development of IASS in partnership with its key partners.
- 1.3 In commissioning the study¹ CAS was particularly interested in the evaluation providing the following:
 - Research information from a range of stakeholders about their perceptions of the Independent Advice Support Service
 - Analysis and review of data provided by CAS and CABx on clients using the service, the issues dealt with and the outcomes recorded²
 - Review of information from NHS and CABx about the work of the HSU³
 - Recommendations as to the effectiveness of the service in meeting its original outcomes⁴
- 1.4 The study was therefore designed to explore outcomes in terms of customer satisfaction and operational and service management performance. Furthermore as IASS was a new development both for CABx and for Health Boards the study attempted to identify the nature of strategic outcomes addressed.
- 1.5 In parallel with this study has been a separate piece of research into NHS complaints services, commissioned by the Scottish Health Council. This is being undertaken by Craigforth Consultancy & Research, who had previously reported on 'Experience and Attitudes in relation to NHS Complaints since the Introduction of the New Procedure'.⁵ This research is timed to inform the current debate about Patients' Rights and part of its remit will be to look at levels of access among marginalised groups to NHS complaints services. It is expected that this will further inform the findings and recommendations from this current study.

¹ Invitation to tender

² Interim report to IASS Advisory Group (Sept 08)

³ Ibid.

⁴ Interim reports to IASS Steering Group (July 08) and Advisory Group (Sept 08) on achievement of specific operational performance outcomes, and questions to be addressed by the HSU and by IASS consortia.

⁵ Dec. 2006

Approach and methodology

- 1.6 Unlike evaluation studies that run from the start of a new programme, this study was commissioned two years after the HSU was set up and less than twelve months before its funding is due to finish and funding to the first of the CABx is up for review. However for the majority of other CABx they have still two or more years to go before continuation funding is reviewed. This means that this study is serving a number of different aims, namely providing an assessment of progress to date, but as importantly providing evidence to begin focused conversations with stakeholders and planning around the future shape and development of the service.
- 1.7 With this in mind the focus has been primarily on shared learning and in making recommendations to the partners involved in delivery and in reviewing the services. We have been interested in exploring the range of views on what IASS is, who it is for, how it's delivered, and therefore have attempted to identify the perspectives of various groups of stakeholders on service outcomes (see table 1). Hence our emphasis on qualitative tools which can capture the views of different health service providers, health service users, and interested observers such as the Scottish Government, the Scottish Health Council, and the Scottish Public Services Ombudsman.

Core focus on health service users	Secondary focus on health service providers	Focus on other stakeholders e.g. referral agencies, SPSO, Scottish Government
Extending knowledge of NHS complaints procedures and support for raising issues about NHS care	Extending access and informed advice on NHS complaints procedures and support for effective resolution of health care issues	Extending access and informed advice on NHS complaints procedures and support for effective resolution of health care issues
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Table 1: Range of outcomes agreed with stakeholders

- 1.8 Finally IASS is part of a much broader policy agenda of Patient Focus and Public Involvement, Better Health Better Care, and action aimed at addressing health inequalities and patients' rights, and sits within the context of public sector guidelines on procurement of client-centred services.
- 1.9 Our approach has been to involve those delivering and using IASS, and those funding or advising on the service, as research participants. They have participated through: taking part in telephone interviews, e-surveys, focus groups and facilitated workshop discussions:- submitting monitoring and other reports, and demonstrating the IASS website

and training materials [See Appendix 3]. In all 288 workers and clients contributed to the findings.

- 1.10 **In conclusion**, the study comes at a time of debate and discussion around Patients' Rights, and assessment of progress in delivering 'patient-centred care' and improving the patient experience. IASS is only one small part of this jigsaw, and this study was only able to scratch the surface of what the service is and means to those that use it. It can therefore only provide the starting point for a far more in-depth discussion by the main players involved in the future of independent advice and support services, and in their contribution to improving 'the patient experience'.

SECTION 2 BACKGROUND

The Policy Context

*"We want patients to receive care from NHSScotland staff that is respectful, compassionate and responsive to what patients want."*⁶

- 2.1 Patient-centred health care is high on the policy agenda. The Scottish Government is committed to a health service which is responsive to individual patient needs, values and preferences. The Scottish Government in its report 'Better Health, Better Care' set out the following principle from NHSScotland's complaints procedure:
*"NHS Scotland is committed to delivering high quality, patient-focused healthcare and to using the views and experiences of the people who use its services as part of a process of continuous quality improvement. Wherever possible, the comments and concerns of patients and their families will be dealt with as they arise."*⁷ The 'Better Together' programme within NHSScotland is charged to deliver improvements in patients experience including *"comparing patients' service experience to what patients want and acting on this information to improve services."*⁸
- 2.2 The Scottish Government is currently consulting on a Patients' Rights Bill⁹ [See Appendix 2]. One aim of the bill is to set out the rights and responsibilities of patients. Proposed key rights include: Access, Respect, Safety, Communication, Information, Participation, Privacy, and Independent Support and Redress. The latter refers to the right *"to comment on care and have concerns addressed"*. This study is therefore timely in focusing on how independent support and redress is being delivered through IASS and to identify learning points from this experience which may inform the response to the consultation on the Bill.

The evolution of IASS

- 2.3 Local Health Councils ceased to exist in Scotland on 31st March 2005. This was part of the then Scottish Executive's plan to reshape patient and public involvement in the NHS. Under the NHS Reform (Scotland) Act 2004, NHS Boards were given the duty of involving patients and the public in all of their work and Scottish Health Councils had the task of ensuring that the NHS Boards met this statutory requirement. As part of NHS Quality Improvement Scotland their role was to put the views of patients and the public at the heart of NHS service improvement.
- 2.4 One service which some of the former local health councils delivered was advice and support to individuals with concerns or complaints about health services. In response to public demand the then Minister for Health and Community Care had discussions with NHS Board Chairs in November 2005 on the funding of a new Independent Advice and Support Service.¹⁰

⁶ The Scottish Government (2008) *Better Health, Better Care : Action Plan*, p5

⁷ The Scottish Government (2005) *Can I help you? Learning from Comments, Concerns and Complaints*. Overview of the NHS Complaints Procedure, p3

⁸ http://www.bettertogetherscotland.com/bettertogetherscotland/CCC_FirstPage.jsp

⁹ Scottish Government, Healthcare Policy and Strategy Directorate (Sep 2008), closing date for consultation 16th Jan 2009. <http://www.scotland.gov.uk/Publications/2008/09/22091148/0>. Section 12 Key Rights.

¹⁰ Independent Advice and Support Service for Users of Local Health and Community Care Services, 2005.

- 2.5 This framework agreement¹¹ led to the signing of a strategic partnership in March 2006 between the then Scottish Executive with CAS (and indirectly with CABx)¹² [See Appendix 1]. The decision was not to go out to tender for both the central HSU and local IASS services. This decision according to CAS was based on the following service assumptions:-
- National coverage was required and consistent delivery of services across Scotland - no other organisation was deemed to have a) the national coverage combined with the local outlets and flexibility of delivery b) the capacity to deliver both complaints support and holistic generalist advice;
 - CABx have a nationally recognised quality assurance system in place both for organisational standards and for quality of advice - this would provide reassurance to both the Government and Health Boards that good quality advice, independently scrutinised by CAS, is delivered by well managed and sound organisations;
 - Patients and their carers already knew and trusted the CAB brand¹³;
 - The service would provide good value for money in that 'levels 1 and 2'¹⁴ complaints handling and general advice were delivered by volunteers.
- By contracting with CAS, and through Health Boards with CABx, it was felt that this would avoid:
- the potential post code lottery of service delivery,
 - inconsistent services and standards,
 - uncoordinated reporting,
 - lack of national perspective and ability to report nationally.
- 2.6 *"NHS Boards will fund the implementation of the IASS locally, through a strategic partnership with a consortium of their local Citizens Advice Bureaux, and will commission the consortium to provide the service to meet the needs of their population."* Implementation of this directive was left to Health Boards to negotiate with local consortia of CABx. This coincided with a number of other directives and with reviews of clinical services which had funding implications for Health Boards¹⁵. Discussions by Health Board Chairs and senior officers with the Scottish Government further delayed the launch of the programme, and this, combined with extended negotiation of Service Level Agreements (SLAs) in some Health Board areas, resulted in a staggered start to the service across Scotland [See Appendix 6].
- 2.7 The HSU, based in the offices of CAS in Edinburgh, was set up in April 2006 with three year Scottish Government funding. Its role was to support the CABx and NHS Boards in establishing IASS through coordinated provision of information, training and marketing. The Unit also convened meetings of the IASS Advisory and Steering Groups.
- 2.8 The next section will explore the Key Challenges for CABx, the HSU, and Health Boards in establishing and developing partnership working and delivery of IASS.

¹¹ Scottish Government (2006) Patient focus and public involvement : Independent advice and support service. HDL(2006)13

¹² According to CAS this strategic partnership was ratified with the current Scottish Government

¹³ A MORI survey of clients reported I March 2007 that 98% of clients questioned said they trusted CAB services, and 97% praised "the professionalism, competency and efficiency" of staff.

¹⁴ Nationally recognised types of advice services e.g. basic information and action on behalf of clients but not representation.

¹⁵ Source of evidence: telephone interviews with health service representatives and focus groups.

SECTION 3 KEY CHALLENGES

- 3.1 This section will explore some of the challenges identified by research participants in developing and delivering IASS. This has been split by stakeholder interests and has been designed to provide the background to key findings and to inform learning points and recommendations from the study.

Establishing and developing the IASS service - the role of the HSU

- 3.2 The HSU developed an extensive range of products and services to support the initial setting up of IASS, for example:
- providing templates and guidance on: Memorandum of Agreement between CABx members of IASS Consortium; selection criteria for lead CABx;
 - providing guidance on the national service framework to be applied to local service development and service level agreements with NHS Boards; assisting with funding negotiations between CABx and NHS Boards;
 - establishing skills competences for post holders; developing learning needs analyses and training plans; providing IASS training in core standards for delivery of IASS; and assisting in the recruitment and induction of staff;
 - developing a communications strategy including the production of promotional materials translated into community languages and formats; contributing to local awareness raising campaigns through provision of materials and delivery of awareness raising sessions; organising national and local launch events (the national launch in September 2007 in conjunction with the Scottish Health Council and Scottish Public Services Ombudsman - guest speaker Shona Robison, Minister for Public Health; and local launches in conjunction with NHS partners).
- 3.3 In addition, as the service developed, further products and services were developed to support IASS and generalist CAB advisers to deal with clients' concerns, queries and complaints about NHS services and health-related issues. These were delivered through the intranet resource of CAS - a comprehensive resource with interactive elements where IASS workers can communicate with each other through discussion boards, share good practice,¹⁶ and also download content:
- 'Bureau manager support' to advise and resource CAB managers responsible for managing IASS;
 - A guide to resources on the CAS intranet; 'hot topics' section which highlights issues of current interest; a client information pack;
 - Guidance and training on recording - stats, strategic outcomes, the stats recording software
 - Specialist training e.g. mental health, gender and sexuality, and long-term care
 - Newsletters on IASS issues; and resource bank with tips and advice about communications; templates for recording and reporting data, writing letters, recording case work etc; signposting information for national organisations e.g. the NHS e-library; NHS Equality and Diversity monitoring.
- 3.4 An Advisory Group was set up by the HSU in July 2006 made up of the following representative bodies - The National Complaints Association of Scotland, The Scottish Public Services Ombudsman, The Scottish Health Council, The Scottish Government

¹⁶ www.caslink.org.uk and www.caslearning.org.uk.

(Health Directorate), officers from NHS Boards (Director for PFPI, Public Health practitioner), GPs, and CABx managers. Their input has been important in terms of advising on the establishment of IASS. The development of IASS was guided by a Steering Group composed of IASS lead CABx managers as well as other CAB managers with expertise in health projects.

- 3.5 The role of the HSU in relation to IASS is essentially to provide support and guidance by :
- assisting local IASS consortia to establish and deliver an effective service, and to develop and monitor quality indicators;
 - assisting local CABx and NHS Boards including Special Health Boards to market the service with a national identity.

As each CAB is an independent charity with staff and volunteers accountable to local committees, the main means of influence that the HSU has is that each CABx must meet nationally agreed quality standards in order to remain part of the CAB service.

The HSU has therefore invested considerable time in providing the framework and tools necessary for a nationally recognisable service such as common branding, national press releases about the service, common quality assurance standards, and development of a statistical package for reporting at both a local and Scotland level. In addition by contributing to NHSScotland and governmental think-tanks, workshops and conferences, the coordinator has attempted to ensure that IASS is promoted as a national service delivered by local partners. Therefore the challenge has been developing a nationally recognisable service that achieves the objectives as set out in the framework agreement [See Appendix 1].

- 3.6 There have been delayed and phased starts to the service across Scotland, and therefore the HSU training officer has had to take account of this in planning the delivery and facilitation of induction training. This has also presented a challenge in promoting organisational and service learning between IASS workers and across CABs. The response to this has been:- the publication of IASS newsletters, a dedicated IASS discussion board, IASS networking and training sessions for workers, and IASS awareness raising sessions for bureaux advisers.
- 3.7 The delay in getting the full service up and running has also meant that it's also been difficult to identify policy issues at a national level that can be taken up by CAS. Increasingly the HSU is the first port of call for information on CABx clients' experiences of the NHS, and the challenge has been to develop ways in which local experiences can be brought together in order to assess whether there is any learning for NHSScotland and for informing consultations such as that around Patients Rights. For reasons of confidentiality it has not been possible to use single cases to illustrate examples of how systems need to change to meet patients rights. However as the number of cases being dealt with by IASS workers increases this will become less of an issue.

Establishing and developing the IASS service - the role of CABx Lead/Business Managers

- 3.8 All CABx who are full members of the Association in Scotland either independently or working together in Consortia deliver IASS. Within each consortium one bureau has taken on the additional work of managing the service on behalf of the CABx in that area. On top of assisting with recruiting and inducting specialist staff lead managers have been responsible for negotiating SLAs with their respective Health Boards, with support as required by the HSU team.

- 3.9 As noted in the press release by CAS at the time that the strategic partnership was signed with the then Health Minister - "CABx are poised to assume a key new role in providing advice and support to NHS patients and the public." As well as being a new type of partnership with NHS Boards, it has also been a new way of working for CABx themselves, and therefore being able to operate 'seamlessly' as a Consortium can be assumed to have involved internal organisational negotiations prior to agreeing Memorandums of Agreement.
- 3.10 An important element in planning for the delivery of IASS was agreeing how to ensure there was a service across the whole of every Health Board area - whether to go for one IASS worker or a number of part-time workers, and which office(s) would they be based, and how to ensure access during office hours through dedicated help lines. These operational decisions required negotiation between Consortium members, followed by seeking the approval of Health Board funding partners. A key challenge has been to balance the needs and expectations of clients, CABx, and Health Board partners.
- 3.11 Lead CABs have also been responsible for coordinating the reporting frameworks which are central to funding agreements with Health Boards. This has involved collating statistics from individual CABx based on data on clients and health issues dealt with by IASS specialist workers. In addition increasingly Health Boards are requesting data on clients who have been assisted in coping with other issues impacting on their health (such as benefits and debt) by generic advisers (most of whom are volunteers)¹⁷. The challenge for managers in conjunction with IASS workers and the HSU has been to respond to these information needs of Health Boards efficiently by analysing client data in a way that is meaningful to health service providers and also fits with the CAS statistical package. The HSU has been rolling out training on a new modified statistical program, and this work has gone in tandem with discussions with Health Board colleagues on their information requirements.
- 3.12 The final challenge for lead managers has been presenting within the formal Health Board review process the 'added value' that IASS brings. Most of the NHS officers attending these meetings are directly involved in delivering or managing complaints procedures within the hospital acute setting and have a more limited remit in relation to the primary health care sector. Some NHS interviewees however are aware of some of the underlying reasons for why it's difficult for CAB managers to satisfactorily present the outcomes and impact information that their NHS colleagues are interested in. The main reasons cited have included:-
- There can be an overemphasis on concerns and complaints which become formalised, and less on cases prevented from becoming formalised through early intervention, or on services delivered by non specialist staff in assisting people to cope with other issues impacting on their health.
 - The focus tends to be on the acute sector, as most NHS members attending review meetings are Health Board employees¹⁸. Therefore there may be less discussion around support for primary health care cases which do not involve the acute sector.
 - Unless IASS workers are present at review meetings, lead managers may lack detailed knowledge of the pattern issues being dealt with, what proportion are complex, the level of intervention required etc.

¹⁷ 85% of CAB workers are trained volunteers. Source: press release on strategic partnership between NHS Scotland and CAS to deliver IASS, March 2006.

¹⁸ In the case of Lanarkshire there is coordination of acute and primary health care sector complaints procedures

Developing the service and establishing the IASS brand

- 3.13 IASS specialist staff are employed to promote as well as deliver services to clients. This has meant splitting their time between responding to the needs of clients and getting the word out to the general public through posters and leaflets, press releases, and speaking to referral agencies. In conjunction with colleagues in Health Boards some IASS workers have also been promoting the service internally within the NHS through presenting to specialist forums of GPs, practice managers and clinical leads.
- 3.14 The IASS service is promoted as having two elements¹⁹:
"We can help you (or someone else on your behalf) if:- you have comments or complaints about the treatment you're received in hospital, from your GP, dentist, nurse, or from any other part of the NHS, and you're not sure what to do next; ill-health or disability is having an impact on other areas of your life, and you'd like some advice or help. The Independent Advice and Support Service is part of the Scottish CAB service, and funded by local NHS boards."
The CAB brand, that promotes the principle that services are free, confidential, independent, and impartial, is emphasised. The challenge has been to promote the service in such a way that it is recognisably delivered by CABx as a specialist service, and at the same time reassure funders that this service provides additional benefits to patients and carers on what was previously provided by CABx.
- 3.15 IASS workers deliver a specialist service. They in turn support and coordinate the advice and support given by generic workers most of whom are volunteers who deal with stage 1 and 2 enquiries, such as more straightforward advice on procedures or where else to go for help and assistance. IASS workers play a critical role in advising on cases and ensuring quality assurance. The challenge is to report on this side of their work as well as outputs and outcomes in relation to direct case work.

Developing partnership working with Health Board colleagues

- 3.16 Health Board workers are very supportive of the principle of independent advice and support²⁰. The framework agreement sets out clear guidance to Health Boards on partnership working in terms of promoting good communication through a named lead who would provide: "up-to-date information on NHS procedures and policies; and contact names and information on organisational structures and accountability to facilitate appropriate contacts and referrals"²¹. In addition Boards were directed to advertise the service, have a clear referral system, and fund the establishment of the service. The challenge for Health Boards has been to develop partnership working on the ground on an informal basis as well as formally through review meetings. This has been challenging in terms of time invested in developing these working relationships, and in ensuring shared understanding of 'how things are done', which may be very different to how things are done in other Health Board areas. This presents a learning curve for all involved, and one which has to deal with changes in personnel within Health Boards and staff turn-over among IASS workers and lead CABx managers.
- 3.17 The way that funding for IASS came about - with a directive from NHSScotland following discussions at a Scottish (not Health Board) level, on not putting IASS out to competitive

¹⁹ IASS publicity leaflet

²⁰ E-survey of health service providers. See Appendix 7.

²¹ HDL(2006)13

tendering - is reported by Health Board lead officers as one factor in what is felt to have led to a lack of clarity about service specifications and what the SLAs mean in practice. This process was different from the tendering process that is more usual within Health Boards. There has therefore been a process of attempting to work out jointly and to define mutual expectations and what might reasonably be expected to evidence 'added value' of IASS delivery by CABx. This is particularly difficult in a climate where 'the patient experience' is prioritised but according to health service providers the mechanisms for achieving this are still being developed by NHS Boards.

- 3.18 One of the areas of discussion within Health Boards is around how to compare the client base of complaints services within the NHS with complainants seeking support from CABx, whether supported by IASS specialist workers or CABx advisers. Health Boards have identified a range of information that may assist their organisational and service learning around patient needs. They are interested in answers to the following questions:
- Is there an increase in numbers or types of clients such as those who might be reluctant to go through formal channels or who might prefer independent advice and support?
 - Is there an increase in facilitated resolution of issues and therefore a reduction in the use of formal channels?

The challenge has been in how to develop and standardise monitoring and evaluation frameworks that can answer these questions. There is also the challenge that the focus is on evidence around 'the public pound' and equivalent spend within NHS instead of 'the patient experience' and health impacts on patients and carers.

The role of The Scottish Health Council

- 3.19 The role of The Scottish Health Council is set out in the framework agreement in terms of monitoring local services to ensure that they are delivered in line with the framework. Their assessment of performance is expected to:
- "help the IASS providers concerned to better meet the needs of their users
 - help NHS Boards judge if the services being provided are in accordance with the appropriate standards and if they are meeting the needs of the patients
 - help the Scottish Executive Health Department monitor and assess if IASS is being delivered effectively and equitably across Scotland".

In addition The Scottish Health Council is expected "to monitor arrangements in relation to inter-Health Board arrangements, Special Health Boards, and the Independent sector".²² Their specific locus is around access to the complaints service and to advice and support in pursuing enquiries. The research²³ they have commissioned may provide useful information on what patients are looking for from advice and support services, but unfortunately the results of this will not be available until later this year. The development of IASS therefore is missing out in evidence that might contribute to the development of complementary services by Health Boards, IASS and other agencies such as advocacy organisations.

The role of The Scottish Public Services Ombudsman (SPSO)

- 3.20 As noted above, the SPSO like the Scottish Health Council has been instrumental in advising on the establishment of the service. This has included:- provision of training by

²² HDL(2006)13.

²³ Craigforth Consultancy & Research

its senior health investigator; making available on-line its 'unacceptable actions' guidance for dealing with persistent complainants, and an electronic version of its complaints form with tick boxes to ensure complaints are correctly submitted and can be dealt with. As the IASS model is now established and systems and training are in place the role of both the SPSO and The Scottish Health Council in relation to IASS and the HSU may change.

- 3.21 **In summary**, a number of challenges have been identified which will be examined with reference to key findings and recommendations for shared learning. The key themes are:
- Developing a nationally recognisable service, delivered by CABx as a specialist service.
 - Balancing the needs and expectations of clients, CABx, and Health Board partners.
 - Promoting organisational and service learning between IASS workers, across CABs, Health Boards, and NHSScotland, which can contribute to improving the patients experience and inform consultations such as 'Patients Rights'.
 - Reassuring Health Board funders of additional benefits of the service to patients and carers by meeting reporting requirements i.e. presenting client data in a way that is meaningful to health service providers, to the Scottish Government and to other interested partners.
 - Continuing the development of working relationships and shared understanding of 'how things are done', and of how NHS and IASS services might complement each other by impacting on improvements to 'the patient experience' and that of carers.

SECTION 4 KEY FINDINGS

- 4.1 This section will set out the key findings that will inform the recommendations and learning points from the study. It will examine measures of achievement against a range of operational and strategic outcomes, from the viewpoint of different groups of stakeholders.
- A) Customer satisfaction outcomes - the impact on and perceptions of individual clients, health service partners, other referral agencies and stakeholders;
 - B) Operational and performance outcomes against service standards, including the effectiveness of the service, questions of value for money, and process outcomes in terms of quality measures (accessibility and responsiveness, equality and diversity, and accountability)²⁴;
 - C) Strategic outcomes.

A) Customer Satisfaction

The perspectives of health service users

- 4.2 Fifteen clients (a mixture of patients and their carers) agreed to take part in telephone interviews. Of these eleven were existing users of CAB services or knew the CAB as a place to go for advice. Three were referred by voluntary sector advisers or friends and one by an NHS patient liaison officer.
- 4.3 The comments from this small sample of clients²⁵ suggest that IASS workers are meeting customer needs and that the service is delivering in a client-centred and sensitive way [See Appendix 4]. The main benefits of the service offered appear to be:
- good listening skills
 - support in formulating and writing succinct letters
 - helping to set up face to face meetings
 - following up delays to requests from patients/carers for information
 - supporting requests for apologies
 - signposting patients to the support that GPs can give in dealing with concerns about treatment within the acute sector

Clients report that the support given to them has been critical to them in having their concerns acknowledged, throwing some official weight behind their letters, and generally being allowed to decide how far they want to take matters.

- 4.4 It's noteworthy that for those dealing with a recent bereavement (partner had died) or disabling illness, as a result of an NHS related incident, getting an apology (and not financial compensation) was uppermost in their minds.
- 4.5 The question of trust appears to be critical. By finding someone who will listen to concerns there appears to be a process of rebuilding trust in the NHS and in its systems

²⁴ HDL (2006) 13

²⁵ IASS workers like other CAB workers do regularly seek feedback via client satisfaction surveys. A review of these surveys was not included in this study.

and procedures. Active facilitation of face to face discussions and apologies appear to be significant in this process.

The perspectives of health service providers

- 4.6 Health service interviewees suggested four ways in which patients and their carers could benefit from input by IASS workers.
- Having a choice of who to get help from - "*empowering the complainant*"
 - One stop shop for different types of advice and support - "*they look at the person in a holistic fashion*"
 - When clients don't understand the system or their rights and responsibilities
 - When clients don't want to complain but are seeking some type of resolution.

However it was difficult for NHS Boards to undertake quality assurance checks on what the experience of patients and carers is in practice because of reasons of confidentiality and data protection. A number of Health Boards are interested in receiving reports on client satisfaction rates - on health related services provided by volunteer advisers as well as by IASS workers - and on the quality of intervention and of advice given.

"I want to know not just what you did but independently how the patient felt about what support they got – was it too much support or did it have a measurable outcome, identifiable or visible?"²⁶

It is hoped that future research by the Scottish Health Council will provide some independent feedback on these different aspects of customer satisfaction and service quality.

- 4.7 Health Boards as well as being funding and service partners are also customers. In the main, on a personal level, health service interviewees reported that informal contacts between IASS workers and their counterparts work well. However at an organisational level perceptions of the quality of partnership working are influenced by other factors. These will be considered in the next section under operational and performance outcomes.

The perspectives of other stakeholders

- 4.8 The Scottish Public Services Ombudsman (SPSO) along with The Scottish Health Council has been active in supporting the development of the service. The SPSO considers good quality advice and support useful for helping people know how to go about pursuing issues about the NHS. As a customer of IASS the SPSO is keen to see formal complaints being appropriately dealt with by IASS workers either via Health Boards or via Independent Practitioners. Their experience is that patients and carers are usually seeking one or more of the following: a genuine apology; that things will change and what happened to them won't happen to someone else; or seeking compensation in which case they would be advised on the legal route. Their experience fits with customer feedback on how IASS has helped clients.

The Scottish Health Council's role relates to auditing access to services including IASS. They do not have evidence on access to IASS but this is something that will be revisited later this year. They are interested in investigating levels of awareness of the service by the general public, and their local staff have had discussions with various Health Boards around better promotion of the service. They are also interested in how the CABx are

²⁶ Senior Health Board Manager.

promoting the service, and ensuring access arrangements through telephone enquiries when IASS officers are unavailable.

B) Operational and performance outcomes

Effectiveness of the Service

- 4.9 Interviewees were asked to comment on their perceptions of both elements of IASS:
- advice and support services to patients wishing to make a complaint or raise concerns about NHS services; and
 - information and advice to patients on a variety of issues that impact on their health and well-being in order to maintain or improve these."²⁷

Responses to the question of effectiveness appeared to be judged differently by Health Boards and by CABx depending on which component was the primary focus and what indicators were being used. Inevitably the first element was the main focus for the majority of NHS staff managing patient liaison and complaints procedures, while for CABx and IASS workers coming from a holistic perspective on client needs, both elements were equally important and often inseparable.

Quality & Service Standards

- 4.10 Research participants also commented on the standards of services achieved. These were set out in the framework²⁸ and are essentially about process outcomes which link to the quality assurance standards of CAS and its member bureaux. These are built into training for staff and quality assurance systems for services delivered by CABx. The specific quality indicators for IASS were:
- Independent effective advice on problem resolution and supported use of complaints procedures;
 - Accessible, client-centred;
 - Equitable and valuing diversity;
 - Responsive and accountable - early resolution and prompt response;
 - Holistic - addressing other issues that impact on health.
- 4.11 Views on both effectiveness and quality have been analysed under a number of emerging themes. These themes also reflect what research partners describe as learning points and as areas for further exploration. These ideas have been incorporated in the next section under learning points and recommendations. The themes emerging from this study in order of importance are²⁹ :-
- Working relationships
 - Reporting
 - Effective intervention
 - Referral procedures and managing expectations
 - Communications and marketing

²⁷ HDL(2006)13. Section 2.2.

²⁸ HDL(2006)13 Appendix One. Standards on: management policies and procedures; accountability; accessibility; client centred service; independence; information services; quality assurance (technical and organisational audits); monitoring and evaluation; confidentiality and consent; staff training and supervision; equality and diversity; complaints procedure; and meeting legislative requirements.

²⁹ Order determined by the proportion of interviewees who highlighted each theme.

- Training and mutual learning
- Flexibility and responding to local variations

Working relationships

- 4.12 The staggered start to the programme was in the main to do with the working through of funding and other formal agreements between CABx and Health Boards. There have been some changes in delegated responsibilities within Health Boards which have been extremely positive in terms of building working relationships, and Health Boards have invested input at Director level to supporting the programme.

At a less formal level some Health Boards have set up regular joint meetings between NHS patient liaison/feedback personnel which appear to work well. Even where such meetings do not happen induction training is provided and information on NHS personnel contacts. One Health Board is even considering extending access to the internal Health Board intranet. Health Boards are keen that IASS workers do take up opportunities for closer working, and in particular opportunities for joint working on individual client cases.

*"We want to be the first port of call for IASS worker X to phone up and talk through a query and then follow with correspondence, so the letter doesn't come in blind - we have had conversation about the things behind the letter."*³⁰

Some Health Boards are further developing this through joint procedures and protocols so that there is clarity in terms of lines of communication between respective staff in the NHS and CABx.

*"We have agreed that any concern will be directed to X who will take forward the investigation...very happy for IASS to go through the process with X to oversee it e.g. that's a fair investigation, or no I think you could have done more in that area."*³¹

IASS workers appear to be very positive about day to day working relationships with their Health Board colleagues. However these good working relationships on the ground do not automatically translate into building trust at a higher organisational level. One factor may be that working relationships have not in all cases been sufficiently reinforced with productive exchange of information designed to inform questions relating to expectations of what IASS is and should be achieving. This is explored in the next section under reporting.

Reporting

- 4.13 IASS is a two-pronged service delivered in very different types of areas (in terms of population size and density) by IASS workers (the majority part-time) and by generic advisers (most are volunteers). It has been a major challenge to agree reporting frameworks with Health Boards that fits with this type of delivery.

Clients are not concerned about which service they are accessing. From the clients' perspective they seek a seamless service from the CAB, a service which is generally rated highly by the public, and which they can access freely whether it is about housing or health problems. The IASS casework approach follows other CAB casework procedures - informing, explaining, writing on behalf of clients as required until everything possible is done to reach a resolution for the client and to offer other forms of advice and assistance

³⁰ Complaints Manager

³¹ Senior Health Board Manager

as appropriate e.g. benefits entitlement. However the distinction is important to NHS funders. They are interested in having a detailed breakdown which sets out exactly which services delivered by CABs they are funding. Inevitably comparisons are made with evidence from complaints and feedback teams, and also to support provided previously by the former local health councils (even though it is acknowledged that such comparisons may not be appropriate).

*"Complaints managers monitor contact with IASS workers and we have a complaints database...If a client writes direct we would have no knowledge that they have had advice from IASS."*³²

Health Boards admit they were also unclear initially about what data they required and how they wanted it presented, including down to what level (taking account of confidentiality issues). Defining what is meaningful to Health Boards has been a learning curve for CABx, who are used to different types of reporting on other services. What is defined as meaningful appears to have two elements - auditing information, and information that informs learning about system failure.

"Reports were confusing - when we explored we found that the columns were unrelated totally so didn't make any sense to us. We need to know what themes refer to what service and how many issues there are for that particular service, and whether it is one complainant with a number of issues."

*"We have tried to agree a common dataset so we can compare the types of issues that are coming to IASS and to us, and whether there is any variation, whether anything we could learn from that."*³³

Effective intervention

- 4.14 A key area of interest to Managers of NHS complaints teams, the SPSO and the Scottish Health Council, is to what extent intervention by IASS workers results in more effective use by patients and their families of the NHS complaints system. As important is the opposite side of the coin to what extent does their intervention avoid concerns having to go through the complaints system as a result of satisfactory resolution of problems at an earlier stage.

*"Our focus is rather than getting to formal complaints which gives no satisfaction - for me the process is fundamentally flawed - it is far better to deal with issues as they arise at the time...and try to resolve them as informally as possible."*³⁴

The current reporting framework of IASS, which is modelled on that used by Health Boards, does not adequately address data on prevention of concerns becoming complaints.

As noted above Health Boards are also interested in being able to assess the quality of intervention. Quality assurance systems and close working relationships are regarded as ways to assist Health Boards get a view on the effectiveness of interventions by IASS.

Referral procedures and managing expectations

- 4.15 There is a generally positive attitude by NHS staff to an independent advice and support service. 93% of NHS staff agree that people are entitled to advice and support to deal with concerns about NHS services; and specifically people should receive support when things go wrong in large organisations [See Appendix 7 - report on NHS e-survey]. There is

³² Senior Health Board Manager

³³ Senior Health Board Managers

³⁴ Senior Health Board Manager

little evidence however of widespread referrals from NHS personnel to IASS. This appears in part to be the result of lack of informed knowledge about the service. 47% of respondents were aware of organisations providing independent advice and support and of these only 10% were aware that the CAB provided such a service. From feedback from both clients and health service staff posters and leaflets do not appear to be sufficient publicity. Various health service and IASS interviewees commented on the need for face to face contact with IASS workers in order to promote understanding of the service as this was felt to lead to more referrals being made. There was also a suspicion that NHS workers did not refer to IASS because they were concerned that problems might “*become formal complaints*”³⁵ if referred. Getting over a more positive message to frontline workers appears to be a major challenge for both NHS and CAB managers.³⁶

- 4.16 There was some concern voiced around managing expectations of clients and how well IASS workers and CABx dealt with ‘habitual complainants’. The SPSO has circulated their policy on ‘habitual complainants’ as a way of helping IASS workers to deal with this. Although there was no evidence that this was a common occurrence there was concern that habitual complainants might turn to CABx for help, involving Health Boards in reinvestigating complaints that had been previously been investigated³⁷. It was felt this could be addressed through liaison arrangements.

Communications and marketing

- 4.17 The CAB ‘brand’ is an established brand which has a ‘high street’ presence in most towns in Scotland and as noted previously is a trusted source of information and advice for the general public and for public officials.
*“It’s not just some organisation out there that we have no idea what kind of a service they are going to get. We have a good idea what a IASS case worker will provide for them. They have a feel for it locally.”*³⁸
Its non-partisan image has been attractive in terms of attracting funding contracts with the public sector³⁹. The evidence from the study is that the IASS brand is difficult to promote independently of the strong CAB brand. However the Scottish Government is keen that IASS is not subsumed into the CAB brand and remains as a free standing service which Health Boards can commission.

How the service is marketed has also involved detailed discussions on the content of leaflets, and the balance between the various logos of CAS, NHSScotland, and Health Board logos to ensure that clients are aware that the service is being delivered locally by a local provider.

Training and mutual learning - “singing from the same song sheet”⁴⁰

- 4.18 Induction training is seen as an important way of ensuring that workers without a health service background develop an understanding of how NHS services work in order to give

³⁵ Interview with Health Board Manager

³⁶ Focus Groups with Health Board Managers; interviews with health service providers

³⁷ Focus Groups with Health Board Managers.

³⁸ Complaints Manager

³⁹ HDL(2006)13. Section 1.

⁴⁰ Focus Groups with Health Board Managers; interviews with health service providers

informed advice and information. The complexity of the organisation was highlighted as difficult for new staff to find out about.⁴¹

- 4.19 As noted above the SPSO organised training for IASS workers and the feedback was that this helped workers develop a greater understanding about the underlying rationale for the systems and procedures of the Ombudsman. The monthly commentaries on recommendations by the Ombudsman in the reports to Parliament was also signposted as a useful reference point for workers interested in informing themselves about factors that impact on the outcome of appeals.
- 4.20 There was debate among both health service managers and IASS workers around definitions and the distinctions between:- advocacy, and information support and advice; between inquiry, investigation, complaint, and resolution; and between complaint and appeal. These distinctions were seen as an important element of mutual learning.
- 4.21 They were also seen as indicative of desired cultural changes within the NHS and within the general public
- that patients and their carers raising concerns should be encouraged as part of NHS feedback systems
 - that managers should expect to receive complaints as part of system learning.
- "95% of complaints are about systems that failed...We are interested in setting up feedback loops, so we go back to senior managers to ask how they have changed their systems."*⁴²

Flexibility and responding to local variations

- 4.22 Only in four Health Board areas are full time IASS workers employed. The decision on whether to go for full or part time workers was left to local CABx. The advantages of going for part-time workers included: geographical spread, meeting changing demands, and peer support from other workers. The flexibility this provided to CABx however was questioned by some Health Boards whose perception was that services were not delivered consistently because of differences in style and abilities of workers.⁴³ There was a feeling that a more centralised service supported by use of the helpline and sessional outreach workers in rural areas might be as or if not more effective.
- 4.23 **Added value, value for money and 'the public pound'**

Evidence on achievement of operational and performance outcomes (summarised above by themes) is based primarily on perceptions of workers. While health service interviewees, along with IASS workers and the HSU team, recognise that it is still early days in terms of the full roll out of IASS nationally, a recurring theme for health service managers has been value for money. How is this to be measured? What type of evidence is required? What are appropriate comparators? Is public money being well spent or should more resources be invested within the NHS? Given that this issue is covered in the current consultation on Patients Rights, it will be interesting to see to what extent views on IASS inform responses to this consultation.

⁴¹ Interviews with IASS and health service managers

⁴² Focus group with Health Board Managers

⁴³ Focus group with Health Board Managers and Interviews with health service managers

C) Strategic outcomes

- 4.24 The HSU has been responsible for supporting the development of IASS and for encouraging the sharing of good practice models and information on effective service delivery. This strategic goal has been difficult given the time investment required to coordinate the establishment of IASS across Scotland, and to work with external stakeholders (including patient support groups, NHS Boards, the Scottish Health Council, the Scottish Government Health Department and the Scottish Parliament).⁴⁴
- 4.25 A recent Advisory Group meeting of IASS has begun to look at how the HSU might begin to impact strategically by for example applying some of the evidence from collated case studies and statistics to influence policy and procedures. NHS Complaints Coordinators are interested in exploring with the HSU how to maximise shared learning about NHS services based on what is learnt from in-depth work with clients by IASS and CAB advisers. IASS workers report that the two main areas of complaint for clients are a) the attitudes of NHS staff and b) the limitations of oral and written communications. This is also the finding on complaints against the NHS reported on by the Ombudsman.⁴⁵ Unfortunately the small number of clients that individual IASS workers are dealing with at any one time, particularly in rural Health Boards or in areas where there are part-time posts, means that it is difficult to identify recurring patterns at a Health Board level. However the HSU is well placed to share learning at a regional or Scotland level and to contribute to strategic discussions around access barriers and the redesign of services - evidence required to strengthen the Government's focus on 'patients as partners in care'.

The next section will summarise the main learning identified by research participants and their recommendations for addressing these.

⁴⁴ HDL(2006)13. Section 6.

⁴⁵ "In the health sector I note that several issues persistently recur: poor care of the elderly, record-keeping and communication." Professor Alice Brown, Ombudsman – Ombudsman's Commentary, 23rd April 2008

SECTION 5 LEARNING AND RECOMMENDATIONS TO KEY STAKEHOLDERS

Introduction

- 5.1 This study is about IASS but it is also about how this service relates to the complaints and patient liaison services of Health Boards, and the contribution of IASS and CABx workers to addressing a holistic response to patients needs. The themes explored in this section have been informed by key challenges and findings identified by research participants who took part in interviews, focus groups and e-surveys. The focus is on shared learning and ways of beginning a 'conversation' with strategic partners around better meeting customer needs, by building on the strengths of IASS and addressing challenges jointly with funding and strategic partners.

Theme 1: Partnership working

- 5.2 There is an acknowledgement that IASS is still bedding in and that partnership working needed to be developed further. Building trust was felt to be an important element of this. Formal review meetings were useful but informal meetings around specific cases or issues was felt to be more important in establishing an understanding of each other's business. One Health Board and local bureaux have provided opportunities for workers to shadow each other to better understand how each organisation works, another Health Board invited the IASS worker to attend induction training with complaints workers, a third was planning to invite the IASS worker to a joint event around Health Board cross-organisational learning. These were seen as ways to develop partnership working.

Recommendation 1: CABx in conjunction with HSU to explore ways in which to promote partnership working with Health Board and NHS colleagues including convening joint workshops and events.

Theme 2: Information sharing

- 5.3 As noted in previous sections effective information sharing is important in building trust and confidence between IASS workers and their NHS colleagues. There a number of suggestions being explored to improve on the quality of information sharing. These include standardisation of reporting including provision of templates by Health Boards; and development of a case study template by the HSU. Tools for sharing information on clients that helps to resolve issues and at the same time takes into account confidentiality issues are also being explored by several Health Boards.

Recommendation 2: As a matter of urgency a review of reporting frameworks and satisfaction with information sharing to be undertaken by HSU in conjunction with CABx managers and funding partners.

Theme 3: Sharing Learning

- 5.4 There were a number of examples cited by health service and IASS workers of joint presentations to groups of staff e.g. Chief Nurses Forum, ward managers, practice managers, and GP meetings. These were seen as examples of useful methods of making

face to face contact with groups of workers and of extending their understanding of the benefits of working with patients and their carers in a holistic way that addressed financial as well as health concerns. Managers of patient liaison and complaints teams were in turn keen to extend understanding among IASS workers of the feedback systems being developed within the NHS and how IASS might work with staff in further developing such systems. The SPSO has contributed to an IASS network training event, and other specialist training has been delivered by the HSU for workers. There are also plans to further develop the on-line training tools for CABx to include interactive IASS training, including training on specialist topics.

Recommendation 3: That the HSU and IASS workers in conjunction with Health Board partners develop opportunities for joint in-service training at a local and national level in each other's respective approaches to dealing with complaints.

Theme 4: Communications and publicity

- 5.5 The design of IASS leaflets was developed following consultations with stakeholders including Health Boards. This involved compromises being made, and attempts to address DDA compliance and local identity of services. The HSU led on marketing of the service. There were a number of suggestions in relation to the branding of IASS. The Advisory group discussed the value of a strap line such as that used by Macmillan: *"The Macmillan CAB partnership provides financial information and advice for cancer patients, their families and their carers"*. The wording for IASS suggested by the Advisory Group was: *"CAB Health Partnership supporting people with health concerns."*
- 5.6 There were also suggestions on communicating the existence of IASS to the general public and health service providers. Several respondents suggested more innovative approaches to targeting services at groups most in need - such as the use of telephone helplines, and public 'market places' like shopping centres and community health settings. One Health Board is considering sending out a covering letter with IASS leaflets which will be jointly signed by the Health Board representative and by the lead CABx manager. A GP proposed the development of a 'prescription pad' that can be used by GPs to signpost patients to IASS and to support on benefits. This was felt to be a very effective way to publicise the service within the community health care sector and among the general public. The same GP suggested that the HSU identify one or more Champions among clinical leads who would be in a position to promote the service within Health Boards. Emphasising the health support angle was felt to be more effective among GPs and the medical profession than the complaints angle. However practice managers felt that support in managing complaints would be welcomed by their colleagues, particularly in facilitating groups of patients in the feedback process on improvements to GP and other community health services. A common theme in these suggestions is the idea that there is a need for an IASS communication strategy to address different markets within the health sector in order to get buy in to promotion of the service among the general public.

Recommendation 4: That the HSU in conjunction with CABx and Health Board partners develop a joint marketing and communications strategy.

Theme 5: Cultural change and the patients' experience

- 5.7 There was an acknowledgement by health care workers that a culture change is needed, particularly in rural areas, in terms of attitudes among the general public to raising

concerns about delivery of health services. In very remote areas the fear of losing a GP or optician or chemist was felt to discourage complainants. However, even in heavily populated areas, the feedback was that people often preferred not to complain because they wanted some kind of resolution (such as an explanation or apology) and they weren't convinced that by complaining they would achieve this. Some health service managers felt that IASS workers can provide a valuable preventive service by supporting people who turn to them for advice early on in a complaints process. By helping clients to articulate problems and working closely with health service colleagues it was felt they may be able to achieve earlier resolution of problems than through more formal procedures. Preventing concerns becoming complaints was felt to be an important contribution that IASS could make to changing cultural attitudes to informal resolution of concerns.

Recommendation 5: That IASS workers and Health Board colleagues explore innovative approaches to rapid feedback and resolution of health concerns.

- 5.8 In summary, IASS is evolving as a model for advice and support around health concerns. Supported by the HSU of CAS it has developed new ways of working across the CAB network. This report has reflected on the learning that has come out of IASS and of developing a new way of working with Health Boards in Scotland. The report has identified a number of practical ways to build on these lessons in order to achieve outcomes for patients and their carers.

APPENDIX ONE

EXTRACTS FROM FRAMEWORK AGREEMENT

[HDL(2006)13 1 March 2006]

For action: Chief Executives, NHS Boards. Chief Executives, Special Health Boards

PATIENT FOCUS AND PUBLIC INVOLVEMENT: INDEPENDENT ADVICE AND SUPPORT SERVICE

Purpose

1. This letter confirms the discussion at the NHS Board Chairs meeting on 28 November 2005 when the Minister for Health and Community Care indicated that NHS Boards should fund an Independent Advice and Support Service for patients, carers and the public across their local area.

Background

2. The Health Department have been working with Citizens Advice Scotland, the NHS, the voluntary sector and Citizens Advice Bureaux to develop a national Framework which will ensure quality and equity of services across NHSScotland.
3. Local Independent Advice and Support Services (IASS) should be based on the enclosed national Framework, which reflects Boards' responsibility for ensuring that patients, carers and members of the public are supported when making a complaint and/or provided with the information and support they need to access and make better use of NHS services. The establishment of the Scottish Health Council, and the introduction of the new complaints procedure⁴⁶, have reemphasised the importance of good communication and learning from patient experience and feedback in developing patient focused services.
4. NHS Boards will fund the implementation of the IASS locally, through a strategic partnership with a consortia of their local Citizens Advice Bureaux, and will commission the consortia to provide the service to meet the needs of their population. The service should be available to all people living in the NHS Board area, including those whose service may be provided by another NHS Board, for example by a mainland Board for a patient of an Island Board; by a Special Health Board, for example by the Golden Jubilee Hospital or the Scottish Ambulance Service; or through the independent sector.
5. The Health Department will fund a Central Support Unit based within Citizens Advice Scotland to provide support to local Citizens Advice Bureaux and NHS Boards to implement the IASS. The service must be established and operational as quickly as practicable during 2006; the Department will be in touch to find out the proposed date for implementation. The Scottish Health Council will monitor these arrangements to ensure overall compliance with the principles of the Framework.

Director of Healthcare Policy and Strategy

⁴⁶ *Can I Help You?* <http://www.show.scot.nhs.uk/Publications/ME/complaints/docs/1guidance010405.pdf> 1 March 2006

PRINCIPLES OF IASS

Free. The IASS will be provided free at the point of delivery.

Independent. The IASS must actively maintain its ability to provide advice and take action on behalf of users, in the interests of those users.

Accessible. The IASS will be known as, '*The Independent Advice and Support Service for NHS Users*' throughout Scotland so that it is easily identifiable. It must be readily accessible to the population served by the commissioning NHS Health Board.

Co-operative. The IASS will demonstrate a willingness to work on behalf of those who use the service in a co-operative spirit with other local and national organisations both voluntary and statutory.

Working to improve services. The IASS will supply appropriately anonymised evidence to those authorised to monitor the effectiveness of local NHS services (e.g. the NHS Board, Scottish Health Council, NHS Quality Improvement Scotland) to facilitate improvements in local NHS services.

Promoting equality and valuing diversity. The IASS should be delivered in a manner that encourages equal opportunities and in particular the observance of equal opportunity requirements and recognise and respond sensitively to the individual needs, background and circumstances of people's lives' so that, irrespective of their age, gender, ethnicity, disability, religion, sexual orientation, mental health, economic or other circumstances, they have access to the right health services for their needs.

Responsive and accountable. The IASS should actively seek the views of NHS service users and other stakeholders to ensure that the service it provides is effective. The IASS will have a clear procedure identifying how any person can make a complaint or raise concerns about the service.

A Central Support Unit, based at Citizens Advice Scotland, will be funded to be available to all IASS providers who are contracted by an NHS Board. It will:

- provide support staff for the new IASS providers;
- provide marketing and publicity materials for the new IASS;
- provide information and guidance on data collection to IASS providers and will manage the collection, collation and monitoring of data from across Scotland;
- encourage the development and sharing of good practice models and information on effective service delivery; and
- co-ordinate the introduction of the IASS providing support and liaison to all stakeholders (including patient support groups, NHS Boards, Citizens Advice Bureaux, the Scottish Health Council, the Scottish Executive Health Department and the Scottish Parliament).

FUTURE DEVELOPMENT OF THE INDEPENDENT ADVICE AND SUPPORT SERVICE

The Central Support Unit will provide support to assist local providers and NHS Boards to investigate the possibilities, negotiate with stakeholders, prepare funding bids, etc.

RESPONSIBILITIES OF NHS BOARDS

The NHS Board will undertake to: promote good communication between it and the IASS provider. It will provide

a) a named senior person to liaise with the IASS provider and who will be directly responsible for the provision of:

- up-to-date information on NHS procedures and policies; and
- contact names and information on organisational structures and

- accountability to facilitate appropriate contacts and referrals.
- b) advertise the IASS to patients, carers and staff as an independent support service for patients who wish to complain about NHS treatment, care or services they have received or who are experiencing stress or anxiety because of illness.
- c) have a clear referral system to facilitate patients accessing assistance at a convenient location.
- d) provide funding for a sufficient period to allow the IASS to become established. The initial contract between the IASS provider and the NHS Board should be for a period of 3 years. An annual independent assessment will be performed by the Scottish Health Council to determine the effectiveness of the service. The contract should provide a termination clause that can be invoked if either party fails to fulfil their contractual terms.

APPENDIX TWO

EXTRACTS FROM PUBLIC CONSULTATION ON A PATIENTS' RIGHTS BILL

[Closing date 16th Jan 2009]

Section 38. Communication

A Patients' Rights Bill will ensure that at all stages of their care and treatment a patient is entitled to: independent advice and support, or to an advocate or other supporter;

Section 44. Information

By April 2009 a National Health Information and Support Service. This will bring together quality assured local and national information from the NHS, the voluntary and other sectors, which patients and their families will be able to access online, by telephone or in their local high street.

Section 62. Independent Support and Redress

To achieve a culture of feedback and learning, rather than one of complaints and blame, we need to ensure that our systems for feedback and redress are easy to use, understand, accessible and appropriate to all patients and effective in supporting patients' rights.

Section 63. Independent Support and Redress

Patients who want to feedback or complain if difficulties arise, can currently do so:

- ◀ at local level through staff or the NHS Board;
- ◀ with the support of the Independent Advice and Support Service;

Section 64. Independent Support and Redress

We need to be proactive to ensure that a patient's right to redress is met and that they have the support they need to navigate this system and get the quality care and treatment they have a right to.

Section 65. Independent Support and Redress

Support and advice to exercise patients' rights should be easily available where healthcare is delivered. Patients should not have to seek this out for themselves.

Section 66. Independent Support and Redress

Boards need to consider the ways in which they proactively support patients to ensure they are able to exercise their rights. They are already required to deliver an Independent Advice and Support Service to support patients and their families use health services effectively and address health-related issues such as access to benefits and making a complaint.

Section 67. Independent Support and Redress

So that patients are fully aware of and able to exercise their rights, we will ensure that each NHS Board designates independent Patients' Rights Officers who will be a point of contact for patients and will be widely publicised to patients. We will also examine other new approaches to make sure that: patients are aware of their rights; local resolution happens as difficulties arise; feedback is provided to ensure the health service routinely learns from patients' experiences and, if things go wrong, patients or their families are supported to obtain appropriate redress. One possible approach may be to expand Boards'

current Independent Advice and Support Service to provide Patients' Rights outreach within local health services.

Section 68.

The evidence is that in most cases what people are looking when they seek redress is an explanation or apology, and an assurance that lessons have been learned, but in some cases financial redress will be appropriate.

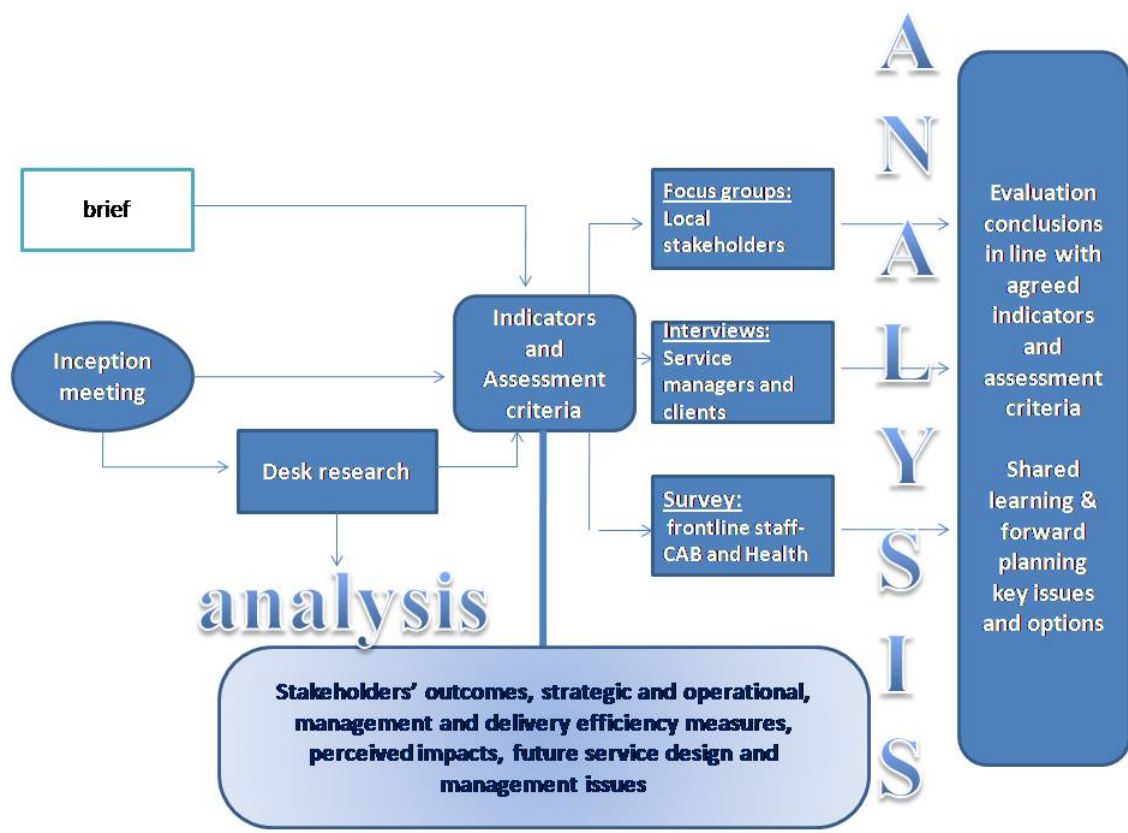
APPENDIX THREE
SUMMARY OF METHODOLOGY

The study involved the following elements :

- ◀ Desk Research - Compilation of monitoring data at Health Board level against operational & strategic outcomes; comparison with models in England/Wales
- ◀ Design, promotion and analysis of survey monkey questionnaire for CAB workers and volunteers [36 responses]
- ◀ Design, promotion and analysis of survey monkey questionnaire for health service staff [181 responses]
- ◀ Individual Interviews with IASS delivery staff & management [18]
- ◀ Individual Interviews with health service staff and other stakeholders [16 +]
- ◀ Individual Interviews with clients [15] plus analysis of client surveys by IASS
- ◀ Delivery of Focus Groups with health care stakeholders [3 *Health Board areas, 15 participants*]
- ◀ Discussion on interim findings by CAS/CAB Managers (Steering Group, 23rd July 2008)
- ◀ Discussion on draft interim report by Advisory Group (18th Sep 2008)

Summary of stakeholders and how involved

Health service users	Health service providers	Other stakeholders e.g. referral agencies, Scottish Government
Telephone interviews with health service users and carers who have used IASS	Telephone interviews with: Health board representatives from each territorial Health Board in Scotland; 1 GP 1 Practice Manager	Telephone and face to face interviews with: 1 Scottish Health Council rep 1 SPSO rep
	Focus Groups with Health Board representatives	Facilitation of discussion at Advisory Group:
	E-survey with health service workers	E-survey with CAB generic advisers



Summary of Approach

APPENDIX FOUR

SAMPLE EXTRACTS FROM CLIENT INTERVIEWS

Responses of Clients to the following questions

1. *Why did you turn to the CAB and not the NHS patients liaison/feedback/complaints team? How did you find out about the service?*

"I didn't know about the NHS feedback service. I just dropped in at the XCAB as I didn't know they had a service and was referred to IASS" "I didn't want to speak to anyone in the hospital about my situation"

"I never had much faith in the hospital, so I decided to go to the CAB"

"I would like to see that part of the service more widely known"

"Publicity? I didn't pay much attention to tell you the truth. At my age you don't tend to bother with posters or leaflets"

"I wouldn't have know about the service if I hadn't worked as volunteer with the CAB"

2. *What kind of help did you require?*

"My GP kept on fobbing me off. But (the IASS worker) set up an appointment with my GP. As soon as (the worker) walked in - didn't need to say anything, the calmness of it. The GP listened and he agreed that we would have a meeting at the hospital with the relevant staff. With (the worker) sitting beside me everybody behaved in a proper business like way...I wanted to know what went wrong...There is a problem with this particular hospital where people over 60 are sent"

"They kept shoving me back and forwards to one another...Nobody wanted to take responsibility for it as whatever department deals with it they have to pay for it. It was like an in-house political argument with the lot of them."

"I wanted to put pressure on the NHS to have care in my home. Social work said it was difficult to put a care package in place"

3. *What did the IASS worker do to help you with your problem?*

"It's the best thing I ever done. I got a letter of apology from the surgeon for the delay"

"(The IASS worker) helped me know how to gather more information to help myself; told me to record every appointment and things that were said to me; told me to speak to my own GP; helped me get in touch with the right people. (The worker) listened to what I had to say and between the two of us the letters the worker wrote for me were brilliant - I could never have worded the letters the way (the worker) did, made more official looking; advised me on what to include and what to leave out; made the letter less complicated and shorter so didn't need as many pages"

"(The IASS worker) told me who to write to at Health Records Dept and followed up by phoning the Head of the Department to find out why no reply; and then helped draft a formal complaint letter - so precise/short to and to the point. Is (the worker) a lawyer?"

"(The IASS worker) wrote on behalf of me and within a week got everything I needed. Another worker helped with money matters - I didn't understand the letters"

"(IASS) has written on my behalf. I've hit the time bar. I know I'm running out of time. Until I became aware I didn't know I should have refused treatment. (The IASS worker) is going to find out what's happening - in their letter (Acute sector service) they say I can meet and speak to senior staff. It affects your social life as it's so embarrassing. Medical treatment takes your confidence away. Coming up against certain parts of the medical people I am very exasperated by the attitude they have taken"

"You can talk to (the IASS worker). (The worker) is down to earth. Nobody seems to want to listen nowadays"

"(The IASS worker) is very professional and more important less involved; got the ball rolling as I felt I was getting nowhere with the consultant. I wouldn't have got further tests if hadn't gone to the CAB"

"I wanted to find out what to do about it - advised, and wrote letters for me. I was in debt when I started with treatment as I had to give up my job. Now I am doing voluntary work (driver for disabled children) and will be applying for a job with the ambulance service once I have built up my strength"

4. What further help do you require?

"I don't want to sue. I am just waiting to see what the outcome of it is, but I would like an apology. Don't know their names but I want it from the ones who spoke to me"

"Some people have advised me to sue them but how can you sue someone who saved your life? All I want is to earn my living. I don't want to be on incapacity benefit. If I don't stand up and ask the questions - is this how they want to treat people?"

5. Are you getting other help from the NHS?

"My GP did help after intervention by IASS"

"The other GPs wouldn't do the test I wanted. I know my body and I knew there was something wrong. A female doctor in the end referred me for tests"

"My GP gave me a letter to put in for incapacity benefit. The District Nurse was helpful in advising me on how to look after my husband at home and NHS24 was good"

"After I was advised (by IASS worker) to talk to my GP my GP admitted that he had never had to deal with this before for a patient either but told me in future to talk to the receptionist if I needed further help"

"I have correspondence from the specialist (in another area) who wrote on my behalf but (the specialist) was given short shift by the medical staff in my Health Board. If they are treating a highly respected specialist like that what chance have I got?"

APPENDIX FIVE

OVERVIEW OF FOCUS GROUPS WITH HEALTH CARE PROVIDERS

Three focus groups were convened : Grampian (Aberdeen), Lanarkshire (Motherwell) and Dumfries and Galloway (Dumfries). The following range of workers attended:

- ◀ **Hospital sector:** Director Corporate Communications, General Manager of Mental Health, Patient Services Manager, Public Involvement Officer, Feedback Advisor, 3 Hospital Administration Managers, Cancer Information and Support Manager, Renal Palliative Care Charge Nurse
- ◀ **Primary care sector:** Patient Services Manager, Practice Manager [2 Practice Managers⁴⁷],
- ◀ **Voluntary sector:** Coordinator of Dumfries & Galloway Coalition of Disabled People

Focus Groups were asked to consider three related themes, and within each theme there was reflected discussion around a range of issues :

1. What is the added value of independent advice and support in dealing with concerns and complaints about health services?
 - Promoting cultural change - building trust, reducing defensiveness, and getting people to raise concerns
 - Meeting legislative rights of patients; promoting advocacy
 - Providing alternatives - to folk who have no family or are from equality groups who tend to have access problems; to the service previously provided by the local health councils; providing alternative to going to the Ombudsman
 - Referring on to other advice and advocacy services
 - Working closely with colleagues in feedback/patient liaison teams
2. What is the added value of independent advice and support to:
 - a) the 'patient's experience'
 - b) 'the redesign of health services' and
 - c) the promotion of 'patients as partners in care'?
 - Influencing in-house procedures within the NHS hospital sector; proactive approaches - feedback-audit
 - Providing alternative models
 - Promoting local resolutions, sooner the better
 - Dealing with system failure
3. How can the reach of independent advice and support be extended to sections of the population whose take up of services tends to be lower and who are less likely to make use of complaints procedures?
 - Publicity
 - Standardised monitoring systems
 - Option to renegotiate the SLA to increase accountability
 - Standardisation of advocacy and advice and support across Scotland
 - Increasing reach throughout the NHS

⁴⁷ Workers unable to attend the focus groups but contributed later through telephone interview or written submissions

APPENDIX SIX

START DATES OF IASS ACROSS SCOTLAND - 2006 TO 2008

NHS Board Area	CABx in area (* lead CABx)	Start Dates
Lanarkshire	Airdrie*, Bellshill, Clydesdale, Coatbridge, Cumbernauld, East Kilbride, Hamilton, Motherwell & Wishaw	Sept. 2006
Western Isles	Barra, Harris*, Lewis, Uist	Oct 2006
Greater Glasgow & Clyde	Bridgeton, Castlemilk, Citizens Advice Direct, Drumchapel, Dumbarton, Easterhouse*, East Dunbartonshire, East Renfrewshire, Glasgow, Greater Pollock, Maryhill, Parkhead, Renfrewshire, Rutherglen & Cambuslang	Interim service Dec 2006 (Full service April 2007)
Grampian	Aberdeen*, Banff & Buchan, Moray	Jan. 2007
Shetland	Shetland	Jan 2007
Borders	Central Borders, Peebles*, Roxburgh	April 2007
Dumfries & Galloway	Annan, Castle Douglas, Dumfries*, Stranraer	April 2007
Tayside	Perth, Dundee, Arbroath*, Forfar, Montrose	May 2007
Lothian	Dalkeith, Edinburgh Central*, Gorgie/Dalry, Haddington, Leith, Musselburgh, Penicuik, Pilton, Portobello, West Lothian	Interim service April 2007 (Full service July 2007)
Forth Valley	Clackmannanshire*, Denny & Dunipace, Falkirk, Grangemouth & Bo'ness, Stirling	June 2007
Orkney	Orkney	July 2007
Highland	Argyll & Bute, Caithness, Inverness, Lochaber, Nairn, Ross & Cromarty*, Skye & Lochalsh	Interim service Aug. 2007 (Full service Jan. 2008)
Fife	CARF*, Cowdenbeath, Cupar, Dunfermline, Glenrothes, Kirkcaldy	Sep. 2007
Ayrshire & Arran	East Ayrshire*, Arran, Irvine, Kilbirnie, Largs, Saltcoats	May 2008

Source: HSU

APPENDIX SEVEN

E-SURVEY OF HEALTH SERVICE PROVIDERS

An e-survey was conducted between August and September 2008. Its purpose was a) to seek views of NHS workers on independent advice and support to patients/carers in raising concerns and complaints; and b) to assess levels of awareness to IASS. 181 NHS workers took part in the survey. The following are the main findings:

Attitudes towards independent advice and support

- ◀ 93% of respondents agree that people are entitled to advice and support to deal with concerns about NHS services.
- ◀ 91% of respondents support the view that people should receive support when things go wrong in large organisations.
- ◀ The main reasons for this were: fairness ["It would enable all individuals with valid concerns to raise them"]; the opportunity to resolve matters informally ["Many people do not like to make a fuss but comments should be encouraged and not always seen as complaints"]; and having the time to sort out a problem ["With the NHS being so busy and under pressure, having an independent person to call on would be beneficial for opinions, support and time"].
- ◀ 71% of respondents were supportive of such advice and support being independent from the NHS - ["sometimes outside support allows people to reflect...and may in fact prevent a complaint"].
- ◀ There were concerns about inappropriate complaints - ["unrealistic expectations" and "too many people want money for situations that are without anyone doing anything wrong"].
- ◀ The top three reasons given for signposting people to independent advice and support, were: 65% [when people need advice from someone not connected to the NHS]; 58% [to avoid formal complaints by providing help with the informal resolution of problems]; 58% [to deal with difficult complaints that need an adviser to get to the bottom of the problem]. A further comment was: "to get them (patients or their carers) to act reasonably and frame proper complaints and it stops them from abusing us".

Awareness of independent advice and support organisations

- ◀ 47% were aware of organisations which provide independent advice and support in their areas;
- ◀ Of these 33% referred to either "CABx" or "IASS"; 24% were aware of CABx as a generic source of independent advice and support; and 13% of respondents knew of IASS
- ◀ 8% of total respondents knew that CABx deliver IASS, and 0.06% were aware that CABx were responsible for IASS.

In summary there is strong support for independent advice and support among NHS workers. However awareness of IASS and that CABs deliver IASS compares poorly with a relatively high awareness of independent advice and support services including CABx. There appears to be an information gap in relation to the IASS profile within the NHS and in promoting it as a CAB-managed service.

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