

Citizens Advice Scotland

Scottish Association of Citizens Advice Bureaux



1939-2009: 70 years
of Scottish CAB advice

Patient Rights (Scotland) Bill 2010

Submission to the Health and Sport Committee

Citizens Advice Scotland and its 83 CAB offices form Scotland's largest independent advice network. CAB advice services are delivered through 222 service points throughout Scotland, from the islands to city centres.

The CAB service aims:

to ensure that individuals do not suffer through lack of knowledge of their rights and responsibilities, or of the services available to them, or through an inability to express their need effectively

and equally

to exercise a responsible influence on the development of social policies and services, both locally and nationally.

The CAB service is independent and provides free, confidential and impartial advice to everybody regardless of race, sex, disability or sexuality.

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Summary

4. Citizen Advice Scotland (CAS) welcomes the ethos and health care principles that underpin the Patient Rights (Scotland) Bill. However, we have specific concerns with some of the main provisions of the Bill
5. CAS supports the following features of the Bill:
 - The introduction of the Patient Advice and Support Service (PASS)
 - The creation of the post of Patient Rights Officer
 - The introduction of the right to make complaints and provide feedback
 - The commitment to providing patients with details on the support and advice available to them and information on how they can make complaints (section 1, clause 8, part 2c)
 - The commitment to ensuring that those making a complaint are given details of the advice and support available to them, that the details of this advice and support is publicised, and that complaints should be monitored (section 1, clause 11, part 3)
6. CAS has concerns regarding:
 - The lack of obligation on the NHS to provide feedback on submitted complaints
 - The lack of detail provided on the role and structure of the Patient Advice and Support Service and the Patient Rights Officers
 - The lack of clarity on whether and how the service standards set by the Independent Advice and Support Service (IASS) will be undertaken and maintained by PASS
 - Patient Rights Officers covering level one and two complaints about the NHS (see appendix)*
7. Although the Bill will improve patient rights in Scotland, we are concerned that the NHS is not under any obligation to proactively provide information to patients on the progress of complaints and concerns raised. In addition, there is no obligation on the NHS to provide this information to the Patient Advice and Support Service either when the service has assisted the patient in filing complaints, concerns or comments.
8. There is also a lack of clarity on how the new advice and complaints service will affect the holistic support and advice work currently being carried out by the Independent Advice and Support Service.

Introduction

9. Citizens Advice Scotland (CAS) is the umbrella organisation for Scotland's network of 83 Citizens Advice Bureau (CAB) offices. These bureaux deliver free, impartial and confidential frontline advice services through more than 200 service points across the country, from the city centres of Glasgow and Edinburgh to the Highlands, Islands and rural Borders communities.
10. In 2008/09, the Scottish CAB service dealt with just under **one million** client issues resulting in **2,677** enquiries handled by bureaux across Scotland each day of the year. The sorts of issues dealt with by bureaux include welfare benefits, housing, debt, consumer and employment. The CAB service in Scotland strives to ensure that people have access to information about their rights and responsibilities.
11. Last year the CAB service in Scotland dealt with over 29,000 sickness benefit issues and 59,260 disability benefit issues. . In this period the service also dealt with a total of **324,800** debt issues, **257,444** benefit issues, **86,897** housing issues and **74,017** employment related issues accounting for **76%** of all client issues.
12. The Independent Advice and Support Service (IASS) is a part of the CAB service in Scotland. Funded by local NHS boards, IASS offers advice and support to all NHS users and their families in relation to any concerns and complaints they may have regarding care received from the NHS. The service also provides general advice and has a holistic outlook to supporting its clients, as patients' health concerns are frequently interlinked with other issues they are experiencing such as debt or employment issues which can have a significant impact on people's health and well being¹.
13. CAS welcomes the Patient Rights (Scotland) Bill, although we have serious concerns about the following:
 - NHS feedback following submission of a complaint
 - The role and structure of the Patient Advice and Support Service (PASS)
 - The role of Patient Rights Officers
 - The lack of provision for independent evaluation of PASS and the outcomes that it produces'

¹ Greater Glasgow and Clyde Citizens Advice bureaux report assisting with **1154** issues through the IASS service in 2008/09.

Concerns and Recommendations

Section 11: Complaints

14. CAS is concerned that the Bill does not explicitly include a requirement for the NHS to provide feedback to patients who have submitted a complaint, commented on their experiences of the NHS, or raised concerns about its services.
15. We recommend the inclusion of a requirement for the NHS to provide feedback both directly to patients and to the Patient Advice and Support Service (PASS) when it has been involved in supporting a patient. This would allow PASS to monitor the NHS's response to the complaints and comments it receives, and measure the impact that PASS has had on any improvements made to the services provided by the NHS.

Section 12: Patient Feedback

Please note that the concerns and recommendations we outlined above in relation to section 11 of the Bill also apply to this section.

16. While CAS welcomes the establishment of PASS, which builds effectively on the work already being carried out by IASS, we have some concerns about how this service may operate.
17. The precise role and possible structure of PASS is unclear, as provision on both a local health board basis and national basis are mentioned in the Bill, associated explanatory notes and memoranda.

More clarity is also required on how Patient Rights Officers would be managed by PASS, both in health board areas and across Scotland..

18. It is essential that the service is impartial, independent and confidential. Based on our experiences with IASS, we therefore consider that the service will need to have in place the following elements:
 - Reliable, quality assured, current and comprehensive information sources
 - Effective training and support for staff
 - Independent quality control systems and clear criteria against which its management, administration, service provision, advice and information provision can be measured and reported on
 - Clear systems for collecting performance information and statistics for reporting to the NHS, the Scottish Government, the Scottish Health Council , with this information made available in the public domain
 - Delivery structures that ensure consistent service provision across the whole of Scotland (avoiding any post code lottery or variation in standards) and that ensure local access to support wherever possible

- Systems to ensure that the service is well publicised.
19. The establishment and maintenance of a central support service to cover the whole of Scotland will be crucial to the effective delivery of PASS. IASS's experience to date indicates that central provision is required to:
- Gather, collate and report on statistics and other data in relation to the performance of the service on both a health board and Scotland-wide basis. Without a central resource, consistency of reporting will be lost and it will not be possible to gather data for national stakeholders with which to measure, benchmark and compare performance
 - Provide standardised training programmes to ensure that all Patient Rights Officers have the appropriate knowledge, skills and competencies
 - Provide social policy information in terms of trends, patterns, and issues raised by users of the service for use by the NHS and others in policy development
 - Market the service consistently across the whole of Scotland to potential users, NHS staff, agencies who are likely to refer patients, and to the general public.

Section 14: Patient Advice and Support Service: Establishment and Funding

Please note that the concerns and recommendations we outlined above in relation to section 12 of the Bill also apply to this section.

20. CAS strongly recommends that PASS continues with the provision and delivery of general information, advice and support service to patients, their families and carers as currently provided by IASS. Feedback from a sample of IASS users suggests that the holistic advice and information provided by this service is highly valued. Furthermore, Aberdeen University published a report a few years ago outlining the positive impact bureaux outreach services had on patients and their families in Aberdeen².
21. Independent research evidence³ clearly demonstrates that the provision of information and advice about, for example, welfare benefits, debt, housing and employment assists people in the following ways:
- It reduces anxiety and stress and helps users to feel more in control of their situation

² Farmer, Jane and Lucy Kennedy, 'CAB outreach services evaluation: A report on the impact of Citizens Advice Bureau outreach services at Aberdeen Royal Infirmary and Banff and Buchan on client health and professional workload' by Jane Farmer and Lucy Kennedy, University of Aberdeen, Department of Management Studies, May 2001.

³ Abbott, Stephen and Hobby, Lindsay, 'The Impact of Advice, a brief report', 2003, available at http://www.asauk.org.uk/fileLibrary/pdf/The_Impact_of_Advice.pdf; Citizens Advice Cymru, 'Better advice, better health project'

- This in turn reduces the need for prescriptions such as anti-depressants, required by some patients to help them cope, and reduces the number of visits that they make to GPs and other health professionals
- It can help people to move out of health care accommodation and back to their homes by assisting them to access both the support services and adaptations to their homes that they need in order to do so.

22. It will be important that the budget for PASS includes costs relating to marketing, training, performance reporting and provision of information.

Section 15: Patient Advice and Support Service (PASS)

Please see our comments on section 14 (above).

23. IASS is currently delivered by bureaux across Scotland. General advice and information on welfare benefits, debt, employment, housing, relationships and access to health services is delivered alongside information and advice on level one and level two complaints about the NHS. The Bill suggests that all such work would be carried out by paid Patient Rights Officers. We are concerned that this will result in:

- Loss of integration of complaints and patient rights associated work with a broader, more holistic service which caters to users' social and economic needs as well as their NHS-related ones
- Reduced access to the service, particularly in remote and rural areas. At present, NHS users can access IASS through over 200 outlets across Scotland and they can be referred for specialist help by an IASS caseworker from any one of these locations. Any immediate or urgent concerns can be dealt with on the spot, prior to a referral being made
- Higher service costs. A considerable amount of the work assigned by the Bill to Patient Rights Officers could actually be very effectively dealt with by local CAB advisers. This would create economies of scale and cost savings that would not be present if the service were to be delivered solely by Patient Rights Officers, as outlined in the Bill
- Patient Rights Officers are unlikely to be able to assist users with all of their information and advice needs. Users may, for example, require assistance with claiming welfare benefits or managing complex debt. IASS is built onto the existing information, advice and support structure available through the CAB service and at the moment, users can be referred to in-house specialists where relevant. It is important that PASS continues to make similar provisions available to users.

24. CAS agrees that it is important for patients to take responsibility for their own health and well-being. We recommend that PASS plays a role in assisting and

educating patients through the provision of health information; assistance to access, interpret and effectively use health information; and referrals to appropriate support services.

25. We also recommend that an independent evaluation of PASS be carried out annually.

Section 16: Patient Rights Officers

Please see our comments on section 15 (above).

Section 17: Duties to share information

26. While CAS broadly welcomes these provisions, we feel that this section of the Bill could be strengthened through the following:

- Placing an obligation on the NHS to market PASS effectively
- Placing an obligation on the NHS to provide feedback to patients and, where relevant, to PASS about changes or improvements made as a result of the feedback, comments or complaints made by NHS users

Conclusion:

27. CAS supports the principles of the Patient Rights (Scotland) Bill, ensuring that patients are able to exercise their rights and are aware of their responsibilities. We also welcome the creation of PASS and the new role of Patient Rights Officers.
28. We are, however, concerned that PASS may fail to provide the holistic service that is available to patients currently through IASS. If this element of service provision is omitted from the new structure, the efficiency and cost effectiveness that would have resulted from its use for level one and two complaints will be lost.
29. Consequently, we recommend that the structure and role played by PASS and Patient Rights Officers be clarified and that adequate provisions be made to ensure patient well being and the success of the service.

EXPLANATORY NOTES:

30. We strongly support the provision of education, training and awareness-raising about PASS and the role of Patient Rights Officers through NHS Education for Scotland (NES). Experience of delivering IASS has demonstrated the importance of this in ensuring take up of the support service.