About Advocacy

The Scottish Independent Advocacy Alliance Magazine *Winter 2012*

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Editorial

What better way to spend one of these chilly winter evenings than by the fire wrapped up in a thick blanket, with a hot beverage of your choice, reading the winter edition of our magazine. Here you can read about the importance of independence in advocacy, the latest edition of our advocacy map, and the exciting Inspire Project, giving a history of the advocacy movement in Scotland. Also, we have contributions from the General Pharmaceutical Council and the Nursing and Midwifery Council; as well as a contribution from Ceartas Advocacy on service user involvement. So, sit back and enjoy, and please don't forget to pass on the magazine to a friend or colleague when you've finished.

Vincent Finney
Editor

Next issue:
Please contact enquiry@siaa.org.uk if you have content for a future edition.

Thank you:
The SIAA would like to thank all the individuals who have contributed to this magazine.

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Scottish Independent Advocacy Alliance

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An electronic copy of this magazine can be downloaded from our website: www.siaa.org.uk.

SIAA News

Shaben Begum MBE, Director

Quality Assurance, Performance Poetry and an Advocacy Champion at our 10th AGM

The 10th SIAA AGM took place recently and as ever it was a day of debate, discussion and catching up with colleagues from across the movement, throughout Scotland. We also had the serious business of voting on the SIAA converting to a Scottish Charitable Incorporated Organisation and taking on a quality assurance function. Both the resolutions were successfully voted through. This vote was the culmination of work over the last few years where members have been consulted and have voted at different AGMs for the SIAA to take forward the quality assurance agenda. The next steps involve agreeing a business plan with our funders in the Scottish Government and hopefully carrying out evaluations in the not too distant future. We will as always keep members updated.

Ian Brooke, Jo McFarlane, Shaben Begum

The AGM was also a celebration of the SIAA advocating for advocacy for 10 years; our annual report creatively illustrates some of our key achievements over the years. For me the most significant has been the publication of a set of overarching Principles and Standards used by all advocacy organisations. The *SIAA Principles and Standards for Independent Advocacy* were then used as the basis for a range of other documents. These helped advocacy partners have clear expectations from the advocacy role, advocates to reflect on their practice, and organisations to improve the quality of advocacy delivered.

We had performance poet, Jo McFarlane entertaining and inspiring us with poems about her experiences of using mental health services and how independent advocacy helped her regain control of her life. You can read a selection of Jo's poetry on our website.

Dr Joe Morrow, President of Mental Health Tribunal Scotland (MHTS), is a well-known advocacy champion and spoke about the importance of independence and ensuring quality. Dr Morrow spoke at length about the MHTS taking steps to improve the service it provides, the involvement of advocates at Tribunal hearings and the importance of written personal statements. He also spoke about the value of the *SIAA Mental Health Tribunal Guidelines* and how they are used by all Tribunal panel members.

Why is Independence in Advocacy Important?

Muriel Mowat, Research and Quality Officer, SIAA

In the last edition of About Advocacy I posed the question 'Why is Independent Advocacy Important?'

The article looked at the impact that disadvantage or powerlessness can have on individuals, how advocacy can support people to gain or regain control over their lives and the impact that can have on their physical and mental health and wellbeing. In this edition I am looking at why independence is important to ensure consistent quality in delivery of advocacy.

The recognition of the importance of independence in advocacy has been longstanding. As early as the late 1990s, before the establishment of the Scottish Parliament, the Scottish Health Advisory Service (SHAS), in their document *Advocacy — A Guide to Good Practice*, identified independence as an 'Essential Feature of a Good Quality Advocacy Service'. The document focuses on advocacy for NHS service users. SHAS also makes clear the need, not only for independence, but for a clear perception of independence on the part of NHS users. This is no less true today and also applies, not only to users of NHS services but, to users of any services.

These ideas are echoed in the Scottish Executive document *Independent Advocacy — a Guide for Commissioners* published in 2001. This recognises the need for advocates to be completely on the side of the service user with no potential for any conflicts of interest. The document goes on to state that advocacy should seek to include those most at risk of exclusion and least able to represent and defend their own interests and that advocacy organisations and groups should be firmly rooted in, supported by and accountable to, the community they serve. It also stresses the need for advocacy organisations to be 'constitutionally and psychologically independent' of local and national government and the statutory and voluntary sector service system.

The main barriers to truly effective advocacy recognised in these documents are conflict of interest **and** service user perception.

Some people may have family, friends or other carers to help them to speak up. However sometimes, if they do, family members may have their own ideas about 'what is best' for the person involved and may therefore have a conflict of interest.

An advocacy organisation whose sole focus is provision of advocacy can, as the 2001 Guide for Commissioners says, *'stand in a different place and see things from a different perspective.'* They are less likely to encounter any conflict of interest in their advocacy role. A worker providing advocacy who is employed by an organisation that provides other services may find that they have a conflict of interest in their advocacy role. If the person for whom they are advocating has an issue with a service provided by the employer it may be difficult for the advocate to challenge their employer.

An important part of the advocate's role can be to support an individual to gather as much information as possible, to make informed choices and to consider the possible outcomes of choices. In a situation where different services are

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Why Should Advocacy be Independent?

Nurses, social workers, care staff, doctors, teachers and other professionals look out for and speak up for the people they serve. It's their job, it's part of their professional code of conduct, it's part of being a decent human being. But they aren't and can't be independent.

But to be on someone's side, advocates have to be structurally and psychologically independent of the service system. Independent advocates — whether paid or unpaid — can be entirely clear that their primary loyalty and accountability is to the people who need advocates, not the agencies providing health and social services, and not to the government. Independence doesn't mean being right all the time. Independent advocates are no more virtuous that service providers. They just stand in a different place and see things from a different perspective.

Independent advocates do not have the same conflicts of interest as professional workers who are expected to make judgements about who is most deserving or most eligible for a service. Because advocates do not have this sort of power over people and do not control access to resources they are in a better position to see things from the person's point of view rather than the system's point of view. They can focus on representing the interests and wishes of the people who need an advocate, and be clear that this is their role.

Independent Advocacy: A Guide for Commissioners: A Guide for Health Boards, NHS Trusts, Local Authorities and anyone involved with advocacy, Scottish Executive, 2001.

being considered, if the advocate is employed by an organisation that provides the type of service being considered, that may create a conflict of interest for them in supporting the individual making their informed choice.

It can be possible to put in place policies and procedures to minimise the impact of any conflict of interest, but some are more easily mitigated against than others. The fact that almost all advocacy organisations now are funded, at least in part, by statutory funders, can create some degree of conflict of interest, if the advocacy organisation is supporting an individual or group to challenge the agency funding them. This is clearly acknowledged and effort is made to avoid this by having robust Service Level Agreements in place between the advocacy organisation and funder. Such an SLA will acknowledge the potential role of the advocacy organisation in this situation and the funder should

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welcome this kind of input as an opportunity for learning and improving their services.

"We stay very true to our advocacy principles and these are hurdles that we have to jump. As an advocacy organisation independence is a major factor for us, that although we are commissioned and we get funding, we still retain our independence because that gives the people that use our service confidence in us."

— Angela Woolridge, Partners In Advocacy

"The fact that we got money from the Council didn't stop us when we had to advocate for someone against them."

— Morag McClurg, AIMS

The perception by a service user of any links between the advocacy organisation and a service provider can provide a significant barrier to advocacy support being sought. If a service user has an issue or concern about an agency from which they have accessed a service they may be unwilling to approach an advocacy organisation if they believe there is a connection between the two. As the SHAS document states *'users must be able to see and have confidence that it is independent.'*

"You can't be an offshoot of a statutory organisation because you're never independent"

— Angela Woolridge

Over the past 10 years an increasingly large proportion of independent advocacy organisations have been established and funded. In 2001 there were over 60 organisations providing advocacy in Scotland of which 50% were independent with their sole focus being provision of advocacy. Many advocacy organisations originally established by service providers recognising the need for advocacy for their client group were then supported to become independent of their parent organisation. This was in response to the recognition of the potential barriers created by the perception of a link between the advocacy project and the service provider. By April 2012 there were 59 organisations of which 81% were independent advocacy organisations.

We do recognise that good quality advocacy can be delivered by a non-independent advocate and that independence cannot always be assumed to be synonymous with good quality. Nevertheless independence is an important facet in quality of advocacy provision.

Independence

Most people who work in agencies providing health or social care services do their best to safeguard and empower people. But they often have to manage limited resources while maintaining their professional role and identity. This can present them with a conflict of interest. Sometimes it is hard for them to be critical of the services they provide and to see that, despite their best efforts, they are failing some people.

If advocacy is to be effective, it must be independent of any service provider. NHS users must be able to see and have confidence that it is independent. Relevant issues include:

- *how the service is funded and managed;*
- *where it is located;*
- *its public image and identity including, for instance, letterheads and logos;*

and

- *relationships with NHS staff and health professionals*

Advocacy: A Guide to Good Practice, The Scottish Office, Dept. of Health, Scottish Health Advisory Service.

Inspiring our Future: Stories of the Advocacy Movement in Scotland

Barbara Brown, Researcher, Inspiring Our Future Project

It has been a joy to work on the Inspire Project and I am very excited now that the project is in its final stages. I am looking forward to sharing the final report with everyone who is interested in the story of the advocacy movement and hope people enjoy reading it as much as I have enjoyed writing it.

During the course of researching the project, it has been my privilege to meet with many of the extraordinary people who have been involved with advocacy in different ways, over the last twenty-five years or so, who have kindly shared with me their experiences, passion and commitment to independent advocacy.

In the course of preparing my report I have come to learn all about the *Principles and Standards and Code of Practice for Independent Advocacy*. I have gained an understanding of the significance and importance of independence and the avoidance of conflicts of interest; and have become familiar with different models of practice across a wide and diverse movement.

During my research I had the opportunity to visit several advocacy organisations delivering different models of advocacy in new and innovative ways. I have had the chance to meet with some exceptional people and chat to them about their experiences and achievements; to find out what makes them passionate about advocacy and what they feel is important for the future of the advocacy movement in Scotland. I have also had the fantastic opportunity to meet with some of the pioneers of advocacy who championed the movement in its early days.

"Sometimes people ask me when I'm going to retire. I say, I'll keep going until my body tells me to stop."

—Jimmy McIntosh, MBE, Chair, Partners in Advocacy

My research has led me back over twenty-five years, to the very first user-led groups, the first public meetings where people stood up and demanded to be heard. Early advocacy projects which began from the roots of local communities and the first citizen advocacy partnerships; people trying to change the system from within and intrepid patients who stood up to hospital authorities.

Throughout the preparation of this report, it has become very apparent to me that the advocacy movement in Scotland is diverse and far-reaching, with lots of organisations delivering different models of advocacy. It is clear that there are some

remarkable people with very strong viewpoints on a range of issues. What struck me most, though, is that each and every one is fiercely committed and intensely passionate about advocacy, whatever the model of delivery, whether it be a citizen advocacy partnership, a collective advocacy group or an organisation delivering short-term individual advocacy.

While writing the report, I asked people what they thought was important to the future of advocacy in Scotland, and what has become apparent is that people agree on the key foundations of advocacy, one of these being independence, and what they feel are the major issues facing the advocacy movement. In the course of preparing the report it has become clear that the advocacy movement in Scotland faces a challenging future, there are a number of key issues to be tackled and there is much work still to be done to give a voice to those people who are unheard.

What is clear to me is that while the advocacy movement is diverse and wide-ranging, with different organisations delivering different models of advocacy across a wide and diverse community, the passion and commitment to advocacy remains the same, and there is some amazing, literally life-saving work being done every day by extraordinary people.

The final report, *Inspiring our Future: Stories of the Advocacy* movement in Scotland, will be published in the next few months.

"There have been people who have told me that thanks to an advocacy worker they did not attempt suicide, they did not end up homeless, because we kept them in the waiting room for their appointment."

— Chris Mackie, Director, Advocard

The 2011–12 Advocacy Map: *an analysis*

Muriel Mowat, Research and Quality Officer, SIAA

The fifth edition of the Advocacy Map is about to be published. The first was published in 2002 by the Scottish Human Services Trust, the second by the Advocacy Safeguards Agency and the remaining three by SIAA.

The map shows the spending pattern across all NHS Boards was similar to that of the 2009/10 year. Chart one shows the comparative spend, per person, per annum, by NHS Boards and Local Authorities, on advocacy. It is further split to show spend on independent and other advocacy with spend on independent advocacy shown in red. The information used was provided by all NHS Boards and all Local Authorities. Population figures are taken from the General Register Office Scotland Mid 2011 Population estimates Scotland.

Chart two shows the levels of non-statutory funding by NHS Board area. Spend from all non-statutory sources in 11/12 was £510,096 down from £668,748 in the 2009/10 year. As with all other sources of funding the economic downturn has contributed to increasingly tight budgets for these trusts and grant awarding bodies and increased competition for these more limited funds. Despite the decrease in these awards this total shows the significant added value independent advocacy organisations can bring to NHS Board and Local Authority areas.

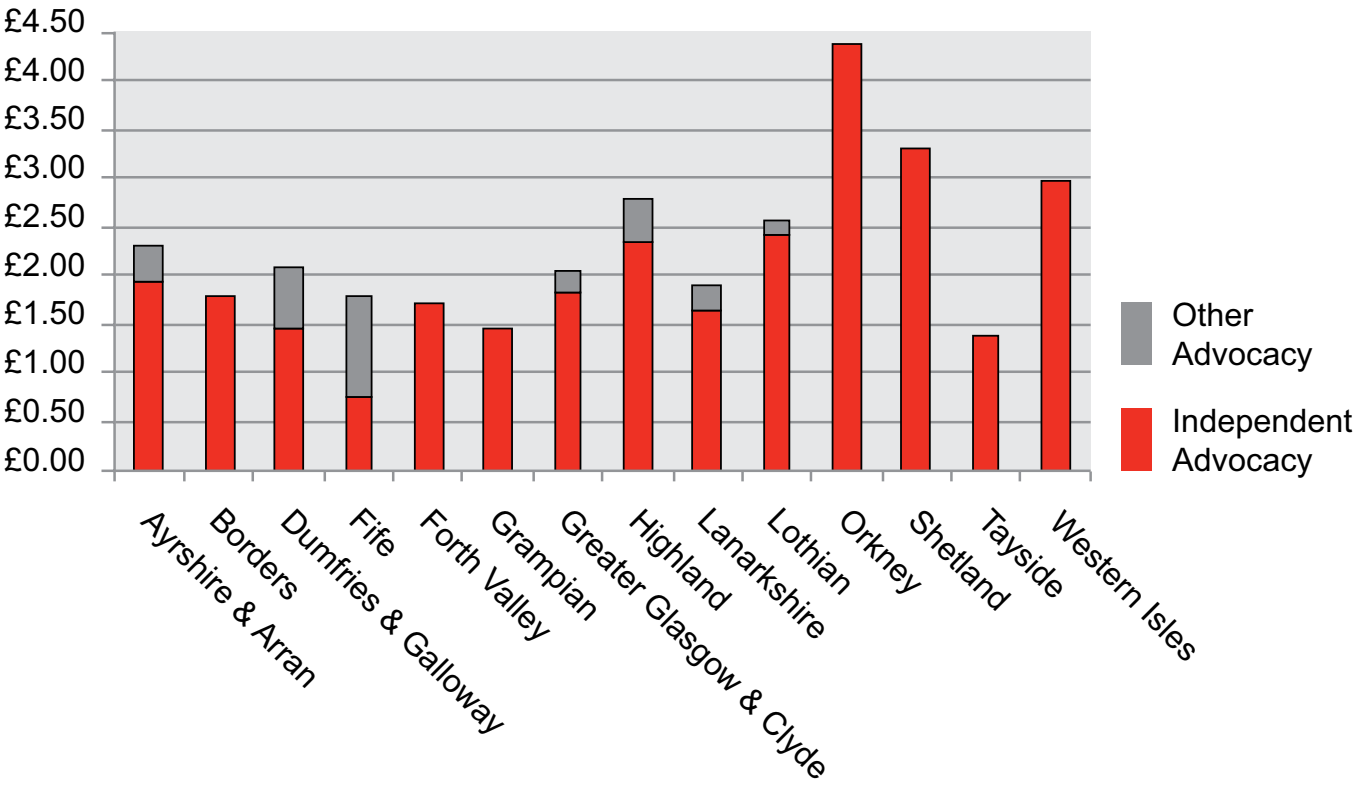
Additional statutory spend on advocacy from The State Hospitals Board for Scotland and the Scottish Government brings the total spend in the 2011–2012 financial year from all sources to £11,751,093. That equates to per person, per annum spend of £2.23.

As in the 2009/10 year over 25,000 people accessed advocacy in the 2011/12 year. More For Less, the SIAA report on the impact of the recession on delivery of advocacy reported increased demand for advocacy along with, in many cases, reducing resources. As a result of reducing resources many organisations have had to create waiting lists and prioritise referrals. It has not been possible for many organisations to increase numbers of referrals followed up.

Scottish advocacy organisations employed 430 paid staff and 1000 volunteers in 2011–12. That's 20 fewer paid staff and 200 fewer volunteers than the year before.

The World Health Organisation report *'Mental Health: New Understanding, New Hope'* estimates that, at any one time, around 850,000 people in Scotland will have some form of mental health problem. The NHS Health Scotland *Health Needs Assessment Report* estimates that around 150,000 people in Scotland have a learning disability. Research suggests that around 20 in every 1000 of the population have a mild to moderate learning disability and between 3 and 4 in every 1000 have a profound learning disability. Alzheimer Scotland Action on Dementia estimates that there are around 82,000 people of all ages suffering from dementia. These figures suggest that, at any one time, in Scotland there are 1,082,000 people (21% of the total population) who have a statutory right of access to independent advocacy.

Chart One: Independent and other advocacy spend per head of population 2011– 2012



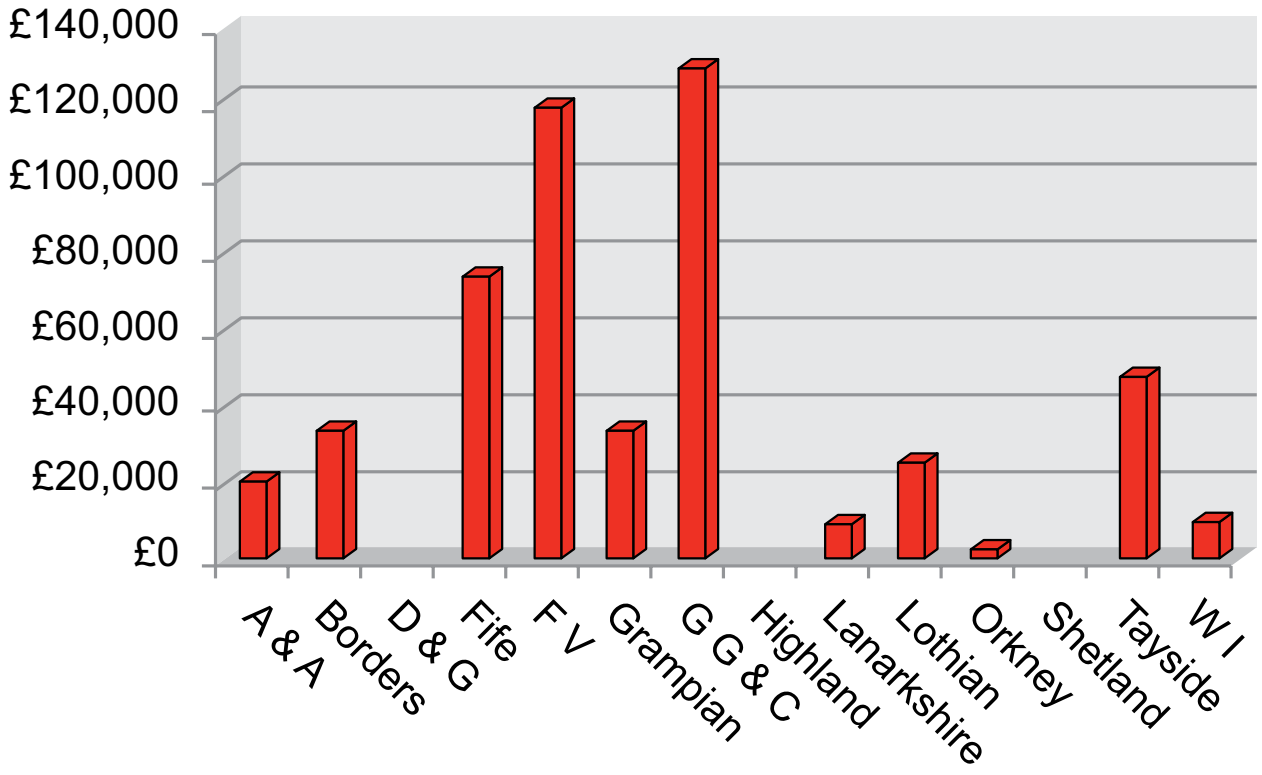
Gaps in provision

Many organisations identified gaps in provision with common themes emerging. Organisations were specifically asked for information on accessing advocacy by members of BME communities and by those with physical disabilities. 17 organisations do not routinely record ethnicity when taking referrals. 29 organisations said they had worked with people from BME communities in the 2011/12 year but 12 of those do not keep records of numbers of such referrals. Five organisations said they had not worked with people from BME communities.

Only 9 advocacy organisations stated that they were directly funded to provide advocacy for physical disabilities. A further 7 were funded either to work with people eligible to receive a community care service or to provide a generic service and 2 more organisations are funded to provide a generic service for children and young people, including those with a physical disability. 15 organisations stated that they only work with people with a physical disability who also meet their access criteria e.g. learning disability, mental health problem, older person.

Continued on page 12

Chart Two: Non statutory spend on advocacy 2011 – 2012



This means that 16 local authority areas do not have any advocacy provision for people with physical disabilities. This is likely to be a particular issue for people wishing to apply for Self Directed Support in the future. In such a situation access to independent advocacy support will be available across Scotland for those with mental health problems, learning disabilities or dementia but will only be available in certain local authority areas for those with physical disabilities.

Gaps remain in relation to access to independent advocacy for those in prison. This is of particular concern as statistics from the Mental Health Foundation show that only 1 in every 10 prisoners does not have some kind of mental disorder. In late 2011 responsibility for healthcare for prisoners transferred from the Scottish Prison Service to NHS Boards. The strategic advocacy plans in many areas recognise this as a gap in provision and in some areas work has begun to address this.

Provision of advocacy for children and young people has increased with advocacy now available in all NHS Board areas although not all local authority areas. Not all are independent advocacy providers. In some areas provision is only available for looked after and accommodated

children and young people while in others it may only be available for those with a mental disorder. Nevertheless this has increased from provision shown in past years.

Many of the group identified as having limited or no provision have been identified in previous editions of the Advocacy Map. In some areas there appears to have been no significant increase in advocacy provision although provision has increased in others. Organisations report that increased access criteria established with updates to, or new, Service Level Agreements/Contracts are not always accompanied by increases to funding. Increases in demand for independent advocacy arising from this have led to the need for prioritisation and waiting lists.

Maintaining Quality

The small increase in statutory funding, in part offset by the reduction in trust or other non-statutory funding, suggests at least maintenance of the status quo if compared with the 2009/10 figures. In the current economic climate this is encouraging and demonstrates the on-going commitment of national and local government to provision of advocacy. There remains however, some way to go before independent advocacy is available to all who need it. It is also important to keep in mind the work to be done to ensure that increasing demands do not have any impact on the quality of the advocacy delivered.

A Map of Advocacy across Scotland 2011–12 is an electronic publication and is available on our website.

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Provision of advocacy for children and young people has increased with advocacy now available in all NHS Board areas.

General Pharmaceutical Council: *Making sure pharmacy services are safe*

General Pharmaceutical Council

Lynsey Cleland, Director for Scotland

Pharmacies have an important role in the care of patients in Scotland and now do far more than dispensing medicines on prescription. This includes offering a growing number of services, from blood pressure screening to help with stopping smoking. The expert advice offered by pharmacy professionals can be invaluable for patients, particularly those with complex and long-term health conditions. It is our job at the General Pharmaceutical Council to make sure that the public are kept safe, when they use all of the services now on offer in a pharmacy.

The General Pharmaceutical Council is the independent pharmacy regulator for Great Britain. Our role is to protect the health, safety and wellbeing of patients and people who use pharmacy services. We do this in two main ways — by registering competent professionals to practise pharmacy and by regulating the system for managing and delivering pharmacy services from pharmacies. There are 4,328 pharmacists, 1,987 pharmacy technicians and 1,282 pharmacy premises based in Scotland on our register.

Our work touches the lives of pharmacy professionals from the day they start their training to when they cease to practise and register with us. We set standards, accredit courses and approve qualifications for pharmacists and pharmacy technicians. We also assure the quality of the year-long pre-registration training which pharmacist trainees must undertake, and run the final assessments that candidates must pass to apply for registration. We check that registered pharmacy professionals are keeping their skills and knowledge up to date throughout their working life.

We publish standards that registered pharmacy professionals and those who operate registered pharmacies must meet to stay on the register, and produce guidance to support safe and effective pharmacy practice. When concerns are raised that our standards are not being met, we investigate those concerns and can take action against the registered pharmacy professional involved. The most serious of those actions is removing someone from the register. Our website provides details on what to do if you have concerns about a pharmacy professional.

I was appointed as the Director for Scotland to lead our work here and make sure we regulate in a way which reflects developments in pharmacy and health in Scotland. This includes working with organisations like the Scottish Independent Advocacy Alliance, and engaging with members of the public in Scotland, to make sure we understand what patients expect from their pharmacy services.

We recently consulted with members of the public and representatives from patient organisations and pharmacy and NHS bodies across the country on a new approach to regulating registered pharmacies. This will change the standards all pharmacies have to meet and how they are inspected and the feedback we received is helping us to make sure that this achieves the best outcomes for patients and people using pharmacy services in Scotland.

For more information about the General Pharmaceutical Council, or to visit our online register, go to **www.pharmacyregulation.org**

The Nursing and Midwifery Council — *Safeguarding the health and wellbeing of the public*

Former NMC Assistant Director of Scotland and Northern Ireland Affairs

The Nursing and Midwifery Council (NMC) was set up in 2002 by the Nursing and Midwifery Order 2001 to be the nursing and midwifery regulator for the UK.

We exist to safeguard the health and wellbeing of the public, not to represent nurses and midwives. Also, to set standards of education, training, conduct and performance for nurses and midwives; hold the register of those who have qualified and meet those standards; provide guidance to help nurses and midwives keep their skills and knowledge up to date and uphold our professional standards; and have clear and transparent processes to investigate and deal with nurses and midwives who fall short of our standards.

There are many organisations which support nurses in carrying out their roles but our job is to ensure that only those who reach our high standards of education, training and conduct continue to provide care. The standards we expect are set out clearly in the NMC code of conduct and in specific guidance, such as *Guidance for the Care of Older People*, available on our website. Treating people as individuals, and respecting their dignity, is the first principle of the code that nurses and midwives must follow.

We also set standards for nurse and midwife education. Before being able to apply for registration, nurses and midwives must complete an education programme approved by us. These programmes are normally three years in length and students spend half their time in clinical practice developing the skills they will require to provide safe, effective and person centred care.

If a nurse or midwife fails to meet these standards they can be referred to us for investigation. This may lead to them appearing before a panel, which will decide whether they are fit to continue practising as a registered nurse, whether they should be struck off the register or whether they can continue to practise with restrictions for a period of time. Panels are made up of lay people and registered nurses or midwives.

Anyone can make a referral to us about a nurse or midwife. We advise that you raise your concern locally, usually with the employer, in the first instance. However, if it is not appropriate to rely on the employer for any reason, and if the nurse or midwife potentially poses a threat to patient safety, you should report the matter directly to the NMC, which will investigate your concerns.

The NMC is not here to punish nurses or midwives for isolated incidents but to make sure that they continue to meet our standards. All hearings are held in public unless there is a specific reason (usually relating to the health of the nurse or midwife) not to. In Scotland, most of the hearings are held in our Edinburgh office and the outcomes of hearings are posted on our website.

For more information see the Nursing and Midwifery Council's website: **www.nmc-uk.org**
To see a hearing phone 020 7462 5800/1 or e-mail: **observer.bookings@nmc-uk.org**
For information and advice phone 020 7637 7181

Still Game: service user involvement

Pam Thomson, Involvement Worker, Ceartas Advocacy

In 2010 a few of our service users spoke of wanting to give something back to Ceartas and ensuring that others knew how valuable advocacy could be.

We ran an event called 'Having our Say', designed to help people become more confident about getting what they want and having more control over their lives. They decided to call themselves Still Game because they had all been through so much in life, but were still here and still wanted to contribute. The group worked together for six months and, at our AGM in 2010, they gave a moving account of how advocacy had helped them and what they felt about the services they use. This gave us the passion to expand on what had been created.

The following year I was appointed as Involvement Worker and began to work alongside Still Game. A number of service users were invited to a meeting to discuss how they would like to see the group develop, and from this meeting we were able to expand Still Game, so that all service user groups have the opportunity to be represented. They meet on a monthly basis in the Ceartas offices and the group has four main aims: to have their say; to contribute to the development of Ceartas; to get involved in the organisation; and to have fun! Still Game members feel that they influence the development of the service and therefore help improve others' lives. Also they have a meaningful voice in the organisation and see their ideas being put into practice; as well as enjoying the social aspect of the group.

One of the first tasks undertaken by the group was to write their 'Journey with Ceartas', through which people reflected on how they had come to use the advocacy service and what difference it had made to them. Some of these advocacy journeys have now been digitally recorded by IRISS and can be used in advocacy presentations and training. It is also a great way of helping volunteers and new staff members understand advocacy from a service user's perspective.

We are excited about the future of Still Game and what we are yet to achieve. The feedback from the members is so positive that we have recently begun to chart their own personal development of how they have grown in confidence and their ability to speak up; also in their understanding of each other and in their ability to contribute. Still Game is now at the very heart of Ceartas and is vital to the development of the organisation.

Ceartas Advocacy, East Dunbartonshire,
www.ceartas.org.uk