Inquiry into regulation of care for older people

Scottish Independent Advocacy Alliance

Introduction

Research and policy on providing quality personalised social care frequently illustrates the importance of people having the opportunity to make their views heard about their care and of taking a rights based approach to care provision. This is true both in the day to day provision of care and also as part of the regulation of care. As a movement which safeguards people’s rights and empowers people, Independent Advocacy should play a key part in ensuring a high quality of care for older people and identifying where the quality of care is poor.

The SIAA believes that all older people should have access to Independent Advocacy. The presence of Independent Advocacy protects the most vulnerable in care, including those with dementia, profound learning disabilities and profound communication difficulties. Independent Advocacy can also help people to have their say in the care they receive and improve their quality of life. By doing so it complements the wider regulation of older people’s care services in Scotland.

The benefits of Independent Advocacy to older people in care

Independent Advocacy, directed by the SIAA principles and standards\(^1\), can help to improve care, address isolation, safeguard rights and give people a voice:

- **Independent advocacy puts the people who use it first**
  An independent advocate puts the people that they support first and is directed by the needs, interests, views and wishes of the person they support. Independent advocates enable the person they support (their advocacy partner) to become more empowered, less alone and isolated, to access information, and speak up for themselves. The advocate will also speak up on behalf of their advocacy partner where requested. Where the advocacy partner lacks capacity the independent advocate observes, questions, challenges and ensures their rights are upheld.

  If a person wishes to make a complaint regarding their care, they know that their independent advocate will be there to support them throughout the process and to ensure that their rights are safeguarded.

• **Independent advocacy is accountable**
Unlike any other provider, the advocate will only act as directed by their advocacy partner and is accountable only to their advocacy partner, the advocacy organisation and the law. Where a person lacks capacity, the advocate will act in accordance with the SIAA Non-Instructed Advocacy Guidelines (based on the SIAA Principles and Standards) and the law. Independent advocates are knowledgeable about relevant legislation, policy and rights. This means that whatever the advocate does is rights based and also based on the views of the person they support and not on any other basis, empowering the individual.

• **Independent advocacy is as free as it can be from conflicts of interest**
Independent advocacy is independent of all other service providers, structurally, financially and psychologically, which means that advocates can help a person challenge those in charge of key decisions and resources without being limited by conflicts of interest. Because independent advocacy organisations are recognised as being independent from service providers, a person is more likely to raise a concern with an advocate than with a service provider. In addition, where a person’s rights are being infringed, the independent advocate is able to engage with the service provider using their knowledge of the law and human rights to ensure the person’s rights are upheld.

• **Independent advocacy is accessible**
An independent advocate will work with an individual for as long as they need them and when they need them. In addition, independent advocacy is free to the person to ensure that is available to the widest range of people, regardless of ability or life circumstances. Independent advocacy organisations try to reach people who will benefit from independent advocacy and are proactive at engaging with care providers and disseminating information about their work. However, many face many barriers to engaging with care services as highlighted in our written evidence to the committee:

> “The SIAA is aware of incidents where independent advocates have been discouraged from supporting people in care, either through the lack of information given to service users about Independent Advocacy (despite the requirements under the National Care Standards), or where advocates have been actively blocked from engaging with service users.”

**The benefits of Independent Advocacy to the regulation of care**

In addition to tackling the barriers older people face making their views known, Independent Advocacy can directly support the work of regulators. This was highlighted in the SIAA written evidence to the Health and Sport Committee:
• Because Independent Advocacy organisations are seen as independent from service providers, individuals are sometimes more likely to approach an independent advocate for support. This may be because they wish support to challenge decisions made by service provider, because they wish support from a third party when dealing with service providers to ensure they receive all the support they are entitled to, or because they are wary of services provided by the state or others. This means that an independent advocate may be aware of any concerns around care earlier than any service provider. Independent advocates can therefore empower individuals to raise issues and help to address them prior to problems within a care service escalating to the point they require outside intervention.

• Independent advocates working with people who lack capacity will observe and question the quality of care received, ensuring that it takes full account of the person’s rights.

• Both announced and unannounced inspections can give establishments too much time to get prepared and as a result the inspection may not give a full picture of the care service on a day to day basis. Independent advocates who visit regularly and without prior notice are more likely to get a clearer picture of the quality of care and can therefore challenge service providers and ensure people’s rights are upheld.

• Independent Advocacy organisations can support service users during inspections and also provide information to inspectors regarding their experience of the care service.

• Independent advocates can comment on the care service’s compliance with the National Care Standards particularly those relating to Independent Advocacy.

How can better access to Independent Advocacy for older people be achieved?

• Resources, including training and education for and about independent advocacy, must be available at a local and national level.

• Local and national decision makers must work with local independent advocacy organisations to provide independent advocacy to all who need it, this includes access for those who may be in receipt of private care services.

• Public authorities must make sure independent advocacy that supports particular groups, are available as needed.

• Those commissioning independent advocacy must follow the guidance laid out in the SIAA document Independent Advocacy: A Guide for Commissioners.

• Decision makers must always consider the role and inclusion of independent advocacy when developing new policies, legislation and strategies.

• Service commissioners must ensure that all independent advocacy organisations in Scotland adhere to the SIAA Principles and Standards for Independent Advocacy.
Independent Advocacy is, is not...

<table>
<thead>
<tr>
<th>Independent advocacy is:</th>
<th>Independent advocacy is not:</th>
</tr>
</thead>
<tbody>
<tr>
<td>• about standing alongside people who are in danger of being pushed to the margins of society.</td>
<td>• making decisions for someone.</td>
</tr>
<tr>
<td>• about standing up for and sticking with a person or group and taking their side.</td>
<td>• mediation.</td>
</tr>
<tr>
<td>• a process of working towards natural justice.</td>
<td>• counselling.</td>
</tr>
<tr>
<td>• listening to someone and trying to understand their point of view.</td>
<td>• befriending.</td>
</tr>
<tr>
<td>• finding out what makes them feel good and valued.</td>
<td>• care and support work.</td>
</tr>
<tr>
<td>• understanding their situation and what may be stopping them from getting what they want.</td>
<td>• consultation.</td>
</tr>
<tr>
<td>• offering the person support to tell other people what they want or introducing them to others who may be able to help.</td>
<td>• telling or advising someone what you think they should do.</td>
</tr>
<tr>
<td>• helping someone to know what choices they have and what the consequences of these choices might be.</td>
<td>• solving all someone’s problems for them.</td>
</tr>
<tr>
<td>• enabling a person to have control over their life but taking up issues on their behalf if they want you to.</td>
<td>• speaking for people when they are able to express a view.</td>
</tr>
<tr>
<td></td>
<td>• filling all the gaps in someone’s life.</td>
</tr>
<tr>
<td></td>
<td>• acting in a way which benefits other people more than the person you are advocating for.</td>
</tr>
<tr>
<td></td>
<td>• agreeing with everything a person says and doing anything a person asks you to.</td>
</tr>
</tbody>
</table>

Independent Advocacy facts and figures

- The SIAA Map of Advocacy 2009-10 found that, of the 14 Scottish Health Board areas, 5 had limited or no advocacy for older people. This was particularly true for older people living in the community.
- 55% of Independent Advocacy organisations believe that their current level of funding is not sufficient to meet demand for their services.
- 32% of Independent Advocacy organisations have seen a decrease in statutory funding since April 2009.
- In the past 5 years 17% of advocacy organisations sought funding to work with older people but only 57% of these were given funding.
- 83% of advocacy organisations expect demand for their services to increase over the next financial year. Reasons include the impact of the recession and changes to public services.
There are a total of 54 Advocacy organisations throughout Scotland employing 450 paid staff and 1,200 volunteers. Advocacy Organisations endeavour to support as many people as possible despite limited resources and, in 2009-10, supported over 25,000 individuals from a range of backgrounds including older people, individuals with a mental health problem, and individuals with a learning disability.

An estimated 26,750 older people in Scotland’s care homes may have a legal right to Independent Advocacy under the Mental Health (Care and Treatment) (Scotland) Act 2003.

£10,122,280 = Total statutory spend on advocacy in Scotland 2009/2010 (equivalent to 0.1% of the total NHS Scotland spend in 2009/2010)

£1.95 = Total annual spend on advocacy per head of population in Scotland in the 2009/2010 year. This is an average figure.

Case Studies

Independent advocates challenging poor practice

“Last year my colleague and I visited a small care home which we know well. Normally when we visit the residents are sat around the living area with the TV droning on in the background with nobody really watching this. The staff, who are very young, are often having a chat and not interacting with the residents or offering any stimulation in the way of activities etc. To our surprise on this particular day, the TV was switched off and NOBODY was in the living area at all. Indeed they were all sitting in the garden wearing their best summer clothes (including sunblock and sunglasses), listening to music, interacting with the staff and sipping on cool drinks. We were astounded but it all became clear when the staff informed us that the Care Commission had turned up for their announced inspection! We managed to speak to the Care Commission officer at the time and we questioned how the residents of the care home spent their time and activities planners etc.”

- An Independent Advocate

Independent Advocacy supporting those who find it difficult to make their views heard

“Mrs X was referred to Ceartas by her GP who was concerned at the level of care provided in the care home. There had been an incident within the care home which resulted in Mrs X sustaining an injury. The funding local authority and host local authority were in dispute as to who was responsible for investigating this under Adult Support and Protection procedures. The GP felt that Mrs X was in danger of having her views marginalised and her rights undermined.

Mrs X lacked capacity and had difficulty with verbal communication so a non-instructed advocacy approach was used. The advocacy worker ensured that Mrs X had her right to access appropriate communication aids through speech and language input. The advocacy worker was then able to make use of the aids to
determine Mrs X's views around the situation. Mrs X was clear that she wished to remain in the care home, although she expressed concern at being provided care by certain members of staff following the incident. Mrs X did not want to participate in the review and case conference process. The advocacy worker was able to attend such meetings on her behalf and to express her points of view.

Independent advocacy ensured that Mrs X's views were kept at the heart of the review and decision making process; she was able to remain in the care home of her choice; steps were taken to ensure that care was provided in accordance with her wishes. Advocacy remained involved over a 12 month review period to ensure that Mrs X remained happy with the care provided. The presence of a Ceartas worker in the care home ensured that Mrs X had ongoing access to advocacy support when required for review purposes and also to ensure that she could raise concerns should they arise."

- Ceartas (an Independent Advocacy organisation in East Dunbartonshire)

Shaben Begum
Director
Scottish Independent Advocacy Alliance
23 September 2011