

in partnership with



A Review of Literature *relating to independent advocacy and survivors of stroke*



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The Scottish Independent Advocacy Alliance is a membership organisation devoted to the promotion, support and defence of independent advocacy across Scotland. The author of this review, Muriel Mowat, is Research and Quality Officer with the Scottish Independent Advocacy Alliance.



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1 Stroke in Scotland

A stroke is a brain attack caused by a blockage to the blood supply to a part of the brain. Blockages are usually caused by a clot, (ischaemic strokes), or a bleed, (haemorrhagic strokes). Blood carries essential nutrients and oxygen to the brain and without a blood supply, brain cells can be damaged or destroyed. A stroke is sudden and the effects on the body are immediate.

Some people may also experience a transient ischaemic attack (TIA), also sometimes referred to as a mini stroke. The symptoms are very similar to those of a stroke but the difference is that they go away. An episode can last for minutes or a number of hours, but not longer than 24 hours. If symptoms persist after 24 hours then it is more likely to be a stroke.

The Stroke Association, in partnership with other agencies, has been raising awareness of stroke as a medical emergency through the FAST campaign, highlighting the need to get the right diagnosis and treatment quickly within an effective time. Getting this right can make a significant difference in recovery and the level of impairment stroke survivors experience.

Of the 12,500 to 15,000 people in Scotland who have a stroke each year around a third will die, a third will recover well and a third will survive with one or more impairments. The effects can be profound. Lives can change in an instant. Many stroke survivors and their families face living a different life from the one they planned and may need support from care services in their daily living.

Stroke has been recognised by the Scottish Government as a clinical priority. High profile initiatives have been introduced to raise public awareness and tackle some of the key risk factors associated with stroke such as smoking, obesity and alcohol misuse. Stroke however, is likely to remain a major public health issue for decades to come.

Research and clinical practice in Scotland has made a significant contribution to improvements in the prevention, diagnosis and treatment of stroke world wide. Better, quicker interventions have been developed, operating to national standards and guidelines with acute care now generally provided in dedicated units by trained staff. Stroke survivors generally speak positively about their experience of acute care and the rehabilitation available both in hospital and at home in the first months following discharge.

Significant gaps in longer term supports however have been identified both by people affected by stroke and agencies involved in their care. This includes access to services such as physiotherapy and communication support after the initial rehabilitation period and community based services and groups focussed on peer support, social opportunities, employment and leading an active life.

The Stroke Association in Scotland is working on a number of initiatives aiming for a future where all stroke survivors and their carers are provided with person-centred and holistic support and care which helps to meet the full range of their needs and promotes recovery, quality of life, well being and inclusion. Stroke survivors can and do build a fulfilling life after stroke. As an effective process for initiating positive change for both individuals and communities, access to independent advocacy has been identified as an important step in achieving this future.

In recognition of the need to develop independent advocacy for stroke survivors and their families, The Scottish Government granted three years funding to the Stroke Association Scotland for this purpose. Our partnership with the Scottish Independent Advocacy Alliance was established to ensure the knowledge and skills of the advocacy movement in Scotland are available for this important development.

This literature review will inform the thinking for commissioning three advocacy pilots for people affected by stroke. Working in partnership in this way ensures that limited funding can be used most effectively, making the best of this opportunity to strengthen the voice of people affected by stroke and influence future developments in stroke care.

2 Summary

‘Independent advocacy is a crucial element in achieving social justice. It is a way to ensure that everyone matters and everyone is heard – including people who are at risk of exclusion and people who have particular difficulties in making their views known.’

Independent Advocacy – A Guide for Commissioners
Scottish Executive 2001

The Stroke Association Scotland has been working in partnership with the Scottish Independent Advocacy Alliance (SIAA) to make independent advocacy available to stroke survivors, their families and carers in Scotland. As part of this development the SIAA was commissioned by The Stroke Association to undertake this literature review.

The importance of independent advocacy for vulnerable individuals has been recognised for many years. This recognition in Scotland has led, in recent years, to the inclusion of independent advocacy in legislation. There are currently no advocacy organisations in Scotland providing advocacy specifically for stroke survivors, their families and carers and generic advocacy organisations do not appear to provide advocacy to many stroke survivors.

This review outlines current issues, debate and practice relating to independent advocacy. The paper explores issues around good practice in delivering advocacy to stroke survivors, their families and carers. It also considers different advocacy approaches and models, identifying the advocacy models most likely to be suited to stroke survivors. In addition to these topics the paper considers ways of raising awareness of advocacy amongst stroke survivors, their families and carers.

These explorations raise key issues for consideration and discussion in developing pilot advocacy schemes for those affected by stroke.

3 Introduction

3.1 Aims of the Review

This review has three aims

- To identify good advocacy practice in relation to stroke survivors
- To identify advocacy models and approaches most suited to stroke survivors
- To identify ways to raise awareness of advocacy amongst stroke survivors

3.2 Background

The Stroke Association is a UK wide charity whose mission is to prevent strokes, and reduce their effect through providing services, campaigning, education and research.

The Scottish Independent Advocacy Alliance (SIAA) is a membership organisation. The aim of the SIAA is to promote, support and defend the principles and practice of independent advocacy across Scotland. Membership of the SIAA is made up from advocacy organisations around Scotland.

The Stroke Association Scotland is working in partnership with the Scottish Independent Advocacy Alliance to make independent advocacy available to stroke survivors, their families and carers in Scotland.

Advocacy is a process of supporting and enabling people to:

- Express their views and concerns
- Access information and services
- Defend and promote their rights
- Explore choices and options

The importance of independent advocacy for vulnerable individuals has been recognised for many years.

‘Independent advocacy is a crucial element in achieving social justice. It is a way to ensure that everyone matters and everyone is heard – including people who are at risk of exclusion and people who have particular difficulties in making their views known.’

Independent Advocacy – A Guide for Commissioners
Scottish Executive 2001

‘...advocacy is generally acknowledged to play an important, perhaps a crucial role in the implementation of community care.’

A Right Result – Advocacy, Justice and Empowerment
Rick Henderson and Mike Pochin

This recognition in Scotland has led, in recent years, to the inclusion of independent advocacy in some legislation. *The Mental Health (Care and Treatment) (Scotland) Act 2003* places a duty on health boards and local authorities to ensure access to independent advocacy for those with a mental disorder. *The Adults with Incapacity (Scotland) Act 2000* and *The Adult Support and Protection (Scotland) Act 2007* place a duty on statutory bodies to consider independent advocacy. *The Adult Support and Protection Act* states that if a council decides, after making inquiries under the Act, that intervention is required, it...

‘...must have regard to the importance of the provision of appropriate services (including, in particular, independent advocacy services) to the adult concerned’

Reports from advocacy organisations suggest that there has been some negative impact from this legislation. There has been a tendency, with tightening budgets, for the provision of advocacy to be required to prioritise coverage of statutory obligations at the expense of advocacy for the wider population.

The majority of independent advocacy organisations in Scotland today provide advocacy for people with mental health problems and those with learning disabilities. There are some organisations with a wider scope, some advocate for older people, some for carers and some for adults with a community care issue. There are currently no advocacy organisations in Scotland providing advocacy specifically for stroke survivors, their families and carers.

3.3 Scope of the review

This review outlines current issues, debate and practice relating to independent advocacy. The focus is on independent advocacy for stroke survivors, their families and carers. It includes an analysis of relevant publications, research and policy in the UK with the primary focus in Scotland. It does not include any review of research into experiences of stroke survivors.

The review was conducted through a search of the SIAA library, online searches of the Edinburgh Central Library catalogue and Amazon and online searches using internet search engines. The terms for the search were 'advocacy', 'stroke', 'older people', 'communication problems/difficulties' and 'disabilities'. Many of the books and papers identified using these search terms related solely to learning disabilities and were mostly discarded unless they were felt to have a particular relevance to advocacy and communication difficulties. The reference lists of key books and papers were also checked for relevant references. Given the developments in advocacy over the past few years the review draws primarily on literature published between 1995 and 2008.

There is a range of literature on advocacy in general and for specific groups including people with mental health problems and those with learning disabilities. Within the search for this review there was no publication identified relating to advocacy for stroke survivors. There are some publications on advocacy for older people; these have been included in this review as 75% of strokes occur in people over 65 years.

Stroke survivors, their families and carers may find it difficult to access necessary services or have their voice heard. A survey into the experiences of stigma and discrimination among individuals with brain injuries, published in March 2008, was conducted by the Social Neuropsychology Research Group of the University of Exeter. The survey sample totalled 639 of which 17% were survivors of stroke. A report by Headway stated that the survey showed

'...that it is not only social prejudice that people with brain injuries have to face. The majority of the respondents (60%) claimed to have experienced a lack of post-acute health care, difficulty in obtaining benefits or poor treatment from social services.'

Following a stroke, survivors may have difficulty in communicating their experiences, thoughts and wishes. They may be unaware of what treatments and services are available and what would be most likely to be of benefit to them. They may not know where they can go to seek the information and support needed.

It is recognised that the more done to 'exercise' the brain in the early period following stroke the better the chance of major improvement.

'This is why rehabilitation efforts are so critical in the first few months after stroke – to help speed up and increase the extent of brain recovery from stroke.'

Stroke for Dummies

Access to independent advocacy could have a role to play in ensuring that individuals are fully informed and in supporting them to ensure timely access to necessary treatments and services.

A study, undertaken by the Joseph Rowntree Foundation into the advocacy needs for older people, states that life events often experienced by this group can include the consequences of

- *Retirement which can bring about a reduction of income and social networks.*
- *A decline in physical and mental health, sensory impairment and the need for health and social services.*
- *A change in housing and living arrangements.*

The study goes on to say

'The need for information, advice and advocacy services is not confined to concerns about health and social care or pensions and welfare benefits. It is also concerned with wider aspects of citizenship, including lifelong learning, leisure and employment opportunities. Similarly, such services may be necessary to support older people towards participation and preparation for later life.'

While this study was into the advocacy needs of older people it is evident that some of these experiences will be common to stroke survivors.

'The need for advocacy arises when circumstances have taken away an individual's ability to speak up freely for their interests.'

A Right Result – Advocacy, Justice and Empowerment

Rick Henderson and Mike Pochin

This could be read, specifically, as a description of the impact of stroke and the experiences of a stroke survivor.

One major impact of illness or disability, or indeed any type of disadvantage such as poverty, poor housing or social exclusion can be an imbalance of power. *In Advocacy in Healthcare*, Kevin Teasdale states that:

'power imbalance which determines the need for advocacy arises from all aspects of the experience of illness or trauma, both of which may be regarded as a form of loss of control.'

Independent advocacy seeks to redress such a power imbalance and to empower vulnerable individuals.

Throughout this document the term 'advocacy partner' is used when referring to someone who uses advocacy. Some advocacy organisations use the term 'client' or 'service user'.

4 Good Advocacy Practice in Relation to Stroke Survivors

There are many advocacy organisations throughout the UK delivering advocacy to a range of client groups using a range of advocacy models. The development of these has included development of standards and codes of practice for advocacy. The basic principles for citizen advocacy can be found in a '*Citizen Advocacy – A Powerful Partnership*', published by CAIT, the Citizen Advocacy Information and Training organisation. A code of practice for mental health advocates was published in 1994 by the UK Advocacy network (UKAN).

Despite the diverse models of advocacy in existence in Scotland today there is a broad agreement on advocacy principles and good practice in the delivery of advocacy.

Building on work produced by Advocacy 2000, the SIAA published the *Principles and Standards for Independent Advocacy (2008)* and the associated *Code of Practice*. These documents define the principles of independent advocacy and good practice for all models of advocacy for all client groups.

It is important to remember that these are the principles and standards within which Scottish independent advocacy organisations operate. The Scottish advocacy movement has developed along slightly different lines to those of England and Wales although the principles applying to English and Welsh advocacy are very similar to those of Scotland.

There are four Principles for all independent advocacy in Scotland within which organisations work. Each of the principles has associated standards. These are:

Independent advocacy puts the people who use it first

Associated standards are that independent advocacy...

- is directed by the needs, interests, views and wishes of the people who use it
- helps people to have control over their lives and to be fully involved in decisions which affect them
- tries to make sure that people's rights are protected
- values the people who use it and always treats people with dignity and respect

Independent advocacy is accountable

Associated standards are that independent advocacy...

- is accountable to the people who use it
- is accountable under the law
- is effectively managed

Independent advocacy is as free as it can be from conflicts of interest

Associated standards are that independent advocacy...

- cannot be controlled by a service provider
- and promoting independent advocacy are the only things that independent advocacy organisations do
- looks out for and minimises conflict of interest

Independent advocacy is accessible

Associated standard is

- Independent advocacy reaches out to the widest possible range of people regardless of ability or life circumstances

These principles and standards will apply to advocacy for stroke survivors, their families and carers in the same way that they apply to advocacy for anyone else.

Good practice in advocacy for stroke survivors, as in any advocacy, involves being on the side of the advocacy partner. This is included in Standard 1.1 of the *Principles and Standards*

'Independent advocacy is directed by the needs, interests, views and wishes of the people who use it.'

In *A Right Result* Rick Henderson describes advocacy as...

'the process of identifying with and representing a person's views and concerns, in order to secure enhanced rights and entitlements, undertaken by someone who has little or no conflict of interest.'

Accountability is an important aspect of good practice in any advocacy organisation. This includes accountability to the people who use advocacy and accountability under the law. In addition, advocacy organisations must be effectively managed to ensure good practice and the provision of good quality advocacy. Organisations should have a robust management structure and adhere to the principles and standards for independent advocacy.

Much of the literature stresses the importance of independence in advocacy. *A Right Result* states that *'Project and advocate independence is crucial...'*

This is reflected in Principle 3 of the *Principles and Standards for Independent Advocacy*: *'Independent advocacy is as free as it can be from conflicts of interest.'*

Some reasons for the importance of independence are laid out in *Advocacy – A Guide to Good Practice*, Scottish Health Advisory Service

'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.'

Another recurring theme in the literature is the need to involve advocacy partners in the design and planning of the advocacy service. The *Principles and Standards for Independent Advocacy* state that, in order to demonstrate that it meets the required standards, an advocacy organisation must be able to show that:

'it actively involves people who use the organisation in planning, managing, delivering and evaluating the service wherever possible.'

Advocacy partners can bring their own experiences and perspective to the planning table. Their experiences will have given them a unique understanding of barriers and difficulties which might be encountered, such an insight can be invaluable in the planning process. It is important that those who will use an advocacy organisation are consulted and involved in all stages of the design, development and management of the organisation.

In 2006 the Older People's Advocacy Alliance (OPAAL) UK produced a report as part of the OPAAL user engagement initiative. A focus group identified a number of skills and attributes they valued in an advocate.

- Listening
- Understanding. Knowledge
- Treat you as a person not as a thing
- Not be frightened to speak up for you
- Sympathetic, caring
- Have time to listen
- Patience
- Honesty
- Trust

These skills and attributes are universally valued by anyone using or seeking to use advocacy. They are echoed throughout the *Principles and Standards for Independent Advocacy*. They are important factors when considering good advocacy practice in relation to stroke survivors.

5 Advocacy Models and Approaches Most Suited to Stroke Survivors

There are a diverse range of advocacy models in Scotland today. These are detailed in the *Principles and Standards for Independent Advocacy*.

Citizen advocacy is when ordinary citizens are encouraged to become involved with a person who might need support in their communities... The relationship between the citizen advocate and their advocacy partner is on a one-to-one, long term basis.

Collective advocacy is where a group of people who are all facing a common problem get together on a formal basis to support each other over specific issues. Individual members may also support each other over specific issues.

Peer advocacy is when individuals share significant life experiences... Peer advocates use their own experiences to understand and empathise with their advocacy partner.

Professional advocacy is also known as one-to-one, individual or issue based advocacy. It is provided by both paid and unpaid advocates... They provide support on specific issues and provide information but not advice. This support can be short or long term.

All of the one-to-one advocacy models can be suitable for anyone in need of advocacy depending on their situation or issue. No one model is attached solely to one client group although citizen advocacy organisations tend mainly to work with individuals with learning disabilities. More than one model of advocacy may suit an individual at different stages in their journey.

Different models of advocacy use different combinations of approaches. The casework approach, often used in professional advocacy, aims at a particular outcome and will be wholly directed by the advocacy partner. The partnership approach, used in citizen advocacy, requires a degree of identification with the advocacy partner. The advocate and partner can work together to identify the partner's wishes and work to build the partner's confidence and self esteem.

There are various advantages to different advocacy models depending on the individual and their situation.

In **professional advocacy** the organisation is likely to use a casework approach in addition to a partnership approach. This can ensure that an advocacy organisation, with sufficient resources, can respond quickly to any referrals received. For a stroke survivor there may be a need for a quick response to a request for advocacy. For example, after stroke, on discharge from hospital, an individual may need a prompt response to help ensure access to relevant supports and services. In such a situation it may also be useful for the advocate to have specialist knowledge of stroke treatments and services to enable the advocacy partner to make informed choices on such supports and services. In this situation professional advocacy may be the most responsive model. This could be provided either by a paid worker or by a volunteer advocate.

Peer advocacy uses a partnership approach. A peer advocate can draw on their own experiences to understand and empathise with the person they are working with. Working with a peer advocate can make it easier for the advocate and advocacy partner to have an equal relationship. Some people will feel more comfortable and confident sharing their difficulties and experiences with another person who has had similar experiences. Peer advocates themselves can feel more confident and empowered in such an advocacy relationship.

The **long term advocacy** support offered by citizen advocacy or by long term volunteer advocacy can be beneficial, particularly in situations where people are experiencing social isolation. For people with severe communication difficulties such a long term relationship can be helpful in that it provides the opportunity for the advocate and advocacy partner to get to know one another well. The advocate will then be in a good position to understand the partner's views and wishes. This also provides the opportunity for the advocate to observe the partner's situation and make sure their rights are being upheld. These types of advocacy will use a partnership approach; long term volunteer advocacy may also use elements of a casework approach.

Strengths and weaknesses of these two approaches are laid out in *A Right Result* as follows:

The casework approach	The partnership approach
<p><i>Strengths</i></p> <ul style="list-style-type: none"> • Advocates probably knowledgeable and skilled in dealing with the service system • The advocacy will more or less conform to a uniform standard • Clear guidelines for user control of the advocacy process • ‘Professionalism’ gains credibility with service workers • Relatively fast response times 	<p><i>Strengths</i></p> <ul style="list-style-type: none"> • Solidarity – can transform perceptions of the partner • Allows partners’ views to develop and change • Preventive effects • Escape from the service culture • Supports the person, not simply promoting their wishes
<p><i>Weaknesses</i></p> <ul style="list-style-type: none"> • Casework is not generally preventive • Requires clear direction from the user • May be identified as ‘just another service’ by users • May not help those who want support rather than choices • Possibility of advocate ‘burnout’ 	<p><i>Weaknesses</i></p> <ul style="list-style-type: none"> • Advocates’ skill/expertise is variable • Standards may be harder to define • Varying credibility with the service system • Varying response times

Terry Simpson, Chair of the UK Advocacy Network (UKAN) in his paper on *Advocacy and the Revolution of Empowerment* argues that:

‘Everyone should have access to advocacy when they need it, and advocacy everywhere should have the same basic common principles, whatever the issue. However, while it’s true that all advocacy should have the same high standards, I think it’s also true that each individual’s requirements from advocacy will be different and need a unique and tailor made response.’

As each person’s needs and experiences will be unique to them it is likely that no one approach or model of advocacy will be the ideal for stroke survivors. Some advocacy organisations already offer a range of advocacy models and therefore have the facility to tailor make the advocacy support around the needs of the advocacy partner. At the very least it is important that stroke survivors have access to crisis or short term and to long term advocacy and that there is flexibility built in to the design.

For individuals with severe communication difficulties there may be a need for non-instructed advocacy.

‘The role of the advocate in such a situation would involve gathering as much information about the person and their past and present wishes (if appropriate) as they can... The Advocate would use their common sense, the Principles and Standards for Independent Advocacy, the Code of Practice, the Human Rights Act 1998... and any other relevant legislation or policy to help them think about enabling the person to have the best life possible.’

Principles and Standards for Independent Advocacy

In *A Right Result* non-instructed advocacy is described as:

‘taking affirmative action with or on behalf of a person who is unable to give a clear indication of their views and wishes in a specific situation. The non-instructed advocate seeks to uphold the person’s rights; ensure fair and equal treatment and access to services; and make certain that decisions are taken with due consideration for their unique preferences and perspectives.’

6 Raising Awareness of Advocacy Amongst Stroke Survivors

Principle 4 of the *Principles and Standards for Independent Advocacy* is

Independent advocacy is accessible

The associated standard is:

- Independent advocacy reaches out to the widest possible range of people regardless of ability or life circumstance

In order for advocacy to be accessed people need to know that it exists and what it is. Awareness raising should be considered at every stage of development. As well as the people the organisation is funded to provide advocacy for, the general public, statutory sector and voluntary sector staff should all be targeted in awareness raising campaigns.

Some people may already be aware of advocacy and may have used it at other times in their lives; some people will be unaware of the existence of independent advocacy, some will be aware of advocacy but may think that this is not for them. In order to ensure that all who need to can access advocacy it is necessary to spread information about it as widely as possible.

A method used by citizen advocacy organisations to ensure that they reach out to the most vulnerable in society is described in *A Right Result*:

'Some citizen advocacy schemes adopt a policy of 'assertive outreach' within service systems, paying regular visits to settings such as day centres, residential homes and hospital wards to identify potential partners and make them aware of the scheme... However, this needs to be tempered with a respect for privacy and confidentiality and an understanding that some individuals will choose not to engage with citizen advocacy schemes or with advocates at all.'

This method is likely to use a lot of what can be scarce resources for an organisation. However, if an advocate is visiting an advocacy partner in a situation where they may meet other stroke survivors, they could use this opportunity to pass on information on advocacy and the organisation to other potential partners.

Information can be disseminated through talks, seminars and workshops for user support groups, voluntary organisations which provide relevant services, social care and health staff. This can help with the development of positive relationships between the advocacy organisation and health and social care professionals.

The *Code of Practice for Independent Advocacy* suggests that, to help organisations reach out to a wide range of people, they should

‘Have joint working protocols or relationships with other organisations that work with vulnerable and hard-to-reach people in the community, and, where necessary, provide training and awareness-raising for staff of these organisations and members of the public.’

This can lead to referrals from staff in a range of services and agencies.

Information can be produced in leaflet form, taking care to ensure that these are available in accessible formats. Such information should be available in health centres, social work centres, libraries, stroke services and carers’ centres. Advocacy could also be promoted in relevant web sites and publications. The *Code of Practice for Independent Advocacy* states that organisations must:

‘Have accessible information about the organisation and independent advocacy which is made available to all parts of the community.’

Organisations could also link into events related to the client group such as local stroke clubs. Organisations could consider linking in with carers’ organisations. The Princess Royal Trust for Carers has centres throughout the UK which provides support for carers of stroke survivors. They provide an information workshop for stroke carers which aims to:

‘provide carers an insight into stroke, the signs, symptoms and support available for carers of a person who has had a stroke, and the person the carer cares for. This workshop will also give carers the opportunity to meet other carers who may be in a similar situation.’

The inclusion of advocacy into such a workshop would help in the further spread of information on advocacy.

To raise awareness of advocacy to any specific client group an organisation needs to go to where members of such a group might be. The organisation should use as many different ways of raising awareness and promoting advocacy and the advocacy organisation as possible. One of the best ways of having information spread is by word of mouth. If someone has a positive experience of advocacy they will pass that information on.

7 Conclusion and Recommendations

It is clear that the range of literature on independent advocacy is limited. No publications have been found relating specifically to independent advocacy and survivors of stroke.

Stroke survivors, their families and carers may find it difficult to access necessary services or have their voice heard. Access to independent advocacy could have a role to play in ensuring that this group are supported to make their needs, views and wishes known.

From the review of existing relevant literature, considering the possible experiences, needs and wishes of stroke survivors, there are a number of key points for consideration and discussion in the development of advocacy for this group.

There is a broad agreement, in Scotland, on advocacy principles and good practice in the delivery of advocacy. These are found in the *Principles and Standards for Independent Advocacy (2008)* and the associated *Code of Practice for Independent Advocacy*, both published by the SIAA. These principles should be at the foundation of any advocacy development for stroke survivors.

The development of advocacy should be directed by the people who may use the service. It is important, in developing advocacy for survivors of stroke, that representatives of that group are consulted and involved in all stages of the design, development and management of the organisation. Careful consideration needs to be given to how new advocacy provision can be established as independent advocacy.

An advocacy organisation must be effectively managed to ensure good practice and the provision of good quality advocacy. In any development therefore, robust management structures and clear, transparent operations and systems should be established.

It is apparent that there is no one model of advocacy most suited to survivors of stroke. In advocacy one size does not fit all, each person's needs and experiences will be unique to them. In developing advocacy for stroke survivors, as for any other group, there is a need for flexibility in response. This could be achieved either by offering a range of models in one organisation or by providing access to more than one organisation.

Raising awareness of and promoting advocacy is best achieved by using as many different methods as possible. Leaflets, posters and flyers can be useful, however, to raise awareness of advocacy to any specific client group an organisation needs to go to where members of such a group might be. If someone has a positive experience of advocacy they will pass that information on.

Recommendations

- Advocacy principles detailed in the SIAA *Principles and Standards for Independent Advocacy (2008)* should be at the foundation of any advocacy development for stroke survivors.
- Stroke survivors, their families and carers should be consulted and involved in all stages of the design, development and management of the organisation.
- The development of an advocacy organisation for stroke survivors should include the establishment of robust management structures and clear, transparent operations and systems.
- Organisations should consider how best to provide a flexible response to meet the different advocacy needs for different individuals.
- Raising awareness of and promoting advocacy is best achieved by using as many different methods as possible.

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Useful Organisations

The Stroke Association

The Stroke Association Scotland Office
Links House
15 Links Place
Edinburgh
EH6 7EZ

Tel: 0131 555 7240
Fax: 0131 555 7259
E-mail: scotland@stroke.org.uk
Web: www.stroke.org.uk

Scottish Independent Advocacy Alliance

Melrose House
69a George Street
Edinburgh
EH2 2JG

Tel: 0131 260 5380
Fax: 0131 260 5381
E-mail: enquiry@siaa.org.uk
Web: www.siaa.org.uk

Aphasia Now

www.aphasianow.org

Chest, Heart & Stroke Scotland

Head Office
65 North Castle Street
Edinburgh
EH2 3LT

Tel: 0131 225 6963
Fax: 0131 220 6313
E-mail: admin@chss.org.uk
Web: www.chss.org.uk

Different Strokes

Different Strokes Central Services
9 Canon Harnett Court
Wolverton Mill
Milton Keynes
MK12 5NF

T: 0845 130 7172

F: 01908 313501

info@differentstrokes.co.uk

www.differentstrokes.co.uk

Headway

7 King Edward Court
King Edward Street
Nottingham
NG1 1EW

Tel: 0115 9240800

Fax: 0115 958 4446

Helpline: 0808 800 2244

E-mail: helpline@headway.org.uk

Web: www.headway.org.uk

Long Term Conditions Alliance Scotland

Venlaw Building
349 Bath Street
Glasgow
G2 4AA

Tel: 0141 404 0231

Fax: 0141 246 0348

E-mail: info@lucas.org.uk

Web: www.lucas.org.uk

Scottish Disability Equality Forum

12 Enterprise House
Springkerse Business Park
Stirling
FK7 7UF

Tel: 01786 446456
Fax: 01786 450902
E-mail: general@sdef.org.uk
Web: www.sdef.org.uk

Speakability

1 Royal Street
London
SE1 7LL

Tel: 020 7261 9572
Fax: 020 7928 9542
E-mail: speakability@speakability.org.uk
Web: www.speakability.org.uk