

BOOK 3

■ practice
ISSUES
in advocacy

The Advocacy Conference 2003

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Please note that the views expressed in this
document are not necessarily the views of the
Advocacy Safeguards Agency and the Scottish
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SCOTTISH EXECUTIVE

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GOOD PRACTICE GUIDANCE ON ADVOCACY

The Advocacy Safeguards Agency and the Scottish Independent Advocacy Alliance in association with the Scottish Executive provide guidance about advocacy provision. We are planning a project to revise current guidance. Shaben Begum of SIAA and Chris Mackie of The Advocacy Project led a workshop on good practice in advocacy which highlighted some of the issues advocates, advocacy organisations and others would like guidance on. David Cameron and Jo McFarlane of ASA and Charlotte Lee from the Scottish Executive led a workshop to hear your views about what should be included in guidance.

You told us that it was important that there is guidance for:

- People who have an advocate.
- Advocates.
- Advocacy organisations.
- Commissioners.
- People who refer people to advocacy organisations.
- The wider public.

You thought that guidance should be:

- Written in plain English.
- Available in formats accessible to people who have a visual impairment or for whom English is not a first language.
- Flexible enough to allow local areas to respond according to local circumstances.
- Available on the internet.

You told us that the guidance should include:

- Practical information giving 'how to' guidance.
- More information about what independence means, practical steps for achieving it and for managing conflicts of interest.
- Acknowledgement that funding advocacy contributes to community capacity.
- Qualitative (how people feel about the advocacy support they get) as well as quantitative (how many people received advocacy) indicators.
- Practical information about how to create an accessible advocacy service.
- Information about evaluation, monitoring and review processes.

The consultation process:

- Should give people opportunities for real involvement, not just 'dotting 'i's and crossing 't's'.
- Should involve a wide range of people.
- Could involve a working group.
- Could involve an e-mail group.

A number of people felt that the fact that the Scottish Executive endorsed 'Independent Advocacy: A Guide for Commissioners' added weight to the document and the perception of advocacy. It was thought important that in writing updated guidance there is collaboration with the Scottish Executive.

What is happening regarding guidance for advocacy?

The Advocacy Safeguards Agency and Scottish Independent Advocacy Alliance are reviewing current guidance and planning a project to update it, which will involve liaising with the Scottish Executive. We expect to undertake consultations with a wide range of people later in the year.

CODE OF PRACTICE FOR ADVOCACY IN THE MENTAL HEALTH ACT 2003

The Advocacy Safeguards Agency was asked by the Scottish Executive to consult on and draft the advocacy section of the Code of Practice for the Mental Health Act 2003.

We undertook wide-ranging consultation with advocacy providers, service users, commissioners, Mental Health Officers, medical practitioners and others. During the Advocacy Conference 2003 a range of people took part in workshops and gave views on the Code of Practice. In January 2004 over 200 people took part in the consultation events ASA hosted with the Scottish Independent Advocacy Alliance to contribute to this important document.

What is the Code of Practice?

The Code of Practice will give guidance on how the provisions of the Mental Health Act 2003 should work in practice. The Code of Practice is for people with legal duties under the Act such as Mental Health Officers and hospital managers. The Scottish Executive is planning other information and guidance for other groups of people. In relation to advocacy, the Code of Practice will give guidance on issues including:

- An independent advocate's role.
- How people should be informed about their right to have an independent advocate.
- How people should be helped to access independent advocacy.
- What information an independent advocate should be able to access.

Your views on the Code of Practice

In the conference workshops on the Code of Practice people expressed strong views on what should be included. Some of the key things said in the workshops were:

- People with incapacity should be able to have an advocate and processes should be put in place to make sure this can happen.
- People should be informed about advocacy in a way they can understand.
- Advocacy should also be available for people in the community.
- That collective and citizen advocacy should be recognised.
- Front-line staff should receive training about advocacy.
- Advocates should receive training about the Mental Health Act.
- Advocacy organisations should be independent and relations with funders should reflect that.
- Funding should be available to ensure that the right to advocacy happens in practice.

What will happen next?

Following consultation, we submitted a draft Code of Practice to the Scottish Executive in February 2004. The Scottish Executive's legal and policy teams will scrutinise the draft, alongside other sections of the Code of Practice and will make any changes they think appropriate.

The section on advocacy will be put alongside the other parts of the Code of Practice for the Act and the Scottish Executive will have a public consultation on the entire Code starting in April or May 2004.

The Scottish Executive expects to publish the completed Code of Practice in October 2004.

HOW CAN I GET INVOLVED?

The Scottish Executive's public consultation is your chance to have your say about what you think should be included in the Code of Practice. If you would like to receive a copy of the consultation documents from the Scottish Executive's Mental Health Division when they become available email mentalhealthlaw@scotland.gsi.gov.uk or telephone 0131 244 2591 stating whether you would prefer a copy by post or by email.

ACCESS TO RECORDS AND DATA PROTECTION

It is clear that advocates will sometimes require access to information in order to perform their role effectively. This does not present a problem where a person is able to authorise the release of information to their advocate. When a person has incapacity or communication difficulties that prevents this, it is vitally important that advocates have the information they need to perform their safeguarding role.

Jim Charlton, Senior Officer User Empowerment, Advocacy and Complaints at Glasgow City Council led a very useful workshop to consider the impact of legislation and legal guidance on advocates' work.

This discussion encompassed a range of legislation, including:

- The Data Protection Act (1998).
- Access to Health Records Act (1990).
- Human Rights Act (1998).
- Freedom of Information (Scotland) Act (2002).
- Adults with Incapacity (Scotland) Act (2000).
- Mental Health (Care and Treatment) (Scotland) Act (2003).
- The legal concept of a 'professional duty of confidentiality'.

The key points to emerge were that:

- The Data Protection Act (1998) does not address incapacity, except where a person has a court-appointed power to act on behalf of a person with incapacity.
- Giving information to advocates is permissible under the Data Protection Act 1998 which contains a specific exemption from restrictions on disclosure where the reason for disclosure is to protect a person's vital interests.
- Glasgow City Council has obtained a legal opinion (as yet untested through courts) which covers the Adults with Incapacity Act's data principles and widens the scope for advocates to access information on behalf of people with incapacity.

HOW CAN I FIND OUT MORE?

For information on all things to do with the provision and holding of information try the Information Commissioner's website at www.informationcommissioner.gov.uk

For more information about Glasgow City Council's approach contact Jim Charlton, Senior Officer User Empowerment, Advocacy and Complaints at Glasgow City Council.

Email: Jim.Charlton@sw.glasgow.gov.uk

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COMMUNICATION DIFFICULTIES AND ADVOCACY

Everybody has communication difficulties at some time, for example, as an English speaker in a non-English speaking country or when fatigued or anxious. Some people have additional and/or permanent difficulties using the most common communication channels of verbal language and the written word. Advocates may be involved in supporting people with permanent or temporary communication difficulties. Dr Siobhan Mack led a workshop giving practical strategies for effective communication.

“No matter who we are and what abilities we have we all use the same channels of communication to express ourselves and to understand what is going on around us and other people.

1. Routines.
2. Place/location.
3. Objects.
4. Environmental sounds, smells, taste.
5. Human sounds.
6. Head and body language, eye pointing.
7. Gesture.
8. Facial expression.
9. Signing.
10. Photographs.
11. Symbols and drawings.
12. Verbal language.
13. Written word.

Helping people express themselves

Exploiting the maximum number of human communication channels can help overcome difficulties people may have in expressing themselves.

- Ask the person, the person's nearest carer or speech and language therapist to describe how the person finds it easiest to understand.
- Recognise and respond sensitively to all the expressive communication channels the person tries to use.
- Interpret and check you have it right. Ask the person's nearest carer and/or the local speech and language therapist to describe how the person finds it easy to get their message across.
- Encourage use of gestures - "Can you show me with your hands?"
- Encourage use of objects - "Can you show me what you do?" This is probably easier in a natural context like the person's home.
- Provide opportunity to use photographs - "Can you show me who you have come to see?" Photographs of health staff at reception desk could help some make appointments independently.
- Provide opportunities to use symbols - "Would this be helpful?" For example expressive board, receptionist pack, personal detail card, appointment card.

Helping people understand what you mean

Again, it is useful to use the maximum number of human communication channels.

- Ask the person, the person's nearest carer or speech and language therapist to describe how the person finds it easiest to understand.
- Use routines - scripts, order of stages in a procedure, location etc.
- Use objects - for example, lay the items you are going to use in an assessment in the order you intend to use them, demonstrate what you are going to do before you do it.
- Use head, body language, facial expression and eye point deliberately.
- Use gestures deliberately.

- Use signing. Contact a speech and language therapy department for training - see contact details below.
- Use simple language. Think about your message, use one idea per sentence, use common words and say things in the order you want person to act.
- Use photographs.
- Use symbols resources - health advice sheet, medication chart, appointment card.
- Use drawings.
- Use writing.
- Use a tape recorder.

HOW CAN I FIND OUT MORE?

For more information about what speech and language therapists do visit the Royal College of Speech and Language Therapists website at www.rcslt.org/whatdo.shtml

PHILOSOPHICAL INQUIRY

Philosophical Inquiry (PI) is a practice which allows people to form opinions about things they may not have thought about before and share their thinking with others. Morag McClurg, Service Manager at North Ayrshire Advocacy, led a fascinating workshop about PI and explained how it works. Using PI people can become more confident self-advocates and deal more positively with conflict situations. Thankfully, it requires no formal knowledge of philosophy.

People have found that PI has spin off effects in all areas of their lives. Here are some of the comments people have made about it:

“I found myself telling my friend that I’d prefer to stay in because I was tired, and not just going out with her to keep the peace.”

“My consultant nearly had to pick herself off the carpet when I told her I didn’t agree with her assessment of how I felt.”

“I sometimes wished I hadn’t come to the PI. Then things settled down and I got used to things being different. It makes me look at things in different ways. Once I’ve seen things I can’t unsee them. I want to speak up about it. Sometimes it’s hard. It’s like a windscreen has been wiped clean.”

“I heard this voice in the meeting from the other end of the table disagreeing with what was being said. I had never heard her speak before. I knew she had been in the PI group and wondered how she’d got on. I found out that afternoon. What a difference.”

HOW CAN I FIND OUT MORE?

If you want to find out more about Philosophical Inquiry contact Morag McClurg at North Ayrshire Advocacy Project. Tel: 01294 472 362.

WHAT PRICE INDEPENDENCE?

Independence means that the people and organisations who provide advocacy should, as far as possible, be free from conflicts of interest that would make it difficult for them to support the person they are advocating for. If an advocate also works for a care provider it might be difficult for them to advocate for someone who has issues about their care. For this reason, certain safeguards have been put in place which say that:

- Independent advocacy projects should not be managed by any organisation providing health and/or social care services.
- Independent advocates should not also provide health and/or social care services for any organisation in the same NHS health board area as the one the advocacy organisation serves.

This provides major challenges to advocacy providers. Sheilis Mackay, Advocacy Manager at Advocacy Highland, Pauline Kimantis, Project Manager at the Highland Carers' Project, Moira Paton, Head of Community Planning and Development at Highland NHS Board and Keir Hardie from the Highland Community Care Forum, led a thought provoking workshop to explore the issues and challenges independence raises. They are discussed here in relation to Highland, but they apply to advocacy across Scotland in both urban and rural areas.

“Context

- The majority of the 208,900 Highland population live in and around Inverness and this total figure is expected to decrease over the next ten years particularly in rural areas.
- The population is spread across a wide geographic area - 33% of the total land area in Scotland (size of Belgium) and some communities are very small and remote.
- Over 70% of the rural population in Highland work for the local authority or for health services.

Challenges

- It is often difficult to recruit volunteers; this is the case in urban areas but can be particularly challenging in rural areas.
- With over 70% of the rural population in Highland working for local authority or health services there are obvious restrictions on the number of people who can work as independent advocates. This has meant having to refuse over 12 potential volunteers in the past two months across Highland.
- In more densely populated areas like Inverness 25% of people work for local authorities or health services.
- Finding people to serve on the board of advocacy organisations can also be difficult as many who may want to do so also work providing health and/or social care services in the area.
- There is confusion about what constitutes a health and/or social care service and there needs to be clarity in this area.

The challenges described mean that in some areas organisations are struggling to provide the level of advocacy required.”

What will this mean in the future?

The Advocacy Safeguards Agency recently assisted the Scottish Executive in producing the Code of Practice for the Mental Health Act 2003 as it relates to advocacy. In that document there is clarification of independence, which is repeated above. This means that people employed to provide health and/or social care services can be advocates in a different health board area to the one they work in. It also means that people who work for a health board or local authority but do not provide health and/or social care can be advocates in any area.

These distinctions have not always been clear and we are aware that further national guidance is needed. We will be reviewing and consulting on guidance later this year and will speak to a range of people to ensure that the revised guidance is clear and meets people’s needs.

ADVOCACY AND INCAPACITY

Hilary Patrick led a very useful and informative workshop about advocating for people who lack capacity. This is a very important area of work for advocates, and one about which there is some confusion. The difficulties and dilemmas involved in working with people with incapacity were highlighted.

Key ways of working which help included:

- Finding out the person's past wishes and, as far as possible, present wishes. Talking to the person and people who know the person.
- Finding out the best way to communicate with the person. Family, carers and/or professionals such as speech and language therapists may be able to help.
- Supporting the person to participate as fully as possible in decision making.

HOW CAN I FIND OUT MORE?

The Lord Chancellor's Department in England and Wales has produced a useful booklet 'Making decisions: helping people who have difficulty deciding for themselves: A guide for social care professions'. While advocates have a different role to that of statutory social care professionals this guide contains a useful summary in Part 9 on how to establish a person's wishes when s/he lacks capacity. However, it should be remembered that while some of the practice issues may be the same, the legal context is different. It can be downloaded from www.dca.gov.uk/family/mi/index.htm

HOW CAN I FIND OUT MORE?

Dementia North based at Northumbria University has produced a very useful guide to developing dementia advocacy services called 'Hear what I say: Developing dementia advocacy services', which addresses issues relating to incapacity. Copies can be requested from Dementia North. Tel: 0191 215 6110. Email: hs.dementianorth@unn.ac.uk

For information about dementia contact the Dementia Services Development Centre, Stirling University. Tel: 01786 467740.

www.stir.ac.uk

BARRIERS TO ACCESSIBLE INCLUSIVE ADVOCACY FOR PEOPLE WHO NEED IT

What gets in the way?

People told us that they wanted to discuss the barriers for them as service users, advocacy providers or advocacy commissioners. This is what you told us.

Finding out about advocacy

- It's difficult to find out about advocacy because there is not much information about it and some of it is hard to understand.

Getting an advocate

- In some places there is no advocacy and in others there are long waiting lists.
- When you need one most is when it is most difficult to ask for one. For example, when on medication in hospital you may lose confidence due to medication, the situation or environment.
- If you don't have a voice or if you have a different voice (eg touch talker) it is harder to get listened to.
- It can be more difficult to access advocacy in rural areas where people may feel more isolated.
- Sometimes you don't fit the box because you live in the 'wrong' place or don't have the 'right problem'.

Other people's views on advocacy

- Some people don't want advocacy - staff, families, psychologists, councils can sometimes get in the way.
- There seems to be a lack of political will to make it happen.

Challenges

- Difficult to reach the most vulnerable people, as they tend not to come forward.
- Advocacy organisations are often operating at capacity and ability to meet need is constrained by funding.
- Sometimes there is unrealistic costing of services which means that there are not enough resources for core administrative functions.
- Difficult to attract and retain volunteers.

Money and planning for advocacy

- There isn't enough advocacy available for people.
- It is sometimes a problem convincing planners to allocate money to advocacy.
- There are often rigid structures and no ring-fenced money for advocacy. We need local agreements and more flexibility about how money is spent.
- Development of advocacy can be piecemeal.

Rural issues

- Distinct needs of rural areas aren't taken into account. The spread of some areas means that it can be difficult for people to access advocacy locally, transport links are often poor and expensive to use. It can be especially difficult to find a pool of volunteers in rural areas. People living in small communities in rural areas may prefer someone from outside to be their advocate.

How do we make sure that people who need it get accessible inclusive advocacy

What needs to happen?

This is what you told us.

We are looking at everything that came out of the conference and will be taking some of the ideas and suggestions forward in new guidance for advocacy that will be out for consultation in 2004/5.

Raise awareness

- We need to work together to get the message across so that more people know what advocacy is and how it can help people.
- We need to attract volunteers from a range of backgrounds and be creative about getting people involved.

Champion advocacy

- Joint planning groups need to look at advocacy and take ownership of what is happening in their areas.

A Safe place

- The environment in which advocates and their partners meet should be safe both physically and emotionally for both people.
- Advocacy partners need to know that information shared will be kept confidential (and the boundaries of confidentiality) and that the advocate will act on their behalf and share their views, not make decisions for them.
- Advocates need to know that they are free to express the views of their partner.

Specialist services and services for everyone

- Need advocacy organisations for everyone so that people don't 'fall through the net'.
- Specialist and generic providers need to work together.
- A 'one stop shop' generic advocacy service with a number of specialist workers could provide a possible model especially for smaller local authority areas.

Reaching vulnerable people

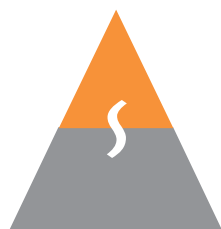
- Need to ensure that funding for advocacy projects covers development activity so that workers can get out into communities more proactively and reach more vulnerable people.

Training for health and social care staff

- Advocacy needs to have a higher profile on the curriculum for health and social care staff.

Is it working?

- There needs to be ways to measure the impact of advocacy on people's lives. These need to take account of how people feel about the advocacy support they get, we should focus on quality, not just quantity.



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