

BOOK 2

making  
advocacy

more

accessible

The Advocacy Conference 2003

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MAKING ADVOCACY MORE ACCESSIBLE • 2

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# ADVOCACY FOR EVERYONE?

## Selma Rahman Children in Scotland

Selma applauded the work that is done by advocates and advocacy organisations to support and empower people.

She challenged us all to consider:

- How accessible is advocacy and to whom?
- What are we doing to promote diversity and inclusion?
- Which sections of society are missing out on advocacy and what can we do about it?

“The question that you pose in the title of this conference ‘Advocacy for Everyone?’ is a brave one. This led me to pose the question: How accessible is advocacy and to whom?”

In addressing this question, it should be recognised that the role of advocacy within our society has been, and sometimes still is, marginalised and overlooked, treated with grudging recognition and treated as a poor relation within that poor relation: the voluntary sector.

But we know that from the individual to the family, from the neighbour to the neighbourhood and way way beyond, advocacy is vital in so many aspects of our daily lives.

Advocates are involved in the day-to-day experiences of people’s lives, there are not many pieces of legislation or policy that do not impact on the people advocates support or the work advocates do.

The establishment of the Scottish Parliament has led to a much more people-driven, people-oriented government, which in the main serves the people. Advocacy has become increasingly important politically as a key mechanism for social justice. As part of the formalisation of community planning

structures, strategies to promote social inclusion, and now, the Mental Health Act 2003, independent advocacy is being recognised in statute and legislation. The value of, need for, the role of, and the right to, independent advocacy are finally beginning to be acknowledged.

There remain challenges though.

## Diversity

The most recent Scottish Household Survey and the 2001 Census show that the diversity of Scotland cannot be denied. But how self-evident is that diversity in advocacy...even here today?

Turn to the person next to you...take a moment, introduce yourself...exchange your name and where you're from. What did you see? What did you hear? If you shook hands, what did you feel? What did you experience? The likelihood is that putting aside gender, you saw, heard, touched, experienced...a mirror image of yourself. Where is the diversity of Scotland, within the field of advocacy here, now, at this conference, amongst you, the body and infrastructure of advocacy within Scotland?

The need for advocacy for children and young people is now very apparent in light of recent

policies on anti-social behaviour and additional support for learning: are you reaching them and engaging with them?

Older people may also be particularly vulnerable; is your organisation working with them? Funding is often an issue in working with both younger and/or older people because funding streams sometimes specify age limits of 18-65. We need to change this.

Are you working effectively with disabled people? Are you supporting people from ethnic minorities, if not, what can your organisation do to improve this? Which sections of society are currently 'missing' or under-represented?

Is your advocacy organisation accessible? Is there a need to be accessible in evenings, or at weekends?

We need to plan both nationally and locally to make plans and take action.

## It is everyone's responsibility

All of us, no matter what the level of our work, have a responsibility to make sure advocacy is inclusive, diverse and accessible.

You must be applauded for having the maturity, confidence and willingness to ask key

questions about accessibility. The barriers that exist are not insurmountable. Embracing diversity to ensure inclusivity and accessibility comes with its challenges, but not overwhelming challenges. There is in advocacy a sound understanding of inclusivity, an ethos of working with and for people and there is leadership. Most importantly, there is commitment to ongoing improvement.

There is one debate about inclusivity and accessibility I want to touch on. I am referring to specialisms, are they requirements, or are they a 'get out clause'? We have all heard statements like "oh that's not for us...refer them to that organisation who deal with 'that kind of person', it's not our responsibility". Yes, we know we need specialists and specialisms within advocacy, they bring expertise and added value but they do not absolve any of us of our responsibilities to provide support to people.

I know that with the professionalism, expertise and commitment to inclusion that is the bedrock of the advocacy movement we will continue to respond to the challenge of ensuring advocacy for all, within a diverse and vibrant Scotland."

# PEOPLE WITH DEMENTIA

Melanie Lewin  
City of  
Edinburgh  
Council

Melanie identified the importance of advocacy for people with dementia, many of whom have no-one to support them.

“At the moment there is a lack of advocacy organisations for people with dementia in Scotland. People with dementia will have a right to independent advocacy, once the Mental Health (Care and Treatment) (Scotland) Act 2003 comes into force in April 2005 and this will present challenges to advocacy commissioners and providers.

There are 60,000 people in Scotland with dementia. While most people with dementia are over 65, it also affects 17,000 younger people in Scotland.

Why do people with dementia need advocacy?

- People with dementia are among the most disadvantaged in society - and often subject to ageism.
- The illness can profoundly affect a person's ability to speak for themselves - when they do speak up, their views can be dismissed.
- People with dementia often come to rely more and more on others for help.
- The impact of the illness leads to increased vulnerability to exploitation and abuse.
- The needs of other family members can take priority.

## Challenges

There can be challenges in providing advocacy for people with dementia, such as:

- Issues of consent.
  - He/she may not remember the advocate, or appointments.
  - He/she may not understand what an advocate is.
  - Advocates need special knowledge and training in the use of communication techniques.
  - People with dementia are often dependent on others for referral to an advocacy organisation.
  - People with dementia need more time and there is often a lack of resources with a focus on numbers of people seen rather than quality of advocacy.
  - Advocacy organisations can find it difficult to recruit volunteers or citizen advocates.
- In Edinburgh we are beginning to develop advocacy services specifically for people with dementia.”

## HOW CAN I FIND OUT MORE?

Dementia North Centre and Northumbria University have produced a very useful guide to developing dementia advocacy services called 'Hear What I Say'. Copies can be requested from Dementia North  
Tel: 0191 215 6110  
Email: [hs.dementianorth@unn.ac.uk](mailto:hs.dementianorth@unn.ac.uk)

To find out about advocacy services in Scotland contact ASA for a copy of 2003-2004 Map of Independent Advocacy in Scotland.

## The future

- Things are changing. Owing to the fact that people receive a diagnosis at an earlier stage, people with dementia are beginning to challenge the stigma of dementia.
- People with dementia are beginning to find a collective voice through the development of collective advocacy.

# CHILDREN AND YOUNG PEOPLE

David Cameron  
and Jo  
McFarlane  
Advocacy  
Safeguards  
Agency

Jo and David gave a summary of key findings from their national research study exploring what children and young people want from advocacy.

“Advocacy for children is important because children are vulnerable because of their lack of social, legal and economic status and rights.

In spite of this:

- Only 3% of total statutory funding for advocacy in 2003/4 is spent on children and young people.
- There are only six advocacy organisations for children and young people in Scotland.
- Many advocacy organisations do not accept referrals from people under the age of 18, or in some cases 16, because funding arrangements specify that they work with people over these ages.

To enable the development of advocacy for children and young people the research sought to find out from young people from marginalised groups across Scotland:

- Whether they would use an advocate and in what situations they would find advocacy helpful.
- What kind of advocacy service, and models of advocacy, they would find helpful.
- Potential barriers to them using advocacy and ways of overcoming these.

Young people did identify a need for advocacy in situations where they are particularly vulnerable.



“Most of my life it has felt like no one was listening to me.”

“An advocate could defend young people’s rights.”

Young people are more concerned about an advocate being a good listener, patient, trustworthy, loyal and effective, than whether he/she is independent.

Young people are not familiar with the word ‘advocacy’ and find it off-putting. Young people did not think it would be helpful to split advocacy provision for particular groups of children/young people. They wanted an integrated service that treats them respectfully, taking account of their individual needs.”

David and Jo will be working with commissioners in each locality to address the issue of children and young people’s advocacy as a priority.

## HOW CAN I FIND OUT MORE?

If you are interested in having an advocate, or in becoming one, or just want to find out more, contact the Advocacy Safeguards Agency Advocacy Safeguards Agency for a copy of the Map of Independent Advocacy in Scotland which contains contact details for advocacy organisations in Scotland.

For a copy of the Advocacy for Children and Young People report, or more information on the research contact Jo McFarlane or David Cameron at the Advocacy Safeguards Agency.

# DEAF OR HARD OF HEARING PEOPLE

Lilian Lawson and  
Alison Anne  
Brownlie  
Scottish Council on  
Deafness and  
Visible Voices

Alison is the Senior Community Advocacy Officer for Visible Voices, an advocacy project for deaf and hard of hearing people who use British Sign Language, and Lilian is the Director of the Scottish Council on Deafness. They talked about some of the challenges we need to address to ensure that advocacy for deaf, deafblind and hard of hearing people meets their needs.

“We need to listen to what people want and provide advocacy that works. Mainstream services should accept support from deaf and deafblind organisations to learn about the access issues.

A sign language interpreter is generally used to work with deaf sign language users in mainstream advocacy but this is not the best option because deaf sign language users want one-to-one advocacy too. More deaf sign language users should be advocates so advocacy organisations need to employ more people with British Sign Language skills. For deafened and hard of hearing people, other types of communication support may be necessary to facilitate communication between them and their advocates. Such communication support includes lipspeaking, speech-to-text transcription and inductive loop systems.

There is a need for mainstream organisations to ensure they have the knowledge that would help to bridge the gaps. One way to do this is through sharing knowledge and encouraging employee swaps so that deaf and deafblind advocates learn about mental health or young people’s issues and vice versa.

It is important to provide more training opportunities for deaf and deafblind people

and raise awareness of advocacy so that more deaf and deafblind people become advocates and deaf children need to learn about advocacy earlier.

Mainstream services may not be able to empathise with deaf and deafblind people but some deaf and deafblind people do not want to work exclusively with deaf and deafblind organisations.

In short, deaf and deafblind people should have a choice about whether to have a deaf, deafblind or hearing advocate.

It is important that an assessment is made of what is available now so that we know what the extent of the problem is and can work towards resolving it. The 1994 conference highlighted the need for advocacy - but little has changed! Advocacy for deaf and deafblind people needs to be funded. Some civil servants have questioned the need, they should listen to us - it's very important."

## HOW CAN I FIND OUT MORE?

### Contacts:

Scottish Council on Deafness

Textphone: 0141 248 2477

Tel: 0141 248 2474

Fax: 0141 248 2479

Email: [admin@scod.org.uk](mailto:admin@scod.org.uk)

[www.scod.org.uk](http://www.scod.org.uk)

### Visible Voices

Textphone: 0141 559 5364

Fax: 0141 559 5908

Email: [scotland@bda.org.uk](mailto:scotland@bda.org.uk)

[www.bda.org.uk](http://www.bda.org.uk)

# PEOPLE FROM MINORITY ETHNIC COMMUNITIES

Eleanor McKnight, Policy Project Manager at the National Resource Centre for Ethnic Minority Health and Charlotte Lee from the Scottish Executive led a stimulating workshop about how advocates can work more effectively with individuals from a minority ethnic background and at the same time challenge discriminatory practice.

“There are now policy and legal requirements around cultural competence and race equality, which public bodies, including health organisations, need to fulfil; advocacy services have a clear role to play in helping to meet these requirements.

Advocates can also play a crucial role in supporting people. A psychiatrist related the following experience:

“I saw a woman who had been all round the hospital departments. She had severe headaches and she had had every test under the sun. Finally, the doctors decided it must be psychosomatic so they sent her to me. I was the first doctor who’d arranged for a health advocate to speak to her directly instead of her husband interpreting. It turned out the headaches were caused by her husband hitting her. She hadn’t been able to tell anyone before.”

Clearly, people from a minority ethnic background can benefit from advocacy but only if the following barriers to access are overcome:

- Different people’s interpretation/understanding of advocacy as a concept.
- Lack of outreach and publication of the services available.

- Language and cultural barriers.
- Previous negative experiences of 'service' provision.
- Impact of discrimination and racism ignored.
- Lack of confidence in approaching minority ethnic organisations and staff.
- Hesitancy to change and recognise that one service does not necessarily suit all.

During the workshops participants identified a number of things that would help to overcome some of the barriers people from minority ethnic communities may face in accessing advocacy:

- Individual and organisational commitment to make advocacy more accessible.
- Resources in community languages.
- Recruit and support bilingual staff, volunteers and management committee members.
- Develop outreach strategies - for example work with further education colleges.
- Make links with minority ethnic organisations.
- Training - formal and informal, and including the use of trainers from minority ethnic communities.
- Have ground rules for collective advocacy groups that embrace anti-discriminatory practice."

## HOW CAN I FIND OUT MORE?

National Resource Centre for Ethnic Minority Health

Tel: 0141 300 1037

Minority Ethnic Health Inclusion Project

Tel: 0131 537 7538

Minority Ethnic Learning Disability Initiative

Tel: 0131 623 2200

Commission for Racial Equality

Tel: 0131 524 2000

[www.cre.gov.uk/scotland/](http://www.cre.gov.uk/scotland/)

Fair For All

[www.scotland.gov.uk/library3/society/ffas-00.asp](http://www.scotland.gov.uk/library3/society/ffas-00.asp)

Race Relations Amendment Act 2000

[www.homeoffice.gov.uk/comrace/race/raceact/](http://www.homeoffice.gov.uk/comrace/race/raceact/)

# SEXUALITY

Not very much is known about people with learning disabilities who feel attracted to people of the same sex. Partners in Advocacy (Edinburgh) has been funded by Communities Scotland to do a study in Edinburgh into the provision of advocacy for people with learning disabilities who have, or wish to have, same-sex relationships or are questioning their sexuality.

Advocacy is a good way to help people get a fair deal and have the kind of life they want. Advocacy can help people who feel attracted to people of the same sex but they need to know how to help and the Partners in Advocacy research could do this. Julianne Dickey, Director of Partners in Advocacy is coordinating the research. She will be working with community researchers to find out what sort of problems people have and how advocates can help.

## HOW CAN I GET INVOLVED?

Contact Julianne Dickey at Partners in Advocacy

Tel: 0131 478 7723

Email: [admin@partnersinadvocacy.org.uk](mailto:admin@partnersinadvocacy.org.uk)

# PEOPLE WITH PHYSICAL DISABILITIES

Margaret Petrie and Chris Jones led a workshop about independent advocacy for people with physical disability, having recently completed a needs assessment for the City of Edinburgh Council's Social Work Department.

## HOW CAN I FIND OUT MORE?

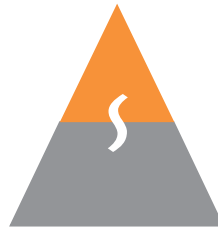
If you would like a copy of Independent Advocacy: Independent Lives, a report on the independent advocacy needs of people with physical disabilities in Edinburgh by Chris Jones and Margaret Petrie contact: Kitty Mason, Planning and Commissioning Officer, Social Work Headquarters, Shrubhill House, 7 Shrub Place, Edinburgh EH7 4PD  
Email: [kitty.mason@edinburgh.gov.uk](mailto:kitty.mason@edinburgh.gov.uk)

“Our research found that there is a real need for independent advocacy for disabled people. As one participant said in exasperation “I’d be happy to have anyone”. Disabled people who participated in the study said that they still experienced discrimination and marginalisation in the way that their needs were overlooked on a day-to-day basis. Independent advocacy, therefore, was considered to be a valuable, and sometimes essential, resource in promoting disabled people’s right to make independent choices about how they live.

Information services for disabled people, social workers and other organisations noted that the demand for advocacy outstrips what is available.

The study also found that people with a disability were often unaware about advocacy so awareness raising would be useful for disabled people, organisations of and for disabled people, and health and social service staff working with disabled people.

Having access to a combination of models of advocacy was felt to be important so that people have a choice of having a citizen advocate, a professional advocate or of joining a collective advocacy group.”



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