



**LOUD
AND
CLEAR**

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LOUD AND CLEAR

THE ADVOCACY NEEDS OF DEAF PEOPLE

Report of an event organised by the Advocacy Safeguards Agency in collaboration with the Scottish Council on Deafness, the British Deaf Association, the National Deaf Children's Society, Deaf Children's Society for East of Scotland and AdvoCard.

29 May 2003

FOREWORD

The Advocacy Safeguards Agency (ASA) is funded by the Scottish Executive Health Department to make sure that good quality independent advocacy is available to everyone in Scotland who needs it. Since our work began in May of 2002, we have been made aware time and again of the additional barriers faced by some groups of people in accessing what independent advocacy there already exists. We are also very committed to making sure that, as much as possible, new developments in independent advocacy are able to meet the diversity of need that exists. How this can be achieved, will be the main focus of The Advocacy Conference which we are organising in association with the Scottish Independent Advocacy Alliance (SIAA) in October of this year.

For this reason, we were particularly pleased when we were approached by Lilian Lawson of the Scottish Council on Deafness (SCOD) and Alison Anne Brownlie of the British Deaf Association (Scotland) (BDA) to do some work on the independent advocacy needs of Deaf and hard of hearing people.

I want to thank Lilian and Alison for their assistance and support in organising this event, as well as Carolyn Finlayson of the Deaf Children's Society for East of Scotland (DCSES) and Bryan Davies of AdvoCard. We sought the involvement of AdvoCard because we happened to know that one of their staff, Janette McDougall, had been learning British Sign Language (BSL) and that they were looking at how to make their volunteer training more accessible. We are also grateful to the contributions made on the day by Paul McCusker from NDCS Scotland and Irene Fortune a Development Worker from Fife, as well as David Cameron and Jo McFarlane of ASA.

Of course, there would have been no event without the Deaf and hard of hearing people from all over Scotland who came to share their experiences and ideas with us.

I was personally extremely impressed by the commitment of all those who took part, it helped to remind me once more that despite the things which divide our lives and experience, we all have more in common than we sometimes realise. Events like this help us all to understand each other and our particular needs better. I learned a great deal, I think we all did, and I would just like to say that this was one of the most positive events in which it has been my pleasure to take part.

Adrienne Sinclair Chalmers

**Director
Advocacy Safeguards Agency**

1.0 INTRODUCTION

1.1 PURPOSE OF THE DAY

- To be clear about what independent advocacy is
- To describe work which is already happening in the Deaf community
- To look at how independent advocacy services work
- To look at how other groups of people have used independent advocacy
- To work out how existing independent advocacy services could be more inclusive of Deaf and hard of hearing people
- To look at the need for specific independent advocacy services for Deaf and hard of hearing people
- To look at how Deaf and hard of hearing people can themselves become independent advocates.

Because of the wide scope of the day, we decided to concentrate in the workshops on independent advocacy for individuals.

1.2 PROGRAMME

THE MORNING SESSION

- Welcome and scene setting from chair
- What is independent advocacy?
- Community advocacy
- Advocacy for school leavers
- Providing independent individual advocacy

THE AFTERNOON SESSION

- Personal experiences of using advocacy
- More personal perspectives

WORKSHOPS

- How the workshops were organised
 - Interpreters
 - Deaf advocates and hearing advocates
 - Everybody's business
 - Information
 - Networking
 - Priorities
 - Choice
 - Training
 - Needs Assessment

CLOSE

MAIN RECOMMENDATIONS

1.3 WHO TOOK PART

As well as the people who are listed in the programme, Carolyn Finlayson from DCSES volunteered to be Adrienne's sighted assistant for the day. Janette McDougall from AdvoCard got the best chance she has had in a long time to practice her BSL (and proved she was much more fluent than she gave herself credit for!).

There were Deaf and hard of hearing people from as far away as Caithness.

2.0 THE MORNING SESSION

2.1 WELCOME AND SCENE SETTING FROM CHAIR

Lilian introduced the day. She said that by the end of the day everyone would have a clearer understanding of what advocacy is and how it differs from other types of support. Importantly she reminded us that this was not just about Deaf and hard of hearing people using independent advocacy, but about how they could become independent advocates themselves.

2.2 WHAT IS INDEPENDENT ADVOCACY?

Adrienne spoke about the two different types of independent advocacy collective advocacy where people with a common cause get together to have their say; and individual advocacy where you have someone to stick up for what you think and want. An individual advocate can be paid or unpaid and short or long term. Some people just want to have the support of an advocate to deal with a particular situation. Other people want an advocate who will be around long term.

She explained why it was so important that advocacy of any sort was independent because the whole point about advocacy is that someone is there for *you and nobody else*. Advocacy is not about giving people advice or putting words in their mouths.

She then explained what ASA did and why. ASA works to make good quality independent advocacy available to everyone in Scotland who needs it. They help health boards and local authorities work out what

independent advocacy services need to be in place, carry out evaluations of existing services and make sure that all relevant policies and laws mention the importance of advocacy. ASA recently helped to make sure that the new Mental Health Act had in it the right of access to independent advocacy. This was very important because although it is for people with mental health difficulties, learning disabilities and people with personality disorders, the right to access advocacy will, of course, affect Deaf and hard of hearing people who fall within these categories under the Act, and the people who pay for and provide independent advocacy services will have to prepare for this.

However, we have to face the fact that it isn't always going to be possible to set up a special service for Deaf and hard of hearing people. Such services might be possible in areas where there are more people, but even then, Deaf and hard of hearing people should be able to choose to use, for example, an independent advocacy service which specialises in advocacy for children.

2.3 COMMUNITY ADVOCACY

Alison told us about the work she and her colleague Caroline Thomson do as Community Advocacy Officers with the BDA.

The BDA has a community advocacy project called Visible Voices, and as this is expanding, they have more time for individual advocacy, but this is still limited because there are only the two of them to cover the whole of Scotland.

The BDA's Visible Voices was started in the mid 1990s to improve communication between Deaf people and the local government. The BDA works through community advocacy and consults widely on issues that affect Deaf people. They are independent because they don't work or get paid for by the councils. They work with and for Deaf people. They help Deaf people set up their own groups and help them to get their voices heard. They support people to get what they want, whether or not they agree with them.

What is advocacy?

Alison described two main roles for advocacy:

- To protect vulnerable people
- To give them a stronger voice.

Why is community advocacy important?

It gives people more control over their own lives and not only helps them to access services but can also help make those services better. They help the Deaf community in decision-making and in lobbying for changes so that their needs can be met. Deaf people have not had this before.

What does community advocacy mean?

She stressed that advocacy was about working with or alongside people and not for them. She said that if she and Caroline just worked *for* them they wouldn't be doing their job.

What makes a good quality advocacy service?

She said that their independence was a sign of their quality. They are only answerable to Deaf people and their wishes. They do not agree or disagree with any of the groups of people they work with. For example, one group could favour sensory centres, so they would support them in achieving that. Another may not want a sensory centre, and they would help them too.

What do Community Advocacy Officers provide?

They give information, seek funding, provide training and presentations and empower people. There are a variety of needs, all similar, some may require more training than others. Some have members who can help other forums.

To date, there are no other specialist providers of advocacy services for Deaf people. Most mainstream advocacy services are there for Deaf people to use, but are not fully equipped.

2.4 ADVOCACY FOR SCHOOL LEAVERS

Paul McCusker, Project Officer for the NDCS Scotland

NDCS works with young people and their families to help them make informed choices about their lives. Some of the most difficult times for people are when they are going to a new school or leaving school. Because of this, they are keen that independent advocacy be included in the new Education Bill.

The transition to university or employment can be a big jump out of the comfort zone and into the real world. A CD Rom was produced of a collection of stories of Deaf children all over Scotland. One girl in Shetland had never met any other Deaf children until she left school. Some children on the CD commented that they had no sense of self-

identity when they left school. The NDCS help children to make this transition.

It is difficult to collect evidence about what Deaf children do when they leave school. Lots of Deaf children have to face multiple barriers, for example Deaf children are 25% more likely to have mental health problems than their hearing peers and this figure has doubled in the past ten years. A lot of Deaf people have low self-confidence and having a befriender can help. It is important that advocates and befrienders play a role. It is also crucial that the advocates and befrienders are Deaf. We have a team of ten staff, some use BSL, some English and some a combination of the two. We provide whatever support is needed.

Our befriending project works all over Glasgow and is aimed at 11-18 year olds. We try to reach 122 people around Glasgow over 80% are in mainstream schools. Our service is regular and can provide 8 hours support per person, per month. We pair people up with a befriender and try to match children with someone who remembers what its like going through the transition. We also support the parents through the process.

2.5 PROVIDING INDEPENDENT INDIVIDUAL ADVOCACY

Bryan Davies is the Co-ordinator of AdvoCard which provides independent individual advocacy for people who use mental health services.

AdvoCard was set up by mental health service users in 1994 and is still user-led. For a while it was only able to work in North East Edinburgh, but now covers the whole city.

AdvoCard has three key principles:

- Independence - If they have no conflicts of interest, particularly with service providers, they are completely independent and don't shy away from challenging the people who fund them
- User-led - The organisation was set up by mental health service users and their constitution says that at least half the management committee must be service users. They also encourage service users to become volunteer advocates
- Community-based - This makes us easier to find out about and access.

Volunteers who have successfully completed a ten-week training course carry out all the advocacy work. The training covers the principles of advocacy and how to focus on the needs and beliefs of the person they are working with.

AdvoCard has two different types of advocates. Some people do long-term work with just one person and others join a bank of short-term advocates. The staff team supports both kinds of advocates continuously.

Of AdvoCard's 60 volunteers, about a third do long term work and two thirds short term work.

Why do people need an advocate?

The list of things advocates help people with are endless. It might be because they don't have the information or the confidence to negotiate a different treatment with a doctor. It might be about accessing services. It might be about rent arrears.

What do advocates do?

We are not experts at AdvoCard, we simply empower people to access information and have their voices heard. What we don't do is offer counselling or befriending, they are very different.

How can I get an advocate?

It is easy to access AdvoCard, you just ring us or come in off the street. There is no appointment / referral system, we keep barriers to our service to a minimum. If a person isn't able to come in on their own we encourage them to bring a relative. We would then match them with a volunteer who would work with that person to resolve the issue.

We don't lead in any way, we always take the lead from the mental health service user. We support people in different ways sometimes it could be giving someone advice before a meeting and other times we might speak on someone's behalf. It all depends on what the person wants.

How can we be more accessible?

AdvoCard is looking to become as effective as possible for everyone. Under the new Mental Health Act anyone with a "mental disorder" has a right of access to independent advocacy. We have to ensure we are effective. We work with anyone over the age of 18 who is a mental health service user. We want to ensure our service is accessible to people who are Deaf or hard of hearing and we also want to attract Deaf and hard of hearing people as volunteers. We are focussing on that at the moment, which is partly why I am here today.

At the moment, it isn't too good, we have one member of staff - Janette McDougall – who is trained to level 2 sign language (BSL), and we are also installing a loop in our main training room, that is imminent. I am hoping to get information on how to make us more accessible and to make our training and volunteer support more accessible. I am looking forward to the workshops.

How do you publicise your service?

We use a number of leaflets and posters, we have three different types - one aimed at potential mental health service users, one aimed at workers like support workers/GPs etc and one aimed at potential volunteers. We target those in specific areas in Edinburgh. I also do presentations like this on a regular basis. Thank you.

Lilian - We now have two people doing short presentations, Jo McFarlane, from the Advocacy Safeguards Agency is going to talk about her experiences of independent advocacy and Irene Fortune from Fife Deaf Action about how Fife Deaf Action members have benefited from community advocacy.

3.0 THE AFTERNOON SESSION

3.1 PERSONAL EXPERIENCES OF USING ADVOCACY

Jo McFarlane, Development Worker with the Advocacy Safeguards Agency told us about the difference advocacy has made to her life. We have used as many of Jo's own words here as possible because they are so strong.

“The reason I started this job is because I use mental health services and have done for 14 years, during which time I got involved in advocacy, using individual and collective advocacy services.

I first became mentally unwell when I was 17 and still at school, and spent a number of years in a hospital in my twenties. It was a horrible time. The practice of treating people was quite intrusive, and certainly most of my experiences as a detained patient were awful. I was given copious amounts of drugs, injections etcetera, with horrendous side effects, including difficulty walking and speaking and having saliva coming down my chin, which made it difficult to be socially accepted. I was also given ECT and was locked in wards, and forcibly injected if I got upset or angry. This may not be everyone's experience, but it did happen to me.

When I was 25 I was discharged and moved into supported accommodation. The doctor said I would not be fit to be in a relationship, to study, or to work, or anything. The prognosis was very negative, my self-esteem was low and I had lost most of my friends.

In hospital there was a Patients' Council, run by patients themselves supported by workers - collective advocacy. The worker from the Patients' Council saw me and said I would benefit from going to a meeting and talking about my experiences. I went and was very soon hooked. It changed my life. It's not self-help, it was about bringing together collective experiences and drawing conclusions.

I was elected to chair the group and became involved in influencing managers in the hospital resulting in significant improvements in things like the quality of the food and staff attitudes. The Patients' Council led me to getting involved in other things. I became involved with other people who shared similar experiences. I got angry about the way people are treated, not just in mental health, but across the board people who are treated badly.

Before I became involved in collective advocacy, I had internalised the negative labels and felt that as a sick person with a label, it was my own fault. I thought I was always going to be ill and the negative prognosis didn't help. I ended up thinking it was all to do with me and didn't see the wider picture. Collective advocacy helped me on a practical level and raised my self-esteem and self-confidence, it helped me to start challenging bad practice and getting involved to improve things. Following the prognosis my doctor gave me, I used to think I wouldn't be able to take paid work, but I did courses and voluntary work and counselling courses. People said I couldn't do that, but I did not listen because of the confidence I gained from the advocacy organisations I got involved with.

When I came out of hospital in 1995 I was still unwell for a while. We all fluctuate in various ways and I had to go back into hospital a few times. Last year was the last time, and I started to use individual advocacy services to challenge the system. I was again detained at that time, and my doctor told me to end my relationship with my partner because people with my illness should not be in a relationship and other very negative things. I contacted AdvoCard, and spoke to Bryan. It was terrific. The advocate came and sat down with me as an independent person who I could confide in and talk about the diagnosis and the treatment, and about being let out even just for an evening. She didn't offer advice, she

listened and we planned a course of action to influence the doctors and then go on to meet my objectives and get out of hospital. I decided not to challenge the powerful doctors but that meeting with the advocate helped me to make an informed decision and set out my objectives. At the end of the meeting I decided my priority was to get out of hospital and back to my partner, and college, and that was really helpful.

I think people who are denied a voice need support. I may be quite confident in speaking, others in hospital are not because of the power balance - when you have such a label people have prejudices about you, and think you can't have any influence over your life. But you can. Advocacy helped me to see this. It also empowered me in a much more long-term way. Last year I applied and got my first job. I am really happy now.

The independent nature of the advocacy I experienced was important. They don't try to influence you, but are there solely to help you get your voice heard.

I just want to say, that although I have been talking about mental health problems, there are issues for the Deaf community in which parallels can be drawn. Individual advocacy is important to both groups because they are denied a voice and do not get taken seriously or are ignored and denied access to full participation in the community.

Collective advocacy politicises these issues and helps us to self identify, and work out our own solutions. For example I understand that the Deaf community identify as a linguistic minority, and not as a disabled group as many others might see them. In the same way mental health service users are given labels, or diagnoses and treated accordingly with little account taken of our views of what is in our best interests. One way of reclaiming power is through collective advocacy.

Both Deaf people and Mental Health service users can progress their agendas and get them taken on board, rather than being the passive recipients of other peoples' judgements. Collective advocacy helps us to gain self-confidence and learn skills, which, having come from minority groups who are discriminated against, both Deaf people and Mental Health service users, might not have had the opportunities to do before. The skills and confidence we acquire can help us to be more included in society.

I hope that gave you a bit of a flavour of a users experience of advocacy."

There were a number of comments from the floor.

People commented that Jo's experience shows how powerful advocacy can be and congratulated her on her achievements. There was agreement that there were parallels between Jo's experiences and those of some Deaf people.

3.2 MORE PERSONAL PERSPECTIVES

Irene Fortune, is a Development Worker and is from Fife.

"I am a Development Worker for Deaf people. I teach children aged from 3 to 15 years level one and two sign language. I worked in social work for about 16 years. I then got my current job as a Development Worker. My boss was bringing in people from round the Deaf world and we set up a Deaf advisory group that met three or four times a year but we just used to end up repeating ourselves. Then I got a new boss who said no it can't be us who does this, it has to be you Irene.

I got a bit worried about what I was going to do, but I asked someone and he said that we needed to sort out a constitution and set up a committee and officers.

It was hard to do this ourselves. Then about 3 months ago Alison and Caroline from BDA got involved and helped us set ourselves up. Every month we meet and it is very successful. We have a constitution now, but it feels like the 6 years before that were wasted.

We have now become Fife Deaf Action, and we meet monthly, it is much better now, but without Alison and Caroline's help we couldn't have done it."

Lilian thanked Irene for offering to speak at extremely short notice. She said that it showed how a Community Advocacy Officer could turn things around.

There were some comments from the floor.

A delegate thanked Alison for setting up Inverness and Highland Visible Voices and noted it as really positive and invited more Deaf people to get involved.

4.0 WORKSHOPS

4.1 HOW THE WORKSHOPS WERE ORGANISED

For the workshops we split into two groups. We looked at:

- What people wanted from independent advocacy
- What the difficulties and barriers were when trying to access independent advocacy
- How these difficulties could be overcome

We did this in two parts, one in the morning and one in the afternoon.

The discussion in the two groups was very wide-ranging. It seemed to make sense to pull people's comments together around common themes.

1 Interpreters

Both of the groups talked through the issue of advocacy and interpreters. It is worth saying at the start that everyone was absolutely clear that advocacy and interpretation were two entirely different things. An interpreter should not be used as an advocate and an advocate should not be used as an interpreter.

There were similar issues for people who did not have English as a first language. The Ethnic Minority Advocacy Service in Glasgow, for example, has advocates who speak many community languages, but they do not act as interpreters and will always try to get a specialist interpreter along to help if they are going with someone to a meeting.

2 Deaf advocates and hearing advocates

Everyone felt that there should be more Deaf and hard of hearing people acting as advocates. Hearing people could make good advocates for Deaf people, but they would need to have some understanding of the issues for Deaf people. If they were going to be able to communicate with Deaf people without an interpreter present, they would have to have reached level 3 at BSL. It wasn't just about whether or not hearing people could sign. They had to be good at using plain language.

3 Everybody's business

There was a recognition that the Deaf community is quite small and it's easy for everyone to get to know everyone else's business. People living in rural areas have similar feelings.

An advantage of using a mainstream service away from the places that lots of Deaf people go to all the time would be that it would be easier to do it discreetly. For this reason people thought it would be good if they could go to see an advocate at an anonymous place like a volunteer centre or a Citizens Advice Bureau.

Although interpreters treat any information they come across as part of their job as confidential, people said they could feel awkward if they were in an upsetting situation and then the next day the same interpreter turned up at another meeting they were at. If some advocates were BSL users, this would be easier.

Independent Advocacy services need to look at how they can work to recruit, train and support Deaf advocates. They should also try to find advocates who want to learn BSL and get the funds to put them through the courses. They should also have procedures for what to do if a Deaf or hard of hearing person approaches them for help, such as when and how one would arrange access to interpretation services.

4 Information

A lot of Deaf people don't know about independent advocacy. They don't know what it is, they don't know how it can help them or where they can get it.

There was a lot of discussion about the sorts of things which would help:

First of all, information about advocacy which Deaf and hard of hearing people could access should be made available to people who work with Deaf and hard of hearing people. For example, people felt that it would be very useful if interpreters knew about advocacy so they could suggest that people could make use of it. GPs were mentioned specifically. It seemed to people that if a GP thought a Deaf person didn't understand what they were being told about treatment, diagnosis and so on they should encourage the Deaf person to get an advocate.

Mainstream independent advocacy services need to remember that printed material like leaflets may not be much good to Deaf people. They

should look at how they get information across to Deaf and hard of hearing people in their area.

There are various methods of getting a message across to the Deaf community. Ceefax and specialist TV programmes, for example.

5 Networking

An important part of Deaf and hard of hearing people being included in independent advocacy services will be by making sure that good networking takes place between Deaf and hard of hearing groups and services, and independent advocacy services and the people who fund them. This will help the Deaf community to learn more about independent advocacy and where to get it. It will help independent advocacy services to understand more about the needs of Deaf people and be “Deaf friendly.” It will help funders to understand the level of need in the Deaf community for independent advocacy and how best to meet it.

6 Priorities

Several people stressed the importance of independent advocacy being available to people when they are young and when they are old. We had already said that starting a new school or finishing school and going into college or their first job can be even more stressful for Deaf people than for hearing people. Also, like other young people, sometimes their parents get plenty of opportunity to say what they want, but the child doesn't.

It was also felt that a group whose needs were not being met at the moment were people who were hard of hearing.

7 Choice

People were very interested in having a choice of what type of independent advocacy they used. There was a keenness to be able to access mainstream independent advocacy services, but where possible people wanted to have the choice of a service just for Deaf people.

8 Training

- Mainstream independent advocacy services need to have Deaf awareness training
- Mainstream independent advocacy services need to train advocates in communicating with Deaf and hard of hearing people
- Deaf and hard of hearing children need to be taught at school what independent advocacy is and what it can do for them

- Deaf and hard of hearing adults need to be able to access training about what independent advocacy is and how they can become independent advocates
- Interpreters, teachers and service providers need to be trained in what independent advocacy is and where people can get it.

9 Needs Assessment

A piece of work needs to be done to assess the level of need across Scotland for independent advocacy for Deaf and hard of hearing people and the best means of delivering it identified.

BDA Community Advocacy Officers could be invaluable in this work.

5.0 CLOSE

Adrienne thanked everybody who was involved in the day. She referred specially to Jo's contribution after lunch, which was an extremely moving personal account of what independent advocacy had meant to her. She also reminded everybody of the young girl in Shetland whom Paul had talked about who grew up thinking that she was the only Deaf person in the world. If advocacy could do anything it was stopping that sort of thing happening.

She said that what had been talked about would be written up in a report and presented at The Advocacy Conference in October and she encouraged the people there to come to it. There would be all sorts of people who use, provide and fund independent advocacy there. They would be encouraged to think how they could do better by Deaf and hard of hearing people.

If we had learned one thing during the course of the day, it was that we all have difficulties, we just experience them in different ways but together we can do something about it.

Adrienne (the author of this report) finished by having an enthusiastic, if imperfect bash at the BSL sign for advocacy.

Lilian thanked ASA for putting on the day and everybody who took part and wished all a safe journey home.

6.0 MAIN RECOMMENDATIONS

- Needs assessment needs to be done for the Deaf and hard of hearing population
- At least one professional individual advocacy officer who has BSL skills to work all over Scotland as a resource to any specialist and mainstream independent advocacy services
- Funding needs to be sought for training hearing advocates on how to communicate with Deaf and hard of hearing people
- Mainstream independent advocacy services should have a procedure for working with Deaf and hard of hearing people
- Where the size of the local Deaf community will support it, health boards and local authorities should look at the possibility of making separate specialist provision for Deaf and hard of hearing people.