

Commitment by the European Deafblind Network to future action specifically for persons with severe disabilities or with complex needs

Lucy Drescher, 5 June 2008

I work for Sense in the UK. Sense is a member of the European Deafblind Network (EDbN), a network of deafblind people, families and professionals across Europe supporting one another and lobbying on the rights of deafblind people at a European level.

People who are born deafblind as a result of premature birth, birth trauma, rubella during pregnancy or other causes often also have additional disabilities, including learning and physical disabilities, leading to problems with communication, mobility and access to information.

The European Deafblind Network has two main aims in its campaigning work. The first is to raise awareness of deafblindness and the second is to make sure that the needs of deafblind people are included in the European policy making process.

In 2004 EDbN members successfully lobbied MEPs to sign a Written Declaration on the rights of deafblind people, which led to the adoption of this Written Declaration by the European Parliament. Since then individuals and organisations have been using this Written Declaration to try and persuade their governments to recognise deafblindness as a unique disability. This is important because deafblind people are so often pushed into existing deaf, blind or learning disability services that are inappropriate, particularly if they have additional disabilities. What deafblind people need is services provided by people who have specialist knowledge. In the UK we have guidance for local authorities on the services they should be providing for deafblind children and adults. We are still campaigning for implementation of this guidance, but we do at least have this recognition. At the moment there is campaigning going on in Austria, Italy and Spain to get recognition of deafblindness by their governments.

EDbN is trying to input into the European policy making process wherever possible to try and ensure that the needs of people with deafblindness are included. We feel that it is particularly important for groups of disabled people that are formed to comment on policy development at international, European and/or national level include parents/carers/advocates so that the needs of people with complex dependency needs who are unable to speak for themselves are represented.

We intend to publicise the report and recommendations amongst members of EDbN and encourage them to use the report when lobbying on issues facing people with complex dependency needs at both national and European levels.

At a national level EDbN members will continue to campaign on the specific issues within the report such as the need for early intervention, specialist

knowledge of the communication, mobility and information needs of deafblind people with complex dependency needs and specialist services.