Draft Quality Standards for Adult Hearing Rehabilitation Services

CONSULTATION RESPONSE

DEAFBLIND SCOTLAND

Deafblind Scotland is a membership charity with the aim of helping deafblind people to live as rightful members of their own communities and to encourage and support contact between deafblind people and sighted hearing people. We liaise with health and social services providers to make appropriate assistance available to deafblind people in Scotland, and we work in partnership with statutory and other agencies to improve the quality of life for deafblind people.

Across Scotland, Deafblind Scotland estimate that there are up to 5000 people who will have severe visual and auditory impairment that results in difficulties with accessing information, communication and mobility. Most deafblind people will be over 60 and will have become deafblind as part of the ageing process. The majority of our members and service users will be hearing-aid users.

The European Parliament Declaration of Rights of Deafblind people recognises deafblindness as a distinct disability separate from hearing or sight impairment. This distinct group cannot automatically benefit from mainstream services, or services for people who are either deaf or blind. As membership organisation working with this uniquely disadvantaged group of people, and in the context of the above declaration, Deafblind Scotland welcomes the opportunity to respond to the Draft Quality Standards for Scottish Hearing Rehabilitation Services.

1. Defining and implementing outcome-based quality standards that are founded on efficiency and convenience for patients is vital. Many of our members have significant difficulty in accessing health services because of mobility and communication issues, so simpler, easier access is fundamental to a patient-focused service.
2. The provision of easily understood information for deafblind people in the format they find most useful is the key to involving people in their assessment and treatment. Correspondence from health practitioners and clinics often come in standard forms, such as appointment cards, that are difficult or impossible for our members to read. The responsibility for providing information in the most appropriate format rests with the agency or service producing the correspondence, and every effort must be made by the agency or service to ascertain the most effective format through discussion with the patient.
3. Standard 2 also describes, in Section 2a.vii, how "all staff with direct patient contact receives deaf-awareness and communication training as part of their induction". This training must include training on deafblindness-awareness. Deaf-awareness training itself will not be sufficient to ensure staff can work with deafblind people, and the

exclusion of deafblind-awareness training from this induction process introduces a potentially discriminatory aspect to the standards.

4. In addition, to the welcome support for the use of all available technology to support the communication process, the standards should also reflect that environmental features, such as appropriate lighting, are very important for people who have addition visual impairments, if they are to be able to make use of their remaining sight.
5. The Individual Management Plan is obviously a pivotal element in the development of the standards. In particular, "The goal of the service is to alleviate listeners' activity limitations rather than manage hearing losses". The IMP clearly would be required to accommodate, additional personal, medical or social considerations that impact on the patient's life. This would obviously include the effects of dual sensory impairment. It is the responsibility of Hearing Rehabilitation and Audiology services to establish how they would do this and this requires to be clearly described in the Standards.
6. The use of a self-report questionnaire in the process of drawing up an IMP may be problematic for deafblind people, many of whom will require addition support to do so. Deafblind Scotland strongly urges the adoption, by all Scottish Health Boards, of the NHS Management Executive Letter guidance, MEL 1998 (4), –

"*All Health Boards and NHS Trusts should be aware of their responsibilities in this area (recognising the deafblind people are the most disadvantaged of its user groups) and have appropriate arrangements in place to ensure that all deafblind people are afforded the services of a Guide/Communicator when they attend hospital or GP surgery".*

7. The availability of professionally qualified Guide/Communicators for dual sensory impaired people attending medical appointments, including Audiology consultations, is vital if a patient-focused process, like the configuring of an Individual Management Plan, is not to founder through communication and information difficulties.
8. Deafblind Scotland welcomes the potential within the IMP of referral to, or signposting of, other agencies and services. Deafblind Scotland has 700 members, and our membership service provides a range of support, information and news, which may be of benefit to individuals identified as being dual sensory impaired.

In conclusion, whilst significant efforts are being made to develop patient-focused audiology services, without the inclusion of very specific support, communication and information measures, it is unlikely that deafblind people will benefit from the patient-focused nature of the Standards. We therefore advocate that:

- Guide/Communicators are available for all deafblind people attending Audiology clinics
- Information and correspondence is available in a range of formats that reflect deafblind people's requirements

- Deafblind – awareness training is mandatory during staff induction, in addition to deaf-awareness training.

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