

# the **Bold View**

Low Vision Services Implementation Group Newsletter

## The Low Vision Services Implementation Group

After producing the Low Vision Report in 1999 the Low Vision Services Consensus Group formed an Implementation Group to monitor progress. The group guides the work of the Implementation Officer and meets three times a year and examines the activities of local LVSCs.

Mary Guest is an original member of the Consensus Group, and has been successful in ensuring that the needs of deaf children are considered. Mary has also helped to produce the report: 'Vision care for deaf children and young people'. Guidelines for professionals working with all deaf children, a joint publication by the National Deaf Children's Society and Sense the National Deafblind and Rubella Association.

'Vision care for deaf children...' identifies the importance of an ophthalmic examination following confirmation of deafness and that good vision assessment of a deaf child will require extra preparation and an understanding of the specific needs, especially communication needs, of the child. The document also describes the roles that audiology and ophthalmology working together can play to ensure that deaf children receive appropriate vision care.

A key part in the report describes the ophthalmic care pathway for the deaf child from birth, from diagnosis of deafness through to transfer to adult care. It suggests that the care pathway should differ from that of the hearing child in the frequency of checks made and the type of tests used eg. an electroretinogram (ERG) for children aged 7 to 9 with sensorineural hearing loss where the cause of deafness is unknown.

Free copies can be obtained from either Sense or the National Deaf Children's Society. Contact: Mary Guest, Sense, 11-13 Clifton Terrace, London N4 3SR. Tel: 0207 272 7774, Fax: 0207 272 3862, Text: 0207 272 9648. [Enquiries@sense.org.uk](mailto:Enquiries@sense.org.uk), [www.sense.org.uk/visioncare](http://www.sense.org.uk/visioncare).

**Inside: Committee activity • Eye Clinic links • Specialist groups**

**More is more**

The great news is that there are now 66 LVSCs. Recent additions include Walsall in the West Midlands and Kingston and Richmond in London. There appears to be some sort of ripple effect emerging as demonstrated by the recent growth in numbers around Manchester and in London boroughs. Certainly many of the recent calls enquiring about the establishment of a LVSC have been inspired to do so by a colleague from a bordering area.

In the last edition there was mention of the regional workshops that had been planned. These have proved to be very successful and many attendees have expressed interest in continuing to meet on a regular basis.

A regional meeting is to be organised in the South East and it is hoped that well established groups will have the chance to meet with agencies that are seeking to set up new committees. We are especially keen to encourage service users to take part and will be working with the LVSCs to see what practical assistance can be offered to ease attendance.

Another exciting development is the creation of a support network for people that chair the committees. We are starting with a series of 'pilot' meetings – the first taking place in Birmingham bringing together committee leaders from as far apart as Worcester and Stoke on Trent.

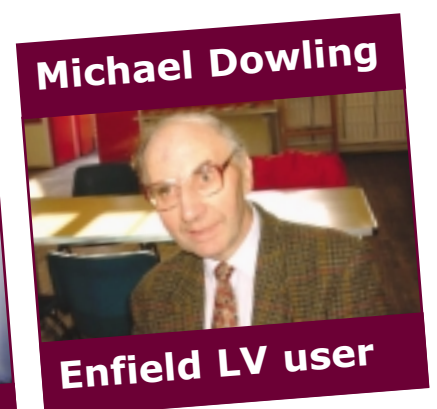
If you belong to a LVSC outside the South or Midlands region and would like assistance in setting up a regional group please contact Mary Bairstow on 0121 665 4248 or at [mary.bairstow@nib.org.uk](mailto:mary.bairstow@nib.org.uk).

**LVSC Committee activity**

- ✓ Torbay Committee has ensured that all the LV services in local hospitals have access to rehabilitation workers based in the clinics.
- ✓ Weston Super Mare LVSC has developed a questionnaire and shared this with local LVSCs. A clearer picture should emerge of the needs of users in the South West.
- ✓ Gateshead welcomed in January its first service user of its brand new Low Vision service. This is one of the first new services funded as an Eye Care Services Pilot.
- ✓ Walsall service users were surprised to discover that one of the

standards for Low Vision Services covers emotional support. They are now keen to develop a set of local recommendations.

- ✓ Enfield and Haringey are facilitating a meeting for local optometrists to explain the registration process and the new forms (LVI, RVI and CVI).



## Hospital Information Services – Eye Clinic Liaison Officers (ECLOs) and others

This article continues our explanation of various terms used in LV Services.

Many LVSC members will be familiar with the section in the LV Report that outlines the role of the committee. One responsibility is that of ensuring eye departments identify ‘an individual as a point of contact for people who are diagnosed’. Many local voluntary organisations have, for a number of years, provided this service. These hospital information services are well established and well received in many areas.

Another approach is to appoint an ECLO or Eye Clinic Liaison Officer – although the terms are often used to describe the service rather than the individual person.

The common feature is that ECLOs are based within an eye clinic and offer people attending the clinic support and information. One notable aspect of their role is to make contact with a person/and their carers at the time when they receive a diagnosis. The impact of receiving this diagnosis is evident through reports from LVSCs detailing personal experiences.

Michael Dowling, at a recent LVSC meeting at Enfield and Haringey, explained how upsetting it was to hear his ophthalmologist use the word ‘registered’. “The idea that he wanted to put me on a list felt like I was

receiving a sentence” – he told the Committee. He added that it had taken him several months to recover from this interview in the eye clinic.

As well as offering emotional support an ECLO or an equivalent service can provide information and advice and form a link between busy health and social care professionals.

This role can be difficult, as it requires a person to be skilled in dealing with individuals at a potentially traumatic time. Anyone working in this role needs to be an accomplished team member. An ECLO or member of a hospital information service has to be able to appreciate the ways that eye care professionals work whilst ensuring the users needs are met.

People fulfilling these roles come from many different backgrounds and may be paid professionals or volunteers. To clarify and support the role of these sorts of services a Hospital Information Group was created. It has representatives from a variety of agencies and meets four times a year to examine the provision of hospital information services in the UK. The group is used to share good practice and disseminate information. Issues discussed that affect service provision include quality standards, resources and the training needs of volunteers.

For more information contact either: Martin Sissons, at Action for Blind People at [martin\\_s@afbp.org](mailto:martin_s@afbp.org) or Fran McSweeney, at RNIB at [Fran.McSweeney@rnib.org.uk](mailto:Fran.McSweeney@rnib.org.uk).

**Specialist groups provision**

As the Implementation Project progresses it has become evident that there is a need to give special direction to the LVSCs about the needs of specific groups. As mentioned in the last edition of 'Bold View' there are now two sub-groups of the LV Services Implementation Group. One group is looking at the needs of children and young people and the other at issues for people with learning disabilities. Immediately both groups have identified the need for further guidance and both have been charged to produce additional information for LVSCs.

These documents or 'Charters' should very soon be available in the New Year and will be accompanied by another document giving guidance on emotional support services.

Another area that requires particular attention is that of services for people from minority ethnic groups. In Tower Hamlets and Birmingham there are two particular projects that have recognised the importance of LVSCs and are seeking to inform the LVSC in aspects of good practice.

In Birmingham a research project undertaken by the Thomas Pocklington Trust looked at the information needs of people from various backgrounds. Local and national agencies were involved in a series of workshops. Action for Blind People, RNIB, Birmingham Focus and Birmingham Social Services worked together to produce local information. Mary Bairstow, the national Implementation Officer, visited a variety of community organisations including two local Temples and a local African-Caribbean Day Centre. A valuable part of the project was the use of volunteer optometrists who, with the help of interpreters, explained various common eye conditions.

The need for all the local agencies to build on this work has been noted. As a result of this the LVSC has been asked to consider minority ethnic issues and representatives who took part in the research are to attend the Birmingham LVSC.



**Mary visits a**

**local temple**

'Bold View' is a quarterly newsletter written and edited by Mary Bairstow for the LV SIG. It is distributed to people and organisations with an interest in low vision. The aim is to inform people of the progress of LV Implementation. Articles about specific projects are reviewed by local contacts. Comments and contributions are welcome. Copy date for inclusion in the Summer issue is June 3rd 2005.



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