Review of Community Eyecare Services in Scotland

FINAL REPORT

December 2006
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(Annexes A and B are attached to the report, all other annexes are available at www.scotland.gov.uk/eyecarereview)
List of website links in the report:

- Annex C
- Summary of the responses to the public consultation
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Access to the report

Copies of this report are available in Braille, in large print and on tape. Electronic copies are also available on request. The report has been produced in summary form, with references to more detailed material in annexes and on the Scottish Executive website www.scotland.gov.uk/eyecarerreview. If readers have difficulty accessing the website, the information can be provided in alternative formats by contacting Mike Cairns on 0131 244 3572.

Terminology

There are many ways to describe sight problems. The formal certification and registration system uses two categories: “blind” and “partially sighted”. When the system was changed in England recently, “blind” was replaced by “seriously sight impaired” and “partially sighted” changed to “sight impaired”. This report recommends that similar changes be made in Scotland, as part of the review of certification and registration. It is difficult to reach a consensus on terminology. Some people find the word “blind” unacceptable, others prefer its simplicity. In this report neither the old or the new registration terms will be used. More general terms, like “visually impaired”, “people who have a serious sight problem” and “sight loss” will be used to describe a spectrum from complete absence of vision to a partial impairment that affects the individual’s ability to function.
Foreword by Lewis Macdonald MSP, Deputy Minister for Health and Community Care

I am very pleased to introduce the report of the Review of Community Eyecare Services in Scotland. The review was commissioned in March 2004. The review group was asked to consider the full range of community services available to visually impaired people in Scotland, and to make recommendations for modernising the system to ensure that it meets individual needs.

A great deal of work has gone into the review and I would like to take this opportunity to thank all of the contributors. One of the key messages of the review is that visually impaired individuals receive a better service if the helping organisations work closely together. This message is at the heart of the government’s approach to improving health and social care for everyone. The principle of partnership working is evident both in the way in which the review has been conducted and in the conclusions that have been reached. There have been contributions from a wide range of service users, from professionals and from voluntary organisations.

Some changes are already underway. In particular, the new eye examination, introduced on 1 April this year, is opening up opportunities for optometrists to work more closely with the hospital eye service and to become more involved in local eyecare networks. The review has set out examples of good practice, both for adults and for children, that can be applied across Scotland.

The response to the public consultation has demonstrated both an appetite for change and a broad consensus on the way forward. The focus on building local services designed to meet local needs is consistent with the future direction of health and social care in Scotland. The review sets out an agenda for action to improve the quality of life for all visually impaired people in Scotland. It is a pleasure to welcome such a positive and timely document.

Lewis Macdonald
Deputy Minister for Health and Community Care
EXECUTIVE SUMMARY AND KEY RECOMMENDATIONS

The review of community eyecare services in Scotland brings together a series of initiatives, all of which are intended to improve the quality and consistency of support offered to visually impaired people. Loss of sight can create a wide range of problems for the individual and no single agency or profession can deal with all of them. Within the wider context of current government policy on reforming health and social work, the review brings together all of the agencies involved in providing services to visually impaired adults and children. The aim is to create a local, integrated network of support which is readily available to individuals who are either born with serious sight problems or who lose their sight later in life.

Different approaches have been taken to the various aspects of the review. Some changes have already been made, like the new arrangements for optometry that were introduced in April 2006. Other areas of activity have been the subject of detailed scrutiny by interagency working groups, which have made proposals for change. The review has set out to be open and inclusive in its approach, involving both service users and service providers. The response to the public consultation shows that there is a broad consensus, both about the need to modernise community eyecare services and the general direction of change.

The review has produced some detailed recommendations. The emphasis is on organising services around the patient by integrating support at a local level. This principle is applied to services for adults and for children, but the report makes a strong case for recognising the particular needs of visually impaired children and organising support that is tailored to individual needs. There are examples of good practice which can be used as a guide. The report recommends changes to the certification and registration system, which is the formal link between health and social work. It is important that services are designed to include those who have additional disabilities or impairments. The report sets out some common standards, based on good practice, which should guide the planning and delivery of services. Finally, the report lists the practical steps that need to be taken to achieve lasting changes to the quality and consistency of support for all visually impaired people in Scotland.
Introduction to the review
INTRODUCTION TO THE REVIEW

Purpose of the review

In March 2004 the Deputy Minister for Health and Community Care announced a review of eyecare services in Scotland. A group was established to review arrangements for the provision of eyecare services in the community in Scotland, and to provide recommendations on good practice for effective models of care. The aim is to encourage the development of integrated eyecare services to ensure patients receive a good quality and efficient service, in a convenient setting without undue wait.

The review has been timely in bringing together some outstanding tasks, like the review of certification and registration, with some exciting new developments in eyecare, like the expanding role of the community optometrist in Scotland. The original remit of the review group was expanded to include an examination of particular needs of visually impaired children. The study of interagency work in three localities builds on earlier work (“Sensing Progress” Scottish Office 1998) and on several community-based co-management schemes like the Glasgow Integrated Eyecare Service (GIES), the Lothian Optometry Cataract Initiative (LOCI) and the Grampian Glaucoma scheme. (Details are given in annex J at www.scotland.gov.uk/eyecarereview). In parallel, the Centre for Change and Innovation (CCI) has developed patient pathways for a range of eye conditions.

The strength of the review is that it deals with all of these important issues in a coordinated way, within the policy framework set by “Delivering for Health” and “Changing Lives” (Scottish Executive 2005 and 2006). At a more detailed level, there are links between the review of community eyecare services and other work in progress within the Executive, like the Rehabilitation Framework and the Equipment and Adaptations Advisory group. The recommendations of the review provide the basis for a strategy that includes all eyecare professionals and carers. The aim is to make optimal use of professional expertise in a setting that is acceptable to visually impaired people.
Background

Traditionally, within the NHS, the first point of contact for most patients with an eye condition is their General Practitioner. This has limited the level of care being provided for many people as GPs often do not have the necessary equipment, expertise or experience to adequately diagnose and manage more complex eye conditions. Hospital eye departments have been used to manage the latter with the diagnosis and management of ophthalmic conditions being undertaken by ophthalmologists. Demands on the hospital eye service and an acknowledgement that some patients currently attending hospital eye departments could be dealt with in the community has led to a need to review how eyecare services are designed and provided. The recent changes to General Ophthalmic Services offers GPs and others the opportunity to make greater use of optometrists, and so free up both GP appointments and reduce pressure on the hospital eye service.

Crucial to this is the need for cost-effective care, avoiding the unnecessary duplication of tasks. It is acknowledged that better use could be made of a number of professionals (optometrists, orthoptists and ophthalmic nurses as well as rehabilitation and social workers) to deliver care in settings more appropriate and convenient to the patient. Given their numbers, and geographical spread, optometrists are a key group of clinicians in the primary care sector. Although they have been underused in the past, there is a growing number of informal co-management schemes with local GPs and NHS Boards across the country. Such schemes have demonstrated the need for a level two optometric service (as described in annex G at www.scotland.gov.uk/eyecarereview). Optometrists have been granted supplementary prescribing rights, with independent prescribing rights to follow. This will enhance their capability to manage anterior segment disease and chronic eye diseases such as glaucoma, in the community and in hospital settings.

The current review of community eyecare services is not the first attempt to modernise the way in which visually impaired people are supported in Scotland. In 1998, the report “Sensing Progress” (Scottish Office 1998) was published. That report covered similar ground to the current review. The only recommendation from “Sensing Progress” that was fully implemented was the establishment of a working group to examine the certification and registration of blind and partially sighted people in Scotland. The working group reported in 2002 and the Scottish Executive Health Department commissioned further work on the subject. The conclusions of the earlier working groups have been taken into account in the current review of community eyecare services. The review has also benefited from the opportunity to observe the changes made to the certification and registration system in England in 2004.
In addition to the review of eyecare services, the Executive has also been working towards improvements in the broader context of sensory impairment. A Sensory Impairment Action Plan is being prepared covering visual impairment, hearing impairment and dual sensory loss. The plan examines issues that are common to individuals across the spectrum of sensory impairment.

The lack of progress on the recommendations from the two earlier reports has been a source of frustration for many visually impaired people in Scotland. It had been widely believed that visual impairment services were in need of reform when the work began on “Sensing Progress”. Despite earlier disappointments there has been a great deal of commitment to the work of the current review and there are high expectations that the review of community eyecare services will lead to positive change.

Format of the report

The report gives a brief description of a series of linked initiatives that have taken place in the past two years, all of which contribute to the recommendations for change. A more detailed account can be found at www.scotland.gov.uk/eyecarereview. There has been widespread consultation on all of the work that has been done. A summary of the responses to the consultation can be found at www.scotland.gov.uk/eyecarereview.

Context of the community eyecare review

A number of drivers for change can be identified: demographics, workforce, changing technology and waiting times.

The changing demographics within the Scottish population will lead to an increase in the older population and a corresponding rise in the incidence of serious sight problems, by as much as 40% to 80%. Maintaining optimal vision in older people is essential if they are to remain independent. Timely access to glaucoma diagnosis and treatment, cataract removal and support with low vision aids are all part of a holistic approach to keeping older people safely at home and avoiding hospital admissions for falls and other accidents.

There are shortages in several key professional groups that will undermine service redesign unless they are remedied. (Details are given in annex D at www.scotland.gov.uk/eyecarereview.) The shortage of orthoptists and trained rehabilitation workers already create problems in the delivery of integrated community services, both for adults and for children.
Changing technology can enhance communication between partners in the eyecare network and communication with patients. In both primary and secondary care there has been increased use of digital imaging and automated computerised vision field screening. Other less elaborate techniques have also contributed to the quality of communication between eyecare professionals. Improved communication with patients has been one of the features of the study of interagency work in the three localities (as described at www.scotland.gov.uk/eyecarereview).

Waiting times can be reduced by closer cooperation between optometrists and ophthalmologists and the updated optometry arrangements offer opportunities to make such improvements. The review makes recommendations that will improve the support offered to patients as they progress through the system.

The principles that should underpin any changes are; improved access to treatment and support, better communication with patients, a multi-disciplinary approach and greater equity in the availability of assistance. One of the aims of the review is to ensure that some basic principles are followed when services are redesigned. Patients should expect to receive an integrated health and social care service in a convenient local setting, without undue wait. Every stage in the patient journey should be linked: from the first indication of a sight problem, through diagnosis and treatment to assistance in coping with impaired sight. The review recommends that this can be achieved by the establishment of community eyecare networks. The review does not cover the organisation and regulation of clinical services.
Work done in the course of the review
WORK DONE IN THE COURSE OF THE REVIEW

The changing role of the community optometrist

With the introduction of free NHS eye examinations from 1 April 2006, the role of the high street optometrist has expanded from the testing of sight to the provision of a more extensive eye health examination. Given that optometrists are the largest professional group in the field of eyecare, this has enhanced their capability to manage eye disease in the community setting. All of the optometrists and optometric medical practitioners (OMPs) listed with Health Boards since 1 April 2006 to provide general ophthalmic services have had to demonstrate their competency in the use of optometric equipment and to ensure that they have the appropriate range of equipment available for use with their patients. By doing so they have achieved level one competence, as set out in the interim report of the review of community eyecare services. This was an important step towards the integration of community eyecare services.

The changes will have a range of benefits for patients and they will make more efficient use of health resources. The removal of the charge will encourage wider use of optometry services and the majority of patients will benefit from regular sight testing. The extended eye examination will enable optometrists to detect early signs of sight problems and to deal with these in partnership with the hospital ophthalmology service. The updated arrangements enable GP’s and other members of the local eyecare network to refer patients to optometrists for the management of common eye conditions. Some conditions can now be treated and reviewed by optometrists while more complex cases can be worked up to a higher clinical level before they are referred to the hospital.

The extended role of the optometrist also offers the opportunity for greater involvement in the local eyecare network. The interim report of the review described the changes in optometry in some detail, including examples of joint work, like the GIES scheme in Glasgow. In addition, two of the three locality studies undertaken as part of the wider review examined the contribution of community optometry networks. In both instances, optometrists played a key role in identifying problems associated with failing sight, supplying low vision equipment and referring patients on for other local services. Details are given in the section of the report on locality-based interagency work which can be found at annex F www.scotland.gov.uk/eyecarereview.
Centre for Change and Innovation (CCI) patient pathways

Alongside the initial review of eyecare services in Scotland the CCI Outpatients Programme established several projects to help improve the interface between primary and secondary care. Seven pathways of care (Strabismus, Glaucoma, Flashes and Floaters, External Eye Disease, Diplopia, Cataract and Age Related Macular Degeneration) were developed and published on the CCI website www.cci.scot.nhs.uk. The pathways are being piloted and the results will be evaluated.

Certification and registration

The formal link between health and social care services for visually impaired people is the certification and registration system. When a serious sight problem is identified, the individual is referred to a consultant ophthalmologist. If the condition cannot be cured, the consultant will certify the individual as blind or partially sighted. With the patient’s consent, the consultant will send the certification form to the local authority (or its agent) for inclusion in the local register of blind and partially sighted people. The principle benefits of registration are: it is a passport to a range of financial benefits; it is used by some organisations as a means of allocating their services; and it is the main source of data on the extent of visual impairment.

The current system of certification and registration in Scotland is widely considered to be out of date. The definition of blindness, based on the 1948 National Assistance Act, was originally devised to identify adults who were unable to work because of sight problems. The definition is irrelevant to the majority of the visually impaired population. A working group looked in detail at the shortcomings of the current system and made a range of recommendations which can be found in annex H at www.scotland.gov.uk/eyecarereview.

In summary, certification and registration in Scotland should be modernised and some aspects of the recently revised English system should be adopted. There should still be two levels of certification, but the terms “blind” and “partially sighted” should be replaced by “seriously sight impaired” and “sight impaired”. The English reforms also introduced two stages of notification, prior to certification. Notification is a mechanism for putting patients in touch with helping agencies while they await certification. It is also recommended that the clinical criteria for certification be extended to reflect the changes in clinical practice since 1948.
In defining sight impairment in adults and in children, care should be taken to ensure that those who have additional impairments are included in the planning and delivery of services. For example, there is evidence that many adults who have learning disabilities have undetected sight problems. Particular attention should be paid to the needs of visually impaired children, as is illustrated by the following description of work undertaken by an eyecare review working group on children’s services.

**Services for visually-impaired children**

There are significant differences between the nature of visual impairment in children and in adults. The causes of visual impairment can be divided into three categories: problems of the eye, the optic nerve or the brain. In contrast to sight loss in adults, which is predominantly a consequence of problems of the eye, the majority of children suffer visual impairment because of damage to the optic nerve or the brain. Almost all sight problems occur before or at birth, or in the first twenty-eight days of life. It is estimated that 70% of visually impaired children have an additional disability. (Visual Impairment Scotland 2003)

The distinctive nature of childhood visual impairment requires a specialist response. Vision is required to access information, to interact socially and to move around safely. Impaired vision in childhood can limit development in each of these areas and can lead to long term education and social disadvantage unless appropriate provision is made at an early age. The needs of visually impaired children are primarily met by education services, with additional input from hospital, optometric, orthoptic and social services when required.

The working group looked in detail at the needs of visually impaired children. There was some overlap with the work of the certification and registration working group. The detailed recommendations of the working group can be found in annex E at www.scotland.gov.uk/eyecarereview.

In summary, the working group emphasised the need to recognise the particular needs of visually impaired children, rather than treating them as small adults. Access to specialist support and equipment is essential to minimising the impact of visual impairment in the child’s development. Above all there should be strong local links between health, education and social care services. The CVISTA scheme in Tayside is given as a model of good practice. All of the helping agencies in the area work together in a single network, which is coordinated by a community paediatrician. This gives the families of visually impaired children a single point of contact and a guide through what can be a confusing array of statutory and voluntary organisations.
The emphasis on the inclusion of visually impaired children in mainstream education is welcomed, but the working group’s recommendations stress some of the practical issues involved in making social and educational inclusion a reality. Some of the essential building blocks are: the teaching of mobility and independent living skills at an early age; the availability of specialist equipment, both at home and at school; and a guarantee that curriculum material is in an accessible format. Underpinning all of these essential services is the employment of specialist staff. A summary of the workforce implications of implementing the community eyecare review is given in annex D at www.scotland.gov.uk/eyecarereview.

The inclusion of children and young people in the certification and registration system was debated at some length. It is estimated that less than 50% of children are currently registered, which calls into question the relevance of the system. However, there has been some concern expressed about children and their families losing out on benefits that are linked to registration. It is recommended that visually impaired children remain within the scope of the system until the changes in certification and registration have been made. The working group recommended a notification system, to assist local support networks to identify visually impaired children in their area and to facilitate the collection of accurate national data.

**Locality-based interagency work**

One of the recommendations of the “Sensing Progress” report was that local authorities should consider the establishment of interagency sensory impairment centres. There are some examples of good practice in Scotland and one of the objectives of the eyecare review was to examine the validity of the locality interagency model of working. A study was set up on three sites: Edinburgh, Fife and Forth Valley. In each area there was a good level of joint working between health, social work and the voluntary sector.

An initial audit was carried out on the nature and quality of the services provided in each of the three localities. The audit included a survey of a sample of service users. In each locality, a management group was established, with representatives of the local service providers. They were invited to identify weak points in the system and the Health Department allocated pump-priming money to assist with setting up the study. Progress was monitored by the management groups, supported by an external consultant and an advisor from the Health Department.

At the end of the six-month period, a second audit was undertaken to measure progress. The audit included a second survey of service user's
views. The conclusions of the study are set out in the form of key elements for a successful locality interagency model. These are derived from the assessment of the work undertaken in the three localities and they have been discussed in detail with the three local management groups. Details of the assessment of the three localities can be found in annex F at www.scotland.gov.uk/eyecarereview.

In summary, the study demonstrated the benefits for both patients and staff of attempting to provide a seamless local service. There were variations in the configuration of services on the three sites, as they adapted to local circumstances. However all three shared a common objective: to provide a continuum of care that covered every stage in the patient journey. For example, a community optometry assessment might result in the issue of low vision equipment to deal with an immediate problem. A referral from the optometrist to the ophthalmologist could take place in parallel with the involvement of a social worker or rehabilitation worker and it might lead to a more detailed assessment of long term needs and the provision of a more extensive package of care. In all three sites information services were developed to ensure that patients and carers could be kept well informed at every stage in the journey. This is particularly important at the critical point when the ophthalmologist diagnoses permanent visual impairment. For example, one site developed a personalised information summary which could be given to the patient, detailing the diagnosis of the eye condition, the prognosis and the help available to cope with the impact of sight loss.

Joint working on a shared site encouraged mutual learning and reduced the gaps between services for the patient. The advantages were apparent both in a hospital-based setting with social care on site and in community settings with facilities for regular ophthalmology clinics. In two of the localities, community optometry networks were successful in extending the reach of the joint service and providing an improved first point of contact for individuals, particularly those who were in the early stages of coping with sight problems. Above all, the approach was to design local services around the patient, rather than sending patients on a journey around a range of disjointed services.

**Setting national standards**

When the Interim Report of the Eyecare Review was published for consultation in October 2005, there was strong support for the proposal that one of the outcomes of the review should be: “setting and maintaining national standards that can be adapted and implemented locally”.
A working group was formed to look in more detail at national standards. (Membership of the working group is shown in Annex A). The work of the group was informed by the study of interagency work in the three localities and by other examples of good practice. The members of the group decided that standards should be expressed in terms of outcomes for patients. They devised a framework of service outcomes that is described in detail in annex I at www.scotland.gov.uk/eyecarereview.

In summary, the framework sets out the maximum time a patient should have to wait for an initial assessment of need and, if required, a complex assessment. It is recommended that simple services, like the provision of low vision equipment, be provided without delay. Lengthy and bureaucratic referral procedures should be avoided and there should be a facility for fast tracking of urgent cases between partners in the eyecare network. Where a complex support package is provided there should be regular reviews to ensure that the assistance matches the changing needs of the patient. Clear, personalised information about current and future care arrangements should be provided. The particular needs of members of minority ethnic groups should be taken into account when planning services.

In order to achieve consistent standards across Scotland, the working group identified four key elements that should be present in all local service planning for visual impairment. Service delivery should be based on an integrated model of health and social care, with enhanced communication and joint infrastructure. At the core of service planning is the need for a workforce with the competencies, capacity and capability to meet the health and social care needs of visually impaired adults and children. There must be integration with local performance management and accountability arrangements, to ensure continuous performance and quality improvement which is the subject of periodic external review. Finally, and crucially, planning must include the involvement of service users in the shaping and fine tuning of local services.
Conclusion, recommendations and an agenda for change
CONCLUSION, RECOMMENDATIONS AND AN AGENDA FOR CHANGE

The aims of the eyecare review, as set out in the introduction to this report are “to encourage the development of integrated eyecare services to ensure patients receive a good quality and efficient service, in a convenient setting without undue wait”.

The eyecare review has pursued these objectives in a series of linked initiatives which are described in this report. Some changes have already been implemented, like the introduction of the updated GOS arrangements. In other areas of activity, like the reviews of certification and registration and children’s services, the report makes clear recommendations for change. The study of interagency work in three localities both provides evidence of the value of joint working and it offers practical examples of service improvements. Similarly, the work on clinical pathways offers guidance on better integrated health services.

The response to the public consultation on the review carried the clear message that there has to be greater consistency in the quality of local services, so the report has set out some simple standards to ensure greater equity in the provision of eyecare services.

One of the positive aspects of the review has been the wide involvement of so many stakeholders, not only in the working groups which produced the detailed recommendations but also in the quality of the response to the public consultation. Moving from recommendations to action will also require a broad consensus and Community Health Partnerships have a key role to play in making a reality of the review at a local level.

Although the review has examined some aspects of community eyecare in considerable detail, it was always the intention that the different themes be brought together as the basis for an integrated service. For example, the expanded role of the community optometrist will facilitate the proposed improvements in certification and registration. The model of local support networks has been developed separately for children (the CVISTA scheme) and for adults (the study of three localities) but the guiding principles are the same.
Key recommendations of the community eyecare review
KEY RECOMMENDATIONS OF THE COMMUNITY EYECARE REVIEW

The detailed recommendations of the working groups and the outcomes of the locality study can be found at www.scotland.gov.uk/eyecarereview.

The key recommendations can be summarised, using the three elements of the remit of the review: integration, quality and efficiency.

1. Integration of community eyecare services

   • An integrated, patient-centred approach should be taken to the design of eyecare services, both for children and for adults.

   • The planning of services should be based on a broad definition of visual impairment, to include those who have additional disabilities or impairments. The particular needs of members of minority ethnic groups should be taken into account.

   • The principles underlying the CVISTA scheme on Tayside should be applied across Scotland. For adult services the lessons learned in the study of three localities should influence local developments.

   • The extended role of the optometrist should be used to strengthen both clinical management of patients and their links to community support.

2. Quality of care

   • The certification and registration system should be modernised in line with recent changes made in England and the clinical criteria for certification should be broadened.

   • No decision should be made about removing children from registration until the new arrangements can be evaluated.

   • The patient’s need for assistance should be based on an individual assessment of need, rather than on registration status

   • Minimum service standards should be established to ensure that patients receive a consistent quality of service across Scotland
3. Efficiency of services

- Community Health Partnerships should review local arrangements for community eyecare. In particular, they should consider the workforce implications of implementing the review and the arrangements for the supply of specialist equipment for visually impaired adults and children.

- The review offers the opportunity to involve community optometrists in local joint planning and in the delivery of integrated eyecare services. This opportunity will be enhanced by the local development of level two optometry schemes throughout Scotland. (Details in annex G at www.scotland.gov.uk/eyecarerereview.)
The agenda for change
THE AGENDA FOR CHANGE

The recommendations of the working groups, summarised above, received widespread support in the response to the two public consultation exercises carried out during the review. In order to implement the recommendations, the following tasks need to be undertaken.

1. The review of the certification and registration system

   • New forms need to be produced and distributed to eyecare professionals to facilitate the three stages of notification and certification. Both the forms and the guidance issued in England can be modified for use in Scotland.

   • The changes should be widely published and an implementation date for the new system should be set.

   • Advice needs to be taken on the detail of extending the clinical criteria for certification.

2. Services for visually-impaired children and young people

   • Following the implementation of the new certification and registration system, visually impaired children, young people and their families should be consulted on whether they should remain in the system. If the consensus is to take children out of the system, an alternative means of data collection will have to be set up.

   • The CVISTA model, and other local variations of it, should be promoted as models of good practice. In particular, local notification systems should be established, either in place of registration or in parallel with it.

   • A decision will have to be made on the establishment of a national notification scheme, to collate and use demographic and clinical data.

   • Other detailed recommendations need to be implemented, like the teaching of mobility and independence skills, wider access transcription services and consistency in the supply of specialist equipment.
3. Improving interagency co-operation on a locality basis

Community Health Partnerships are ideally placed to take a lead on delivering this objective, using the example of the three localities and the increased involvement of optometrists in local eyecare networks. Health Boards should review the progress made by CHPs towards more integrated eyecare services by December 2007.

4. Infrastructure issues

The changing structure of the population will lead to an increase in the numbers of visually impaired older people. The report highlights the need for workforce planning to ensure that there are sufficient numbers of key staff available to provide high quality services to an expanding population.
ANNEX A

Membership – Review of Community Eyecare Services in Scotland

Dr Gareth Davies, Medical Director, NHS Forth Valley (Chair)

Alison Buchanan, Scottish Branch Chair, British and Irish Orthoptic Society

Mike Cairns, on secondment from RNIB Scotland to the Scottish Executive Health Department

Donald Cameron, Optometry Scotland

Irene Fleming, Scottish Branch Chair, British and Irish Orthoptic Society

John Heaton, Member of the public

Dr Jeffrey Jay, Consultant Ophthalmologist

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**ANNEX B**

**Glossary**

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>CCI</td>
<td>Centre for Change and Innovation</td>
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<tr>
<td>CHP</td>
<td>Community Health Partnership</td>
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<tr>
<td>CVISTA</td>
<td>Children’s Visual Impairment Services Tayside Agencies</td>
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<tr>
<td>DDA</td>
<td>Disability Discrimination Act</td>
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<tr>
<td>GOS</td>
<td>General Ophthalmic Services</td>
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<tr>
<td>GP</td>
<td>General Practitioner</td>
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<td>QIS</td>
<td>Quality Improvement Scotland</td>
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<td>RNIB</td>
<td>Royal National Institute of the Blind</td>
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<td>SEHD</td>
<td>Scottish Executive Health Department</td>
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<td>SWSI</td>
<td>Social Work Services Inspectorate</td>
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Annex C

EYECARE REVIEW: SUMMARY OF THE CONSULTATION ON THE REVIEWS OF CERTIFICATION AND REGISTRATION AND CHILDREN'S SERVICES AND THE STUDY OF INTERAGENCY WORK IN THREE LOCALITIES.

1. General comments the eyecare review

Almost all of those who commented on the overall review did so positively. They agreed with the need to modernise the response to visual impairment in Scotland and they approved of the general approach taken by the review. The following quotations come from the range of respondents:

- “The proposal would be of great benefit” (visually impaired individual)
- “A comprehensive and lucid document” (optometrist)
- “It is timely, comprehensive and a progressive document” (RCN)
- “A good paper and I support all its recommendations” (consultant ophthalmologist)
- “Welcomes the reports and if the recommendations are implemented services will improve greatly” (voluntary organisation)

There was a minority of respondents who criticised some aspects of the review. Two respondents considered that the review was unnecessary and that the Executive should have implemented the recommendations an earlier report: “Sensing Progress” (Scottish Office 1998). Two other respondents were concerned about the summary nature of the documents. They wanted to see more evidence to support recommendations and one suggested that the proposals should be subject a cost benefit analysis. Another asked that there should be cross-references to other reports. Some of the language used in the report was criticised. For example the use of the word “patient” was thought to imply a medical model of care.

2. The Review of certification and registration.

2.1 General comments. Most respondents commented on the report on certification and registration and there was a clear consensus that the present system is in need of reform. There were various views expressed about the detail of change. The single most controversial recommendation was the proposal to take children out of the registration system.

2.2 Responses to the specific recommendations of the Report on Certification and Registration.
Recommendation 1: That the new system should retain the certification of the patient’s condition by a consultant ophthalmologist, but it should be based on a wider range of clinical criteria than visual acuity and visual field.

There was broad support for the retention of certification by a consultant ophthalmologist. However three responses suggested that the task could be taken over by or shared with optometrists.

There was also broad support for the proposal to widen the clinical criteria for certification. It was suggested that near visual acuity be included (in addition to distance acuity) as a better indication of the patient’s ability to cope with daily living. It was also recommended that a test of contrast sensitivity be added.

A significant number of respondents commented on the link between clinical assessment and the wider consideration of the patient’s social circumstances. There were differing views about the most efficient method of achieving a holistic assessment of the patient: some suggested that medical and social information be collected on the same form, others found this option impractical.

There was strong support for linking certification of visual impairment with the single shared assessment process. It was recommended that particular attention be paid to the assessment of those who had additional disabilities.

In summary: the recommendation was accepted, with more detailed work to be done on the detail of clinical criteria and the links between clinical and social factors.

Recommendation 2: That the terminology be changed: “blindness” to be replaced by “profound visual impairment” and “partial sight” to be replaced by “visual impairment”.

Although the majority of respondents agreed that the terminology should change, there was less agreement about the best words to use. The word “blind” was seen by some as stigmatising, but the suggested alternative “profound visual impairment” was also unpopular. It was suggested that the terms used in the English certification and registration system be adopted: “severely sight impaired” to replace “blind” and “sight impaired” to replace “partially sighted”.

One respondent proposed that only one category was required. One respondent referred back to the “Sensing Progress” report, where it was recommended that there be spectrum of sight loss, rather than two discrete categories of visual impairment. This recommendation was considered by the working group, but rejected because of the complexity of the legal position following devolution. Whatever terms are adopted, there was a strong view that they should be clearly
defined and their definition should be widely shared, particularly with other agencies which use registration as a passport to benefits. It was suggested that the same terminology be used for adults and children. Several respondents recommended that changes in terminology should not be introduced until there was clear understanding of the changes.

In summary: although a range of views were expressed, the majority of respondents favoured a change in terminology. The most popular option was to adopt the terms used in the English system. The change in terminology should be well-publicised.

Recommendation 3: **That the collation of statistical data be based on certification, rather than registration.**

There was wide support for this proposal. The only dissenting voices pointed out that data would be collected at several stages in the patient journey and that the current system enables register holders to keep the data up to date.

In summary, the recommendation was accepted by most respondents.

Recommendation 4: **That the current single stage registration system be replaced by a three stage system of notification of the patient’s need for assistance, based on the new arrangements in England.**

This recommendation was supported by all of the respondents who commented on it. The only proviso was that the new system should not delay certification. Two respondents did not consider that the English system had been described in sufficient detail in the report. There were several comments on the need to avoid the problems experienced during the introduction of the new system in England.

In summary the recommendation was accepted, subject to clear arrangements for implementing the change.

Recommendation 5: **That the patient’s need for assistance should be based on an individual assessment, rather than registration status.**

All of the responses to this recommendation were positive. The single shared assessment was widely seen as the best mechanism for involving the appropriate professionals in the assessment of individual need. One suggestion, from Guide Dogs, was that there should be an intensive course of rehabilitation
offered immediately following the diagnosis of uncorrectable sight loss. Practical skills in coping without sight, or with reduced sight, could be combined with emotional support. One respondent highlighted the needs of people who are in residential or nursing home care. They should be included in local eyecare services. One respondent pointed out need to consider the particular needs of members of minority ethnic groups, as recommended in “Sensing Progress”.

In summary, the recommendation was accepted.

Recommendation 6: **There should be a separate system for certifying visual impairment in children and planning and co-ordinating services for them.**

There were widely differing views about this recommendation. The majority of respondents agreed that children and young people are not well served by the current certification and registration system, but there was no clear consensus about the best alternative. The main concern was the risk that families will lose current financial benefits if children were no longer registered. Some who agreed with the recommendation to take children out of registration qualified their agreement: for example one respondent suggested that young people should be eligible to come into the adult system at sixteen rather than eighteen, to fit in with planning the transition from school. It was also proposed that any change should be delayed, to ensure that the financial benefits of registration are not lost in the interim. Several respondents simply opposed the recommendation: they considered that children are better off remaining in a revised registration system. It was strongly suggested that any change should be preceded by detailed consultation with families.

The creation of a separate system for coordinating support for children received broad support. More detail will be given in the analysis of comments on the report on children’s services.

In summary, the shortcomings of the current system were acknowledged, but there were reservations about change. It may be that the best solution is to make the changes to the registration system first, then consider the question of the inclusion of children.

Recommendation 7: **That the introduction and implementation of change be properly resourced, to avoid the problems experienced in the introduction of the new certification and registration system in England.**
This recommendation was supported by all of the respondents who commented on it. Several respondents were concerned that a more efficient system for identifying need might lead to a greater demand for services. Others emphasised the need to plan for the implementation of the review. Reference was made to past reports which had delivered excellent recommendations on modernising visual impairment services in Scotland, but those recommendations had not been implemented. The Scottish Executive was seen to have a key role in coordinating change on a national basis and several respondents referred to the importance of Community Health Partnerships in improving local services.

In summary, the recommendation was accepted.

3. The report of the working group on children’s services.

3.1. General comments. Not all of the respondents commented on the report on children’s services. Of those who did, the report was generally welcomed. The majority of the contributions stressed the need to consider the particular needs of children, rather than simply including them in services designed for adults. The report was welcomed by the parent of a visually impaired young person as a good model for introducing much needed change. Reference was made to the importance of sight screening in schools, a topic which was raised in the interim report of the eyecare review.

3.2 Responses to the specific recommendations of the Report on Children’s services

Recommendation 1: That the planning of services is based on the broad definition of moderate and profound visual impairment, to include children who have additional disabilities.

Most of those who commented on this recommendation supported it. There were requests to include children who had Usher’s syndrome and those children who have both visual and hearing impairments. Several respondents commented on the need to define the terms precisely and there was a suggestion that research was required to establish the incidence of childhood visual impairment, using the broad criteria. It was also suggested that the terminology used to describe visually impaired children should be the same as that for adults.

In summary, the recommendation was accepted, subject to more detailed definitions being established.
Recommendation 2: That minimum standards should be established for interagency cooperation to meet the needs of visually impaired children and their families.

Less than half of the respondents commented on this recommendation. Those who did were generally positive about it and agreed that action should be taken to remedy geographical inconsistencies. It was suggested that the word “minimum” be dropped, lest it encourage a lowest common denominator approach. Several respondents linked this recommendation with recommendation 3 and commended the CVISTA scheme as a template for establishing standards for interagency work. Several respondents recommended that standards should be underpinned by inspection, particularly if they are linked to wider children’s planning structures.

In summary, the recommendation was supported by the minority of respondents who commented on it.

Recommendation 3: Local services: the CVISTA scheme on Tayside is an example of good interagency practice, focussing on the needs of the child or young person. The principles underlying the scheme (see Annex 2) should be applied across Scotland.

The response was similar to that for recommendation 2. Those respondents who commented on the CVISTA scheme did so positively, although one doubted if the model was appropriate for remote rural areas. One respondent suggested that the CVISTA scheme should be independently evaluated before it was recommended as a national model. Several respondents pointed out that there were other similar models for supporting children and young people who are visually impaired or who have other additional needs.

In summary, the CVISTA model was supported by almost all of those who commented on it.

Recommendation 4: The deployment of specialist staff: minimum standards should be established in terms of a ratio of key professionals to the population of visually impaired children.

The response to this recommendation was mixed. As with other recommendations on children’s services, it attracted only minority interest. Most of those who supported the recommendation qualified their support. Some suggested that geographical differences would make a staff ratio difficult to establish, particularly in more remote areas. Further training for generic staff
and the sharing of specialist staff between localities were suggested. The ratio, if used, should take into account the needs of children who have additional disabilities. One respondent predicted that ratios would reduce the number of staff working with visually impaired children. An alternative suggestion was the adoption of an idea from Finland, where a visually impaired child in a mainstream school is counted as five children when class sizes are set.

In summary, the recommendation is not supported in its current form.

Recommendation 5: **Mobility and independent living skills should be taught to children, starting in the preschool years and the emphasis on inclusion should extend beyond practical issues to include emotional and psychological skills.**

This recommendation received almost unanimous support from those who commented on it. However, the low levels of specialist staff in Scotland were seen as a barrier to achieving the objectives of the review. The initial findings of research currently being done for Guide Dogs supports this position: services are sporadic and there is a lack of clarity about the training and qualification of staff who should provide this essential support to children.

In summary, the recommendation was supported, with concerns expressed about having sufficient staff to make it a reality.

Recommendation 6: **Visually impaired children and young people should have access to leisure services, consistent with their rights under the Disability Discrimination Act.**

As with other recommendations on children’s services, this one received wide support from the minority of respondents who commented on it. Better information about the leisure services that were accessible to visually impaired young people was seen as an important factor. One comment was that underinvestment in leisure activities for children could have a disproportionate impact on future attainment. Several respondents assumed that the DDA would automatically lead to better access to leisure services, another thought that the Act might make it more difficult.

In summary, the principle underlying the recommendation was accepted.

Recommendation 7: **Certification and registration: any new system must make sense in terms of the needs of children and young people, rather than being just an extension of the adult system. A system of notification should be considered, in addition to registration or in place of registration.**
This recommendation links to recommendation 6 in the Certification and Registration report. Although there is general support for the principle of adapting the registration system to meet the particular needs of children and young people, there are a varying views about how this should be achieved. Notification in place of registration was more popular than notification in addition to registration. The other contentious area was whether a system of notification should be local or national. One argument is that the system should be local, so that information about the child is shared among local service providers, as in the CVISTA system. The opposing argument is that the information about the child’s visual impairment should be collected centrally, and then passed out to local support networks. The latter argument is heavily supported by Visual Impairment Scotland, a specialist voluntary organisation which already operates an informal notification system. They argue that central collection of data is more efficient. Some local service providers take the view that the organisation of services comes first and data can be collected from them.

In summary, there is little doubt about the principle of adapting registration to meet children’s needs. There are different views about how this can be achieved.

**Recommendation 8:** The responsibility for commissioning, supplying and maintaining equipment, technology and low vision aids should be clarified, so that families know what level of service they can expect.

There was broad support for this recommendation. Respondents confirmed the disparity of service levels across Scotland and the adverse effect that it had on individuals. Several respondents commented that families need to be made aware of what equipment is available. It was suggested that the issue should be considered in the broader context and linked to the Audit Scotland report “Equipped for Inclusion”. Bridging the gap between home and school is considered to be a crucial issue. If children have access technology in school, its value is diminished if they cannot use it at home. As with other recommendations, there was concern that the system should be properly funded. This recommendation is linked to recommendation 9.

In summary, the recommendation was supported.

**Recommendation 9:** A national transcription service should be established.

There was unanimous support for this recommendation from the thirteen respondents who commented on it. Several mentioned the need for proper
funding for the centre and there were several suggestions about how it might be organised. In summary, the recommendation was supported.

4. The study of interagency work in three localities.

4.1. General comments on the study.

Most of the respondents commented on the study. Almost all found it to be a useful document and one which was consistent with current government policy on joint working and the emphasis on primary care. There were two dissenting views: one correspondent found the methodology of the study less rigorous than it should have been and another would have preferred a more detailed description of the three localities. Only one respondent opposed the concept of closer interagency working on a locality basis on the grounds that it might not be in the interests of individuals who had more specialist needs. Another significant comment was that none of the three localities chosen have a significant minority ethnic population and this issue should be explored further, as recommended in the report “Sensing Progress.” The majority view was that the study was helpful in setting out three models which could assist other areas to consider their approach to integrating services for visually impaired people. It was suggested that other examples of good practice be added to the report of the study of the three localities.

The report on the study did not contain recommendations, so the following comments are grouped around the last section of the report: Key elements of a successful locality interagency visual impairment service.

Key element 1. The development of a well established working partnership between key staff in health, optometry and social care (both in the statutory and voluntary sectors)

There was unanimous support for the principle of partnership working. One suggestion was that service users should be included in the partnership and another stressed the importance of involving the parents of visually impaired children. The absence of coterminous catchments areas was raised by both health and social work professionals. It can be difficult for a busy ophthalmology unit which serves several local authority areas to adapt to different approaches to organising patient support. Similar problems are experienced by local authorities which are divided between hospital catchment areas. Several respondents commented on the practical difficulties of achieving effective partnerships in remote rural areas. This issue was also raised in under
the Key Element 4, below. Community Health partnerships were widely seen as the ideal vehicle for promoting local joint working.

Key element 2. The integration of different services to create a continuum that covers every stage of the patient journey. The re-referral of patients should be avoided, particularly when all that is required is a simple assessment and the issue or reissue of low vision equipment.

There was general agreement to this approach to service delivery. In response to this and to the two following key elements, a substantial number of respondents commented on the shortage of specialist staff in Scotland and the limited training opportunities for some specialisms. This issue was covered in the Interim Report of the Eyecare Review and several respondents were concerned that it should not be omitted from the final report of the review. There were few other detailed comments, other than a request for more information than was contained in the report of the study.

Key element 3. The integrated approach enables joint ownership of work between partners and the provision of a seamless service. For example, a community optometry assessment might result in the issue of low vision equipment to deal with an immediate problem. The subsequent involvement of a social worker or rehabilitation worker might lead to a more detailed assessment of the patient’s long term needs and a more extensive package of care.

Again there was agreement with this statement. There was considerable interest in the community optometry networks which had been established in two of the three localities. Although some respondents questioned the wider involvement of optometrists, the majority view was that the new contract will act as an incentive for greater integration. The importance of the single shared assessment was stressed by several respondents. It was suggested that the Community Health Index could be used to strengthen communication links between agencies.

Key element 4. Joint working on shared sites establishes closer cooperation, better understanding of each worker’s role and flexibility based on mutual trust. This leads to best practice and better use of scarce resources.

Although this conclusion of the study was supported in principle, several respondents pointed out the practical difficulties of co-location in remote rural areas. The absence of coterminous boundaries, raised in 6.1.1 above, was also seen as a practical barrier. One suggested solution was the creation of virtual
centres, using well developed IT links. Optometry practices were suggested as potential remote locations, linked to a central sensory impairment centre.

Key element 5. **There appear to be substantial gains from organising services around a multi-agency low vision clinic, whether this is located in hospital or in the community.**

Some of the comments on 6.1.4. above are also relevant to this statement. Multi-agency low vision clinics, or clinics located in community settings were seen by some respondents to be excellent but expensive solutions, best suited to urban areas. Of the three examples studied, only one is purpose built, the other two are in adapted premises.

Key element 6. **There should be a recognition that services need to continually adapt and improve.**

There were very few comments made about this statement.

Key element 7. **The guiding principle should be organising services around the patient, rather than sending the patient to find the service.**

There was unanimous support for this principle from those who commented on it. Several respondents stressed the need to include patients who have additional impairments.

Key element 8. **The involvement of service users should be built into the planning and development of services.**

Again, this statement did not attract many comments, but it was not contradicted.
Annex D
Workforce

Ophthalmic Nurses

In 1985 the Ophthalmic Nursing Board was disbanded and with it the qualification of Ophthalmic Nursing Diploma or Ophthalmic Nursing Certificate. In Scotland various courses provided by schools of nursing within universities and validated by NES (and previously NBS) have matched the Ophthalmic Nursing Board qualification with the exception of the competencies required for operating theatre departments. NES maintain that operating theatre competencies are a separate discipline and should not be part of an ophthalmic nursing programme. A variety of factors, funding issues, central belt location of courses and small size of ophthalmic units contributed to the poor uptake of places on the available programmes. The financial viability of the provision further reduced the availability of courses and opportunity for nurses to gain the desired competencies within a formal academic structure.

In England, Schools of Nursing within universities have amalgamated with various Departments of Ophthalmology and provide appropriate learning environments and support to gain an ophthalmic qualification. Currently there is a short course in Ophthalmic Nursing run by Robert Gordons University's Virtual Campus. However the course has no practical element in it and has been set up to provide insights to learning as opposed to ophthalmology. NHS Lothian Hospitals Division, primarily Princess Alexandra Eye Pavilion, in conjunction with Queen Margaret University College has developed 2 modules (Essential Skills for Ophthalmic Nursing, Sections 1 and 2) aimed at post registration nurses working in ophthalmology. Teaching and academic support is provided by nursing, medical and technical staff from Princess Alexandra Eye Pavilion, Edinburgh. A further emergency ophthalmology module, aimed to facilitate the development of nurse practitioner roles will be piloted in the very near future. Places on these programmes are very limited so that for the foreseeable future there will be a continuation of the current situation within many Departments of Ophthalmology.

In these, nurse specialists are utilised to run clinics in primary care, ocular hypertension and glaucoma. There are also many nurse led activities without which many departments could not function e.g. nurse led minor surgery service, nurse-led pre-admission assessment, and nurse led casualty service. Numbers of patient episodes are not recorded.
This has been possible because ophthalmologists in individual departments have provided the appropriate training and education for nurses to obtain the required competencies and thus extend their role, usually for protocol driven tasks.

**Orthoptists**

Orthoptists are Allied Health professionals primarily working within the NHS. Although most orthoptists are employed by the acute sector their clinical services span both primary and acute care.

The orthoptist’s role is to assess, diagnose and manage all binocular vision defects and disorders of eye movements, this includes childhood strabismus (squint) and amblyopia (reduced visual acuity), but also a broad spectrum of acquired adult eye conditions resulting from health problems such as thyroid dysfunction, neurological disease, trauma, stroke, multiple sclerosis and diabetes.

Due to the broad nature of orthoptists’ education in vision sciences new graduates now have the skills to do visual field assessment and glaucoma shared care, low vision aid services, stroke rehabilitation and biometry.

Vision screening is a primary care service in which orthoptists have been involved since 1976. The recent document “Health for all Children” by Professor David Hall has recognised orthoptists’ expertise in vision screening and has recommended that all children in Scotland should be screened by orthoptists at age 4 years for vision defects.

Concern has been expressed about the low number of orthoptists currently employed in Scotland (the BIOS workforce survey in 2003 estimated that there were 100, but as some work on a part-time basis, the full time equivalent was 69).

**Rehabilitation Workers**

There are currently sixty rehabilitation workers employed in Scotland. The standard qualification for rehabilitation workers is the Certificate in Education in Rehabilitation Studies. The three main tasks of the rehabilitation are: independent living, communication skills and
orientation and mobility. Most are employed by local authority social work departments or by voluntary organisations which work under contract to them. The role and training of rehabilitation workers is currently under review. The aim is to transfer the only training course in Scotland from the Guide Dogs School of Rehabilitation to a university campus.

Guide dogs has carried out an extensive survey of the number of rehabilitation workers and the range of their activity. The survey will be published late in 2006. It will be important to consider the future shape of rehabilitation services for visually impaired people within the wider context of the Scottish Executive’s rehabilitation framework.

**Social Workers**

Some social workers specialise in the area of blindness and partial sight. They have a similar role to their colleagues in local authority community care teams: assessing individual need and arranging, purchasing or commissioning services to meet that need. They are often called upon to offer emotional and practical support at the point of registration and they can have a longer-term role in supporting individuals and families. Increasingly visual impairment social workers’ caseloads involve the management of complex cases, where blindness or partial sight is linked to other chronic disabilities.

The study of interagency work in the three localities stressed the value of social workers as members of the local eyecare network.

**Ophthalmologists**

Ophthalmologists are medically qualified doctors who have specialised in the management of diseases of the eye and disorders of vision, and practice ophthalmic surgery. In general ophthalmologists work in hospital practice with the support of nursing staff, orthoptists and optometrists. In two of the three localities included in the study of interagency work, ophthalmologists ran regular clinics in community settings, in addition to their hospital work. (In the third locality, the interagency network was hospital-based) The ophthalmologist was seen as a key member of the local network and the study identified positive outcomes for patients.
Optometrists

Optometrists are eyecare professionals who are trained to detect and correct refractive errors, to carry out comprehensive eye examinations, screen for eye disorders and to prescribe treatment and/or manage a wide range of common eye conditions. Optometrists work in both the community and hospital settings. Optometrists examine and screen for eye disorders in people of all ages, from pre-school screening to managing age-related conditions such as glaucoma, cataract and macular degeneration.

Increasingly optometrists are involved in multi-disciplinary co-managed schemes for cataract, glaucoma, ocular hypertension, and diabetes. These are set up between primary and secondary care, to provide convenient and rapid access to care for many patients. These improve the quality of care for many people, with the added benefit of reduced waiting list times. Further details on some of these schemes are included in Annex D.

Specialist areas of optometric practice are; low vision management, dyslexia investigation, contact lens work, dry eye management, red eye management, managing patients with specific learning difficulty and examinations for those with learning disability, pre- and post-operative ocular examinations and triaging eye conditions in the community.

Optometrists have been supplementary prescribing rights that will assist with the management of external eye disease and chronic eye conditions such as glaucoma. In two of the three localities studied, optometrists enhanced the quality of the interagency service by providing community optometry networks. The new GOS arrangements, introduced in April 2006, offers the potential for greater involvement of optometrists in local eyecare networks.
Annex E
A REPORT TO THE EYE CARE REVIEW STEERING GROUP
FROM THE WORKING GROUP ON CHILDREN'S SERVICES

1. The context of the report

1.1 In March 2004, the Deputy Minister for Health and Community Care announced a review of eyecare services in Scotland. A group was established to review arrangements for the provision of eyecare services in the community and to provide recommendations on good practice for effective models of care. It became apparent early in the life of the review that the main emphasis was on services for adults and there was insufficient attention paid to children and young people. There are significant differences between visual impairment in children and in adults. A separate group was established to look in detail at eyecare services for children, and to make recommendations for change, as part of the wider review.

1.2 Vision is required to access information, to interact socially and to move around. Impaired vision in childhood can limit development in each of these areas, and can lead to long term educational and social disadvantage unless appropriate provisions are made from an early age. The needs of visually impaired children are primarily met by educational services for visual impairment from early childhood, with additional input from hospital, optometric and social services when required.

The provisions accorded by blind and partial sight registration are designed for the needs of adults but do not adequately address the needs of children with visual impairment.

There is a need to ensure that all children with visual impairment are not developmentally or educationally disadvantaged on account of poor vision. This requires that all children whose visual impairment places them at risk of such disadvantage are optimally managed, with equity of service provision throughout the country. A system of notification which leads to optimal service provision is therefore required.

This report seeks to address the distinct needs of visually impaired children of pre-school and school age.
2. **Terminology**

2.1 Different words are used to define the loss of sight or visual impairment. No single term is acceptable to all, so it is necessary to determine the terminology that is to be used in the report. The traditional terms "blind" and "partially sighted" are still widely used, but when describing serious sight problems in children it might be more appropriate to use the terms "profound visual impairment" in place of "blind" and "moderate visual impairment" rather than "partial sight". The age range covered in the report will be from birth to eighteen years old.

3. **The number of children and young people in Scotland who have a visual impairment**

3.1 One of the drawbacks of the current certification and registration system is that it does not provide an accurate estimate of the size of the visual impairment population. This is particularly so for children and young people, where it is estimated by Visual Impairment Scotland (VIS) that approximately 50% of those eligible to register do not do so. VIS\(^1\) holds a large database of visually impaired children and it is calculated that the incidence of profound visual impairment is 12 per 10,000 live births, giving a number of approximately 1400 in Scotland. This estimate is broadly similar to those European countries which have more accurate measurement systems: 13.1 per 10,000 in Sweden and 12.9 per 10,000 in Denmark. However there may be some children with multiple disabilities who have not had their eyes examined by an eye specialist. These children are not included in the statistics because their numbers are unknown.

3.2 The VIS survey also includes estimates of the nature of visual impairment in children. Almost all sight problems occur before, at birth, or in the first 28 days of life. The largest single category is cerebral visual impairment. This statistic is important when planning services for children because there are significant differences between the nature of visual impairment in adults and in children. Causes of visual impairment can be divided into three categories: problems of the eye, the optic nerve or the brain. In contrast to sight loss in adults, which is

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\(^1\) Vision Impairment Scotland: “A new system of notification of childhood visual impairment and the information it has provided on services for Scottish children” (VIS 2003)
predominantly a consequence of problems of the eye, the majority of children suffer visual impairment because of damage to the optic nerve or the brain. It is estimated that 70% of visually impaired children have an additional disability. Again, this estimate is consistent with the result of European studies.

4. **The policy context**

4.1 There is a range of policy initiatives that will influence the development of services for visually impaired children and their families:

4.1.1 The emphasis on local planning and delivery of health education and social services. The Government's joint futures policy is changing the shape of service planning, with the introduction of community health partnerships.

4.1.2 The Education (Additional Support for Learning) (Scotland) Act 2004 will provide a framework for service planning that will be particularly relevant to children who have visual impairment and those who have a visual impairment and additional disabilities.

4.1.3 Other recent changes in education will also be relevant, such as the greater involvement of parents, the emphasis on integration in schools and measures to improve access for children who have impairments. The Disability Discrimination Act was extended to education in 2002.

4.1.4 Some of the changes proposed in the wider eyecare review will affect children, young people and their families such as the emphasis on integrated, locality-based services and the review of the certification and registration system.

5. **The problems faced by visually impaired children and their families**

5.1 The circumstances of each individual child or young person are unique, but there are some problems that will be common to many of them.

5.1.1 *Education*. The majority of visually impaired children and young people in Scotland attend mainstream schools and colleges. A significant minority are still in special schools. The choice between mainstream and specialist
education can depend on what is available locally, as well on the particular needs of the child. There have been several legislative changes designed to assist with access to mainstream education. Although greater access to local schools is generally welcomed, a recent survey\(^2\) has shown that there is still some way to go to achieve full social inclusion. The authors of the report made the following points:

- While it is generally accepted that the development of social competency in school years promotes lifelong social inclusion, the practicalities and legalities of ensuring access to the curriculum have often taken precedence over social inclusion.

- The Government and education providers should accept that inclusion is as much about the ethos and social life of schools, colleges and universities as it is about access to the curriculum. The focus needs to shift from the individual performance of the blind child to the forming of relationships between the child and the social environment.

- Social competence may be directly addressed through classes on personal and social development or as linked programmes with other subjects.

- HM Inspectors of Schools found there were gaps and weaknesses in programmes and noted that a programme that serves most pupils well might not meet the needs of some vulnerable pupils.

5.1.2 Social inclusion. Good friendships are very important to the self-esteem and confidence of any child. For the visually impaired child this is equally true, however various factors can contribute to their lack of success in establishing social relationships. Children who have a visual impairment find it difficult to "see and send body language efficiently" where visual clues typically make up 80% of human communication. Both visually impaired children and their sighted peers can be unprepared in dealing with each other. Unsure of etiquette and suitable activity to share, children

\(^2\) Marianna Buuljens and Joan Stead with Mary Dallas: “Promoting social inclusion of pupils with a visual impairment in Scotland”. (Scottish Executive 2002)
are restricted in their spontaneous play. Visually impaired children find it difficult to access many activities and social clubs available to their peers.

It is important for visually impaired children to receive support for developing strategies to deal with social situations and improve social competence across mainstream education for all pupils. Many educational institutions employ buddy schemes or mentoring which can be used to prevent misunderstandings and misconceptions amongst peer groups. Children with visual impairments also need to meet with other visually impaired children to prevent feelings of isolation. It is important to note that social acceptance should not be measured by the number of negative incidents between pupils but rather an examination of positive experiences. The aim is to achieve mutual and reciprocal friendships between visually impaired children and their peers, both sighted and visually impaired. Raising awareness of visual impairment in the community can be helpful in gaining social acceptance.

5.1.3 Isolation. The families of visually impaired children may feel isolated. The relatively low incidence of childhood visual impairment means that there may not be a family in similar circumstances in their locality. If support services are not well-coordinated, the feeling of isolation can be exacerbated. Attendance at mainstream schools does not necessarily prevent isolation, if a child is the only the visually impaired pupil in the school. The same can apply to the parents who may feel excluded from discussions that are exclusively about issues affecting sighted children.

5.1.4 Communication. The problems of isolation, described above, are sometimes exacerbated by poor communication. The communication problems may be directly with the child or young person, with the family or between professionals.

5.1.5 Mobility and Independence. Mobility and independence training should be tailored to the needs of the individual child or young person. If visually impaired children are to benefit from integrated education and wider social inclusion, they must have the confidence to move around
independently and safely. This provision of assessment, advice and training should begin in the preschool years. The RNIB report "Shaping the Future"\(^3\) revealed that only two of the twenty-three Scottish local authorities who responded routinely assessed all visually impaired children to check the need for mobility and independence training. Others reported that the mobility needs of some children were assessed or they responded to requests for mobility assessments. Mobility and independence training is provided by trained rehabilitation workers. Although there are some rehabilitation workers who specialise in working with children, the majority are located in adult services. The training and deployment of rehabilitation workers is currently under review. It is recommended that specialist, post qualifying training in working with children should be developed. Early support to families and training to support growing independence are essential if children are to achieve their potential.

6. **Current inequalities in the support offered to blind and partially sighted children and young people and their families**

6.1 The variation in the range and quality of local support networks. One of the conclusions of the Riddell Report\(^4\) was that:

"Successful provision for children with severe low incidence disabilities depends on a range of factors, not least of which is the importance of effective interaction and shared commitment between agencies"

This comment is relevant to visually impaired children, both in terms of statutory agencies and the contribution made by the voluntary sector. In addition to the national voluntary organisations, like VIS and RNIB, which offer services across Scotland, there are local societies for the blind which have well developed children's services, but there is no consistent pattern. There are also areas in which effective networks have been developed with little voluntary sector involvement. However some

\(^3\) Sue Keil et al: “Shaping the future- The social life and leisure activities of blind and partially sighted children and young people aged 5 to 25” (RNIB 2001)

\(^4\) “Report into the education of children with severe low incidence disabilities”.-the Riddle Report. Scottish Executive 1999
agencies only offer support to children who are registered as blind or partially sighted. Given the limitations of the registration system, particularly for children, this must leave many unsupported. What is lacking is consistency; effective support should not be an accident of geography. The wider Eyecare Review emphasises the importance of achieving minimum service standards in a way that is consistent with local circumstances.

6.2 The variations in the employment of specialist staff in education, health, rehabilitation and social care. The RNIB report "Shaping the future"\(^5\) revealed inconsistencies in the number of specialist staff employed by local authority education departments. Of the staff that were in place, there were variations in the level of training and qualifications. The situation is similar in social work, health and rehabilitation. Uneven levels of support affect both children and their families. In order to achieve consistency, there should be minimum levels of specialist staff established, based on a ratio of staff in relation to the number of visually impaired children and young people in the locality.

6.3 Access to curriculum materials. A recent and as yet unpublished survey by RNIB Scotland\(^6\) showed wide variations in the arrangements for making curriculum material accessible for all visually impaired school children and students in Scotland. It is estimated that 375 texts are required each year to cover the primary school curriculum and 785 for secondary schools, excluding recreational reading. The Scottish Executive has funded an extensive pilot project to test the use of DAISY, a CDRom-based system which can generate audio, Braille and large print in a user-friendly format. Other countries have established national transcription centres, to provide a reliable source of accessible curriculum material. The evaluation of the DAISY pilot project\(^7\) suggests that a national transcription service should be created in Scotland.

6.4 Access to technology, at home and in school, for education and for leisure activities, and the availability of training and technical support. The DAISY system, described in paragraph 6.3

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\(^5\) Sue Keil et al: “Shaping the future- The social life and leisure activities of blind and partially sighted children and young people aged 5 to 25” (RNIB 2001)

\(^6\) Linda Sorensen: “Research into a national transcription service for education.” (RNIB 2005)

\(^7\) Joan Haston: “DAISY project, external appraisal” (RNIB 2005)
is only one example of the technology that is available to visually impaired children. To make best use of what is available, there should be a detailed multi-disciplinary assessment of individual needs, followed by regular reviews. The needs of the child will change over time, as will the technology available. Children and young people with a visual impairment are especially dependant on technology at home for accessing information and for leisure. If all of the potential benefits of technology are to be realised, staff and parents, children and young people need to be kept up to date. The cost of acquiring equipment, assessment, training and maintenance has to be met. As with other aspects of supporting visually impaired children and their families, access to technology is a postcode lottery: local authority policies on the funding of technology vary widely.

6.5 The supply of low vision aids. There are inconsistencies in the local arrangements for supplying low vision aids to visually impaired children and adults. It is expected that this issue will be addressed in the wider Eyecare Review.

6.6 Certification and registration. The current system for certifying and registering visual impairment in Scotland is generally thought to be in need of modernisation. The system is particularly inappropriate for children who have a visual impairment. Because of the sometimes complex nature of sight problems in children it can take some time to establish a definite diagnosis. A working group is currently considering changes to the system, including the introduction of formal notification of visual impairment and better coordination of services at a locality level. In this context, “notification” is taken to mean a formal process of referring the families of visually impaired children to the most appropriate local agencies, without the need for registration. One agency would take responsibility for the initial identification of the child’s need and would coordinate the support package The Children's Visual Impairment Services, Tayside Agencies (CVISTA) scheme has demonstrated the value of a well-coordinated local network dedicated to visually impaired children and their families. A detailed description of the CVISTA scheme is in Annex 2 of the report. Recent changes in education, in particular the introduction of Additional Support for Learning are consistent with such an approach.
6.7 Sight screening. The fourth report of Professor Hall's committee on screening\textsuperscript{8} recommended changes to the practice of sight screening in pre-school settings and in schools. There are variations in practice between different areas in Scotland. The Scottish Executive is in the process of commissioning research into sight screening in schools in Scotland, to determine the most effective model.

6.8 Support for the child or young person during the periods of transition. There are critical points in the life of any child when effective support will be particularly important:

- from home to pre-school provision
- from pre-school to primary school
- from primary to secondary school
- from school to tertiary education or employment.

- Each step serves to aid the child's development in a number of critical ways.
- Changes the nature of their dependence on and increases in their independence from others
- Widens their social world and increases the range and complexity of their personal networks and relationships
- Moves them physically further and further away from the security of home and local community: they are moving into ever noisier, busier and more demanding environments
- Promotes a sense of personal worth and competence
- Enables them to understand their ability to affect their world
- Learn new skills and knowledge
- Experience and understand new emotions and feelings
- Develop emotional resilience which will enable them to cope effectively and happily with each new transition and the associated demands

\textsuperscript{8} Health for all children 4 (Hall 4) Royal College of Paediatrics and Child Health 2003
Celebrate success and meet problems in positive and effective ways.

Children and young people with visual impairment experience the same successes and struggles as their sighted peers. They too depend on help and encouragement from others. However, they face unique challenges and have unique needs. They will often need more time and an enhanced level of support in order to prepare for and adjust to a new stage in their lives: both in overcoming practical obstacles and dealing with emotional and social demands and with the anxieties and uncertainties associated with change. Their additional support needs would include:

- Co-ordinated multi-agency planning, including the involvement of family members. This should take place well in advance of the transition point. For example, planning for a move from primary to secondary school should take place in primary 6.
- Clear advice and assistance, well in advance of each new step
- Early opportunities to visit new placements become more important as the child grows older
- A rigorous and systematic induction programme.
- Prior assessment, provision and training on any new technology required
- The teaching of any skills that will facilitate the smooth transition, for example, mobility and orientation skills based on the new placement.

7. Examples of good practice

7.1 Local coordination of health, social care and education services. Within the changing statutory framework for educating and supporting visually impaired children and young people, some local authorities, like Fife and East Renfrewshire, have developed efficient structures for cooperation and liaison. The CVISTA scheme in Tayside has a highly developed model of interagency cooperation. (see annex 2). This approach to shaping services
around the needs of the child or young person has the support of the Visual Impairment Paediatricians (Scotland) Group.

7.2 Consistent support and information for parents, children and young people. There can be tensions between the roles of service provider, advisor and advocate. Voluntary sector organisations are often well placed to offer an information, support and advocacy service. Both VIS and RNIB offer such a service on a national basis. Some local societies, like VISIBILITY and the Highland Society for the Blind have well developed children's services. A problem that is common to both local authorities and voluntary organisations is that children's services are sometimes an adjunct to adult services, rather than a specialist area of work. This can lead to difficulties in identifying who is responsible for commissioning information and support services for visually impaired children.

7.3 Making cultural and recreational activities available to visually impaired children and young people. The requirements of the Disability Discrimination Act and the Education (Disability Strategies and Pupils' Educational Records) (Scotland) Act 2002 should make all facilities and services accessible to all children. Some national and local voluntary organisations, like RNIB Scotland, VIS and VISIBILITY have developed specialist services, but there is no consistent level of provision across Scotland.

7.4 Meeting the needs of children who have other additional needs. The nature of childhood visual impairment, described in paragraph 3.2, means that many children have additional disabilities. Specialist services should be available to all children and young people who have additional needs to ensure that their sight problems are diagnosed and support is offered to them. There are examples of good practice in Scotland: like the Sensory Support Service (Visual Impairment) in Fife where the Community Paediatrician acts as a link between families and the local support agencies in health, education and social care.

8. **Recommendations for change**

It is recommended that there should be widespread consultation with visually impaired children and young people and their families, and with service providers on the following proposals for change.
8.1 That the planning of services is based on the broad definition of moderate and profound visual impairment, to include children who have additional disabilities.

8.2 Minimum standards should be established for interagency cooperation to meet the needs of visually impaired children and their families in Scotland.

8.3 Local services: the CVISTA scheme on Tayside is an example of good interagency practice, focussed on the needs of the child or young person. The principles underlying the scheme should be applied across Scotland. (see Annex 2)

8.4 The deployment of specialist staff: minimum standards should be established in terms of a ratio of key professionals to population of visually impaired children.

8.5 Mobility and independent living skills should be taught to children, starting in the preschool years, and the emphasis on inclusion should extend beyond practical issues to include emotional and psychological skills.

8.6 Visually impaired children and young people should have equal access to leisure services, consistent with their rights under the Disability Discrimination Act.

8.7 Certification and registration: any new system must make sense in terms of the needs of children and young people, rather than being just an extension of the adult system. A system of notification should be considered, in addition to registration or in place of registration.

8.8 The responsibility for commissioning, supplying and maintaining equipment, technology and low vision aids should be clarified, so that families know what level of service they can expect.

8.9 A national transcription service should be established.
ANNEX 1

MEMBERSHIP OF THE WORKING GROUP ON CHILDREN’S SERVICES.

Valerie Breck, Operational Director, VISIBILITY

Rod Burns, Early Education and Childcare Division, Scottish Executive Education Department.

Dr. Margot Campbell, Associate Specialist, Child Health, NHS Tayside.

Mary Dallas, Education and Family Services Manager, RNIB Scotland.

Sandra Gollan, Chief Executive, Dundee Society for the Blind.

Professor Gordon F. Dutton, Consultant Ophthalmologist, Royal Hospital for Sick Children, Yorkhill.

Gladys Henderson, Head of Orthoptics, NHS Lanarkshire

Jane Horsburgh, Policy Officer, Guide Dogs

Rosemary Laxton, External Consultant, Phase Three Consultancy.

Tom Lowe, Senior Psychologist, North Lanarkshire Council.

John Ravenscroft, Head of Centre, Scottish Sensory Centre.

Danny Sweeney, Sensory Impairment Team Leader, North Ayrshire Council Social Work Department.

Mike Cairns, on secondment from RNIB Scotland to the Scottish Executive Health Department. (Convenor of the Working Group)
ANNEX 2

CHILDREN’S VISUAL IMPAIRMENT SERVICES
TAYSIDE AGENCIES (CVISTA)

CVISTA is an interagency group of professionals in Tayside working in a coordinated way to provide services for children with visual impairment and their families.

There are three CVISTA teams in Tayside, one in each of the local authority areas, Dundee City, Perth and Kinross and Angus.

The first CVISTA team was established in April 2003. Prior to this, the situation with regard to provision of services for children with visual impairment was as follows.

- It was apparent that there were many professionals from health, education, social services and voluntary agencies providing services for visually impaired children and their families.

- Individual professionals were providing valuable services but were doing so mostly independently of other agencies. Some examples of interagency working were in place, although frequently on an informal basis and although referrals between the agencies were being made, these were mostly on an ad hoc basis and there was no formal, agreed interagency referral pathway.

- There was lack of communication between professionals who were not always aware of the services provided by other agencies and did not fully understand the role of other professionals. This often resulted in overlap and duplication of work, with parents at times feeling overwhelmed by the number of professionals involved. At other times there were gaps and delays in services being provided.

- For many aspects of service provision, registration on the blind and partial sight register was required. However, many children not on the register were known to have a degree of visual impairment requiring additional support. In addition, it was increasingly recognised that many children with neurological conditions, particularly those with complex needs have visual difficulties. These difficulties were not being fully identified and taken into account when considering the child’s developmental and educational needs.

CVISTA Teams

The CVISTA teams were initiated by a community paediatrician. This was following successful bids to the Changing Children’s Services Fund in the three local authority areas of Tayside. The Changing Children’s Services Fund was a Scottish Executive initiative providing short term funding in local authority areas to reorganise children’s services to make them more effective and efficient with an emphasis on interagency working.
The CVISTA teams comprise professionals from Health, Education, the Societies for Blind and Partially Sighted People, The Guide Dogs for the Blind Association, RNIB Scotland, SENSE Scotland, PAMIS, Parent to Parent and Barnardos.

There are local variations in the way in which services are provided across Tayside. However all three teams have adopted a similar approach to develop coordinated interagency services for children with visual impairment.

**THE CVISTA TEAM APPROACH**

**Aims of Providing Services for Visually Impaired Children and their Families**

The CVISTA teams first agreed their joint aims. These were for each individual child,

- to achieve their developmental potential
- to achieve their educational potential
- to make friends and form relationships
- to have access to sporting and leisure activities
- to be able to develop their own interests
- to have equal opportunities for tertiary education and employment
- to be as independent as possible
- to be included in society

**The Process for Achieving Aims**

The teams also agreed the process for achieving these aims which would be by

1. partnership with parents
2. mapping interagency referral pathways
3. coordinated interagency management plans

**1) Partnership with Parents**

Parents need to be given information about the cause of the child’s visual impairment and about the support services available. Parents are key people in the management of their child’s visual impairment and professionals need to be able to advise and support them in implementing strategies which will maximise their child’s development and independence.

**2) Interagency Referral Pathways**

Firstly the professionals clearly defined their individual roles and the services provided by their agencies. The teams then mapped out interagency referral pathways. To facilitate this task the teams thought of a baby or young child newly diagnosed as having a visual impairment and mapped their journey with input from the appropriate agencies at the appropriate times.
There are in fact two pathways for visually impaired children:-

1. For the infant or young child newly diagnosed as having a visual impairment with no associated disability.

2. For the infant or young child with visual impairment associated with developmental delay and complex health needs. These are the children who are likely to have cerebral visual impairment.

The Dundee CVISTA pathways are given here as examples.
Interagency Referral Pathway - 1 (Dundee Team)

The infant or young child newly diagnosed as having a visual impairment with no associated disability.

1. Ophthalmology

Concerns about a child’s vision may be raised by their parents or by any other person having contact with the child. Referral to ophthalmology is usually from the General Practitioner or may be from a paediatrician if the child is in the Neonatal Intensive Care Unit, ward or attending an outpatient clinic when concerns are raised. All children who have visual difficulties which are not corrected by wearing glasses should be assessed by an ophthalmologist.
2. **Blind / Partial Sight Register**

If the child has a significant visual impairment, when appropriate and if the parents are in agreement, the ophthalmologist will register the child on the blind/partial sight register, which is held by the local Blind and Partially Sighted Society.

3. **Parent Support**

Early parent support is extremely important and Parent to Parent is an organisation supporting parents of children with special needs. There is a support worker at Ninewells Hospital who supports parents of children in the Neonatal Intensive Care Unit and ward and who can also be called to a clinic to support parents who have just become aware of their child’s difficulties.

4. **Community Visual Impairment Team**

The ophthalmology team refer to the community visual impairment team. This is a joint referral to the specialist teacher for visually impaired children and to the community paediatrician. The specialist teacher takes on a key worker role and visits the family at home.

5. **Developmental Vision Clinic**

The community paediatrician is a doctor specialising in child development and visual difficulties. Children with visual impairment are at risk of having developmental delay. It is important that the development of pre-school children with visual impairment is monitored at the developmental vision clinic and strategies put in place to promote development. The occupational therapist also has a specialist knowledge of how children acquire independence. They have particular experience in developing strategies to help the child reach their potential.

6. **Functional Vision Assessment Clinic**

Functional vision is the sight available for use in every day activities. Detailed information on functional vision of children of all ages is essential for parents and professionals and is the starting point for strategies for development, education, mobility and independent living skills. The multidisciplinary clinic comprises an orthoptist and/or optometrist, a community paediatrician and a specialist teacher for visually impaired children. Orthoptists are expert visual assessors of children and are crucial in carrying out the initial functional vision assessment. A hospital optometrist is also involved with the functional vision assessment team to incorporate low vision aid assessment from nursery stage onwards. Low vision aids include magnifiers for close work and telescopes for distance. Low vision aids are alternatives to more technical supports and are essential for out of school learning and independence. Following the assessment the community paediatrician compiles a report explaining the child’s visual difficulties in the context of their medical problems. Together with the VI teacher the team devise developmental and
educational strategies including the use of low vision aids and distribute the report to the child’s parents and all the professionals involved.

7. **Visual Impairment Scotland**

The community visual impairment team notify the child to Visual Impairment Scotland when it is appropriate and if parents are in agreement. Visual Impairment Scotland is a national organisation based at the Scottish Sensory Centre in Edinburgh. This organisation has developed a new notification system for visually impaired children and provide an information and contact service for visually impaired children and their families.

8. **Other Therapists**

The child may require speech and language therapy to aid language development and communication and may also benefit from physiotherapy with regard to motor development. These referrals are made by the community paediatrician.

9. **The Guide Dogs for the Blind Association**

Mobility training has been identified as the key to future independence. It is rarely appropriate for a child to have a guide dog, although this may be considered at the time of transition to adulthood. The Guide Dogs for the Blind Association however provide specialist mobility instruction to children at home, at school and in the community. The association have entered into a service agreement with Dundee City Education Department and are involved with visually impaired children as soon as they start to be mobile. The association works very closely with parents, specialist teachers and occupational therapists in this regard.

10. **Educational Psychology**

The specialist teacher refers the child on to educational psychology at age two years for assessment and identification of their educational needs and to plan for nursery and school provision.

11. **The Dundee Blind and Partially Sighted Society**

The Blind and Partially Sighted Society has the statutory duty to maintain the blind and partial sight register. The society provides services mostly to children who are on the register but also to other children with significant visual impairment who, for whatever reason, are not registered. Services provided are broadly divided into social work care management services including assessment of need and rehabilitation provision. If necessary the society can provide services at any point. However, to coordinate roles and to avoid overlap and duplication the society input is in close liaison with the community visual impairment team who have the lead role in coordinating the child’s management. The appropriate time for parents and children to become acquainted with the society is at age three years. At this point
services are discussed and advice can be given on equipment, toys, games and low vision products e.g. talking watches, the availability of travel passes from age five years and so on. Further input depends on the individual needs of each child. When not actively involved the society as a statutory body have a monitoring role and will receive details of the interagency management plan. This is until the child is aged fifteen years when the society then has a key role with all visually impaired children in post-school planning to ensure smooth transition to adulthood and continuing of appropriate services.

12. RNIB Scotland

Referral to RNIB Scotland is when required and of course parents can self-refer and are given the contact information in this regard. RNIB services are extensive but family services include provision of information and advice, home visits, hosting of supported family group events and advice on local and national support networks. RNIB also provide technology services and training. They also offer advice and support to post-sixteen pupils. In addition RNIB provide consultation and mediation services to assist parents if they are unhappy with any aspect of their child’s management.

Interagency Referral Pathway - 2 (Dundee Team)

The infant or young child with visual impairment associated with developmental delay and complex health needs
1. In this pathway too assessment and diagnosis of the child’s medical difficulties are carried out by the hospital teams.

2. Parent to Parent are available for support.

3. Registration on the blind and partial sight register is carried out if appropriate.

4. There is a different community team coordinating the care of these children, the community complex disability team, which is led by a consultant paediatrician.

5. The community visual impairment team have an important role with these children although visual impairment is only one aspect of their difficulties. The team carry out functional vision assessment and make appropriate recommendations with regard to visual strategies for the child which are incorporated into other aspects of the child’s management.

6. Notification to the Visual Impairment Scotland Register is carried out if appropriate.

7 & 8. Referrals to other visual impairment agencies are made if required.

Other support agencies are available for this group of children -

9. The Social Work Child Health Team undertake assessment of need and make appropriate provision.

10. Sense Scotland is an organisation providing services to deaf, blind and multiply impaired children and their families. They have particular expertise in communication strategies.

11. PAMIS provides support to the families of children who have profound and multiple learning disabilities. They also promote the inclusion of people with profound disability into society.

12. Barnardos provide community support for families of children who have severe and profound learning disability.

13& 14. The Pre-school Home Visiting Teacher liaises closely with the specialist teacher for visually impaired children and referral to educational psychology is made for planning of educational needs.
(3) **Coordinated Interagency Management Plans**

The key to delivering appropriate services in a coordinated way is to have an interagency management plan in place for each individual child from the time visual difficulties are identified. The services provided are more important than exactly which agencies are involved as these vary from area to area.

In the CVISTA model, the community paediatrician is the overall team coordinator. The visual impairment teacher is involved with children with visual difficulties from birth until leaving school. It is the visual impairment teacher who has the keyworker role for individual children.

Together the community paediatrician and visual impairment teachers form the core community visual impairment team for children. This core team has the responsibility to work closely with parents, to gather information, to organise appropriate assessments and to involve other professionals as agreed in the interagency referral pathways. Services are provided according to the child’s needs.

The Interagency Management Plan records the agencies currently involved with the child, a medical summary, education details and additional information and points for discussion including current concerns. There then follows a check list of assessments and supports required leading to an action plan with action points for individual professionals. The plan review date is also included.
The plan proforma follows.

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MEDICAL SUMMARY:

EDUCATION: IEP/CSP

Mainstream with peri support/VI Resource Location/Specialist School

Equipment

Date of Education Review:

Additional Information/Points for Discussion
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<th>Assessment/Input</th>
<th>Ongoing/Support/Review</th>
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The Practical Model

- The core team (community paediatrician and visual impairment teachers) meet three monthly to discuss interagency management plans. (i.e. once a term).

- The mobility officer is also usually involved at these meetings as they have input at some point with most of the children.

- The CVISTA professionals have identified that a rehabilitation worker should also be an essential team member. However, a national shortage of rehabilitation workers contracted to work with children is acknowledged.

- Other key professionals who may be involved with many but not all of the children, e.g. Sense Scotland, the Blind and Partially Sighted Society will attend part of the session and the children with whom they are involved are grouped together for discussion.

- When a new plan is drawn up a review date is set. Not all plans are reviewed three monthly, for example some may be reviewed annually. At certain points in a child’s life such as transition times, the plan is likely to be reviewed more frequently.

- Parents do not attend the interagency management plan meetings as many children are discussed in the one session, however parental consent is required for the process to take place and the visual impairment teacher or
other appropriate professional takes the parental concerns and point of view to the meeting as well as feeding back after the meeting to discuss any suggested action points.

Key Points

- The community visual impairment team can be involved with any child who has a visual difficulty and involvement does not depend on
  
  o the child being registered blind or partially sighted
  o there being a definite diagnosis
  o a prognosis of deterioration or improvement

- Referral to the team does not automatically trigger the entire interagency referral pathway but involves professionals at the appropriate times according to the needs of the individual child. For some children the core community visual impairment team may monitor their developmental progress and if vision improves they may not ultimately have any additional support needs. For other children all agencies are involved in a coordinated approach until transition to adulthood.

The Additional Support for Learning Act

The act gives the education authority the responsibility of identifying and providing appropriate provision for children with additional support needs living in the local authority area. The act puts a duty on health, social work and other appropriate agencies to support the education authority in this responsibility.

The main document pertaining to a child’s additional support needs in school is the IEP (Individualised Educational Programme) and if the child’s needs cannot be met by education alone, then a CSP (Coordinated Support Plan) is drawn up with input from the relevant agencies. Additional support needs should be identified from birth or as soon as they arise and, if appropriate, a coordinated support plan put in place at age three years.

The CVISTA model enables the agencies providing services to visually impaired children to fulfil their duties under the act. The interagency management plan informs the child’s individualised educational programme or coordinated support plan and supports schools in their responsibility to ensure that the appropriate additional supports are in place for individual children.

Review of Blind and Partial Sight Registration of Children in Scotland

Review of this process is being undertaken as part of the Eye Care Review. The CVISTA model circumvents many of the disadvantages of the current registration system and provides locally coordinated services to children according to their individual needs.
Best Practice Guidelines / National Standards

In order to provide the optimal assessments and services detailed in the interagency management plan, the CVISTA professionals have identified a need for comprehensive guidelines. In many of these areas no minimum standards or guidelines for childrens' services exist.

As a Tayside-wide project, CVISTA has already drawn together good practice guidelines for mobility and orientation training with similar guidelines for the acquisition of independence skills currently in progress. However, national standards for all areas of service provision are required along with an appropriate system to ensure implementation.

Dr Margot Campbell
Community Paediatrician

October 2005
1. **Introduction**

1.1 In March 2004, the Deputy Health and Community Care Minister launched a review of community eye care services. The review was wide ranging and covered all aspects of the patient's journey from the first detection of a sight problem to full diagnosis, treatment (where possible) and support in adjusting to a visual impairment. The system for certifying and registering people who have been diagnosed as having serious and uncorrectable sight problems was examined in detail. Attention was given to the particular needs of visually impaired children and young people. The importance of the high street optometrist as a first point of contact with patients was acknowledged and a new contract has been introduced to widen the optometrist's role. In pursuit of a more holistic, patient-centred approach, a study was set up to examine interagency work in three localities in Scotland.

2. **The reason for the study**

2.1 A series of reports have been critical of the quality of support available to visually impaired people in Scotland. "Sensing Progress" (Scottish Office 1998) (1) reported that services were inconsistent and the poor communication between health and social work often left people without support for long periods. The picture of widely varying levels of service was reflected in a series of reports by RNIB (2). Visual Impairment Scotland (3) published a report in 2003 that highlighted the difficulties faced by children and young people. The eyecare review was seen as an opportunity to look in detail at the problems of delivering integrated services and in particular to focus on localities which had achieved some success in collaborative working.

3. **The study**

3.1 Three localities were chosen for the study. They were selected because they had achieved a high level of joint working that involved all of the key partners in community eyecare. Each of the three localities had developed a working model that was appropriate to their geographical characteristics and fitted the local configuration of services. There are other examples of good interagency work in Scotland, but
they do not all include all potential partners. The emphasis on locality working is stressed because of the importance of making services accessible to all visually impaired people.

3.2 The three localities chosen for the study were Edinburgh, Fife and Forth Valley. The starting point was to demonstrate different approaches to problems that had been identified in earlier research. Three critical issues were identified:

3.2.1 Helping people to gain access to help at the earliest point in the patient journey.

3.2.2 Ensuring that long term support is available (if required) when the nature of the sight problem is diagnosed and its impact on the life of the individual can be foreseen.

3.2.3 The provision of accurate and accessible information at every point in the patient journey.

3.3 A management group was established in each of the three sites, with representatives of local stakeholders. The groups were supported by an external consultant and by the project coordinator from the Health Department. Each management group identified ways of strengthening the local network and the Health Department provided short-term funding.

3.4 The expected outcomes from all three sites were:

3.4.1 All patients who had significant sight problems would be offered up to date information about their diagnosis, treatment, available services and financial benefits. The information should be available at local health centres, high street optometrists, social work departments, eye clinics and other relevant community facilities.

3.4.2 All patients should have early access to low vision services, including the supply of equipment to assist them to cope with the impact of sight loss. Contact between the members of the interagency support network should also make it easier to prioritise referrals to the eye clinic.

3.4.3 Immediate assistance should be available to patients at the critical point when the diagnosis of uncorrectable sight loss is
made. This should include emotional support (when required) and information about the likely impact of the eye condition and the help that is available. The benefits of registration should be explained to the patient. This approach aims to make best use of scarce professional resources by tailoring the level of support to the needs of the patient.

3.5 The audit process.

3.5.1 The external consultant carried out a detailed audit of service patterns in each locality, prior to the start of the six month study. The initial audit included a survey of patients' views about local services. At the end of the six month period another audit was done to measure changes. Again, a sample of patients' views was taken and the service providers were invited to comment.

4. The characteristics of the three localities

4.1 Edinburgh. Edinburgh was chosen for inclusion in the study because of changes being made in the Princess Alexandra Eye Pavilion. The Clinical Director took advantage of additional space becoming available in the Eye Pavilion to create a patient support and research facility which he called Visioncentre 3. In addition to the research programme, an interagency team was recruited to improve the level of patient support within a very busy eye hospital.

4.1.1 Issues identified in the initial audit were:

- The length of the patient journey, from the first indication of a sight problem to an appointment with a consultant ophthalmologist and subsequent referral to the local social care agency. It could take more than a year to complete the journey.

- Limited support for patients while they waited for an appointment with the Consultant Ophthalmologist

- Limited resources for low vision: only one half-day low vision clinic per week

- Variations in the volume and quality of information for patients at every stage of the process.
4.1.2 Activity undertaken as part of the eyecare review:

- The establishment of a community optometry scheme, to provide rapid and uncomplicated access to low vision equipment and to bring community optometrists into the local eyecare network.

- Additional low vision clinics

- The establishment of a patient support centre, staffed by a social worker, a rehabilitation worker and an information worker. (A welfare rights adviser was later added to the team.)

- An information audit and the creation of an information strategy.

4.2 Fife. Fife was chosen because it has a well developed, community-based, Sensory Impairment Centre. The centre is run by Insight, the local society for the blind, which provides social work and rehabilitation services on behalf of Fife Council. Fife Healthcare Trust has well established, ophthalmology-led low clinic in the centre. The third main partner is the local optometrists group. They had set up a ground-breaking community optometry scheme that covered Fife. The scheme had been closed down because of lack of funding, but it was reinstated as part of the eyecare review.

4.2.1 Issues identified in the initial audit were:

- Response times were better than the Scottish average. The majority of newly registered patients who were referred to the Insight team were seen within four weeks.

- Although there was a limited amount of information for patients in the general eye clinics, the low vision clinics based in the Centre (and the cataract clinics) had a good supply of relevant and accessible written information.

- There was a high level of integration between the eyecare professionals, leading to a flexible and efficient service.
4.2.2 Activity undertaken as part of the eyecare review:

- The re-establishment of the community optometry network
- The introduction of a patient information summary sheet, to give patients customised written information when they attended clinics
- The testing of a GP referral pad, to encourage earlier referral of patients with sight problems to the Sensory Impairment Centre.
- An attempt to make closer links with a hospital outside of the area which took some patients from Fife.

4.3 Forth Valley. Forth Valley was the most complex of the three localities chosen. It brought together social work and rehabilitation staff from three local authorities, along with medical staff based in two hospitals. It was included in the study because a consortium of the three local authorities, the Health Board, national voluntary organisations and local service user groups were in the process of building a community-based Sensory Impairment Centre. The aim of the six month study was to examine the impact of the new centre on local services. In the event, delays in the building programme meant that the centre did not open till the end of the study period, so the activities studied were hospital-based.

4.3.1 Issues identified in the local audit were:

- Variable waiting times for social work assessment after certification: from under four weeks in Clackmannanshire to eight weeks in Falkirk.
- Very limited written information at the eye clinics
- Better waiting times for the low vision equipment clinic than the other two localities in the study, on average three weeks.

4.3.2 Activities undertaken as part of the eyecare review:

- The establishment of additional social work and rehabilitation posts, to increase joint working with clinical staff at eye clinics.
The establishment of a multi-disciplinary registration clinic, to give rapid access to the relevant professionals at the point of certification and registration.

The creation of additional low vision clinics to facilitate access to low vision equipment while waiting for an appointment with the ophthalmologist.

The publication of a new information booklet, in accessible formats, covering all of the agencies involved.

5. **The results of the study**

5.1 The results of the study can be summarised under three headings:

- The impact on patients
- The development of working relationships between the staff involved in the three areas
- Lessons about managing change.

5.2. **The impact on patients.**

5.2.1 **Earlier access to low vision equipment.** The re-established community optometry network in Fife and the new network in Edinburgh both made equipment more accessible to patients. (The configuration of optometry services in Forth Valley was different to the two other localities, with a higher level of hospital based optometrists. The local high street optometrist's group decided not to opt into a community optometry network.) In Fife and Edinburgh, participating optometrists were supplied with a stock of simple low vision aids. The impact on patients was very positive. In Fife, 58% of patients were seen by a community optometrist within two weeks of being referred, a further 24% within a two to four week period. In Edinburgh, 72% of patients were seen within two weeks, 8% within four weeks and the remainder within five to seven weeks. All of the response times are considerably shorter than low vision clinics can usually offer. In Fife, the Sensory Impairment Centre also provided a focal point for other services and it was widely used by patients whose first contact was with community optometry. The majority of those who
used the Sensory Impairment Centre were not registered as blind or partially sighted, demonstrating its effectiveness as an early point of contact. The newer community optometry scheme in Edinburgh had a lower rate of referring on to the patient support centre (19%), possibly because referral protocols were not well established. **Patients who used the service expressed a high level of satisfaction with it.** It gave rapid and uncomplicated access to equipment and problems could be resolved quickly. For those who needed other forms of assistance, the community optometry network provided a good first point of contact with other services.

5.2.2 **Earlier access to health and social care.** The interagency model succeeded in giving patients earlier access to the full range of health and social care services. In Fife, where there is a well-established ophthalmology-led clinic sited in the Sensory Impairment Centre, waiting times for patients who had not previously seen an ophthalmologist fell from seventeen weeks to ten weeks during the study. One of the strength of locating the clinic in the centre is the availability of social workers and rehabilitation staff on site. In Edinburgh, 331 patients visited the patient support centre in the six months of the study. Of those who were referred by clinicians, 83% were seen on the same day. This is considerable improvement on the previous waiting time for social work contact. Those patients who presented more complex problems were referred on to RNIB (Edinburgh and the Lothians) for longer term support. In Forth Valley, the delay in opening the new Sensory Impairment Centre made it difficult to assess the impact of change. Pending the opening of the new centre, multidisciplinary low vision clinics were organised in the hospital. The new clinics did offer a faster and more efficient "one stop" service. As indicated above, the community optometry networks in Edinburgh and Fife were successful in putting patients in touch with other agencies. This service was particularly important for patients who were not yet registered; in Fife they formed 64% of the patients referred on by community optometrists, in Edinburgh 45%. **In summary the community optometry networks and the multi-agency arrangements were successful in improving the efficiency of the service, at every stage in the patient journey. This was the case for patients who needed only minimal assistance, as well as for those with more complex needs.**
5.2.3 Improved information. One of the aims of the study was to improve the quality of information at every stage of the patient journey. In Fife, the new information sheet was developed. When patients and their carers attend clinics, they are given personalised information summaries which describe in plain language the nature of the sight problem, its likely impact and the names and contact details of those who can offer assistance. In Edinburgh, a worker was employed to devise an information strategy, which is being implemented. In Forth Valley information about all of the services available has been brought together in a single publication. Each of the localities took a different approach to improving information for patients, as they were at different stages of development. All three have achieved some success in making information more available to patients.

5.3 Improving working relationships. In all three sites, the staff involved were positive about the advantages of closer working. There were some teething troubles, as hard-pressed members of staff had to adapt to change, but all of them could see the benefits of creating a more seamless service for patients. In Fife, the reintroduction of the community optometry network brought a key group of staff back into the local network. In Edinburgh, the creation of Visioncentre 3 has brought a wider range of staff into the Eye Pavilion and new links have been formed between professional groups. In Forth Valley the presence of social work staff in registration clinics has been seen as a positive development, both for patients and for the staff involved. Since the end of the six month study, the new centre has opened and the benefits of closer working relationships are apparent. In summary, the staff involved in the study have been positive about the experience of closer working relationships. Although the detail of organisational arrangements may not be directly apparent to patients, the impact on the quality of the services has been widely appreciated.

6. Managing change

6.1. Although most of the objectives of the study were met, there are some lessons to be learned about the way in which the study was set up, the difficulties of "grafting on" a new development in busy work settings and the need to link local projects to the wider environment.

6.1.1 Bottom up or top down development? The setting up of the three locality studies was negotiated directly with key staff, rather than through a more formal approach to the agencies that
employed them. Organisational issues were resolved, but there were some delays in starting the studies. There is, perhaps, a balance to be struck between local creativity and formal strategic planning.

6.1.2 Extending local networks. Not all of the local initiatives succeeded. A planned GP referral scheme did not materialise. Initial enthusiasm for the project was not sustained in practice. Similarly, an attempt to synchronise referral procedures with a large hospital in an adjoining area proved to be more complex than expected. In both cases there was no lack of good will on the part of any of the participants. More detailed planning might have highlighted the difficulties of matching different systems, particularly in a time limited project.

6.1.3 The impact on existing services. In Edinburgh, the creation of the patient support centre was welcomed by all of the staff in the Eye Pavilion, but the impact of the changes did create additional pressures for an already hard-pressed group of staff. The problems were resolved in the course of the project, but better preparation might have smoothed the way. Similarly the need to collect data for the study meant additional record-keeping in all three localities and it required flexibility and goodwill from support staff and managers to accommodate the additional work.

6.1.4 The time limited nature of the project meant that the building of professional relationships was sometimes done more quickly than was ideal. An agreement to enter into a joint project does not guarantee a smooth transition from previous working practices. The study proved that successful partnerships are possible and beneficial to patients and staff, but the complexities of creating them should not be underestimated.

6.1.5 There were varying levels of organisational change taking place in the three localities, during the period of the study. This made life difficult for staff directly involved in the studies and sometimes for others. In retrospect, a more detailed reconnaissance of the three localities might have helped to anticipate the problems of managing change in a turbulent environment.
7. **Key elements of a successful locality interagency visual impairment service**

7.1 The development of a well established working partnership between key staff in health, optometry and social care (both in the statutory and voluntary sectors).

7.2 The integration of different services to create a continuum that covers every stage of the patient journey. The re-referral of patients should be avoided, particularly when all that is required is a simple assessment and the issue or reissue of low vision equipment.

7.3 The integrated approach enables joint ownership of work between the partners and the provision of a seamless service. For example, a community optometry assessment might result in the issue of low vision equipment to deal with an immediate problem. The subsequent involvement of a social worker or rehabilitation worker might lead to a more detailed assessment of the patient’s longer term needs and a more extensive package of care.

7.4 Joint working on a shared site establishes closer co-operation, better understanding of each worker’s role and flexibility based on mutual trust. This leads to best practice and effective use of scarce resources.

7.5 There appear to be substantial gains from organising services around a multi disciplinary low vision clinic, whether this is located in hospital or in a community setting.

7.6 There should be a recognition that services need to continually adapt and improve.

7.7 The guiding principle should be organising services around the patient, rather than sending the patient to find the service.

7.8 The involvement of service users should be built into the planning and development of services.
REFERENCES


   "Shaping the Future" RNIB (2001)
   "Improving lives" The Improving Lives Coalition (2001)

Annex G
Community Optometry Model for the Future

Two levels of community-based care have been proposed depending on the nature of involvement, clinical competency, training, and patient management. Initial assessment may lead to treatment there and then, or may enable the patient to be treated by other specialties and follow the relevant care pathways.

There are principles that would be common to any optometry based service such as:

• Wide and easy access for most patients (optometry practices are near to where people live)

• Delivery in community optometric practices or other appropriate setting, e.g. residential home, personal home

• Flexible and convenient appointment systems

• Rapid access to an eyecare professional - within one week for most patients

• Flexible capacity for repeat procedures as required

• Accurate and effective differential diagnosis in a community setting

• Communication of findings to the patient with the opportunity to advise and counsel as required

• Effective channels of communication between all stakeholders GPs, hospital ophthalmology and social care – preferably by NHS Net

• Direct, prioritised referral to the acute/secondary sector by optometrists as required
Level 1

Level one was introduced in April 2006 as part of the revision of General Ophthalmic Services. It has been implemented across Scotland and forms the basis of the New NHS Eye Examination, of which the key components are:

- An eye health check
- External examination of the eyes by slit lamp biomicroscopy
- Internal examination with slit-lamp biomicroscopy (with dilation and condensing lens where necessary)
- Assessment of pupil reflexes and extra ocular motor function
- Supplementary tests as required to ensure an accurate diagnosis (repeat/additional procedures)
- Diagnosis and treatment of commonly occurring eye conditions up to referral to level 2 management or a care pathway
- Measuring intra-ocular pressure when clinically necessary by applanation tonometry
- Automated perimetry when clinically necessary
- Refraction and muscle balance tests
- Prescribing of optical aids
- Direct referral for ophthalmological or orthoptic assessment
- Maintenance of appropriate clinical records including a full data set of findings

This level of initial assessment identifies the general nature of an eye condition; it’s probable aetiology and describes the appropriate patient journey. It also helps to reduce inappropriate referrals to the acute sector and provides a facility to prioritise those that need to be referred to hospital.
Level 2

This would involve some additional training and would be delivered in the community, in audited practices by accredited optometrists. This is a similar service to the GIES system currently operating in south Glasgow and the HIES system in Highland.

This could include the following key components:

- The capacity for the primary management and treatment of many common eye conditions by Optometrists within their scope of practice
- The safe management of a wide range of external/anterior eye conditions
- The co-management of chronic eye disease such as glaucoma, cataract, diabetes, macular degeneration, and dry eye disease.
- The development of community Low Vision networks
- Accurate and effective diagnosis and ongoing treatment of children with strabismus
- Option as an entry point for access into Eyecare pathways

This level of initial assessment will provide a more sophisticated analysis of the condition. It will provide more detailed understanding of the condition that will allow treatment, management and counselling within primary care, and ensure appropriate prioritised referral for those that need to be sent onto an Ophthalmology department.

This would provide an improvement in eyecare delivery for a large number of patients with moderate additional training/ accreditation for most Optometrists.
Annex H
THE REVIEW OF CERTIFICATION AND REGISTRATION IN SCOTLAND

A REPORT TO THE EYECARE REVIEW STEERING GROUP FROM THE WORKING GROUP ON CERTIFICATION AND REGISTRATION

1. The context of the report.

1.1 The system for certifying and registering people as blind or partially sighted is widely regarded as outdated and inefficient. There have been several reports which have recommended changes in Scotland: "Sensing Progress" (1998) and "The Report of the Certification and Registration Working Group" (2001). Both reports have been well received in the blind community in Scotland, but no action has been taken to change the system. A further study was commissioned and a report was produced in 2003, which confirmed the need to modernise the health and social care response to sight loss. The current working group was set up in March 2005, as part of the more broadly based review of eyecare services in Scotland. The aim is to make recommendations for a radical overhaul of certification and registration in the report of the eyecare review.

1.2 The certification and registration system in England was changed in 2004. The Scottish working group has had the benefit of advice from colleagues in England, both about the changes that have been made and the way in which those changes are being implemented.

(A summary of the new English Certification and registration system is given Annex 2 of the report)

1.3 The current certification and registration system in Scotland is based on the provisions of the 1948 National Assistance Act, as amended by the Social Work (Scotland) Act 1968. An individual who has a serious and uncorrectable sight problem can be certified as blind or partially sighted by a Consultant Ophthalmologist. With the patient’s consent, the certification form can be passed to the local authority, or its agent, and the patient can be placed on a register. Thus the certification and registration system is, among other things, the formal point of contact between
health and social care services. Visual impairment can create many practical, emotional and social difficulties in daily living and the experience of certification can be traumatic, so an efficient link between helping agencies is essential. For a variety of reasons that will be explored in this report, the current system of certification and registration in Scotland does not provide that link for many blind and partially sighted people.

1.4 Terminology. Different words are used to define loss of sight or the absence of sight and no single term is acceptable to all. The current registration system in Scotland still uses the terms "blind" and "partially sighted", so these terms will be used in the report, for the sake of clarity. The term "visual impairment" will also be used as a general description of both blindness and partial sight.

2. The objectives of certification and registration.

2.1 The Scottish Certification and Registration Group, working group, which reported in 2001, identified four main objectives:

2.1.1 A way of identifying people with a visual impairment who may need assistance in coping with sight loss.

2.1.2 A means of "passporting" benefits and services to people who have a visual impairment

2.1.3 A vehicle for carrying information between social and healthcare professionals

2.1.4 A means of collecting statistical information about the numbers of people who have a visual impairment and the causes of their impairment, as a means of informing service planning.

2.2 One of the aims of the wider eyecare review is to eliminate gaps in the current system for identifying sight loss to improve the quality of the response to the individual. The certification and registration system is at the core of the current, unsatisfactory response to blindness and partial sight, so change is essential if the objectives of the eyecare review are to be achieved.
2.3 A replacement for the current certification and registration system must include performance standards: so that patient can be confident that assistance will be offered within a reasonable timescale in a convenient setting. Community Health Partnerships will be required to publish their performance in relation to national standards and these should include services for people who are blind or partially sighted.

3. The shortcomings of the system.

3.1 As part of this review, a wide range of health and social care professionals were consulted, in addition to organisations representing blind and partially sighted people. Drawing on that consultation and on the work of earlier groups, the deficiencies in the current system can be summarised as follows

3.1.1 The definition of blindness for the purpose of registration. The threshold for registration is that an individual must be "so blind as to be unable to perform any work for which eye sight is essential."(The National Assistance Act 1948) The definition is limited because it is a by-product of legislation that was primarily concerned with the regulation of the workforce. It is perhaps an indication of the marginalisation of blindness that such a partial definition has remained at the core of the registration system for more than fifty years. Partial sight is not defined in the original legislation, but it is in the Scottish Office guidance: "A person who is not blind... but who is substantially and permanently handicapped by congenitally defective vision or in whose case illness or injury has caused defective vision of a substantial and permanently handicapping character."

3.1.2 The clinical criteria for the certification of blindness and partial sight are also regarded as archaic and unsatisfactory. Again, this may simply be a matter of history. The test is limited to visual acuity and visual field. These have been described as "blunt instruments." Clinical criteria based on modern ophthalmology should be used for assessing the degree of visual impairment, and its impact on the individual.
3.1.3 It has been argued that certification and registration should be more broadly based than a clinical judgement of the extent of visual impairment. The impact of blindness on the individual should be taken into account in terms of social circumstances, income and social care (if required). A more broadly-based definition of blindness would be consistent with the objectives of the eyecare review.

3.1.4 Registration is voluntary and there are wide variations in registration rates. Research by RNIB and others suggests that many people eligible to be registered have either chosen not to be or, in the case of many older people, they have not been offered the opportunity to be certified and registered. Partial registration leads to inaccuracies in calculating the incidence of blindness and partial sight. It also means that a substantial proportion of the blind and partially sighted population is excluded from the formal mechanism for triggering assistance.

3.1.5 There is evidence that registration may be used as a rationing rather than an enabling mechanism. The registration system was designed to identify those in need of support. However, because of the limitations listed above, it is less than accurate. In the absence of an assessment of an individual's needs, failure to register should not be taken as evidence that help is not required. This argument should apply to a range of financial benefits where registration currently confers eligibility.

3.1.6 Certification and registration is a linear process. There are often long delays between different stages of the process: from initial referral to diagnosis and certification by a Consultant Ophthalmologist; and from certification to registration and the offer of assessment to determine eligibility for assistance. There is no formal mechanism for triggering assistance during the period of the waiting. (Although some areas have developed good interagency links to overcome this problem). The impact of the delays will vary: from irritation for those who may not need anything more than simple low vision equipment to real hardship for many who are struggling alone to cope with degenerating sight.
4. The needs of particular groups within the blind and partially sighted population.

4.1 The blind and partially sighted population of Scotland is not a homogeneous group. The impact of visual impairment will vary between individuals, but it is possible to identify several subgroups within the wider population who have particular characteristics that should be taken into account when considering the reform of certification and registration.

4.2 Children and young people. There are significant differences between sight loss in children and in adults. Research by V.I.S and others has highlighted the following factors:

- The main cause of blindness in children is damage to the brain or to the optic nerve. By contrast, most adult blindness arises from damage to or diseases of the eye.

- Children commonly present with impaired vision very early in life. In adults, the main cause of blindness is age related macular degeneration, which usually takes the form of gradual loss of vision over a period of years. The difference is considerable. Loss of sight accords previous memory and an entirely different linguistic framework based on prior sight. Impairment from birth due to eye damage results in major brain adaptations. In children vision contributes to the development of the child in the acquisition of social, intellectual and mobility skills. Those without vision need additional assistance from an early age to prevent permanent disability.

- It is estimated that more than half of children who have severe sight loss have additional disabilities.

- The incidence of visual impairment in children in Scotland is lower than the incidence of adult blindness. (There are estimated to be 1400 blind and partially sighted children, in a total visually impaired population of around 90,000). Low incidence can mean that the families of blind and partially sighted people feel isolated.

- Although the use of the word "blind" is difficult for many people, it can be argued that it is particularly unacceptable
for families to accept such a definitive diagnosis of an infant. It is argued that the impact of childhood visual impairment requires a different range of responses to loss of sight, or failing sight, in adults. In children vision contributes to the development of the child in terms of the acquisition of social, intellectual and mobility skills.

4.3 Dual sight and hearing loss. Dual sensory loss or deafblindness often goes unrecognised. It is a low incidence disability and many health and social care professionals do not come into contact with it. The point of certification of blindness or partial sight can be particularly traumatic for an individual who already has hearing impairment. The fear of having a second impairment confirmed may be exacerbated by communication problems with ophthalmologists and other staff involved in the registration process. The problem could be ameliorated by providing appropriate communication support at the point of certification and throughout the registration process. It would be even more helpful to introduce patients to a potential support group at an early point in the process of diagnosing sight problems, so that detailed information on dual sensory loss and contact details could be provided.

4.4 Multiple Disability and sight loss. The current system of registration and certification fails to meet the needs of people with learning disabilities and suspected sight loss. Research by RNIB and others suggests that one in every three people with a learning disability has a degree of visual impairment. The publication of the Scottish Executive report "Same as You"( 2000), which set out a strategy for the development of learning disability services in Scotland, failed to recognise the extent of undiagnosed sight loss. RNIB Scotland is working with some local authorities to develop an optometry-led service to provide vision screening and practical assistance for individuals who have a learning disability.

4.5 Older people. It is estimated that 90% of the blind and partially sighted population is over the age of retirement. The incidence of visual impairment rises sharply with increasing age. A recent study commissioned by RNIB estimated that one in four of the over 85 population has a visual impairment. Older people are by far the majority of the blind and partially sighted population, but research by RNIB and others suggests that this group are poorly served by the certification and registration system.
5. Outstanding proposals for change.

5.1 The limitations of the certification and registration system have been apparent for many years. In Scotland, the Social Work Inspectorate Report "Sensing Progress" (1998) recommended that a multi agency working be set up to review the system. The report of a working group was published in 2001, but no action has been taken to implement its recommendations.

5.2 The certification and registration system in England was reviewed and extensive changes were made in 2004. The working group has had the benefit of advice from colleagues involved in the English review and some aspects of the new English system will be incorporated into recommendations for change in Scotland. A summary of the new English system is given in Appendix 2.

5.3 The Scottish Paediatric Ophthalmologists Group has made recommendations for changing the system of registration for children and young people. It is argued that the current system of certification and registration is particularly inappropriate. An alternative approach, based on local, multi agency cooperation, underpinned by the provisions of the Education (Additional Support for Learning) (Scotland) Act 2004, should be considered. The alternative model is described in more detail in the report of the Working Group on Children's Services. A report by Professor Dutton, on behalf of the Scottish Ophthalmology Group, is attached in Annex 4.

6. Factors that might limit change.

6.1 The legal framework. The legal framework for certification and registration in Scotland is the 1948 National Assistance Act, as amended by the 1968 Social Work (Scotland) Act. The scope for change is limited by the complexity of legal position. The report "Sensing Progress" recommended that a shift from two categories "blind" and "partially sighted" to a spectrum of sight loss that might be more a more accurate reflection of the reality of visual impairment. The new system in England has retained two discrete categories, although the terminology has changed. The legal advice given to the working group in Scotland is that it would be very difficult to move to a system based on a spectrum of visual impairment.
6.2 As described in paragraph 2.1.2 above, the current certification and registration system is a passport to a range of concessions and financial benefits. Any change that threatens these would be understandably resisted. The debate should be about eligibility for benefits and support based on personal need, rather than on an inaccurate and anachronistic system of registration. There should be wide consultation before any change is introduced.

6.3 Paragraph 2.1.4, above describes the collection of statistical information as one of the purposes of the system. It could be argues that the deficiencies in the current system devalue the data that is generated by it. However, an alternative means of collecting epidemiological and clinical data could be based on the collation of certification returns.

6.4 The complexities of change might be seen as a barrier to progress. There were problems with the implementation of the new certification and registration system in England. In planning change in Scotland, the English experience should be taken into account.

7. Recommendations:

7.1 The Working Group recommends that there should be a widespread consultation on the following proposals for the modernisation of the certification and registration system in Scotland:

7.1.1 That the new system should retain the certification of the patient's condition by a consultant ophthalmologist, but it should be based on a wider range of clinical criteria than visual acuity and visual field.

7.1.2 That the terminology be changed: "blindness" to be replaced by "profound visual impairment" and "partial sight" be replaced by "visual impairment."

7.1.3 That the collection of statistical data be based on certification, rather than registration.
7.1.4 That the current single stage registration system be replaced by a three stage system of notification of the patients need for assistance, based on the English system.

7.1.5 That the patient's need for assistance be based on an individual assessment, rather than registration status.

7.1.6 That there should be a separate system for certifying visual impairment in children and planning and co-ordinating services for them.

7.1.7 That the introduction and implementation of change be properly resourced, to avoid the problems experienced in the introduction of the new certification and registration system in England.

March 2006
ANNEX 1

THE MEMBERSHIP OF THE WORKING GROUP ON CERTIFICATION AND REGISTRATION.

Alex Davidson, Head of Adult Services, South Lanarkshire Council and Chair of the ADSW Standing Group on Disability

Professor Bal Dhillon, Consultant Ophthalmic Surgeon, Princess Alexandra Eye Pavilion

Professor Gordon F. Dutton, Consultant Ophthalmologist, Royal Hospital for Sick Children, Yorkhill.

Jane Horsburgh, VSS and Rehabilitation Services Development Officer (Scotland), Guide Dogs

Rosemary Laxton, Research Consultant, Phase Three Consultancy

Tom Leckie, Social Work Inspector, SWIA

Bryn Merchant, Assistant Director, RNIB Scotland

Frank Munro, Optometry Scotland

Jeannie Munro, Vulnerable People's Unit, Scottish Executive

Elaine Noad, Scottish Executive Efficiency in Government Team

Drena O'Malley, Chief Executive, Deafblind Scotland

Shelagh Palmer, Health Coordinator, VISIBILITY

Steve Whittacker, Optometric Advisor to the Scottish Executive

Mike Cairns, on secondment from RNIB Scotland to the Scottish Executive Health Department. (Convenor of the group)
ANNEX 2

A SUMMARY OF THE ENGLISH CERTIFICATION AND REGISTRATION SYSTEM (FROM 2003)

1. Terminology. The categories "blind" and "partially sighted" have been replaced by "severely sight impaired" and "sight impaired."

2. Notification. One of the criticisms of the old system was that patients had to wait for certification before any contact was made with social work services. There were sometimes further delays between registration and contact with the patient. To overcome the problem of leaving patients without support, the new English system has introduced three points of contact:

Letter of Vision Impairment (LVI) is a letter that can be given to the patient by the optometrist when a sight problem is first detected. The LVI is based on a national template, adapted by the local authority to give local information. The patient can insert personal details and send the letter to the local authority, requesting assistance.

Referral of Vision Impaired Patient (RVI) is a referral form that can be completed by any member of staff in the hospital eye service. With the patient's consent, the form can be sent to the local authority. It does not depend on the nature of the eye condition and it does not have to wait for the ophthalmologist's diagnosis. Neither does its completion depend on eligibility or willingness to register.

Certificate of Vision Impairment (CVI). This document replaces the BD8/BD1 form. It contains more information about the practical and emotional problems facing the patient. The form has also been modified to improve the collection of epidemiological data.

3. Implementation. There were problems with the introduction of the new system in England. The change was not well publicised and some Eye Clinics continued to use the BD8 after the introduction of the CVI form. However, RNIB reports that the new system is popular with in the areas where it has been properly implemented.
ANNEX 3

THE RECOMMENDATIONS OF THE 2001 REPORT ON CERTIFICATION AND REGISTRATION IN SCOTLAND.

1. Review the content, format and usage of the BP1 form.

2. Consult the relevant Whitehall Departments on replacing the current criteria for certification with a fuller assessment of visual impairment.

3. Consult the relevant Whitehall Departments on replacing "blind" and "partially sighted" with "visual impairment", to describe a continuum of sight loss and to consider a numeric score.

4. Establish a notification system.

5. The Scottish Executive to set up a development fund to support good practice initiatives.

6. The Social Work Inspectorate to regularly review the certification and registration process in Scotland.

7. Healthcare Trusts and Local Authorities to ensure full assessment by multidisciplinary schemes, based on three core areas: clinical information, visual function and quality of life.

8. Registered individuals should have their health and social care needs, including changes in their visual function, regularly reassessed.

9. Trusts and Local Authorities to investigate the needs of ethnic minority groups and make provision for them.

10. Each Local Authorities to establish a local multi-agency strategy and resource group to ensure a team approach to implementing these recommendations.

11. All local authorities to maintain accurate and up to date registers, or registers of notified individuals.
12. Social Work Departments, or their agents, to notify Education Departments of registered children and notification forms to be processed centrally as well as locally.

13. Initial contact should be made within two weeks of registration and, where appropriate, a community care assessment should be offered.

14. Primary Care teams and residential and nursing home staff should consider the benefits of registration.

15. All register holders should:

- provide accurate, up to date and accessible information on services and benefits
- have local agreements about the referral of patients
- have made provision for skilled emotional support
- have community-based staff in eye clinics, with access to low vision services.
ANNEX 4

PRELIMINARY RECOMMENDATIONS OF THE SCOTTISH PAEDIATRIC REGIONAL OPHTHALMOLOGY GROUP

Andrew Barr  Queen Margaret Hospital, Dunfermline
Godfrey Bedford  Dumfries and Galloway Royal Infirmary
Andrew Brown  Wishaw and Hairmyres Hospitals, Lanarkshire
Bill Church  Aberdeen Royal Infirmary
Gordon Dutton*  Royal Hospital for Sick Children, Yorkhill, Glasgow
Leonard Esakowitz  Royal Alexandra Hospital, Paisley
Brian Fleck  Princess Alexandra Eye Pavilion, Edinburgh
Nick George  Ninewells Hospital, Dundee
Jennifer Gillen  Stirling Royal Infirmary
Ivan Hanna  South Ayrshire District General Hospital
Tim Lavy  Royal Hospital for Sick Children, Yorkhill, Glasgow
Caroline MacEwen  Ninewells Hospital, Dundee
Jane MacKinnon  Royal Hospital for Sick Children, Yorkhill, Glasgow
Alan Mulvihill  Princess Alexandra Eye Pavilion, Edinburgh
Robert Murray  Borders General Hospital, Melrose
Alistaire Purdie  Royal Alexandra Hospital, Paisley
Chris Scott  Aberdeen Royal Infirmary
Shona Sutherland  Queen Margaret Hospital, Dunfermline

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INTRODUCTION

The implications for visual impairment in a child are different to those in adulthood.

In adults pre-existent vision is lost.

In children, visual impairment is present from birth or has an onset in early in life in the majority of cases.

Vision in children is required to learn information, mobility and communication. Thus the developmental implications of impaired vision are profound.

The social and financial costs to the community in failing to provide an optimal and timeous education for each affected child can be considerable.

When vision is impaired from an early age, alternative learning strategies are required from the outset to optimise development.

Optimal education is therefore a prime requirement from the time vision impairment is diagnosed. Late intervention is detrimental to development and education.

The needs of the visually impaired child are therefore different to those of the visually impaired adult. For this reason a different or additional system of blind and partial sight registration for children is required, which specifically addresses the needs of every child with visual impairment.

VISUAL IMPAIRMENT IN CHILDREN

Approximately 50% of cases of impairment of vision in children are due to damage to the eyes or optic nerves, and 50% are due to damage to the parts of the brain responsible for vision.

Visual impairment due to eye and optic nerve damage

Children who have eye or optic nerve damage have impairment of vision, which can be easily understood. Their vision is blurred (although they know such vision to be their normal) and they compensate by means of magnification or getting close to what they want to see. Such
children who have little or no vision can compensate well on account of their intact brain function, if appropriate intervention and help are instituted at an early stage.

**Visual impairment due to brain damage**

Children who have damage to the visual brain have visual impairment, which is more complex. Those who have little or no vision due to brain damage commonly have special needs and the majority have severe cerebral palsy. Those who have functional vision can have complex visual disorders, which depend upon which part of the visual brain is damaged. The education of these children has to be planned on a case-by-case basis, changing with the development of each child.

There is a large group of children who have impairment of cognitive vision due to damage to the brain. Some have impaired visual acuities, but many have visual impairment, which ranges between mild and severe despite having normal visual acuities.

**REGISTRATION OF CHILDREN**

**Current definitions**

The current legal definitions of blindness and partial sight are well established. They were based on the needs of the working adult population and extrapolated to children. For the reasons outlined below, this is an inappropriate concept framework for the registration of children.

**Pitfalls of the current definitions**

The current definitions require the consultant ophthalmologist to predict the future with accuracy. While this is possible in children born with certain obvious conditions such as
anophthalmia (being born without eyes) this is not possible for the majority of conditions.

The concept framework for blind registration for a child is that the child should have such a level of visual impairment that he or she will grow up to be unable to perform work for which vision is essential. The concept framework for partial sight registration is that the child should have substantial visual impairment in the long-term. There is no consideration of the needs of the child in either of these definitions.

These definitions were formulated for visual impairment due to eye or optic nerve dysfunction but not brain dysfunction. Visual impairment due to brain dysfunction is now the commonest cause of visual impairment in children. It is very difficult to predict future vision for this group, as gradual improvement in vision can take place over a number of months or even years.

In order to ensure optimal service provision from the earliest age children should be registered as visually impaired.

However:

- A significant minority of children gradually develop much better vision than expected, resulting in blind registration being inappropriate.

- A smaller minority undergo deterioration of vision resulting in partial sight registration being inappropriate.

- The terminology is such that there is an understandable reluctance to register a child as visually impaired at an early age. Such children may then never be registered because it does not become part of their future management plan.
Advantages of the current system

The administration of the current system can be efficient. The consultant ophthalmologist provides notification of eligibility for registration, the form is transferred to the appropriate local authority, and the social work department provides the required service. However, the deficiencies in this service are well recognised.

Disadvantages of the current system

The terminology of blind and partial sight registration can be frightening for some. The concept of 'Notification of visual impairment' (the degree of which could be on a sliding scale) warrants consideration.

There is no central record of useful statistics concerning childhood visual impairment in Scotland

Service planning requires accurate information concerning the population for whom the service is planned. The most accurate information currently available is held by Visual Impairment Scotland.

Delay or failure to register a child

There are many reasons why children who could benefit from registration are not registered.

These include:

- Difficulties in according an accurate diagnosis and prognosis at an early age. The concept of registration may then not be considered at a later stage.
• The ophthalmologist may not prioritize registration amongst the number of clinically important aspects required during the short time available at each consultation.

• There may be optimism that the condition will improve, both in infants and in children with treatable diseases such as uveitis. This means that a child who needs temporary help rarely receives it because of reluctance to label a child as visually impaired. (There is no currently accepted system of temporary registration for those who need it. This facility is required.)

• Parents or carers may not want their child to be stigmatised by registration.

**Service provision for a child is dependent upon a voluntary system**

As blind or partial sight registration in a child is voluntary, the system of service provision for children with visual impairment is 'hit or miss'. (Most children (but not all) are identified by community paediatrics and referred (often late) for appropriate educational services.)
The registration form is completed by a Consultant Ophthalmologist only and does not address the implications of visual dysfunction

The current role of the Consultant Ophthalmologist who carries out registration of a child with VI is ostensibly to act as a financial 'gatekeeper'. The registration form (as it is currently completed) provides information about diagnosis and the limits of vision only.

It is not common practise for an ophthalmologist to consider the social and educational aspects of visual dysfunction in a child, as these data are not collected as part of the medical management of eye conditions.

The criteria for registration are inappropriate in certain cases

The causes and types of visual dysfunction in children have changed considerably since the inception of the blind and partial sight registration system. In particular brain dysfunction is now the principal cause of visual impairment. This type of visual impairment can be profound, for example inability to see things which move (akinetopsia), or inability to see objects or text against a cluttered background (simultanagnosia) or inability to recognise objects or people (visual agnosia) all profoundly impair vision even in the context of normal visual acuity. Yet the recommendations concerning which children can be registered do not address any of these common conditions, which can render a child profoundly visually impaired. (The paradox arises that a high functioning child with albinism, who only requires magnification, commonly receives a superior service from visual services than a child with good acuities but who is profoundly visually impaired on account of brain dysfunction.)
The disabilities and needs of the child are not considered

The process of registration should, but does not address the needs of the child.

The registration document records medical data concerning diagnosis and the limits of visual function but it does not provide the following:

- An up to date record of functional vision which is required for optimal education
- A copy for the parents / carers
- Information concerning the specific limitations of vision with respect to mobility, social interaction and access to information, and the strategies which are required to deal with each of these elements.
- Recommendations concerning the optimal management and educational plan for the child, which are updated on a regular basis.

Provision of services

The standard service provisions which result from registration *per se* are not designed for children. They are designed for adults.

There are multiple examples of best practise in Scotland but these have been developed locally and need to evolve into national standards.

The excellent services children receive which are provided through education, should be, but are not integral to the registration process, and the provision of such services is not uniform across Scotland.
OPTIONS FOR A NEW SYSTEM OF REGISTRATION OF CHILDREN

1. Retention of the current system

The easiest option is to follow the English approach and to retain the current system. This would not, however, address any of the issues addressed above.

2. Modification of the current system

The addition of a needs based system

The needs based system described in paragraph 3A below could be added to the current registration system.

3. Replacement of the current system by an alternative

A clear, efficient, helpful service is required which meets the ever changing needs of a developing child throughout his or her childhood. The following issues therefore need to be addressed.

(A) The development of a system founded on the needs of each child

Young children 'know' their vision to be normal. Thus anything which is smaller, faster, or more crowded than can be seen is 'not there' and cannot be learned from.

At the time of registration a formal structured process of functional visual assessment is required. This must be combined with a matched response aimed at ensuring that appropriate provisions are made.
It is recommended that such an assessment is carried out in the community and the results of this assessment are added to the registration data.

These data should be related to the ability of the child to use vision for communication, mobility and access to information.

Similarly the social needs of the child should also be identified in the community and formally recorded.

(B) The definition of visual impairment in children

The definition of visual impairment in children should be based upon their needs. A system needs to be developed which addresses this issue.

(C) Multi-party (including parental) notification of needs

All those with responsibilities to the child (including the parents) have a duty to ensure that each child with visual impairment receives optimal services and care. A system, which allows the registration process to include a record of needs based on vision, warrants development.

This should be attainable by requiring all those working with the child to efficiently make their contribution thus facilitating 'joined up working' by the parents, ophthalmology, education, social work and the voluntary sector. This needs to be 'crisp', clear and efficient (and not bureaucratic.)
(D) Automatic updating of recognition of needs as the child develops

As the VI child grows and develops so do his or her needs. An agreed process of updating the child's records by his carers is required.

(E) Ensuring that the system is clear and efficient with minimum form filling, optimum transparency, with key information for each child remembered by all parties is the ultimate goal

(F) A statutory requirement for notification?

No child should be inappropriately disadvantaged on account of poor vision. The current voluntary system of registration leads to significant numbers of children being so disadvantaged. There is a good argument to follow the Danish approach and to make notification of visual impairment a statutory requirement. The criteria for such notification would need to be agreed, but should include the concept that any child who has poor vision requiring additional specialist educational / mobility assistance should be notified. Such a notification system would provide for the needs of the child and could be supplementary but integral to the registration system.

(G) Re-registration as an adult at the age of 18 years

For those children whose vision has improved or deteriorated a system needs to be in place to review their registration status when they reach adulthood.
4. Options for change

(A) The process of registration

The process of registration for children warrants evaluation. We recommend that the current registration form should be completed by the ophthalmologist in a way similar to previously. This should trigger a vision based needs assessment (on a basic clear proforma) by the visiting teacher and social worker, complemented by the parents / carers. The resulting information should automatically be circulated to all interested parties (including the parents).

An efficient means of achieving this aim would be to have a single central 'clearing service' for all registration documents for Scotland. (The current system does not allow for equity of service provision.) This central office would therefore hold the national statistics but would primarily aim to provide a service to children by ensuring that all appropriate parties are fully informed about every VI child.

(B) The services received

The services provided for each child need to be integrated, as they indeed are in many parts of Scotland.

(C) A patient held record?

The 'top down' provision of services is an international standard. However it is paternalistic and does not empower the developing child. The concept of the patient / client held record warrants consideration.
CONCLUSION

Registration of children should meet with the following ideals:

- It should provide a gateway to optimal service delivery, which should be fully integrated throughout childhood.

- It should empower each child, and his or her parents and carers to help their child.

- There should be complete equity of service provision.

- It should ensure that no child is inappropriately disadvantaged on account of poor vision.

- The current review of blind and partial sighted registration provides an opportunity to move towards these ideals being met.
INTRODUCTION

The interim report of the Review of Community Eyecare Services set out the expected outcomes of the review. In the public consultation that followed the publication of the interim report, the expected outcomes were generally welcomed and the one which attracted most support was:

“setting and maintaining national standards that can be adapted and implemented locally”

A working group was formed to look in more detail at national standards. (Membership of the working group is shown in Annex A). The work of the group was informed by the study of interagency work in the three localities and by other examples of good practice. The members of the group decided that standards should be expressed in terms of outcomes for patients. They proposed the following framework:

FRAMEWORK OF SERVICE OUTCOMES AND UNDERPINNING FACTORS

1. The service user can expect the following:

Where a diagnosis of uncorrectable sight loss has been made, the following arrangements should be in place, through integrated eyecare networks, for service users to meet their health and social care needs:

- contact by the relevant service provider within twenty working days with an offer of an initial assessment to determine what further support is required
- the provision of simple interventions (e.g. a lamp or magnifier) at the same time as the initial assessment or in accordance with the needs of the service user.
- simple referral pathways from initial assessment to complex assessment, or to other relevant services
- a complex assessment (where indicated) within twenty working days of the date of the initial assessment
- ongoing support, including the provision of simple services, should be offered from the point of initial assessment to the commencement of the complex assessment
- a review date should be set, following the complex assessment
- clear, personalised, accessible information about current and future care arrangements with advice regarding help, assistance and key contact points.
2. Local service planning and provision
The planning and provision of services through integrated eyecare networks should include:

- service delivery based on an integrated model of health and social care, with enhanced communications and joint infrastructure
- a workforce with the competencies, capacity and capability to meet the health and social care needs of visually impaired adults and children
- integration with local performance management and accountability arrangements to ensure continuous performance and quality improvement which is the subject of periodic external review.
Annex J
Shared and Delegated Care Schemes

The Glasgow Integrated Eyecare Service

Background

The Glasgow NHS Board established the Glasgow Integrated Eyecare Service (GIES) in January 2002, providing a wide-ranging scheme for the management of many eye conditions by community optometrists.

This followed concern among GPs about the long waiting times for ophthalmology outpatient appointments. Most GPs do not have the necessary equipment to examine eyes comprehensively, but it was recognised that optometrists do. In addition, optometrists have the appropriate training to make a more accurate diagnosis in most cases.

GIES allows GPs to refer eye problems to an accredited optometrist for management, treatment and ongoing referral to the secondary sector as appropriate. All local optometrists were invited to join the scheme and a number underwent a period of training and accreditation before being placed on the scheme. The accreditation process included a mixture of lectures, clinical workshops and sessions with the ophthalmologists in hospital clinics. All practices were visited and audited to ensure the necessary apparatus was available. All participating optometrists attend monthly CPD peer review sessions, six-monthly training days and ongoing attendance at the ophthalmology outpatient departments.

Results

The results to date have been very encouraging and the scheme has been adopted in several other areas of the UK as far apart as Devon and the Highlands.

The Glasgow NHS Board has audited various aspects of the scheme several times and published findings include:

- 77% of patients are retained and managed safely in primary care
- All referrals to GIES are seen within two weeks, 90% within four days
- There has been an 80% reduction in topical antibiotic prescribing
• The introduction of effective direct referral
• A significant reduction of inappropriate referrals to hospital out-patient eye clinics.
• That all referrals to the secondary sector were considered appropriate by the receiving ophthalmologist.
• That GIES has provided prompt, precise differential diagnosis for patients
• Reduced waiting times for many patients to a competent eye health professional
• The delivery of a high quality community eyecare service
• A high patient and professional satisfaction rating has been reported

**Patient Satisfaction Survey (May 2004)**

GIES has been well received by patients, and of those who quantified the level of service (99%):

• 77% said that the service was excellent
• 19% said it was good
• 4% said it was average
• less than 0.5% said the service was below average or poor (1 respondee)

This is consistent with the 2003 patient satisfaction response, which produced a corresponding percentage split of 76:22:2:0 split against the above categories and maintains the high patient satisfaction with the service.

*Information:*

• 98% said they stated that the optometrist had given them sufficiently understandable information about their eye/condition (92% in 2003)

*Access:*

Of those who quantified quality of access:
• 99.3% of patients thought they had been seen quickly enough
• 97% found it easy to get to the optometrists’ premises
• 79% were given a list of different optometrist by their GP

This represents a consistent level of satisfaction from patients, suggesting that a high level of care is being maintained and that patients are generally satisfied with the service overall and that there is added value in a local, convenient service delivered in optometric premises.

**General Practitioner Survey (2003)**

The local GPs using the service were asked their opinion and the following results were recorded:

• 92% stated they found the service easy to use
• 92% stated that the patient report was received in a reasonable time
• 100% stated that patients were seen within a reasonable time (all patients seen within a week)
• 100% stated that sufficient detail was contained in the report from the GIES optometrist
• 100% were happy with the care their patient received
• 100% would use the scheme again

**Ophthalmology Audit**

The lead ophthalmologist at the Southern General Hospital, Glasgow was invited to review a random sample of anonymised GIES patient records and reports. He was asked to comment on the clinical performance of the GIES optometrists and the quality of care provided. He was asked to comment on the diagnosis, the appropriateness of the treatment/management, the appropriateness of referral and to provide an overall concurrence rate. The results from the 104 randomly sampled records were as were as follows:

A. Do you agree with the diagnosis?
   Yes  94
   No   1
   N/A  9

B. Do you agree with the management/treatment provided for this patient?
   Yes  98
C. Should this patient have been referred to the Hospital Eye Service?

Yes 3
No 101

(Subsequent analysis proved that the three patients were actually referred)

D. Overall, on a scale of 1-5 (5 excellent, 4 very good, 3 good, 2 average, 1 poor) how would you rate the management/treatment of this patient?

1 poor) how would you rate the management/treatment of this patient?

1 0
2 0
3 4
4 31
5 68
N/A 1

Overall Professional Experience

The view of professional staff at the South Glasgow Acute Division is that the GIES scheme is a positive service development, which has provided improvements in service for patients and other stakeholders in the service.

The GIES project has taken a large number of patients who would have otherwise been referred to the hospital outpatient department and assessed, treated and discharged, or referred on again as appropriate to each individual. Approximately 77% of the patients do not require to be referred on to outpatients. The referrals received at hospital are more appropriate, relevant and presented in a way to assist the determination of patient priorities. Referrals received from GIES provide relevant ophthalmic facts, which are objective and evidence based. This removes subjectivity and emotion from the referral process and allows hospital clinicians to make a more rapid and accurate decision.

The provision of supporting clinical information and outcomes of clinical investigations such as visual field tests also speeds up the
decision-making process – much of which can be carried out at the first visit.

There are fewer concerns raised by primary care colleagues regarding delays in seeing patients and GPs now have an effective alternative to hospital referral. This means that patients are seen earlier and can receive treatment more readily. Additionally, there is a reduced risk of inappropriate interventions occurring in the primary care setting.

Overall, the GIES has led to an improvement in the working relationship between primary and secondary care. Optometrists are using effective intervention with patients and referring appropriate patients to Secondary Care services.

Next Steps

The future role of GIES will be considered by the NHS Board taking account of new developments including the updated GOS contract, Glasgow Acute Services Review and the Review of Eyecare Services in Scotland Interim report.

It is anticipated GIES will:

• Continue to develop a model of assessment and, where appropriate, treatment of patients with eye problems in the community, thus reducing demand on hospital ophthalmology outpatient clinics and so contributing to a reduction in waiting times
• Develop protocols for managing patients with chronic eye disease, for example by discharging stable glaucoma patients into the community for ongoing monitoring by GIES optometrists
• Develop an electronic patient management and referral network by ensuring participating optometrists are connected to NHS net email systems via an appropriate broadband connection
• Developing improved communication with GPs so that all referrals – including those from other community optometrists – are channelled through GIES optometrists for additional examination and work-up. Consideration can then be given as to whether the patient can be appropriately managed/treated in the community or alternatively what additional tests and procedures need to be arrayed out prior to direct, prioritised referral to secondary care.
CATARACT SCHEMES

There are a number of cataract referral schemes across the country with slightly differing protocols utilising direct referral from optometrists.

Ayrshire and Arran – One-Stop Cataract Service

This novel cataract scheme was set up several years ago to reduce the waiting times for patients requiring uncomplicated cataract surgery. Local optometrists were invited to participate in the scheme that allows for direct referral of patients with cataract to a hospital where they will be able to book patients in for surgery on a specified date if there is no complication or co-morbidity. If there is another condition present or the potential for complications, the patient is referred to an out patient clinic for further assessment.

The accredited optometrists carry out a detailed examination of a prospective patient to exclude other ocular morbidity working to a specific protocol for referral. This includes dilated slit lamp biomicroscopy, a detailed retinal examination, IOP measurement, refraction and a report. The optometrist also reviews the patients post operatively and has final discharge responsibility.

All referrals for surgery made by optometrists to date has been considered appropriate, accepted by the consultant surgeon and received their surgery as planned.

[Ayrshire and Arran NHS Board. Fast Track Cataract Service. 2000]

Lothian Cataract Initiative (LOCI)

Prior to the introduction LOCI scheme some 33% of all referrals to hospital for cataract surgery decided, or were advised, not to go ahead. Often the risk of surgery was the pivot upon which marginal cases declined to go ahead. This was a wasteful method of sifting the referrals. A smaller number had other eye disease accounting for the reduced VA.

All practices in Lothian were invited to participate in a community based triage system for these patients and eventually 12 practices in Edinburgh went through a 6 session training scheme and this list of accredited
optometrists was circulated to all GPs and Optometrists in Edinburgh and the Lothians.

The essentials of the LOCI scheme are as follows:

• The examination includes assessment of cataract type, whether this is the only reason for reduced vision and whether this is affecting the patient's daily function. Discussion includes an explanation of the risks and complications.

• Initial findings show the numbers who now pass to the hospital and do not go ahead with the operation has dropped from 33% to 2%, demonstrating a dramatic reduction in inappropriate referrals, and a similar reduction in wasted clinical time at hospital.

[Lothian NHS Board. Lothian Cataract Initiative. 2001]
GLAUCOMA SHARED CARE

Grampian Glaucoma Referral Refinement and Monitoring Scheme

This delegated care scheme was developed from the Manchester model.

In this scheme all patients suspected of having glaucoma are referred via a co-ordinator to an accredited optometrist for further assessment and confirmation, diagnosis or discharge.

The accredited optometrists are based in the community and work within an agreed set of criteria. The examination involves applanation tonometry, corneal pachymetry, optic disc examination by slit lamp biomicroscopy and supra threshold visual field testing – repeating procedures as necessary to confirm findings.

Patients are then categorised as normal and discharged, as ocular hypertensive or confirmed cases of glaucoma.

The accredited optometrist in accordance with the protocol for all confirmed cases and some ocular hypertensives commences treatment. The confirmed cases of glaucoma are referred on to the OPD to be assessed by the consultant ophthalmologist.

The ocular hypertensive cases are retained and managed in the community by the optometrist.

A total of 900 patients will enter the scheme in the first year, a random sample will be asked to attend the ophthalmology clinic as part of the quality assurance.

It is expected that this scheme will have appositive impact on the patient journey, improve quality of care for many people and reduce the number of inappropriate referrals to eye clinics.

Annex K
Epidemiology of Common Eye Disease

Glaucoma

Chronic glaucoma is a potentially blinding disorder requiring lifelong care once the diagnosis is made. The prevalence of glaucoma rises from 1-2% of the over 40s, to 5% of the over 75s. It is expected that the prevalence of glaucoma will increase by 40% by 2020.

Glaucoma affects approximately 1-2.5% within the white Caucasian population in Scotland; something in the region of 80,000 people living with this lifelong, sight threatening condition. The incidence within African Caribbean groups is significantly higher. The prevalence of ocular hypertension is around 5% of the over 50 age group.

At present glaucoma care accounts for approximately 30-40% of all outpatient visits in ophthalmology departments. Some 15-20% of new referrals are glaucoma related. Of this group 33% are confirmed of having the disease, 33% are considered suspicious and require further follow up and 33% are found to be negative. Therefore 66% could be described as inappropriate referrals and these patients could be effectively managed in the community.

Transferring the management of chronic glaucoma to the community would free up a substantial number of valuable outpatient visits.

The triage/filtering of glaucoma referrals and the transfer of stable glaucoma patients to the community for ongoing management is one of the areas being considered by the CCI Eyecare Pathway working group.

Cataract

Cataract is a common ocular condition and affects the vast majority of people with age. Approximately 80% of people over the age of 65 will have some form of visual disturbance due to cataract.

Cataract is usually managed in the early stage of the condition by community optometrists observing the development of the condition and offering counselling and advice to patients. Often early cataract will result in significant changes in refractive error and appropriate advice and alterations to spectacle prescription will suffice at this stage.
Ultimately most 47 patients are referred for cataract surgery and modern surgical techniques have a remarkably high success rate.

Approximately 3.2% of the population over 65 years of age would benefit from cataract surgery at any one time – some 26,016 people in Scotland. It is estimated that the demand for cataract surgery will increase by 70-80% by 2020.

Studies have indicated that approximately 80% of people with cataract are not in contact with an eyecare practitioner and often suffering the consequences of visual impairment unnecessarily.

AMD/ARMD

Age-related macular degeneration is a common finding particularly in older people and is the most common cause of irremediable serious visual loss in people over 65 years of age. Macular degeneration also accounts for 14% of new partial sight and blind registrations for the working population (aged 16-64).

In 2002 813,000 people were over 65 in Scotland; approximately 400,000 had some form of visual impairment in one eye, 20% of who have visual impairment in both eyes. ARMD is the commonest cause of permanent visual loss in people over 65. The condition has resulted in visual impairment to approximately 90,000 Scots this year.

It is expected that the incidence of ARMD will increase by 40-50% by the year 2020.

ARMD is the leading cause of blind and partial sighted registration in people over 65 – approximately 50% due to ARMD. In addition RNIB estimates suggest that under certification is as high as 64% for blind and 74% for partial sighted registration.

Diabetes

Diabetes affects over 3% of the population in Scotland there are approximately 190,000 people living with the disease, and this number is increasing (Diabetes UK). Estimates suggest that some 40% of diabetics remain undiagnosed at any one time.

Approximately 6% of diabetics have sight threatening eye disease. Diabetes is the commonest cause of visual impairment in people of
working age. In addition maculopathy is more common within the diabetic population and cataract tends to present approximately ten years earlier in patients with diabetes.

It is expected that the incidence of diabetes will increase by about 300% by the year 2020.

Vision and Falls

There is a growing body of evidence indicating a correlation between visual impairment and falls. NICE have recently produced advice and guidance relating to falls in older people and have established the link of impaired vision and falls. The NICE advice indicates that an assessment of visual function should be an integral component within the multifactorial assessment programme for someone who has fallen or is at risk of falling. Most of the studies thus far seem to have limited their concern to loss of central vision; more work needs to be done on loss of peripheral vision and the consequent risk of falls.

The association between falls and poor vision exposes just one of the hidden costs of visual impairment.

A RNIB study estimated that £25m spent on rehabilitation and mobility training for older blind and partially sighted people would save £220m in the social and healthcare costs of falls.