



## SCOTTISH EXECUTIVE

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Your ref:  
Our ref:

6 April 2006

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Dear Colleague

### **REVIEW OF COMMUNITY EYECARE SERVICES IN SCOTLAND**

I am pleased to send you copies of three documents which have been produced in the course of the review of community eyecare services in Scotland.

In October the Deputy Minister for Health and Community Care launched an interim report of the eyecare review, which focussed largely on the extended and preventive role of the community optometrist, but also highlighted other areas of eyecare, including the services needed for those who have significant visual impairment. We received many positive comments on the proposals for the extended role of the optometrist and I am pleased to say that the new optometry contract was introduced on 1 April 2006.

The three reports enclosed cover other aspects of community eyecare in Scotland: a review of certification and registration, an examination of needs of visually impaired children and young people, and the outcome of a study of integrated eyecare services in three localities. All three documents take a holistic view of the needs of the patient and there is some inevitable overlap between them. Taken together with the improvements in community optometry, they map out a better approach to the provision of eyecare services and they will form the basis of the final report of the eyecare review which we expect to issue later in the year.

We would be interested to hear your views on the three documents. The reports on certification and registration and on children's services were produced by multidisciplinary working groups. Each report contains recommendations for change. I would welcome your comments on any aspects of the two reports, but in particular your comments on the recommendations that have been made by the working groups. The third document describes the outcome of a study of interagency working in three localities in Scotland.

I would be interested to receive your comments on the study and in particular on the potential to roll out this model of interagency care for visually impaired people throughout Scotland.

Yours sincerely

DR JONATHAN PRYCE  
Head of Primary Care Division

## GUIDANCE AND ADDITIONAL INFORMATION ON CONSULTATION

We would be grateful if you would clearly indicate in your response which paper you are responding to, and which parts of the paper you are responding to as this will aid or analysis of the responses received.

This consultation and all other Scottish Executive consultation exercises, can be viewed on line on the consultation web pages of the Scottish Executive website at <http://www.scotland.gov.uk/consultations>. You can telephone Freephone 0800 77 1234 to find out where your nearest public internet access point is.

The Scottish Executive now has an email alert system for consultations (SEconsult: <http://www.scotland.gov.uk/consultations/seconsult.aspx>). This system allows individuals and organisations to register and receive a weekly email containing details of all new consultations (including web links). SEconsult complements, but in no way replaces the SE consultation list and is designed to allow stakeholders to keep up-to-date with all consultation activity, and therefore be alerted at the earliest opportunity to those of most interest. We would encourage you to register.

### Handling your response

We need to know how you wish your response to be handled and, in particular, whether you are happy for your response to be made public. Please complete and return the responsee information form attached to this letter as this will ensure that we treat your response appropriately. If you ask for your response not to be published we will regard it as confidential, and we will treat it accordingly.

All respondents should be aware that the Scottish Executive are subject to the provisions of the Freedom of Information (Scotland) Act 2003 and would therefore have to consider any request made to it under the Act for information relating to responses made to this consultation exercise.

### Next steps in the process

Where respondents have given permission for their response to be made public (see responsee information form), these will be made available to the public in the Scottish Executive Library by the end of September 2006 and on the Scottish Executive consultation web pages by the end of September 2006. We will check all responses where agreement to publish has been given for any potential defamatory material before logging them into the library or placing them on the website. You can make arrangements to view responses by contacting the SE Library on 0131 244 4565. Responses can be copied or sent to you, but a charge may be made for this service.

### What happens next?

Following the closing date, all responses will be analysed and considered along with any other available evidence to decide on the way forward. A final report on the review of community eyecare services in Scotland will be issued later in the year.

## Comments and complaints

If you have any comments on how this consultation exercise has been conducted, please send them to Eric Gray at the address below.

Comments on the three documents may be sent by 10 July to:

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## ANNEX A

### RESPONDEE INFORMATION FORM

Please complete the details below and attach it with your response. This will help ensure we handle your response appropriately:

Name:

Postal Address:

Consultation title: Review of Eyecare Services in Scotland – Interim Report

1. Are you responding as: (please tick one box)

- (a) an individual  (go to 2a/b)
- (b) **on behalf of** a group or organisation  (go to 2c)

#### 2a. INDIVIDUALS:

Do you agree to your response being made available to the public (in SE library and/or on SE website)?

- Yes (go to 2b below)
- No, not at all

2b. Where *confidentiality is not requested*, we will make your response available to the public on the following basis (please tick one of the following boxes)

- Yes, make my response, name and address all available
- Yes, make my response available, but not my name or address
- Yes, make my response and name available, but not my address

**2c. ON BEHALF OF GROUPS OR ORGANISATIONS:**

Your name and address as respondees *will be* made available to the public (in the SE library and/or on SE website). Are you content for your response to be made available also?

Yes

No

3. We will share your response internally with other SE policy teams who may be addressing the issues you discuss. They may wish to contact you again in the future, but we require your permission to do so. Are you content for the Scottish Executive to contact you again in the future for consultation or research purposes?

Yes

No

# **THE REVIEW OF COMMUNITY EYECARE SERVICES IN SCOTLAND: A STUDY OF INTERAGENCY WORK IN THREE LOCALITIES.**

## **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

1. "Sensing Progress" The Social Work Services Inspectorate (1998)
2. "Insights: Services for Visually Impaired People in Scotland" RNIB Scotland (2000)  
  
"Shaping the Future" RNIB (2001)  
  
"Improving lives" The Improving Lives Coalition (2001)
3. "A New System of Notification of Childhood Visual Impairment and the Information it has Provided on Services for Scottish Children" Visual Impairment Scotland (2003)

# **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<sup>1</sup> 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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<sup>1</sup> 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<sup>2</sup> 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

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<sup>2</sup> 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 some times 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"<sup>3</sup> 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<sup>4</sup> 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

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<sup>3</sup> 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)

<sup>4</sup> "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"<sup>5</sup> 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<sup>6</sup> 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<sup>7</sup> 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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<sup>5</sup> 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)

<sup>6</sup> Linda Sorensen: "Research into a national transcription service for education." (RNIB 2005)

<sup>7</sup> 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<sup>8</sup> 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

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<sup>8</sup> 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)

## **ANNEXE 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.

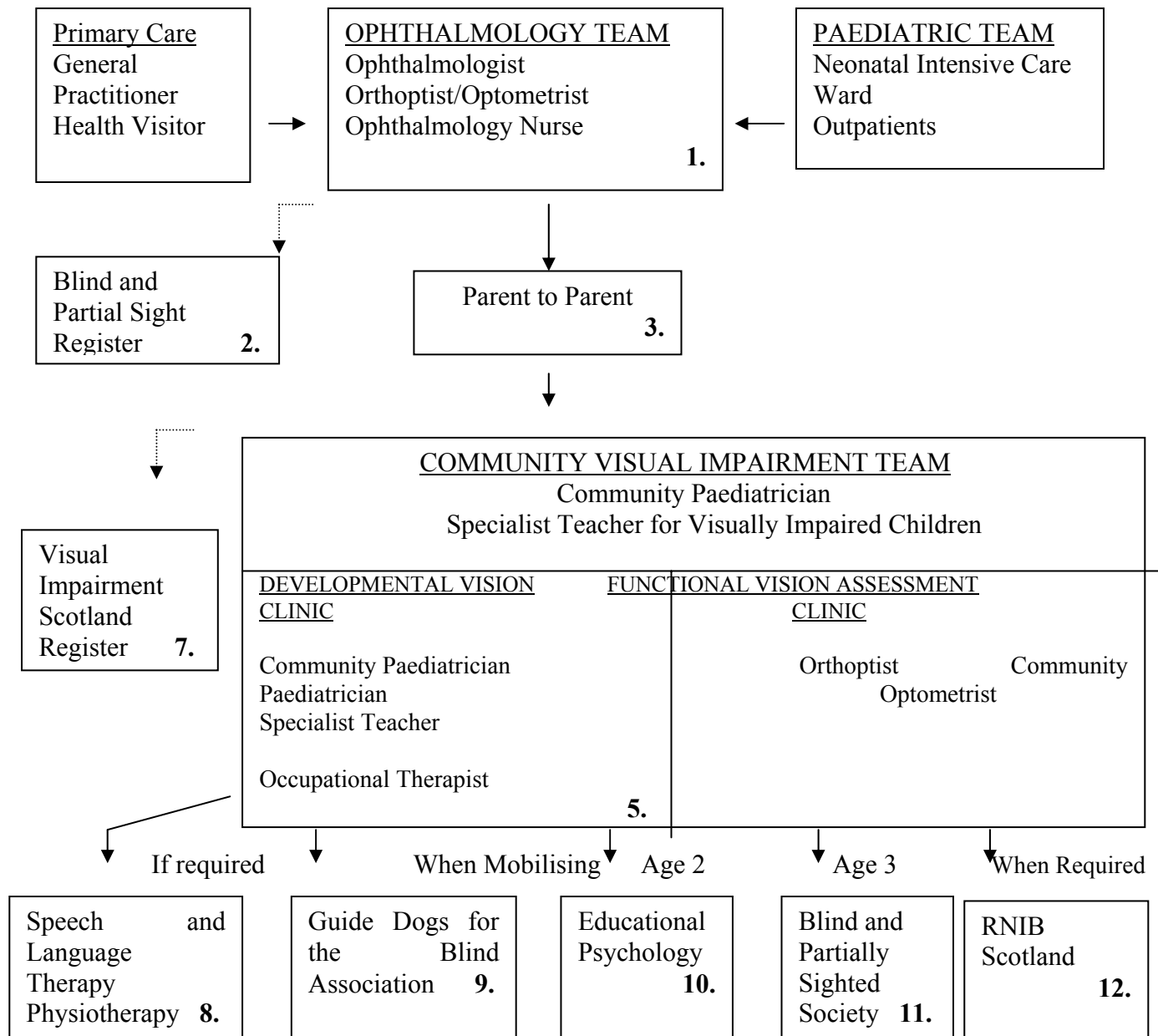
There are in fact two pathways for visually impaired children:-

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. Orthoptist 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

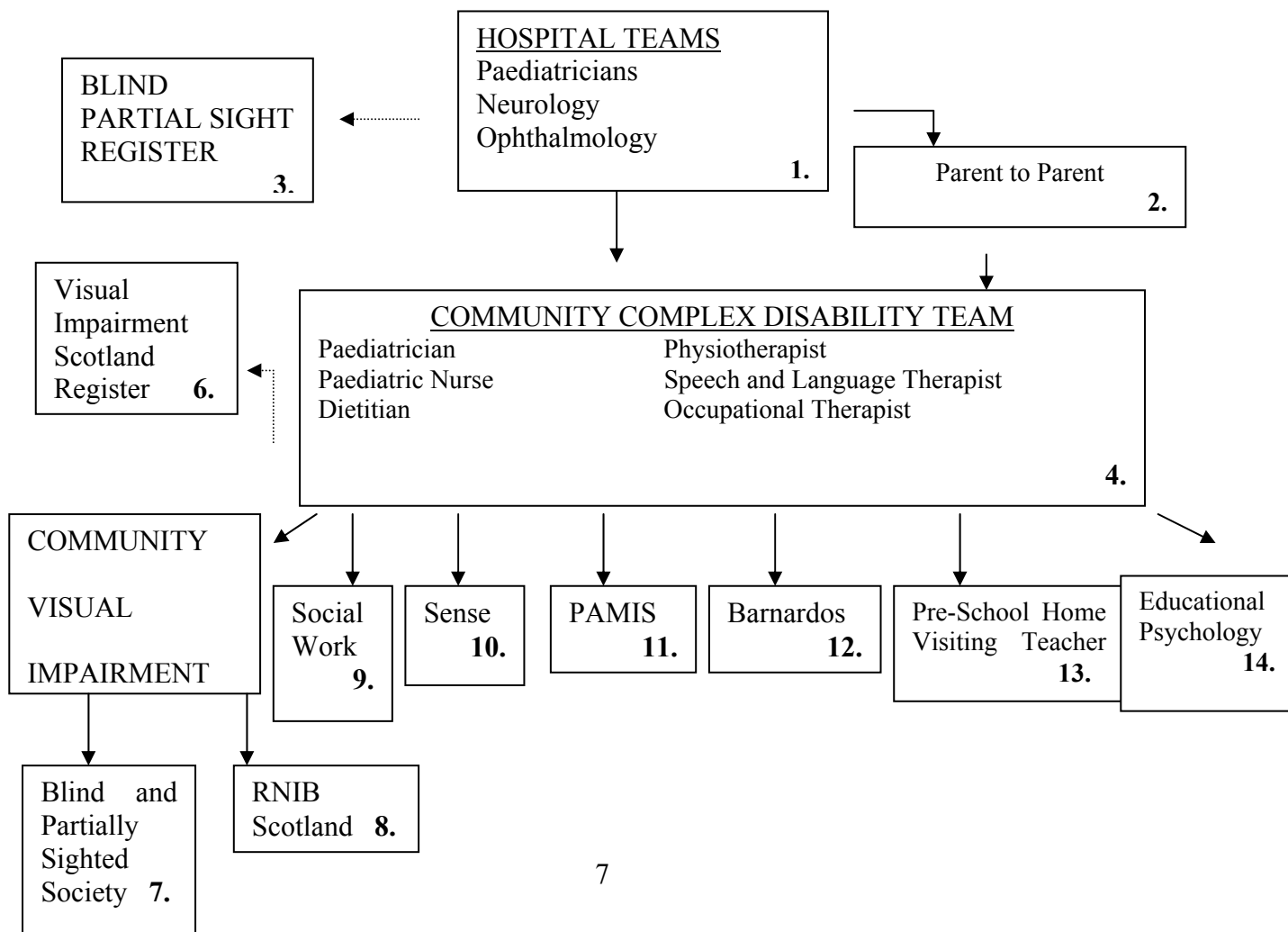
services are discussed and advice can be given on equipment, toys, games and low vision products e.g. talking watches, the availability of travel passes from age five years and so on. Further input depends on the individual needs of each child. When not actively involved the society as a statutory body 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.

Date of Plan:  Present:	 <p><b>CVISTA</b> INTERAGENCY MANAGEMENT PLAN</p>
Name:	
Date of Birth:	
Address:	
Telephone Number:	
Parent/Carer:	
School Attended:	
Registration Status:	

Agencies Actively Involved at Present	Contact Person	Telephone Number

MEDICAL SUMMARY:

**EDUCATION: IEP/CSP**

Mainstream with peri support/VI Resource Location/Specialist School

Equipment

Date of Education Review:

Additional Information/Points for Discussion

	Assessment/Input	Ongoing/Support/Review
Ophthalmology		
<i>Functional Vision</i>		
Low Vision Aids		
Technology		
Developmental (including therapy)		
Communication		
Social Skills		
Orientation and Mobility		
Independence		
<b><i>Leisure/Social Activities</i></b>		
Emotional Wellbeing		
Educational Psychology		
Social Work		

<b>ACTION PLAN</b>		
Action Item:	Person Responsible	<b>Deadline</b>
Action Item:	Person Responsible	<b>Deadline</b>
Action Item:	Person Responsible	<b>Deadline</b>
Action Item:	Person Responsible	<b>Deadline</b>
Action Item:	Person Responsible	<b>Deadline</b>
Action Item:	Person Responsible	<b>Deadline</b>

Action Item:	Person Responsible	Deadline
Action Item:	Person Responsible	Deadline
PLAN REVIEW DATE		

### 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 indepenence 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

# **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 argued 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 but 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 for 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**

### **RECOMMENDATIONS TO THE CERTIFICATION AND REGISTRATION GROUP**

**MEETING 12 JULY 2005.**

### **BLIND AND PARTIAL SIGHT REGISTRATION OF CHILDREN IN SCOTLAND**

### **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.

