

# **Review of Community Eyecare Services in Scotland**

## **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1.1 The system for certifying and registering people as blind or partially sighted is widely regarded as outdated and inefficient.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.

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## **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 Whittaker, Optometric Advisor to the Scottish Executive

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

## **Visual impairment in children**

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.

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.

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.

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.

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.

