

# A clear vision:

## Eye care for children and young people in special schools in Wales

June 2012



# Executive Summary

This report shows that as a society we are neglecting the eye care of pupils in special schools. The National Service Framework specifies that children and young people with disabilities need early diagnosis or identification of difficulties and early intervention (WAG 2005). Community dentists visit special schools to assess pupils and provide treatment for any problems identified. There is no such provision for eye care.

This report is based on a postal survey of 39 schools followed by eye tests conducted on young people in 5 of the 44 special schools in Wales.

The report's key findings are:

Over one third of pupils have never had a sight test

- Only 6% of pupils have visual problems recorded in their Statement of Special Educational Need as a primary or secondary need. This project found that one in five pupils impairment that is likely to impact on their education.



## Case study

**Pupil C, who was 15 years old, was found to be very long sighted. He had very complex needs and the majority of his support at school was carried out one-on-one at close proximity. Staff wondered why he got so “tired and upset” after a short time. He now wears his glasses full time and a review has shown him to be improving significantly in core skills at school.**



- Over 50% of all pupils need spectacles, whereas only 30% had previously had them prescribed. Some children without glasses have high levels of long or short sight.
- The study suggests that at least one fifth of pupils with low vision could have normal vision with spectacles

## Case study

**The school had been struggling to get an appropriate head rest for pupil D but due to lack of communication between the different professionals, his nystagmus had never been considered. The head rests in question were placed at a point *maximising* the nystagmus and his head had been strapped in place. This may have induced oscillopsia (perception that the world is moving). D, who is 15 years old, had been trying to pull his head in the opposite direction, to a position where his vision would be better.**

## The recommendations

- An optometric service should be provided to pupils in special schools
- A transitional service should be established to support pupils in special schools to become familiar with having sight tests in a community practice
- Every special school should have a room allocated and equipped for sight testing
- Optometrists accredited to provide one or more of the Welsh Eye Care Services should be offered training and accreditation to provide the service in special schools
- A short consent form should be sent to parents / guardians and followed by a phone call to collect relevant history and symptoms
- A trained optical assistant and/ or a dispensing optician should accompany the optometrist
- Pupils who have a sight test in the special school service should be issued with a General Ophthalmic Services (GOS) voucher
- Parents and pupils should be able to choose spectacle frames from a selection offered by the special school service or attend an optometry practice
- Optometrists testing in special schools should work in partnership with school nurses
- A central administration team should book appointments and order spectacles and equipment
- Copies of reports and referrals should be provided to parents and (with parental consent) others who support or care for the child
- The administration team, the clinical lead and Welsh Eye Care Services Board should be responsible for quality assuring the service



## The authors

This was a collaborative project between RNIB Cymru and the School of Optometry and Vision Sciences, Cardiff University. It was funded by Welsh Government through the Children's Low Vision Project.

**Dr Maggie Woodhouse**, Senior Lecturer, Cardiff University. Principal Investigator and specialist in eye care for people with learning disabilities.

**Dr Barbara Ryan**, Clinical Lead, Low Vision Service Wales. Co-Director Wales Optometry Postgraduate Education Centre, School of Optometry and Vision Sciences, Cardiff University. Project Manager and Chair of the Advisory Group.

**Nathan Davies**, Children's Low Vision Advocate, RNIB. Provided liaison with schools and prepared and distributed the paper work.

**Aideen McAvinchey**, Optometrist. Assessed the children, prescribed spectacles, referred to appropriate agencies and liaised with schools and families.

## Other contributors

Particular thanks go to the following contributors:

**The Advisory Group** who contributed to the development, implementation, evaluation and reporting of the project.

Nicola Crews	RNIB Cymru
Sali Davis	Optometry Wales
Eurfon Nyhan	Optometry Wales
Sue Keil	RNIB
Judith Downs	Orthoptist, ABM University Health Board
Sue Gray	Gwent Visual Impairment Service
Jan Perry	Gwent Visual Impairment Service
Andy Millington	Optometrist (also involved in assessing children)

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## Foreword

This report highlights failings, but also proposes solutions. The report clearly shows that as a society we have failed to provide young people in special schools with the eye health care they need. This is particularly worrying for several reasons. Firstly, the prevalence of visual impairment among this group is far higher than the population average. Secondly, it means that many of these already disadvantaged young people face further obstacles because of unrecognised sight problems.

Some of the case studies in the report reveal worrying levels of ignorance and neglect of eye health. For example, the report finds some young people seen by the optometrists during their research “had severe visual impairment or high refractive errors that were detected for the first time.”

However, the aim of the report is not to apportion blame. We cannot change the past. We can change the future. So the report sets out clearly what we should do and how we should do it. Most of the recommended changes – such as annual sight tests in schools – are neither costly nor complex. Other recommendations include working more closely with school nurses on eye health, talking to parents and training optometrists to work with children in special schools.

Implementing these recommendations to correct refractive errors and help young people with visual impairments will bring many benefits. At a very simple level, enabling these young people to see better means they will get more from education. That will also reduce behavioural problems and ultimately lead to young people who are more socially integrated and more economically productive.

I would like to thank the authors and researchers for the time and effort they have dedicated to this report. I am sure that everyone will join me in welcoming the recommendations set out in this report and ensuring that we act on them.

Finally, the report serves as a reminder that we should guard against complacency. No matter how effective we believe vision services to be in Wales, we should always strive to improve them and ensure that they are available to all.



**John Sanders**  
Chair Low Vision Service Wales Advisory Group  
May 2012

# Contents

---

Executive Summary	1
-------------------	---

---

Contributors	3
--------------	---

---

Foreword	4
----------	---

---

1.0	Introduction	6
-----	--------------	---

---

2.0	Current eye care services in special schools in Wales	9
-----	---	---

---

3.0	The eye care needs of children and young people in special schools	11
-----	--	----

---

4.0	Feedback from schools, optometrists and parents	20
-----	---	----

---

5.0	Future Services	25
-----	-----------------	----

---

6.0	References	31
-----	------------	----

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## 1.0 Introduction

The National Service Framework states that children and young people with disabilities need early diagnosis or identification of difficulties and early intervention (WAG 2005). Community dentists and support staff visit special schools in specialist vans to assess the oral health of pupils and provide treatment for any problems identified.

This project aimed to determine if sight tests should also be made available in special schools. Sight is extremely important in the learning and development of a child or young person. If a child or young person has a visual impairment, it is important that parents and school staff are aware of it, it is corrected or treated when possible and/ or teaching strategies are adapted to incorporate vision enhancement techniques (such as enlargement) or other senses (such as touch or hearing).

### 1.1 Special educational needs (SEN)

#### **What are special educational needs?**

Many children and young people will have special educational needs (SEN) at some point during their childhood. SEN has a legal definition, which is set out in the Special Educational Needs Code of Practice:

*Children have special educational needs if they have a learning difficulty, which calls for special educational provision to be made for them.*

Children have a learning difficulty if they:

- (a) *have a significantly greater difficulty in learning than the majority of children of the same age; or*
  - (b) *have a disability which prevents or hinders them from making use of educational facilities of a kind generally provided for children of the same age in schools within the area of the local education authority.*
  - (c) *are under compulsory school age and fall within the definition at (a) or (b) above or would so do if special educational provision was not made for them.*
- (Department for Education and Skills 2001)

#### **What is a special school?**

The national policy and legislative framework for inclusive education mean that many children and young people with SEN can be educated, and have their needs met in their local mainstream school with specialist support. However, there are some children and young people for whom inclusion in mainstream educational settings is neither viable nor beneficial because of the nature, extent and diversity of their individual needs, disabilities or impairments. For these children and young people, attending a special school may be more appropriate and suitable.

The National Service Framework for Children, Young People and Maternity Services in Wales defines special schools as:

an educational establishment specifically resourced to meet the needs of the most complex and challenging young people in communities. Typically they will provide an environment for the delivery of education as well as social and health needs. (Welsh Assembly Government 2005)

### ***Special schools in Wales***

In 2010, there were 44 maintained special schools in Wales with 4181 pupils. Of these, 3985 pupils had a Statement of SEN. The majority of pupils (56%, n=2238) had learning difficulty (moderate, severe, profound and multiple) as their primary (major) SEN. A considerable number of pupils (21%, n=828) had autistic spectrum disorders as their primary or major need.

Many of the disabilities and medical conditions found among pupils in special schools are gender-related e.g. Down's syndrome, autism and Fragile X syndrome are all more common in boys. Therefore, it is unsurprising that 2935 (70%) of the 4181 pupils on roll in special schools in Wales in 2010/11 were boys (StatsWales 010094 2011).

## **1.2 Refractive error and visual impairment among pupils in special schools**

Fewer than 1% of pupils in special schools in Wales had visual impairment recorded as their primary or major need (StatsWales 010102 2011).

In a study of children in special schools in Glasgow, 12% were found to have low vision or blindness (according to WHO criteria). Of 228 pupils tested, 105 (46%) had refractive error that needed correction and all types of refractive error were significantly higher in the study group compared with the general population. The study concluded that the prevalence of reduced visual acuity was high and that uncorrected refractive error was a major cause of this (Das, Spowart et al. 2010).

Children with SEN, including but not limited to learning disabilities, are more likely to have refractive errors and visual impairment than children without SEN (Warburg 1979; Sobrado, Suarez et al. 1999; Mwanza, Nkidiaka et al. 2000; Warburg 2001; Leekam, Nieto et al. 2007; Nielsen, Skov et al. 2007a; Nielsen, Skov et al. 2007b; Ghasia, Brunstrom et al. 2008; Ashwin, Ashwin et al. 2009). In addition, it is well known that children and young people with learning disabilities often have co-existing impairments, such as hearing loss or visual impairment (Cockerill 2002).

## **1.3 Assessment of vision in special schools**

The Hall report recommends that a visual assessment of all children aged 4 to 5 should be carried out and that children of any age with suspected visual deficits, a significant family history or any neurological or disabling condition should be routinely referred for a visual assessment (Hall and Elliman 2008). These recommendations have been endorsed by the UK National Screening Committee, which advises ministers and the NHS in all four UK countries about all aspects of screening policy ([www.screening.nhs.uk/vision-child](http://www.screening.nhs.uk/vision-child) Accessed 21st July 2010).



Following the recommendations of the original Hall report (published in 1989), the Government published the National Service Framework (NSF) for Children, Young People and Maternity Services in 2004 (Department for Education and Skills and Department of Health 2004) and a Wales version was launched in 2005 (Welsh Assembly Government). These NSF's set out health services that would be offered to all children and this included a national programme for school vision screening.

In spite of the fact that guidelines and recommendations about vision assessment are in place, not all areas have established these services. Although children and young people in special schools are at greater risk of refractive error and/ or visual impairment, a recent Ophthalmic Service Guidance report for ophthalmologists outlined that 'Not all healthcare regions fund school screening outside mainstream schools so children with a learning disability are less likely to be able to benefit.' (Pilling 2011)

As well as screening, the NSF for Children, Young People and Maternity Services (Welsh Assembly Government 2005) states that disabled children in Wales and their families need particular support from health and education including early intervention to maximise the development and prompt delivery of services to meet assessed needs.

## 2.0 Current eye care services for children and young people in special schools

### 2.1 The survey

Children and young people in special schools are known to be at a much greater risk of visual impairment than children in mainstream schools. It is important to detect and/or correct visual problems and/or to adapt teaching strategies to take account of deficits. However, unlike dentistry, there are no specialist eye care services for children and young people in special schools in Wales.

To address concerns that refractive errors and sight problems are going undetected, we conducted a postal survey about eye care services in special schools in Wales. The purpose of the survey was to determine the prevalence of known refractive errors and sight problems among the pupils and to determine the extent to which clinical visual assessment took place.

We piloted a questionnaire, developed in consultation with an Advisory Group, in 4 Special Schools in Wales (Merthyr Tydfil, Pontypridd, Swansea and Llandudno) and then sent it to each of the 44 maintained special schools in Wales in February 2010. We sent a follow-up questionnaire to non-responders approximately eight weeks later and conducted telephone interviews with the schools that did not return the postal questionnaire. Follow-up continued until July 2010. The responses were entered into an SPSS database.

### 2.3 The findings

#### Responses

In total, 39 (89%) of the 44 Special Schools responded; 26 completed the questionnaire and 13 completed telephone interviews. The schools that responded were distributed throughout the whole of Wales. There were 3298 pupils in the 39 schools that responded.

#### Pupils wearing spectacles

In total, 21 schools provided information about both the number of pupils on roll and the number of pupils who wore spectacles. Of the 2067 in these schools 464 (22%) were reported to wear spectacles.

The vast majority of schools (24 out of 26, 92%) reported that some pupils were reluctant to wear their spectacles for the following reasons:

- *Name calling/ peer pressure/ embarrassed/ not cool/ fear of teasing*
- *Some hide spectacles/ break them/ left at home*
- *Unable to perceive benefits/ can't be bothered*
- *Don't like feel of things on face or head/ behaviour issues affect compliance*
- *Poor fit/ ill-fitting spectacles/ uncomfortable with wheelchair headrest*
- *Lack of parental support in maintaining eye care*

## **Vision Screening**

In total, 20 out of 38 schools (53%) reported that vision screening took place in school:

- 47% by orthoptists
- 36.8% by School Nurses
- 31.6% by Qualified Teachers of pupils with Visual Impairment (QTVIs)
- 15.8% by optometrists.
- Other responses in isolated schools included a QTVI on the school staff, the Community Paediatrician and the School Doctor.

NB Some schools had more than one professional 'screening' hence the total is more than 100%.

Pupils had their vision screened at different ages in different schools:

- 13 out of 19 schools screened in 3-5 year olds;
- 10 schools (53%) in 7-11 year olds;
- 12 (63%) in 11-14 year olds; and
- 9 (47%) in 14-16 year olds.

Some schools in which vision screening took place, reported that not all pupils were screened (9 out of 16, 56%). The reasons for not screening all pupils included:

- *Consent not being received*
- *Severity of disability*
- *If pupils join school later, not screened unless there is concern*
- *Only pupils that teachers are concerned about are screened*
- *Unsure about screening criteria*

In total, 23 out of 24 schools (96%) reported that it would be useful if routine vision screening took place in school. The one school that did not think routine vision screening would be useful reported that it already happened.

## **Reported visual impairment**

We asked the schools to record the number of pupils who had a known visual impairment, as their primary or secondary Special Educational Need. Of the 2257 pupils on roll in these 24 schools, 138 (6%) have known visual impairment as the primary or a secondary Special Educational Need.

## 3.0 The eye care needs of children and young people in special schools

### 3.1 Introduction

The survey shows that, despite a very high prevalence of refractive error and visual impairment among pupils, consistent eye care is not provided in special schools in Wales. The reported prevalence of refractive error and/ or visual impairment among the pupils suggested that a large number could potentially have sight problems that had not been identified, corrected or treated.

We therefore decided to provide eye care services in a sample of special schools over a period of one year. We did this to

- a) determine the extent of undetected sight problems and
- b) identify how services can be developed to ensure children and young people in special schools can achieve their full visual potential.

### 3.2 Methods

#### The schools

Five schools which had responded to the postal questionnaire were selected. The five schools were all generic special schools and all had reported that vision screening did not already take place. The schools provided a good range of locations and local demographics.

School name	Location	Age (years) on roll	Number of pupils
Maesgwyn School	Aberdare	11-19	102
Ysgol Heulfan Y Canol**	Wrexham	3-16	28
Crownbridge School	Pontypool	2-19	80
St. Christopher's School	Wrexham	6-19	240
Portfield School	Haverfordwest	3-19	108
<b>TOTAL</b>			<b>558</b>

**Table 1. The five schools that took part in the project including the number and the ages of pupils reported by schools in the questionnaire.**

\*\* Y Canol is a resourced provision in Ysgol Heulfan, which caters for the needs of children with severe learning difficulties and/or profound and multiple learning difficulties.

### **Informing parents and gaining consent**

Schools sent parents/ guardians the information about the project, the sight tests, and the project team. They were asked to sign a consent form to enable their child to have a sight test. Responses were returned to their child's class teacher.

### **Ethical approval**

The project team approached the South East Wales Research Ethics Committee and the National Institute for Social Care and Health Research (NISCHR) for advice about ethical approval. As the project did not involve NHS patients, their relatives, staff or premises, the study did not require NHS ethical approval. In addition, the project was considered a service evaluation or audit rather than a research study. Scrutiny by the School of Optometry and Vision Sciences Research/ Audit Ethics Committee at Cardiff University was sought and the project was approved.

### **Pre-assessment sessions**

Previous research shows that pre-teaching children about vision screening procedures can be an important part of a successful vision screening programme (Bachman, Bachman et al. 1994), Therefore we decided to provide pre-assessment sessions in each pilot school. During these pre-assessment sessions, the pupils would have the opportunity to handle, experience and become familiar with the resources and equipment used during the sight tests. The sessions would also enable staff to find out about the content and structure of the sight tests. These sessions were offered to all participating schools.

### **The sight tests**

At each participating school, a room was assigned for sight tests. As far as possible, blackout was installed at windows so that the room could be darkened. Timetables were drawn up in advance and each pupil attended at an allocated time, accompanied by an adult. Whenever possible, this was a parent/guardian, teaching assistant or school nurse who knew the child.

The following information was recorded for each pupil. Procedures were carried out appropriate to each pupil's co-operation or abilities.

- General observations of visual behaviour
- Comments by member of staff on visual behaviour / ability
- Fixation (ability to look directly at a target)
- Eye movement control (ability to make appropriate, smooth and accurate eye movements in all directions)
- Uncorrected visual acuity, and corrected if wearing spectacles
- Refractive error by retinoscopy (with drops on a separate occasion if clinically required)
- Accommodation (focusing for near tasks) by dynamic retinoscopy
- Binocular vision (ability to use both eyes together) and depth perception
- Visual fields (extent of 'all-round' vision)
- Ocular health by ophthalmoscopy, and slit-lamp if warranted
- Intraocular pressures if clinically required



- Final prescription for refractive error and final corrected visual acuity
- Dispensing details if spectacles advised
- Referral details if warranted
- Advice to parents and school

The parents and school were provided with a copy of the report from the sight test and the child was referred to the GP, hospital eye service or sensory support service at the Local Education Authority if required.

### **Spectacle dispensing**

Parents were able to select one of four options if their child was identified as needing spectacles. The four options were described in the consent form and parents were asked to indicate their preferred choice:

1. Parents chose spectacle frames from a given selection  
A form was included in the consent pack, which had photographs of the twelve available spectacle frames. Parents were asked to select their preferred frame in each size.
2. Parents gave responsibility for choosing frames to the project team  
Parents could indicate on the consent form that they were happy for the project team to choose a suitable spectacle frame for their child.
3. Parents requested that the NHS voucher was sent to them  
Parents requested the NHS voucher so that they could attend an optometry practice to choose spectacles with their child.
4. Parents who attended their child's sight test chose the frames  
Parents attending their child's sight test chose a frame with input from their child.

For options 1, 2 and 4, the optometrist ordered the spectacles and dispensed them in school.

The project team sent prior information about the details of the project to the Local Optometric Committees and to all the optometrists and specialist teachers in the areas in which the five pilot schools were located.

### **Data entry**

The information from the record cards was coded and entered into an SPSS database.

## **3.3 Results**

### **3.3.1 Pre-assessment sessions**

Two of the pilot schools explained that logistically (because of time and staffing constraints), it would not be possible for the pre-assessment sessions to take place. One pilot school agreed to the pre-assessment sessions, which took place approximately two weeks before the sight tests. Although the sessions were a useful opportunity to meet pupils and staff, they were not as successful as anticipated.

For example, one of the objectives of the session was for the pupils to experience being in a darkened room. This was to replicate the conditions (lighting levels) during the sight tests. However, it quickly became apparent that the majority of pupils were already accustomed to (and enjoyed) being in a darkened room: Special schools generally have darkened sensory or stimulation rooms, which contain flashing lights or other sensory stimulation resources.

### 3.3.2 Sight tests

Some schools did not send the consent forms to all pupils but it has not been possible to determine how many families were not informed about the project. Testing is continuing in some of the schools. At the time of analysis (2nd February 2012), 152 pupils had completed a sight test and their parent had given consent for the data to be used.

Pupils were aged between 3 years 6 months and 22 years, with a mean age of 13 years. Forty-three pupils were of primary age (under 12 years).

Previous history (gained from the consent form and follow-up phone calls to parents) is shown in table 2.

Previous consultations and/ or spectacles	Percentage (number)
Local optometrist	41% (62)
Hospital clinic	21% (32)
No previous consultations	38% (58) (Age range 5 to 21 years, mean 13 years)
Prescribed spectacles	47% (44 of the 94 who had previously had a sight test)

**Table 2. Previous history of consultations or prescription of spectacles (gained from the consent form and follow-up phone calls to parents).**

### Spectacle wear

Of the 44 pupils who had been prescribed spectacles, exactly half (22 pupils) had the spectacles with them on the day of the test. This suggests that a significant proportion of pupils did not wear their spectacles or that they had been damaged but had not been repaired or replaced. Children, 16 or under, are entitled to a voucher towards the cost of repair or replacement. Those over 16 may be entitled to a repair voucher if the Local Health Board agrees that the loss or damage was due to illness.

### Habitual visual acuity

Habitual visual acuity refers to the level of vision the pupil had on the day of testing. It was recorded with spectacles if the child usually wore them in school. Therefore, some children identified as having reduced vision may have had a correctable visual impairment but at the time of testing this was not corrected.

Twenty children did not co-operate for monocular acuity so the binocular score was used in these cases. A further six children were not testable on acuity because their vision was too poor to be recorded. Only one child was uncooperative for testing.

The WHO defines low vision as LogMAR acuity of 0.5 or lower in the better eye and blindness as LogMAR acuity poorer than 1.3. Of the 151 children whose acuity could be recorded (including those who were clearly too visually impaired to be tested), 11% (16 children) would be classed as having low vision and 4% (6 children) were blind in their habitual state. Of these 23 children, there were three whose visual problems were not previously known to parents or the school. In these pilot schools, the total number of children with low vision or blindness was 15%.

Of the children undergoing their first sight test, 3 met the WHO criterion for low vision.

Hall and Elliman (2008) consider that a visual acuity of 0.3 (6/12) or poorer be used as a referral criterion for screening, on the grounds that an acuity of this level is likely to impair quality of life. This cut-off equates approximately to the UK driving standard as an adult with 6/12 or poorer would struggle to read a number plate at 20.5 metres (Drasdo and Haggerty 1981). For the purposes of this report, we will refer to this level of acuity as 'visual impairment'.

Overall 20% (30 pupils) had visual impairment in their habitual state. O'Donoghue, McClelland et.al. (2010), using the same criterion for visual impairment, reported a prevalence among pupils of mainstream schools in Northern Ireland of 1.5% among 6-7 year olds and 3.2% among 12-13 year olds.

In the Hall report, the criterion recommended for referral from vision screening is a visual acuity of 6/12 or poorer in either eye (using a Snellen chart). Leaving aside the difficulties in using a Snellen chart for children with special needs, this criterion would result in the referral of 37% of special school pupils.

### Visual acuity tests

Several tests for acuity were available to the optometrist, who chose the test appropriate to each pupil's age and ability.

- For 2 pupils, the acuity test was not recorded.
- A letter chart (Keeler LogMAR crowded, which presents a single line of four letters at each acuity level and has a matching card if needed) was used for 59% (85 pupils).
- A picture chart (Kay Pictures crowded, which presents a single line of four pictures at each acuity level and has a matching card) was used for 15% (14 pupils).
- A preferential looking chart (Cardiff Acuity Test, in which the optometrist observes the pupil's eye movements to determine when a picture is seen) was used for 26% (37 pupils).

### Prescription of spectacles

Overall, 53% (80 pupils) received a prescription and 47% (72 pupils) did not require spectacles. The pupils prescribed spectacles for the first time ranged in age from 4 to 22 years, with a mean age of 13 years 8 months.

Altogether 29% (17 children) who had never had an eye test were prescribed spectacles. This included the 3 children who had low vision in their habitual state.

Spectacles prescribed	Number (percent)	Reason for prescription	Number (percent)
No spectacles prescribed	48% (72)		
Spectacles prescribed	53% (80)	First time prescription	24% (36)
		Changes in prescription	15% (23)
		New pair for reasons of wear and tear	14% (21)
Total	100% (150)		53% (80)

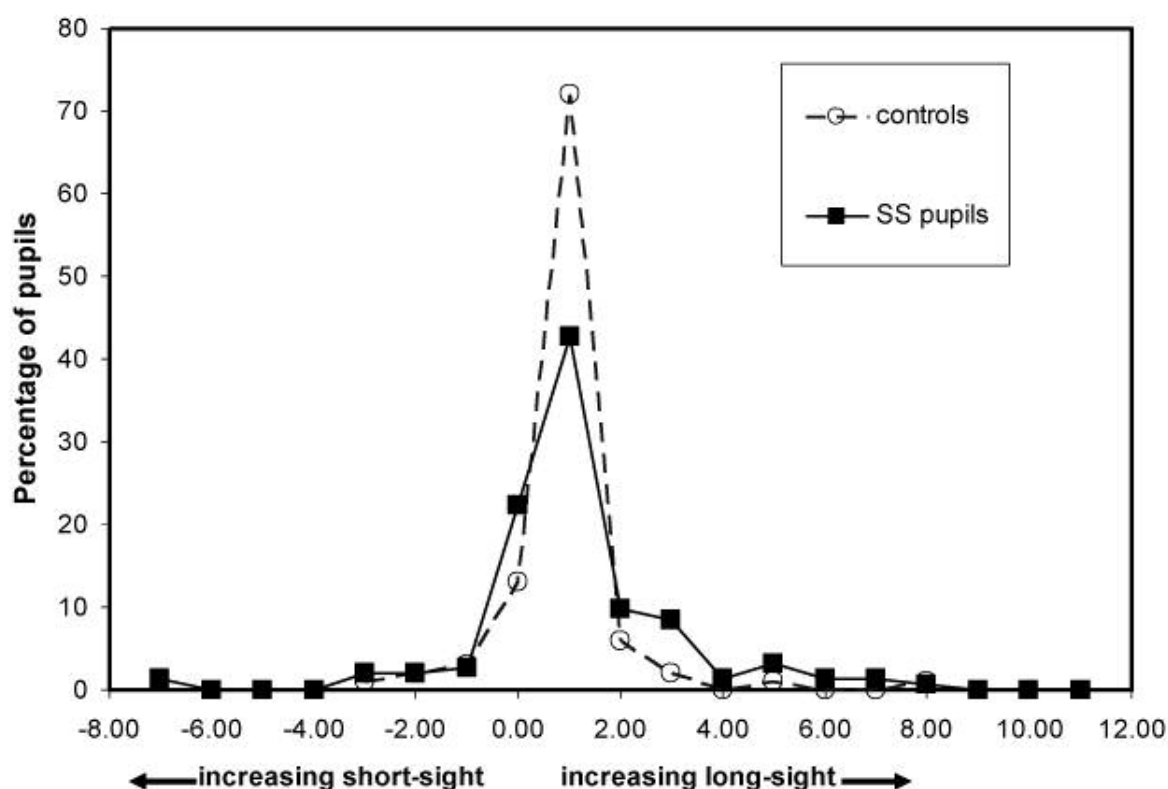
**Table 3. Spectacles prescribed to pupils and spectacle wear.**

### Refractive error

Cycloplegic drops were used for 9.2% of pupils (14 pupils).

There is no agreed definition of what constitutes refractive error and different studies use different criteria as well as different techniques for measuring refractive error. We have chosen to present our findings graphically. Figure 1 compares the results of this study with those of McClelland (2004) who reported the results of sight tests of 128 typically-developing school pupils (aged 4-18 years) in Northern Ireland.

Pupils in special schools in Wales were more likely to have refractive errors that would warrant spectacle correction and they had higher long sight (hypermetropia) or short-sight (myopia) than the typically developing children in Northern Ireland. In both groups, the most common refractive error was a small amount of long sight (hypermetropia) which is represented by the peak. However, for typically-developing school pupils (the controls), this peak is much higher, representing 72% of pupils, compared with 33% of special school pupils.



**Figure 1. The distribution of long and short-sight among 128 typically-developing school pupils (controls)<sup>1</sup> and 152 pupils attending special schools.** <sup>1</sup>Data courtesy of Julie McClelland, from her study in Northern Ireland.

In the McClelland (2004) study, astigmatism was considered clinically significant if the value was 1.00DC or higher. McClelland reported prevalence in her typically developing group of 3.9%. In the present study, 34% of special school pupils had significant astigmatism.

### Eye movements and binocular vision

Overall, 71.7% (109 pupils) had full eye movement control, 10.5% (16 pupils) had nystagmus and the remaining 17.8% (27 pupils) had some other form of abnormal eye movement.

Binocular status was recorded for 151 pupils of whom 24.5% (37 pupils) had squint (strabismus).

### Accommodation

The accuracy of accommodation (near focusing) was assessed in 140 pupils; 12 pupils were unable or unwilling to participate in the evaluation. Inaccurate accommodation was recorded for 13.2% (20 pupils) and a further 20.7% (29 pupils) could produce accurate accommodation that was not sustained. Thus, overall, 33.9% (49 pupils) had an accommodative deficit, i.e. difficulty focusing on near tasks, which means that school work would be out of focus.



## Ocular disorders

All but one pupil cooperated for an eye health examination. Of the 151 pupils, 47% (71 pupils) had at least one ocular disorder. Descriptions of the disorders are shown in Table 2.

Site	Disorder	Percentage of pupils	Number of pupils
Lids / lashes	Blepharitis	27	41
	Meibomian gland dysfunction	20	30
Cornea	Scarred	7	10
	Hazy / other	6	9
Lens	Interocular lens	1	1
	Cataract	1	2
	Hazy	7	10
Retina	Abnormality	3	5
Disc	Atrophy	2	3
	Enlarged cupping	2	3
	Other	15	22

**Table 2. Ocular disorders recorded. Note that some pupils had more than one disorder**

## 3.4 Discussion

### 3.4.1 Visual impairment and refractive error

The findings of this project support those of other studies reporting that the prevalence of visual impairment and refractive error is greater in children in special schools and children with learning disabilities (Warburg 1979; Sobrado, Suarez et al. 1999; Mwanza, Nkidiaka et al. 2000; Warburg 2001; Leekam, Nieto et al. 2007; Nielsen, Skov et al. 2007a; Nielsen, Skov et al. 2007b; Ghasia, Brunstrom et al. 2008; Ashwin, Ashwin et al. 2009). Specifically, pupils in special schools are much more likely to have long-sight (hypermetropia) or short-sight (myopia) (Ghasia, Brunstrom et al 2008).

The results in Wales were similar to the finding of the only other published study conducted in special schools in the UK. The Glasgow-based project found 12% of pupils had low vision or blindness (according to WHO criteria) compared to 15% in Wales. The Glasgow project found that 46% of pupils had refractive error that needed correcting compared to 53% in Wales (Das, Spowart et al. 2010).

In children attending mainstream schools in Northern Ireland, visual impairment (habitual visual acuity less than 6/12) of 1.5% was found among 6-7 year olds and 3% among 12-13 year olds (O'Donoghue, McClelland et al, 2010). In special schools in Wales the prevalence was about 10 times higher (20%).

### **3.4.2 Undetected visual impairment and refractive error**

It was not always clear from the information provided by schools and/ or parents whether a visual impairment had previously been detected in a pupil. However, of the 152 pupils tested in this project, 20% were found to have a visual impairment; over one third of pupils had never had a sight test and 24% of pupils were issued with spectacles for the first time.

It was not just in younger children that eye problems had gone undetected. One young person who was 21 years old needed spectacles but had never had an eye test. The mean age of those who had never had a sight test but were found to need spectacles was 13 years. In addition, it is apparent that not all those with undetected eye problems were mild cases; a number of the cases outlined by the optometrists had severe visual impairment or high refractive errors that were detected for the first time.

The results of this study highlight that the ophthalmic services available for disabled children with complex health needs in special schools in Wales are falling a long way short of those that are aspired to in the NSF for children and young people (Welsh Assembly Government 2005).

### **3.4.3 The need for eye care services for children and young people in special schools**

The very high prevalence of visual impairment and refractive error in children and young people in special schools and the high levels of undetected visual problems found in this project indicate the need for improved eye care services for this population.

The potentially high referral rate from screening, the high prevalence of refractive error and the fact that 47 % had an ocular disorder suggest that a full sight test would be most useful for children and young people in special schools. Vision screening (simple testing using a reduced number of tests) by a non-ophthalmic professional is unlikely to be cost saving, efficient or in the best interests of the pupils and their families.

The service that is developed for children and young people in special schools in Wales should have the following clear goals:

1. All visual problems should be detected
2. All refractive errors identified should be corrected
3. Advice about, minor ocular conditions such as blepharitis and meibomium gland dysfunction should be provided
4. Effective links with schools, parents and other professionals

## 4.0 Feedback from schools, the project optometrists and parents

### 4.1 Obtaining feedback

Feedback was obtained from schools, the project optometrists and parents.

#### **Feedback from the participating schools**

A postal questionnaire was sent to each pilot school after the sight tests had taken place. The postal questionnaires enabled the schools to provide feedback about the vision care programme.

#### **Feedback from the project optometrists**

The project optometrists were asked to keep a diary of any issues that would be helpful for developing services in the future. In addition, they were asked to keep a record of a range of cases for which the sight tests proved particularly helpful.

#### **Feedback from parents**

Fifteen (about 10%) parents were randomly chosen and asked to complete a questionnaire administered over the telephone. The questionnaire asked for feedback about the experiences of the parent and pupils of the vision care programme.

### 4.2. Results

#### **4.2.1 Feedback from schools**

All five schools completed the postal questionnaire.

#### **Testing in school compared with testing in optometry practices**

All five schools reported that it had been useful for the pupils and the school to have the sight tests in school. They also all reported that it would be 'very useful' for the pupils to have regular sight tests in school.

*'A worthwhile project that the school has been very happy to take part in. Please can we have you back on an annual basis? This has been such a benefit for our pupils'*

Most schools felt that it would be more beneficial for pupils to have sight tests in school compared with having sight tests in optometry practices. The familiar surroundings, the difficulties that parents experienced in taking their child to places like optometry practices and the very many appointments the children had to attend were all given as reasons for this. One school commented that it would be beneficial for pupils to have eye tests at optometry practices because it enables them 'to have the experience of a normal visit to the opticians'. However, the limitations of assessing pupils in optometry practices were also reported:

*'pupils intimidated by new surrounding'*

*'logistical problems, e.g. access with large specialist wheelchairs'*

### **Benefits for the pupils, staff and the school as a whole**

Schools reported that a positive aspect of the sight tests taking place in school was that the pupils did not need to take time off school. For many of the children their complex health care needs require them to attend a lot of appointments. They also explained that testing in school was beneficial to the pupils because they were in familiar surroundings, and more relaxed.

The schools found that the pupils were proud of their spectacles and showed them off to other pupils. This led to a positive peer pressure which encouraged more children to have their eyes tested.

The staff reported that it was very helpful to have up to date information about which pupils needed to wear glasses and when they needed to wear them.

The schools also found that there was an enormous increase in staff awareness regarding visual impairment and that staff were more aware of the needs of specific pupils who had a visual impairment and more confident about ways to support them.

*‘Staff were able to see the impact of improved vision with some pupils.’*

### **Logistical challenges for the school**

The schools were invited to record the extent to which the pilot project fitted in with whole-school routines, class timetables and staff commitments. In total, three schools reported that the pilot project fitted in very well with whole-school routines. Two schools reported that the pilot project fitted in ‘quite well’ with whole-school routines but they also noted that although it was not always easy to fit in the project, the benefits outweighed any inconvenience. They explained that they found it difficult to fit the testing in because many of the children had complex timetables.

Finding a suitable room that was not being used and which could be blacked out was also difficult for some schools. Two schools reported that they hadn’t been realistic about the number of days allocated to test children.

Schools stressed the importance of involving school nurses.

### **About the information provided**

All the schools reported that the consent pack for parents was good or very good. However, one school noted that the information for parents contained too much detail especially as some of the parents have learning disabilities. Another suggested that shortening it may improve the consent rate. Another school noted that giving parents more notice about the eye tests would have been better.

### 4.2.2 Project optometrist's feedback

The project optometrist provided the following comments and feedback:

#### **Information and consent forms for parents/ guardians**

Having information from parents/ guardians about the pupils' history and symptoms was essential. However, some schools advised that although informing parents is important, long information sheets and questionnaires are off-putting for many parents. One school added information and the take up for sight tests in that school was poor.

A compromise that worked well was providing a short consent form without a questionnaire followed up by a phone call to parents/ guardians. Parents agreed to initial testing and supplied a contact telephone number for the optometrist to take a history and symptoms over the phone. This approach was time consuming but was effective in gaining relevant information and ensured a good uptake.

#### **Organising appointments**

The project team, in conjunction with the schools, developed daily assessment timetables, which allowed one hour for each pupil's sight test. In the first school, it quickly became apparent that the project team needed to be flexible with the assessment timetables. For example, some pupils were absent from school when their sight tests were due to take place. Some pupils had other commitments and priorities in school, such as participating in sports events or going on class trips. The assessment timetables were frequently adapted.

Booking days to visit the schools, sending consent forms to the school to distribute to parents, chasing consent forms, collecting the consent forms from the schools and booking appointments were all time consuming tasks.

#### **Dispensing**

A full day was needed to enable children to collect their spectacles and for them to be fitted. For the project, we used Cardiff University Eye Clinic as a centralised dispensing lab to order and check the spectacles. Spectacles had to be posted to Cardiff, then to the optometrist, who then took them to the school to enable the children and young people to collect them. Delay in one pair could mean a separate visit to the school for one child.

Within the period of the project, a couple of the pupils broke their spectacles. This is likely to happen reasonably frequently with this group of children and young people. Having a local practice linked with the scheme would reduce the difficulties of dispensing, ordering and collecting spectacles and repairing them if they break. It would be preferable if, for this group of children, two pairs could be issued so that they would have a spare pair.

Not all pupils tested were entitled to NHS vouchers, i.e. a few were 19 years or older and did not receive benefits that made them eligible for vouchers.

#### **Room Allocation**

Some of the rooms used for testing were not appropriate or suitable for a testing environment, e.g. noise, location, size and practicality.

#### **Recall dates**

The interval of recall required on clinical grounds varied from 3 months to a year.



## Example case studies

Many cases were encountered that demonstrated the value of the sight tests being carried out. Some examples are given below:

### Case 1

Pupil A is 15 years old, is severely autistic and has Down's syndrome. Mum had taken A into a community optometry practice 2 years before but they were asked to leave the practice as the child's behaviour was upsetting other patients. Since then, A has had no form of glasses despite needing a high prescription for long-sight and astigmatism. Mum was so embarrassed that she had almost resorted to buying A glasses online rather than going to an optometrist.

### Case 2

Pupil C, who was 15 years old, was found to be very long-sighted (over 7 dioptres in each eye). He has very complex needs and the majority of his support at school was carried out one-on-one at close proximity. Staff wondered why he got so "tired and upset" after a short time. He now wears his glasses full time and a review has shown him to be improving significantly in core skills at school.

### Cases 3 and 4

The school has been struggling to get an appropriate head rest for pupil D (who was 15 years old) but, unfortunately, due to lack of communication between the different professionals, his nystagmus had never been considered. The head rests in question were placed at a point maximising the nystagmus and his head had been strapped in place. This may have induced oscillopsia (perception that the world is moving). D had been trying to pull his head in the opposite direction. This is similar to another case, pupil E, whose communicator was placed at a position that forced him to have maximum nystagmus.

### Case 5

Pupil F, who is 14 years old, is very strong and has little communication. She can be very destructive. Mum attempted to take F into a community optometric practice after being discharged from the hospital. Mum was told that "we regret that due to her demonstrative acts we are unable to take F into the testing room". F is physical when frightened but is calmed and soothed by those closest to her. The project optometrist spent 15 minutes talking to her prior to the sight test and it was conducted at a slow pace that did not frighten or upset her. It had been some years since F had a sight test and she was found to need strong spectacles. The first time she wore her new spectacles she didn't pull them off but said "I can see" and asked "I look pretty?".

#### 4.2.3 Parents' feedback

Unanimously, all the parents reported that it was useful for their child to have their vision tested in school. The main reason reported in open questions was that the school environment was more familiar, which made their child feel more relaxed.

*It was a lot easier for our child to have their eyes tested in school as they are familiar with the surroundings.*

Two parents explained that that they had had difficulty taking their children to an optometry practice.

*I've never tried to take our child. It would cause panic attacks and too much stress.*

*We've been trying for ten years to find an optician who can test our child*

However, the project seemed to have made it easier for this to happen.

*Following the project we now take him to our local opticians and he's going to be seen again at the end of March. I'll let you know the outcome.*

All the parents felt that it would be useful for eye tests to take place in school in the future and noted the beneficial effects that the project had had for their child

*Our child asks for her glasses first thing in the morning and has adapted very well to wearing them. We've noticed a huge improvement in her behaviour since she was prescribed glasses. School have noticed that her behaviour has improved. It's also wonderful that the glasses are trendy and our child likes to tell everyone about them.*

When asked how the service could be improved, three parents mentioned that as their children had learning disabilities and/ or behavioural problems, having a second pair of spectacles would be important.

## 5.0 Future Services

As outlined, the results of this project suggest that a full annual sight test is needed for children and young people in special schools. Vision screening (simple testing using a reduced number of tests) by a non-ophthalmic professional is unlikely to be cost saving, efficient or in the best interests of the pupils and their families due to the large number of onward referrals that would be required. This project has provided crucial guidance about what future services should contain.

### 5.1 Assessments in schools or optometry practices

The NSF requires that services for children and young people with disabilities and complex needs promote choice (WAG 2005). The results of this project indicate that ‘one size fits all’ in eye care for children and young people in special schools will not work for every pupil and hence a range of services is needed to meet the needs of all.

Parental information showed that 41% (62 pupils) had had an eye test in a community optometry practice in the past. Using existing community optometry practices should be encouraged for pupils in special schools and the optometrists involved in the project felt that there would be no barriers to this for many of the pupils they examined. However, feedback from parents, school staff and the optometrists indicated that optometry premises were sometimes unsuitable or inaccessible (for example for those pupils using specialist wheelchairs that require special transport) for some children and young people. In addition, many community practices do not have the specialist charts required to test those who have very poor communication and staff lack the training and/or time to provide examinations for those with the most complex needs.

Barriers to delivery of a good service to people with disabilities and complex needs are known to include communication difficulties and the effect of challenging behaviour during consultations, coupled with lack of adequate consultation time (Lennox and Kerr, 1997). The manner in which an eye test is conducted for pupils in special schools is important (Das, Spowart et al. 2010). Visits to the optometrist are infrequent, making the environment less familiar, and the feedback from parents suggests that this can be frightening or stressful. In this study, a high percentage of cooperation was possible as the assessments were made in the familiar environment of the participant's own school, supported by a known caregiver and with enough time. Therefore, an optometric service should be offered to pupils in special schools.

**Action: An optometric service should be offered to pupils in special schools**

Some of the parents who had found using optometry practices stressful wanted to attend the examination with their child but due to work commitments couldn't attend during school times. In addition, whilst testing in special schools may be best in childhood, there are currently no specialist services available for adults with learning disabilities.

Therefore, it will be important to ensure that children are supported to become familiar with having a sight test in community practices in preparation for the future. Therefore, there is an argument for having a transitional service so that pupils from special schools can attend the optometrist from the special school service in the community to prepare them for having sight tests in community practices.

**Action: A transitional service should be established to support pupils in special schools to become familiar with having sight tests in a community practice.**

## 5.2 Pre-assessment sessions

It has been recommended that pre-teaching children about vision screening procedures are an important part of a successful vision screening programme (Bachman, Bachman et al. 1994). However, in this project we found that schools found them difficult to facilitate and that the children did not benefit from them. Therefore, pre-assessment sessions are not recommended to be part of any ongoing service.

## 5.3 Accommodation, furniture and equipment

Some of the rooms used for this project were not ideal as a testing environment, e.g. noise, location, size and practicality. It will be important to allocate accommodation in schools for testing. In some schools it may be appropriate to use the medical/ therapy room. The requirements of a testing room and the furniture for it are:

At least 3 metres in length

Capable of being blacked out with black out blinds

Three chairs (one adjustable height with arms and one adjustable height)

A small desk

A telephone

Control of light in the room with switches near the testing optometrist

A sink

At least one double electrical socket near the testing optometrist

Not shared with staff or activities during testing

Child friendly

**Action: A room should be allocated (this may be the medical/ therapy room) in special schools for sight testing**

The equipment required to provide the service would be:

Cardiff Cards

Kay Pictures chart

Keeler LogMAR chart

Budgie sticks and fixation lights

An occluder

A patch/ frame for occlusion

Two trial frames; one adult and one child

An i-Care tonometer

A direct ophthalmoscope

A retinoscope

A trial case

A table for a trial case

A McClure near vision chart

A portable fundus camera (shared between schools)

A laptop

A portable printer

**Action: Equipment should be provided for sight testing in special schools**

#### **5.4 Training and accreditation**

Optometrists accredited to provide the Welsh Eye Care Service (Eye Health Examination Wales or Low Vision Service Wales) should be offered training and accreditation to provide the service in Special Schools.

**Action: Optometrists accredited to provide one or more of the Welsh Eye Care Services should be offered training and accreditation to provide the service in special schools.**

### 5.5 Obtaining consent from parents

Having information from parents/ guardians about the pupils' history and symptoms was essential. However, schools and the optometrist felt that long information sheets and consent forms are off-putting and diminish the take up of sight tests.

It is recommended that a short consent form is used followed up by a phone call to parents/ guardians to collect relevant history and symptoms.

**Action: A short consent form should be sent to parents/ guardians and followed by a phone call to collect relevant history and symptoms.**

### 5.6 An accompanying support worker

An optical assistant should help with the onsite administration duties such as contacting parents, distributing reports and referrals, filling in forms and retrieving or filing records. A dispensing optician may attend to also assist with the dispensing and collection of spectacles. An optometrist should not test children or vulnerable adults unaccompanied (College of Optometry 2011). Therefore, the assistant or dispensing optician should be available to act as a chaperone. Training should be provided for these personnel.

**Action: A trained optical assistant and/ or a dispensing optician should accompany the optometrist.**

### 5.7 Issuing vouchers

An NHS voucher towards the cost of spectacles (GOS3) would be issued to each child.

Not all pupils tested were entitled to NHS vouchers, i.e. a few were 19 years or over and did not receive state benefits.

Provision should be made in this service to ensure that vouchers are issued to all children and young people who attend special schools.

**Action: All pupils who have a sight test in the special school service should be issued with an NHS voucher (GOS3) towards the cost of their spectacles.**



## 5.8 Dispensing spectacles

Parents and pupils should be offered choice in how they have spectacles dispensed. This should include: parents choosing frames from a selection offered by the special school service; parents give responsibility to the optometrist to choose frames with the pupil; or parents are sent the GOS3 so that they could attend an optometry practice to choose spectacles with their child.

Children under 16 are entitled to an NHS optical repair or replacement voucher. This voucher helps towards the cost of replacing or repairing spectacles if spectacles are lost or damaged. No child is automatically entitled to help with the cost of a second pair of spectacles to the same prescription but there is a process in place for the testing optometrist to request a second pair if it is clinically necessary.

**Action: Parents and pupils should be able to choose spectacle frames from a selection offered by the special school service or attend an optometry practice.**

## 5.9 Working in partnership with school nurses

The NSF for children and young people requires children in special schools to have access to nurses at all times when pupils are on the premises. A number of the schools indicated the importance of involving special school nurses in any ongoing service and ensuring a report was made available to the school nurse to keep with other health care records.

**Action: Optometrists testing in special schools should work in partnership with school nurses.**

## 5.10 Organising appointments in schools and ordering spectacles.

Booking days to visit the schools, distributing consent forms and chasing consent forms would be best done by a central administration team. Flexibility with the assessment timetables is required as the pupils' health, school timetables and commitments are often complex. An ability to follow children up, according to their need will be essential, including an allowance for retests within 3-6 months.

Spectacles would be ordered and distributed centrally by a central administration team in a similar way to low vision aids for the Low Vision Service Wales.

**Action: A central administration team should book appointments and order spectacles and equipment.**

### 5.11 Referral and reporting

Post assessment reports would need to be provided on all children and a copy provided to the parents. With parental consent, a copy would also be given to the school nurse to share with school staff and file with other health records. In addition, a referral or report may be sent to an ophthalmologist, specialist teacher or general practitioner for some children. Ensuring time in a consultation to write the reports would be essential.

**Action: Copies of reports and referrals should be provided to parents and (with parental consent) others who support or care for the child.**

### 5.12 Monitoring and quality assurance

Processes should be continually monitored by the central administration team and a clinical lead should provide clinical governance, including regular clinical audit. The administration and clinical lead would report regularly to the Welsh Eye Care Service Board.

**Action: The administration team, the clinical lead and Welsh Eye Care Services Board should be responsible for Quality assuring the service.**

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