# Wirral JSNA: Children and Young People Eye Health

## **Summary**

- Wirral has approximately 74,900 children and young people (0-19)
- Wirral has 245 children and young people with a significant visual impairment (0-19) as known and accessing services
- Wirral prevalence of children with visual impairment is approximately 3.3 per 1000, which is higher than the expected prevalence of 2.0 per 1,000 population
- There are 17 Wirral children and young people (0.022%) that have both vision and hearing impairment. This is slightly fewer than expected prevalence suggests.
- RNIB estimation is that the total number of children and young people who are blind or partially sighted (aged 0-16) is 127 with a further 67 (aged 17 – 25) giving a total of 194, or approximately 25% lower than those currently using Wirral services
- Almost 1 in 4 Wirral children and young people, known to Vision Impairment service, are in receipt of Free School Meals
- 35% of Wirral young people with Visual Impairment have complex needs and this
  is higher than the estimated 30% (Keil, 2012)
- In Wirral, 175 of 245, or over 71%, of children and young people with vision impairment are in mainstream education
- 70 of 245, or almost 28%, are in generic special schools
- Total number of children and young people registered blind or partially sighted (aged 0 – 17 years (2013/14) is between 37 and 43 with the RNIB suggested estimate being less at 32
- At present there are no Wirral children and young people with vision impairment registered as NEET
- According to local data an Early Years 'Bubble' could be developing through an increase of age specific referrals. This needs further investigation as it has the potential for a variety of service impacts in the future
- There is no current data on the prevalence of genetic eye conditions for Wirral.
- Some children and young people are at higher risk of vision impairment with some ethnic groups, those with learning disabilities, very premature and very low birth weight babies and those from the most economically deprived social backgrounds more at risk
- Inequalities also exist as a consequence of maternal infections, alcohol and drug exposure and smoking
- Figures on sight tests from the NHS Information Centre suggest that only 1 in 4 children and young people have had their eyes tested (2012/13)

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#### What do we know?

#### **Overview**

Vision impairment in children is a low incidence high impact disability. Children with vision impairment have different needs to adults with sight loss. In order to reduce lifelong inequalities, it is important that support is provided from birth, throughout childhood and the transition into adulthood. If this support is not received, then during their development, and life, chances can be severely limited.

Significant vision impairment can delay early childhood development and learning; including social communication, mobility, and everyday living skills. Harris et al (2012) suggests that children with vision impairment are at risk of poor outcomes across a range of emotional and social wellbeing indicators, which McManus and Lord (2012) points to effects on adult life, limiting work opportunities. It can also have a major impact on the wellbeing and coping capacities of the family.

The Healthy Child Programme sets out National Screening Guidelines. There are three key stages at which all children should be screened for ocular conditions and vision impairment. Early detection and treatment interventions are imperative to avoid preventable sight loss. Screening programmes are recommended at the new-born examination, the 6 to 8 weeks review, and the school-entry vision check at the age of 4-5 years: <a href="http://www.screening.nhs.uk/vision-child">http://www.screening.nhs.uk/vision-child</a>

The changes in the <u>Children and Families Bill</u> are a rethink of the way children with special educational needs (SEN) are supported. The new approach to SEN provision places children and young people with SEN or disabilities at the centre of planning. Equally it requires local education, health and social care services working together to ensure they provide the right support in order for them to achieve their ambitions and the best possible educational and other outcomes, including getting a job and living as independently as possible.

#### **Facts and figures**

#### Overview

**WHO definition** A person of low vision is one who has an impairment of visual functioning even after treatment and/or standard refractive correction, and has a visual acuity of <6/18 to light perception, or a visual field less than 10 degrees from the point of fixation, but who uses, or is potentially able to use, vision for the planning and/or execution of a task for which vision is essential.

#### Measuring vision impairment in children

Children with vision impairment have various degrees and types of vision loss. The two common definitions of vision impairment in children are:

**Medical definition** is based on clinical measures of vision, in particular measures of visual acuity. These are also used by ophthalmologists to decide who should be entered onto the Sight impairment Register held by Local Authorities.

**Functional definition** focuses on how an individual child's vision impairment affects the way that they learn, develop and carry out everyday activities.

The following functional definition is generally accepted by the sight loss sector:

The child or young person's vision impairment interferes with optimal development, learning and achievements, unless adaptations are made in the methods of presenting learning experiences, the nature of the materials used and/or the learning environment.

The term 'learning' includes not just academic learning but the acquisition of mobility, life and social skills that in the case of a child or young person with vision impairment would be provided through habilitation education. This definition includes children and young people with other disabilities/impairments in addition to vision impairment, including those with profound and complex needs.

There may be differences between the two approaches. For example, a young person may have a mild reduction in visual acuity but function differently due to other ophthalmic condition, e.g. nystagmus, visual field reduction, cerebral visual impairment (damage to the visual pathways in the brain), and/or additional learning difficulties.

# **Key Facts**

The number of children with vision impairment is increasing according to **Mitry et al (2013)**, which is demonstrated by a steady year on year increase of children registered as blind or partially sighted.

Key facts about vision impairment in children and young people (Vision 2020UK Children and Young People Social Research Group) with comparative figures for Wirral

Two in every 1,000 (0.2%) children and young people up to the age of 25 in the UK have vision impairment based on the WHO definition (Tate et al, 2005)
(Cumberland et al, 2010). This is an underestimate because it does not include children whose vision impairment does not meet the WHO definition but affects them educationally and socially.

There are approximately 74,900 children and young people (0-19) in Wirral. 245 children and young people (CYP) aged between 0 – 19 are known to have a significant visual impairment in Wirral (Wirral Sensory Support Service database, 2015). Accurate numbers for those between 20 and 25 are not currently available. This gives a Wirral prevalence of 3.3 per 1000, which is higher than expected.

2. 5 in every 10,000 (0.05%) of children up to the age of 16 are <u>severely</u> sight impaired/blind. This group of children is included within the overall 0.2% estimate in 1 above. (**Rahi & Cable, 2003**)

There are 49 children and young people with severe or profound visual impairment (**Wirral Sensory Support Service database**, **2015**).

3. An estimated 31 in every 100,000 (0.031%) children and young people up to the age of 19 in the UK have co-occurring vision and hearing impairments. (Vision 2020UK Children and Young People Social Research Group)

17 Wirral children and young people (0.022%) have both vision and hearing impairment, slightly fewer than expected. This may be due to under recognition and likely will improve with the ongoing closer working between the Hearing Impairment and Visual Impairment services. (Wirral Sensory Support Service database, 2015)

4. Some children and young people are at higher risk of vision impairment

This includes some ethnic groups, with learning difficulties, very premature and very low birth weight babies and those from the most economically deprived social backgrounds. (Vision 2020UK Children and Young People Social Research Group)

 The estimated numbers of children and young people with vision impairment in the UK and England are: (Vision 2020UK Children and Young People Social Research Group)

| l          | JK     | Eng        | land   |
|------------|--------|------------|--------|
| Ages 0-16: | 26,000 | Ages 0-16: | 22,000 |
| Ages 0-18: | 29,000 | Ages 0-18: | 24,000 |
| Ages 0-25: | 41,000 | Ages 0-25: | 34,000 |

6. In England in 2013, there were 25,700 children and young people supported by local authority Visual Impairment (VI) specialist education services. Included in this figure are 9,535 aged 0-17 registered as blind or partially sighted. (*Note: There has been some difficulty with recording information from hospitals outside Wirral. This issue is being resolved during the next 12 months so figures may change*)

Wirral Borough Council is supporting 245 children and young people with vision impairment. This includes 79 registered as blind or partially sighted. Note: registers are constantly updating so figures will fluctuate over time

7. Around 20% of children and young people with vision impairment have additional special educational needs and/or disabilities (SEND) and a further 30% have complex needs. (**Keil**, **2012**)

35% of Wirral young people with Visual Impairment have complex needs (Wirral Sensory Support Service database, 2015).

- 8. Two thirds of childhood vision impairment was present from birth or diagnosed in the first year of life. (Vision 2020UK Children and Young People Social Research Group)
- 9. The causes of vision impairment in childhood are different from the causes in adults, the most common being: cerebral vision impairment (CVI), which is where there has been damage to the visual pathways in the brain, affecting the way that visual information is processed; disorders of the optic nerve; and disorders of the retina. Many children and young people have more than one sight disorder.
  (Vision 2020UK Children and Young People Social Research Group

## Causes of vision impairment in children

The causes of vision impairment in childhood are generally different to the causes of sight loss in adults. The four most common causes are:

Cerebral Vision Impairment (CVI) is ante- or post-natal damage to the vision processing parts of the brain. Cerebral vision impairment accounts for 48% of blindness in children (Rahi and Cable, 2003) and between 32% and 45% of all children with vision impairment (Flanagan et al, 2003)

Wirral has recently started a database to include diagnoses for children with VI. This data is currently incomplete however the data available suggests that 45.5% have Cerebral Vision Impairment.

**Optic nerve disorders** are a group of conditions where the optic nerve doesn't transmit light signals to the brain correctly and accounts for about 28% of severe vision impairment in children. (**Rahi and Cable, 2003**)

Currently figures suggest 17% of children with VI in Wirral have an optic nerve disorder. This number is likely to be higher when data recording is developed.

**Retinal or macular dystrophies** are umbrella terms for a range of inherited conditions which cause the retina to not function correctly. A significant proportion of children with retinal dystrophies have serious co-morbidity, with 13% having dual vision and hearing impairment (Hamblion et al, 2012).

At present 21.4% of children known to Wirral services have retinal or macular dystrophy.

Congenital cataracts can cause significant sight loss which is preventable if it is detected and quickly treated. It is estimated 200-300 children are born with congenital cataract each year in the UK (Rahi and Dezateux, 2001)

There are currently 18 children with congenital cataracts in Wirral.

10. Children and young people with vision impairment are more likely than children without vision impairment to live in families that experience social and economic disadvantage.

Work ongoing to understand how this potential issue is impacting or otherwise on local Wirral Children and young people

11. Nationally about 7 in 10 children and young people with vision impairment attend mainstream schools and around 1 in 3 go to generic special schools. Very few are in schools designated for pupils with vision impairment; most children in these schools have complex needs. (Vision 2020UK Children and Young People Social Research Group)

In Wirral, 175//245, or 71.4%, of children and young people with vision impairment are in mainstream education, 70/245, or 28.6%, are in generic special schools and 5 are in schools designated for pupils with visual impairment in out of borough placement. (**Wirral Sensory Support Service database, 2015**) *Please Note: registers are constantly updating so figures will fluctuate over time* 

12. The educational attainment of pupils with vision impairment up to the age of 16 (as a group) is not as good as pupils with no SEND. However, the gap is far smaller for pupils with vision impairment as their only SEND. (Vision 2020UK Children and Young People Social Research Group)

Wirral has started to collect attainment data and this will continue to understand implications for children and young people with vision impairment

13. Around one in 4 children and young people aged 16 to 25 with vision impairment are students. This is the same proportion of the general population of 16 to 25-year olds. (Vision 2020UK Children and Young People Social Research Group)

14. Children and young people with vision impairment are twice as likely (44%) as their sighted peers not to be in employment, education or training (NEET). (Vision 2020UK Children and Young People Social Research Group)

At present there are no Wirral children and young people with vision impairment registered as NEET

#### **Local Context**

The <u>RNIB Sight loss data tool</u> can be used to provide an estimate of the number of children and young people with related sight loss issues in Wirral.

**Table 1:** Wirral numbers regarding children and young people and eye health (2015)

| Certification* and Registration**  | Wirral          |
|--|-----------------|
| Total number of Wirral residents registered blind (2013/14)                      | 1,215           |
| Total number of Wirral residents registered partially sighted (2013/14)          | 1,065           |
| Total number of Wirral residents registered as blind or partially sighted        | 2,280           |
| Total number of children and young people registered blind 0 – 4                 | Less than 5     |
| years (2013/14)  |                 |
| Total number of children and young people registered partially sighted           | Less than 5     |
| 0 – 4 years (2013/14)  |                 |
| Total number of children and young people registered blind 5 – 17                | 15              |
| years (2013/14)  |                 |
| Total number of children and young people registered partially sighted           | 20              |
| 5 – 17 years (2013/14)   |                 |
| Total number of children and young people registered blind or partially          | Range 37 and 43 |
| sighted 0 – 17 years (2013/14)   |                 |
| Estimated numbers***   |                 |
| Estimated number of children and young people who are blind aged 0-              | 32              |
| 16   |                 |
| Estimated number of children and young people who are blind aged                 | 17              |
| 17-25  |                 |
| Estimated number of children and young people who are partially                  | 95              |
| sighted aged 0-16  |                 |
| Estimated number of children and young people who are partially                  | 50              |
| sighted aged 17 - 25   |                 |
| Estimated total number of children and young people who are blind or             | 127             |
| partially sighted aged 0-16  |                 |
| Estimated total number of children and young people who are blind or             | 67              |
| partially sighted aged 17-25   |                 |
| Estimated total number of children and young people who are blind or             | 194             |
| partially sighted aged 0-25  |                 |
| Service numbers****  |                 |
| Actual number of children and young people supported by Wirral                   | 245             |
| Sensory Support Service (2015)   |                 |
| <ul> <li>Actual in service number of children and young people with</li> </ul>   | 49              |
| severe or profound visual impairment   |                 |
| <ul> <li>Actual in service number of Wirral children and young people</li> </ul> | 17              |
| that have both vision and hearing impairment                                     |                 |
| <ul> <li>Actual in service number of Wirral children and young people</li> </ul> | 79              |
| that are registered as blind or partially sighted.                               |                 |

| Education numbers*****  |     |
|---|-----|
| Number of Wirral children and young people with vision impairment | 175 |
| that are in mainstream education,                                 |     |
| Number of Wirral children and young people with vision impairment | 70  |
| that are in generic special schools                               |     |
| Number of Wirral children and young people with vision impairment | 5   |
| that are in are in out of borough placement.                      |     |

**Source**: RNIB (2015) <a href="http://www.rnib.org.uk/knowledge-and-research-hub-key-information-and-statistics/sight-loss-data-tool">http://www.rnib.org.uk/knowledge-and-research-hub-key-information-and-statistics/sight-loss-data-tool</a> **Notes**: \* A Certification of Vision Impairment (CVI) formally certifies a person as either sight impaired (partially sighted) or severely sight impaired (blind). Each CVI form is completed by a consultant ophthalmologist in an eye clinic, with a copy sent to the local social services department and providing a formal route to social care services.

The RNIB Survey of Visual Impairment services in England and Wales (2012), specifically the report for England highlights that the total estimated population of pupils with visual impairment in England - up to the end of Year 13 - is **25,074**, giving a prevalence estimate of 0.3%. This is not an estimate of the prevalence of visual impairment, but represents the proportion of pupils in England receiving specialist educational support from VI services. Wirral currently has 245 children and young people accessing services which suggests an estimated prevalence of 0.33% with 245 out of 75,059 children and young people aged 0 – 19. (Wirral 0-19 population in Wirral Instant Atlas)

## Wirral population and future growth

Given that acquired sight loss is age related then any changes in the population of Wirral in the near future are important to understand. This will help us to consider the impact on sight loss services and planning. Population details can be seen in tables 2 and 3.

Table 2: Wirral Mid-Year Population Estimates by age group and gender, 2013

| Ago Bond | Male   | S  | Femal  | es | Perso  | ns |
|----------|--------|----|--------|----|--------|----|
| Age Band | Number | %  | Number | %  | Number | %  |
| 0 to 4   | 9,670  | 6% | 9,264  | 6% | 18,934 | 6% |
| 5 to 9   | 9,525  | 6% | 8,995  | 5% | 18,520 | 6% |
| 10 to 14 | 9,194  | 6% | 8,840  | 5% | 18,034 | 6% |
| 15 to 19 | 9,975  | 6% | 9,221  | 6% | 19,196 | 6% |
| 20 to 24 | 8,763  | 6% | 8,822  | 5% | 17,585 | 5% |
| 25 to 29 | 8,870  | 6% | 9,552  | 6% | 18,422 | 6% |
| 30 to 34 | 8,613  | 6% | 9,121  | 5% | 17,734 | 6% |
| 35 to 39 | 8,193  | 5% | 9,131  | 5% | 17,324 | 5% |
| 40 to 44 | 10,498 | 7% | 11,288 | 7% | 21,786 | 7% |
| 45 to 49 | 11,292 | 7% | 12,456 | 8% | 23,748 | 7% |
| 50 to 54 | 11,305 | 7% | 12,148 | 7% | 23,453 | 7% |
| 55 to 59 | 10,004 | 6% | 10,614 | 6% | 20,618 | 6% |
| 60 to 64 | 9,970  | 6% | 10,337 | 6% | 20,307 | 6% |
| 65 to 69 | 9,519  | 6% | 10,139 | 6% | 19,658 | 6% |
| 70 to 74 | 6,785  | 4% | 7,926  | 5% | 14,711 | 5% |

<sup>\*\*</sup> Upon receipt of a completed CVI form, the social services department offer registration and other relevant advice and support. Registers of blind and partially sighted people are maintained by all local authorities to help them plan and deliver services.

<sup>\*\*\*</sup> RNIB calculated estimate - see guidance notes (7.2) - By applying base prevalence rates to population statistics from Census 2011 we are able to estimate the number of blind and partially sighted children and young people by local areas. Indicators are provided for both blind and partially sighted children and young people aged 0–16 and 17–25 years.

<sup>\*\*\*\*</sup> As provided by Wirral Sensory Support Service 2015 - Note: registers are constantly updating so figures will fluctuate over time

<sup>\*\*\*\*\*</sup> As provided by Wirral Sensory Support Service 2015 - Note: registers are constantly updating so figures will fluctuate over time

|          | 154,247 | 100% | 166,048 | 100% | 320,295 | 100% |
|----------|---------|------|---------|------|---------|------|
| 85+      | 2,797   | 2%   | 5,942   | 4%   | 8,739   | 3%   |
| 80 to 84 | 3,900   | 3%   | 5,567   | 3%   | 9,467   | 3%   |
| 75 to 79 | 5,374   | 3%   | 6,685   | 4%   | 12,059  | 4%   |

Source; Office for National Statistics 2014

Notes: Mid-2012 ward population estimates refer to the 2012 electoral ward boundaries. Estimates for mid-2012 are based on aggregations of whole mid-2012 Output Area (OA) estimates. OA boundaries are not an exact fit (non-coterminous) for ward boundaries and therefore are allocated using a best-fit approach

- The total population in Wirral is expected to be approaching 321,837 in 2016 and is projected to increase to 328,823 by 2028 (table 3). This will be a 2.66% increase in 14 years.
- This in turn, as in table 3, suggests more people could be demanding eye health care and support services in the future as seen by the 2% rise in the 0-14 population

**Table 3:** Wirral resident population projections by age group (Persons) Interim 2016 to 2028

| Age band | 2016   | 2020   | 2024   | 2028   | % Change<br>(2016 - 2028) |
|----------|--------|--------|--------|--------|---------------------------|
| 0 - 14   | 56502  | 58099  | 58291  | 57500  | +2%                       |
| 15 - 44  | 108731 | 106775 | 107775 | 108088 | -1%                       |
| 45 - 64  | 88375  | 87183  | 83759  | 80011  | -9%                       |
| 65 - 74  | 36568  | 37753  | 37234  | 39549  | +8%                       |
| 75+      | 31664  | 34621  | 39927  | 43677  | +38%                      |
| Total    | 321837 | 324431 | 326981 | 328823 | +2%                       |

Source: Office for National Statistics, 2014

Notes 2012-based Subnational Population Projections. Clinical Commissioning Groups in England, mid-2012 to mid-2037 - Population figures are derived from single year of age for persons, males and females for local authorities, created as part of the process in producing the subnational population projections. Data are unrounded for use in models and creating user defined age groups. Users should note the metadata provided with these data.

Vision 2020UK Children and Young People Social Research Group suggest that children and young people with vision impairment are more likely than children without vision impairment to live in families that experience social and economic disadvantage. A measure of understanding the implications is knowing the number of children with vision impairment in receipt of Free School Meals (FSM) given the qualifying criteria relate to a range of social benefits. In table 4 below we see the number of Wirral children and young people known to service in receipt of FSM, which relates to almost 1 in 4 children and young people.

**Table 4**: Free School Meal status of Wirral pupils with a Visual Impairment (VI) known to Support Services (January 2015 School Census)

|                            | FSM* | Non-FSM** | Not recorded | Total |
|----------------------------|------|-----------|--------------|-------|
| Known to Wirral VI Support | 51   | 132       | 39           | 222   |
| Service                    | 23%  | 59%       | 18%          | 100%  |

Source: Wirral Council Education Information Section – Wirral Schools Census January 2015

**Notes**: \* Free School Meals - In England a Free School Meal (FSM) is a statutory benefit available to school aged children from families who receive other qualifying benefits and who have been through the relevant registration process. <a href="https://www.gov.uk/government/uploads/system/uploads/attachment\_data/file/266587/free-school-meals-and-poverty.pdf">https://www.gov.uk/government/uploads/system/uploads/attachment\_data/file/266587/free-school-meals-and-poverty.pdf</a>
\*\*non-Free School Meals

Vision 2020UK Children and Young People Social Research Group also suggest that some ethnic groups have a higher risk of visual impairment. The ethnicity of Wirral pupils with a Visual Impairment (VI) known to Support Services is recorded in the School Census (January 2015). This highlighted that the vast majority of pupils with a VI are White British origin.

Though 18%, or 39 pupils, had their ethnic status unrecorded. The known numbers, 3%, reflect local Census 2011 ethnicity data, or a slight under representation, as 5.03% of Wirral residents are from ethnic background other than White British/White (Census, 2011)

**Table 5**: Recorded Ethnicity of Wirral pupils with a Visual Impairment (VI) known to Support

Services (January 2015 School Census)

|                            | White/White other | Other<br>ethnic<br>groups* | Information not obtained/<br>Refused | Not<br>recorded | Total |
|----------------------------|-------------------|----------------------------|--------------------------------------|-----------------|-------|
| Known to Wirral VI Support | 172               | 7                          | 4                                    | 39              | 222   |
| Service                    | 77%               | 3%                         | 2%                                   | 18%             | 100%  |

Source: Wirral Council Education Information Section (2015)

Notes: \*Other ethnic groups include - Any other Asian background, any other Mixed background Bangladeshi, Chinese, Indian and Irish

# **NHS** sight tests

The most widely available tool for case detection in the general population is the sight test as this includes both refraction, with prescription of spectacles where required, and an assessment of eye health with onward referral in cases of possible eye disease.

Wirral has a similar level of NHS sight testing as other areas in the North West totalling 83,230 in 2012/13. However, this still only covers approximately one quarter of the total local population.

Figures on sight tests from the NHS Information Centre, in table 6, suggest that only 1 in 4 children and young people have had their eyes tested.

**Table 6:** Estimated numbers of 0-15s & Students to have had a NHS Eye Test compared to overall population numbers, Wirral, 2012/13

|                    | NHS Eye Tests<br>in 2012-13 | Population<br>Figures* | Percentage of population who have had an NHS Eye Test |
|--------------------|-----------------------------|------------------------|---|
| 0-15 & Students as |                             |                        |   |
| 16 to 18 year olds | 19400                       | 71545                  | 27.1%   |

Source: NHS Information Centre (2014) and Instant Atlas Wirral (2014)

Notes: \* Population figures are cumulative single year age

# School screening

Children and young people in school have routine screening in Foundation Year2 (F2), Year 2 (Y2) and Year 6 (Y6), conducting by screeners trained by orthoptists. Special school pupils have screening by qualified orthoptists as they are more difficult to test.

Arrowe Park Hospital completed child squint surgery on 38 Wirral children from April 2014 to 2015.

In general numbers of Wirral Children and young people with a visual impairment remain stable. The Vision Support Team (Head of Service) takes a 'snapshot' annually on these numbers. Table 7 describes the main causes of visual impairment as recorded by Wirral Vision Support Service in the academic year 2014 -15. This data has been collected using a new database and represents the first year of data available in this detail. It is hoped that the use of the new database will more readily identify the numbers of children referred annually with CVI. This will evidence the perception amongst education and health professionals that there has been an upward trend in this diagnosis although this years is the first data collected

Table 7: Main Causes of Childhood Visual Impairment (Wirral Vision Support Team) 2014/15

| Type of eye condition            | Number known to service (year) | Percentage to service (year) |
|----------------------------------|--------------------------------|------------------------------|
| Cerebral Vision Impairment (CVI) | 51                             | 45.5%                        |
| Optic nerve disorder             | 19                             | 17.0%                        |
| Retinal or macular dystrophies   | 24                             | 21.4%                        |
| Cataracts                        | 18                             | 16.0%                        |
| Total                            | 112                            | 100%                         |
| Other                            | 104                            |                              |
| Nystagmus*                       | (42)                           |                              |
| Astigmatism**                    | (12)                           |                              |
| Unknown***                       | (29)                           |                              |
| Awaiting Diagnosis****           | (21)                           |                              |

Source: Wirral Sensory Support Service database, 2015

Notes:

According to this improving local knowledge, an *Early Years 'Bubble'* may have grown even greater in last twelve months as seen in the percentage increase of early years referrals, noted in Table 8 below. This has potential impact on staffing and other needs for the future.

Table 8: Referrals of Early Years\* Children to Wirral Sensory Support Service, 2014/15

| Period for referrals to Wirral Sensory Support Service | Early Years* as a percentage of referrals to services |
|--|---|
| 2012-13  | 17%   |
| 2013-14  | 26%   |
| 2014-15  | 39%   |

Source: Wirral Sensory Support Service database, 2015

Notes: \* Early Years - constitutes ages from 0 to pre- School Entry noted as F1 or Foundation 1

Due to a concerted effort that integrated children and young people within mainstream or generic provision with support as required, the number of out of borough placements for children and young people with a vision impairment has reduced over the last eight years, and is predicted to remain low for the following two years.

Work continues to both understand previous trends and predict any future changes to numbers of children and young people who might be born, or otherwise, with a visual impairment.

<sup>\*</sup> see definition here

<sup>\*\*</sup> see definition here

<sup>\*\*\*</sup> In some cases there is no recorded or known reason given for eye conditions

<sup>\*\*\*\*</sup> As stated, a diagnosis has yet to be confirmed, often in children under 1 or before Foundation Stage at school

# What is this telling us?

#### **Overview**

Wirral continues to perform well in its support for children and young people with a visual impairment in line with national guidance. Some key aspects include:

- Low number of out of counties these are expensive but are set to continue to reduce
- Low number of Education & Health Care plans due to use of the NatSip criteria and close working relationships with parents/health and settings.
- Improvements in early years intervention due to stronger links with health this will in turn reduce costs and improve outcomes in the long term due to early intervention
- Vision Support team has already sought peer review linked to the Quality Standards developed for SEN support and Outreach Services by the Department for Children Schools and families (DCFS)(2008) and has been rated as good with some outstanding features
- There are no 'Bases' for pupils with a visual impairment as all are educated in local settings.

#### **Local views**

# Service users and Family Consultation Event July 2015

An event has been run in July 2015 with Wirral Society of the Blind & Partially Sighted at Ashville Lodge. This offered the opportunity to canvas information from both parents and children (as service users) on the service. This in turn provides further information and options to develop jointly commissioned service provision between Health and Education organisations. Service users and others were also asked to use their knowledge in developing a targeted leaflet and poster for use in eye clinics and more generally across eye venues across Wirral. This event will be followed up with a postal questionnaire in September 2015 with published analysis of the results in autumn 2015.

## National and local strategies and plans

Vision 2020 UK Children and Young People's group have developed guidelines and a pathway; which sets out the key needs and support milestones for children and young people and their families from the moment vision impairment is identified through to transition into the adult pathway.

These guidelines are intended for those responsible for commissioning and providing services for children and young people and their families. They will assist with the interpretation and implementation of the UK Vision Strategy across health, education and social care. The guidelines and pathway can be found here

**Time of diagnosis:** A key working approach should be available to provide information and support to parents to help them understand and accept their child's vision impairment and its implications in terms of any specialist needs (Rahi et al, 2005) (Rahi et al, 2004)

Early support for babies and young children with vision impairment: A prompt referral should be made to a local authority specialist vision impairment education advisory service. Support can then be provided by a qualified teacher of children with vision impairment (QTVI). Support is particularly important in the first 2 years as development of social and communication skills can be seriously impeded (Dale and Sonksen, 2002). Support resources can be found here

There is a long established service in Wirral which uses the developmental journal as the basis for support.

**Education:** Educational services have statutory responsibilities under SEN and equalities legislation. Approximately two thirds of children are educated in mainstream schools, or mainstream schools additionally resourced for learners with vision impairment. (**Keil, 2012**)

**Mobility and low vision assessments:** Children with vision impairment require training in mobility and independence skills, including daily living activities. This is usually provided by a children's mobility officer/ habilitation worker. Low vision assessment, advice and dispensing of aids are important to assist children in all aspects of independent living.

Currently <u>VisionUK</u> are establishing a consultative process for an <u>English Vision Strategy</u> to address the problems faced on a daily basis by individuals with sight loss and also for maintaining good eye health. More information can be found <u>here</u>

## **Current activity and services**

Wirral services for children and young people with Visual Impairment (VI) already work closely together to provide joined up services. There is a Vision Strategy Group, including service users, which meets three times a year to monitor performance of all services for VI.

Wirral has a slightly higher number of children and young people with vision impairment as would be expected for its population. In line with good practice, most of these are now educated alongside their sighted peers in mainstream schools. They are supported by a peripatetic team of Qualified Teachers of the Visually Impaired (QTVI), supported by Higher Level Teaching Assistants and Teaching Assistants with additional qualifications in vision impairment and a paediatric habilitation specialist. Service is offered from age 0-19, though this may increase to 25 in line with SEND reforms.

The <u>National Sensory Impairment Partnership</u> (NATSIP) <u>criteria</u> are used to categorise the level of support required. The quality of the support has been recognised by an informal OFSTED inspection requested by the service to benchmark the service. The number of out of borough specialist placements has decreased by over 50% in the last 10 years, as children are better supported locally.

There is a well organised ophthalmic team with two consultants with an interest in children, supported by optometrists and orthoptists. The team runs a Low Vision Aid clinic jointly with Sensory Support Service, where the child's QTVI attends with the child and parents/carers.

A vision assessment clinic is run by a community paediatrician with a special interest in children with VI together with the Sensory support service, where children and young people with VI are seen jointly. Members of the team also attend multiagency meetings at school and other settings to support teaching and other staff in managing the children and young people.

There is an orthoptist led vision screening service in primary special schools alongside the examination offered by community optometrists. The quality of the screening service is regularly reviewed.

There is good parent support with a weekly Early Years visual stimulation group, regular home visits from the Team and a weekly Early Years mobility group. Wirral Society for the Blind holds a weekly evening activity club for children. There is also an annual event for parents and children hosted by the Society in partnership with the Vision Support Team.

## **Key inequalities**

The <u>UK Vision Strategy</u> indicates that there is a higher prevalence of visual impairment in Special Schools and in lower economic groups

Particular groups are more at risk of developing vision impairment:

 Premature and low birth weight babies are at risk of underdevelopment of ocular structures, increased risk of squint, and cerebral vision impairment (Mitry et al, 2013 and Rahi and Cable, 2003). Very premature and low birth weight babies are at particular risk of retinopathy of prematurity, a preventable condition. Ocular screening on premature babies is recommended.

Guidelines can be found <a href="here">here</a> or at <a href="https://www.rcpch.ac.uk/system/files/protected/page/ROP%20Guideline%20-%20Jul08%20final.pdf">here</a> or at <a href="https://www.rcpch.ac.uk/system/files/page/ROP%20Guideline%20-%20Jul08/system/files/page/ROP%20Guideline%20-%20Jul08/system/files/page/ROP%20Guideline%20-%20Jul08/system/files/page/ROP%20Guideline%20-%20Jul08/system/files/page/ROP%20Guideline%20-%20Jul08/system/files/page/ROP%20Guideline%20-%20Jul08/system/files/page/ROP%20Guideline%20-%20Jul08/system/files/page/ROP%20Guideline%20-%20Jul08/system/files/page/ROP%20Guideline%20-%20Jul08/system/files/page/ROP%20Guideline%20-%20Jul08/system/files/page/ROP%20Guideline%20-%20Jul08/system/files/page/ROP%20Guideline%20-%20Jul08/system/files/page/ROP%20Guideline%20-%20Guideline%20-%20Guideline%20-%20Guideline%20-%20Guideline%20-%20Guideline%20-%20

- Genetic eye conditions can affect any structure of the eye or visual pathway. They
  are prevalent in socioeconomically deprived groups and in ethnic minority populations,
  particularly South Asian (Hamblion et al, 2012). There is no current data on the
  prevalence of genetic eye conditions in Wirral.
- Maternal infections such as measles and rubella can cause childhood vision impairment. Measles immunisation is necessary to reduce preventable childhood blindness (Gilbert and Foster, 2001). MMR immunisation rates in Wirral are at 95% for children having first dose by age 2 years. This is currently above the English average and historically these rates have always been good.
- Alcohol and drug exposure: a high percentage of children suffering from foetal alcohol syndrome have vision impairment and develop eye abnormalities (Stromland, 2004) (Ribeiro et al, 2007). Maternal drug misuse affects the development of the eye and visual system causing sight loss (McGlone et al, 2009). There are high rates of alcohol misuse in Wirral highlighted by hospital stays for adults with alcohol related harm being almost a third higher than the English average, with opiate/crack drug use estimated at approaching twice the national average (14.2/1,000 people compared to 8.4/1,000 people for England) (Wirral Health Profile, 2015)
- Smoking: exposure to maternal smoking increases the risk of prematurity, low birthweight and of ocular complications. In Wirral the percentage of women smoking at the time of delivery is not currently known (Wirral Child Health Profile 2015)
- Children with learning disabilities have a very high prevalence of vision impairment.
   The estimated prevalence rate for vision impairment in the learning disabilities population aged 0-19 in the UK is 5.6%. (Emerson and Robertson, 2011)

#### **Further considerations**

An 'Early Years Bubble' may be developing where higher than expected numbers of children aged under 5 are registering with the VI team. This requires further investigation as it is likely to have implications for services and schools in the future. Though there is uncertainty how and when children and parents will access local services and so subsequent increased demand occur.

With the development of the All Age Disabilities Partnership Board and its associated work streams it is likely to have outcomes for those children, parents and services in relation to VI with the opportunity to enhance their care and support

Local services provided by Local Authorities, especially Education, and those from Health providers through CCG and other partners are likely to be affected as a consequence of the continuing national austerity measures. The exact nature of any changes remains unknown but there are a number of initiatives that look to improve client and patient journeys.

As a consequence of reduced funding to Local Councils then alternate models of work are being considered such as Shared Services and Local Authority Trading Companies (LATCs) which could alter how support is provided but not necessarily reducing quality or outcomes

#### Links

Wirral Local Offer http://localofferwirral.org/

NatSip http://www.natsip.org.uk/

RNIB http://www.rnib.org.uk/

Actionaires www.actionforblindpeople.org.uk

Guide Dogs <a href="http://www.guidedogs.org.uk/">http://www.guidedogs.org.uk/</a>

NBCS http://www.blindchildrenuk.org/

**UK Vision Strategy** Eye health and sight loss; statistics and information for developing a Joint Strategic Needs Assessment Version 4: January 2015 here

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