



Improving access to eye care for adults with learning disabilities in South Devon

Description

Children and adults with learning disabilities (LD) have a much higher incidence of visual impairment (VI) and this increases significantly with the severity of the LD and with age¹ Whilst children are monitored regularly by an orthoptist within the school setting, individuals with LD over the age 19 years are at significant risk of dropping out of the eye care system. There have been reports of 14-15% of learning disabled adults having a visual impairment severe enough to make them eligible for registration as blind or partially sighted²⁻³. However, in Devon cross referencing the LD register with the register of blind and partially sighted people, found that of 1,866 people with a LD only 34 were registered as visually impaired i.e. 1.82%. It was clear that under registration was occurring. This was effectively blocking access to rehabilitation services via the CVI (Certificate of Vision Impairment).⁴ Therefore, it was essential to improve the access to eye care so that adults with LD could be identified as visually impaired or blind.

Following a pilot study in South Devon, the orthoptists have developed a service to ensure all adults with a learning disability (LD) are able to access eye tests within our local area. This service allowed us to address the wider determinants of healthcare to reduce health inequalities in adults with learning disabilities.

Context

The Government White Papers (2001, 2009) on 'Valuing People'^{5,6}, state that all people with a learning disability should access routine sight checks at their local optometrist. However, for those people with profound LD / complex needs specialist services are required.⁷⁻⁹

As AHPs, Orthoptists are ideally placed to provide a coordinator role between primary and secondary care and to raise awareness amongst other AHPs of the importance of considering referral for vision assessment prior to treatment planning.

South Devon LD population estimates

(Figures calculated using PANSI online tool and utilising the VI and blindness prevalence rates of 5% and 2% for 18 – 54 year olds and 11% and 3% for 55yrs+.¹⁰)

- Estimated total adult LD population for South Devon =5257,
- Visually impaired LD adults= 403
- Blind LD adults= 132

Hence, the unmet need of the local population of adults with LD led to the following aim and objectives:

Aim

To develop a service to improve access to eye care for adults with LD in South Devon.

Objectives

Orthoptist to provide a baseline home functional vision assessment for those people not able to access routine sight tests.

Creation of a multi-disciplinary team (MDT). Inclusion of the Primary Care Liaison Nursing (PCLN) Teams was essential, plus representatives from the Local Optical Committee, Sensory Teams, Diabetic Eye Screening Programme, Consultant Ophthalmologist, and nurses from both Eye Outpatients and the Eye Surgery Unit and local LD commissioners.

Method

A successful grant application (£14,000) to run a pilot project in 2007 revealed 81% of the sample (n=37) of LD individuals required a further follow up for their eye care and 10% were certified as visually impaired.

The grant was used to partially fund the orthoptic extended role, purchase specialist equipment (Figure 1) for functional vision screening and production of the final report.¹¹



Figure 1: Specialist equipment used to assess vision in adults with LD

Outcomes

A total of 243 orthoptic home visits have been completed to date, however the outcomes of 111 visits captured in the last 5 year period are detailed in the table (Table 1) below. All the individuals with LD were initially referred because they were not able to access routine sight tests.

Table 1: Outcomes of 111 orthoptic home visits (2012 – 2017).

Outcome	%
Discharged to local optometrist	27

Referred to hospital eye clinic for treatment	21
Referred to hospital eye clinic and subsequently discharged to optometrist	15
Advice strategies only	9
Follow up orthoptic review	9
Referred to diabetic screening service	5.4
Declined / Deceased	3.6

Key learning points

- Creating a strong MDT network, especially in primary care to ensure accurate referrals and chairing a service review meeting twice a year to maintain momentum.
- Raising awareness locally, by the production of local easy read materials, for example our 'Getting my eyes checked' leaflet.
- Raising awareness nationally. Providing evidence for reports e.g.
- Making Reasonable Adjustments to Eye Care Services for People with Learning Disabilities 2013, pages 11 and 13¹²
- SeeAbility Delivering an Equal Right to Sight 2016, page 56¹³
- I represented the British and Irish Orthoptic Society (BIOS) at the launch of the SeeAbility Delivering an Equal Right to Sight report in the House of Lords in July 2016
- I hosted an information gathering day for commissioners from NHS England to look at our service model in April 2018.
- Development of desensitisation pathways.
- Links with the diabetic eye screening service.
- Transition to adult services.
- This can be a challenge and will require the development of a national database of people with LD, to help identify those most at need. Currently the Orthoptist provides an annual "hands on" talk at local special schools, to promote the importance of regular sight tests for those young people making the transition to adult services.

Future plans include:

- Promote cohesive services nationally, by sharing information and providing information for SeeAbility, England Vision Strategy (EVS) and Commissioners at NHS England.
- Improve the CVI registration process through supported care and follow up of individuals with LD.

- Continue to build our service at a local level to ensure the local need for adults with LD is met and the wider determinants of access to eye health care are addressed.

References

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