

# Improving eye care for children with learning difficulties: a view from SeeAbility

BY MAREK KARAS

**Marek P Karas** from sightless charity SeeAbility examines why children with a learning disability do not access the eye care they need and asks how the system needs to change.

Children with a learning disability are 28 times more likely than their peers to have a serious sight problem, but for many these problems may go undetected [1].

SeeAbility's recent study [2] examined the eyes of almost a thousand pupils in special schools in England. We found clear evidence of unmet need; almost half of the children reported no previous eye care, 119 children had an undiagnosed visual problem, and 122 children were prescribed spectacles for the first time. These findings reinforce similar worrying patterns found in other studies conducted in Wales [3] and Scotland [4].

## Why are so many children not accessing the eye care that most of us take for granted?

For the majority of the population, problems with vision are usually detected through routine trips to an optometrist. However, in our sample, only around 10% of children in special schools had ever had a high-street eye-test – a finding that mirrors other studies.

Public Health England recommends an in-school vision screening test at age four to five for all children, which consists of a monocular LogMAR measurement [5]. However, our results clearly show that this routine screening is not appropriate for those with more complex needs. Only one child that we examined would have passed this screening test, either because of their existing vision problems or because they just wouldn't be able to complete the test.

Of the children we worked with, the least likely to have accessed eye care in the past were those with autism. This reflects previous research [6] showing that this group of children can find it particularly difficult to deal with the clinical environment and the sight testing process, especially if they feel unprepared.

## Why is this so important?

The World Health Organization constitution



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[7] states that everyone has a fundamental right to “the highest attainable standard of health.” Missing out on early eye testing and / or screening can mean that conditions such as strabismus and refractive error go undetected. In the worst cases, leading to irreversible and completely avoidable vision loss.

Feedback from parents and teachers has shown us the positive difference receiving appropriate eye care can make to children's lives. The mother of one 16-year-old told us that her daughter's need for spectacles had been recognised at age six, but she had been told that she would never get used to them because of her autism. With ongoing support in school, she is now wearing her correction and is much more confident and less accident-prone as a result. Teachers have further highlighted that children who have previously had behavioural problems are more engaged and less frustrated once they have received appropriate eye care.

## What should be done in schools?

There are a number of changes that could be made to the current eye care system which would help to ensure that people with learning disabilities had equal access to good eye care.

As a result of an ongoing campaign by our organisation, SeeAbility, with support of all national eye care professional bodies, NHS England has recently committed to



In-school eye examination with one of SeeAbility's optometry team.

providing an in-school sight-testing service for children attending special schools. Once fully implemented, eye examinations provided within all special schools will make a big difference to over 100,000 children with complex needs. Sight problems will be identified routinely, children will become used to the sight-testing process and staff will gain a fuller understanding of the visual abilities of the children they work with. Over time, families will become more aware of the importance of eye care, not only at school but into adulthood. Crucially, this model will bring the dispensing of spectacles into the school setting, providing ongoing support and advice.

The development of policy initiatives to meet the eye care needs of the special school population is only the first step. To make these envisaged services a reality, the programme will need optometrists, dispensing opticians, orthoptists and ophthalmologists to take up the challenge of providing or supporting multidisciplinary teams within these schools.

## Beyond special schools

With planned programs for in-school eye care services in England [8] and Wales [9], and ongoing work towards this same goal in Northern Ireland [10], the needs of children will hopefully be met. However, there is much still to do in addressing the visual needs of all people with learning disabilities.

Adults with a learning disability similarly do not access eye care services but have a high risk of serious sight problems [11]. People still mistakenly believe you must speak or read to have an eye examination, but with the correct adaptations, no one is 'too disabled' to be tested. We need to continue to change the system, implementing an accessible community-based pathway to an eye test, available at no cost, for all people with learning disabilities [12]. This will ensure access to eye care, not just at school but throughout a person's life.

Progress has been made in Scotland where there are funded community eye care services for everyone with a complex need [13]. As well as supporting optometrists with training, an additional appointment to complete the eye examination has been made available since October 2018 as part of continual improvements to general ophthalmic services (GOS).

Poor access to healthcare leaves people with learning disabilities dying many years younger than others [14]. Poor eyesight might not be life-threatening, but it is life-changing. It is time to end this unequal right to sight.

#### References

1. SeeAbility. Children in Focus: a clear call to action. 2018 <https://www.seeability.org/Handlers/Download.ashx?DMF=c5f622ea-5c9e-4e9c-a4f7-7c6d6c0c0228>
2. Donaldson LA, Karas M, O'Brien D, Woodhouse JM. Findings from an opt-in eye examination service in English special schools. Is vision screening effective for this population? *PLoS one* 2019; **14**(3):e0212733.
3. Woodhouse JM, Davies N, McAviney A, Ryan B. Ocular and visual status among children in special schools in Wales: the burden of unrecognised visual impairment. *Arch Dis Child* 2014; **99**(6):500-4.
4. Das M, Spowart K, Crossley S, Dutton GN. Evidence that children with special needs all require visual assessment. *Arch Dis Child* 2010; **95**:888-92.
5. Public Health England. Child vision screening. 2017 <https://www.gov.uk/government/publications/child-vision-screening>
6. Gow L. What is the Experience of Primary Eyecare for Children with an autistic spectrum disorder? A grounded theory investigation. Thesis, London South Bank University. 2015. <http://researchopen.lsbu.ac.uk/2001/1/Louise%20Gow%20final%20thesis%20Sept2015.pdf>
7. World Health Organization. Constitution of the World Health Organization. 2006. [https://www.who.int/governance/eb/who\\_constitution\\_en.pdf](https://www.who.int/governance/eb/who_constitution_en.pdf)
8. NHS England. The NHS Long Term Plan. 2019. <https://www.longtermplan.nhs.uk>
9. NHS Wales. SPECS service development. 2018. <http://www.wales.nhs.uk/sitesplus/documents/862/Item%202%20SPECS%20Service%20Development%20Project.pdf>
10. Ulster University. The Special Education Eyecare (SEE) project. 2019. <https://www.ulster.ac.uk/research/institutes/biomedical-sciences/research/optometry-and-vision-science-research-group/research/the-special-education-eyecare-see-project>
11. Scottish Government. PCA 2018 (o) 02. General Ophthalmic Services (2018) [https://www.sehd.scot.nhs.uk/pca/PCA2018\(O\)02.pdf](https://www.sehd.scot.nhs.uk/pca/PCA2018(O)02.pdf)
12. LOCSU. Clinical Pathways: People with Learning Disabilities. 2019. <https://www.locsu.co.uk/commissioning/pathways/learning-disabilities>
13. Starling S, Willis A, Dracup M, et al. 'Right to sight': Accessing eye care for adults who are learning disabled. *J Intellect Disabil* 2006; **10**(4):337-55.
14. University of Bristol Norah Fry Centre for Disability Studies. The Learning Disabilities Mortality Review Programme. Annual Report December 2017 <https://www.bristol.ac.uk/university/media/press/2018/leder-annual-report-final.pdf>

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