



Live. Love. Thrive. Belong.

Stephen Kinnock MP
Minister of State for Care
Department of Health and Social Care
39 Victoria St
London
SW1H 0EU

17 December 2024

Dear Minister Kinnock,

Improving eye care for people with learning disabilities in the next NHS 10 year plan

We are writing to you to renew our calls for an equal right to sight for people with learning disabilities and ask you to take action.

With a new NHS 10 year plan scheduled for publication in 2025 there is an opportunity to make eye care much more accessible for people with learning disabilities.

Our coalition of voices and organisations have championed efforts to improve eye care for people with learning disabilities for many years, whether it be better awareness and training, to accessing sight tests and sight saving treatments, or ongoing support to live with a sight problem.

There are alarmingly high levels of sight problems amongst people with learning disabilities, adults with learning disabilities are 10 times more likely and children with learning disabilities 28 times more likely to have a serious sight problem compared to the general population. The more severe a person's learning disability is the more likely they are to have a serious sight problem, but less likely to be self-reporting an issue.

Sight problems are in many cases very treatable, however many people with learning disabilities are not accessing their right to NHS eye care. As an

example, at least 4 in 10 children who attend special schools have never had any eye care. In other studies half of adults with learning disabilities had not had a sight test for over two years.

The mechanisms to tackle these eye health inequalities are lacking at a national level. In many cases, this leaves people with learning disabilities using hospital outpatient services or reliant on charitable or local initiatives to fill the gap.

The new government's support for the NHS Special Schools Eye Care Service is therefore very welcome. A proof-of-concept model of eye care in special schools in London and the North of England has worked exceptionally well for the past three years, reaching thousands of children who had never had a sight test or access to the glasses they needed before.

However, there are concerns a new scheme is about to 'go live' across the country that will reduce the standard of service and funding on offer, while increasing the bureaucracy for parents, schools and providers to take part. Children who need eye care the most could still miss out or remain under hospital care, particularly if there are no providers able to deliver where it is needed.

SeeAbility's eye care champions have set out their 10 calls for reform from lived experience¹. Key calls we would like to highlight and support, are those that the DHSC and NHS England have the power to implement:

- Introducing the safeguards and sustainable funding the NHS special schools eye care service needs, so that it is available to as many children and schools as possible, delivering outcomes equivalent to the proof-of-concept scheme.
- Directing Integrated Care Systems to introduce a learning disability eye care pathway in their areas as an enhanced eye care service for children not attending special schools and for adults with learning disabilities.
- Amending regulations so everyone with a learning disability is eligible for an annual NHS sight test as a new 'high risk' group eligibility

¹ Please find here <https://www.seeability.org/our-policies-publications/policy-positions/eye-care-learning-disabilities>

category, aligned and co-ordinated with the right to an annual GP health check.

These improvements would be part of the government's shift of care towards prevention and community care, reducing pressure on outpatient eye clinics. We also urge you to ensure that people with learning disabilities are being identified and prioritised to have the treatment they need given pressures on waiting lists.

The health inequalities experienced by people with learning disabilities are amongst the very worst experienced by the general population. Some are dying of avoidable health issues, at least two decades on average before their peers. The Covid-19 pandemic has exposed these health inequalities further. We cannot have the situation that people with learning disabilities are experiencing preventable sight loss as well.

We look forward to hearing from you* and would welcome the opportunity to meet to discuss how together we can reduce these health inequalities.

Yours sincerely,



Lisa Hopkins, Chief Executive, SeeAbility and Lance Campbell, Joanne Kennedy, Rebecca Lunness and Grace McGill, SeeAbility Eye Care Champions team

** If you would like to respond c/o SeeAbility, it will ensure that the letter is circulated to all co-signatories below.*

Ace Anglia Ltd

Affinity Trust

Association of British Dispensing Opticians (ABDO)

Association of Optometrists (AOP)

Beyond Words

Jim Blair, Learning Disability Nurse Consultant and Associate Professor (Hon) Learning Disabilities Kingston and St. George's Universities

Bradford People First

British and Irish Orthoptic Society (BIOS)

Bury People First

Certitude

The Challenging Behaviour Foundation

Choice Support

Contact

Council for Disabled Children

The CVI Society

Steve Darling MP

Down's Syndrome Association

Fight for Sight

FODO – The Association for Eye Care Providers

Daniel Francis MP

Future Directions CIC

The Guide Dogs for the Blind Association

Glaucoma UK

Hackney People First

Happy Smiles

Baroness Hollins

Inclusion North

Incontrol-able CIC

Keratoconus Group

KeyRing

Learning Disability England

Lewisham Mencap

Lewisham People's Parliament

*Professor Julie-Anne Little, Professor of Optometry and Vision Science,
Ulster University*

LOCSU (Local Optical Committee Support Unit)

Lord Low of Dalston CBE

Macular Society

Paula McGowan OBE

Mencap

Moorvision

Nasen (National Association for Special Educational Needs)

National Association of Special Schools (NASS)

National Network of Special Schools (NNoSS)

National Sensory Impairment Partnership (NatSIP)

The Northam Care Trust

Nystagmus Network

Health Experts by Lived Experience, Opening Doors

People First Independent Advocacy

PMLD Link

*Professor Rachel Pilling, Professor of Special Needs & Learning Disability
Eye Care, University of Bradford*

Primary Eyecare Services

Retina UK

RNIB

The Royal College of Ophthalmologists

*Professor Kathryn Saunders, School of Biomedical Sciences & Centre for
Optometry and Vision Science, Ulster University*

School and Public Health Nurses Association (SAPHNA)

Jim Shannon MP

Thomas Pocklington Trust

Baroness Uddin

United Response

VIEW (The professional association for the vision impairment education workforce)

Visionary

Voluntary Organisations Disability Group (VODG)

Dr Margaret Woodhouse OBE, School of Optometry and Vision Sciences, Cardiff University

The Worshipful Company of Spectacle Makers