

Rt Hon Sajid Javid MP
Secretary of State for Health and Social Care
Department of Health and Social Care
39 Victoria St
London
SW1H 0EU

Amanda Pritchard
Chief Executive
NHS England
Skipton House
80 London Road
London
SE1 6LH

8 June 2022

Dear Secretary of State and Amanda,

Improving eye care for people with learning disabilities

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 refresh of the Long Term Plan, and a White Paper on health disparities due soon, 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. The national NHS sight testing system constrains what is possible and, in many cases, this leaves people with learning disabilities using hospital outpatient services or reliant on charitable or local initiatives to fill the gap. To NHS England's credit it had started to address this inequality through a new NHS Special Schools Eye Care Service, but we are all concerned that the expected rollout for all special schools appears to have stalled.

The health inequalities experienced by people with learning disabilities are amongst the very worst experienced by the general population. The way Covid-19 further exposed the health inequalities experienced by people with learning disabilities means reforms are even more vital.

SeeAbility's eye care champions have set out their 10 calls for reform from lived experience¹, launched to coincide with the World Health Organisation Integrating eye care guide for action² on 24th May. Key calls we would like to highlight and support, are those that NHS England and DHSC have the power to implement:

- Continuing the expected rollout of the NHS Special Schools Eye Care Service in all special schools, and ensuring there is the national funding and national commissioning certainty it needs long term.
- 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 category, aligned and co-ordinated with the right to an annual GP health check.

¹ Please find here <http://seeability.org/easyread-eyecare-policy>

² Please find at <https://www.who.int/activities/integrating-eye-care-in-health-systems---guide-for-action>

These improvements would not just meet duties to address health inequalities but also reduce pressure on outpatient eye clinics as part of the new NHS transformation programme. 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.

People with learning disabilities 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

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*

Rt Hon the Lord Blunkett

Bradford People First

British and Irish Orthoptic Society (BIOS)

British Institute of Learning Disabilities (BILD)

Bury People First

Calderdale Self Advocacy Network

Ryan Campbell CBE and Treloar's

Cerebra

Certitude

The Challenging Behaviour Foundation

Choice Support

The College of Optometrists

Contact

Council for Disabled Children

The CVI Society

Rt Hon Sir Edward Davey MP

Down Syndrome UK

Downs Side Up

Down's Syndrome Association

EQUALS

Clive Efford MP

Clenton Farquharson MBE

Federation of Leaders in Special Education (FLSE)

Fight for Sight

FODO – The Association for Eye Care Providers

Foundation for People with Learning Disabilities (FPLD)

Future Directions CIC

Get on Down's

Glaucoma UK

The Guide Dogs for the Blind Association

Professor Chris Hatton, Manchester Metropolitan University

Baroness Hollins

Inclusion North

Incontrol-able CIC

Keratoconus Group

KeyRing

Learning Disability England

LOCSU

Lord Low of Dalston CBE

MacIntyre I4t (Inspired for Training)

Macular Society

Marsha de Cordova MP

Siobhain McDonagh MP

Paula McGowan OBE

Medicine in Specialist Schools (MiSS)

Mencap

Moorvision

Nasen (National Association for Special Educational Needs)

National Development Team for Inclusion (NDTi)

National Down Syndrome Policy Group

National Sensory Impairment Partnership (NatSIP)

Yvonne Newbold MBE

North Somerset People First

Nystagmus Network

Opening Doors

Pathways Associates

People First Keighley and Craven

*Professor Rachel Pilling, Professor of Special Needs & Learning Disability
Eye Care, University of Bradford
Portsmouth Down Syndrome Association
Positive about Down Syndrome
Primary Eyecare Services
RCGP Special Interest Group for Learning Disability
Respect in Bexley, Bexley Mencap
The Royal College of Ophthalmologists
RNIB
Professor Kathryn Saunders, School of Biomedical Sciences & Centre for
Optometry and Vision Science, Ulster University
School and Public Health Nurses Association (SAPHNA)
Sense
Professor Darren Shickle, Professor of Public Health, University of Leeds
Sibs
Special Schools Voice
Sutton Vision
The Ups of Downs
Thomas Pocklington Trust
Baroness Uddin
VIEW (The professional association for the vision impairment education
workforce)
The Vision Foundation
Visionary
VoiceAbility
Voluntary Organisations Disability Group (VODG)
West Berkshire Learning Disability Partnership Board
Dr Margaret Woodhouse OBE, School of Optometry and Vision Sciences,
Cardiff University
The Worshipful Company of Spectacle Makers*