

Our Futures Matter

Make sure no child with vision impairment is left behind



Young Vision Alliance
See our potential

Foreword

As parents of children with vision impairment in England, we are pleased to be joining forces with leading sight loss organisations to campaign for better support for our children.

Like all parents and other carers, we want the best for our children, for them to reach their full potential, and to achieve their ambitions.

Every child with vision impairment has the capacity to achieve but we know that far too many are being failed – by Government, by local authorities and by schools.

The specialist support they so vitally need to develop into confident, independent adults is disappearing and we have to fight on a daily basis to ensure they get it.

This includes support at school to read, to access the curriculum to develop independent learning skills, training in getting to and around school safely and help in learning social and everyday living skills so they can enjoy having friends and doing the same activities that other children and young people do.

Our children have the right to an inclusive, high quality education just like every other child. Join us in making sure no child with vision impairment gets left behind.

 L Whitcott

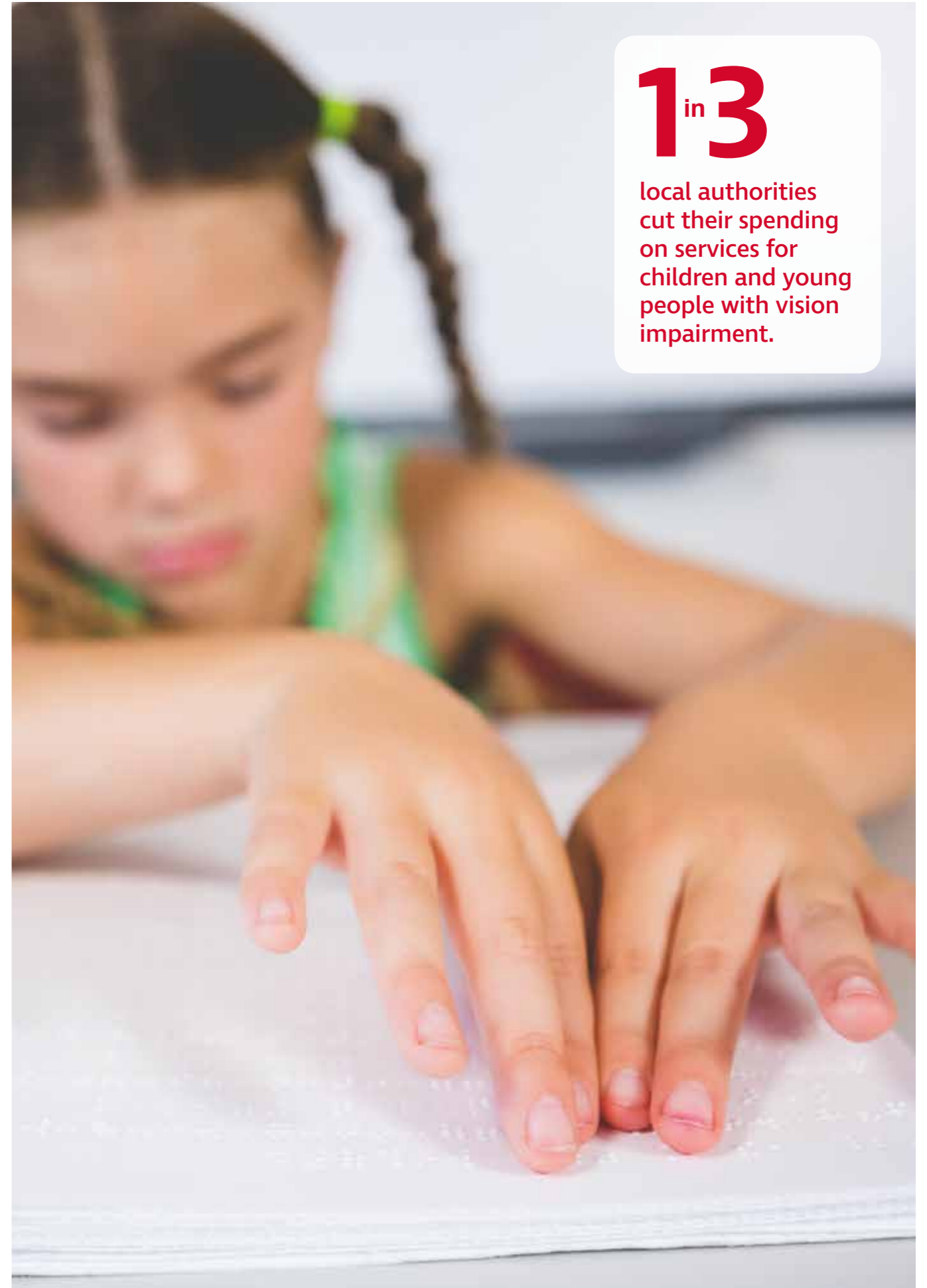
Clare Norton-Smith

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This campaign is supported by the Young Vision Alliance, made up of parents, young people with vision impairment and major sight loss organisations including: Royal National Institute of Blind People (RNIB), Guide Dogs, Hab VI UK, Moorvision, Nystagmus Network, Royal National College for the Blind (RCB), Royal Society of Blind Children (RSBC), Thomas Pocklington Trust, VICTA, Vision Impairment Education Workforce (VIEW) and Vision UK.

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local authorities cut their spending on services for children and young people with vision impairment.



Sight loss and learning

Sight is central to how children learn and develop – through play, language and visual prompts. While sighted children learn incidentally by watching people and things around them, learning opportunities have to be actively provided to children with little or no sight. This has to be done in a structured way, starting when they are babies, to ensure that their early development is not delayed.

That's why children and young people with vision impairment need specialist

support. Without it, they will be unable to learn on equal terms with sighted children. Having the right support in place can remove the barriers to learning and enable them to succeed not just at school but as adults with full lives.

There are estimated to be just over 34,500 children and young people aged 0-25 with vision impairment in England (1). This makes children with vision impairment a low incidence group with most teachers only coming across one or two throughout their career,

if any. That means it is unlikely that most teachers would build up the expertise and understanding to support these children's needs.

Specialist support for children and young people with vision impairment comes from Qualified Teachers of Visual Impairment (QTVIs), Qualified Habilitation Specialists (QHSs) and specialist schools and colleges.

QTVIs provide vital support such as helping with learning and development

in the early years, teaching braille, teaching children and young people the skills they need to access information independently and advising and training mainstream teaching staff.

QHSs help children and young people develop their mobility and independent living skills including getting to, from and around school, travelling around their community, dressing and washing and social communication skills to enable them to take part in social and leisure activities.

There was a

15%

decrease in the number of teaching assistants (TAs) employed to support children and young people with vision impairment between 2017 and 2018.



Failing our children

A combination of the lack of specific government policy and sweeping cuts to local authority provision means that children and young people with vision impairment are being failed and are not receiving the specialist support they need.

The Special Educational Needs and Disability (SEND) Code of Practice (2015) does not go far enough in setting out what specialist support a low incidence group like children with vision impairment should receive, leaving local authorities lacking clear guidance on what they must provide.

Local authorities, faced with significant cuts to funding, have drastically reduced their provision for children with SEND. We asked local authorities to tell us about their services for children and young people with vision impairment through a recent Freedom of Information (FOI) request by RNIB (2).

We found that:

- **1 in 3 local authorities cut their spending on services for children and young people with vision impairment over a 12-month period from 2016/17 to 2017/18.**
- **At least 700 pupils with vision impairment had their level of support reduced during the same 12 months.**
- **Over a third of local authorities who had provided comparable data for 2017 to 2018 saw a decrease in the number of QTVIs.**

- **There was a 15% decrease in the number of teaching assistants (TAs) employed to support children and young people with vision impairment between 2017 and 2018, among local authorities who provided the data.**

Given the low incidence rate of children and young people with vision impairment, it is extremely concerning that at least 700 are no longer receiving the support they once did. Many more may be starting with less support than they need.

Without specialist support, it is less likely they will be able to reach their full potential as indicated by the fact that around 38% of young people with a seeing difficulty aged 16-25 are NEET – not in employment, education or training – almost double the amount (20%) of 16-25 year olds in the general population (3).

A longitudinal study by the University of Birmingham of 80 young people with vision impairment found that a high proportion felt unprepared for adult life, having left education without certain skills in place or without having support (4). The study found evidence of improved outcomes for young people who received specialist support.

If funding for specialist services continues to be reduced, it is likely that the number of young people with vision impairment who are NEET will rise.

“As parents, we feel it is a huge waste of talent and a shocking failure of the Government to ensure that our children can achieve their goals”.



A long fight

It is unacceptable that families face a long fight for their child to receive their right to an education. This must change.

Of course there are, some excellent examples of good support that children and young people with vision impairment do receive and that has a hugely beneficial impact on their lives.

However, many of those children only got that support after a long fight by their families. In a recent survey by the Young Vision Alliance with 288 parents of children with vision impairment, we found that 47% of the parents had been forced to challenge poor educational provision because their child wasn't getting the support they needed. Some had taken them out of school as a result and several had resorted to expensive and lengthy legal action.

The Government must review the current system of support to ensure that children and young people with vision impairment are not being systematically failed. They must be given the support they all need to reach their full potential.

You can call on the Government to:

Ensure that every child and young person with vision impairment;

- 1. Is assessed by education and habilitation VI specialists and given a plan, upon diagnosis, which is reviewed regularly. This plan must define the specialist support required to enable the child to fully access their learning and develop their independence.**
 - 2. Has access to the same learning materials at the same time as their sighted peers, fully adapted to their needs.**
 - 3. Receives clearly and appropriately adapted national tests and exam papers of high quality, with relevant past papers freely available.**
- Ensure that every local authority;
- 4. Requires all school staff who support and teach children and young people with vision impairment to receive vision impairment awareness training from an appropriately qualified specialist.**
 - 5. Is given sufficient funding to provide and effectively manage appropriate numbers of QTVIs and QHSs to meet the needs of all children and young people with vision impairment, as defined by national standards.**



At least

700

pupils with vision impairment had their level of support reduced between 2016/7 and 2017/18.

Specialist support throughout education

You can call on the Government to:

- **Ensure that every child and young person with a vision impairment is assessed by education and habilitation VI specialists and given a plan, upon diagnosis, which is reviewed regularly. This plan must define the specialist support required to enable the child to fully access their learning and develop their independence.**

Every child deserves to receive the support they need no matter where they live.

From the moment a child is diagnosed with vision impairment, it is vital that they are given access to specialist support which continues throughout their childhood.

The 2015 SEND Code of Practice is clear that children with disabilities should receive support to ensure they can access the full curriculum, and that services should maximise young people's independence. Specialist services for children and young people with vision impairment must continually adapt support and teaching to maximise independent study, mobility and living.

Specialist support should include support from a QTVI in development and learning, and a QHS in mobility and independent living skills.

No child should be prevented from participating fully in school and extra-curricular activities.

The level and quality of specialist support varies greatly around the country, with some local authorities providing an excellent service but many are struggling with too few staff to cope with extremely high caseloads and large geographical areas to cover.

As outlined above, the FOI request found:

- **a decrease in the numbers of QTVIs and TAs employed by local authorities to support children and young people with vision impairment.**
- **of those QTVIs still in place, 13% are dealing with double the average caseload – in excess of 100 children.**
- **most local authorities had less than one full-time equivalent qualified habilitation specialist to provide mobility and independent living skills to cover all the children and young people with vision impairment in that area.**

The power of specialist support

Lack of support leads to isolation

John is 16 years old and has retinitis pigmentosa, a progressive condition which can lead to severe vision impairment. Over the course of his education, the support John has received has been varied and inconsistent (5).

He didn't receive support from a teaching assistant until year ten and for many years he felt that his class teachers did not understand his vision impairment or how it impacted his learning.

Materials were often not provided in John's preferred format – large print – which, when it came to his GCSEs, led to him losing marks on his coursework.

John says: "I need printed materials in a size 24 font, but this was often not provided. I didn't do as well as I expected in one of my exams as I lost marks on the coursework side of the subject and this was because I could not access the learning materials."

Good support enables Michael to excell

Michael is 15 years old, has Leber Congenital Amaurosis a genetic condition that causes blindness, and lives in Gateshead with his mum Joanne.

Michael began receiving regular specialist support from a Special Education Needs Assistant when he started school and went on to learn braille. He is provided with specialist equipment, has regular one-to-one support from a specially trained teaching assistant and has been given mobility training to help him navigate around school and to enable him to travel home independently using the bus.

Michael is excelling in school and has already passed his Computer Science GCSE and his BTEC Media with grades at 9 and Distinction *(star) respectively. He achieved these qualifications a year earlier than usual (he sat and passed them when he was 14 years old) and is expected to achieve a set of top grade GCSE's when he sits the rest of his exams in the Spring of 2019.

Joanne says: "If Michael didn't have this support, I don't know what would have happened. It is so important to get it right from the start, throughout school, so that they can reach their full potential."

The same materials at the same time

You can call on the Government to:

- **Ensure that every child and young person with a vision impairment has access to the same learning materials at the same time as their sighted peers, fully adapted to their needs.**

Every day in class, children and young people are asked to copy information from the board, read through handouts, do their homework on a printed sheet of paper, watch videos or read a passage from a book.

None of this is possible for children and young people with vision impairment unless they are given support and the materials are provided in alternative formats that they can access. For example, handouts transcribed into braille or produced in a larger font size, homework in accessible digital formats or videos being audio described.

Young people must also receive specialist support to learn the techniques required to access work alongside their peers, for example, how to use assistive technology.

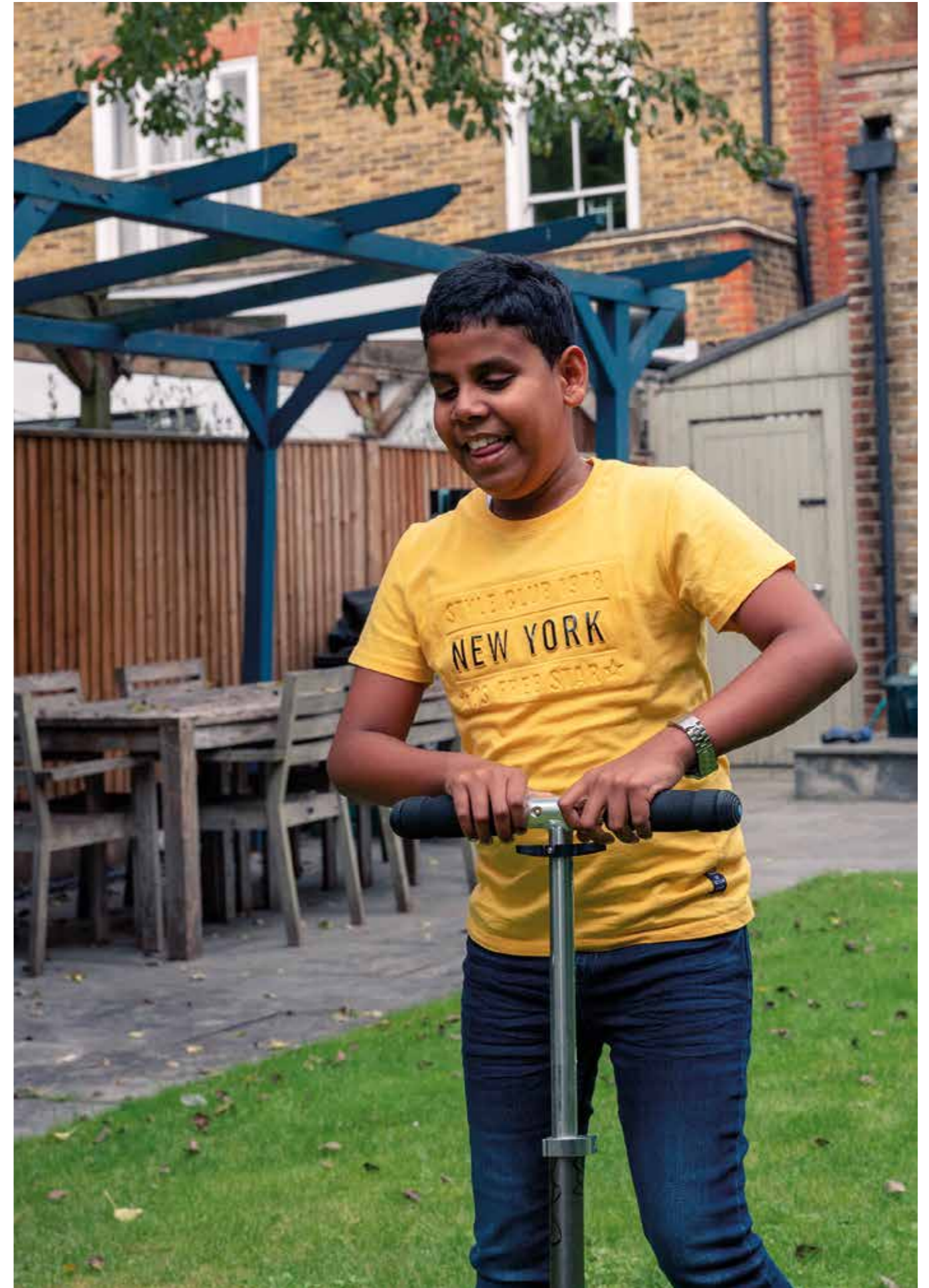
All too often, this doesn't happen.

A constant struggle

Jorja is ten years old and lives with her mum Laura in Chichester. Her school years have been a source of constant struggle in accessing the information and support she needs.

Every day, Jorja faces challenges which affect her learning, with large print reading materials repeatedly forgotten about and equipment which would enable her to participate fully in class not provided. Laura has had to buy equipment for Jorja, including a kindle and laptop, with her own money, due to delays in the local authority providing them.

Laura says: "The stress and anxiety that these repeated issues cause is phenomenal. I don't feel I get much support. It's often just me winging it, trying different things to see what will work."



Equal opportunity in exams

You can call on the Government to:

- **Ensure that every child and young person with a vision impairment receives clearly and appropriately adapted national tests and exam papers of high quality, with relevant past papers freely available.**

Exams can be a stressful time for any student. When you are visually impaired, this is compounded by additional fears. Will I get the paper in large print or braille, so I can read it? Will there be any mistakes in the modified papers? Will I be allowed to use my specialist equipment during the exam?

Children and young people with vision impairment must be given better support to access exams and national tests. This includes receiving all exam and test papers correctly presented in large print or braille.

Schools also need more support to ensure they apply for appropriate access arrangements such as having a reader to read out a question or describe diagrams, having a scribe to write at sufficient speed, or using specialist technology like a braille writer or magnifier.

Currently, children and young people with vision impairment face a number of problems when accessing exams. In a recent Young Vision Alliance survey with 53 children and young people with vision impairment, we found that:

- almost half of the young people surveyed said there were mistakes in the modified exam papers they received
- just under half did not have access to papers in an accessible format for revision
- only one-quarter had no difficulties at all when undertaking exams.

Research by the RNIB in 2015 into the accessibility of GCSE papers found that there was, on average, 2.3 problems per braille paper that would have a high impact on the candidate, and 1.75 per large print paper (6). The standard exam papers would be expected to contain no problems. The presence of any problems or errors in a modified paper means that the candidate may be unable to gain marks for those questions, confusion could waste valuable time, and this could affect their overall grade.

This is not acceptable.



Exam problems

Abdul is 16 years old, registered blind and lives in Manchester. He is a braille reader and has had many difficulties in getting specialist support over the last five years, leading up to his GCSEs.

During year 11, Abdul had different teaching assistants for each of his GCSE subjects, many of whom

did not understand his vision impairment or his requirements for accessing course materials.

Abdul says: "It is so important that past exams are made available in an alternative format so that students like me can prepare for exams just like our sighted peers can".

Awareness training

You can call on the Government to:

- **Ensure that every local authority requires all teaching staff who support children and young people with vision impairment receive vision impairment awareness training from an appropriate specialist**

If teachers and TAs don't have an understanding of vision impairment, children will miss important learning and fall behind with school work and social development.

As well as having support from a highly trained specialist, it is important that children and young people are taught and supported every day by class teachers and TAs who understand their vision impairment and how to help them access learning and develop their independence.

Children and young people have told us of the frustration and isolation they feel being in a classroom where no one understands their needs and teachers either assume they are coping or they are simply not paying attention. We also know of instances of teachers and TAs providing the wrong kind of support such as making the wrong adjustments to materials, failing to encourage use of equipment, and getting in the way of opportunities for children and young people to mix socially with peers.

Teachers did not understand her vision impairment

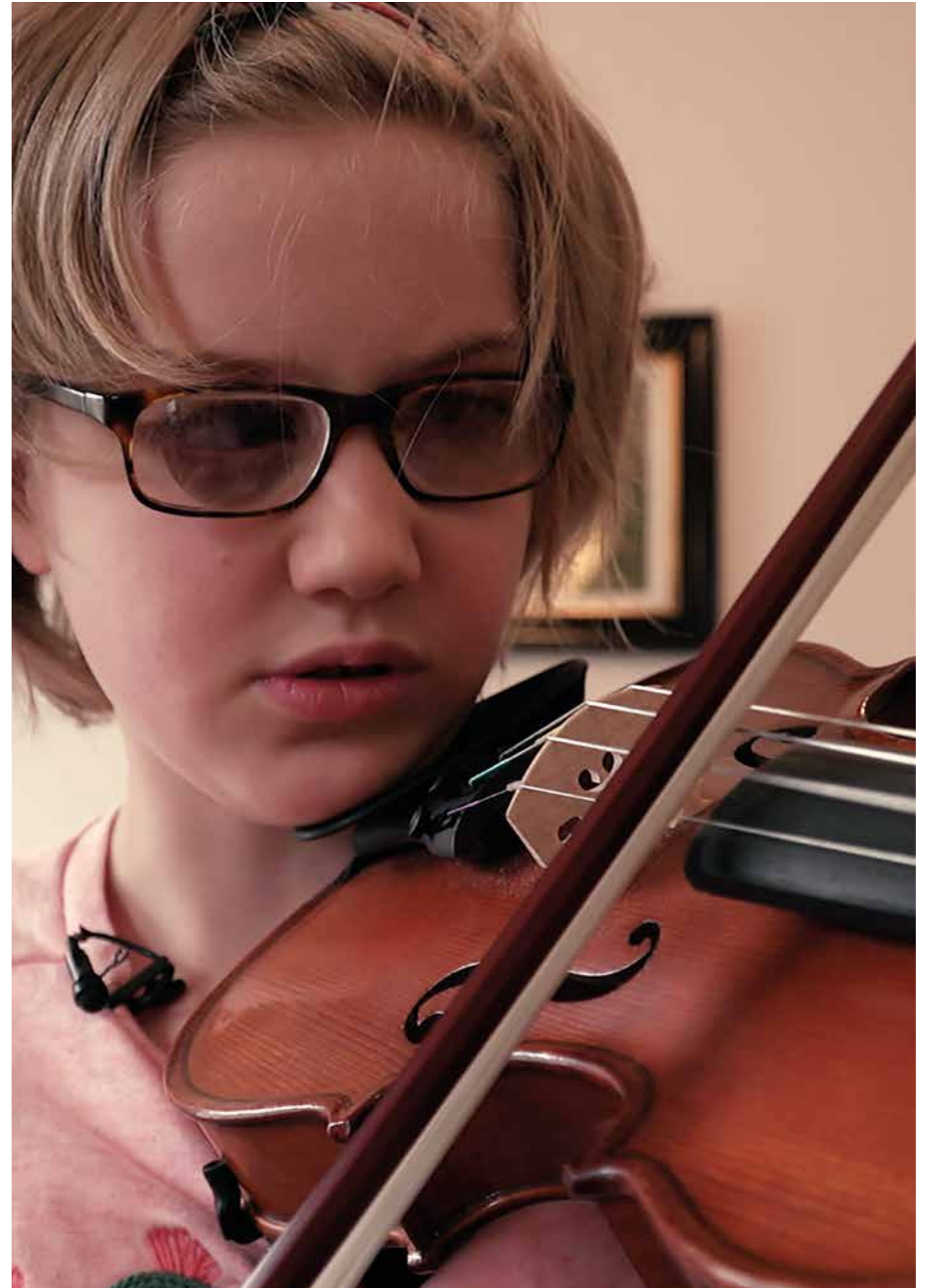
Romilly is nine years old and lives with her mum Clare, dad Adrian and sister Astrid in London.

Diagnosed as severely visually impaired from birth, Romilly initially got excellent support from a specialist QTVI in her early years. The QTVI retired when Romilly reached school age and the support she received dropped dramatically. It was down to her parents to fight to get her the support she needed.

Her mum Clare constantly had to remind teaching staff that Romilly needed to sit in strong light, that she couldn't see facial or hand gestures, and that she needed to be at the front of the class.

"Romilly didn't always get the materials in time. She didn't have a light which would have helped her enormously. She didn't have an iPad. She didn't have teachers that understood her vision impairment. Romilly has an amazing personality and tries hard to keep up so teachers assumed she was more capable than she was," explains Clare.

Romilly now receives support from a specialist teaching assistant and a habilitation specialist, but this support was threatened recently when, due to budget cuts, the local authority looked to remove most of the funding Romilly relies on. Romilly's parents are currently campaigning to ensure her specialist support continues.



Funding that meets local need

You can call on the Government to:

- **Ensure that every local authority is given sufficient funding to provide and effectively manage appropriate numbers of QTVIs and QHSs to meet the needs of all children and young people with vision impairment in their area, as defined by national standards.**

In order that specialist support is available for all children with vision impairment across a local authority, it is important that the employment and management of specialist staff is maintained centrally. This is funded through High Needs Funding allocated to local authorities but there is increasing pressure on this funding and many have had to make significant cuts as a result.

Our survey found that 44% of the parents said that their child's school or college did not have sufficient funding to meet their child's needs.

And the FOI request revealed that one in three local authorities cut their spending on services for children and young people with vision impairment over the twelve-month period from 2016/17 to 2017/18.

Cutbacks lead to reduced support

Eight-year-old Ellie and six-year-old Holly both have a rare eye condition called aniridia and live with their parents, Darren and Carolyn, in London. They have received very different levels of support despite having the same condition and being just three school years apart.

Ellie received support from a QTVI before she went to nursery and throughout the early years. But when it came to Holly's turn, cuts to the service had been made and she received much less support and to a lower standard. The cutbacks combined with poor processes at the local authority also meant it took two years for them to produce an Education, Health and Care Plan (EHCP) for Holly.

Darren explains: "For Ellie, we didn't have any problems at all because the support was there. There was definitely a marked difference between the levels of support for the two girls. The process for Holly was frustrating, very long and drawn out. She wasn't left completely high and dry but until the EHCP was in place, she couldn't receive the support she was entitled to."

Conclusion

The need for specialist support for children and young people with vision impairment is clear. Parents should not face a lengthy fight to ensure their children receive their right to an education.

It is time for the Government to review the current system of support for children and young people with vision impairment to ensure that they all get the support they vitally need to allow them to participate in education and all the opportunities childhood has to offer, and fulfil their potential in life.

References

1. RNIB Sight Loss Data Tool, available at www.rnib.org.uk
2. In July 2018, RNIB sent a Freedom of Information request to all 152 local authorities in England. We received responses from 113 local authorities. 1 in 3 of those local authorities cut their spending on services for children and young people with vision impairments.
3. Hewett R. and S. Keil, Labour Force Survey investigation, (2016). Note: 'Seeing difficulty' in this investigation is self-reported by participants who have sight loss of sufficient severity to affect their everyday lives.
4. R. Hewett, G. Douglas and S. Keil, Reflections of Transition Experiences by Young People with Visual Impairments aged 19-22 (2017).
5. Name has been changed at the individual's request.
6. Cobb R and Keil S, The quality of GCSE exam papers in braille and modified large print (2016).

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Laura, parent

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