

## 4Sight Vision Support

Children and Young People with Visual Impairment  
Mapping Project 2018



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## Maisy's Story

Maisy (not her real name) is a typical 14-year-old teenager, living with her mother and attending Main Stream school in West Sussex. Maisy has worn glasses since she was 3 years old. Through Nursery, Primary and Secondary school, no-one realised that Maisy could not see very well at all. Maisy really struggled with her reading and school work in general, she had no enthusiasm for books or for learning, all of which was put down to Down's Syndrome.

Maisy thought everyone saw as she did, she did not know the difference. At around 12 years Maisy got 3/28 questions right in a test, her Mum quizzed her verbally and realised that she had good topic knowledge. She asked the school if Maisy could re-take the test using larger and darker font, Maisie's mark increased to 27/28. Suddenly everyone realised that Maisy sight was much worse than anyone realised.

**Should this have taken so long to identify, when Maisy was known to various services: her GP, Southlands Eye hospital, ROVI team, Sensory Support Team, teachers at school?**



## Introduction

Since 1921, 4Sight Vision Support has been working to improve Health and Wellbeing outcomes for people with Visual Impairment across West Sussex. A recent Membership and Stakeholder Survey carried out in 2016, reported that the majority of our beneficiaries are people over 65 years old, and only a small amount of our work is with Children and Young People (CYP) with Visual Impairment (VI) and other disabilities.

As a result, this Mapping Project has been undertaken by Susie Brown from Time Aside Sensory Art on behalf of 4Sight Vision Support, in order to help us to better understand what work is already being provided by our colleagues in the Statutory and Voluntary Sectors to support CYP with VI.

The rationale of the Mapping Project is to better inform us about the current provision for CYP with VI in order to identify where there are gaps or duplication in services to help our business planning activities. We are very keen to build collaborative working relationships with colleagues in the sector to provide appropriate service provision for CYP with VI.

## Number of Children and Young people with Visual Impairment in West Sussex

The Royal National Institute for the Blind suggests that the prevalence of visual impairment in CYP is two in every 1,000 (0.2%), up to the age of 25 in the UK. However, variation in definitions and service provision means that caution is required in interpreting any single estimate of the prevalence of visual impairment or blindness among CYP in the UK. <sup>1</sup>

It is estimated that over 450 CYP have some level of visual impairment in West Sussex: 113 children aged 0-16 years are estimated to be severely sight impaired or blind, and 37 young people aged 18-24 are predicted to have a severe visual impairment.

The 1989 Office of Population Censuses and Surveys (OPCS) child disability survey shows that children were likely to either have mild to moderate visual impairment with few other disabilities, or to have visual impairments

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<sup>1</sup> IPC Institute of Public Care, Oxford Brookes University (2016) Comprehensive needs assessment of the life pathway for people with disabilities



of a more severe nature, along with several other disabilities of a severe or profound nature.

It is estimated that half the children receiving support from visual impairment services may have additional disabilities, and this proportion may be even higher for children with severe visual loss. In a study by Rahi and Cable<sup>2</sup>, stated that 77% of children newly diagnosed with severe visual impairment or blindness had additional non-ophthalmic disorders or impairments. Keil<sup>3</sup> found that around 20 per cent of young people with visual impairment have additional special educational needs and/or disabilities (SEND) and a further 30 per cent have complex needs.

### The Compass Disability Register or Compass Card

The Compass Disability Register, which is compiled and managed by Amaze in Brighton, collects anonymous data to provide a clearer picture of the number of children with disabilities and needs in West Sussex. In return the families receive a discount card to events and leisure activities.

West Sussex County Council believes there are over 7,800 children with disabilities in the County.<sup>4</sup>

The Compass Card shared their data with us, they have 2,384 children 0-25years registered, which is 28% of the total of CYP in West Sussex with disabilities. Out of the 2,384 registered CYP there are 481 CYP with VI. If these figures were extrapolated there could be over 1,572 CYP with VI in West Sussex.

It is important to note, that many children with an eye condition remain undiagnosed during Early Years, particularly if a child has Special Needs, such as Down Syndrome and more complex disabilities. What is alarming is that some children have not been diagnosed until teenage years, as the eye condition was considered due to their other disabilities which may not be the case. Therefore, caution is needed, as the number of children with VI in West Sussex could be considerably higher.

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<sup>2</sup> Rahi J and Cable N (2003) 'Severe visual impairment and blindness in children in the UK' The Lancet, Vol 362, Oct 25, 2003.

<sup>3</sup> Keil (2014) Local authority Vision Impairment (VI) education service provision for blind and partially sighted children and young people: Report on findings from RNIB Freedom of Information (FOI) requests 2013, RNIB.

<sup>4</sup> Shortbreaks presentation June 2018

### Visually impaired Children and Young People educational needs

As a generalisation most CYP with VI attend main stream schools across the County. Some are supported by the West Sussex County Council Sensory Support Team. Table one: shows the break-down by district.

**Table one: Visually Impaired Children within different School types in West Sussex<sup>5</sup>**

	Adur	Arun	Chichester	Crawley	Horsham	Mid Sussex	Worthing	Total
State-funded Primary School	10	10	15	15	10	20	10	85
State-funded Secondary School	10	15	15	10	10	20	5	80
State-funded Special Needs School	0	0	10	5	5	5	10	30
<b>Total</b>	<b>20</b>	<b>25</b>	<b>40</b>	<b>30</b>	<b>25</b>	<b>45</b>	<b>25</b>	<b>195</b>

Other secondary centres such as The Lavinia Norfolk Centre, a special unit within the Angering School supports 8 pupils with VI. In general, CYP with VI attend Special Needs Schools, such as: Ingfield Manor School, near Horsham who have a Special Unit for VI.

Primary age children with VI attend Primary Schools all around the County, such as The Parklands Community School, Chichester who have a Special Unit.

Early years and young children are supported by Children and Family Centres, through GP Practices, Health Visitors and the Child Development Team.

<sup>5</sup> Please note that totals may not match the sum of their parts due to rounding, non-zero figures below have been suppressed as 'x'. Department of Education Freedom of Information - FOI2018-0033382 31/07/2018

## The Mapping Project

The information contained within this report has been collated by collaborative working with partner organisations and obtaining data from West Sussex County Council (WSCC) via Freedom of Information request. Between July and October 2018, we conducted telephone and face to face conversations using a pre-designed questionnaire with 17 families with CYP with VI across West Sussex. Through this supportive process the interviewer was able to capture their experiences in more detail. Participation was voluntary, with no active follow up.

## Data Collection

We were informed that the following services are currently being used and are working well.

Blatchington Court Trust	Young Carers
4Sight Vision Support	Occupational Therapy
Audiology	Orthoptist
Chichester and Portsmouth Down Syndrome Group	Physiotherapy
Child Development Centre	Sight for Surrey
Compass card	Speech Therapy
K2 Family Fun Days	Sport for Choice
Little PACSO - Parent and Carer Support Organisation	West Sussex Parent Carer Forum
Look Sussex	WSCC Disability Team
WSCC Short Breaks	WSCC Sensory Support Team

### Feedback on services from parents/carers:

“Blatchington Court- have varied activities, mainly just Saturdays”.

“They came into school, taught me to touch type and taught me braille”.

“The schools have been helpful, and he now has his own TA.”

“The West Sussex Connect to Support webpage is very time consuming to use because local groups and activities are listed as ‘A to Z’, so you really need to know what service you are seeking beforehand.”

A number of interviewees stated that they have received little of no support or do not know where to go or who to contact for support. Below is some of the feedback from parents/carers on services they reported were not working well.

The “Sensory Support Team, were very slow to start.”

As soon as my child reached teenage years, it “feels like she’s been dropped.”

As my child gets older, 14 years, “services seem to tail off for him.”

Her “Secondary School, have not been particularly helpful, teachers do not realise she needs enlarged print. (Special Educational Needs Co-ordinator) Senco, have also not been particularly helpful.”

“I’ve had no help at all. I just want help for my boy.”

I do not know “what is available.”

I have received “no help at all for 6.5 -7 years, no support, no signposting from anyone, nor from the hospital, nothing!”

I was “not even given a leaflet, nothing. There are no leaflets in the eye clinic.”

The “Sensory Support Team are very slow to support with larger letters or to get magnifiers and equipment into school- 2 years!”

The “Speech Therapy was too slow to start, so we went privately, but this became too expensive, so he’s now regressed.”

In West Sussex there is “nothing in this part of the county, it is all miles away in Brighton.”

We asked interviewees if they believed there are any gaps in provision and were informed:

Not sure	No Gaps	Gaps in provision
17.6%	17.6%	64.8%



We asked what types of services interviewees feel are needed for CYP with VI and for parent/carers?

We need a “shortened waiting list for Young Carer’s.”

We need a “lot more support, I only found out about PACSO six months ago, and was left for six and a half years of no support at all.”

We need “activities closer to home, as travel is very difficult.”

We “need more information, coffee meetings, so that we feel less isolated and do not have to explain all the time.”

We “need Braille service and assistance.”

We “need to understand what the Guide Dog eligibility is, as I have been taken off the list because I do not go out enough!”

I need “more help generally, with housing needs - a wet room downstairs, a bedroom, as I am sleeping on the sofa.”

We need “hydro-therapy, Sensory, Art Club, meeting parents of similar children, not in school time. More contact with physio and other services.”

We need “more information early on, and more support, as I felt very isolated especially at the beginning and for my husband.”

We need “people being more reliable, and more contact from services.”

## What we have learnt

The Mapping Project has shown that services are fragmented, poorly coordinated and communicated and that statutory services are not integrated with visual impairment community services. There are many gaps especially, around parent/carer understanding of the pathway to services, information and support and of who is providing the service.

There was also confusion as to who should be responding to new referrals, for example: five referrals were sent to the Adult Outreach team,

“who felt unqualified and under informed to be able to support CYP with VI with their other complex needs.”

Along with many of our voluntary sector partners, we are well aware of the pressures that both the Local Authority and NHS are facing with regard to budgetary pressures and increased demand for services, but the visual impairment community organisations are not standing still.

We believe that, in line with the new thinking around integrated care systems and integrated commissioning, if statutory and voluntary organisations work together using a place-based approach, we can bring together a fuller and more appropriate range of community assets to improve opportunities and long-term outcomes for CYP with VI in West Sussex. This will support the aims of both the NHS Long-Term Plan and the West Sussex County Council ‘Starting well in life’ agenda.

### Recommendations

Our Mapping Project has identified a number of gaps and our recommendations could be viable solutions:

**Key Recommendation - Establishment of an integrated stakeholder forum for CYP with VI.** To improve communication between statutory and voluntary sector providers to ensure a more integrated approach is achieved.

#### Other gaps and recommendations:

Identified gap in Provision- A sense of need in West Sussex	Possible Solution - Ways forward- Recommendations
<ul style="list-style-type: none"> <li>Lack of Information, especially at point of diagnosis or too much information in too many different places.</li> </ul>	<ul style="list-style-type: none"> <li>One Stop Shop for information for West Sussex - either on line and/or in 4Sight Vision Support Centres in Bognor, Shoreham, Midhurst.</li> <li>Access for providers to WSCC held register (of people with a Certificate of Vision Impairment).</li> </ul>
<ul style="list-style-type: none"> <li>Basic and more detailed information at hospital eye clinics.</li> </ul>	<ul style="list-style-type: none"> <li>4Sight Vision Support Eye Care Advisors to carry info, top up and leave in waiting areas at hospital eye clinics.</li> </ul>

<ul style="list-style-type: none"> <li>• Parent /Carers of CYP with VI feeling isolated as they have lack of contact with professionals and similar families.</li> </ul>	<p>4Sight Vision Support to set-up;</p> <ul style="list-style-type: none"> <li>• Support Groups for parent/carers and VI CYP to help lessen isolation with referral, information and signposting knowledge.</li> <li>• Support groups and activity/social groups for the VI CYP themselves to enhance personal independence, choice and emotional health and wellbeing.</li> </ul>
<ul style="list-style-type: none"> <li>• There are gaps in service, especially in areas not covered by Blatchington Court Trust in the North, West and Mid Sussex areas.</li> <li>• <b>Referrals:</b> there are low levels of CYP referrals being received by 4Sight Vision Support.</li> </ul>	<ul style="list-style-type: none"> <li>• The engagement of a full or part time CYP Outreach Worker specialising in Children’s Eye Care throughout West Sussex.</li> <li>• This role to directly support the CYP and their families.</li> <li>• This role to work with other staff members to actively help improve health and wellbeing, promote independence, and prevent isolation.</li> <li>• This role to attend networking and activity events.</li> <li>• To actively seek and encourage referrals for CYP with VI.</li> <li>• Working with statutory services (i.e. NHS, WSCC RMOs/ROVIs etc), to embed referral pathways, and;</li> <li>• Working with families and CYP with VI, with referrals, providing appropriate information and support and practical help, signposting families to other services, especially newly diagnosed CYP.</li> <li>• Helping build networks of support and resilience for CYP, siblings and parent/carers.</li> </ul>
<ul style="list-style-type: none"> <li>• Lack of funding available to 4 Sight Vision Support and others to develop services.</li> </ul>	<ul style="list-style-type: none"> <li>• Funding applications could be applied for to develop these identifies services provision.</li> </ul>

<ul style="list-style-type: none"> <li>Many children with disabilities may have undiagnosed VI because of their other disabilities.</li> </ul>	<ul style="list-style-type: none"> <li>Regular eye care screening leading to diagnosis in Special Needs Schools, as per Seeability latest Report of their Work.</li> </ul>
<p><b>Gaps in provision - Nationally</b></p> <ul style="list-style-type: none"> <li>National shortage of Mental Health Services and Counselling for CYP with VI.</li> </ul>	<ul style="list-style-type: none"> <li>Therapy sessions, therapeutic sessions, counselling sessions or activities with a skilled therapist using open listening techniques to encourage dialogue to help build better emotional wellbeing, independence and resilience.</li> </ul>
<ul style="list-style-type: none"> <li>Other activities</li> </ul>	<ul style="list-style-type: none"> <li>New type of Accessible Technology Club, with all the new specialist Apps being available for the younger generation of people with VI.</li> </ul>

### Conclusion and next steps

In conclusion, the Mapping project has shown there are gaps in the service provision for CYP with VI. The main gaps being; information and knowledge and this could have a negative effect on growth, normalisation and psychological well-being, as well as increasing isolation and decreasing resilience. This also influences self-esteem and confidence.

Therefore, it is our opinion that the suggested recommendations all need to be addressed in order to support appropriately CYP with VI to develop into confident, independent young adults.

Our next steps are to work in partnership with Blatchington Care Trust and we welcome conversations with statutory and community services to ensure that our work is aligned with the West Sussex plan for CYP with VI.

## Acknowledgments

We would like to thank all the interviewees for their honest thoughts and opinions. Also Maisy and her family for sharing their personal journey - this report would not have been possible without them.

In addition, we would also like to thank Blatchington Court Trust, Look Sussex, SeeAbility, WSCC Sensory Support Team, Amaze, the West Sussex Parent Carer Forum, Healthwatch West Sussex and Dr Maggie Woodhouse Cardiff University for their support and help with this Mapping Project.



4Sight Vision Support would like to give particular thanks to Susie Brown for her excellent work and dedication to the cause on this project. We would also like to thank Cheryl Berry for her advice and support in the latter stages of this project.

## 4Sight Vision Support

### **Making a positive difference for people living with sight loss.**

For nearly 100 years, 4Sight Vision Support have been the leading sight loss charity supporting the visually impaired community of West Sussex.

At the heart of our holistic and person-centred services is a commitment to ensuring that a diagnosis of sight loss is not a one-way road to loss of independence and isolation. Our 3,000 members and 300 volunteers create a community that inspires and mentors its peers to maintain and transform their own lives into positive and fulfilling ones after sight loss.

Bognor Regis Vision Support Centre

Bradbury Centre, 36 Victoria Drive, Bognor Regis, West Sussex, PO21 2TE

Main Tel: 01243 828 555 Fax: 01243 838 003

Email: [enquiries@4sight.org.uk](mailto:enquiries@4sight.org.uk)



## Time Aside Sensory Art

Under the leadership of Susie Brown, Time Aside Sensory Art has established itself as an innovative and highly respected organisation with a proven track record of delivering successful SEND work across Sussex, which has improved outcomes and health & wellbeing for disabled children & young people and their parents/carers. Susie, a qualified Non-Directive Play Practitioner has over fifteen years of experience working with children and adults of all abilities in East & West Sussex.

(Susie was elected Woman of the Year for 'Community, Charity and Voluntary Sector' for East and West Sussex in 2012. Sponsored by The Body Shop.)

## References:

1. IPC Institute of Public Care, Oxford Brookes University (2016) Comprehensive needs assessment of the life pathway for people with disabilities.
2. Rahi J and Cable N (2003) 'Severe visual impairment and blindness in children in the UK' The Lancet, Vol 362, Oct 25, 2003.
3. Keil (2014) Local authority Vision Impairment (VI) education service provision for blind and partially sighted children and young people: Report on findings from RNIB Freedom of Information (FOI) requests 2013, RNIB.
4. Shortbreaks presentation June 2018.
5. Department of Education, figures for CYP with VI in schools in West Sussex. Accessed via Freedom of Information (FO12018-0033382 31/07/2018).

## Appendix 1

### CYP with VI Mapping Survey

Your Name	
Name of child	
Email	
Mobile Number	
District of West Sussex (circle)	Adur/Arun/Chi/Crawley/Horsham/Mid-Sussex/ Worthing/outside County
Age of Child/Young Person	
Primary condition	
Secondary condition	
Possible eye condition	
Is your child registered blind or have a certificate of Visual Impairment?	
What type of diagnoses?	

Which school does your child attend?	Main School/Special School
Does your child have any special needs?	
Which services do you use?	
What is working well?	
What is not working so well and why?	
Do you think there are gaps in Provision?	
What other services would you like to see on offer for your child?	
What other types of services, information or support would you find helpful for yourself?	
What have you found to be working well, Best Practice in West Sussex or have heard about in other counties?	
Are there Activities suitable for your VI Child?	

With which Group, Club or organisation?			
Where does this take place?			
How often do they run?	Weekly	Monthly	School Holidays
What other Activities, Events would you like to see on offer?			
Siblings to be included?	Yes		No
How far are you willing to travel?	Under an hour	Over an hour	Longer
Ideas and contact for partnership working?			
Any other comments or ideas			
Anything else you would like to share with us?			

Are you happy for us to hold your personal details?			Yes		No
Do you give consent for us to contact you			Yes		No
Verbal consent	Yes	No	In person	Interview by telephone	
Name and Signature					
Date			Time		



## Appendix 2

### CYP with VI Collated Mapping Survey from 17 telephone responders

Survey demographics							
<b>Gender</b>				<b>%</b>			
Males/Boys				52.9			
Females/girls				47.1			
Location of responses							
Chichester	Horsham	Crawley	Mid Sussex	Worthing	Adur	Outside WS	Arun
5.8%	5.8%	11.8%	11.8%	11.8%	11.8%	11.8%	29.4%
Age Range							
The age range was 2 years to 26 years							
Primary Eye Condition				Secondary Eye Condition			
64.7%				35.3%			
Nursery School		Special Needs School		Main Stream School			
5.8%		29.5%		64.7%			
Registered Blind or have a certificate of impairment							
Not sure		No		Yes			
11.7%		17.6%		70.7%			

<b>Children with other special needs</b>	
<b>With special needs</b>	<b>Without special needs</b>
47.1%	52.9%
<b>The types of visual impairment and special needs</b>	
<ul style="list-style-type: none"> <li>• Long sighted +21 born with cataracts and Nystagmus both eyes</li> </ul>	
<ul style="list-style-type: none"> <li>• Nystagmus x2</li> </ul>	
<ul style="list-style-type: none"> <li>• Short sighted -10, born with cataracts both eyes, has implants, squint</li> </ul>	
<ul style="list-style-type: none"> <li>• Congenital hypopituitarism with septa-optic dysplasia, bilateral syndactyly, multiple pituitary hormone deficiencies with diabetes insipidus, severe visual impairment, complex seizure disorder, small stature</li> </ul>	
<ul style="list-style-type: none"> <li>• Optic Atrophy</li> </ul>	
<ul style="list-style-type: none"> <li>• Lebers Congenital Amourosis</li> </ul>	
<ul style="list-style-type: none"> <li>• 17% Frosted vision, hydrocephalus, global delay, ADHD, autistic</li> </ul>	
<ul style="list-style-type: none"> <li>• Short sightedness developing, Down Syndrome, hearing loss in both ears, speech difficulties</li> </ul>	
<ul style="list-style-type: none"> <li>• Cataracts removed both eyes, Nystagmus, Down Syndrome, speech difficulties</li> </ul>	
<ul style="list-style-type: none"> <li>• Peters Anomaly, spina bifida</li> </ul>	

<ul style="list-style-type: none"> <li>• Optic atrophy, (albinism), dyspraxia, anxiety</li> </ul>
<ul style="list-style-type: none"> <li>• Nystagmus, Down Syndrome plus new development see Case Study</li> </ul>
<ul style="list-style-type: none"> <li>• V.I. undiagnosed, ATRX syndrome, developmental delay</li> </ul>
<ul style="list-style-type: none"> <li>• Registered blind, diagnosis unknown to us, hydrocephalus, cerebral palsy grade 5, dyslexia</li> </ul>
<ul style="list-style-type: none"> <li>• Retinopathy of Prematurity ROP</li> </ul>

**Q1: Which services do you use currently?**

Blatchington Court Trust  
 WSCC Sensory Support Team  
 WSCC Disability Team  
 Child Development Centre  
 Occupational Therapy  
 Physiotherapy  
 Speech Therapy  
 Audiology  
 Orthoptist  
 NHS only  
 West Sussex Parent Carer Forum  
 K2 Family Fun Days

Compass Card

Sport for Choice

WSCC Short Breaks

Little Pacso - Parent and carers Support Organisation

Portsmouth Downs Syndrome Group

Chichester Downs Syndrome Group

Look Sussex

Sight for Surrey

4 Sight Vision Support

Young Carers

**Q2: What is working well in West Sussex?**

Blatchington Court Trust x2

Blatchington Court came to school x2

Blatchington are amazing

Blatchington Court have very varied activities, but mainly just on Saturdays

Sensory Support Team are brilliant

Surrey Guide Dogs

4 Sight Vision Support

My Guide - volunteer guider

Sight for Surrey x2

There is not a lot

Little Pacso

Prescriptions glasses for swimming

Time Aside Sensory Art

K2 Crawley Family Fun Days

**Q3: Which services are not working so well and why in West Sussex?**

Sensory Support Team

Sensory Support Team, were very slow to start.

Speech Therapy were too slow to start, so we went privately, this became too expensive, so he's now regressed.

The Sensory Support Team are very slow to support with larger letters or and get magnifiers and equipment into school, this took 2 years!

Child ages

As my child gets older, 14 years, services seem to have tailed off for him.

As soon as my child reached teenage years, it feels like she's been dropped.

Support from schools

Her secondary school, are not particularly helpful, teachers do not realize she needs enlarged print, Senco (Special Educational Needs Coordinator) are not particularly helpful.

No help at all for 6.5 -7 years, or no support, no signposting from anyone, even from the Hospital, nothing!



Support from Eye Clinics

Not even given a leaflet, nothing. No leaflets available in the eye clinic.

West Sussex has nothing in this part of the county, everything is miles away in Brighton.

Generally

It is difficult to know what is available.

I've had no help at all. I just want help for my boy.

**Q4: What other services would you like to see on offer for your child?**

A shortened waiting list for Young Carer's.

Yes, a lot of it, especially quicker access to speech therapy.

Hydro-therapy, Sensory /Art Club, Meeting parents of similar children, not in school time. More contact with physio and other services.

Activities closer to home. Not to have to travel so far.

Anything and everything, more information- Coffee meetings, to feel less isolated and not having to explain all the time.

Activities nearer to us, OK now but was harder at the beginning.

Help with everything, we need help with housing - a wet room downstairs and a bedroom, I am sleeping on the sofa.

Braille service and assistance.

A lot more support, only found PACSO six months ago, six and a half years of nothing-no support at all, anything everything.

Guide Dog eligibility, I have been taken off list because I do not go out enough!

More info early on, more support, felt very isolated especially at early diagnosis and for my husband.

People being more reliable, more contact for all services, meeting parents with children with similar difficulties, not necessarily in school time.

#### **Q5: Other comments**

We use Sight for Surrey because there was nothing for us in this part of Surrey. We are ok now do not need any help.

She has motion sickness, cannot travel far.

I was not diagnosed until I was 5 or 6 not sure why.

One website to go to for all V.I. charity info.

School has been very helpful, he has a TA.

Sensory Team only been to home once in 6 years but come to school regularly.

We'd like a RNIB braille underground map for London.

More wheelchair-based activities, anything that has changing facilities with a hoist and a changing bed, ramps to access, lift if needed to other floors.

To get/find help you need to do it yourself, nothing handed, everything is a battle.

Would have liked more info and support.

The Sensory Team ROVI is amazing, taught me to touch type at Primary school, they took a long time to get it started, Blatchington is amazing, social events, equipment, counselling service, advocacy.

Not much help for legal type services from RNIB, if under 30years ok because of Blatchington, once over 30 who would help, that's wrong.

We want a Buddy for our son, we have tried, but it's so complicated with us having to do all the wages, insurance, holiday pay etc. we've given up, just wanted a bit of help for a few hours occasionally that's all.

My husband Mum had same condition, I told the midwife this was a worry, she laughed at me.

They send me emails about judo, but Blatchington Court have never come around as they said they would. I've never been offered any help, no support at all, I knew he was blind from the beginning.

**Q6: Gaps in provision**

Not sure

No gaps

Gaps in provision

17.6%	17.6%	64.8%
<b>Q7: What activities are available?</b>		
<p><b><u>Specialist V.I. Providers:</u></b></p> <p><b>Blatchington Court Trust, Look Sussex</b></p> <p><b>British Blind Sports-</b> Sporting Events and Activities around the country.</p> <p><b>Disability Cricket - Sussex-</b> Blind cricket</p> <p><b>Goal Ball-Albion in the Community-</b> Some mixed disability sports, including blind sports.</p> <p>There seems to be more choice in the east part of the County and Worthing, because all these specialist providers and are based close to Brighton. But in the North, the West and Mid-Sussex there are very few, if any activities by specialist providers.</p> <p>West Sussex County Council Short Break Providers are listed on <a href="https://westsussex.local-offer.org/">https://westsussex.local-offer.org/</a>. These Short-break Activities range from swimming, sport, music, dance, drama, sensory art, art and craft, cookery skills, life skills, buddying, tech, outdoor events, animal events, fishing, Lego and much more.</p>		
<b>Q8: Are there Activities suitable for your VI Child?</b>		
<p>There are a vast range of activities available to CYP with disabilities, including CYP with VI across West Sussex.</p> <p>The staff and the activities are not specifically designed for children with VI in mind.</p>		

The Activities are open to children with a wide range of disabilities, sometimes making this difficult for children with V.I. to access.

Several Short break Providers have 1:1 support/buddying/volunteers on hand to enable children with V.I.

Often the parent/carer and siblings are present at these Events, especially Family Fun Days, but these can be busy, causing noise and sensory overload. Most venues overcome this by providing a Quiet Zone or Sensory Room.

**Q9:** Responses in order of popularity, either by being the most involved in already or the most wanted activities. Although a long listing it does show the range of activities CYP VI are and would like to be involved in to increase resilience.

Number	Activity
8	Sensory Play
7	Sensory Art
6	Music - general
5	Animals
5	Outdoor
5	Blind sports - general
4	Cookery
4	Pottery
3	Drumming, percussion
3	Cricket



2	Judo
2	Rock climbing
2	Abseiling, Zorbing
2	Roller skating
2	Ice skating
2	Swimming
2	Goal Ball
2	Lego, construction
2	Tech, how things work
2	Being with a Buddy
2	Social Events, BBQ
2	Counselling
1	Advocacy
1	Golf
1	Tennis
1	Bowls
1	Horse riding
1	Walking, rambling
1	Singing
1	Piano
1	Guitar
1	Baby group

1	Fun relaxed sports practice throwing, catching, learning the rules, building confidence
1	Ideas- residential, Little Canada, Isle of Wight
0	Life Skills

<b>Q10: Would you like siblings to be included in the activities?</b>		
Yes	No	N/A
53%	23.5%	23.5%
<b>Q11: How far are you willing to travel?</b>		
Under an hour	Over an hour	
64.7%	35.3%	