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Paediatric low vision service evaluation - Sheffield Teaching Hospitals NHS Foundation Trust

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Abstract:	This retrospective service evaluation was conducted to evaluate the low vision (LV) clinic and its impact for children attending Sheffield Teaching Hospitals (STH) between 2012- 2022. The main cause of vision impairment (VI), LV aids used and their impact on distance and near visual acuity (VA), was extracted from medical records. Index of multiple deprivation (IMD) were determined using each child's postal code. The most common causes of VI were retinal disease (32%), albinism (16%) and nystagmus (12%). One third of children with VI lived in areas of the lowest decile IMD. Two thirds were certified as sight impaired (SI) or severely sight impaired (SSI). LV aids significantly improved near and distance vision ($p<0.001$). Given that the high number of children with VI lived in socioeconomically deprived areas, LV clinic and LV aids should be available for all children with VI regardless of their socioeconomic or registration status.

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Introduction:

Receiving a diagnosis of vision impairment (VI) as a child or young person is described as a sentinel event (1), due to its far-reaching impact and association with other quality of life predictors (2). Growing up as a child or young person with VI (CYPVI) has been described as a double minority disability. CYPVI represents both the minority of disability and the minority of the VI population(3). Given this, the well-evidenced higher vulnerability of CYPVI to physical and mental health difficulties necessitates effective clinical care and support(1,4). CYPVI have similar aspirations to their sighted peers, yet educational and achievement rates are significantly lower in this population(5) demonstrating an attainment gap, which needs addressing (6). Low vision services, wherein low vision clinicians, qualified teachers for children and young people with vision impairment (QTVIs) and support services work together with a child centred approach, provide opportunity integration of health and education, optimising vision and support, in effort to diminish the attainment gap.

All CYPVI require optimal clinical care, social and educational support. Given that the majority of CYPVI are diagnosed within the first year of life(1) , it is usually parents and carers who may initially require support for their child's vision, health and development(7). During childhood, support needs typically shift from parents and carers to the child or young person, aiming to optimise their vision where possible and promote independence, aspiration and achievement (8). As CYPVI may be more likely to come from low-income families, the potential social and financial deprivation may compound these challenging circumstances and increase the need for intervention and support(1).

A LV clinical service aims to help patients maximise use of their residual vision to live independently with the best possible quality of life(9). Identification of refractive error and the wearing of refractive correction are important in CYPVI(10). However uptake of the free eye test, including a refraction, is under-utilised especially for children with multiple disabilities despite being available to all children(11).

Hospital LV appointments in the UK typically include assessment of visual function and tasks requiring support. LV aids and strategies are selected and training given on their use, based on patient need, the required task(12) , and educational need. LV aids may be optical or electronic with a range of magnification strengths(13). Signposting to support services, such as an eye clinic liaison officer (ECLO), mobility training, support in education or workplace, support at home and socially is important (14). Despite the wide range of available LV aid technology, LV clinical services across the UK vary in the availability of a service for

patients, particularly paediatric patients and the types of LV aids available(15). To address this, best practice standards for LV services have recently been produced(16).

In Sheffield, the Sheffield Teaching Hospital (STH) LV clinical service has been available since 1995. A previous service evaluation by Theodorou and Shipman highlighted the main causes of low vision and types of low vision aids prescribed(17). The STH LV clinical service is situated in a tertiary referral centre. Referrals are received from Sheffield, the wider South Yorkshire County and at times from the Yorkshire region(18). Patients are referred by health care professionals, ECLOs and low vision support services. Self-referral is not possible. Children and adults are seen in the service, however children with significant additional needs may be seen at a separate and dedicated multidisciplinary children's special needs centre (Ryegate Children's Centre). LV aids at STH are free to borrow on a long-term basis, on the proviso that they are returned if no longer required or if another aid is more suitable (for example a different magnification). More than one LV aid may be issued if required.

This study aimed to evaluate the STH paediatric LV clinic and characteristics of CYPVI service-users. A key aim was to understand the impact of the service on visual outcomes.

Methods:

Following University of Sheffield ethical approval (051586) and STH service evaluation registration (11584). A cross-sectional service evaluation of all children under 18 years of age who attended the LV clinical service at STH between January 2012 and December 2022 was conducted. All LV appointments during this time were reviewed. Data were extracted and pseudo-anonymised by the primary researcher who was not a member of the LV clinical team. Children seen at Ryegate Centre were not included.

Data were extracted on age, sex, and certificate of visual impairment (CVI) status either sight impaired (SI) or severely sight impaired (SSI) or not registered reported here as low vision (LV). The aetiology of VI was recorded (albinism, aniridia, cornea, glaucoma, lens, high refractive error, uvea, retina, optic nerve, visual pathway and cortex, nystagmus or others). In cases where multiple aetiologies existed, the main cause was recorded, e.g. albinism and nystagmus was recorded as albinism. Postal codes were used to identify the index of multiple deprivation (IMD) decile using the English indices of Deprivation 2019 postcode look up tool(19) (1 represents the 10% most deprived areas and 10 represents the 10% least deprived areas in England)(20).

Clinical data of the first recorded visit for each participant were collected. This included best corrected distance visual acuity (BCDVA) for either eye (OD, OS) and both eyes open (OU) using an age and ability appropriate visual acuity (VA) test (ETDRS, crowded LogMAR test or Kay pictures). Best corrected near reading acuity (BCNVA) to threshold OU was recorded (N print series) where testing was possible. LV aid type and magnification strength were recorded for distance and near. BCDVA and BCNVA were recorded both with and without LV aid.

Results:

In total 222 CYPVI attended 974 LV appointments, face-to-face (n=880) and via telephone (n-94), which occurred during the COVID pandemic. There were fewer females (n=86) than males (n=136). The age range was 3 to 17 years (median 9 years) shown in Figure 1. Regarding CVI status, 13.5% were SSI, 54.1% were SI and 32.4% were not certified or there was insufficient information about their certification status (LV). Data on IMD is shown in Figure 2, where 30.2% were found to be living in the lowest decile of deprivation.

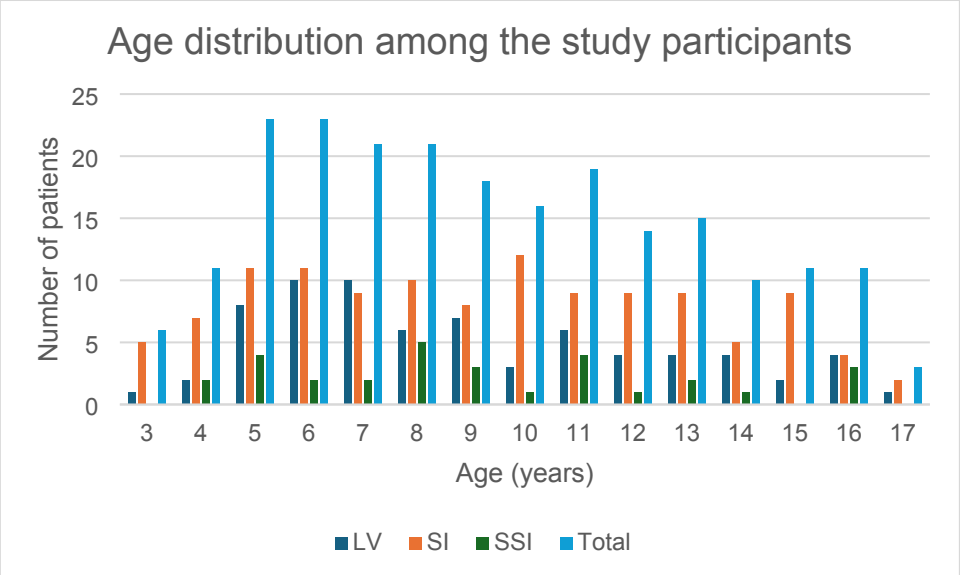

Figure 1: Clustered bar chart demonstrating the age distribution among the 3 groups of CVI registration status and the whole study participants (n=222)

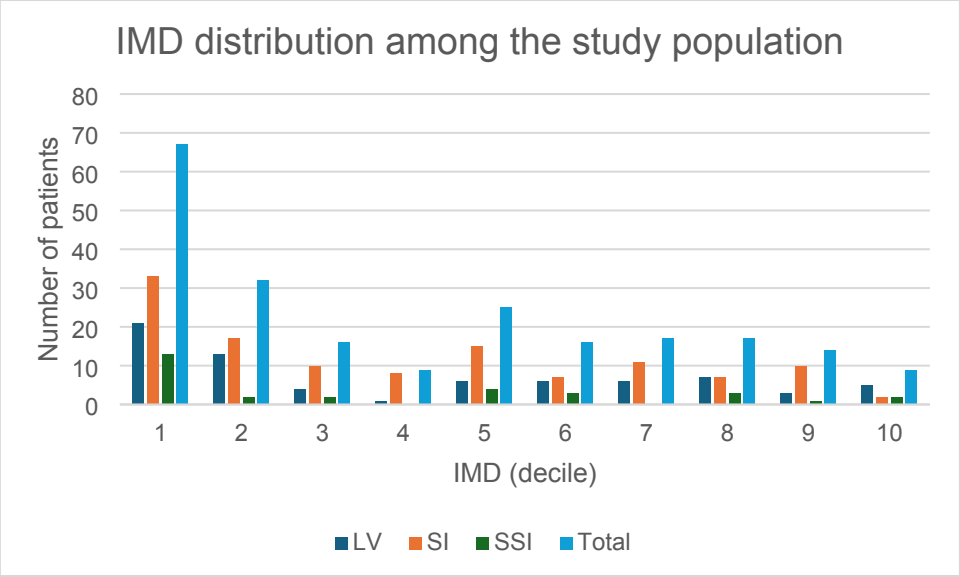

Figure 2: Clustered bar chart demonstrating the index of multiple deprivation (IMD) deciles distribution among the 3 groups of CVI registration status and the whole study participants (n=222)

The main causes of low vision:

Retinal pathology was the main cause of low vision in the whole study cohort (32%). Albinism, nystagmus and optic nerve diseases represented 16.2%, 12.2% and 11.7%. In subgroup analysis, retinal pathology was also the most frequent cause in both the SI (35.8%) and SSI (43.3%) group as shown in Figure 3.

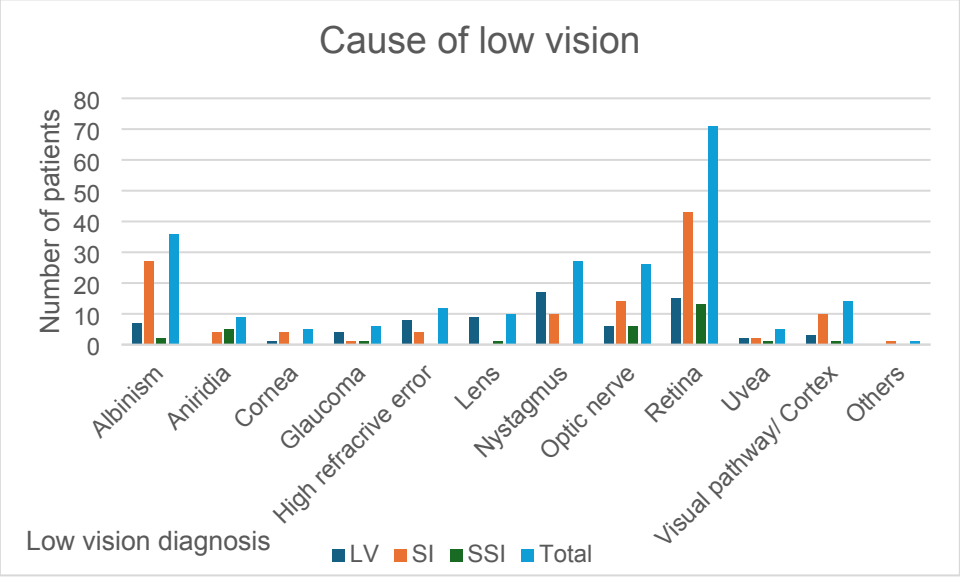

Figure 3: Clustered bar chart demonstrating the main cause of low vision diagnosis among the 3 groups of CVI registration status and the whole study participants (n=222)

Vision with and without LV aids

Spectacles were worn by 80% of CYPVI and 17% had non-significant refractive error while 3% were not wearing spectacles despite having recorded refractive errors. Mean BCDVA was 0.73 (OD), 0.69 (OS) and 0.62 (OU) LogMAR. VA data were asymmetrically distributed (skewness value: 0.84, 0.73 & 0.98 respectively), therefore non-parametric analysis was conducted.

For the purposes of statistical analysis, patients were grouped into the following categories: distance LV aid users and non-users. Distance LV aid non-users had significantly better BCDVA (U=2925, p=0.008). Distance LV aid users had significantly improved BCDVA with distance LV aid (compared to without the LV aid) (z=7.773, p<0.001) (Table 1).

Near reading acuity testing was possible in 171/222 patients with N print series. Of these, 42/171 did not trial a near LV aid and 35/171 were able to read N8 or smaller without an LV aid. The remaining 129/171 trialled a near LV aid, which made a significant improvement to their BCNVA (MH 115.5, p<0.001) (Table 1). Reduced Kays test was used for 37/222 patients as appropriate for age and ability.

Table 1: paired measurement of the BCVA among low vision aid users for distance and for near without and with using (LVAs).

	Without using LVA		**With using LVA**		**Test of sig.**	**P**
BCDVA	**BCDVA OU (n=99)**		**BCDVA aided (n= 92)**		**Z 7.773**	**<0.001 ***
Mean ± SD.	0.67 ± 0.31		0.1 ± 0.25			
Min. – Max.	0.2 – 1.8		-0.3 – 1.0			
Median (IQR)	0.6 (0.46 – 0.85)		0.1 (-0.01 – 0.2)			
BCNVA	**Threshold BCNVA (n=129)**		**BCNVA aided (n=106)**		**MH 115.5**	**<0.001 ***
	No.	%	No.	%		
N8 and smaller	53	41.1	85	80.2		
N16 to N10	53	41.1	18	17		
N32 to N18	19	14.7	3	2.8		
> N32	4	3.1	0	0.0		

IQR: Interquartile range z: Wilcoxon signed test MH: Marginal Homogeneity test

***p≤0.05 (Statistically significant)**

Low vision aid usage:

Near LV aids were used by 77% and distance LV aids were used by 51% of CYPVI. Table 2 shows the types of near and distance LV aids used with the popularity of dome magnifiers and binoculars evident. Main-stream electronic devices including mobile phones and tablet computers were used by 4.05% of patients.

Table 2. Type of distance and near low vision aids used in the whole study cohort during the first visit. (n= 222)

Distance low vision aid (LVA)		Near low vision aid (LVA)	
Distance LVA type (n / %)		**Near LVA category (n / %)**	
Binoculars	68 (30.6%)	Dome Mag	106 (47.7%)
Monocular	44 (19.8%)	Hand-held/ pocket Mag	22 (9.9%)
		Stand Mag	19 (8.6%)
		Pocket & Stand Mag	7 (3.2%)
		Dome & Stand Mag	9 (4.1%)
		Dome & Pocket Mag	8 (3.6%)
Distance LVA magnification strength (n / %)		**Near LVA magnification strength (n / %)**	
4x	10 (4.5%)	Low magnification power (≤ 3x)	24 (10.8%)
6x	17 (7.7%)	Medium magnification power (3.50x to 6x)	62 (27.9%)
8x	50 (22.5%)	High magnification power of (≥7 X)	5 (2.2%)
10x	2 (0.9%)		
Total	79 (35.6%)		

Low vision strategies advised:

Guidance and advice on the importance of good lighting and glare avoidance was discussed with 58% CYPVI. Direction regarding high contrast print materials and colour contrast was recorded as discussed with 39% of CYPVI. Other strategies included advice on position in the classroom (10.3%), using a closer reading distance (3.1%), a raised desktop (2.7%) and enlarged print (9.4%) were also recorded as discussed.

Discussion:

The key aim of this study was to understand the characteristics of children attending the paediatric LV service at STH and its impact on visual outcomes during an 11-year period. Children attending were between 3 and 17 years of age, which was comparable to other paediatric LV studies(21). Figure 1 shows

a peak of 23 patients attending the clinic at the age of 5 and 6: the beginning of primary school in the UK education system. Similarly, 21 patients attended the clinic at the age of 8 -transition to junior primary school- and 19 attended at the age of 11 (transition to secondary). These transition points implicate the need of CYPVI for extra support to cope with the education workload and new school environment.

Figure 2 shows that 30% of our patients lived within the 10% most deprived postal codes in England, 45% lived within the lowest two deciles and 52% lived within the lowest 3 deciles of IMD. The majority of children (67%) lived in areas ranked in the lower half of IMD. This was a similar trend to that reported in the UK, where higher incidence of low vision has been found in areas with lower socioeconomic status(1,22). This picture is similar in the USA(23) and is also found globally (24).

Aetiology of LV:

Figure 3 shows retinal diseases, mainly involving the macular and photoreceptor dystrophies as the main cause of VI in both the SI (35.8%) and SSI (43.3%) groups. Mitry et al reported that the main causes of SI in English and Welsh children in 2010, were retinal dystrophies (16.6%), cerebral visual impairment (13.6%) and albinism (10%) while the main causes of SSI were cerebral visual impairment (29.3%), retinal dystrophies (16.3%) and optic atrophy (7.2%)(25). In the current study the percentage of patients registered as SI and SSI was 67%. We still have a third of our patients who were not on the visual impairment register which can account for the difference between our study and Mitry's. Visual pathway and cortex causes were the most common aetiologies of LV (48%) in a later UK study(1). In their study, Solebo et al, compared the aetiology of newly diagnosed children (under the age of 16) with severe visual impairment and blindness (SVI/BL) in 2000 and 2015. They found the incidence of retinal dystrophies and albinism were slightly lower in 2015 (11.4% & 3.9%) than 2000 (13.1% & 4.3%) while visual pathway/cortex causes increased from 49.5% in 2000 to 60.7% in 2015(22). It is possible cerebral visual impairment was not common in our paediatric LV clinic (3.4% of SSI group) due to children with additional needs being seen at Ryegate specialised centre, or under recognition of the condition. In our study, out of 30 cases of SSI, retinal diseases and albinism accounted for 43.3% and 6.6%. These different figures could be attributed to the inclusion of visual pathway and cortex diseases in Solebo's study and it being a nationwide study compared to our low vision clinic-based study.

Vision with and without LV aids:

Sunness et al highlighted the importance of refractive correction to improve VA in patients with VI(26). Despite this, it is recognised that there is underutilisation of the eye tests available to all children in the UK, especially by children with VI attending primary special schools (11). Our study emphasises that refractive correction is essential to review at the beginning of a LV appointment as spectacles were worn by 80% of our CYPVI and only 17% had non-significant refractive errors. Gyawali and Moodley highlighted VA improvement using refractive correction in children attending a school for the blind in Eretria. They reported

a significant decrease of severe vision impairment (SVI) from 24 to 7 children with refractive correction alone(27).

Distance LV aids significantly improved distance VA (see Table 1) with the mean BCDVA improving from 0.67 Log-MAR to 0.1 using LV aids. This agrees with Kavitha et al in their 2013 study of Indian children with low vision. They found that out of 148 eyes (74 patients), eyes with BCDVA of 6/18 to 6/6 increased from 0.67% to 41.2% using LV aid(21).

Significant improvement of near reading acuity with LV aids was recorded (see Table 1). The percentage of children able to read N8 or smaller print increased from 41% to 80% with the use of a LV aid. Our results agrees with Kavitha et al (2013). They found that eyes with BCNVA of N36 to N18 decreased from 54% to 4.72% while those with BCVNVA of N12 to N8 increased from 40 % to 50 % with using LV aid(21).

LV aid usage and strategies.

Near LV aids were used by the majority (77%) of our patients, as seen in Table 2. Dome magnifiers were the most popular (47.7%). Hand-held (9.9%) and stand magnifiers (8.6%) were the least popular. Theodorou and Shipman reported dome and stand magnifiers (illuminated and non-illuminated) were used by 83% of children(17). Our data suggests a decline in dome and stand magnifier use for near, as only 56.3% of children used these LV aids. Other strategies adopted by school such as provision of education material in accessible format including large print, high contrast and digital format as well as peer pressure and fear from being recognised as a person with disability could explain the slightly lower uptake of near LV aids in our cohort. The use of technology and electronic LV aids was low (4.05%). This may be due to expense as they are not provided within the NHS LV clinical service. Purchasing electronic and technology-based LV aids would be a cost borne by the families of the CYPVI. Considering the low socioeconomic status of our cohort, digital poverty and the attainment gap reported by Solebo et al may be significant factors in these figures (22,28). Some digital provision has been possible for some school age CYPVI in this cohort, depending on their area, however this provision is far from universal. Hadad et al in their clinic-based study of Brazilian children with low vision reported that only 42 out of 385 patients (10.9%) were prescribed near LV aids with 57% of these aids being stand magnifiers(29). In their study, LV aids were provided by the study investigators which could limit the number of aids prescribed for each patient in contrast to the National Health System (NHS)-funded policy in the UK.

Despite the use of near LV aids by the majority of CYPVI (77%) ,half (50.4%) used or tried distance LV aids, either binoculars (30.6%) or monocular telescopes (19.6%). However, this is lower than previously reported by Theodorou and Shipmen (83%)(17). The use of mainstream electronic devices such as smart phones with built in navigation applications and fear of being recognised as visually impaired may explain the lower uptake of distance LV aids in our study. Distance monocular LV aid use in an Eritrean study was 27.9%, however this was exclusively in those with VA 6/18-3/60 due to a lack of distance VA benefit in those with worse than 3/60 VA who represented 54.7% of the study participants (27). In their study of

Brazilian children under the age of 15, Haddad et al reported distance LV aids were prescribed in 25.7%. Monocular and manual telescopes were the most frequently used distance aids with the majority (74.8%) of these aids being prescribed for children with moderate and severe VI(29). In our study, we had higher rates of prescribing both distance and near LVAs. Possible explanations for this include the loan-based protocol of issuing LVAs for patients on the NHS and the possibility to issue more than one LVA for a patient in case he benefits from using them all.

Regarding advice on LV strategies, options related to improving lighting, using task lights, avoiding glare and maximising contrast have been recommended by the Royal National Institute of Blind People (RNIB) in their framework for LV clinical care(16). In our CYPVI cohort, advice on lighting and glare avoidance was recorded as given in 58%. Brunnström and colleagues reported the importance of light adjustment to improve task performance as well as quality of life in people with low vision(30). Advice on use of contrast was recorded in 39% of CYPVI. Higher contrast reading material has been shown to improve reading speed in LV simulations(31). Other less frequently advised strategies included positional advice for the classroom, closer reading distances and raised desktops (10.3%, 3.1% & 2.7%). This likely reflects the nature of the STH LV clinical service being bespoke to each individual patient with a symptoms-based approach.

The earlier service evaluation:

The earlier service evaluation of the first 14 years of running the service was conducted by Theodorou and Shipman and showed similar trends of the main causes of vision impairment and more prescription of distance low vision aids than our study(17). Analysing the impact of using LV aids on both distance and near VA was not included in their study. In current service evaluation this item was added to indicate the importance and usefulness of LV aids issued for CYPVI on loan basis funded by NHS.

A recent low vision quality framework has been produced by the RNIB in association with the UK low vision providers community. This framework serves as a road map for establishing low vision services. It covers choosing accessible location, good referral and booking system. In addition to assessment of visual function, it covers training on LVAs both optical and electronic if available (16). The current service evaluation was conducted before the RNIB recommendation was published and it agrees with it on the importance of the visual function assessment and LV aid trial and training during LV clinical appointment. Although it was designed for adult services and illustrates what a low vision appointment should include, the framework can be used with slight modifications for paediatric services as well.

Prospective analysis of LV aid usage and their impact on visual function in correlation with age and key transition periods in CYPVI could be the next step to gain in-depth insights of the LV service which is essential for service improvement to provide a patient-centred service.

Conclusion:

Retinal diseases were the most common causes of VI in children attending the STH LV clinical service. Most CYPVI lived in the lowest socioeconomic areas. The low use of technology and electronic aids in our cohort may reflect both digital and financial poverty, which need to be addressed. LV aids prescribed free of charge have been observed to make a significant improvement in near and distance VA in the majority of CYPVI. Whilst near LV aids were used more frequently than distance LV aids, this is likely to reflect the difficulty with near visual tasks being the main driver for a LV clinical referral. LV clinical care should remain symptoms based, and a patient centred approach should be considered for both assessment and management.

Recommendations:

1- Paediatric low vision service should be easily accessible to patients who need it irrespective of their status of visual impairment registration.

2- A good referral system is important to identify people in need for these services. Eye care professionals should be aware of this system to increase the effectiveness of the service.

3- Both distance and near LVAs (especially that with medium and low magnification strength) should be available at least for trial in the low vision clinics so that the patient can see if they benefit from using these before investing their money purchasing them.

Competing interests:

We have no competing interests to declare.

Supplemental information:

Access to supplemental information and anonymized raw data will be considered on reasonable request from the lead author.

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