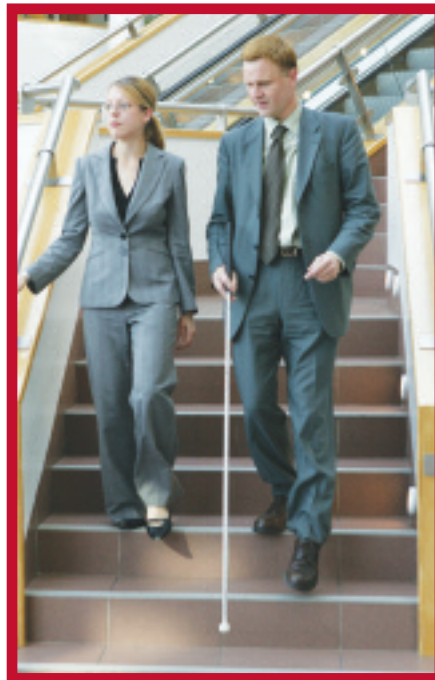

A question of independence

A call for action to improve sight loss support services across the UK

Barbara McLaughlan, Anita Lightstone, Steve Winyard



“I am registered blind through age-related macular degeneration but I am able to cope fairly well because of the help I get. First of all my son and daughter do a lot of the household chores. I am really glad I have family to support me. It would be so much more difficult if I was on my own. Still, I do not want my children to do everything for me so it is important to me to continue to go out, particularly to the local shopping centre. After I was diagnosed, Moorfields referred me to Social Services straight away and they came to my house for an assessment. They put proper lighting in the kitchen which makes a big difference. Then I went to the RNIB Low Vision Centre at Judd Street who did a thorough assessment and provided me with two magnifying glasses and a pair of sunglasses. I use the small magnifier to go shopping. It allows me to read sell-by dates and I can also use it to read headlines in the papers. The large magnifier helps me with watching television. When you go blind at my age you need all the help you can get to stay independent and avoid going to a nursing home. I am so glad I was referred to the right people straight away ”

Susanne Eves, 86, registered blind due to age-related macular degeneration

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Executive summary

Background

Two million people in the UK are living with sight loss. This can range from difficulties reading a newspaper, driving and recognising a friend across the room, to blindness that makes it difficult to cook, look after personal hygiene or leave the house without assistance. Even with major action on eliminating avoidable sight loss the number of people with sight loss is likely to increase significantly within the next 25 years, primarily because of the ageing of the population.

Current health and social care agendas flag up the importance and value of preventative approaches. Good quality, integrated low vision services enable people with sight problems to retain or regain their independence and avoid the depression and dependency that so often accompany this disability. At the same time quality low vision support contributes to their general health and wellbeing. However, it is widely recognised that services in the UK are fragmented, difficult to access and lacking an holistic, multidisciplinary approach. Steps have been taken to remedy this situation with Scotland, Wales, Northern Ireland and England pursuing their own paths towards improving services.

Report findings and calls for action

This report describes the findings of a survey of low vision service providers and primary care organisations in the UK conducted in 2004/5 on behalf of AMD Alliance UK and RNIB. The results show that efforts to improve services need to continue, particularly in relation to the level of funding, the degree of multi-disciplinary working, channels used to raise awareness of existing services to the general public and the quality of services.

The survey provides a wealth of information that is being discussed in detail in the body of the report. For this executive summary we would like to focus on four issues where we feel that action is most important.

1. Funding

It is clear that we will need more services to meet the needs of the growing number of older people with sight loss. Yet the funding for low vision and rehabilitation services allocated by local government and local and regional health commissioning bodies appears to be inadequate, since 30 per cent of respondents who do not provide a service said that funding was the reason.

- We call on central and devolved governments to increase the funding for low vision services and for PCTs and social services departments to carry out audits of low vision and rehabilitation services in their area, identify funding gaps and commission services with a multi-disciplinary, holistic approach.

2. Multi-disciplinary and multi-professional working

The importance of an integrated approach to low vision rehabilitation is widely recognised. Such an approach allows patients to benefit from the expertise of ophthalmic professionals, social workers and rehabilitation specialists to ensure that they receive the best help available. The survey shows that many of the respondents have relationships with other agencies. However, the number of links varies considerably and the results indicate that a particular area of concern is that of emotional support. With less than 20 per cent of respondents reporting links with counsellors and only 28 per cent of providers stating that they provide counselling services it is fair to assume a serious gap in service provision in this area.

- We call on commissioners to ensure that the services they commission cover the aspect of emotional support. Where service level agreements do not include an obligation to provide such support, commissioners need to check that formal links with other agencies are in place to ensure adequate provision.

3. Information about existing services

Whilst most service providers make an effort to raise awareness of their services in hospital eye clinics, give advice during consultations or provide posters and leaflets in their own waiting rooms, only a minority (less than one in five) provide information about their services via GP surgeries. This means that people usually have to be “in the system” to learn about available services and little effort is being made to reach those who do not realise that their eye condition may be treatable or are not aware of the support they can get to help them live with sight loss.

- We call on service providers to use the template letter in the Appendix to contact GPs about providing information to patients regarding low vision services in their area.

4. Quality of services

Service providers and PCTs were asked how they perceived the quality of service in their area. The responses were very varied and reflect the persistent variability in services across the country. One third of providers and PCTs felt that services in their area were very good or good, another third felt they were satisfactory whereas a quarter of providers and one sixth of PCTs said they were unsatisfactory. 12 per cent of providers did not reply to this question and 20 per cent of PCTs did not know the answer.

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- We call on central and devolved governments to require service providers to audit their services on a regular basis, involving users, voluntary organisations, Low Vision Services Committees and local optical committees to cover all angles of service provision. These audits should use established benchmarks and clear procedures for enforcing the implementation of any resulting recommendations should be put in place.

These are essential steps to provide all people with sight loss with adequate, high quality services as and when they need them. However, at present there is no clear mechanism in place to ensure that this objective is achieved across the country. The devolved nature of health and social care and the multitude of agencies providing services is both an essential element of and an impediment to progress. Devolved services ensure that local structures and needs are taken into account, yet the reliance on local decision-taking has created a system that lacks accountability and perpetuates the postcode lottery in the provision of services.

- We call on the Government to appoint a Chief Vision Officer to provide clear benchmarks for the quality of eye care services to be achieved across the country, monitor the implementation of forthcoming recommendations on low vision pathways and serve as a focus point for stakeholder discussions about the future of low vision services.

Given the projected increase in the number of people with sight loss due to the ageing of the population, such an appointment would give a clear signal that the Government is taking seriously the sight loss challenge that is facing our health and social care systems in the coming years.

1. The sight loss challenge

Two million people in the UK are living with sight loss. This can range from difficulties reading a newspaper, driving and recognising a friend across the room to blindness that makes it difficult to cook, look after personal hygiene or leave the house without assistance. Of the two million people with sight loss approximately 380,000 are registered blind or partially sighted, including 315,000 people in England, 20,000 in Wales, 38,000 in Scotland and 5,000 in Northern Ireland. In addition, up to 76,000 people who are eligible to be registered are not registered either because they have chosen not to or because they are not known to social services or the medical profession [1]. Given the predicted increase in the number of elderly people over the next 25 years the number of people at risk of sight loss will increase significantly. We may be able to limit the increase in the number of people who will need sight loss support services through the provision of high quality eye care services and appropriate preventative measures. However, the fact remains that the number of elderly visually impaired people who need help to remain independent will increase. This will not only put further pressure on already struggling sight loss support services across the country but also raise NHS costs due to sight loss related falls and other related issues.

2. The RNIB/AMD Alliance UK low vision services survey

2.a Background to the survey

In 2004 the AMD Alliance UK and RNIB decided to carry out a survey of low vision services in the UK to obtain an up-to-date view of the type and range of services provided, the level of inter-agency working and the overall quality of services as perceived by service providers and PCTs.

The survey was conducted against the background of research carried out in 1997/8 [2] [3] which showed that low vision services in the UK were fragmented, difficult to access and lacking a holistic, multi-disciplinary approach. This general assessment was largely confirmed in subsequent reports by the Low Vision Services Consensus Group [4] and the AMD Alliance International. The AMD Alliance International concluded in 2003:

“The receipt of low vision services in the UK remains a postcode lottery. Some areas have excellent, easily accessible services and others have none at all. Much work is being done by various agencies but there is much still to be done. With adequate funding and commitment from relevant professionals, community-based low vision services need to be established that respond to local need and which are easily accessed by those people needing them and not just those who meet the criteria for registering as severely sight impaired/blind or sight impaired/partially sighted. There also need to be mechanisms by which an individual can re-refer themselves back into the system as and when they feel they need to. Additionally, awareness must be raised within the community of the availability and benefits of low vision services.” AMD Alliance International (2003) [5]

Since the problems in low vision services provision were highlighted in 1999, efforts have continued to improve services. With responsibility for health and social care being devolved to national level, England, Scotland, Wales and Northern Ireland have formulated their own proposals for improving services for people with sight loss and are at different stages of implementation.

In 2002, the Welsh Assembly allocated £1 million per year for the implementation of the Low Vision Scheme as part of the Wales Eye Care Initiative. Optometrists are being trained and accredited to provide low vision services in the community at no cost to the recipient. Around 120 optometrists have been accredited since the introduction of the scheme. This number is likely to remain constant as optometrists leave the scheme due to retirement and new optometrists join from time to time. It is hoped that waiting times for the receipt of low vision devices will be cut from up to 18 months in hospital based low vision clinics to five

weeks under the new scheme. However, issues regarding the provision of rehabilitation services still have to be resolved.

In Northern Ireland where low vision services used to only be available in the large hospitals of Belfast and Londonderry, services are being established in local hospitals province-wide, making them much more accessible to people outside the major cities. Accessibility is also being improved through the establishment of a wide variety of referral sources as well as outreach activities that benefit from close cooperation between optometrists and rehabilitation specialists.

In England and Scotland there has been a number of promising policy initiatives. The Scottish Executive acknowledges the appropriateness of the multi-disciplinary, community level approach advocated by the Low Vision Consensus Group. It has consulted widely on the current difficulties with services for people with visual/sensory impairment and has proposed the establishment of various working groups to consider how best to meet the needs of people with a sensory impairment. An evidence-based approach is being used to identify what changes need to be made to community care services. This work is ongoing to address the major problems in service provision identified by RNIB Scotland in its 2005 report *Buy Your Own White Cane* [6].

In England the Department of Health published the First Report of the National Eye Care Services Steering Group which outlined proposals for a number of new eye care pathways in May 2004. These included new pathways on age-related macular degeneration, glaucoma and low vision and a number of recommendations relating to service delivery, funding, regulatory issues and key outcomes. Low vision pathway pilots were set up in Gateshead, Barking and Dagenham and Havering, Sutton and Merton with Wandsworth. Later, pilot sites were extended to include Brighton, Hartlepool, Northumberland, Waltham Forest, Morecambe Bay, Hampshire (New Forest) and Mid and East Devon and South Worcester. The challenge will be to provide an evidence base of best practice examples that can then be used to roll out the pathways across England. It is hoped that their implementation will not only improve referral processes but will also help service providers to achieve sustainable improvements to the quality of their services.

Recognition of the problems faced by people with sight loss has led to the development of *Progress in Sight* [7], a set of national standards of social care for visually impaired adults. In addition, 75 Low Vision Services Committees have been established in England to improve inter-agency working. The impact of the *Progress in Sight* standards and of the low vision services committees will be discussed in the context of our survey presented below.

The efforts described above are all the more important when we look at research into the effects of insufficient support on the quality of life for people with sight loss [8] [9]. The picture is one of loneliness, social and economic deprivation and poor health among significant numbers of people with sight loss. To highlight just the key findings:

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- In 2003, 73 per cent of older people with sight loss surveyed by RNIB lived in poverty (which, in line with the Government's definition of poverty equated to £195 per week). This compares with 27 per cent of all pensioners.
- Economic deprivation is equally a major factor for those of employment age due to the high levels of unemployment amongst people with sight loss. Three out of four blind and partially sighted people of working age are not in paid employment with many of them living close to the poverty line.
- Isolation due to lack of mobility is a major problem with 76 per cent of people with sight loss saying that they get out of the house never, rarely or less than before they lost their sight.
- This inability to leave the house is not necessarily compensated by people visiting to help since 64 per cent of people with sight loss do not receive a daily visit from someone they trust, and 29 per cent are visited less than once a week or even less than once a month.
- Those with poor vision or registered blind or partially sighted are three times more likely to report their health as poor or fair than people with good vision.
- All of these problems are particularly acute in ethnic minority communities [10].

These findings suggest that more efforts are needed to improve the quality of life for people with sight loss. The question is: what is the most effective way to help people with sight loss overcome the challenges they face? Recognising the paucity of scientific evidence about the impact of low vision services on the quality of life of patients [11] [12] we have decided to base our own study on what appears to be a general consensus amongst practitioners in the field: low vision services are most effective if they focus on early intervention, particularly in terms of emotional support, and adopt a holistic approach facilitated by multi-agency working. This consensus has informed the compilation of our questionnaires and the analysis of the survey results and provides the background against which the findings of the low vision services survey should be read.

2.b Methodology

The survey consisted of two questionnaires, a general questionnaire and a questionnaire for primary care organisations.

General questionnaire

The research was conducted via a postal questionnaire, which was sent to a range of potential providers of low vision services. The questionnaire was sent out with a covering letter and a return Freepost envelope. Prior to its distribution the questionnaire was sent to key stakeholders for their comments and it was also piloted with a small sample of respondents before the main mailing. The pilot was carried out in November and December 2004 and the main mailing was conducted from December 2004 onwards. This was followed

up by a series of reminder mailings and phone calls in 2005. Respondents were also given the option to complete the survey online. The majority of replies were obtained via a self-completion postal response.

Table 1: Total sample

	Mailed	Returned	Response rate
Hospital	280	208	74%
Local society	188	94	50%
Opticians/optometry practice	1,667	915	55%
Social services departments	172	152	88%
Teachers	222	126	57%
Total	2,534	1,498	59%

In addition three out of five universities providing courses for optometrists responded to the survey. However, because of the small sample size they are not included as a separate category in the analysis.

For a postal questionnaire these are excellent response rates. The response rate from social services departments is particularly noteworthy and due in large part to the efforts of Anne Bristow, Chair of the Sensory Impairment Working Group of the Association of Directors of Social Services (ADSS). However, we should note that the overall response rate did not reach the high level of the Culham/Ryan survey. We believe that the main reason for this was our decision not to use a shortened questionnaire to elicit responses over the phone. We used the phone follow-up merely to encourage recipients to return the survey.

Primary care organisations questionnaire

A separate questionnaire was mailed to 285 primary care organisations across the UK. The data collection procedure was the same as with the general questionnaire: the questionnaire was sent with a covering letter and a Freepost envelope to directors of commissioning and was followed up with a second mailing and a telephone reminder. Again, respondents had the option of filling in the questionnaire online but this option was chosen by very few.

Unfortunately, we did not receive responses from any primary care organisations outside England so that the information provided does not cover Scotland, Wales and Northern Ireland. In total, 94 Primary Care Trusts (PCTs) completed and returned the questionnaires (a response rate of 32 per cent). For a copy of both questionnaires please visit the AMD Alliance UK section of the RNIB website at www.rnib.org.uk.

Non-responder questionnaire

A short questionnaire with five key questions for each of the groups (general or PCT) was used for a non-responder survey that was conducted by phone. The results established that there was no non-responder bias. We therefore believe our survey results to be representative of all respondents.

Survey results are reported at the 95 per cent confidence interval level.

3. Survey results

The survey was conducted with two main objectives in mind:

- To ascertain the current level of low vision services provision across the UK. The main focus was on the type and range of services provided.
- To assess the level of cooperation between different low vision services agencies.

In addition the survey results shed light on important areas of concern:

- waiting times and frequency of appointments
- the issue of funding
- the issue of access to services, primarily in relation to information provided to potential users
- the quality of services as perceived by service providers and PCTs.

3.a Profile of service providers

Out of the 1,498 respondents the majority (873 or 58 per cent) were based in optometry/opticians practices, 285 (19 per cent) were hospital based, 130 (9 per cent) were based at social services offices/facilities, and 113 (8 per cent) were based at resource centres. In addition, 79 respondents (5 per cent) were based in voluntary sector organisations, 59 (4 per cent) were based at schools, 61 (4 per cent) provided domiciliary care only, 25 (2 per cent) worked from nursing care homes and 20 (1 per cent) were based at universities.

Table 2: Where respondent is based (base: all respondents: 1,498)

Location	
Resource centre	8%
Social services office/facility	9%
Domiciliary	4%
Nursing/care home	2%
Opticians/optometry practice	58%
Hospital	19%
School	4%
University	1%
Voluntary sector	5%

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For most types of agency covered by the survey, the provision of low vision services is part of their remit. 88 per cent of social services provide low vision services against 79 per cent of hospitals, 75 per cent of local societies and 71 per cent of specialist teachers. The only type of agency that is less involved in the provision of services are optometry/opticians practices. With just over half of these not providing a service, optometry/opticians practices are the largest group of non-providers against 12 per cent of social services departments, one in five hospitals, one in four local societies and almost one in three specialist teachers.

3.b Types of services provided

In our survey we made a distinction between service providers who sell and/or provide optical devices and home adaptations/daily living aids, and those who provide other services such as mobility training, assessment for home adaptations, emotional support and financial advice. The results show that – with the exception of opticians/optometry practices – a large majority of services providers do more than just selling or providing equipment. 77 per cent of social services provide additional services, followed by 65 per cent of hospitals, and 61 per cent each of local societies and specialist teachers. All universities that responded (three out of five) also provide additional services. The category of providers least involved in low vision services other than selling or providing low vision equipment are opticians/optometry practices. Out of those providing services only a quarter provide additional services.

Table 3: Type of service provided (base: all respondents: 1,498)

	None	Sell/provide equipment only	other services
Hospital	21%	14%	65%
Local society	25%	14%	61%
Opticians/optometry practice	51%	24%	25%
Social services	12%	11%	77%
Universities			100%
Teachers	29%	10%	61%

3.c Reasons for not providing services

The main reason why potential providers do not deliver services is that they believe someone else is already providing an adequate service in the area. 40 per cent of respondents gave this reason. This essentially matches their response to the question as to how they assess the quality of services in their area: 84 per cent believe that the quality is good or satisfactory.

Lack of funding is given as a reason for not providing services by 30 per cent of respondents, not sufficient need by 25 per cent, lack of trained staff by 24 per cent and lack of space by 14 per cent. However, this overall picture hides large variations amongst different agencies and is biased towards the views of optometry/opticians practices because of this group's large sample size.

If we compare the individual providers it becomes clear that lack of funding is much more of an issue for optometrists than for local societies and hospitals (34 per cent, 21 per cent and 18 per cent respectively named funding as a reason for not providing services). Only 19 social services departments gave this reason. By contrast, lack of space is a bigger problem for local societies since one in four gave this reason for not providing services. Lack of trained staff is another important problem for local societies with 30 per cent naming this as a reason followed by opticians with 27 percent whereas specialist teachers, hospitals and social services appear to have less of a problem recruiting staff. For 17 per cent of specialist teachers, 16 per cent of hospitals and as few as six per cent of social service departments this was an issue.

Table 4: Reasons for not providing a low vision service (base: all saying they do not offer one: 589)

Reason	
Other adequate service in area	40%
Lack of funding	30%
Not sufficient need	25%
Lack of trained staff	24%
Lack of space	14%

Most importantly, opticians/optometrists appear to be much less confident than other potential providers that there are other adequate services in their area. Only 36 per cent gave this as a reason for not providing services against 61 per cent of hospitals, 58 per cent of specialist teachers and 46 per cent of local societies that were non-providers of services.

3.d Multi-disciplinary and multi-professional working – the importance of an holistic approach to low vision support services

A multi-disciplinary or integrated approach with an emphasis on multi-professional working is generally accepted as a key element of improving the delivery of low vision services. For some this simply means that the provision of low vision devices is combined with training in their use [13]. But more often integrated, multi-disciplinary services are seen as services where ophthalmic and optical practitioners, social workers, and rehabilitation officers carry out joint assessments with patients and carers to decide on the best course of action for each individual patient [14] [15] [16]. Cooperation with other agencies to reach and inform people who have just been diagnosed with sight loss is an objective under standard 8 of the national standards of social care for visually impaired adults (Progress in Sight). These also include standards on providing emotional support (standard 13), training for independence (standard 14) and the provision of equipment (standard 15) all of which are part of an holistic approach to sight loss support [17].

Since the move towards more integrated working is an ongoing topic we asked respondents to indicate the external agencies or professionals with whom they and/or a member of their low vision team have links. In addition, we asked whether these links were formal or informal.

Table 5 shows the results for all respondents that offer some kind of low vision service (even if it is only selling/providing aids and devices). Amongst these respondents, three quarters have a link of some kind with ophthalmologists and two thirds have links with optometrists/opticians. At the other end of the spectrum, just one fifth has a link with medical social workers, counsellors or other disability services (such as Sense, Deafblind UK and physiotherapists). Given the increasing recognition of the need for emotional support to prevent depression and maximise the likelihood of successful rehabilitation [18] [19] the lack of links with counsellors is particularly worrying.

Table 5: Links to external agencies (base: all offering some service: 905)

Service	Respondents with links to relevant external professionals
Ophthalmologists	79%
Opticians	62%
Local societies	60%
GPs	55%
Social workers	48%
Rehabilitation workers	43%
Specialist teachers	36%
LV Services Committee	27%
Employment advisors	23%
Medical social worker	19%
Counsellors	18%
Other disability service providers	18%

Overall, there are slight increases in the proportion of respondents who have contact with external agencies in comparison with the Ryan/Culham survey. Links with ophthalmologists seem to have increased particularly strongly (from 58 per cent to 79 per cent).

Table 6 compares both surveys where figures for the same professional categories are available. Links with optometrists are not included since they are not listed separately in the Ryan/Culham survey.

Table 6: Proportion of respondents who have contacts with other agencies

Service	1997/98	2004/05
Ophthalmologists	58%	79%
Local societies	52%	60%
GPs	49%	55%
Social workers	41%	48%
Rehabilitation workers	31%	43%
Specialist teachers	31%	36%
Counsellors	12%	18%

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Similar to the data on reasons why respondents do not provide services, the average hides large variations among services providers. When we look at the individual providers, social services have the highest number of external links, with a vast majority reporting links with ophthalmologists, opticians, local societies, GPs, rehabilitation workers, specialist teachers and employment advisers. The one area where social services' inter-agency working appears inadequate is in the important area of emotional support. Only 39 per cent of social services have links with counsellors. Even if we link this with the number of social services that provide emotional support as part of their own services (51 per cent) there are still 37 per cent that do not provide counselling services and do not have any links with counsellors. It is likely that patients covered by these services do not receive the emotional support they need unless they have been signposted to counselling services by other agencies, such as their GP. However, the picture does not look any better for hospitals, the other main provider of services. Out of 164 hospitals only 63 (or 29 per cent) offer counselling, and out of the 101 hospitals that do not offer counselling 84 (or 83 per cent) have no links with counsellors. With only 41 per cent of local societies having links with counsellors it is reasonable to assume that there is a serious gap in service provision in this area, which should be of major concern to service providers.

The survey also indicates that it will be a challenge to increase the role played by optometry/optician practices in the provision of multi-disciplinary services since they are least likely to have links with other agencies and tend to focus on selling low vision devices.

3.e The role of Low Vision Services Committees (LVSCs)

In the context of multi-agency working it is worth looking at the role of the Low Vision Services Committees which have been set up across England to improve low vision services, primarily as a forum to promote inter-agency working and patient involvement in the planning of services.

If we look at Table 7 it becomes clear that the ability of LVSCs to generate links with service providers varies considerably. Whereas 84 per cent of local societies and 75 per cent of social services report links with their LVSC the figure is 64 per cent for hospitals, 48 per cent for specialist teachers and goes down to a mere 22 per cent for opticians. In the majority of cases these links are formal.

Table 7: Links to other agencies: (base: all offering a service: 905)

	Hospital	Local society	Opticians	Social Services	Teachers
Base: all offering some service:	n=163	n=70	n=448	n=131	n=90
Ophthalmologists	91%	71%	73%	89%	83%
Opticians/optometry practices	83%	70%	44%	83%	73%
Local societies	84%	61%	40%	89%	76%
GPs	55%	56%	55%	73%	34%
Social workers	61%	76%	24%	84%	66%
Rehabilitation workers	71%	79%	15%	75%	57%
Specialist teachers	56%	44%	9%	76%	71%
LVSC (if know about local committee)	44% (64%)	57% (84%)	13% (22%)	44% (75%)	20% (48%)
Employment advisors	21%	51%	3%	77%	27%
Medical social worker	26%	29%	7%	47%	19%
Counsellors	29%	41%	6%	39%	9%
Other disability services	16%	36%	2%	61%	27%

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This variability was also flagged up in an evaluation of Low Vision Services Committees conducted by Warwick University in 2005 [20]. Whilst 92 per cent of Low Vision Services Committees report links with social services, 86 per cent work with hospital services and 70 per cent with the voluntary sector, only 51 per cent work with education services.

So how do these agencies perceive the impact of the establishment of a Low Vision Services Committee on the provision of low vision services in their area?

Table 8 (overleaf) is based on the respondents who know they have a committee and expressed an opinion about its impact (443 service providers and 51 PCTs). The survey results show a somewhat divided picture. Whereas just over half of respondents stated that the committee had made a positive or very positive impact, just under half of all respondents felt that it had made no difference. However, there was quite strong variation between the different agencies. Social services and specialist teachers were particularly likely to have noticed a positive impact (63 per cent and 68 per cent respectively) whereas only 40 per cent of optometry/optician practices took this view against 60 per cent who felt that the Committee had made no difference.

Among local societies 27 (62 per cent) felt the committee had made a positive impact, 15 (34 per cent) thought that it had made no difference and two local societies (4 per cent) felt that the impact had been negative.

When we asked primary care trusts the same question a similar picture emerged. Out of 51 PCTs who were aware of a Low Vision Services Committee in their area 30 (or 59 per cent) felt that the committee had a positive or very positive impact on the provision of low vision services in their area. By contrast, 16 (or 31 per cent) stated that it had made no difference and 4 (8 per cent) did not know. None of the PCTs stated that the committee had made a negative impact.

This picture should encourage Low Vision Services Committees to continue their efforts and improve in areas that have been identified as weaknesses by the Warwick evaluation including:

- promotion of communication and good practice
- service user involvement
- dealing with specialist needs
- multi-agency working
- improving services.

Table 8: Impact of Low Vision Services Committee (base: all offering other services and excluding no replies/no committee: 441)

	Very positive	positive	No difference	Negative
Hospital	20%	42%	38%	
Local society	21%	41%	34%	4%
Optician/Optom	11%	29%	60%	
Social services	27%	38%	35%	
Teachers	32%	36%	32%	
Total of the above	18%	35%	47%	
PCTs	22%	43%	34%	

3.f Information about existing services

Links between agencies are clearly an important aspect of the provision of services and low vision services committees can play an important role in this area. However, any efforts made towards a more holistic, multi-agency approach are of limited benefit if potential clients are not aware of the existence of these services.

We asked how respondents provide information about their services to people with sight loss. The results shows that providers use a variety of channels, including PCT patient prospectuses, posters and leaflets in their own waiting rooms and advice during consultations. What is striking is that only a small minority of providers (18 per cent) provide information about their services through GP surgeries. This means that people generally need to be already “in the system” to find out about available services. There is a large number of people who would benefit from help but may not yet have reached a level of sight loss that would entitle them to being registered as blind or partially sighted. Some people may not have seen an eye health professional in years because they were told by their ophthalmologist at some point that they had, for instance, dry AMD and that nothing more could be done for them. Providing information about available services via GP practices would raise awareness amongst the general public and would filter down to those in need of support.

Table 9: How respondents promote services (base: all offering other services: 615)

Information channel	
PCT/PCO prospectus	9%
Poster/leaflet in own waiting room	24%
Poster/leaflet in GP's practice	18%
Hospital eye clinic	50%
Advice during consultations	61%

We would encourage service providers to use GPs as a key channel to raise awareness of their services. The Appendix contains a template letter that could be used for this purpose.

The most effective approach would be for a list of all available services to be provided to GPs rather than each provider approaching GPs individually. In areas with a Low Vision Services Committee, the committee could co-ordinate such an approach.

3.g Waiting times

The Culham/Ryan survey found that 84 per cent of respondents had waiting times of less than two months and three per cent had waiting times over six months [15]. In our survey 79 per cent had waiting times of less than two months for optical devices assessments and 62 per cent for home adaptations/daily living aids. 10 per cent waited two to six months for optical devices and 12 per cent waited the same length of time for home adaptations/daily living aids.

There are also interesting variations between the agencies. Hospitals and social services seem to struggle most. 20 per cent of hospitals and social services reported that patients waited between two and six months to be assessed for optical devices and 2.5 per cent of hospitals reported waiting times of six to 12 months. By contrast 65 per cent of optometry/opticians practices reported waiting times of less than two weeks and 24 per cent said that patients waited between two weeks and two months. Local societies also do well with one third reporting waiting times of less than two weeks and well over a half between two weeks and two months (although this is based on a numerically small sample – 27 respondents).

Table 10: Waiting times per agency: optical devices (base: all saying they offer this service: 455)

	Under 2 weeks	2 weeks – 2 months	2–6 months	6–12 months	1 Year +
Hospital	7%	68%	20%	2.5%	
Local society	33%	59%	4%		
Optician/optom	65%	24%	3%	0.5%	
Social services	15%	42%	20%		2%
Teachers	14%	32%	4%		4%
Total	38%	41%	10%	10.4%	

Table 11: Waiting times per agency: home adaptations/daily living aids (base: all saying they offer this service: 229)

	Under 2 weeks	2 weeks – 2 months	2–6 months	6–12 months	N/A	No reply
Hospital	10%	48%	33%	3%		3%
Local society	25%	45%	5%		5%	20%
Social services	11%	25%	12%	1%	14%	33%
Total	21%	33%	12%	1%	8%	23%

These results show that one person in 10 waits between two and six months before being assessed for optical devices (one in five for those receiving services from hospitals or social services). The picture is similar for assessments regarding home adaptations/daily living aids with 33 per cent of hospitals reporting waiting times of two to six months and three per cent waiting times of six to 12 months [22].

All in all too many people continue to wait too long for assessments for low vision devices and home adaptations/daily living aids. A study commissioned by RNIB in 1998 shows that 70 per cent of people with sight loss would like to have been seen within two weeks of diagnosis reflecting the fact that most people with sight loss need help to be able to carry on with fundamental daily activities such as making a hot meal, going shopping or reading their post. The concern is that it may only take a relatively short time for them to lose essential life skills and therefore their autonomy.

3.h Specialised training and frequency of appointments

We asked respondents whether their clients received specialised low vision training – if appropriate – in the use of their low vision devices and in the use of home adaptations/daily living aids .

At first sight the results were positive. 84 per cent of providers of low vision devices said that they provided training in their use, either always or usually. The proportion for home adaptations/daily living aids was 86 per cent.

Table 12: Training in use of optical devices and home adaptations (base: 438 providers of optical devices and 191 providers of home adaptations.)

	Always	Usually	Rarely or never	No reply
Optical devices	62%	22%	6%	9%
Home adaptations	65%	21%	3%	9%

When we look further into the number of training appointments given we can see one possible reason why a large number of low vision devices are no longer being used within a month or two of issue. 40 per cent of providers of low vision devices offer only one training appointment. Whilst 20 per cent of providers offer two or three appointments, only 27 per cent offer as many appointments as needed. Encouragingly the picture is more positive in the area of home adaptations/daily living aids. Here 47 per cent of providers offer as many training appointments as necessary and only 21 per cent offer one appointment only.

Table 13: Number of training appointments provided by respondents (base: all those offering services and training: 390 for optical devices and 169 for home adaptations/daily living aids)

	One	Two	Three to five	As many as needed	No reply
Optical devices	40%	14%	3%	27%	8%
Home adaptations	21%	10%	4%	47%	11%

As in other areas, there is considerable variation between the different categories of providers. Social services are most likely to offer as many appointments as needed (50 per cent for optical devices and 59 per cent for home adaptations). Opticians are at the other end of the spectrum. Only one in ten offer as many appointments as needed for training in optical devices whereas well over half offer just one training appointment.

It may be unrealistic to expect all service providers to offer as many appointments as needed and this may also relate to funding issues. There will always be a conflict between the demands for an increased number of new assessments and lower waiting times and the needs of people who have been assessed and still need help with the use of devices. However, it is clear that more needs to be done to come closer to this ideal, possibly by building closer inter-disciplinary links.

Such links enable services to be truly centred around the needs of each service user with flexible and innovative approaches to the delivery of services to ensure best use of resources, both financial and human. By developing relationships and sharing information between service providers the needs of each individual with sight loss are met most effectively.

3.i Funding

For those providers who do not feel that someone else is providing an adequate service in their area, funding is the main reason why they do not offer services themselves. We looked at the way current providers are funded. The answers show a wide range of funders with hospitals and social services providing more than half of the funding. Despite the White Paper “Our health, our care, our say” (2006) [23] calling for more services to be moved out of hospitals into the community, we believe that large hospitals should continue to provide low vision services as this may be the most convenient location for some patients. Most importantly, large hospitals hold highly specialised expertise needed by some people with sight loss. At the same time outside providers should be encouraged to improve and increase access and choice, and become the providers for the majority of people with sight loss.

**Table 14: Which authority/agency is the main funder - by sample
(base: all offering some services: 905)**

Hospitals	
NHS hospital contract	67%
PCT/PCO	14%
Local authority/NHS combined	9%
Local societies	
Voluntary sector	39%
Social services	20%
PCT/PCO	17%
Opticians/optoms	
Private	45%
PCT/PCO	17%
NHS hospital contract	14%
Social services	
Social services	57%
NHS hospital contract	23%
Teachers	
Dept of education	53%
School	13%

It is interesting to see the relatively minor role played by PCTs. This may be linked the low level of priority given to low vision services by PCTs. Only 11 per cent of PCTs saw low vision services as a high priority, 43 per cent gave them medium priority whereas 46 per cent of PCTs either saw low vision services as a low priority or they did not answer the question. PCT engagement clearly needs to increase significantly to address the growing need for low vision services. However, despite moves to strengthen the commissioning role of PCTs, the current outlook is rather discouraging. Only 21 per cent of PCTs asked whether they were planning to commission more services said yes, just over half said no and one in four did not know.

Table 15: Intention to commission new low vision services. (base: all respondents: 94)

Yes	21%
No	51%
Don't know	25%

Not surprisingly out of the 28 PCTs who said that low vision was a low priority, 19 did not plan to commission new services and four did not know whether they would commission new services. By contrast, seven out of 10 of the PCTs that give low vision services a high priority also said that they would commission more services.

Partly, the lack of PCT involvement reflects the reality of low vision services being “hidden” within the overall budgets for ophthalmology contracts. Low vision services are not included as a separate item in these contracts making it difficult for PCTs to audit the level of service provided. The Government White Paper for England “Our health, our care, our say” promotes a preventative approach that allows people to stay in their own environments with the necessary help for as long as possible. Low vision services help people with sight loss achieve this objective and PCTs should include their delivery in their strategy towards reaching the goals set down in the White paper. Policy announcements such as the White Paper represent an important steer for PCTs to take low vision services seriously. In addition, an increase in funding is essential to improve low vision services across the country. The £73 million allocated through Action on Cataracts (a government programme to reduce waiting times for cataract operations) has been used very successfully to reduce waiting times for cataract operations. According to the National Eye Care Services Steering Group approximately £40 million per year is required to address the problems in low vision services provision in England alone and provide a comprehensive low vision service (including assessment, examination, rehabilitation and low vision aids and assuming the need to carry out 200,000 low vision assessments per year) [24].

3.j Quality of services

How do service providers perceive the quality of low vision services in their area? We asked service providers and PCTs to rate the services in their area on a scale from 1 (very good) to 5 (unsatisfactory). We did not give a yardstick as to what represents a good or a poor service and did not define the area in question. Our main purpose was to get a broad picture of the quality of service provision through the eyes of service providers.

Table 16 is based only on respondents who answered the question (88% of the service providers, and all PCTs). The responses provide a mixed picture, but the balance of opinion was positive rather than negative. Overall, one service provider in four feels that services in their area are less than satisfactory or unsatisfactory. By contrast 33.5 per cent of services

A question of independence

providers said that the services in their area were good or very good whereas 30.5 per cent thought they were satisfactory.

Table 16: Quality of services (general questionnaire) (base: all respondents: 1498)

	General questionnaire	PCT questionnaire
Very good	12.5%	10%
Good	21%	24%
Satisfactory	30.5%	30%
Less than satisfactory	18%	14%
Unsatisfactory	6%	2%
No reply (general questionnaire); don't know (PCT questionnaire)	12%	20%

A supplementary question asked respondents to explain their rating. The reasons for a good rating were:

- feedback from users is positive
- it is a well-established service
- it is a professional service; staff are well-trained
- services have improved.

Those giving a negative response explained that this was because:

- the service was too slow
- there was insufficient funding
- there was not a full service
- patients were unaware of the service
- the service was too far from patients
- generally it was stretched.

Most of these comments are reflected in the findings about the main reasons why potential providers do not provide services.

The responses by PCTs to the same question largely mirror the answers to the general questionnaire, although a larger number of PCTs stated that they did not know.

The responses to the question on quality are inevitably influenced by the way providers see the quality of their own services and, for PCTs (20 per cent compared to 12 per cent of service providers), whether they are involved in commissioning services and what level of priority they give to these. Proper audits, involving providers, funders and service users and using a fixed set of criteria would be required to obtain a more objective picture.

This would reveal why services are unsatisfactory, for example, whether there is an issue of sub-standard quality because of lack of cooperation between agencies, lack of staff, underestimated need, or whether it is merely a funding problem, in that service providers are competent but need more funding to improve their reach. Modernisation techniques and procedures should then be applied to bring the services to a good standard.

At present auditing is a weakness in the system as illustrated by the answers provided to a question as to what funders expect in terms of accountability. It is surprising, to say the least, that 40 per cent of respondents stated that their funders expect nothing from them in terms of accountability. Only 16 per cent require yearly audits, 14 per cent ask for accounts and 11 per cent measure accountability in a variety of different ways (ranging from six monthly monitoring to quarterly returns and monthly statistics).

4. Conclusions and calls for action

The low vision services survey flags up a number of issues that should inform the discussions about the implementation of new pathways for low vision service provision as well as efforts across the countries to improve access to and the quality of services. Multi-disciplinary working, advertising of existing services, waiting times and frequency of appointments, training in the use of low vision devices and home adaptations/daily living aids, funding and quality of services all remain areas of concern.

Positive action needs to be taken to ensure the successful implementation of new low vision pathway in England and of new schemes for the provision of low vision services in Scotland, Northern Ireland and Wales if they are to lead to the necessary improvements. This includes the training of professional staff to work in the services based on a multi-disciplinary approach.

Above all, the survey results suggest that the following actions are essential to ensure that the health and social care systems in the UK can cope with the sight loss challenges they are facing:

Action 1: Funding

For those service providers who do not think that low vision services in their area are adequately provided by other agencies, lack of funding is the main reason why they do not provide services themselves. As a key commissioner of community services PCTs need to take a stronger interest in low vision support services to identify areas of under-funding and look at innovative and effective ways of commissioning these, particularly in a community setting.

- We call on central and devolved governments to increase the funding for low vision services and for PCTs and social services to carry out audits of low vision and rehabilitation services in their area, identify funding gaps and commission services with a multi-disciplinary, holistic approach.

Action 2: Multi-disciplinary and multi-professional working

The importance of an integrated approach to low vision rehabilitation is widely recognised. Such an approach allows patients to benefit from the expertise of ophthalmic professionals, social workers and rehabilitation specialists to ensure that they receive the best help available. The survey shows that many of the respondents have relationships with other agencies. However, the number of links varies considerably and the results indicate that a particular area of concern is that of emotional support. With less than 20 per cent of respondents reporting links with counsellors and only 28 per cent of providers stating that they provide counselling services it is fair to assume a serious gap in service provision in this area.

- We call on commissioners to ensure that the services they commission cover the aspect of emotional support. Where service level agreements do not include an obligation to provide such support, commissioners need to check that formal links with other agencies are in place to ensure adequate provision.

Action 3: Information about existing services

It is a considerable weakness of low vision services provision that people generally need to be “in the system” to gain knowledge of available services.

- We call on service providers to use the template letter in the Appendix to contact GPs about providing information to patients regarding low vision services in their area.

Action 4: Quality of services

Whilst it is encouraging to see that one third of respondents to the survey feel that the services in their area are good or very good this leaves two thirds of providers judging the services in their area as merely satisfactory, less than satisfactory or even unsatisfactory.

- We call on central and devolved governments to require service providers to audit their services on a regular basis involving users, voluntary organisations, low vision services committees and local optical committees to cover all angles of service provision. These audits should use established benchmarks such as Progress in Sight. Whatever benchmarks are used – it is essential that governments accept responsibility for enforcing their implementation.

These are essential steps to provide all people with sight loss with adequate, high quality services as and when they need them. However, at present there is no clear mechanism in place to ensure that this objective is achieved across the country. The devolved nature of health and social care and the multitude of agencies providing services is both an essential element of and an impediment to progress. Devolved services ensure that local structures and needs are taken into account, yet the reliance on local decision-taking has created a system that lacks accountability and perpetuates the post-code lottery in the provision of services.

- We call on the Government to appoint a Chief Vision Officer to provide clear benchmarks for the quality of eye care services to be achieved across the country, monitor the implementation of forthcoming recommendations on low vision pathways and serve as a focus point for stakeholder discussions about the future of low vision services.

Given the projected increase in the number of people with sight loss due to the ageing of the population such an appointment would give a clear signal that the Government is taking seriously the sight loss challenge that is facing our health and social care systems in the coming years.

Notes and references

- [1] Tate, R. et al, 2005. **The prevalence of visual impairment in the UK: a review of the literature.** London: Unpublished report commissioned by RNIB.
- [2] Culham, L.E. and Ryan, B., 2002. Low vision services for vision rehabilitation in the United Kingdom. **British Journal of Ophthalmology**, 86 (7).
- [3] Culham, L.E. and Ryan, B., 1999. **Fragmented Vision – survey of low vision services in the UK.**
- [4] Low Vision Services Consensus Group, 1999. **Low Vision Services. Recommendations for future service delivery in the UK.**
- [5] AMD Alliance International, 2003. **UK Country report on early detection and low vision rehabilitation.**
- [6] RNIB Scotland, 2005. **Buy Your Own White Cane.** RNIB
- [7] Association of Directors of Social Services, 2002. **Progress in Sight – National standards of social care for visually impaired adults.**
- [8] Vale, D., 2004. **Unseen – neglect, isolation and household poverty amongst older people with sight loss.** London: RNIB.
- [9] Thomas Pocklington Trust, 2005. **An investigation into the circumstances of older people with sight loss: analysis of the English Longitudinal Study of Ageing.** Research findings number 9.
- [10] Thomas Pocklington Trust, 2005. **Our Vision Too: Improving access of ethnic minority visually impaired people to appropriate services; building a supported community referral system.** Research findings number 8.
- [11] Smallfield, S. and Lou, J.Q., 2006. The effectiveness of low vision rehabilitation on quality of life: an evidence-based practice approach to answer clinical questions. **Occupational Therapy in Health Care**, 20 (2).
- [12] Agency for Healthcare Research and Quality, Not dated [online]. **Vision rehabilitation: care and benefit plan models. Literature review.** Available from: www.ahrq.gov/clinic/vision/index.html#intro
- [13] Shuttleworth, G.N. et al, 1995. How effective is an integrated approach to low vision rehabilitation? **British Journal of Ophthalmology**, 79 (7), 19-23
- [14] Hinds, A. et al, 2003. Impact of an interdisciplinary low vision service on the quality of life of low vision patients. **British Journal of Ophthalmology**, 87 (12), 91-6
- [15] Culham, L.E., Ryan, B., 1999. **Our better vision – What people need from low vision services in the UK.** London: RNIB.

- [16] Rughani, S., 2005. Uniting vision – advances in low vision care. **New Beacon**, 89. Number 1040
- [17] The Association of Directors of Social Services, 2002. **Progress in sight: national standards of social care for visually impaired adults.**
- [18] AMD Alliance International, not dated. **Vision loss and depression – literature review** [online]. Available from:
<http://www.amdalliance.org/information/depression/literaturereview.php>
- [19] Horowitz, A., Reinhardt, J. P., and Boerner, K., 2005. The effect of rehabilitation on depression among disabled elders. **Aging and Mental Health**, 9 (6), 563-570
- [20] Gibson, A., Hundt, G. and Stuttaford, M., not dated. **Low Vision Project National Evaluation Report.** The University of Warwick.
- [22] Please note that we have included “no reply” responses in the table on waiting times for home adaptations/daily living aids because of the high number of teachers, local societies and social services who did not reply to this question (70 per cent, 20 per cent and 33 per cent respectively). Also, because of the small numerical sample we have excluded universities and teachers (1 and 10 responses respectively) from the chart on home adaptations and daily living aids. The number of “no reply” responses for the question on low vision devices was 13.3 per cent for social services and 39.3 per cent for specialist teachers.
- [23] Department of Health, 2006. **Our health, our care, our say: a new direction for community services.** Department of Health, White Paper
- [24] NHS Modernisation Agency, 2004. **National Eye Care Services Steering Group. First report.** NHS

Appendix

Template letter to GP practices to encourage the dissemination of information about available sight loss support services

Ideally, this letter should be sent to GPs with a list of all major service providers to ensure that the information provided is not seen as indirect advertising of individual services. In areas with Low Vision Services Committees, these could aim to co-ordinate efforts to send this letter to GPs.

Dear [GP],

Two million people in the UK live with a level of sight loss that makes it difficult for them to undertake everyday tasks such as reading bills, letters or newspapers, driving or cooking. As a result of an ageing population, the number of people with sight loss is set to grow.

Recent government announcements place a great deal of emphasis on the importance of early intervention and prevention in health and care policies. Low vision services can offer advice and information on the type of help and support available to aid safe and independent living for people with sight loss.

If one of your patients has problems with their sight that cannot be remedied through medical intervention, a low vision assessment will determine what help they need to make use of their remaining vision to live independently and safely. Many people with sight loss are at an increased risk from falls and they are more likely than people with normal vision to require medical attention as a result. Low vision services include advice to help prevent falls from happening.

In addition, some low vision services can also provide much needed emotional support to help someone through the often difficult period of adjusting to sight loss, and the effects this will inevitably have on their life and that of their family.

Please find attached a list of low vision services available in your area. We would like you to make this list available in your waiting room and to refer patients with sight problems to these services even if their level of sight loss has not reached the threshold for being registered partially sighted or blind.

For further information please contact: [insert list of major service providers]

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UK members of the AMD Alliance International

The AMD Alliance UK is an informal alliance of the UK members of the AMD Alliance International, a global organisation that aims to raise awareness of AMD, as well as improving prevention, early detection and access to treatment, rehabilitation and low vision services. For more information please visit www.amdalliance.org.

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“Sight is the sense we most fear losing. Imagine a diagnosis of irretrievable sight loss combined with the realisation that you have to be lucky to get the whole range of services that might make the difference between independent living on the one hand and depression and dependency on the other. Urgent action is needed to ensure that people with sight loss are given all the support they need as and when they need it.”

**Steve Winyard, Head of Policy and Campaigning RNIB
and Chair of the AMD Alliance UK**

This report is available in large print, braille and audio. To request your copy please contact Barbara McLaughlan, RNIB on +44 (0)20 7391 2302 or email bmclaughlan@rnib.org.uk