Finding your own way around: experiences of health and social care provision for people with a visual impairment in the UK

Authors

Suzanne Hodge (corresponding author)

Division of Health Research, Lancaster University, Lancaster, UK

Email: s.hodge@lancaster.ac.uk

Tel. 01524 592712

Clare Thetford

Health and Community Care Research Unit, Liverpool University, Liverpool, UK

Email: clare.thetford@liv.ac.uk

Tel: 0151 794 5330

Paul Knox

Department of Eye and Vision Science, Liverpool University, Liverpool, UK

Email: pcknox@liv.ac.uk

Tel: Tel: 0151 794 5736

Jude Robinson

Department of Sociology, Social Policy and Criminology, Liverpool University, Liverpool, UK

Email: j.e.robinson@liverpool.ac.uk.

0151 794 2981

Abstract

The systems of support for people with a visual impairment in the UK are complex and can be difficult to access, involving input from a range of health and social care services. In this paper we report qualitative findings from research looking at people's experiences of accessing health and social care services. These highlight the inconsistencies and variability in existing systems of support for people with a visual impairment, and show that access to services is largely dependent on the agency and initiative of individual service users in establishing networks of support for themselves. This means that those who are less able to do this may find themselves without the support necessary to maintain or improve their quality of life. We argue that health and social care agencies need to be more proactive in addressing the support needs of people with a visual impairment beyond the point of initial diagnosis or registration.

Keywords: Long-term; low vision; registration; sight impaired; qualitative; support needs

Introduction

There are currently around 350,000 people registered either Severely Sight Impaired (SSI) or Sight Impaired (SI) in England, Scotland and Wales (NHS Information Centre, 2011, National Statistics, 2010, National Statistics, 2012). However, research suggests that more than one in ten people aged over 75 in England, Scotland and Wales have a level of visual impairment that would make them eligible for registration (Evans, 2005). If these were all registered the number of people aged over 75 registered in England and Wales alone would increase to over 500,000 (based on 2011 Census data).

There is particularly strong evidence for the impacts of visual impairment on older people, for whom it has been shown to impact negatively on quality of life (Mitchell & Bradley, 2006); to be associated with reduced levels of social participation (Alma et al., 2011) and social support (Burmedi et al., 2002a, Verstraten et al., 2005); and to be an important risk factor for falls (Legood et al., 2002). There is also a well-established link between visual impairment and depression (Burmedi et al., 2002b, Evans et al., 2007, Chou, 2008). Although there is less evidence for the impacts of visual impairment on working-age adults, a similar picture seems to exist as for older people (Nyman et al., 2010).

Registration, particularly as SSI, can be the key to accessing vital financial and social support to keep people active, healthy and engaged. To be registered, an individual must first be formally assessed and certified by a consultant ophthalmologist. At the point of diagnosis or certification, they may be directed to an Eye Clinic Liaison Officer (ECLO) (also referred to as a Sight Loss Adviser) or other early intervention support worker who can provide initial support and advice, including information about other sources of support. The role of ECLO was first established by the Royal National Institute of Blind People (RNIB) in the mid-1990s (Subramanian et al., 2011) but has expanded significantly in recent years, so that there are now approximately 120 ECLOs and about the same number of similar early intervention posts in hospitals throughout the UK (RNIB, 2015a), although these are thought to cover only 30% of eye departments in the UK (RNIB, 2015b). However, these services have not been established as a statutory element of eye health care, and there is great variation in

the way they are set up; from full-time professional, fully funded positions to part-time posts held by volunteers. Furthermore, with most ECLO posts reported to be funded on an annual basis, there is ongoing concern for their future existence (RNIB, 2014).

Once an individual has been certified, their statutory Social Services Department (SSD) is notified and they should then be contacted by a social worker asking them if they wish to be registered as SI/SSI. They should also be asked about their support needs, and offered an assessment. Following registration, or referral to Social Services, individuals may be offered a range of low vision (LV) services including rehabilitation; low vision aids (LVAs); advice about welfare benefits; and emotional support. These forms of support can be vital in enabling people to maintain their independence and quality of life. However, although there is agreement about what should be included in such services, there is no standard model of provision (NHS Eye Care Services Programme, 2007). Thus there is considerable variation in the level of service offered and in the ways in which services are configured in the UK (Dickinson et al., 2011).

This paper explores this landscape of complex service provision through the experiences of people with a visual impairment. It is based on research conducted in North West England and North Wales by researchers from the University of Liverpool. The aims of the research were to explore the changing support needs of people with a longstanding visual impairment from the clinical, visual function and quality of life perspectives.

Methods

The research was conducted in two phases; the first in 2007, the second in 2010. Findings from the first phase have been published separately (Thetford et al., 2009; 2011). This paper draws primarily on the qualitative findings from the second phase, focusing particularly on participants' experiences in the three years between the two phases of the study. In the first phase, qualitative data were derived from narrative interviews (Wengraf, 2005, Wengraf, 2001); in the second phase, from semi-structured interviews. Separate ethical approvals were obtained for each phase: for the first from a NHS Research Ethics Committee (REC); for the second from a university REC.

Thirty seven people with a visual impairment were interviewed for the first phase of the study; all were living with sight loss that was uncorrectable with glasses or contact lenses. Participants were recruited via local voluntary organisations working with people with a visual impairment. Consent was sought from participants to be contacted about taking part in a follow-up interview: all consented to this. In 2010 participants were invited to take part in a follow-up interview, with the aim of finding out how their needs had changed in the intervening three years. Twenty one (57%) of the original sample of 37 consented to be re-interviewed. Six people declined to take part; eight had died; and two were untraceable.

Informed consent was taken, either written or audio-recorded, at the start of each interview. The interviews were digitally audio-recorded, transcribed and anonymised.

A thematic approach to analysis of the data from the second phase of the study was developed by the research team. This approach needed to be broad in scope, to allow the data to be explored from a number of different angles relevant to the study. It also needed to allow the findings from the second phase of the study to be integrated and compared with those from the first. In order to build 'inter-rater reliability' into the analysis (Armstrong et al., 1997) three members of the research team independently coded two of the transcripts, identifying segments of text that seemed to carry interest or meaning in relation to the research topic. This process showed there to be a high degree of convergence across the three coders. Differences tended to be in the breadth of coding adopted, for example, whether to code bereavements, major illnesses and changes in domestic circumstances under separate codes or under a single code of 'life events/changes'. It was decided to adopt a broader coding strategy, given the relatively small sample size, and the fact that visual impairment was the central issue around which other issues were being examined. The codes developed as a result of this process were then mapped onto the codes used in the original study and a thematic framework developed (Spencer et al., 2003). The first author then used this thematic framework to code all the transcripts, using the NVivo qualitative software package. The coded data were then reviewed, refined and sorted into a set of final thematic areas that addressed different aspects of the study.

Findings

Participants

Participants were initially recruited by advertising the study through voluntary organisations providing services to people with visual impairments in Merseyside, Cheshire and North Wales. The final sample was drawn from a mix of urban and rural localities across these areas. Although we do not claim that participants form a statistically representative sample of people living with a visual impairment, they do reflect a range of characteristics and experiences not untypical of this population. The gender composition of participants in the second phase was less balanced than in the first, (13 women, 62%, compared to 19 women, 51%, respectively). The mean age of participants in the second phase was 72, which, allowing for the elapse of three years, was similar to that in the first (68). In the first phase, 34 of the 37 participants classed themselves as White British, compared to 20 of the 21 participants in the second. The employment status of participants was similar in both phases, with 16 (76%) of the 21 participants in the second phase describing themselves as retired, compared with 28 (76%) in the first.

Findings related to a number of thematic areas: changing visual health; the changing context of people's lives; and accessing support. Full findings from the study are reported elsewhere (Hodge et al., 2011). In this paper we report findings relating to participants' access to formal systems of health and social care provision.

Clinical services

One of the main issues highlighted in the first phase of the study was, for many people, the lack of regular, ongoing eye clinic appointments once they had received an initial diagnosis. Recent developments in the treatment of eye conditions, particularly wet age-related macular degeneration (AMD), have improved the outlook for many patients. However, at the time that most of the study participants were diagnosed, the options were much more limited. Many, particularly those with wet AMD, were discharged at the point of diagnosis, left with the message that nothing could be done for them.

By the time of the follow-up interviews little had changed: with some exceptions, those who had been attending regular eye clinic appointments at the time of their first interview were still doing so; those who were not then were still not. One exception was Maureen who, at the time of the first interviews, had not seen an ophthalmologist for several years. However, she had recently experienced a medical condition which had affected her sight temporarily and as a result she now found herself back 'in the system':

> I seem to be like caught up back in the system, because they wanted to discharge me last time I went, well the registrar did. And then when the consultant came over he said 'oh no, we'll ask for more tests to be done' or whatever. And when I spoke to a lot of the people in the walking group they were saying don't let them discharge you because things like, you know there's new tests coming up all the time... *Maureen, 58*

Like Maureen, other participants recognised the importance of staying 'in the system', in order to continue having their vision monitored. Even when there was nothing further that could be done to improve their sight, those who were receiving regular monitoring wanted to continue doing so in case new treatments became available, and, more basically, in order not to be abandoned by services:

> I imagine once I've had both these cataract operations done I'll be discharged and that will be the finish of it. (…) I'd much prefer to still be on their books and even if it's 12 months ahead have another appointment to go back. I think it's partly knowing that you still belong. If you're discharged you're thrown out, you're finished with, you're put on the scrap heap. And that's very depressing. *Isabel, 84*

What these findings reflect is a sense of the system of ophthalmological care being an important source not only of hope, but also of affirmation of the individual's social and personal worth.

Another important function of clinical care is that it can enable access to other services such as rehabilitation. However, in the first interviews it was clear that not only had many people been discharged with the message that nothing could be done for them clinically, but they had not received any information about other services that could help them (Thetford et al., 2009; 2011). By the time of the follow-up interviews, there had been one positive development: the establishment of ECLO posts at all three hospitals used by participants in the study; at the time of the first interviews only one

of the three had an ECLO. This was commented on positively; however, it was perceived to be primarily targeted at newly diagnosed patients:

> I believe they now have somebody in their clinic two days a week that's there, well for support to give like new patients to tell them about [voluntary organisation] and other things like that. But I've only heard about this second or third hand, I've not actually been told about it. The clinic, I think they still fall down by not giving you information, access to information, telling you about things that are going on. *Isabel, 84*

Community optometry

Another key element of clinical care is community optometry. One of the key roles optometrists play is in identifying secondary, and potentially treatable, eye conditions, such as cataracts and glaucoma. Where people had a good relationship with their local optometrist, this could be a valuable source of advice, as in the case of Jill, who developed a detached retina:

> I was still going to the optician's yearly and of course I got frightened and to be honest with you I didn't quite know what to do so I thought well there's nothing they can do till the morning in any case so I rang the optician up and she said go straight to [town] hospital. *Jill, 86*

Community optometrists can thus be a valuable element of the clinical care pathway. However, whilst some participants' experiences of optometry services were very positive, others reported more mixed experiences:

> I used to go to [high street chain of opticians], great, and then all of a sudden they started doing it like sort of mass produced, I'm not even sure you see an actual optometrist, I don't know who the hell you see but it's a bit like being in a factory you know (...) They gave me glasses that I couldn't read with, they couldn't seem to get the right sort of distance. *Maureen, 58*

Registration

Registering as SI or SSI can be the key to accessing social care services in the UK. However, findings from the first interviews showed that not everyone who was eligible for registration was registered (Thetford et al., 2011). By the time of the follow-up interviews little had changed in terms of participants' registration status, with the majority registered as either SI (n=11) or SSI (n=7), and only one individual moving from SI to SSI.

However, becoming registered does not necessarily mean that people are automatically directed to the services and benefits that this entitles them to. Many years after first being registered there were still examples in our study of people only recently finding out about benefits that they would have been entitled to years before, for example: 'I don't know how people sort of like find like the Disability Living Allowance. I may have been entitled to that 12 years ago when I first registered as blind but I didn't know about it...' (*Maureen, 58).*

There was also evidence that some participants' registration status needed to be reviewed, as their level of impairment had worsened. Frank had been registered SI for over a decade, but his eyesight had deteriorated significantly: 'I really should go for a

reassessment. I can barely see anything now'. He had been discharged by his ophthalmologist some years before, so in order to be reassessed and registered as SSI he would need to be referred back. However, he had other physical health problems which meant that his sight loss was not his main concern. He was, however, in regular contact with his GP, who should have been aware of his deteriorating vision and could have referred him back to an ophthalmologist.

Social services

Local authority SSDs are the main statutory bodies responsible for ensuring social care is provided to people registered as SI or SSI. Most people in the second phase of the study were registered as SI or SSI and so would have had some contact with either a social worker or a rehabilitation officer at some point. However, models of provision varied considerably across the localities covered in this study, as across the UK. In two areas, SSDs provided assessment and rehabilitation services, but in others these were contracted to voluntary sector providers.

In the first interviews there was a high level of dissatisfaction with the accessibility of SSDs, with a variety of problems highlighted; three years later the same problems were reported. These included long waiting times, not knowing who to contact, limited contact time, limited follow-up and lack of resources:

> ...this liaison officer I saw at the hospital, she wants me to see a social worker again. Because I haven't seen one since I was first diagnosed. But she phoned me up last week and she's got an eight week waiting list. So, it will be well into the

> New Year before she can come. But, I won't qualify for help in the house or anything like that, because my savings are still too high. *Teresa, 72*

For Teresa the problem was mainly the long waiting time to see a social worker, but also the fact that her main need was for help with cleaning that she was unlikely to be able to access from Social Services. Frank similarly needed home help but had also found that his SSD did not provide this. He also expressed a wish for some ongoing contact and emotional support. However, the only contact he had had with Social Services had been a one-off visit to arrange for an adaptation to his bath because of his other health problems:

> It would be nice to have someone to talk to and let all your problems out wouldn't it? I did have a lady here from Social Services, but I think she was rather keen to get away you know, she arranged to have a chair lift in the bath, but I haven't seen her since. *Frank*

Similarly Eva had had no contact with Social Services since she was first registered:

> ...they do advise you but obviously they've got so much to do that unless they really - they obviously can't be here, there and everywhere at the same time can they, so I, I mean I know at least I know there is somebody there that I could call upon if I really were in need. *Eva, 75*

Eva was increasingly dependent on her husband, and her quality of life and emotional well-being were badly affected by her deteriorating eyesight. Although she was aware that she could contact Social Services she did not feel that her support needs were significant enough to warrant it. Several participants described how, after an initial

contact when they were first registered, it was left up to them to make contact should they need anything in the future.

Interestingly, two participants in the follow-up interviews had received valuable help from Social Services since their first interviews, but in both cases this was not because of their visual impairment. In his first interview Andrew described being badly affected by his situation and felt as though he had been abandoned by statutory services, being eligible only for registration as SI, not SSI, limiting his access to benefits that he felt would have helped him. However, by the time of his follow-up interview Andrew's situation had improved significantly, largely because he was now receiving support from a Local Authority mental health service; he had received no further support specifically related to his visual impairment. Rita had also benefitted from input from Social Services since her first interview, but again, not because of her visual impairment, but because she had had surgery on her foot. She explained that Social Services had provided a range of aids and adaptations that had never been offered on the grounds of her visual impairment, despite being registered SSI:

> So we had Zimmer frames, high toilet seats and toilet frames and commodes and you name it, and they even came and put a hand rail at the top of the stairs, one going down the two stairs at the far end of the landing, one going all the way round to the wash house, but none of this because I was blind, because I'd had an operation on my foot! *Rita, 72*

Two individuals were unusual in receiving visual impairment related support from Social Services, although in both cases the support provided was to some degree

‘unofficial’. Richard had established a good relationship with his social worker over a number of years, and despite the fact that the initial reason for the support (learning Braille) no longer applied, he was continuing to receive support: ‘Oh I still speak to the social worker yes. I mean it technically hasn’t stopped, she’s still technically teaching me Braille but we don’t seem to do much Braille’ (*Richard, 59)*. Peter’s support came from a rehabilitation officer: ‘I was put in touch with [Social Services] when I first was registered. I was partially sighted but I still had a rehabilitation officer, actually it wasn’t Bob it was somebody else, but Bob’s been there a long time now’ (*Peter, 64).* The reason for Peter’s support was mainly because the rehabilitation officer who supported him was a former colleague.

The voluntary sector

For the majority of participants, the voluntary sector figured much more prominently than the statutory sector in the networks of social support they had established. This was partly due to the fact that across the area covered by the study the voluntary sector played a significant role, with two large organisations involved in providing services to people with a visual impairment. Furthermore, study participants had been recruited via these organisations. Each provided a similar range of services including assessment and rehabilitation, training, equipment and activities. However, although both organisations provided LVAs, in the area covered by one of them they were free of charge whereas those living outside this area had to pay for them.

Voluntary organisations were also an important source of information e.g. about benefits and new treatments: ‘...the Macular Group in [city] are quite good, they get

somebody out, certainly every couple of years to talk about benefits and what is available' (*Isabel, 84);* 'I'm a member of the RP [retinitis pigmentosa] Society, so if things come out you know I do hear sort of, yes through them usually if there's anything happening in the way of treatments...' (*Richard, 59).* This practical information and advice also came through involvement in support groups:

> We just play games, have a cup of tea and a bit of a chat and a biscuit, it's only for a couple of hours but it gets you out, doesn't it. You listen to their problems and they listen to yours. Compare notes can't you and things. See what they can get. I know one or two people that are in different council boroughs and they get different things that I can't get. *Andrew, 58*

One of the most important aspects of the voluntary sector was the opportunity it provided for mutual support which, for many people, had been crucial in helping them to adjust to their visual impairment:

> I loved people and I loved going out but you're completely lost then, you're really lost and then my daughter seen a cutting in the paper for the [club] in [town]. And I was in that for quite a long time, for partially sighted and blind people, and I found that got me seeing other people in similar circumstances as myself. And I think that's the biggest shock is losing your sight and accepting it is the bigger part isn't it? *Lily, 82*

Four of the participants in the follow-up study also worked as volunteers, either providing support or campaigning for improvements in services and policy. For those who were no longer able to continue in paid employment because of their visual

impairment, being able to have an active role as a volunteer was important to their sense of identity.

Networks of support

A key theme in both phases of the study was the importance of the networks of formal and informal support that participants built. This often involved the individual going to considerable efforts to manage a complex web of arrangements. For example, Isabel was in her 80s and at the time of the first interviews was living with her husband, but by the time of the follow-up interviews her husband had died. Although she reported having struggled on her own at first, she had eventually developed a good network of support. She used a home delivery service for shopping and a community transport service to get her to regular social activities. Her daughter lived nearby and although she received some informal support from her, she was keen not to be dependent on her.

In one way, stories such as Isabel's are positive; there are services and resources that can enable people to live fulfilled and independent lives. However, in order to access them, the individual needs to be resourceful, motivated and informed. For many people, the complex network of agencies involved in delivering services is confusing and overwhelming. Several individuals in the follow-up study were not accessing the services they needed, because they did not know how to, were unwilling to seek out further support or because those services simply did not exist in the area they lived in.

Discussion

The findings reported here create a picture of a system of variable support for people with visual impairments, access to which is largely dependent on the initiative and good fortune of the individuals themselves. Participants in the study described networks of support involving varying degrees of input from formal health and social care services, informal sources such as family and friends and voluntary sector organisations. The voluntary sector was particularly important, both in facilitating mutual support and opportunities for people to use their skills and experience as volunteers and as a provider of essential support services and information. Local authority SSDs generally played a much less significant role in participants' support networks. Where participants reported positive examples of good practice, these tended to be due to the particular circumstances of the individuals themselves, and especially to their relationships with individual workers who were able to exercise their discretion as 'street-level bureaucrats' (Lipsky, 2010) to provide valuable, but not necessarily formally sanctioned social care.

The key element in the system of health and social care provision for most people with a visual impairment is the clinical care system. Not only can this be a source of hope and personal validation; it also represents the gateway to other forms of support through the registration system. Yet the disparity between the numbers of people registered and the numbers actually living with a visual impairment suggests that this system is not functioning properly. The declining numbers of people registered is a particular source of concern (Barry & Murray, 2005, Boyce, 2012). This may be due

partly to the fact that there are several points on the route to registration at which people might 'slip through the net', and to the fact that all the processes involved can be slow and difficult (Boyce, 2012). However, as a starting point, it is important that people are made aware of the benefits of registration.

Because access to services is so dependent on the individual agency of the person with a visual impairment, information plays a vital role. One of the key findings from the first phase of the study was the lack of information given to people when they were first diagnosed or registered (Thetford et al., 2009). A similar finding has emerged from research by Beverley et al. (2011) which shows that people with a visual impairment obtain most of the information they need not from health care professionals but independently from a range of sources. The rolling out of ECLO services has been an important development that should help to improve access to information about the registration process and sources of support, although evidence of their impact is as yet limited (Conway et al., 2012, Subramanian et al., 2012, Subramanian et al., 2011) and concerns exist about their future funding (RNIB, 2014). However, they are targeted primarily at people newly diagnosed. What the findings from this study highlight is the importance of ensuring that those who were diagnosed before these services were in place are made aware of their existence, and indeed that all patients with a visual impairment attending outpatient appointments are reminded about them. This is because diagnosis is often a shocking event (Thurston et al., 2010, Hodge et al., 2013), as is the point of certification/registration (Boyce, 2012), and not always the time at which people are ready to receive information and support. If anything, the growth in early intervention services reinforces one of the key messages

from the first phase of our study; the need for people to be given multiple opportunities to receive information and access services, as they adjust to having a visual impairment, and as their support needs change (Thetford et al., 2009). The follow-up phase of our study provides further evidence of those changing support needs.

The first phase of our study, looking back over the whole of people's experience since they became visually impaired, showed that access to rehabilitation and social support had been limited. The second phase shows that little had changed. Those who had access to support in 2007 were still accessing it, but those who had received little formal support by 2007 had still not received any. This may be part of a wider issue, which is the lack of uptake of health and social services by older people. The reasons for this include the perceived lack of accessibility, appropriateness and affordability of services; as well as a tendency to view the effects of ageing as inevitable, which may deter people from seeking help (Howse et al., 2004). Thus there is a risk that those who do not actively seek out support are left to their own devices. However, an appearance of coping can mask a situation in which the individual is having increasing difficulty with daily living tasks, becoming socially isolated and, potentially, depressed. Certainly in the three years between the first and second phases of this study, people's needs had changed, with some participants finding certain daily living tasks increasingly difficult as their sight deteriorated and their social circumstances changed. For some this meant having to rely more on support from relatives and friends, but many were drawing on a mix of formal and informal support. However, negotiating

their way around the network of services available involved a significant degree of resourcefulness that not all those in our study were in a position to muster.

Reinforcing the message of previous research, this study highlights the importance of people's support needs being regularly reviewed (Percival, 2003). As a minimum, we suggest that SSDs, or agencies holding the SI/SSI registers, should make annual contact with those registered to provide them with updated information about services and ask if their support needs have changed. Where this is done it is reported to have been experienced positively (Douglas et al., 2008). GPs also have a role in ensuring that people's eye health is just as carefully monitored as their physical health and that people are referred back into secondary services where appropriate (Sinclair, 2014).

One of the key routes of entry back into secondary services is via community optometrists. However, one of the issues highlighted in the first phase of our study was that, where participants had been diagnosed with an 'untreatable' condition such as AMD and discharged from an eye clinic with the message that nothing could be done for them, they had also stopped having eye tests (Thetford et al., 2008). The lack of information and support provided at the point of diagnosis meant that people often had little understanding of their condition and of the importance of continuing to have their eye health monitored. Again, the rolling out of ECLO services could be invaluable in highlighting the importance, particularly with those newly diagnosed, of attending for regular eye checks-ups. However, although some of those in our study reported very positive experiences of community optometry services, others reported negative

experiences. So although there is value in establishing a relationship with a good community optometrist, there can be difficulties in accessing adequate services.

Finally, it should be noted that due to the recruitment strategy used for this study, all the participants had had some contact with voluntary sector organisations at some point; it is very likely that there are many more individuals living with a significant level of visual impairment in the community whose access to services is even more limited. This underlines the need to make information about sources of support widely available, not only through specialist and non-specialist health services but also through other information channels such as newspapers, social media, places of worship and community centres.

Conclusion

Visual impairment is associated with high levels of unmet need. In order to have their support needs met, individuals often have to build complex networks of formal and informal support for themselves. Service providers must take a more proactive role in reaching out to individuals and improving access to services for all who need them. The rolling out of ECLO services represents an important step, particularly in informing people about sources of support, the benefits of registration and the importance of having regular eye check-ups. However, it is also important that this information is directed not just at people who are newly diagnosed but at all those attending eye clinics with a visual impairment. Social Services Departments should make regular contact with everyone on the SI/SSI registers to invite them for a reassessment of their support needs. Finally, general practitioners should have a more proactive role in

considering the eye health of patients as part of their overall health needs, referring into secondary eye care where appropriate. If implemented, these changes would go some way to preventing people with visual impairments from being left to find their own way around the complex systems of support that they currently have to navigate if they are to have their support needs met.

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