

# Summary - Report of Engagement with People with Vision Impairment

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## **SUMMARY**

### **REPORT OF ENGAGEMENT WITH PEOPLE WITH A VISION IMPAIRMENT**

#### **ABOUT HEALTHWATCH WORCESTERSHIRE**

Healthwatch Worcestershire (HWW) gathers feedback about local publicly funded health and care services and makes recommendations to those who run them about how they could be improved from a patient, service user and carer perspective.

#### **WHY THIS WORK**

Healthwatch Worcestershire has a long-standing interest in the experiences of adults living with significant vision impairment in Worcestershire. We recognise that whilst each person's experience of vision impairment is unique, this community of people may experience additional barriers when seeking to access and use health and social care services. Risk of vision impairment is heavily influenced by health inequalities.

The RNIB estimates that there are around 24,000 people living with significant vision impairment in Worcestershire. Of these, it is estimated that approximately 15,000 people meet the criteria to be registered as Sight Impaired (Partially Sighted) or Severely Sight Impaired (Blind) .

At 31<sup>st</sup> December 2023 there were 2111 people registered as Sight Impaired or Severely Sight Impaired in Worcestershire.

## **WHAT WE DID**

HWW held focused group discussions with 4 groups of people living with vision impairment in Worcestershire, engaging with 55 vision impaired people. We also worked with local organisations for Visually Impaired people to verify the key themes that emerged from these discussions, and to develop the recommendations that we have set out in this Report. The organisations are Sight Concern Worcestershire; Macular Society and Worcestershire Sight Loss Council. We gathered this information between October 2023 and February 2024.

We spoke with more women than men. We are conscious that we have largely engaged with those people who are connected to existing services.

## **WHAT WE FOUND OUT**

### **Diagnosis, Certification and Registration**

We heard of mixed experiences of receiving a diagnosis and prognosis of a vision impairment from ophthalmologists, and of the type of support people subsequently received. Positive examples were greatly appreciated, but were not consistently echoed by others. We were informed of an apparent lack of sensitivity when the diagnosis of vision impairment had been explained. Some reported they were not directed to, or given any appropriate information about what would happen next. The role of support organisations was not always clearly explained.

For some people, we were told that registering as sight impaired or severely sight impaired with Social Services

had been straightforward, positive and helpful. Others stated that they had not been aware of the registration process, or found it a difficult process to understand and navigate. Some people reported they were not aware of being registered at all, and could not recall being contacted by anyone from Social Services. People with vision impairment who are eligible to be registered may be missing out on some key benefits that registration can bring.

### **Eye Clinic Liaison Officer (ECLO) Role**

The organisations that we spoke with identified a gap in service provision in Worcestershire in that we are the only Integrated Care Board in the West Midlands that does not have an ECLO role in hospital settings. The lack of the ECLO co-ordinating role has led to some people feeling unsupported at the potentially distressing time of diagnosis and Certification. Individuals and organisations we consulted expressed support for ECLO workers to be made available to eye clinics in Worcestershire where a diagnosis may be made.

### **Access to Health Services**

Some individuals described the difficulties they experienced trying to book follow up appointments which had been advised by an ophthalmologist. They faced barriers in getting through to the appropriate person and then facing wait times for an appointment. Cancellation of appointments, often without adequate or accessible notice was another issue that people had experienced. We were also told by several individuals and local organisations that there is no 'Out of Hours' access to

hospital ophthalmology services in Worcestershire, and that patients must use relevant services in Birmingham.

### **Support to Adapt to Day to Day Life**

We were informed about significant variation in the support that people had received to enable them to adapt to day to day life. This included access to mobility and orientation training, daily living skills and other learning opportunities. Not everyone at the Groups we consulted had heard of, or were aware of the role of the Worcestershire County Council Sensory Impairment Team. It appeared that there was sometimes confusion about the role of different agencies, the services they provide and which agency the individual had been in contact with.

### **Awareness about Vision Impairment amongst Health and Care Service Staff**

We heard some reports of good practice by staff who went the “extra mile” to support Vision Impaired people. Conversely, we heard about a lack of awareness about interacting with those with vision impairment. Examples identified included lack of verbal communication, inaccessible instructions and information, lack of knowledge about how to guide a person with a vision impairment and perspex screens which make it more difficult for some vision impaired people to see and hear what is being said. Many people said that the lack of awareness by staff had led to considerable difficulties for them, which could be improved by appropriate vision awareness training.

## **Information and Advice Required by Vision Impaired People**

We were told by the majority of those consulted that inaccessible information was a major problem for them. Appointments, information and advice about NHS and Social Care services is often very difficult to read. Printed information has generally been the principal format provided by NHS and Social Care, in many different font sizes, types, colours and formatting systems. Printed material is gradually being superseded by online information, and similar issues of inaccessibility are arising due to websites which are not yet fully accessible or user friendly for those with vision impairments. In addition, not everyone is able to use computers, smart phones and the internet. Furthermore, some people informed us they did not have the facilities to access digital information, nor wanted to access digital services. It is worth remembering that many of those who are registerable as sight impaired are older adults who may have little or no experience of using 'smart technology'.

For those who do go online, websites need to be designed so that they are fully accessible, and user-friendly for Visually Impaired people using assistive software. There was also a lack of awareness, amongst those consulted, about the 'Accessible Information Standard' (AIS). People's experience of how the AIS worked in practice also varied widely.

## **CONCLUSION**

Many of the issues raised by people with a vision impairment and documented in this Report are not new. It is likely that our findings are already familiar to those living with vision impairment, as well as to those working in social care and health systems delivering services and support to people living with vision impairment.

This should add a sense of urgency to address the issues that have been raised through this Report. Those people living with vision impairment that we listened to often felt left out and let down by service providers, and felt frustrated by, and resigned to a perceived lack of progress to improve access and accessibility to health and care services. We look forward to the system response.

## **RECOMMENDATIONS**

1. Identify system wide governance and clear leadership at Integrated Care Board level which takes responsibility for health and care services for people living with Vision Impairment
2. Ensure that services meet the requirements of the Accessible Information Standard. This includes a legal requirement to ask people about their communication needs, record and flag this information on records, pass it on to others when appropriate and ensure that the need is met.
3. Ensure that health and social care information is available in a variety of formats as appropriate to people's individual needs. This should include paper, digital and braille formats.

4. Consider the introduction of the Eye Clinic Liaison Officer (ECLO) role within Worcestershire in every secondary health setting where a diagnosis may be made.
5. If resources are not available to fully implement the ECLO role ensure that responsibility for ECLO functions as described by the RNIB are allocated to appropriate clinic staff, so that people get the support they need at diagnosis
6. Consider how people can be provided at the point of diagnosis with access to appropriate information, signposting and advice available in a variety of formats
7. Review processes to ensure that Registration as Sight Impaired is streamlined, and consistently responsive from the perspective of service users
8. Ensure that there is sufficient capacity within the Worcestershire County Council Sensory Impairment Team to meet the requirements of users, and potential users, of the service
9. Consider the provision of vision impairment awareness training for front line staff in health and social care