

## **The changing needs of people with sight loss**

**This publication summarises findings from a research study conducted by Clare Thetford, Jude Robinson, Paul Knox, Jignasa Mehta and David Wong from the University of Liverpool.**

The study was commissioned by Thomas Pocklington Trust to examine the long-term dynamics of the changing support needs associated with sight loss and to explore ways in which health and social services could be tailored to meet these needs better.

The study found that:

- Support needs change over time for people with sight loss, regardless of whether or not vision continues to deteriorate.
- Access to support is required at more than one point in time but most services are provided on a single, time-limited basis, with very limited follow-up.
- The impact of sight loss can be devastating and it affects many aspects of life. This means support needs are often complex.
- Service users are responsible for identifying their needs and accessing appropriate support. This can create problems in obtaining services.

## Background

The impact of sight loss on everyday life changes over time, according to deterioration of vision, and other changes and key events in people's lives. In view of this, the support needs of people even with relatively stable visual impairment may also change over time, throughout the life course. Service providers are not always aware of the changing needs of people with sight loss, or are unable to respond to them.

## Methods

The study had two key components: 1) interviews with 37 people with sight loss and 2) interviews with 18 providers of services for people with sight loss, from Liverpool, Halton, Cheshire and North Wales.

*Interviews with people with sight loss:* involved a biographical narrative qualitative interviewing method which allowed interviewees to tell their own personal story of sight loss and describe their experiences of accessing and using services. Interviews also included a characteristics questionnaire and the National Eye Institute Visual Function Questionnaire which measures self-reported sight loss and its impact on everyday living. The people interviewed included 19 women and 18 men, aged from 24 to 92 years, with four people aged under 50 and 13 over 75 years. They had been living with sight loss for periods ranging from 18 months to 79 years, with the average being around 20 years.

*Qualitative interviews with service providers:* involved open-ended questions, focusing on how service providers currently identify and respond to changing needs of people with sight loss. Service providers interviewed included: consultant ophthalmologists, rehabilitation officers, low vision clinic optometrists, nursing staff, an eye clinic liaison officer, social workers, service managers, a home visitor, a GP and a day centre manager.

## **Diagnosis, prognosis and treatment**

People with sight loss are expected to take responsibility and seek appropriate support for their eye health once treatment options have been exhausted and they are discharged from the eye clinic. However, current support to enable them to do this for themselves is limited and they often leave the eye clinic with an inadequate understanding of their condition and how to access timely, appropriate services.

A lack of awareness of the degree and progression of further deterioration of vision highlights the importance of promotion of regular community sight tests (by an optician) for everyone. For this to be effective, patients must understand the purpose of such tests; this will require more information and support than has been available to date. Further efforts should also be made to ensure that services are more accessible for older people and other vulnerable people who are least likely actively to seek support.

## **Changing social and cultural lives**

Sight loss has wide-reaching and long-term effects on people's lives, with a close association between declining visual function and reducing quality of life. However, the impact of a diagnosis or registration, even when visual function decline is not severe, can also be huge. Sight loss represents a crisis or turning point in the lives of many people, yet service users feel that the implications of this are not fully acknowledged or supported by formal services.

Close relations and friends often take on a great burden of responsibility for the person with sight loss, which can involve providing a great deal of personal care and practical help, but often includes provision of emotional support. The impact on those close to people with sight loss is also huge and there is little support available for them.

Sight loss frequently occurs in conjunction with other serious health and mobility problems commonly associated with age. Hence support needs are often complex and require a coordinated inter-agency response which is currently rarely provided. Formal emotional support is lacking despite clear reports of great need; efforts should be made to improve emotional support available to people with sight loss.

## Accessing help and support

Access to appropriate support was reported to make a huge difference to the impact of sight loss on quality of life, yet the interview data suggest that people with sight loss face considerable difficulties in accessing the support and services they need. A range of barriers prevents service users from accessing support at the specific time of need and, if they need to access them more than once, over longer periods of time.

Registration remains central to being able to access many services and is essential for financial aid. Whilst some people resist registration by choice, others face challenges to becoming registered because of tight eligibility criteria and the required processes. Accessing support often requires an ability to communicate needs and knowing what to ask for; both of these can be problematic. Some people require ongoing support, with continuing contact with service providers in order for needs to be identified and responded to in a timely, effective manner.

## Conclusions

Most services are designed to meet needs on a short-term, time-limited basis but this does not accommodate continual changes in visual function and in people's lives.

The accounts of people with sight loss demonstrate that their needs for support are often continuing and repeated; in view of this, short-term service provision is inadequate. The authors make the following recommendations for service development:

- Greater follow-up and review is required in both clinical and community settings. In community settings, ongoing contact and relationship building between service user and provider should be facilitated. Increased and simplified opportunities are required for both initial and repeated access to support.
- Greater inter-agency communication and cooperation is required. The complex support needs of people with sight loss require a well coordinated system of services.

- Improved communication between medical professionals and patients in ophthalmic settings is essential so that patients have better levels of knowledge and understanding about their eye condition. There should also be increased promotion of and improved access to community sight tests.
- Information, support, signposting and referral should be provided at the eye clinic as a matter of routine on multiple occasions, regardless of registration status.

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## How to obtain further information

A short report, in the form of an 'Occasional Paper' entitled *The changing needs of people with sight loss*, by Clare Thetford, Jude Robinson, Paul Knox, Jignasa Mehta and David Wong, is available from:

Thomas Pocklington Trust  
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Telephone: 020 8995 0880  
Email: [info@pocklington-trust.org.uk](mailto:info@pocklington-trust.org.uk)  
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Copies of the full report and executive summary are available to download from the University of Liverpool website:  
<http://www.liv.ac.uk/haccru/html/reports.html>

Copies of this report in large print, audio tape or CD, Braille and electronic format are available from Thomas Pocklington Trust.

## Background on Pocklington

Thomas Pocklington Trust is the leading provider of housing, care and support services for people with sight loss in the UK. Each year we also commit around £700,000 to fund social and public health research and development projects.

Pocklington's operations offer a range of sheltered and supported housing, residential care, respite care, day services, home care services, resource centres and community based support services.

A Positive about Disability and an Investor in People organisation, we are adopting quality assurance systems for all our services to ensure we not only maintain our quality standards, but also seek continuous improvement in line with the changing needs and expectations of our current and future service users.

We are working in partnership with local authorities, registered social landlords and other voluntary organisations to expand our range of services.

Our research and development programme aims to identify practical ways to improve the lives of people with sight loss, by improving social inclusion, independence and quality of life, improving and developing service outcomes as well as focusing on public health issues.

We are also applying our research findings by way of pilot service developments to test new service models and develop best practice.

*In this publication, the terms 'visually impaired people', 'blind and partially sighted people' and 'people with sight loss' all refer to people who are blind or who have partial sight.*

## Notes



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