Living with sight loss: what can we learn from recent surveys?

A summary of the Knowledge Exchange Network event on 9 March 2015

- What is the link between sight impairment and a child’s experience at school?
- What proportion of people with sight loss feels depressed?
- Are people with sight loss disadvantaged in the work place?
- Which older people are at greatest risk of developing sight loss?
- Are older people with sight loss at risk of financial hardship?

New analyses of several large national surveys enable us to address these, and many other, questions. The Millennium Cohort Study, Understanding Society, Life Opportunities Survey, Labour Force Survey and English Longitudinal Study of Ageing regularly interview large groups of people. They include sufficient people reporting vision problems to allow comparisons with the general population. Reporting and reflecting on these new analyses was the focus of a Knowledge Exchange Network event in March 2015, which brought together researchers with research users to look across the life course. This is a summary of the information shared and discussed on the day.

Children

The Millennium Cohort Study (MCS) follows a large group of children born in 2000. It asks the child, their parents and teachers about a wide variety of topics including health, wellbeing, behaviour, education and social experiences. Out of approximately 12,000 children aged eleven, 233 were identified as having sight impairment; just over half also had another special educational need.
John Harris, Head of Research at Royal London Society for the Blind (RLSB), described how, on a number of aspects of wellbeing, the picture for children with vision impairment was less positive than their sighted peers, particularly so when drawing on their parents’ and teachers’ views. Children’s own views were more optimistic and there were few differences with sighted peers, however they were less likely to feel they are able to do things as well as other people.

The biggest differences were between sighted children and children who had sight impairment and other special educational needs. For example, the latter group were less likely to say they liked school, and less likely to say they were happy with their school work, suggesting that they experience significant additional difficulties, whilst those with only sight impairment may be less disadvantaged.

A consistent finding was that all children with sight impairment were more likely to live in financial hardship: their families were less likely to have at least one parent in employment, to be ‘living in poverty’, and to be finding it difficult to manage financially.

Discussion picked up on the finding that children with sight impairment but no other disabilities were more likely than other groups to use social networking sites, which suggests that they find these an effective way to build relationships.

Elizabeth Clery, Team Leader of Brent Sensory Support Service (Hearing and Visual Impairment) reflected on the findings, highlighting the differing perspectives of children, parents and teachers and the limited access that children with sight impairment have to the range of opportunities that children without sight impairment are able to take for granted. Elizabeth’s team are working hard to tackle barriers affecting children with sight impaired moving to independence. A key part of this is enabling children to participate in decision making, giving increased control over the way they want support delivered. To facilitate this they are developing new ways to obtain meaningful feedback from children and supporting the development of their negotiating skills.
Young people and adults

Both Understanding Society (USoc) and the Life Opportunities Survey (LOS) collect information across a wide range of aspects of life in Britain. Out of nearly 33,000 people in USoc and over 17,000 people in LOS, 791 in USoc and 719 in LOC report sight loss, giving sufficient people with sight loss to undertake meaningful analyses. Kate Flynn, Research Officer from RNIB described sobering findings from their new analysis of latest survey waves, highlighting that, compared to people without sight loss, those with sight loss felt more depressed, were more likely to earn less than £200 a week, had more difficulty accessing benefits services, and were more likely to be carers for someone they live with. They were more likely to report that their participation in education, work, transport, leisure and personal relationships is limited, for example 46% of people with severe sight loss said their involvement in work was limited, compared with 9% of those with no impairment of any kind. Kate reflected that, although it’s too early to comment on trends, disappointingly the results show little improvement since RNIB’s analysis of 2010/11 data.

Sue Keil, National Research Officer for Education, Transition and Employment, RNIB picked up discussion around employment and economic circumstances in her presentation of findings from analysis of the Labour Force Survey (LFS) by the University of Birmingham. LFS is
the largest household survey in the UK, allowing comparisons between those who are ‘long term disabled with a seeing difficulty’ (a wider definition than just those who are officially registered), those who have another long-term disability and the general working age population. Of those who are long term disabled with a seeing difficulty:

- 45% are employed compared to 49% of those who are long term disabled and 73% of the general population;
- 9% are unemployed compared to 7% of those who are long term disabled and 6% of the general population;

Of those not employed, but not officially unemployed, some will be looking after families, students, retired, or have health problems (and therefore in receipt of sickness benefit); however, Sue concluded that people with sight loss are at increased risk of social and economic exclusion. With a higher proportion of people with a seeing difficulty giving up work for health reasons or being long term sick, more emphasis on job retention could make a difference. Sue also described how employment and unemployment rates differ according to age, with the starkest differences being among 16-25 year olds; those who are long term disabled with a seeing difficulty are twice as likely to be unemployed as their sighted peers, suggesting they may need additional support to enter the labour market. Though further education increased employment rates, it did not erase differences; even with a degree, those who were long term disabled with a seeing difficulty were far less likely than people without a disability to be employed.

**Johnathan Holyhead, CEO, Dorset Blind Association** reflected on the value of this information, particularly to support fundraising. He described how such figures can make a difference to writing bids for funds, a major focus of his role, or to present evidence of the need to retain existing, or extend the, support services his organisation provides.
Image of Jonathan Holyhead reflecting on the value of data for fundraising.

**Older people**

The English Longitudinal Study of Ageing (ELSA) began collecting information from over 11,000 people aged 50 and above across England in 2002. Since then participants have been surveyed every two years, enabling analysis of trends over time and, crucially, cause and effect.

Having shown that poor vision is linked with having other health conditions, disability, social exclusion and poverty, new analysis by [James Nazroo, Professor of Sociology, Manchester University and colleagues](#), have used ELSA data to assess aspects of people’s lives that predict deterioration in vision over time:

- being poor;
- seeing oneself as lower down in a social hierarchy; and
- being a current smoker, having hypertension and diabetes.

Experiencing deteriorating vision was in turn linked to:

- increased levels of depression; and
- decreases in quality of life, social engagement and income.
Improvement in vision e.g. through cataract surgery, was linked with some improvements in aspects of people’s lives, though differences were smaller than for deterioration. James concluded that his findings point to a need for policies to tackle the social and economic risk factors for deterioration in vision, to ensure equitable access to treatment, including easy and free access to corrective lenses and to mitigate the negative effects of visual impairment on social, psychological and economic outcomes. Implications for intervention at local level include encouraging clinical commissioning groups (CCGs) and public health services to target resources at those at greater risk of losing their sight.

Paul Bott, Chief Executive of Vista, highlighted the impact of poverty and inequalities on people with sight loss, drawing from James’s research and across the day’s presentations. Vista, as lead for Leicester Ageing Together, has identified that the barriers to people accessing services and social networks are poverty, good transport and the effect of ill health. Vista’s work is therefore focused on promoting eye health in poorer communities, and in languages and style of delivery that people
can readily understand; supporting those who lose their sight to stay in employment; and helping those aged over 50 back into work.

Making data more accessible

At the event Rose Edwards, Researcher, RNIB gave a preview of version 3 of RNIB’s Sight Loss Data Tool. The Data Tool has been an extremely valuable resource for people working across the sight loss sector, bringing together all of the data that are available for a local area. It saves time and energy, providing access to reliable information. Version two is available to download from RNIB’s website: www.rnib.org.uk/datatool. This will be superseded by the launch of version 3 in July. Rose described some of the new features:

- updated information;
- additional indicators, such as rural/urban classifications;
- district level data;
- support for benchmarking against other areas; and,
- greater inclusion of historical and projected trends.

The tool will still retain the function to produce and print a custom report for every area.

Conclusions

The analyses presented give us new information about the challenges faced by people living with sight loss, from childhood into later years. By providing evidence of areas of life where children and adults with vision impairment face significant challenge there is potential to use these findings in writing bids for funding, in campaigns and, with thorough consideration, to inform service delivery. Key issues for people with sight loss are clear:

- entering, and remaining in, employment;
- accessing transport; and,
• maintaining good mental health.

A clear theme across presentations was a link between sight loss and being at risk of poverty:

• children at age 11 with visual impairment were more likely to live in families on low income (MCS);
• over half of adults with sight loss earned less than £200 a week, compared to just over a third with no impairment (LOS);
• 26-44 year olds who are long-term disabled due to a seeing difficulty were twice as likely to be unemployed as sighted peers (LFS);
• low income was both a cause, and a consequence, of sight loss in older people (ELSA).

All of which points to the need for efforts to prevent, and to support those with, sight loss to be targeted at the least affluent. The sight loss sector needs to campaign for increased resources to support this.

People delivering services want more information to support their work. Event participants emphasised that research needs to address relevant questions, avoid duplication, and then to disseminate and communicate findings effectively. The following recommendations for new research were put forward:

• comparing outcomes for children with sight impairment who receive habilitation with those who don’t;
• understanding how additional health conditions combine with sight loss to impact on wellbeing and quality of life;
• international studies comparing the wellbeing of people with sight loss in the UK with those in other countries;
• extending the evidence base for interventions that enable people to get and retain jobs;
• identifying the barriers to people with sight loss achieving their employment aspirations;
• building understanding of the stages people go through in adapting to losing their sight and what contributes to isolation; and,
• understanding how general practice and other health services can more effectively signpost people with sight loss to services and support.

Catherine Dennison

Further reading and resources

The presentations from the day can be accessed at: www.rnib.org.uk/knowledge-and-research-hub/knowledge-exchange-network

Join the Knowledge Exchange Network for the Sight Loss Sector LinkedIn group for information and discussion about new research: www.linkedin.com/groups/Knowledge-Exchange-Network-Sight-Loss-8184539/about

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