

A brief guide to carrying out research about adult social care services for visually impaired people

Nigel Charles

Methods Review 3

Improving the evidence base for
adult social care practice



The School for Social Care Research

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Carrying out research about adult social care services for visually impaired people

ABSTRACT

Carrying out research about adult social care services for visually impaired people presents challenges that are not necessarily found in other fields. The purpose of this review is to draw attention to these challenges and to guide the researcher through them. It does so by drawing on the academic and grey literature. The review covers the ideological context of research in this field; definitions of visual impairment and their appropriate and inappropriate uses in research; misleading claims and reliable evidence about the size and characteristics of the visually impaired people and the reasons that these are important issues for research in the field. Challenges also cover the main topic areas of research and the methodological approaches, both quantitative and qualitative, that researchers have taken to deal with them. Issues common to both types of method cover sampling; the instruments used to collect data; the means of obtaining informed consent from visually impaired people, and organisations that can potentially assist researchers in this field.

KEYWORDS

Visual impairment, visually impaired people, disability, social and medical model, research, emancipatory research, qualitative, quantitative, registered, epidemiology, population estimates, definitions, social care, needs, experience, service providers, informed consent

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CONTENTS

| | |
|---|----|
| Introduction: How should research about social care services for visually impaired people be carried out? | 1 |
| The concept of disability | |
| User involvement and participatory research | |
| What is visual impairment? | 4 |
| Self-definitions and vision related quality of life | |
| Clinical definitions | |
| Administrative definitions | |
| Causes of visual impairment | |
| How large is the visually impaired population? | 8 |
| Epidemiological data | |
| Administrative data | |
| Why are definitions and population estimates relevant to social care research? | 15 |
| Quantitative samples | |
| Qualitative samples | |
| Appropriate and inappropriate use of definitions and population estimates | |
| What areas of research are relevant to social care? | 20 |
| Research interests of visually impaired people | |
| Needs and experiences of people with untreatable conditions | |
| Research with service providers | |
| Research about those with treatable visual impairment | |
| How can informed consent be obtained and data collected from people with a visual impairment? | 27 |
| What organisations can help with social care and visual impairment research? | 29 |
| Appendix: Prevalence estimates | 30 |
| References | 31 |

Carrying out research about adult social care services for visually impaired people

INTRODUCTION: HOW SHOULD RESEARCH ABOUT SOCIAL CARE SERVICES FOR VISUALLY IMPAIRED PEOPLE BE CARRIED OUT?

How does a researcher decide which topics to research that are relevant to the interests and concerns of visually impaired people? Given that the primary focus of this review is social care research, which aspects of service provision and support should be researched? For example, should the focus be on the need for services or should it be concerned with the impact of services? Of course the precise focus of the research question (and therefore the answer to questions such as the ones posed) should be driven by the purpose of the research. And so this review can not be prescriptive about *what* to research but instead will outline some basic ideas about *how* to go about social care research in the visual impairment field.

The focus of this review is on methodological issues and it covers:

- The definitions and causes of visual impairment;
- Estimates of the number of visually impaired people in the UK and some of their key characteristics;
- The appropriate and inappropriate use of these definitions and estimates, including sampling sources and methods;
- Key areas of research relevant to adult social care practice for visually impaired people;
- The engagement of visually impaired people in the research process;
- Data collection techniques that work well in research with people who have a visual impairment.

The review draws on examples of research found in the peer-reviewed and grey literature, mainly published in the last ten years. We start with the ideological context of visual impairment research.

The concept of disability

The concept of disability is as much ideological as it is theoretical. A starting point to understand this is the social model of disability.

The social model of disability is a term coined by Oliver (1990). The essence of this perspective is that it is society that is disabling rather than the physiological and psychological characteristics of individuals. Socially disabling effects can be multiple and varied. For example, they might take the form of the physical barriers in the built environment (such as flights of steps being the only means of access to a building); they might be attitudinal barriers – such as a company’s unwillingness to use adaptive technology to employ a visually impaired person. To paraphrase this view, it is the absence

Carrying out research about adult social care services for visually impaired people

of lifts and ramps or an organisation's employment practices that disable people's mobility, employment and other opportunities.

The social model sets its face squarely against the so-called medical model of disability which constructs disability as entirely inherent to the individual. Social model advocates argue that the medical model locates the causes of disability entirely in, for example, poorly functioning limbs, low levels of visual acuity or disproportionate anxiety in the face of routine adversity. The medical model is deeply flawed because it denies the social causes of disability. The medical model is 'so-called' because, as Low¹ (2001) has argued, a medical model has never been formulated, defined or championed. The model only exists in the eyes of its detractors. This is not to deny that historical and contemporary attitudes and beliefs about disability have marginalised and disadvantaged people with a disability. But the argument is that to attribute this to a 'medical model' denies the phenomena that inherent physiological and psychological characteristics – as well as social factors – can and do play a part *in and of themselves* in the life experiences of people with a disability. Disability academics and activists such as Low argue that disability should be seen as both a social construct and as an experience arising from the specific physiological or psychological characteristics of individuals. Disability arises from the interaction of social and individual factors and responses to it should be designed accordingly (Low 2006).

The World Health Organisation (WHO) has responded to these debates by developing the International Classification of Functioning, Disability and Health (ICF) as a means of conceptualising disability (World Health Organisation). The ICF's underlying principles are that it:

... acknowledges that every human being can experience a decrement in health and thereby experience some degree of disability. Disability is not something that only happens to a minority of humanity. The ICF thus 'mainstreams' the experience of disability and recognises it as a universal human experience...[The] ICF takes into account the social aspects of disability and does not see disability only as a 'medical' or 'biological' dysfunction. By including contextual factors, in which environmental factors are listed ICF, allows to record the impact of the environment on the person's functioning.

Thus, the ICF classifies functioning, disability and health in terms of:

- body functions, such as the function of seeing;
- the physiological and related structures of the body;
- activities and participation by people, such as communication, interpersonal relationships and community life;

1. Colin Low is, *inter alia*, the chair of the Royal National Institute of Blind People (RNIB) and is President of the European Blind Union.

Carrying out research about adult social care services for visually impaired people

- environmental factors and barriers such as the environment, social attitudes and the provision of services.²

This review will be referring to the Network 1000 survey being carried out by the Visual Impairment Centre for Teaching and Research at Birmingham University.³ The study team has made an explicit commitment to the use of the ICF in the design of Network 1000. For example, the study covers questions about an individual's impairment (such as the nature and severity of their visual impairment), their activities (such as what they are able to see and able to do), their participation (such as joining libraries and reading a gas bill), and environmental factors and barriers (such as the presence and absence of accessible written formats).

User involvement and participatory research

The involvement of citizens in the provision of public services has become common in developed countries (Martin *et al.* 1988) with a range of reasons given for its promotion, including the need for greater accountability and an emerging consumerist approach to the provision of services. A parallel agenda has emerged in the involvement of people who use services and of citizens in research, including in the health and disability field. A study and a review of the involvement of visually impaired people in research by Duckett and Pratt (2007) found a demand amongst visually impaired people for their inclusion in research (which the authors refer to as 'participatory' research) and for involvement in research that had a beneficial impact on their lives (which they refer to as 'action', 'emancipatory' or 'empowering' research). The rationale for such forms of research emerges from debates about the social and medical models of disability and the ideological imperative to give people with disabilities a means of rectifying their inequitable treatment by society. However, Duckett and Pratt found a substantial lack of any forms of this research in the academic social science literature on visual impairment. Whether this has changed subsequently is not entirely clear but readers might wish to judge this from some of the examples of user involvement referred to in later sections of this review.

2. Detailed descriptions of these classifications are at <http://apps.who.int/classifications/icfbrowser/> (accessed 25 May 2010).

3. <http://www.education.bham.ac.uk/research/victar/research.shtml> (accessed 25 May 2010).

WHAT IS VISUAL IMPAIRMENT?

If disability is conceptualised in both individual *and* social terms, corresponding definitions of visual impairment are required. This enables visual impairment to be operationalised (that is, made measurable) for the purposes of research. The purpose of this section is to enable researchers to understand how visual impairment can be defined and measured. It covers:

- self-definitions and vision-related quality of life
- clinical definitions
- administrative definitions
- causes of visual impairment.

The terms 'treatable' and 'untreatable' eye conditions will be used in the present paper. These are not technical terms but are convenient means of describing those with different types of eye conditions. Untreatable conditions are those for which there is currently no treatment to reverse the process of sight loss. They include glaucoma and Age-related Macular Degeneration (AMD). (However, treatments to improve the visual acuity for some forms of AMD are becoming increasingly available and so it is not necessarily an untreatable condition.) Those with treatable conditions have sight loss that can often be corrected by surgery (that is, cataracts) or through the prescription of spectacles (that is, refractive error). The point is to draw a distinction between two qualitatively different causes of visual impairment. As we shall see in this and subsequent sections, this is an important distinction to make in the design of research in this field.

Self-definitions and vision-related quality of life

Instruments that use self-defined accounts of the extent of difficulty in seeing provide important information on the limitations or difficulties experienced by individuals as a result of their visual impairment. Such measures have included the use of screening questions about activities, such as being able to see a friend across the road or the ability to read newspaper print, to establish if people have a visual impairment. However, the limitations of such measures were identified by a review of visual impairment prevalence estimates commissioned by RNIB from epidemiologists at the London School of Hygiene and Tropical Medicine (Tate *et al.* 2005)⁴. This prevalence review found that such measures can exclude people who might have a clinically defined visual impairment but who might not report a difficulty with one or other activity. False positives can also be produced when these screening questions are used. This means that social care researchers should not use

4. Hereafter, the LSHTM report will be referred to as the 'prevalence review'. It was completed in 2006 and, although not formally published, a copy is on RNIB's website at <http://www.rnib.org.uk/Search/Pages/results.aspx?k=prevalence> (accessed 3 June 2010).

Carrying out research about adult social care services for visually impaired people

such definitions to estimate the number of visually impaired people in the population. Self-defined definitions limited to reading newsprint or recognising friends are also unlikely to be an effective means of assessing functional ability.

Related to self-definitions are reliable and validated scales that evaluate the impact of vision problems across a range of domains of everyday life including physical and social functioning and psychological well-being. Such instruments are often referred to as vision-related quality of life measures. One of the most widely used and validated instruments is the National Eye Institute Visual Function Questionnaire (NEI-VFQ) from the United States.⁵ This questionnaire asks respondents to rate their attitudes to vision loss and the difficulties they experience carrying out a wide range of daily activities such as domestic tasks, watching TV and taking part in social activities.⁶

Clinical definitions

The World Health Organisation (WHO) defines visual impairment on the basis of distance visual acuity (VA) and this is the reporting standard for all internationally comparative epidemiological studies of visual impairment. A widely used clinical definition of visual impairment is in terms of measures of distance visual acuity using a Snellen chart, the chart familiar to anyone that has had an eye examination by an optometrist. Snellen tests measure the size of letters on a chart that can be read over a distance of six meters. A limitation of Snellen charts is that they are not reliable at lower levels of visual acuity and LogMAR tests have been developed to deal with this.⁷ Other clinical measures may be used, such as field of vision and contrast sensitivity, and these provide alternate or additional information about other visual problems such as peripheral vision or colour recognition.

The prevalence review recommended that consistent national and international measurement standards should be adopted in research about prevalence and other aspects of sight loss, as also recommended by a WHO Working Group (World Health Organization 2003). The review identified the most reliable studies of estimates of the size of the visually impaired population. For the purpose of summarising these estimates, the prevalence review sub-divided the visually impaired population into three categories of visual acuity:

- Severe visual impairment for those with VA $<3/60$.
- Moderate visual impairment for those with VA between $6/18$ and $>3/60$.
- Mild visual impairment for those with VA between $<6/12$ and $6/18$.

Those in the first two groups have a level of visual acuity that would substantially limit

5. http://www.nei.nih.gov/resources/visionfunction/vfq_ia.pdf (accessed 7 June 2010).

6. Section 5 gives an example of the use of the NEI-VFQ in a UK study.

7. A technical discussion of LogMAR and other scales is given in the prevalence review.

Carrying out research about adult social care services for visually impaired people

their vision, ranging from those with little or no light perception to those who, while they have usable sight, will have great difficulty clearly seeing objects and people. Those on the 'mild' category would not be able to recognise a car registration number plate at a distance of 20 meters as required by the UK's Driver Vehicle Licencing Agency (DVLA) to pass a driving test.

People in the first two groups who also have untreatable eye conditions are likely to be eligible for registration.⁸ Those in these groups broadly correspond to the categories 'sight impaired' and 'severely sight impaired' that are now used by the Department of Health for registration purposes. Those in the mild category are unlikely to be eligible for registration. Epidemiological studies of visual impairment also include those with severe, moderate and mild levels of visual acuity that is treatable. Almost all of these people would not qualify for registration. However, their VA is effectively equivalent to being sight impaired and severely sight impaired for so long as their impairment remains untreated. The implications of this for social care research are discussed in section 4.

A person's visual acuity is not necessarily an indicator of the tasks and activities that they are able to carry out. The prevalence review observed that visual acuity is only associated with 20 per cent of the variation in quality of life. Clinical definitions therefore do not necessarily give sufficient information about functional ability and they do not say very much, in themselves, about the social barriers and responses to visual impairment.

Administrative definitions

Registration as blind or partially sighted were the terms originally used in the UK to identify those people whose sight problems meet criteria that effectively act as a gateway to social care and other services. The Department of Health has in recent years changed this terminology.⁹

- The term 'sight impaired' has replaced the term 'partial sight'.
- The term 'blind' has been replaced by the term 'severely sight impaired'.

There are no precise statutory definitions for the terms severely sight impaired and sight impaired. The National Assistance Act 1948 states that a person can be certified as severely sight impaired if they are:

...so blind as to be as to be unable to perform any work for which eye sight is essential.¹⁰

8. The next part of this section summarises what is meant by 'registration'.

9. The new terminology and its definitions can be found at: <http://www.dh.gov.uk/assetRoot/04/11/86/66/04118666.pdf>. The present review has used the new terminology even where the sources of the data presented has used the previous terminology.

10. National Assistance Act Section 64(1).

Carrying out research about adult social care services for visually impaired people

The test is whether a person cannot do any work for which eyesight is essential, not just his or her normal job or one particular job. Most people who have at best corrected visual acuity below 3/60 will qualify as severely sight impaired. The Department of Health guidelines are that a person can be certified as sight impaired if they are:

substantially and permanently handicapped by defective vision caused by congenital defect or illness or injury.

As a general rule, those who are eligible to be certified as sight impaired will include those who have VA of 3/60 to 6/60. They might also include those with VA up to 6/24 or those with VA of 6/18 or better but only if they meet other specific clinical criteria such as limited field of vision. As with clinical definitions, administrative definitions focus on the individual characteristics of a visually impaired person and do not measure their social components.

Causes of visual impairment

As we shall see in the next section, visual impairment is much more common in older people – especially those aged 75 years and over – than in younger people. The most common forms amongst older people of untreatable visual impairment are Age-related Macular Degeneration (AMD) and glaucoma. As treatments to improve the visual acuity become available, these conditions will become less common. The most common forms of treatable visual impairment are refractive error and cataracts. If means are found to improve access to and use of these treatments, they too will become less common. There are, of course, many other causes and the RNIB provides information about them.¹¹

11. The RNIB provides a comprehensive list and description of the main causes of visual impairment. http://www.rnib.org.uk/EYEHEALTH/EYECONDITIONS/Pages/eye_conditions.aspx (accessed 26 May 2010).

HOW LARGE IS THE VISUALLY IMPAIRED POPULATION?

This section summarises the size and socio-demographic characteristics of the visually impaired population derived from administrative data and epidemiological studies. This section will draw largely on the prevalence review (Tate *et al.* 2005) and registration statistics for England,¹² Scotland,¹³ and Wales.¹⁴

Epidemiological data

Working age adults

There are few UK estimates of prevalence amongst adults of working age. Indeed, the prevalence review was only able to identify a review of epidemiological studies in Western Europe, North America and Australia (Nissen *et al.* 2003) as the best estimate of prevalence in the younger adult age groups. The population estimates are shown in Table 1. They have been calculated by multiplying the prevalence estimates shown in Table 9 in the appendix by Office for National Statistics (ONS) mid 2009 population estimates (Office for National Statistics 2010).

Table 1. Estimates of the number of visually impaired people aged 20–59 years (by visual acuity)

| Visual Acuity | |
|---|--------|
| Mild visual impairment (VA < 6/24 – 6/48) | 17,000 |
| Moderate and severe visual impairment (VA < 6/48) | 20,000 |
| All VA < 6/12 | 37,000 |

Sources: Nissen *et al.* (2003) and ONS Mid 2009 population estimates

The visual acuity (VA) ranges used in this table are not the same as those used in the tables on older people in this section. This means that a comparison of the prevalence of visual impairment amongst those of working age with the prevalence amongst older people

12. http://www.ic.nhs.uk/webfiles/publications/Social%20Care/Blind%202008/Blind%20Commentary%202008_final%20v5.pdf (accessed 3 June 2010).

13. <http://www.scotland.gov.uk/Publications/2008/11/24145337/0> (accessed 3 June 2010).

14. <http://wales.gov.uk/topics/statistics/headlines/health2009/hdw20091028/?lang=en> (accessed 3 June 2010).

Carrying out research about adult social care services for visually impaired people

cannot be made. The visual acuity cut-off points and the age-breaks used in administrative counts of those registered and of working age are also different to those used in the prevalence studies of the same group of people. It is difficult to compare these sources but the prevalence review concluded that registration data offer a reasonably accurate estimate of the prevalence of moderate and severe visual impairment in people of working age.

Older people

The prevalence review critically assessed the findings from a number of epidemiological and other studies that have been used to estimate the size of the visually impaired population. It found that reliable UK prevalence studies are largely limited to people aged 65 years and over and it identified two national studies as the best sources for estimating the size of this population. Readers of this review are strongly encouraged to read the prevalence review to grasp the complexity of making these estimates and to understand the caution that is needed when using clinical definitions of visual impairment.

The two studies that the prevalence review identified are the visual impairment component of a Medical Research Council (MRC) study of 14,600 people aged 75 years and over living in the community (Evans *et al.* 2002), and a second study was 1,400 people aged 65 years and over living in their own homes or care homes carried out as part of the National Diet and Nutrition Study (NDNS).¹⁵ These studies are referred to in the tables in this report as MRC and NDNS.

A summary of these prevalence estimates is shown in Tables 10 and 11 in the appendix. Tables 2 and 3 use the appendix tables and ONS population estimates to estimate the number of visually impaired people in the UK. These tables exclude the estimated range (or confidence interval¹⁶) in which the actual size of this population is likely to fall. These tables show that:

- using NDNS data, the estimated number of people aged 65–74 years whose VA is worse than 6/18 with untreatable conditions and untreated cataracts is about 276,000;
- the estimated number of people in this age group with these conditions and whose VA is better than 6/18 but worse than 6/12 is about 503,000;
- using MRC data, the estimated number of people aged 75 years and over whose VA is worse than 6/18 with untreatable conditions, untreated cataracts and untreated refractive error is about 580,000;
- the estimated number of people in this age group with these conditions and whose VA is better than 6/18 but worse than 6/12 is about 549,000.

15. The data from NDNS presented here has not been published. Professor Fletcher and her colleagues who produced the prevalence review were given access to the NDNS data and the estimates and confidence intervals shown in the present paper is a summary of their analysis.

16. A brief explanation of confidence intervals is given in the appendix.

Carrying out research about adult social care services for visually impaired people

Table 2. Estimates of the number of visually impaired people aged 65–74 years (living in their own homes)

| Visual Acuity | 65–74 years |
|--|-------------|
| Mild visual impairment (VA < 6/12–6/18) | 538,000 |
| Moderate and severe visual impairment (VA <6/18) | 296,000 |
| All VA <6/12 | 834,000 |

Sources: NDNS and ONS mid 2009 population estimates

Table 3. Estimates of the number of visually impaired people aged 75 years and over (living in their own homes and residential and sheltered housing)

| Visual Acuity | Age group | |
|--|-------------|-------------------|
| | 75–84 years | 85 years and over |
| Mild visual impairment (VA < 6/12–6/18) | 353,000 | 260,000 |
| Moderate and severe visual impairment (VA <6/18) | 294,000 | 367,000 |
| All VA <6/12 | 647,000 | 627,000 |

Sources: MRC and ONS mid 2009 population estimates

The estimates for the two tables should not be added together to estimate the number of visually impaired people aged 65 years and over. This is because each table use clinical definitions of visual acuity that have subtle but crucial differences. These are:

- the MRC study (used for Table 3) measured the visual impairment of study participants while they were wearing spectacles (known as ‘presenting visual acuity’). This means that the study included those whose spectacles would not have been sufficient to correct for refractive error. Thus, the estimate includes those with refractive errors;
- the NDNS study (used for Table 2) used a pinhole test without the individual wearing spectacles (known as ‘best corrected visual acuity’). This screening method corrects for refractive error and so excludes them from the population estimate.

Carrying out research about adult social care services for visually impaired people

Epidemiologically derived estimates will conflate those with very different types of visual impairment if the studies do not record or make clear in the analysis whether visual impairment is treatable. These estimates will also change over time as the UK population ages and will additionally be affected by the development and availability of treatments to improve visual acuity.

The confidence intervals used in epidemiological estimates, demographic changes and medical developments mean that these estimates should not be used to claim absolute and definitive counts of the number of visually impaired people in the UK. Such estimates do not exist. All estimates should be used judiciously, they should make it clear whether they include treatable and untreatable visual impairment, and they should be explicit about the range of visual acuity they cover. Estimates which are not transparent should not be used at all. This applies especially to those that use self-defined definitions as their basis or which aggregate estimates without making it clear that they include very broad VA ranges and causes.

Readers of this review who wish to consider the epidemiological evidence in more detail should refer to the literature by specialist epidemiologists. A recent re-analysis of the MRC study (Evans 2006) is a good starting point.

Causes of visual impairment

Reliable epidemiological evidence about the number of people with specific types of visual impairment is extremely limited. This is to the extent that the Medical Research Council study used for the tables in the next section is the only UK source and even this is limited to those aged 75 years and over. These estimates are summarised in Table 4. The table is based on the prevalence estimates in Table 12 in the appendix and ONS 2009 population estimates.

The table shows that about half of visual impairment in this age group is accounted for by treatable vision impairment. The other half has registerable levels and types of sight loss. Assumptions should not be made that the same profile of conditions will be found in other age groups. This is because the prevalence of the causes of vision impairment will vary by age group. In particular, untreatable conditions become much more debilitating in later life because the visual acuity of those with these conditions will deteriorate as they get older. Consequently, there will be a higher proportion of those with untreatable eye conditions (such as AMD) in the oldest age groups.

Although the certification and registration process records causes of sight loss, the data are not routinely analysed or published. The most recent analysis of these data by Bunce and Wormald (2006) found that the main causes of being severely sight impaired were macular degeneration (57.2%), glaucoma (10.9%), diabetic retinopathy (5.9%) and optic atrophy (3.1%). Broadly similar proportions were found amongst those who were sight impaired and also included 1.5 per cent whose visual impairment was caused by cataracts.

Carrying out research about adult social care services for visually impaired people

Table 4. Causes of visual impairment: Estimates of the number of visually impaired people aged 75 years and over in the UK with uncorrected presenting binocular VA <6/18.

| Cause | Population estimate |
|-------------------------------|---------------------|
| AMD | 222,000 |
| Glaucoma | 48,000 |
| Diabetic eye disease | 14,000 |
| Vascular occlusions | 4,000 |
| Myopic degeneration | 18,000 |
| Other | 29,000 |
| Refractive error | 194,000 |
| Cataract | 150,000 |
| Treatable visual impairment | 345,000 |
| Untreatable visual impairment | 335,000 |

Source: MRC & ONS Mid-2009 population estimates

Gender

Both the NDNS and MRC studies found that visual impairment is more prevalent amongst older women than men. Because women form a larger proportion of the older population, higher prevalence amongst women means that they represent 74 per cent of the visually impaired population aged 75 years and over (Evans 2006).

Care home and hospital care

There is consistent evidence from studies carried out in several OECD countries that the prevalence of visual impairment is considerably higher amongst those in care homes (with nursing) than those living in the community. For example, the NDNS study found that over a third of those living in nursing homes aged over 65 years had VA < 6/12 (Evans *et al.* 2008a). The largest age group of those admitted to hospital are older people but visual impairment is not associated with an increased risk of admission (Evans *et al.* 2008b). This draws attention to the extent to which older visually impaired people have other health problems (co-morbidity). Social care researchers should not overlook the implications that co-morbidity has for the needs of and support required by visually impaired people. For example, they should not examine the needs arising from visual impairment without taking into account needs arising from other health issues.

Carrying out research about adult social care services for visually impaired people

Administrative data

The assessment of vision and the decision to certify are the responsibility of hospital based ophthalmologists. Those certified as sight impaired and severely sight impaired are usually referred to their local authority adult services department and are asked if they wish to have their name placed on the local authority’s register of those sight impaired and severely sight impaired under the National Assistance Act 1948. The expectation is that those on the local authority register should then have their social care needs assessed and should be given the social care and adaptations to meet these needs.¹⁷

Tables 5 to 7 summarise the counts by local authority adult service departments of those who are registered as sight impaired and severely sight impaired in England, Wales and Scotland. The statistics for Wales show age breaks wider than the ones used for England and Scotland as this is the way in which the Welsh Assembly presents its statistics. Equivalent statistics are not produced by health and social service organisations in Northern Ireland as a registration system does not operate there.

Table 5. England (2008) Local authority counts of those registered as sight impaired and severely sight impaired

| | Age group | | | | | | Total |
|-------------------------|-----------|-------|--------|--------|--------|---------|---------|
| | 0–4 | 5–17 | 18–49 | 50–64 | 65–74 | 75+ | |
| Sight impaired | 805 | 3,975 | 19,330 | 15,655 | 14,805 | 96,270 | 152,980 |
| Severely sight impaired | 700 | 5,140 | 16,845 | 14,105 | 16,055 | 103,345 | 156,285 |
| Total | 1,505 | 9,115 | 36,175 | 17,070 | 30,860 | 199,615 | 309,265 |

Table 6. Scotland (2008) Local authority counts of those registered as sight impaired and severely sight impaired

| | Age group | | | | | | | Total |
|-------------------------|-----------|------|-------|-------|-------|-------|--------|--------|
| | 0–4 | 5–15 | 16–29 | 30–49 | 50–64 | 65–74 | 75+ | |
| Sight impaired | 29 | 423 | 621 | 1,204 | 1,572 | 1,849 | 10,259 | 15,957 |
| Severely sight impaired | 86 | 367 | 588 | 1,777 | 2,039 | 2,079 | 13,026 | 19,959 |
| Total | 117 | 790 | 1,209 | 2,981 | 3,611 | 3,928 | 23,285 | 35,916 |

17. The expectations of the nature of this provision are in Association of Directors of Social Services et al. (2002)

Carrying out research about adult social care services for visually impaired people

Table 7. Wales (2009) Local authority counts of those registered as sight impaired and severely sight impaired

| | Age group | | | Total |
|-------------------------|-----------|-------|--------|--------|
| | Under 18 | 18–64 | 65+ | |
| Sight impaired | 322 | 1,832 | 6,607 | 8,761 |
| Severely sight impaired | 216 | 1,792 | 5,905 | 7,913 |
| Total | 538 | 3,624 | 12,512 | 16,674 |

Doubts have been expressed over the years about whether the registration system identifies all those who have untreatable and registerable visual impairment. There is recent evidence that the registers over and under count those who are registered. Evidence for over counting comes from the Network 1000 project. The recruitment process gave the research team an insight into the accuracy of the registers. They sent recruitment packs to invite a large sample from those registered with 20 adult services departments in England, Wales and Scotland to take part in the study. At the recruitment stage of the sampling process, about 2 per cent of those aged 65–74 years and 6 per cent of those aged 75 years and over were reported as deceased. The overall recruitment rate for the younger age group was 23 per cent and it was 9 per cent for the older group. It is likely that the higher non-response in the 75 years and over group arose because more of them had passed away. Therefore, VICTAR’s 6 per cent estimate for those aged 75 years and over and who were deceased may be conservative. Undercounting might arise if those who qualify for registration have not been identified by health and social care professionals as such and so are not registered. But we lack precise estimates of this. The only reliable one is the prevalence review’s estimate of under-registration at between 0% and 20%.¹⁸ The likelihood of under-registration being towards the lower end of this range is suggested by two studies of Age-related Macular Degeneration (AMD) that inferred that under registration of AMD was probably not substantial (Owen *et al.* 2003; Evans and Rowlands 2004). A comparison of the population estimates in Table 4 and the administrative counts in Tables 5 to 7 is also consistent with this observation. This comparison should take into account:

- under-registration in England, Wales and Scotland for those aged 75 years and over is between zero and about 54,000, the number of deceased people on the registers is at least 20,000, thus the official count of those registered should be upwardly modified by no more than about 34,000. That is, to around 304,000;
- the confidence interval for the population estimate of those with untreatable and registerable visual impairment is 293,000 to 384,000.

18. The estimate is this broad because of wide confidence intervals.

Carrying out research about adult social care services for visually impaired people

Therefore, the modified count of those registered, registerable and who are alive falls comfortably within the confidence interval for the estimated number of the same group of people. This comparison adds credibility to the population estimate and strongly suggests that the registers are a very reasonable measure of the size of the visually impaired population with untreatable conditions. In spite of claims to the contrary by, for example, Hanson *et al.* (2002) and Gosney *et al.* (2010), there is not a substantial proportion of people eligible but not registered.

Another misconception is the often repeated estimate that there are around two million people in the UK with serious sight loss. The veracity of this claim depends on what is meant by 'serious'. Does it cover people whose sight is treatable by routine surgery or the prescription of spectacles? Does it cover those whose visual acuity would disqualify them from driving a car but would be no more serious than this? Readers of this review might want to take into account that the two million estimate is produced by a crude aggregation of the estimates in Tables 2 and 3. This is misleading because such estimates conflate those with treatable and untreatable conditions with a very wide range of visual acuity, some of which is not necessarily debilitating. In particular, Table 4 suggests that a high proportion of this population will have refractive error and cataracts. Also included in these estimates are in the region of one million older people¹⁹ whose visual impairment means that they can not read car registration plates²⁰ but whose VA is no worse than this. This is not to underestimate the barrier that not being able to drive a car presents but it is not of the same magnitude of having a visual acuity worse than 6/18.

WHY ARE DEFINITIONS AND POPULATION ESTIMATES RELEVANT TO SOCIAL CARE RESEARCH?

To design sample surveys of the visually impaired population, knowledge about the population's size and its profile in terms of age, gender, visual acuity and causes of visual impairment is often helpful. Such information is especially useful for stratifying samples, weighting data, and identifying sub-groups of the visually impaired population for sampling and other research purposes. The use of these definitions and estimates is also relevant to understanding the individual and social characteristics of visual impairment. Without this understanding, definitions and estimates can be – and indeed are – used inappropriately. This section covers:

- Quantitative samples
- Qualitative samples
- The appropriate and inappropriate use of definitions and population estimates

19. This is a crude rule of thumb estimate.

20. Section 2.2 covers this criterion.

Carrying out research about adult social care services for visually impaired people

Quantitative samples

The epidemiological studies referred to in this review derived their samples from samples of the older population. This required drawing very large random samples of older people and, among other things, administering visual acuity tests to identify those who have a visual impairment. The prevalence review describes the steps taken to obtain such samples for the MRC, NDNS and other epidemiological studies and readers of this review should refer to that report for an assessment of the relative merits of methods to obtain such samples. While such methods can be very robust (especially for the MRC and NDNS studies), they also require the use of a great deal of time, epidemiological expertise and training fieldworkers in the use of visual acuity screening techniques. This is very costly and is most likely to be beyond the resources of most studies in the visual impairment field.

Local authority registers are not without their limitations. But for the pragmatic and resource-constrained researcher they remain the best available source from which to derive random, quantitative samples of the visually impaired adult population. Indeed, there is little practicable alternative to obtaining representative samples.

A very good example of using registration records to derive weighted samples of the visually impaired population is the Network 1000 study.²¹ It is currently the most well-designed survey of visually impaired people in the UK and it uses registers as a sampling frame. It has been underway for about five years and is a cross-sectional and longitudinal study of the needs and interests of visually impaired people. To recruit participants in the study, an initial sample of around 6,000 people were randomly selected from the registers of blind and partially sighted people held by 20 local authorities in England (16), Scotland (3) and Wales (1). Of this initial sample, around 1,000 individuals were recruited to take part.

Most registered visually impaired people are aged over 65 years. To achieve sub-samples of younger age groups large enough for data analysis, the younger age groups were over-sampled. Subsequent data analysis weighted these data based on the age distribution of those on the 20 registers from which the sample was derived. When weighted, the sample was found to have the expected distribution in relation to gender and registration status (registered as sight impaired and severely sight impaired). They also collected other socio-demographic data such as ethnicity, housing tenure and employment status. However, the information recorded in the registers does not include these data so weighting in relation to these variables could not be made.

Those whose visual impairment is caused by cataracts or refractive error do not ordinarily qualify for registration because usually these are conditions that can be corrected by surgery or spectacles. If administrative definitions are used to identify samples of respondents in social care research, these samples will not include those with untreated

21. <http://www.education.bham.ac.uk/research/victar/research.shtml>.

Carrying out research about adult social care services for visually impaired people

cataracts or uncorrected refractive error but who never the less have a level of visual acuity that is equivalent to those who are registered. This might be an important omission if, for example, studies wish to identify the means by which social care agencies can play a role in enabling older people with a treatable visual impairment to be identified and treated. But there is very little research on this population and there are no convenient sampling frames from which to derive samples.

Qualitative samples

The use of registration records can also be used to obtain qualitative samples, but there are many more potential sources. Qualitative samples can also potentially be obtained from:

- national and local voluntary organisations of visually impaired people. These will include large organisations, such as RNIB, and local specialist voluntary organisations found in many towns and cities;
- statutory and private sector service providers. These will include hospital ophthalmology and low vision clinics, local authority disability, older people's and other specialist teams, housing associations and care homes for older people or other groups;
- organisations representing specific visual impairment interests such as for Braille, sport, and ethnic minorities.

The web addresses of a selection of these organisations are provided in section 7.

The appropriate and inappropriate use of definitions and population estimates

Self-defined, quality of life, clinical and administrative definitions of visual impairment were covered in section 2. They are not inherently 'better' than each other. But they should be used judiciously by researchers to obtain credible samples and to produce credible findings. The appropriate and inappropriate use of definitions is covered next and Table 8 summarises these uses.

Self-definitions and quality of life definitions

These definitions are well suited to identifying and measuring the social factors arising from visual impairment. They can be used to measure the impact of visual impairment, the impact of services and the social barriers faced by visually impaired people. However, the use of too few screening questions can over-simplify this aspect of visual impairment.

These definitions cannot be used to judge the physiological nature of sight loss and should not be used to estimate the number of visually impaired people. This is because they:

- underestimate by not being sensitive enough to all visual impairment;
- overestimate by including those with relatively minor visual problems;

Carrying out research about adult social care services for visually impaired people

- are unreliable as they are influenced by people's changing health expectations and their tolerance, beliefs and attitudes to visual impairment;
- cannot differentiate between those with treatable and untreatable conditions.

Clinical definitions and epidemiological estimates

Clinical definitions focus on the individual characteristics of visually impaired people. They can be used to estimate prevalence rates and population size but they are not a proxy for measuring functional ability. They have statistical value because:

- they use objective measures of the physiological nature of sight loss;
- they are not influenced by subjective factors such as the psychological and social factors that might influence the ways in which those with sight problems regard their visual impairment.

When used to provide prevalence and population estimates, they should make the range of visual acuity in each estimate clear and the method used to assess visual acuity. If not, misleading estimates will be produced. If a study measures presenting visual acuity to identify a sample, it will include those with refractive error. Samples and estimates derived in this way should therefore be used with caution, especially in being clear about whether they discriminate between treatable and untreatable visual impairment.

To obtain large enough samples of visually impaired people using clinical measures requires very large random samples of the general population. Considerable expertise is also required to administer VA tests. These factors make it very expensive to carry out studies or produce samples that require the use of these definitions.

Administrative definitions and counts

Administrative definitions also focus on the individual characteristics of individuals. They can be used as the basis for a reasonably reliable count of the number of people with untreatable conditions and whose visual acuity is likely to be debilitating.

Registers can also be used as a sampling frame to produce qualitative and quantitative samples of visually impaired people with untreatable conditions. However, they cannot be used to sample those with untreatable conditions or those with VA < 6/12. But social care researchers can be reasonably confident about using registration records to derive, at relatively low financial costs, representative samples of those with untreatable visual impairment.

A focus on those with untreatable conditions might be of particular interest to social care researchers given that this section of the visually impaired population might have a greater need than those with treatable conditions for specialist support and adaptive technology. This assumes that those with treatable conditions can have (and are willing to have) their visual acuity improved with spectacles or surgery.

Carrying out research about adult social care services for visually impaired people

Registers are not a precise measure of the VA of the visually impaired population because the terms ‘sight impaired’ and ‘severely sight impaired’ and the criteria used to define them are vague.

Table 8. The appropriate and inappropriate uses of definitions and estimates of visual impairment

| Type of definition/basis of population estimate | Appropriate uses | Inappropriate uses |
|---|---|--|
| Self-defined and quality of life | <p>The definitions can be used for:</p> <ul style="list-style-type: none"> • measuring functional ability, identifying the social impact of visual impairment; and identifying related barriers; • evaluating the need for and impact of services. | <p>The definitions should not be used as a criterion for defining and estimating the number of visually impaired people.</p> |
| Clinical | <p>The definitions can be used for:</p> <ul style="list-style-type: none"> • identifying samples of those with treatable and untreatable visual impairment; • estimating the number of people with treatable and untreatable visual impairment; • identifying and quantifying the causes of treatable and untreatable visual impairment. | <p>The population estimates should not be used as a proxy for measuring functional ability and social barriers.</p> |
| Administrative | <p>The definitions can be used for:</p> <ul style="list-style-type: none"> • estimating the number of people with untreatable visual impairment; • identifying and quantifying the causes of untreatable visual impairment; • sampling frames to obtain representative quantitative and qualitative studies of those with untreatable visual impairment. | <p>The administrative counts should not be used:</p> <ul style="list-style-type: none"> • as a proxy for measuring functional ability and social barriers; • for estimating and identifying those with treatable conditions and those with VA<6/12. |

WHAT AREAS OF RESEARCH ARE RELEVANT TO SOCIAL CARE?

Recent UK research into the life experiences of visually impaired people has used a range of qualitative and quantitative methods to explore their experiences and their access to and use of services. This work has included efforts to include those with additional hearing loss or other disabilities to take part in research and thus enabling research to be participatory. There has also been research on service providers for people with visual impairment. This section uses examples from studies to show some of the main areas of research relevant to social care and examples of the methodological approaches that have been successfully used.

Research interests of visually impaired people

The emancipatory and participatory principles referred to in section 1 have been used to identify the priority research topics of a small sample of visually impaired people by Duckett and Pratt (2007). The researchers carried out qualitative face-to-face interviews with 30 visually impaired people aged between 16 and 98 years. They were recruited through community, voluntary and statutory organisations. Participants were also recruited through snowballing methods. The researchers have also repeated this exercise (Duckett *et al.* 2010). The research topics that visually impaired people identified as important to them were:

- access to the built environment, transport and information;
- the attitudes of individuals with and without a visual impairment;
- the means that visually impaired people use to cope with daily life;
- the types and availability of support;
- the risks of isolation;
- the costs and availability of technological aids.

These findings and the participatory principle could, for example, be used by social care agencies wishing to identify the elements of service provision that their visually impaired service users think should be investigated.

Whether Duckett and Pratt would regard the Network 1000 project as an exception to the lack of participatory and emancipatory research in the visual impairment field is not entirely clear. But the Network 1000 project team has discussed the importance they attach to including people with a visual impairment in the construction of their survey instrument. They held focus group discussions with different groups and individuals with a visual impairment, and the issues raised from these were included within the questionnaire topics (Corcoran *et al.* 2005). Another strategy to promote input into the survey design was the use of open-ended questions in the survey to enable participants to identify research topics and issues relevant to them. Some of the issues raised in the first

Carrying out research about adult social care services for visually impaired people

survey were explored more systematically in the second one. For example, Douglas *et al.* (in press) describe how concern about experiences in eye clinics raised by some participants in survey 1 was examined in detail in survey 2.

Needs and experiences of people with untreatable conditions

The first survey in the UK on the needs and life experiences of visually impaired people was carried out some 20 years ago by Bruce *et al.* (1991) and in doing so broke new ground. Two-thirds of the sample was obtained from a government disability study (Martin *et al.* 1988) and a third was recruited from local authority registers (Tate *et al.* 2005). Inevitably survey data become out-of-date and to partly rectify this researchers at Birmingham University set up the Network 1000 study. It is designed to collect cross-sectional and longitudinal data with two phases of data having been collected – the first in 2005–6 and the second in 2006–7 – using structured questionnaires. The survey instrument was also informed by other surveys within the field, which were useful in formulating question design and at a later date will enable comparisons with other studies to be made.

The first phase interviews covered a broad range of questions about the nature of respondents' visual impairment and other disabilities and specific aspects of life including home, education, work and leisure activities. The Network 1000 questionnaire also covers perceptions of the reasons for any difficulty in these areas and measures the help and support used in managing sight loss.

A study that investigated topics broadly similar to Network 1000 but which used an entirely qualitative methodology was carried out in 2009 (Surrey Social and Market Research 2009). For a qualitative study, this was a large (n=93) deliberative sample, diversified by gender, age, employment and retirement status, cause of visual impairment, other disability, geographical location and ethnicity. The data collection methods used were in-depth interviews, focus groups, case studies and accompanied journeys. The case study component built on data collected through the in-depth interviews by exploring issues in greater detail and over a period of time. The accompanied journeys component required the researcher to accompany visually impaired people in their local neighbourhood to observe the barriers that the built environment presented. These journeys were video-taped to identify the hazards faced by visually impaired people and the means they used for dealing with them. Another qualitative study that explored the needs of visually impaired people used a 'biographical narrative interpretative' method with 37 visually impaired people (Thetford *et al.* 2009). This method focused on enabling the respondent to give their personal account of their experience of sight loss. The assumption is that:

...individual told stories are closest to lived experience and so [the method] is well suited to capturing the realities of life with sight loss.

Carrying out research about adult social care services for visually impaired people

Some of the sample were unable to provide an account of their life story in this way and for these respondents a semi-structured interview was carried out. A similar method was also used by Pavey *et al.* (2008). They used a case study and life history methodology to carry out qualitative interviews with older people with acquired hearing and sight loss. Part of the fieldwork was to interview a small sample of older people to generate a narrative about their life history. The nature of the interview was driven by the respondent to ensure they covered their experience of hearing and sight loss and their past, present and future experiences and expectations. The data were also supplemented by a small number of respondents keeping an audio diary of their life over a seven-day period.

The Thetford study also used the NEI-VFQ to assess the emotional well-being and the visual and social functioning of respondents. The NEI-VFQ (and other quality of life measures) can be used as baseline measures of changes over time; they can be adapted to measure the psychosocial impact of vision loss; and they can be used to evaluate the impact of services. Because such instruments require a great deal of technical expertise to administer and interpret, they should be used with caution. But they are also an enormously valuable means of understanding the impact of visual impairment and can be a more useful instrument than measures of visual acuity or the causes of sight loss. For example, a review of the literature observed that visual functioning might be a better predictor than visual acuity of depression and anxiety (Nyman *et al.* 2009). But the relationship between visual impairment, mental health, quality of life and social functioning is equivocal, probably because of the poor quality of studies carried out in this area. Understanding these relationships also requires consistency in the use of measures of visual acuity in research. This is because inconsistent uses of these measures make it difficult to compare findings from studies, such as those investigating the relationship between sight loss and well-being (Nyman *et al.* 2009). The point is that the way in which visual impairment is defined is an important choice in the research process: definitions are required that are most appropriate to the research questions.

Where the NEI-VFQ has been used, another literature review found a strong relationship between sight loss and mental health in older visually impaired people (Gosney *et al.* 2010). But relatively little research has been carried out that uses instruments such as the NEI-VFQ to measure the impact of interventions on the well-being of working age and older people who have a visual impairment (Nyman *et al.* 2009; Gosney *et al.* 2010). There is clearly a great deal of potential for social care researchers to make more use of instruments such as the NEI-VFQ both in investigating the psychosocial impact of visual impairment and in evaluating interventions to improve it.

A recent survey of housing and support needs was aimed at enabling housing and specialist services to better provide support for visually impaired people of working age (Hanson 2006). Participants in London were identified through social care and other service providers and were asked to complete a questionnaire. A small subsample was followed up with the use of qualitative interviews. A subsequent survey, using a questionnaire administered over the telephone, was carried out with visually impaired

Carrying out research about adult social care services for visually impaired people

people living in urban, suburban, small town and rural areas in the midlands, the south-west and the north-west. Although these were not random samples, they enabled the researchers to achieve a diversity of respondents in terms of socio-demographic and socio-economic status and the nature and experience of sight loss and other disabilities. A similar survey of the housing and support needs of older people was carried out with 400 respondents in three cities using what appears to have been a quota sample (Hanson *et al.* 2002). This study recruited participants to ensure a mix of housing tenure, whether living alone, whether respondents were in touch with specialist services, ethnic status, and experience of other disabilities or health problems. Of particular methodological interest was the researchers' use of lay interviewers, mainly older people, to carry out the interviews. The questionnaire used had also been developed in conjunction with older visually impaired people. The study was also supplemented by qualitative interviews and focus group discussions. A qualitative study of the domiciliary support needs of visually impaired people explored whether these needs were being met (Community Care Research and Consultancy 2003). The study used a structured interview schedule to interview visually impaired people aged over 65 years.

The needs and experiences of visually impaired people from ethnic minorities might potentially be different from other sections of the population. A study by Morjaria-Keval and Johnson (2006) which explored this carried out 15 focus groups with visually impaired people from nine minority ethnic communities. There was also an action research element to the study aimed at raising awareness and knowledge of visual impairment and services. The sample and the method meant that focus groups were carried out by community facilitators who spoke the relevant languages and who were also given information about eye health and related services. The sample was recruited from individuals attending community events.

The second phase of Network 1000 was to quantify access to specialist visual impairment health and social care services, such as low vision clinics and social service support. As with the first phase of the study, a structured questionnaire was used to do this. Such data can be used to identify patterns of service use by the characteristics of individuals (such as the nature of sight loss and age) and how quickly (or whether at all) services are provided. This phase of Network 1000 also evaluated service provision in terms of the satisfaction of visually impaired people and their families with health and social care services (Douglas *et al.* 2008). The evidence from measuring visually impaired people's satisfaction with the services of RNIB is that such measurement is a highly complex activity (Woodfield *et al.* 2002).²² Some aspects of this complexity are common to measuring satisfaction for any service by any type of service user. For example:

- satisfaction is an ambiguous concept and the researcher needs to be especially clear about the service user's meaning of the term;

22. Copies of this report are available from RNIB.

Carrying out research about adult social care services for visually impaired people

- services have multiple elements (such as staff attitudes and organisational efficiency) and satisfaction might vary between each of these elements. This means that measuring satisfaction needs to be specific about which aspect of a service is being investigated. This also means that findings that purport to measure 'global' satisfaction (i.e. satisfaction with all aspects of a service) can be misleading;
- needs and expectations vary and this can shape perceptions of satisfaction;
- people who use services might not be aware of the organisation providing the service. Researchers need to be confident that they and the individual are referring to the same service provider.

Some of this complexity might be unique to the visually impaired population. For example, contrary to the evidence from mainstream customer research, the outcome of visual impairment service provision might not shape satisfaction with the service. Some elements of customer satisfaction lend themselves to quantitative measurement and others to qualitative measures but there is a risk that inappropriate methods can be chosen. Quantitative methods are useful for measuring, for example, changes in satisfaction over time while qualitative methods are especially useful for identifying the contextual factors that shape satisfaction. The complexity of measuring satisfaction (or indeed any aspect of the service user experience) needs to be fully understood and incorporated into the design of any study that is measuring the experience of visually impaired users of services.

Research with service providers

Some of the studies covered in this section on the needs and experiences of people with treatable conditions also supplemented their data with interviews with professionals (Hanson 2006; Thetford *et al.* 2009). These studies carried out qualitative interviews with small samples of professionals responsible for assessing and providing services for visually impaired people in housing, social care and voluntary organisations. Such work is a valuable means of providing contextual information about the experiences and needs of visually impaired people, including professionals' perceptions of these needs and whether their organisations meet them.

Social care research might also focus entirely on service providers, such as by measuring the availability of services. A good example is from the low vision field. Low vision services is a term used to refer to rehabilitation services for visually impaired people. Low vision services include the provision of optical and non-optical aids, many of which are provided in adult services or in partnership with the NHS; modifications to the visually impaired person's home, work and other environments; advice and guidance on the use of residual vision; and the psychological adjustment to vision loss. To quantify the availability of these services nationally, Culham *et al.* (2002) identified around 2500 potential UK providers of these services based in hospitals, adult/social service departments, voluntary organisations, optometry practices and higher education institutions providing optometry training. A

Carrying out research about adult social care services for visually impaired people

self-completion questionnaire was designed in consultation with people who use services and service providers. The purpose of the questionnaire was to identify whether low vision services were provided and, if so, the type of provision. It was not primarily designed as an instrument to assess the completeness or quality of the service. The questionnaire was sent to all potential providers. Non-respondents were followed up with a telephone call to achieve a 100% response rate (with the exception of optometry services for which the response rate was 65%). Subsequent follow-up with the optometric non-respondents found that only a small proportion of them provided low vision services. In short, the survey method used was exhaustive, achieving a remarkably high response rate.

Network 1000 and the Culham *et al* (2002) study have found a high likelihood of variation and inequity in access to and use of services for visually impaired people. A research question that arises from this is the effectiveness of services in meeting need. An exploratory study investigated the potential to gather evidence on the effectiveness of advisory and support services provided by hospital-based eye clinics (Douglas *et al.* 2005). The method used was to interview service providers in nine eye clinics and people who use services in three of them. The services were selected to represent a range of statutory health and social care providers and voluntary organisations. The interviews covered professionals' and service users' perceptions of the experience and impact of the services. The interviews with the professionals were semi-structured, while telephone interviews with service users were more structured. The study also used a scoring system to assess and compare the level and types of provision in these services. As an exploratory study it raised questions about the feasibility and methods required to measure service impact. As such, it could potentially be used as a guide to evaluating the impact of social care services.

Another qualitative study which explored whether and how services can meet needs did so by examining whether the ways in which need is defined and assessed by practitioners creates a risk of inequity in social care provision (Charles and Manthorpe 2006; 2007; 2009). The study was based on the assumption that the way practitioners conceptualise the needs of visually impaired people shapes their identification and response to it. This study links to others exploring similar issues in other areas of social care such as Henwood and Hudson (2008). A vignette methodology was used to explore practitioner decision making. This methodology is well suited to the exploration of perceptions, values and attitudes (Rapaport *et al.* 2008). The constructed vignette set out the circumstances and details of a person who might commonly be encountered by practitioners. The vignette was based on the experiences of a visually impaired older person (who was given a pseudonym) who had given her permission for her story to be used in this way. Although her case was hypothetical, her details were faithfully based on the history of a person of the same age and circumstances. The vignette was used to explore with practitioners the criteria they would use to assess need and eligibility for services. The objective was to gather data to describe and compare assessment practice with a standardised client by a

Carrying out research about adult social care services for visually impaired people

range of practitioners. A fuller discussion of the construction of the vignette and methodology is in the main report and account of the pilot (Charles and Manthorpe 2006; 2007; 2009).

Research about those with treatable visual impairment

It is estimated that in any one year between 3.45 million and 3.95 million of those aged over 60 years (or between 27 per cent and 31 per cent of this age group) do not take up the free eye examinations to which they are entitled at the recommended frequency (Charles 2005; Charles 2007). The prevalence review (Tate *et al.* 2005) concludes that between 52 per cent and 72 per cent of visual impairment in older people (dependent on the age and the definition of visual impairment) is accounted for by untreated refractive error and cataracts. The low take-up of eye examinations might be a factor in the prevalence of untreated but correctable visual impairment but there is no evidence to make this direct link. There is also limited knowledge about those who do not have regular eye examinations or of the characteristics of those who have untreated sight loss.

A recent study by Iliffe *et al.* (2009) explored how primary care could more effectively identify those with treatable conditions. The researchers used the Health Risk Appraisal for Older People (HRA-O),²³ a validated tool for assessing health and lifestyle amongst older people. The characteristics they identified of those who have undiagnosed sight loss included social isolation, depression, the need for assistance with basic living skills, and having impaired memory. However, the prevalence of visual impairment in older people will not necessarily decline even if eye examination take-up is improved if other barriers are not also addressed. For example, a nested trial of vision screening was carried out by the authors of the prevalence review (Smeeth *et al.* 2003). This found that even after people with eye problems requiring treatment or referral had been identified, this did not necessarily result in improved visual acuity. It is also unlikely that the availability of free eye examinations has made a great deal of difference to the identification of treatable visual impairment. (Charles 2007)

Reducing the number of people with untreated cataracts requires understanding and addressing a complex array of factors about the identification and referral of those with cataracts and their acceptance that they have them or that surgery would be beneficial. There is potentially a role for social care researchers to inform this debate, especially in identifying how social care practitioners can play a role in the identification of those most likely to have untreated but treatable visual impairment and to enable them to be referred to the most appropriate services so their visual acuity can be improved.

23.The HRA-O uses questions from the NEI-VFQ to assess visual function.

HOW CAN INFORMED CONSENT BE OBTAINED AND DATA COLLECTED FROM PEOPLE WITH A VISUAL IMPAIRMENT?

Researchers might be concerned about the most appropriate means of corresponding, obtaining consent and using instruments such as questionnaires with people who have difficulty reading because of sight loss. This section covers these issues.

The most important point is that one must not be too prescriptive about the best means of communication other than to tailor communication methods to the preferences of a visually impaired individual. The RNIB has developed its 'See it Right' guidelines about the range of options for making printed information accessible to visually impaired people. This includes web-based information and a 'See it Right' CD-ROM.²⁴ The range of options includes large print, tape, Braille and electronic media. Researchers are advised to refer to this when they are designing their research studies.

The experience from the field is that visually impaired people can successfully be recruited to take part in research if appropriate strategies are adopted. For example, Network 1000 sent information packs in print and tape to the initial sample. This enabled the project to recruit 1,007 respondents to the study. Of these 960 were interviewed. The remaining 47 people had learning and communication difficulties to the extent that it was inappropriate to interview them directly. Fieldwork methods for this part of the sample are described later in this section. The average length of the interviews was 40 minutes and they were carried out over the telephone. The received wisdom is that face-to-face interviews are the preferred option in survey and qualitative research, partly because non-verbal communication helps to establish rapport in the interview. But Network 1000 has found that telephone interviewing is a very effective means of collecting survey data from people with a visual impairment. Other studies referred to in the previous section have also successfully used telephone interviews to collect quantitative and qualitative data, including the use of focus groups over the telephone for the satisfaction study (Woodfield *et al.* 2002).

People with a visual impairment might also have other disabilities. For example, about a quarter of the Network 1000 sample said they had difficulty hearing, most of whom were aged over 50 years (Pavey *et al.* 2007). There are obvious difficulties posed if interviewing those who have difficulty hearing yet novel ways can be found to collect rich sources of data. For example, Pavey *et al.* (2008) gave a small sample of their case study respondents a tape recorder suitable for use by visually impaired people to keep an audio diary. They also used a 'talking label'²⁵ to remind respondents about how to use the equipment and the information for them to record in their diary.

24. 'See it right' information is at: http://www.rnib.org.uk/professionals/accessibleinformation/Pages/accessible_information.aspx (accessed 25 May 2010).

25. <http://www.talkingproducts.co.uk>.

Carrying out research about adult social care services for visually impaired people

There are also those who have more profound levels of dual sensory loss and are represented by organisations such as Deafblind UK. Network 1000 and researchers commissioned by Deafblind UK have collaborated to compare the findings of their research with those people who have dual sensory loss (Pavey *et al.* 2007; Pavey *et al.* 2008). Their advice when communicating with people with dual sensory loss is to tailor communication by:

- using any residual hearing or sight that the person has. This will require speaking clearly but might also include the use of hearing aids, using sign language and using large print;
- using tactile signing such as sign language or a manual alphabet (such as the DeafBlind Alphabet);
- using sign language interpreters;
- using communication aides and devices such as Tellatouch and Telebraile;
- ensuring that lighting and background noise is managed appropriately;
- researchers taking time and care in their approach to communication.

The nature of some additional disabilities might make it difficult for a visually impaired person to directly participate in fieldwork. This might be the case, for example, for those with learning disabilities, dementia or other cognitive impairments. The Network 1000 research team resolved to include such respondents in their study with the help of 'key informants'. These were usually partners, siblings or parents. The questionnaire was adapted to be completed by the key informant about the person on whose behalf they were providing information. Network 1000 acknowledges that this might introduce statistical and other forms of bias into the data but judged it as a pragmatic means of including a group of people who might otherwise be excluded from their research. In a separate section of one of their reports they cover findings from data gathered through key informants (Douglas *et al.* 2006). A qualitative study specifically aimed at the needs of visually impaired people with dementia by Lawrence *et al.* (2008) recruited respondents through dementia and visual impairment services. These included community mental health teams, voluntary organisations and statutory health and social care services. Professionals were asked to identify eligible participants and a letter inviting participation was sent to informal carers. As part of the fieldwork, respondents were also asked to identify the friend or family member and care professional who they thought knew them most well. Those identified in this way were also interviewed.

Obtaining informed consent to participate in research should follow the same principles as in the 'See it Right' guidelines and in the examples shown for data collection. That is, it should be tailored to the needs of the individual. For example, some respondents with limited vision might be willing to sign a consent form if the purpose of the research has been explained to them in a format that they can access. If it is the preference of the

Carrying out research about adult social care services for visually impaired people

respondent, it might be appropriate if an individual known and trusted by them has first reassured them about the integrity of the research that might be explained in printed information. In some instances it might be appropriate for verbal consent to be given and for this to be tape recorded. Alternatively, it might be appropriate to use electronic media, such as email.

WHAT ORGANISATIONS CAN HELP WITH SOCIAL CARE AND VISUAL IMPAIRMENT RESEARCH?

Organisations that have a strong and active interest in research in the visual impairment field include:

Visual Impairment Centre for Teaching and Research, University of Birmingham

<http://www.education.bham.ac.uk/research/victar/>

Thomas Pocklington Trust

<http://www.pocklington-trust.org.uk/>

Institute of Ophthalmology

<http://www.ucl.ac.uk/ioo/>

Institute of Optometry

<http://www.ioo.org.uk/>

Organisations that are primarily service providers or campaigning organisations in the visual impairment field and might be willing to assist researchers with their projects include:

National Association of Local Societies for Visually Impaired People

<http://www.nalsvi.cswebsites.org/>

Royal National Institute of Blind People

<http://www.rnib.org.uk/Pages/>

Guide Dogs for the Blind Association

<http://www.guidedogs.org.uk/>

National Braille Association

<http://www.nationalbraille.org/>

Association of Blind Asians

<http://www.aba-uk.org/>

Organisation of Blind Afro-Caribbeans

www.obac.org.uk

British Blind Sport

<http://www.britishblindsport.org.uk/>

APPENDIX: PREVALENCE ESTIMATES

Tables 1 to 4 in this review are based on three epidemiological studies of the prevalence of visual impairment. Tables 9 to 12 show these estimates. Tables 10 to 12 also show the confidence interval for each estimate. This is the range in which the population size is most likely to fall. Because estimates are derived from samples of the population there is, as with any statistical sample, a ‘margin of error’ in predicting the likely prevalence that exists in the ‘real world’. A confidence interval is a measure of this margin of error. This means that the numbers presented in the tables should not be treated as fixed and finite estimates. Instead, they should be treated as falling within a range in which the true number of visually impaired people is likely to be found. For presentation reasons, these ranges have not been shown in Tables 1 to 4.

Table 9. Estimates of the prevalence of visual acuity in those aged 20–59 years

| Visual acuity | Prevalence estimate |
|---------------|---------------------|
| 6/24–6/48 | 0.07 |
| <6/48 | 0.08 |

Source: Nissen *et al.* 2003

Table 10. UK prevalence estimates for visual impairment amongst people aged 65–74 years living in their own homes, residential and sheltered housing (95% CI)

| | |
|--|-----------------|
| Mild visual impairment VA< 6/12–6/18 | 10.2 (9.1–11.5) |
| Moderate and severe visual impairment VA <6/18 | 5.6 (3.5–7.6) |

Source: NDNS

Table 11. UK prevalence estimates for visual impairment amongst people aged 75 years and over living in their own homes, residential and sheltered housing (95% CI)

| Visual Acuity | Age Group | |
|--|-----------------|------------------|
| | 75–84 | 85+ |
| Mild visual impairment VA< 6/12–6/18 | 10.2 (9.4–11.1) | 19.0 (18.3–19.8) |
| Moderate and severe visual impairment VA <6/18 | 8.5 (7.1–9.8) | 26.8 (23.9–29.7) |

Source: MRC

Carrying out research about adult social care services for visually impaired people

Table 12. Causes of visual impairment: prevalence estimates of visually impairment for people aged 75 years and over in the UK (over/uncorrected presenting binocular VA <6/18) (95% CI)

| Cause | Percentage of visual impairment due to specific causes |
|----------------------|--|
| AMD | 36.2 (32.9–39.5) |
| Glaucoma | 7.9 (6.2–9.6) |
| Diabetic eye disease | 2.3 (1.5–3.1) |
| Vascular occlusions | 0.6 (0.1–1.1) |
| Myopic degeneration | 2.9 (1.9–3.8) |
| Other | 4.7 (3.7–5.7) |
| Refractive error | 31.6 (28.3–34.8) |
| Cataract | 24.5 (21.8–27.4) |

Source: MRC

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