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Vision Rehabilitation Services: what is the evidence?

Final Report

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Glossary of abbreviations:

AMD: Age-related Macular Degeneration

ADASS: Association of Directors of Adult Social Services

ADL: Activities of Daily Living

CPD: Continued Professional Development

ECLO: Eye Clinic Liaison Officer

FACS: Fair Access to Care Services

IADL: Instrumental Activities of Daily Living

LA: Local Authority

OT: Occupational Therapist

RCT: Randomised Controlled Trial

RO: Rehabilitation Officer

ROVI: Rehabilitation Officer - Visual Impairment

VI: Visual Impairment

VR: Vision Rehabilitation

QoL: Quality of Life

Executive summary

Background

Sight loss affects all aspects of well-being including daily functioning and mental health. Demographic trends suggest that the number of people with visual impairment is set to rise significantly, with many people experiencing an additional disability or health problems. By 2050, the number of blind and partially sighted people in the UK is estimated to increase by around 122 per cent, to approximately four million. Promoting preventive and rehabilitation interventions is recognised as a high priority for all care settings as a way of reducing demands on health and social care services. In 2010, the Department of Health urged local authorities to invest in early intervention and consider offering people in need of care and support a short period of rehabilitation before an assessment of longer-term needs is undertaken. The recent Care Act 2014 now requires local authorities (LAs) to actively promote well-being and independence to prevent people reaching a crisis point and has explicitly referred to rehabilitation as an example of tertiary prevention.

Research aims

This research aimed to provide an overview of the evidence base for community-based vision rehabilitation services for people over the age of 18 with visual impairment. The study focused on rehabilitation services funded by local authorities to find out how these services are currently supporting people with visual impairment, what possible outcomes they might achieve and to identify gaps in the evidence base about current service arrangements. The study was carried out in England. Findings were intended to inform a future full scale evaluation as well as inform services.

Research methods

The study took place between October 2012 and September 2014. It involved four main research elements:

- A review of the existing literature on vision rehabilitation services published since 2000 – Stage 1.
- Scoping workshops with people with VI and key professionals – Stage 2.
- A national survey of LAs and voluntary organisations providing vision rehabilitation services– Stage 3.
- Case studies involving focus groups with frontline staff and individual interviews with people with VI who had received vision rehabilitation services – Stage 4.

Current evidence on community-based vision rehabilitation services

The findings from the literature review (chapter 2) show that the evidence base to support the effectiveness and cost effectiveness of community-based vision rehabilitation services (with the exception of group-based interventions) remains patchy and very under-developed, both in scope and quality. However, the review highlighted a number of key messages:

- Vision rehabilitation services, in particular group-based self-management programmes, have the potential to have a positive impact on activities of daily living (such as dressing, toileting), instrumental activities of daily living (such as cooking and shopping) and psychological outcomes (such as emotional adjustment to sight loss).
- There is a high prevalence of depression in people with visual impairment and increased need for emotional support.
- Vision rehabilitation interventions mostly target physical/functional rather than social and emotional issues. A one-dimensional intervention may have limited effect on the wider success of the intervention.

Current state of vision rehabilitation provision

The survey of local rehabilitation services was completed by 87 services (57 per cent response rate). It showed that there is a wide variety of vision rehabilitation provision across England, in terms of the type of providers, specialism within the teams, case loads and waiting times. The two predominant types of providers are LA in-house providers (61 per cent of services) and voluntary sector providers (28 per cent of services). The most common type of team found within LA in-house providers was a sensory impairment team (57 per cent); 75 per cent of voluntary sector providers were specialist vision rehabilitation teams. However, in 40 per cent of services, the initial screening of referrals was sometimes undertaken by professionals without specialist skills in vision rehabilitation.

A quarter of services restricted access on the basis of FACS (Fair Access to Care Services) assessment. Only 58 per cent of services said they measured outcomes, with less than half of these using standardised measurement tools. The voluntary sector services are more likely to be measuring outcomes than LA in-house services (70 per cent and 46 per cent respectively).

Shortages of rehabilitation workers and inadequate staff training and CPD opportunities for staff are areas of concern for managers and rehabilitation workers. 23 per cent of services said their budgets, and 21 per cent of services reported that their staffing ratio, had decreased over the last year. Pressure on budgets and staffing ratios appears to be disproportionate for different services. 27 per cent of voluntary sector services, compared with 14 per cent of in-house services, reported a decrease in their budgets over the last year.

The focus of vision rehabilitation is around mobility, independent living skills and aids and adaptations. Services are less likely to offer emotional support and counselling. Around a third of services offered self-management courses; this includes 25 per cent of LA in-house and 39 per cent of voluntary sector providers. Group work was noted by service managers as a casualty of financial cuts to services.

Staff perspectives – case study sites

Time pressure, inadequate training and networking opportunities and difficulties in collaborating with some external teams are areas of concern for vision rehabilitation workers. The shared feeling among rehabilitation workers was that delays in referral to the rehabilitation team risked care needs intensifying and people getting used to their existing care and losing their motivation to become more independent. They felt that lack of recognition of specialist rehabilitation skills was the key reason undermining timely referrals and joint working with professionals outside rehabilitation teams.

User perspectives – case study sites

People with sight loss in the case study sites participating in the study were positive about the impact of vision rehabilitation services on their safety, confidence and independence; many felt more motivated to make further gains. Some people would have liked earlier access to rehabilitation support and more attention given to their emotional well-being. Group-based activities are considered to be more geared towards older people. Lack of knowledge about rehabilitation services appears to be a key reason why some people with visual impairment do not seek help from rehabilitation services sooner.

Costs of vision rehabilitation services

In the case study sites, on average, for every one hour spent by vision rehabilitation teams in face to face contact with clients, a further one hour and 20 minutes is spent on other tasks such as preparing for visits to clients, writing case notes, taking new referrals and liaising with other professionals. The cost per hour of work as an average across the case study teams is £25. However, it is often more meaningful to consider the cost per hour of face to face contact time or per hour of client-related time; these costs are, on average, £60 and £34 respectively. Differences in the measurement of annual caseload meant that it was not possible to calculate the cost per client.

Key features of ‘good practice’ for vision rehabilitation services

On the basis of this study, the key ingredients of a model of ‘good practice’ for vision rehabilitation services are: staff with specialist knowledge and skills; high quality assessment, including initial screening of referrals; offering personalised and user-led support; delivering a range of training and support, including emotional support, counselling and group-based information and social activities; good access to professionals and skills outside the rehabilitation teams; flexibility to adapt to users’ abilities; timely intervention; regular reviews and follow-up visits; providing people with sight loss with timely and accessible information about vision rehabilitation services and clarity among all health and social care staff about the aims, potential and limitations of vision rehabilitation services.

Conclusions and recommendations

The findings from this research suggest that vision rehabilitation services have the potential to improve the quality of life and independence of people with visual impairment. This supports policy objectives to promote prevention and rehabilitation. However, the study found that robust evidence of impact and cost effectiveness of different models of community-based rehabilitation services is limited in scale and quality. Further research is required to identify what works, for whom and at what costs. This would provide information that can guide future service development and support people with sight loss. This is particularly important in the context of difficult financial situations currently facing local authorities and health services.

The following areas of practice need to be addressed by both commissioners and service providers:

- Protecting specialist assessment;
- Raising the profile of specialist vision rehabilitation skills and increasing understanding among health and social care professionals about the aims, potential and limitations of vision rehabilitation services;
- Improved staff training and networking opportunities;
- Providing accessible and timely information about vision rehabilitation services;
- Greater attention to individual priorities;
- Promoting the use of group-based interventions.

In addition, local authorities should follow recommended practice on supporting people to prevent them reaching a crisis point. The Care Act 2014, coming into force in April 2015, requires local authorities to provide rehabilitation services irrespective of a person’s eligible needs. The Act also specifies that a person’s needs for care and support should be assessed by professionals with relevant experience and training. Hence, local authorities should ensure access to vision rehabilitation is not restricted to a person’s eligibility for care support and that assessments for people with visual impairment are undertaken by individuals with specialist expertise.

Chapter 1 Introduction

1.1 Background

Sight loss is a major health issue, mostly affecting older people. It impacts on all aspects of well-being including daily functioning and mental health. About two million people in the UK are living with sight loss impacting on their daily lives. One out of nine people aged 60 and over and one out of three people aged 85 and over in the UK are living with sight loss (RNIB, 2013). Moreover, demographic trends suggest that the number of people aged over 85 in England is set to increase from just over one to almost three million between 2006 and 2036 (ONS, 2007). This implies that the number of people with visual impairment (VI) is also set to rise significantly. By 2050, the number of blind and partially sighted people in the UK is estimated to increase by around 122 per cent from 2008 estimates, to approximately 4 million (Access Economics, 2009). Two-thirds of people with VI have an additional disability or health problem, such as deafness and diabetes (Guide Dogs, 2007). The total direct NHS expenditure linked to eye health and the total indirect cost of sight loss (including the cost of providing informal care to those living with sight loss) to the UK economy in 2013 is estimated to be around £2.64 billion and £5.3 billion respectively (RNIB, 2013). As numbers of older people and people with long-term conditions increase and public finance constraints persist, managing demands on care services remains a high priority for all care settings.

1.2 Policy background

Attempts to help people to live independently in their own homes have long dominated health and social care policies and strategies (DH, 2005; 2006; 2007). Advancing knowledge about rehabilitation services for people with VI supports this direction.

In a guidance document on eligibility criteria for adult social care published in 2010, the Department of Health clearly urges local authorities to invest in early intervention and prevention and focus on outcomes.

‘Before proceeding to determine eligible needs, councils should consider whether an individual might benefit from a short period of re-ablement or intermediate care to increase what they are able to do for themselves before an assessment of longer-term need is undertaken’ (DH 2010, p.18)

The Adult UK sight loss pathway (Vision2020UK 2013) provides a process map to promote a unified best practice response across local authorities in the UK. The rationale behind the Adult UK sight loss pathway is that offering services to all people in need of support may reduce the number of people that enter the social care system in the first place. This process map was endorsed by the UK Vision Strategy (UK Vision Strategy Advisory Group 2013) and recent ADASS guidance (ADASS 2013), which also clearly explain that vision rehabilitation (VR) should not be dependent on FACS (Fair Access to Care Services) eligibility criteria.

While the more recent Care Act (DH 2014a), coming into force in April 2015, has replaced FACS criteria with a national eligibility threshold, it now requires local authorities to promote wellbeing and independence to prevent people reaching a crisis point, and whether their needs meet the new eligibility threshold:

‘Effective interventions at the right time can stop needs from escalating, and help people maintain their independence for longer’. (DH 2014a, p.9)

‘The local authority’s responsibilities for prevention apply to all adults … whether their needs are eligible and/or met by the local authority or not.’ (DH 2014a, p.13)

With regard to supporting people with established health conditions and complex care and support needs to regain skills and reduce need where possible, the Care Act 2014 states:

‘Local authorities must provide or arrange services, resources or facilities that maximise independence for those already with such needs, for example, interventions such as rehabilitation/re-ablement services and joint case-management of people with complex needs, e.g. community equipment service, handyman services.’ (DH 2014a, p.15)

Furthermore, the importance of specialist assessments is an issue that has been highlighted in recent RNIB reports (Kaye and Connolly 2013, RNIB 2014) and emphasised in the ADASS guidance (ADASS 2013) which states that:

‘Local authorities should consider securing specialist qualified rehabilitation and assessment provision (whether in-house, or contracted through a third party) to ensure that people with sight loss are correctly identified and their independence maximised’ (p.2)

The Care Act 2014 has also highlighted the importance of assessments being carried out by professionals with relevant experience and training:

‘Local authorities must ensure that their staff have the required skills, knowledge and competence to undertake assessments and that this is maintained … Local authorities **should** consider whether additional relevant expertise is required on a case-by-case basis, taking into account the nature of the needs of the individual, and the skills of those carrying out the assessment’ (DH 2014a, p.82).

1.3 Research background

There is ample evidence regarding the unmet needs of people who are visually impaired. Research shows that people with sight loss have an increased need for emotional support (Gosney et al., 2010) and that the quality of life of people with VI is more restrained by lost sources of pleasure and confidence than by constraints on their ability to perform essential activities (Reeves et al., 2004). A recent review of the literature relating to loneliness, social isolation and sight loss suggests that loneliness is linked more strongly to people’s experience of sight loss than the clinical assessment of their vision (Hodge and Eccles, 2014). Rates of depression among older people with VI are reported to be at least twice those of the general population (Burmedi, et al., 2002) and seven times those of their sighted peers (McManus and Lord 2012); yet people with VI and depression are 64 per cent less likely to use any rehabilitation services (Horowitz et al., 2003). There is also some evidence that people with VI receive no offer of counselling and little or no information about equipment and community services at eye clinics (Murray et al., 2010) and this compromises people's short and long-term access to support (Thetford et al., 2009). People with sight loss, particularly those not registered as blind or partially sighted, are also reported to receive no or little rehabilitation training (RNIB, 2006).

Access to rehabilitation services is said to be variable in terms of geographical location, model of service delivery and the duration and content of a rehabilitation programme, depending on service provider and local authority policy (Percival, 2011). While the process of registration as blind or partially sighted is the key to accessing support, a survey conducted between 2006 and 2007 of 884 people with VI reported that 45 per cent of people registered as blind or partially sighted did not receive any explanation of the registration process at the time of certification (i.e. when they were first certified as visually impaired) in the eye clinic and 17 per cent received no help or information in the eye clinic other than medical diagnosis and treatment (Douglas et al., 2008). People who have the greatest needs and who need to rely on others to access services on their behalf are more disadvantaged and people who are not registered are in effect mostly excluded from support services (Thetford et al., 2009).

A survey conducted by Guide Dogs (Guide Dogs, 2007) showed that 19 per cent of respondents who had been registered as blind and partially sighted reported never having had a visit by a social worker or vision rehabilitation worker for a needs assessment. Furthermore, 40 per cent were not offered a service following an assessment of their needs during the five years prior to the survey, and the emotional impact of their sight loss was not addressed. The survey also showed that only 17 per cent of the respondents had received any independent living skills training and just over 37 per cent of people surveyed had received training in orientation and mobility. In line with these findings, a more recent study shows that, of people offered some kind of rehabilitation service, only a small minority receive a full programme of rehabilitation and mobility training. For the rest, the support is limited to a visit by a rehabilitation worker or specialist social worker providing basic aids (such as a liquid level indicator and bump-stickers for kitchen appliances) (Thetford et al*.,* 2009).

Moreover, there appears to be a significant shortfall in the number of qualified vision rehabilitation officers (ROs) to work with adults and children (UK Vision Strategy, 2012) and there is concern that this could result in people with VI being screened out of access to services because generic practitioners may not recognise, or may underestimate, the impact of needs arising from sight loss. As mentioned above, this is particularly important as current ADASS guidance in respect of vision rehabilitation is that rehabilitation should be offered prior to full social care assessment (ADASS, 2013).

There is some evidence that lack of rehabilitation and information can undermine opportunities for social inclusion, affecting the quality of life and well-being of people with VI (Nazroo and Zimdars, 2010); and that people with the highest quality of life scores tend to have less difficulty with independent living skills, activities and mobility (Guide Dogs, 2007). These findings suggest that rehabilitation can be an important contributor to the quality of life for people with VI. The need to ensure that, 'when permanent sight loss occurs, emotional support, habilitation and/or rehabilitation will be provided in a timely fashion, enabling people to retain or regain their independence' is highlighted in the UK vision strategy (RNIB, 2008, p.7) as one of the key strategy outcomes for people with sight loss. However, much of the existing research in this field is focusing on low vision rehabilitation, which is mostly hospital based and takes primarily a clinical approach, focusing on personal physical limitations and functional ability (for example, maximising what is left of the sight) (for example, Reeves et al*.,* 2004; RNIB, 2009). We do not know what community-based services are currently doing actively to support people with VI, what specific service characteristics might maximise people's ability to live independently in the community and how variable access to services is.

Providing such an evidence base is crucial to the development of VR interventions that can target support better, with a view to reducing demands on longer-term care services. Without this knowledge there is a risk that people with VI might be excluded from receiving appropriate interventions that could improve their well-being and promote their independence or experience unnecessary delays in obtaining support.

1.4 Overarching aims of the study

The current study aimed to provide an overview of the evidence base for specific models of rehabilitation interventions for people over the age of 18 with visual impairment. It was carried out in England and focused on rehabilitation services funded by local authorities (but including those provided by local authorities, third sector and private providers) to address the following research questions:

- What are rehabilitation services currently doing to support people with visual impairment?
- What are the possible outcomes that rehabilitation services might achieve?

The study involved four main research elements:

- A review of the existing literature on VR services – Stage 1.
- Scoping workshops with people with VI and key professionals involved in delivering or managing VR services– Stage2.
- A national survey of local authorities (LAs) and voluntary organisations providing VR services– Stage 3.
- Case studies involving focus groups with frontline staff and individual interviews with people with VI who had received VR services – Stage 4.

This study was designed to form the first stage of a future full scale evaluation study (Craig et al., 2008) to determine the cost effectiveness of VR services for people with VI. At the end of the study a workshop was held to feed back results to key informants, use their input to shape presentation of the findings, and assess their support for a future full scale evaluation of VR services. Further information about methods used in different stages of the study can be found within each chapter.

1.5 Research ethics

The study obtained ethics approval from SCREC (Social Care Research Ethics Committee), as well as approval from the ADASS (Association of Directors of Adult Social Services) Research Group. Research governance approval was also sought from the three local authorities taking part in the case studies.

1.6 Project Advisory Group

The study was supported by a Project Advisory Group, which met four times during the course of the study. Members comprised: people with VI who used vision rehabilitation services, representatives from vision rehabilitation services provided directly by LAs and those contracted out, independent providers with no funding from LAs, representatives from the Vision2020UK Rehabilitation and Low Vision Group and Thomas Pocklington Trust.

1.7 Structure of this report

Chapter 2 reports findings from the literature review. Chapter 3 presents the findings from the scoping workshops with people with VI and key professionals and the following chapter reports the findings from the national survey (chapter 4). The next chapter reports the qualitative findings from the three case study sites (chapter 5). Chapter 6 gives an indication of the costs of VR services. The final chapter, chapter 7, discusses the findings and presents concluding comments and recommendations for policy and practice and further research.

Chapter 2 The Literature Review

2.1 The review questions

This part of our work was not a formal systematic review of evidence on effectiveness of rehabilitation service, such as might be carried out to inform the development of guidelines for commissioners. It was, rather, a review carried out systematically, with clear inclusion and exclusion criteria, which aimed to establish the size and robustness of the evidence base on:

- The support needs of people with visual impairment.
- Good practice in vision rehabilitation.
- Rehabilitation service characteristics that have been considered to be effective.
- Possible outcome measures that could be used to assess the success of such interventions in future.
- Gaps in provision of services.

Throughout the project, the focus has been on community-based rehabilitation services that usually, although not exclusively, are commissioned by Local Authorities (LAs). This distinguishes them from low vision services that are usually, though not exclusively delivered from a health service base that tend to concentrate on clinical assessment and prescribing low vision aids. However, different countries organise their vision services in different ways and some international examples of health service-based services may have more in common with LA commissioned services than they do with UK low vision services. This is particularly so in relation to fully multi-disciplinary approaches. This influenced how we searched for and selected material for our review but it was sometimes difficult to draw a line between studies, particularly where the description of the service or intervention lacked detail.

2.2 Searching the literature

With the help of an information scientist, we developed strategies to search a range of electronic databases and internet resources to identify publications that were relevant to our review questions and had been published since 2000. We included both UK and international literature. ASSIA, Google Scholar, Medline, EMBASE, Psychinfo, Social Care Online, Social Services Abstracts, Social Policy and Practice, and Web of Knowledge were the main databases used. We also searched relevant websites for material generated by user-led or voluntary sector organisations. The full search strategies are available from the authors.

The results of the searches were de-duplicated and the resulting 539 records stored in an Endnote database.

We then searched through the output of these searches and, where possible, decided whether a publication was relevant to our main aim, based on the title and abstract of the publication. In doing this, we used a simple algorithm that included our inclusion and exclusion criteria for initial screening (see Appendix 1). Two members of the team – Parvaneh Rabiee (PR) and Gillian Parker (GP) - worked individually through all the records and then came together to discuss decisions; any disagreements were fully discussed and a consensus reached. This process identified 97 publications that seemed of potential relevance and we then obtained full text versions of these.

As full text versions became available PR and GP read them in full, again working individually and then coming together to decide which to include in the full review. By this stage, we had further refined our inclusion and exclusion criteria and designed a second algorithm to underpin our decisions (see Appendix 2). At the end of this process, we had included 58 publications; we excluded a further three during data extraction when close reading made it clear that they did not fit our criteria. In total, then, we reviewed 54 publications. In some cases, a single study had more than one publication and where this was the case, we reviewed all papers related to that study together.

During our initial screening stage, we found eight existing systematic reviews that were, potentially, relevant to our focus. Full reading of these showed that one was exclusively about orientation and mobility training (Virgili and Rubin, 2010) and while we included it for reference checking, we did not include it in the review. Another paper (De Boer et al., 2005) reported guidelines for the referral of people with VI to low vision services that had been developed based on a systematic review of evidence. However, the guidelines did cover the types of intervention that might be helpful for different groups of people with VI and, in doing so, dealt with some aspects of effectiveness. The paper did not describe the underpinning review in any detail but the review's conclusions were included so we have included it here. The other six reviews were included.

We distinguished between primary studies that were essentially qualitative in nature and those that allowed, at the very least, some form of 'before and after' assessment of the impact of visual rehabilitation. Some studies used mixed methods and where this was the case, we assessed their qualitative findings in the qualitative part of the review and their quantitative findings in the quantitative part.

Overall, then we selected, and then extracted and synthesised data from 25 primary studies in the qualitative section, 17 primary studies (reported in 25 papers) in the quantitative section, and seven systematic reviews.

2.3 Data extraction

We developed two data extraction forms for primary studies and one for the included systematic reviews. GP extracted data from the quantitative studies and from the systematic reviews and rechecked these when the findings were synthesised. PR extracted material from the qualitative studies and, again, rechecked this when synthesising findings. The headings used in the forms are at Appendix 3.

2.4 Results of the review of systematic reviews

2.4.1 Details of the reviews

The included reviews and their details are in Table A4.1 in Appendix 4.

Focus

As Table A4.1 shows, some reviews were wide-ranging in their intervention focus – low vision services widely defined (including rehabilitation) (Binns et al., 2012)[1], rehabilitation as a whole (Hooper et al., 2008), Rees et al., 2010) and the whole of occupational therapy (Orellano et al., 2012). The remainder were more narrowly focused; on self-management programmes (Lee et al., 2008) and on interventions specifically in relation to emotional well-being (Nyman et al., 2010). However, the more wide-ranging reviews did often report findings in sub-sections; for example, results about self-management programmes were usually analysed separately. In this paper, we concentrate only on findings about services or interventions that map on to our areas of interest. Therefore, we do not report any review findings about low vision clinic services that were predominantly delivering clinical assessment and prescription of low vision (LV) aids or about in-patient or residential rehabilitation services.

The reviews also varied in how widely they defined the population of interest, with two (Hooper, 2008; Lee, 2008) concentrating on age-related macular degeneration (AMD) and the remainder on low vision or VI more widely defined. Two reviews also concentrated on outcomes of specific interest – Nyman (2010) and Rees (2010) on aspects of psychological outcomes, and Orellano (2012) on instrumental activities of daily living (IADL). Finally, alone among the reviews, Nyman (2010) was limited to material published in the 'grey' literature.

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[1] For ease of reading, in what follows, we provide a full reference for each study when we first mention it but subsequently use only the first author and date of publication (for example 'Hooper et al., 2008' subsequently becomes 'Hooper, 2008'). Full bibliographical details are in the references.

Most reviews included both randomised controlled trials (RCTs) and other designs, but assessed the quality of all included studies before giving weight to their findings in the analysis. The exception was Nyman (2010), which did not make clear whether formal assessment of quality had been carried out.

Given our interest in material published since 2000, by definition none of the reviews was published before this date. However, all had been published since 2005 and four since 2010, perhaps reflecting the growing interest in evidence-based services for people with VI. However, there was wide variation in the dates of the material the reviews themselves included – from two that searched for material published over a 60-year period – 1950 to 2010 – (Binns, 2012; Rees, 2010) to one that searched for material published over a period of just under eight years – 2001 to September 2008 – (Nyman, 2010).

Given the variation in focus and dates of material included, the number of studies identified by each review (other than the one that drew exclusively on grey literature) were not as different as one might have expected, ranging from 72 in Hooper (2008) to 12 in Lee (2008) (with its narrower focus on self-management and AMD). Further, despite their often-differing emphases, many of the reviews included the same studies.

Outcomes assessed

Between them, the reviews synthesised results about the impact of rehabilitation on: quality of life (De Boer, 2005; Hooper, 2008; Binns, 2012; Rees, 2010); visual function (Hooper, 2008; Binns, 2012) other function; (Hooper, 2008; Lee, 2008; Burns, 2012; Rees, 2010; Orellano, 2012); aspects of coping, adaptation or self-efficacy (Hooper, 2008; Lee, 2008; Binns, 2012; Rees, 2010; Orellano, 2012); and mental health (Hooper, 2008; Lee, 2008; Binns, 2012; Nyman, 2010; Rees, 2010). In addition, two reviews examined the relationship between the intensity of the intervention and its effects (Hooper, 2008; Binns, 2012), one explored cost-effectiveness (Binns, 2012), and two (Binns, 2012, Rees, 2010) analysed the relative effectiveness of different models of rehabilitation. As might be expected, the primary studies included in the reviews used a range of methods to assess these outcomes.

Challenges of outcome assessment in the studies reviewed

Several reviews pointed to the difficulty of distinguishing between certain types of outcomes, given the instruments that researchers had used to measure them. This was a particular problem around quality of life (QoL) and visual functioning. Rees (2010) explained that the psychometric properties of many vision-related QoL measure are unclear. As an example, the NEI-VFQ, used in several primary studies as a QoL measure, was actually developed primarily as a functional measure and has not been validated as a measure of psychological function. Binns (2012) also pointed out that there are overlaps in measures of visual function and vision-related QoL measures. Similarly, some studies elided measurement of visual function with more generic Activities of Daily Living (ADL) or Instrumental Activities of Daily Living (IADL) function. There was also overlap in some primary studies between QoL assessment, assessment of wider ‘well-being’ and mental health outcomes. Where possible, we have tried to distinguish between these different outcomes ourselves, but in doing this were entirely dependent on the ways the reviews grouped these outcomes.

2.4.2 Outcomes reported

Quality of life, including vision-related quality of life

Studies that have used generic QoL measures in evaluation of VR services suggest that these services have little impact on this outcome. Binns (2012) concluded that there was little evidence that low vision services (widely defined) improved general health-related QoL. Similarly, Hooper (2008) and Rees (2010) (largely drawing on the same studies) stated that low vision clinic-based services that had an additional multi-disciplinary element had no additional impact over and above usual care on vision-related quality of life. Further, one RCT reviewed by Rees (2010) suggested that such services actually reduced scores on the mental health well-being component of the generic SF-36. Less rigorous designs (non-randomised controlled trials and well-designed pre-test/post-test) have, by contrast, suggested that community based low vision or multidisciplinary services can result in improved QoL (De Boer, 2005; Rees, 2010).

In contrast to these negative conclusions, two reviews pointed to the positive impact on generic health related QoL associated with ‘services that include a group-based component’ (Binns, 2012, p.60) and on vision-related QoL in RCTs of group-based self-management programmes (Hooper, 2008).

Visual and other functioning

Binns (2012) suggests that measures of visual function are rather more sensitive to the benefits of low vision services than are generic QoL measures, as one might expect. However, this review also points out that while a number of studies reviewed had ‘demonstrated significant improvements in ‘vision related quality of life’ following rehabilitation, it [was] the items related to functional measures (particularly near vision) rather than less specific aspects of health-related QoL, that show[ed] the greatest sensitivity to the intervention’ (p.53). Overall, this review concluded that rehabilitation services, regardless of their model, have a medium to large effect on functional ability, largely related to vision function.

In some contrast, Hooper (2008), examining interventions specifically for AMD, concludes that there is strong evidence of **no** benefit from enhanced low vision rehabilitation that adds home visits from a rehabilitation specialist, compared to usual LV clinic care. This review further concluded that involving family members in rehabilitation does not increase functioning or level of security in ADL.

Orellano (2012) states that there is moderate evidence that vision rehabilitation improves IADL function in adults with low vision. However, this conclusion was based on the results of a single (albeit well-designed) RCT that compared multi-component rehabilitation delivered on an individual basis with that delivered involving the family. The conclusion about effectiveness was based on combining the results of the two arms of the trial, and not by comparing the intervention with usual care.

As with QoL outcomes, the messages from studies of self-management or ‘health education’ programmes are more encouraging. Hooper (2008), Lee (2008) and Rees (2010) all conclude that self-management groups, group-based ‘health education’ or problem-solving programmes have benefits in terms of overall functioning or security in performing daily tasks. In one case, (group ‘health education’) there was evidence of this effect lasting into prolonged follow-up.

Coping, adaptation and self-efficacy

This is another area where conceptual overlap between outcomes is found. For example, what is the difference between ‘security’ and ‘self-efficacy’ in daily activity? Further, some reviews present results on coping, adaptation and self-efficacy together and some separately.

The strongest messages from the reviews about this outcome are, again, in relation to self-management approaches. Hooper (2008) concludes that these programmes increase self-efficacy, as does Lee (2008), who also refers to sustained improvement over time. Binns (2012) refers to research that provides good evidence of improved belief in the ability to manage everyday tasks and improved levels of participation in a range of activities. Rees (2010) also refers to improved self-efficacy and adaptation to vision loss, but suggests that not all the effects were maintained at 12 weeks after the intervention.

Only one review (Rees, 2010) reports this outcome for low vision clinic-based services with an added multi-disciplinary element, where a single RCT found no differences in adjustment to vision loss. However, non-randomised controlled trials and well-designed pre-test post –test studies did suggest that multi-disciplinary services could lead to improved outcomes of self-esteem and adjustment to vision loss.

Mental health and psychological outcomes

Self-management and similar programmes also show positive impact in this area of outcomes. Hooper (2008) refers to strong evidence from two

RCTs that such interventions reduce emotional distress and from one RCT each that they decrease depression or improve mood. Similarly, Lee (2008) concludes that self-management improves mood and that this effect is sustained to follow-up. Binns (2012) is also positive about self-management, but refers to good evidence of only a small reduction in depression and weaker evidence of small to medium size effect sizes on a range of psychological outcomes from a range of interventions. This review also pointed to very good evidence for **no** reduction in symptoms of depression for a multi-disciplinary outpatient rehabilitation service, but did point out that the service did not include any element of counselling or psychological intervention. Overall, Binns (2012) concludes that effect sizes for psychological outcomes range from negligible to moderate.

Finally, the Nyman (2010) review, which was restricted both to the grey literature and to emotional well-being as an outcome, came to the view that there was no conclusive evidence about interventions to improve emotional well-being in people with sight loss. However, the literature reviewed did underline the substantial need for emotional support that people with sight loss experience and some potential ways of providing that support. Tele-befriending and face-to-face counselling were mentioned as potentially promising interventions.

Comparing different models and different levels of intervention

Only two reviews attempted to compare different models of rehabilitation (Binns, 2012; Rees, 2010) and both pointed to the difficulties of doing so based on the evidence that was available, and more particularly the poor reporting of the contents of interventions. Binns (2012) referred to two studies (one in the UK and one in the Netherlands) that suggested that adding multi-disciplinary elements to standard low vision clinic-based services did not lead to improved outcomes. This review also concluded that a group-based, problem solving ‘health education’ programme was more effective than an individual intervention. Rees (2010) comes to broadly the same conclusion; that novel approaches specifically designed to improve psychological outcomes, including group-based psycho-education and individual problem solving therapy, showed ‘consistent reductions in emotional distress, and improved mood and self-efficacy’ (p.398). It was also possible that these outcomes might be more pronounced for people who had depressive symptoms at the outset. Further, while standard or extended low vision services might have minimal impact on depressive symptoms, some non-RCT studies suggested that multi-disciplinary services might lead to improved outcomes on vision-related QoL, self-esteem and adjustment to vision loss.

Only two reviews (Hooper, 2008; Binns, 2012) included any information about the intensity of intervention and its relationship to possible impact. Hooper (2008) concluded that a single ‘fair’ RCT of extending rehabilitation into the home setting did not improve outcomes. By contrast, Binns (2012) concluded that services that provided a high level of intervention showed medium to large effect sizes. However, it was also the case that some elements of an intervention (for example, orientation and mobility training) required more intensive input than did others. As a result, the relationship between intensity and outcome might be confounded by the contents of the particular rehabilitation programme.

Cost effectiveness

Only one review (Binns, 2012) examined cost-effectiveness. Despite the breadth of this review, only two studies (both RCTs) met the criteria for inclusion. Methodological problems were identified in both, leading to the conclusion that there was little evidence about the cost-effectiveness of low vision rehabilitation.

2.4.3 Limitations of the evidence from existing systematic reviews

In addition to the difficulties outlined earlier about lack of clarity about which outcome measures were measuring which outcomes, all the reviews pointed to the dearth of high quality evidence in the area of vision rehabilitation. This is particularly the case in relation to the type of community-based rehabilitation that is the focus of our project overall.

One effect of this limited evidence base is that most of the later reviews included the same material, almost in total or in part, and thereby were highly dependent on the few well-designed studies. As a result, some individual studies carried a substantial weight in the reviews. For example, a single, much referred-to RCT (Reeves et al., 2004; Russell et al., 2001) in some reviews stands as a possible disincentive to promoting ‘multi-disciplinary rehabilitation’. Yet, this study actually evaluated a limited ‘add-on’ of home visits from a rehabilitation worker to the usual (mono-disciplinary) care of a hospital-based, low vision clinic. In our opinion, this does not constitute a multi-disciplinary (or indeed community-based) approach. Similarly, because the evaluation of outpatient rehabilitation for veterans in the USA (Stelmack et al., 2007; Stelmack et al., 2008) was a very well designed RCT, it also carried a lot of weight. However, its client group was 98 per cent male and exclusively service veterans, perhaps making it difficult to generalise its findings to the whole population of people with vision loss, and particularly to those in the UK.

2.4.4 Conclusions

We found more syntheses of evidence on rehabilitation for people with vision loss than we had expected at the outset of our work. This seems to reflect the growing interest in providing evidence-based services but it is unfortunate that it does not yet reflect a secure evidence base for VR services. Further, even though there have been some evaluations of services described by some as ‘multi-disciplinary’, none of these reviews would have been able to come to any clear conclusion about the type of community-based services, managed outside the health service, that are the focus of our work. In this context of virtually no evidence, decisions about the future of such services would clearly be premature.

However, something that could help protect such services from the pressures of austerity would be if they were to provide evidence-based *interventions*. The reviews’ findings clearly support the use of group-based self-management programmes within rehabilitation services, whatever shape these services take or whoever commissions or provides them. As Lee and colleagues (2008) argue, given the weight of evidence of their effectiveness, and the possibility that they are more effective than individual case management, service providers ‘need to review and evaluate current practice within low-vision rehabilitation’ (p.176). Another practice recommendation to emerge from the reviews (Rees, 2010) is that, given the high prevalence of depression in people with VI, the workforce in services of all types needs to be skilled and confident enough to recognise and address psychological issues in its client group, or to refer on to specialist services.

2.5 Quantitative studies

2.5.1 Details of the studies

The included studies and their details are in Table A5.1 in Appendix 5. One of the included papers refers to a protocol for a planned RCT (Margrain, 2012) so no outcome data are presented for that study in what follows, although the design details are included.

Inevitably, some primary studies we reviewed were also included in the systematic reviews analysed in the first part of this chapter. This type of overlap is common when different research groups are reviewing similar areas of the literature and where the evidence base is limited. However, our research focus - and therefore our inclusion and exclusion criteria - was different from those of the other reviews and therefore our review of primary studies stands in its own right.

Geographical distribution of studies
Five studies were from the USA, four the UK, three from the Netherlands, and there was one each from Germany, India, Sweden, Australia and New Zealand.

Design and methods

Seven studies were described as randomised controlled trials (RCT’s) and, thereby, were comparing a model of VR with something else – whether ‘usual care’ or some other model of rehabilitation or, where a waiting list control group was used, with no intervention at all.

Nine studies involved some form of pre-test, post-test design: that is, outcomes were assessed before and at some stage after receiving VR. However, only three of these studies compared VR with anything else, making it difficult to come to any robust conclusions about whether VR or time made the difference (if any) that was observed.

A final study (McCabe, 2000) was difficult to categorise; it described how participants were randomised to one model of VR that involved family members and the same model but without family involvement. However, findings refer only to the impact of VR in total, as the numbers randomised to the two groups were not large enough to demonstrate differences between family-focussed and individually focussed VR. We have therefore classed this study, also, as a pre-test, post-test design, with no comparison.

Three studies measured outcomes immediately after the completion of VR and not again. Of those with longer periods of follow-up two measured outcomes at periods between 1 and up to 3 months, four between 3 and 6 months, four between 7 and 12 months, and three at periods beyond 12 months. In one study, it was unclear when final follow-up was.

Most studies reported their methods in some detail and the majority involved face-to-face collection of data, either in participants’ own homes or in service settings. Three studies used telephone interviews and assessment, for part or the whole of the study. No details of the methods used were reported in De Boer (2006).

Given the scoping nature of our review, we did not carry out formal assessment of the quality of the studies included.

Definition of visual impairment

Eight studies did not report how they defined visual impairment for the purposes of their study, although two of these did assess VI clinically during the study. The remainder used a range of cut-off points for the definition of impairment and, reflecting their different national measurement scales, a range of reporting formats. Where possible we have converted the information used in the studies to a logMAR score, to facilitate comparisons of level of VI that the different VR services or interventions were tested on[2]. These are in Table 2.1 below.

Details of sample and participants

A range of inclusion and exclusion criteria were used in the studies we reviewed.

Three studies did not report an age range being applied and only four had lower age limits of under 55 years of age. Most studies thus focused on a limited age range, predominantly from late middle age onwards. These criteria were reflected in the average ages of the participants; where reported (in 11 studies) the average in all but one was over 70, and in three of these, over 80. The exception was a study with a lower age limit of 18 years, where the mean age of participants was 42 years.

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[2] We used a comparison chart of different measurement systems to do this: http://precision-vision.com/Articles/snelleneyetestchartsinterpretation.html#.VBbiO51wbcs

Table 2.1 Definition of visual impairment (acuity) converted to logMAR equivalent in studies where defined at all

Study (first author and date)	Measurement in both eyes (logMAR equivalent [1])	Measurement in better eye (logMAR equivalent)	Measurement in other eye (logMAR equivalent)	Not specified	Other definition
Alma 2012	-	-	-	0.3	
Birk 2004	-	≥ 0.5/0.6	-	-	Bilateral MD
Brody 2002	-	≥ 0.5	≥ 0.7	-	-
Christy 2010	-	-	-	0.3	-
Eklund 2004		≤ 1.0 (sic)	-	-	-
Girdler 2010	≥ 0.3	-	-	-	-
Campbell 2005	-	≥ 0.6	-	-	-
McCabe 2000	-	≥ 0.7	-	-	-
Russell 2001	≥ 0.5	≤ 1.8	-	-	Diagnosis of AMD

The higher the logMAR score, the lower the visual acuity.

Perhaps reflecting the older age of the participants, samples were also likely to contain a higher proportion of women than men. In nine of the 13 studies that reported the sex of participants, women made up over 60 per cent of the sample. One interesting exception to this was the McCabe (2000) study. This was originally set up to compare VR with and without family involvement and reported that men were more likely to be in the family involvement VR group (67 per cent) than the individual VR group (41 per cent). This perhaps reflects the fact that, generally speaking, older women are more likely to live alone than are older men.

The proportion of participants who lived alone varied considerably between studies (from 32 per cent to 87 per cent in the 10 studies that reported this). This variation, to some extent, ran in parallel with the age and sex composition of the sample; a higher proportion of women coupled with a higher average age tended to be associated with a higher proportion of the sample living alone.

The sizes of the studies varied considerably, from initial achieved sample sizes of 22 to 436. There were nine studies with fewer than 200 participants; four with between 201 and 300, and three with more than 300. Rates of follow-up also varied from 91 per cent (Christy, 2010) down to 57 per cent (Eklund, 2004). To some extent, but not always, lower follow-up rates reflected the length of follow-up; Eklund (2004), for example, followed participants for 28 months. However, this was not always the case; Horrowitz (2003) achieved 91 per cent follow-up over a period of between 20 and 27 months.

Nature of the visual rehabilitation service or intervention being evaluated

The details of the VR services or interventions that were evaluated in our included studies are in Table 2.2 below. We have applied our own classification to the description of the VR input. We distinguish between them based on their format (individual or group-based), intensity (defined by number of hours of input), whether or not they were time-limited, content (whether or not they addressed a wide range of issues), whether there was any underlying theory that influenced how and what was delivered and the setting for delivery.

As this table clearly shows, the literature we reviewed fell into two main groups. The first group was studies evaluating multi-component, group-based services that were usually time limited and could be very intense over a short period. The second group was studies of ‘standard’ rehabilitation services that, usually, offered all or some of low vision aids and advice on how to use them, mobility training, advice on activities of daily living and non-optical aids, and psychosocial support.

Table 2.2 Classification of VR input in included studies

Study (First author and date)	Group or individual	Intensity (hours of direct input)	Time limited?	Addressed wide range of issues	Theoretical underpinning	Setting
Alma 2012	Group	42 hours plus 12 ‘motivational’ telephone calls	20 weeks	Yes	Yes	Both clinic and community, to reduce travel time and enhance participation.
Birk 2004	Group	Five group sessions – not clear how long each was.	5 weeks	Mainly psychosocial and information	Yes	Clinic
Brody 2002	Group	12 hours	6 weeks	Cognitive, behavioural and practical, with information	Yes	Clinic
Christy 2010	Individual but delivered in different settings – clinic, community, own home	Varied between arms of trial – min of 12 hours, potential max of 78 hours	Yes, but varied between arms of trial	Traditional rehabilitation training. Three arms with follow-up training, one without.	None articulated	Centre, Home, Centre and Home, Centre with additional motivational visits
De Boer 2006	Individual standard low-vision rehabilitation compared with multi-disciplinary rehabilitation centre	Not reported	Not reported	Not possible to tell – participants could get advice/help ‘if needed’ at multi-disciplinary centre. Standard LVA advice at hospital.	None articulated	Low vision clinics in hospital settings compared with regional multi-disciplinary rehabilitation centre.
Eklund 2004	Group	16 hours	8 weeks	Yes	Yes	Designed for community delivery,

						but in study was delivered in low vision clinic
Engel 2000	Individual, ‘standard, orientation, mobility and rehabilitation.	Not reported	Not reported	No details given of input actually delivered	None articulated	Not clear
Girdler 2010	Group	24 hours	8 weeks	Yes	Yes	Not clear. Perhaps in premises of third-sector service provider
Hinds 2003	Individual ’standard’ low vision rehabilitation	Not reported	Not reported	No details of input actually delivered	None articulated	Low vision clinic with option of domiciliary follow-up visits
Horowitz 2000	Group	Between 36 and 48 hours	4 or 6 weeks	Yes	Based on earlier descriptive study	Not clear but this study extended intervention to rural areas
Horowitz 2003	Individual ‘standard’ rehabilitation services.	Not reported	Not reported	Examined specific impact of receipt of low vision service, skills training, counselling, optical aids and non-optical aids within standard rehabilitation services	No	Not reported.
Kirkcaldy 2011	Group	Not reported	Not reported	Not clear. Described as ‘intensive peer support workshops designed to help people deal with the	None articulated	Not clear

				practical and emotional impact of sight loss' (p.145)		
Campbell 2005	Individual falls prevention programme	1 visit of OT to discuss home safety. 6 home visits for exercise programme. Vitamin D supplements.	6 months	No	Yes	Participants' own homes.
Langelaan 2009	Individual 'standard' rehabilitation input including psychosocial support,	Not reported, but intervention is residential	Not reported	Not reported in any detail, but potentially yes	None articulated	Not clear until discussion section of paper that this was a residential centre.
Margrain 2012	Individual problem solving therapy intervention	Not reported	6-8 weeks	Problem solving with specific focus on avoiding depression	Yes	Own homes and research centre
McCabe 2000	Individual 'standard' rehabilitation with family involvement	Varied with 'person's level of impairment and their capacity to learn new techniques' (p.262)	Not reported	Standard LVA advice and aids with potential for psychosocial support.	In relation to family involvement in rehabilitation	Clinic

2.6 Outcomes assessed

The major outcomes evaluated in the primary studies we included were: activities of daily living and instrumental activities of daily living (8 studies), mental health and emotional well-being (8 studies), and quality of life (7 studies).

Other outcomes were reported in the primary studies: one looked at employment and vocational outcomes and two at social and leisure outcomes. Other outcomes reported included coping, efficacy and autonomy, visual impairment, service use and costs, and general health, but none of these was reported in more than three studies.

Given the importance of synthesising evidence, we report in detail only those outcomes evaluated by seven or more of the studies we included. We also briefly look at what evidence was reported about costs when also considered alongside effectiveness.

2.6.1 Activities of daily living and instrumental activities of daily living

Activities of daily living (ADL) are usually defined as the tasks involved in caring for and moving the body and cover walking, bathing, dressing, toileting, brushing teeth, and eating. By contrast, instrumental activities of daily living (IADL) are those that support day-to-day life. They include: cooking, driving, using the telephone or computer, shopping, keeping track of finances, and managing medication. Some of the studies included here used one and some both types of outcomes, though not always describing them in these terms. Table 2.3 summarises the findings from the eight studies that reported these types of outcomes.

As the table shows, all but one of the studies appeared to show some kind of positive effect – whether from rehabilitation, as such, or from a particular model of rehabilitation. However, there are provisos to be applied here. Few of the studies used psychometrically robust measures. Secondly, two studies showed positive effects on only a small proportion of the tasks or areas of daily living that were explored. Thirdly, some of the studies simply measured change over time, without any control or comparison group. Overall, one study with a comparison group and two RCTs reported positive effects on aspects of ADL or IADL, while one RCT did not.

Table 2.3 Effect of rehabilitation on activities of daily living (ADL) and instrumental activities of daily living (IADL)

Study (first author and date)	Type of activity assessed	Measure used	Analysis	Results: Intervention	Results: Control or post-test (where relevant)	Statistical test and significance	Postive effect reported?
Birk 2004*	ADL and IADL	Modified Multi-level Assessment Instrument	Mean difference between baseline and follow up	Mean difference: 1.3	-4.8	t=2.5 (p=.02) Mann Whitney U = -2.2 (p=0.03) Effect size, corrected for baseline differences of 0.66	Yes
Eklund 2004**	IADL	Instrument designed and tested for psychometric properties by research group	Change for whole group (RP) and individual change (RV) between baseline and follow-up	RP (95% CI): 0.11 (-0.03 to 0.35)	RP (95% CI): 0.34 (0.24 to 0.46)	95% CI for difference between groups at 28m: 0.06 to 0.42 (statistically significant)	Yes
Engel 2000	IADL plus walking	Questionnaire designed by researchers. No apparent testing of psychometric properties.	t-test of change in mean score between baseline and (undefined) follow-up period	All changes non-significant except use of public transport: mean score before: 3.32; after 2.10.	n/a	t test value not reported, p=.015.	On 1 activity out of 12.

Girdler 2010**	IADL	US version of Activity Card Sort – said to be psychometrically robust	Analysis of Co-variance with baseline score used as covariate	Mean score at follow-up: 0.72	Mean score at follow-up: 0.56	Effect size, corrected for baseline, 0.31. p=0.001	Yes
Hinds 2003	IADL	Manchester Low Vision Questionnaire – psychometric properties not reported.	Not clear how difference between baseline and follow-up was tested. Results table refers to 'differences between distributions'.	Three tasks said to show significant change: reading ordinary print (p=0.049), reading large print (p=0.015), reading shop tickets and labels (p=0.001). No other significant differences	-	See previous columns	In 3 out of 19 tasks
Horowitz 2000	ADL and IADL	Single item questions in questionnaire designed by research team. No detail on psychometric properties.	Analysis of Variance to explore effects of time, age and living conditions on each outcome (time being a proxy for effect of rehabilitation)	Mean (SD) score before rehab: Daily household tasks: 1.1 (1.0) Getting to places outside home: 1.8 (1.1) Caring for personal needs: 0.5 (0.6)	Mean (SD) score after rehab: Daily household tasks: 1.0 (0.7) Getting to places outside home: 1.1 (1.1) Caring for personal needs: 0.6 (0.6)	F (1,360) = 8.8, p=0.003 F (1,369) = 10.4, p=0.004 F (1,364) = 8.4, p=0.004	Yes, in three areas tested
McCabe 2000	Mostly IADL with some visual function	Functional Assessment Questionnaire (FAQ) 'previously validated'	t test of differences in mean change score between baseline and follow up,	FAQ mean (SD) change score for 'difficulty': 0.22 (0.82) FAQ mean (SD) change score for	n/a	t test values not reported. 'Difficulty' p=0.03 'Dependency' p=0.01	Yes

		measure of function but modified for specific service setting.	combining data for the two groups	‘dependency’: 0.33 (1.10)			
Russell 2001**	IADL	‘Derived’ from Manchester Low Vision Questionnaire	Divided n of tasks unable but wanted to do by total n of tasks needed or wanted to be able to do, subject of regression modelling adjusting for baseline. ‘Effect sizes’ reported.	Effect size (95% CI) ELVR vs CLVR: 0.04 (-0.02 to 0.11) ELVR vs CELVR: 0.04 (-0.02 to 0.10) CELVR vs CLVR: -0.00 (-0.06 to 0.06)	See previous column	ELVR vs CLVR, p=0.17 ELVR vs CELVR, p=0.15 CELVR vs CLVR, p=0.99	No

*comparison group **RCT

ELVR – enhanced low vision rehabilitation

CLVR – conventional low vision rehabilitation

CELVR – control condition controlling for enhanced contact time in ELVR

2.6.2 Mental health and emotional well-being

Two main types of outcome were reported under this heading – depression and/or ‘negative affect’, and adjustment to sight loss. As Table 2.4 shows, four of the five studies that explored the effect of rehabilitation on depression or negative affect showed a positive impact, as did two of the four that explored impact on adjustment to sight loss (with a third study showing impact at the margins of statistical significance).

One large, statistically sophisticated analysis of survey data (Horowitz, 2003) showed both that rehabilitation, however defined, had an effect on depression and that specific types of rehabilitation input had differential impacts. All types of input contributed to reduced depression over time, but low vision clinical services, optical aids and counselling each had an *independent* effect. Skills training and the use of adaptive aids did not have such independent effects.

Table 2.4 Effect of rehabilitation on depression and/or negative affect

Study (first author and date)	Measure used	Analysis	Results: Intervention	Results: Control or post-test (where relevant)	Statistical test and significance	Positive effect reported?
Depression and/or negative affect						
Birk 2004*	Positive and Negative Affect Scale (PANS)	Mean difference from baseline to follow-up.	Positive affect mean difference: -0.26	Positive affect mean difference: -0.14	t=0.51 (p=0.61) U= -0.49 (p=0.66) Corrected effect size 0.28	No
		As above	Negative affect mean difference: 0.10	Negative affect mean difference: -0.43	t=2.6 (p=0.02) U= -2.3 (p=0.02) Corrected effect size 0.78	Yes
Brody 2002**	Profile of Mood States – assesses distress in previous week	Mean difference and 95% CI from baseline to follow up for within and between groups	Mean difference (SD): -11.64 (25.6) 95% CI (-17.28 to -6.01	Mean difference (SD): 0.14 (21.55) 95% CI (-3.85 to 3.57 F=	Within groups: Intervention F=11.07,p<0.001 Control F=0.004, p=0.05 Between groups: F=13.72, p<0.001	Yes, for both models of rehab, but with bigger effect for self-management. Most of this latter effect explained by greater impact for people who were depressed at baseline
Engel 2000	CES=D (short form – 1 item)	Difference between mean scores at baseline and follow-up	Baseline mean 6.95	Follow-up mean 6.33	t test result not reported. Said to be not significant.	No

Girdler 2010**	30 item Geriatric Depression Scale. Good psychometric properties reported	Analysis of Covariance using baseline scores as covariates	Baseline adjusted mean score 10.58 Follow-up mean score 7.52	Baseline adjusted man score 10.58 Follow-up mean score 10.83	Effect size 0.18, p=0.001	Yes
Horowitz 2003	20 item CES-D	Hierarchical multiple regression used to predict change in depression over time, with use of rehab services as final step in model.	n/a	n/a	Modelling showed a significant independent, positive effect of use of rehab services on depression with an R^2change=0.07, $p<0.01$	Yes
	As above	Similar modelling used to test different types of rehab input on depression. Examined low vision services, counselling, number of optical aids, skills training and adaptive aids.	n/a	n/a	Independent positive effect identified for: low vision services R^2= -0.22, $p<0.01$ counselling R^2= -0.18, $p<0.05$ number of optical aids R^2= -0.18. NS for skills training and for number of non-optical aids	Yes, and also for specific elements of rehabilitation input.
Adaptation to vision loss						
Girdler 2010**	Adaptation to Vision Loss Scale	Analysis of Covariance using baseline scores as covariates	Baseline adjusted mean score: 52.67 Follow-up	Baseline adjusted mean score: 52.67	Effect size 0.05, p=0.058	On the margins of conventional statistical signficance

			adjusted mean score: 62.10	Follow-up adjusted mean score: 55.71		
Horowitz 2003	24 item Adaptation to Age-related Vision Loss (AVL). Reasonable psychometric properties	Analysis of Variance to explore effects of time, age and living conditions on each outcome (time being a proxy for effect of rehabilitation)	Baseline mean (SD) AVL scores: 18.6 (4.3)	Follow-up mean (SD) AVL scores: 20.3 (3.8)	Main effect for time on mean AVL scores: F (1,368) = 85.2, p=0.000	Yes
	Single item, 5 point scale question on feelings of sadness or depression in previous week	As above	Baseline mean (SD): 2.6 (1.0)	Follow-up mean (SD): 2.4 (1.0)	Main effect for time on feelings of sadness or depression: F (1,369) = 19.9, p=0.000	Yes
Russell 2001**	Nottingham Adjustment Scale – ‘relevant sections were selected’, including acceptance	Multiple regression analysis controlling for baseline scores. Pairwise comparisons of differences between means.	Effect size (95% CI) ELVR vs CLVR-0.36 (-3.04 to 2.32) ELVR vs CELVR: -0.73 (-3.29 to 1.84) CELVR vs CLVR0.36 (-2.24 to 2.97)	See previous column	ELVR vs CLVR, p=0.79 ELVR vs CELVR, p=0.58 CELVR vs CLVR, p=0.79	No

*comparison group **RCT

CES-D Center for Epidemiologic Studies – Depression Scale

2.6.3 Quality of life

Table 2.5 shows the results for the seven studies that included quality of life as part of the evaluation. This shows a much more mixed picture than the case with the two previous outcome areas we have looked at.

Here we find two RCTs (Brody 2002, Girdler 2010) showing a positive effect on some aspect of quality of life (in one study, perhaps mediated by pre-existing depression) and one (which was comparing different models of rehabilitation service) showing no effect (Russell 2001).

One other type of study comparing different models did show a positive effect on mobility-related QoL over time for those referred to an optometric service, compared to those referred to multi-disciplinary services (De Boer 2006).

Table 2.5 Effect of rehabilitation on Quality of Life

Study (first author and date)	Measure used	Analysis	Results: Intervention	Results: Control or post-test (where relevant)	Statistical test and significance	Positive effect reported?
Brody 2002**	NEI-VFQ – functional measure of health-related quality of life	Mean difference between baseline and follow-up – within and between groups analysis	Mean difference (SD) 2.64 (9.07), 95% CI -0.60 to 4.67	Mean difference (SD) 0.01 (8.04), 95% CI -1.37 to 1.38	Within groups: Intervention F=5.93, p=0.16 Control F=<1.00, p=.99 Between groups: F=3.89, p=0.05	Yes, mainly explained by greater positive effect on people who were depressed at baseline.
De Boer 2006*	Low Vision Quality of Life Questionnaire	Linear regression of follow-up scores, adjusted for baseline scores and other relevant confounders to compare two models of rehab services	Adjusted mean difference (95% CI): Basic aspects of vision 1.3 (-3.4 to 5.9) Mobility -5.3 (-10.5 to 0.2) Adjustment 4.1 (-1.9 to 10.1) Reading and fine work -1.5 (-7.4 to 4.4)	See previous column	Basic aspects of vision p=0.97 Mobility = 0.04 Adjustment p=0.18 Reading and fine work p=0.61	For mobility related QoL only for those referred to optometric rather than multi-disciplinary services.
	Vision Quality of Life Core Measure (VCM1)	As above	Adjusted mean difference (95% CI): 1.3 (-3.4 to 5.9)	See previous column	p=0.59	No

Girdler 2010**	SF-36 physical component	Analysis of Covariance using baseline scores as covariates	Physical component summary score, adjusted mean. Baseline 36.07 Follow-up 38.86	Physical component summary score, adjusted mean. Baseline 36.07 Follow-up 31.43	Effect size 0.23, p=0.001	Yes
	SF-36 mental component	As above	Mental component summary score, adjusted mean. Baseline 51.94 Follow-up 56.13	Mental component summary score, adjusted mean. Baseline 51.94 Follow-up 53.49	Effect size 0.03, p=0.102	No
Hinds 2003	Vision-related Quality of Life Questionnaire	Compared mean scores at baseline and follow-up. Not clear what tests were used.	Average index score at baseline 2.2	Average index score at follow-up 1.8	p value ‘for differences between distributions’ =0.0061	Yes, for overall score. Mainly accounted for by difference in score on worry about eyesight getting worse, concern for safety at home, and worry about coping with everyday life.

Kirkcaldy 2011	Birmingham Assessment of Low Vision Focus Quality of Life Questionnaire	t test of difference between baseline and follow-up scores	Mean total QoL score at baseline 1.89	Mean total QoL score at follow-up 1.82	t=1.209, p=0.210	No
Langelaan 2009	NEI-VFQ	Random coefficient analysis to deal with correlated and clustered nature of repeated measures of same individuals.	Results for change over time presented in a bar chart that is difficult to read. Text says that at second follow-up, only ‘Dependency’ element of measure remained improved.			Only in relation to ‘dependency’. In further modelling age was seen to be the most important predictor of change for those who received rehab.
Russell 2001**	VCM1	Multiple regression analysis controlling for baseline scores. Pairwise comparisons of differences between means.	Effect size (95% CI) ELVR vs CLVR 0.06 (-0.17 to 0.30) ELVR vs CELVR: 0.12 (-0.11 to 0.34) CELVR vs CLVR -0.05 (-0.29 to 0.18)	See previous column	ELVR vs CLVR, p=0.60 ELVR vs CELVR, p=0.31 CELVR vs CLVR, p=0.64	No

*comparison group **RCT

NEI-VFQ National Eye Institute Visual Function Questionnaire

2.6.4 Service use and costs

Only two studies looked at the costs of rehabilitation services alongside their effectiveness.

Eklund (2004) carried out a cost-effectiveness analysis based on the 131 participants that were still in the RCT at final follow-up (57 per cent of the original sample). The costs to society (the societal perspective) of both models of rehabilitation were calculated. These included the costs of delivering the two models, any other treatments or services that participants had received over the time of the RCT and informal care inputs. The mean total cost for the innovative group-based model (HEP) was Sw Kroner 28,004 and for the standard low vision clinic care was Sw Kroner 36,341. The 95 per cent confidence interval was -28,453 to 11,782, making the difference in overall costs not significantly different statistically (p=0.425). However, the HEP was more effective than the standard low vision clinic service. A health economics, cost per improved case ratio calculation showed that the cost per improved case was Sw Kroner 14,522 for the HEP and Sw Kroner 58,226 for the standard service.

Campbell (2005) looked at the incremental cost of an intervention specifically intended to reduce falls at home for people with visual impairment, making it an unusual study in our review. The RCT compared a home safety programme, an exercise programme combined with Vitamin D supplements, the home safety program and exercise programme combined, and a control condition that involved social visits to the participants. The exercise programme was found not to be effective so was not included in the subsequent health economics analysis, which also used the societal perspective. Cost effectiveness was defined as the incremental cost of delivering the programme per fall event prevented during the one year trial. The programme cost $NZ325 per person to deliver while the incremental cost per fall prevented was $NZ650.

2.7 Conclusions from the quantitative review

The evidence base from which we can draw any robust conclusions about the effectiveness and costs of VR, as such, and about different models of VR remains under-developed. There have been some RCTs in the recent past, but these are the exception among the studies we reviewed and some, though well designed, were small. Small numbers in trials may mean that significant effects remain unobserved, because there is insufficient statistical power to detect them. Beyond the RCTs, there were some robust analyses of survey, or before and after, data to explore the impact of VR but, again, these were in the minority. Other studies were small, with no control or comparison groups, and sometimes poorly designed, leaving them with little that was robust to say, even about change over time.

However, we do feel that there are some strong hints in what we have reviewed about the potential for VR to have a positive impact on ADL and/or IADL and on depression. This latter hint is particularly important, given what we know about the incidence of depression in people with VI. Further, the two studies that attempted a health economics analysis throw open the possibility of group-based VR and specific falls prevention interventions being cost effective. This first finding echoes those from other systematic reviews.

One significant limitation of the evidence we have reviewed is its ability to say anything about the needs of younger people with VI and the outcomes that might be important to them. This seems another large gap in the research base.

Another limitation is the nature of the samples that are included in the more robust evaluations. These studies usually have strict inclusion and exclusion criteria. This means that the populations that are studied are less likely to have other physical conditions and cognitive impairments, less likely to live at a distance from the centre where studies are carried out (and thus unlikely to live in rural areas), and less likely to have a mother tongue that is not English. Thus, even if services and interventions are found to be effective, their effectiveness cannot be assumed to apply to some of the groups who might most need them

2.8 Qualitative studies

This section reviews the included studies that either were wholly qualitative in approach, or that reported quantitative findings, but at one point only, and therefore did not allow any explanation of change. Four of the qualitative studies were longitudinal with data collected at baseline and one to three follow up interviews. We found 25 publications that met our inclusion criteria for this part of the review.

2.8.1 Geographical distribution of studies

Out of the 25 studies, the majority (n=14) were conducted in the US, a smaller proportion (n=6) derived from the UK and the remainders (n=5) were from Australia.

Focus

The studies varied in their focus – mostly on rehabilitation services (Beckley et al., 2007; Boerner and Cimarolli, 2005; Boerner et al., 2006; Cimarolli et al., 2006; Gaber, 2010; Rogers et al., 2000; Soucy-Moloney et al., 2001; Walter et al., 2007; Peel et al., 2011; Rees et al., 2007), some more generally on low vision services (Culham et al., 2002; Percival, 2012). A number of studies focused on the needs of people with sight loss (Cimarolli et al., 2012a; Deremeik et al., 2007; Lamoureux et al., 2004; Whitson et al., 2011; Rees et al., 2007; Peel et al., 2011; Boerner and Cimarolli, 2005; Singletary et al., 2009). We included these if they had implications for rehabilitation support. The remainder focused more specifically on OT practice (Campion et al., 2010; Cimarolli et al., 2012b; Ward et al., 2009), self-management programmes (Rees et al., 2010; Rees et al., 2007), peer support programmes (Buonocore and Sussman-Skalka, 2002; Kirkcaldy and Barr, 2011) or community based educational programmes (Chu et al., 2009; Percival, 2012).

In terms of the study population, five studies focused on older people in general. The rest concentrated on people with low vision, including three on age-related macular degeneration (AMD) and one on blindness secondary to stroke.

2.8.2 Reported outcomes

Only ten studies included in this part of the review explored outcomes of an intervention for people with visual impairment. They focused on a single component of an intervention that was perceived to be effective (for example involving family and friends in group based rehabilitation, Rees (2007)), or on a specific outcome of a rehabilitation intervention (for example its impact on coping patterns over time, Boerner (2006)) or on activities of daily living (Walter, 2007). One study centred more narrowly on outcomes for people with cortical blindness secondary to stroke (Gaber, 2010). Other studies assessed the impact of a specific type of rehabilitation programme, for example self-management programmes (Rees, 2010) or peer support programmes (Kirkcaldy and Barr, 2011; Buonocore and Sussman-Skalka, 2002) on quality of life for people with sight loss. Only one study analysed the outcomes of different service delivery models for people with visual impairment (Rogers, 2000).

Quality of life and well-being - including functional and psychological well-being

The clear message from the studies that evaluated group based self-management and peer support programmes is that these programmes make a positive contribution to the quality of life of people with sight loss.

Rees (2010) carried out a small pilot evaluation of a self-management programme for older adults with vision impairment. The aim of the programme was to enhance participants' skills to manage the practical and emotional consequences of vision impairment. This was achieved by providing information and specialist training (e.g. demonstrating low vision aids and mobility techniques) to the group and by encouraging participants to share their experiences and coping mechanisms and to apply new techniques in their life. The programme consisted of three-hour, weekly, structured group sessions for eight weeks. Using a post-test design and structured interviews with 15 participants to assess the feasibility of the programme, the authors reported that the programme had a positive impact on participants' mood, understanding of low vision and services available, as well as on their ability to manage the challenges of low vision. More specific positive effects of the self- management programme were reported in relation to using additional low vision devices or non-optical aids (e.g. magnifiers, markers and enlarged print items), and the uptake of services and activities (e.g. the audio library and a support group) after the programme.

Two studies evaluated peer support programmes. One (Buonocore and Sussman-Skalka, 2002) focused on a community programme that used trained older adult volunteers to educate and motivate their peers about age-related vision loss and the benefits of vision rehabilitation for people who were visually impaired. Using feedback from 63 volunteers, telephone interviews with 55 volunteers and 49 follow-up telephone interviews with the attendees, the study reported positive effects, with 90 per cent of attendees reporting that they had learned something new that could help them or someone they knew who had a vision problem (p. 289). The programme was also reported to have helped participants to realise that having vision impairment does not mean losing independence. About half of the respondents reported making more frequent visits to an eye doctor, paying attention to changes in vision, and learning about specific eye diseases following the programme (p.296).

The second study (Kirkcaldy and Barr, 2011) examined the impact of RNIB's 'Finding Your Feet' (FYF) peer support programme on the quality of life (QoL) of participants. FYF comprises a series of intensive peer support workshops with people with sight loss, to help them with practical and emotional support. The study used both qualitative and quantitative methods. The quantitative element involved 16 participants completing the Low Vision Focus QoL questionnaire before and after the programme (with three and a half months interval). The results of this are reported in the section of the review that deals with quantitative data. The qualitative element involved interviews with 17 participants, interviews with programme staff and observation notes of three separate programmes.

The qualitative data, showed improvement in participants' confidence and coping strategies and the authors suggested that FYF involvement may have had a positive influence on stabilizing participants' overall QoL.

Improvements in diverse life goals

Cimarolli (2006) explored the perceptions of 47 visually impaired people about the extent to which a US-based vision rehabilitation agency had addressed their desired life goals. They found that clients perceived services to have helped them with a number of life goals. These included: accomplishing daily tasks; increasing motivation, emotional adjustment, and confidence; providing life guidance, direction, and resources; helping with social interaction and enhancing social life; increasing knowledge of the eye condition, inspiring the pursuit of a new goal; acquiring new job or academic skills, and optimising eye health. The two most prominent areas in which rehabilitation services were considered to be effective were helping clients to accomplish daily tasks and adjust emotionally to vision loss. However, the authors suggest that the interrelationship between life goals and the outcomes of rehabilitation services should be considered as 'tentative', as the study is based on people's views rather than an assessment of service effectiveness in terms of improved functional and psychological outcomes (p.11).

A retrospective study (Walter 2007) examined the perceived efficacy of services provided by a comprehensive low-vision centre.

The centre was described as having a goal-oriented approach, operated by a multidisciplinary team providing a range of services including low-vision examination and functional assessments, orientation and mobility evaluations, counselling, community referrals, and device funding. Using a survey, patients were asked to rate the difficulty of the activities of daily living before and after they received rehabilitation. The authors reported that, while the service had made significant improvements in many activities of daily living after rehabilitation, vision related social activities (e.g. conducting normal social activities and entertaining friends and family in one's home) are much less likely to improve. The authors have highlighted a need for rehabilitation services to target vision-related social activities.

One study (Rogers, 2000) examined the effects of two service delivery models: a rehabilitation model and a consultant intervention model. The former used rehabilitation teachers to assess service needs and to carry out instruction. The consultant model relied on consultants with vision rehabilitation backgrounds to train home care managers to assess the need for rehabilitation services and to provide instruction to older people who were visually impaired. The study used information on pre- and post- intervention assessments on levels of performance relating to 41 specific daily living tasks in five domains (IADL, ADL, cooking, mobility, and text access). Findings suggested that the type of service delivery model did not affect the outcomes in three of the domains: ADL, IADL, and cooking. The key difference in outcomes reported in the two groups was that the first group had significantly greater pre-post change scores on mobility, whereas the second group had greater change scores on access to text. However, the authors suggest that no conclusions can be drawn from these findings about the differential effectiveness of the two models, as certain key variables (such as the level of vision impairment) were not included in the regression model used.

Coping and adaptation

The effect of rehabilitation service use on coping strategies was examined by one study (Boerner, 2006). This focused on different types of rehabilitation use (including seeing a low vision specialist, receiving counselling, rehabilitation/orientation and mobility training, optical aids and assistive aids) and three types of coping strategies (instrumental, affective and escape/distraction coping). Using interviews and structured assessments of functional vision loss and functional disability, rehabilitation service use and coping strategies, at baseline and two-year follow-up, the authors concluded that rehabilitation interventions can affect patterns of coping over time, and the scale of such an impact may depend on the type of rehabilitation received.

The study reported that those who use a greater number of assistive aids (like special lighting or large print material) are likely to report more instrumental/problem-focused coping over time, suggesting that the use of aids may enable a person to continue a variety of activities. Those who used a greater number of optical aids tended to report more escape/distraction coping over time, suggesting that the use of optical aids (such as a telescope or magnifiers) can make it possible for older people who are visually impaired to continue to focus on what they can do rather than their limitations.

By contrast, the study reported a positive effect of counselling on affective coping, suggesting that counselling may confront the person with the emotional aspects of the vision loss. The authors suggested that the effect of counselling on affective coping should be regarded as tentative, since the study lacked detailed information about the counselling sessions and those receiving them.

Features of good rehabilitation support

We found no single study specifically examining features of good rehabilitation support. However, almost all studies highlighted some of the areas on which support services would do well to focus their attention. None provides any evidence on features relating to the organisational structure, duration of intervention and leadership and management support that would contribute to the delivery of a good rehabilitation model. This section reports several common themes we have identified.

Holistic/person-centred approach

A number of studies emphasised a strong link between the ability to pursue personal life goals and well-being (Boerner and Cimarolli, 2005; Cimarolli, 2006; Walter, 2007; Cimarolli, 2012a) and hence support a model of rehabilitation programme that is based on an individual’s life goals and priorities (and not just basic daily functioning). Cimarolli (2006) showed that the life goals most frequently mentioned by participants as being important to them are health-related (74 per cent), work, career and education-related (70 per cent) and independence and mobility-related (62 per cent). Based on the evidence from this study, the authors suggest that 'it may be necessary for vision rehabilitation agencies to make the pursuit of life goals part of their curricula' (p.9).

Reporting on the same study, Boerner and Cimarolli (2005) noted that people with vision loss attach great importance to finances, residential and domestic arrangements, family, partner, and personal care. Family life and partner were most often reported as first priority. Improving ones’ relationships, followed by improving vision and improving work life were reported as the highest priorities in terms of the life goals that participants wished to work on over the next five years. However, one study (Deremeik, 2007) examining the needs and goals of low vision rehabilitation for a specific group of people - people with VI living in nursing homes - reported that tasks involving ADLs (such as eating and dressing) are not considered as goals by the participants. The authors suggest that heavy dependence of participants on assistance by staff may have contributed to the participants' failure to list these tasks as goals.

An Australian based study, (Lamoureux, 2004) also highlighted the multidimensionality of quality of life. Using a cross-sectional study involving 319 participants with vision impairment but no vision rehabilitation history and using the Impact of Vision Impairment (IVI) questionnaire, the study investigated the determinants of participation in daily living by examining the interaction of visual, demographic, personal, cultural, and environmental influences on vision-related functioning. The authors reported that mental health contributed not only to the emotional domain but also to other domains including leisure and work, consumer and social interaction, household and personal care and mobility, and that age and duration of visual impairment played no role in the linear regression models. The authors suggest that ‘an intervention aimed at improving quality of life may include strategies to improve not only vision-related rehabilitation but also mental and physical health’ (p.265).

Using a longitudinal design, Cimarolli (2012a) assessed the intensity of specific challenges experienced by older adults with significant vision loss due to age-related macular degeneration. They reported that although functional challenges are predominant, psychological and social challenges are also common and need to be addressed in vision rehabilitation too. Further, the study reported some changes in the nature and intensity of vision-related challenges in these three domains, over a 2-year period. It showed an overall increase in functional challenges, stability in social challenges and a decrease in psychological challenges. Possible explanations provided for this change include the progressive nature of the condition, learning how to use optical aids and adjustment to the psychological challenges. Highlighting the importance of rehabilitation planning to take account of such changes, the authors suggest that ‘vision rehabilitation needs to be a continuous process ... with a focus on re-evaluation and formulation of rehabilitation goals as opposed to a one-time intervention taking place following the initial contact with a rehabilitation service agency' (p.756).

Characteristics of people with VI using vision rehabilitation services

Two studies examined how cognitive impairment can affect effectiveness of rehabilitation programmes. One (Gaber, 2010) focused on the rehabilitation methods and outcomes for people with cortical blindness secondary to stroke. Using a small cohort of patients (n=7) and an examination of their clinical notes, the study compared the effects of therapy efforts on two groups: one group with total blindness and severe cognitive and behavioural impairments and the other group with partial blindness and significant memory impairment but no other cognitive impairment or behavioural problems. The authors reported that the rehabilitation outcomes for these two groups differed significantly.

The first group was reported to have shown almost complete lack of response to any rehabilitation effort. It was almost impossible to teach these patients strategies to compensate for their cognitive impairment; therefore, any rehab efforts to improve functional abilities/independence for this group had to be abandoned. The second group received a joint therapy input from sensory rehabilitation specialists and brain injury occupational therapists focusing on both environmental adaptations and strategies to cope with the memory impairments. Most patients in this group were reported to have shown significant improvement in their QoL. The authors suggest that sensory impairment rehabilitation approaches that rely on using compensatory methods have limited value for patients with severe cognitive impairments and very limited remaining vision. For those with memory impairment but no behavioural problems, collaborative work (including joint assessments, goal setting and implementations) maximises the rehabilitation programmes' effectiveness. Given this was a small study, involving only seven patients, caution should be made when interpreting the findings.

Another study (Whitson, 2011) examined the relationship between cognitive status and task-related functional trajectories among older adults receiving low vision rehabilitation. The study used longitudinal functional data collected from two to three time points from 91 participants to measure their cognitive status and ability to perform seven IADLs. It was found that participants with marginal cognitive impairment experienced steeper functional decline in ability on some measures (e.g. preparing meals and activities that requires distance vision) than those with more severe cognitive impairment. The authors suggest that this finding may reflect the ability of Low Vision service providers to modify care when a person shows sign of obvious memory loss (for example, by repeating their instructions); but when cognitive impairment is more subtle it may go undetected, making it less likely that the person receives appropriate care and more likely that they are more at risk of functional deterioration. The authors highlight the importance of low vision rehabilitation programmes routinely assessing cognitive deficits and conclude that ‘Patients with mild to moderate cognitive impairment should not be excluded from LVR, but programs should be prepared to detect and accommodate a range of cognitive ability’ (p.343).

Types of service delivery

As mentioned earlier, there is some evidence that group-based programmes have the potential to affect a number of client outcomes. By providing an opportunity for social interaction, group based programmes help participants increase their understanding and problem-solving skills, learning not only from professionals, but also from peers.

Based on data gathered from interviews with 48 participants with a range of eye conditions, Rees (2007) identified the areas that a generic low vision self-management course should cover. These included: vision-specific strategies, training in generic problem-solving and goal setting skills, as well as skills to cope with emotional reactions to vision impairment. Practical difficulties (mainly problems with transport to the course and travel costs, but also time and commitment), perceived lack of need, and unclear or negative perceptions of the programme have all been identified as potential barriers to participation. The authors highlighted the importance of ensuring that people can relate to what the programmes offer.

Soucy-Moloney (2001) note, that a group based model for rehabilitation teaching for adults is a ‘"win-win" situation’ (p.180). This is because the agency can provide instruction to groups of consumers in a range of settings while at the same time making efficient use of limited staff. However, the authors suggest that motivation, commitment to the programme, health status and stamina are important criteria when assessing the appropriateness of a consumer to group instruction. This suggests that a group model may not be suitable for all.

Access to specialist skills

We identified three publications relating to the specialist skills required by those providing support to people with vision impairment. All three publications focus on the use of occupational therapy. The first publication (Cimarolli, 2012b) focused on the influence of vision impairment on the use and effectiveness of occupational therapy services in sub-acute rehabilitation[3]. Using structured interviews with 100 older adult rehabilitation patients at admission to a sub-acute unit and discharge data, the study reported important gains in independent function after receiving OT services. On average, 60 per cent of patients were reported to have achieved independence and about 30 per cent were making progress towards independent functioning (p.221). The study concludes that vision loss adversely affects the effective and full use of occupational therapy but gives no details about why this is the case.

The other two publications (Campion, 2010; Ward, 2009), which report findings from a single study, examined the awareness of sight loss within OT practice and explored the education and training needs of OTs working with people with sight loss. Based on a survey of 241 members of two of the College of Occupational Therapists' Specialist Sections (Older People and Housing) and interviews with 19 heads of Higher Education Institutes in the UK, Campion (2010) reported that OTs need further education and training to equip them with the necessary skills and knowledge to improve outcomes for people with sight loss. Ward (2009) also identified improvements that could be made to the undergraduate and postgraduate education of OTs such as having workshops that deal specifically with sight loss.

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[3] Sub-acute rehabilitation refers to rehabilitation support offered to patients who no longer require hospitalisation, but still need skilled medical care in a rehabilitation facility. See: http://www.med.umich.edu/geriatrics/patient/subacute.html

Access to equipment

A single study (Percival, 2012) evaluated a programme that demonstrated daily living devices to older people with sight loss in order to identify participants' support needs and preferences with regards to such devices. The study was based on individual interviews with 60 service users and focus groups with 35 staff, pre-demonstration and post-demonstration. The authors reported that the types of assistive technology that mostly appeal to people with sight loss are those that are 'effective and easy to use', rather than devices that are 'too complex'. Furthermore, the study emphasised the importance of person-centred appraisal to ensure assistive technology packages meet the needs of low vision service users. The study suggests that early induction of daily living devices is likely to help an individual better manage daily activities and gain confidence.

Involvement of family/friends

The value of involving family members and friends in a group-based rehabilitation programme was examined by one small study (Rees, 2007). The study was based on interviews with 21 clients with low vision with different eye conditions and 64 vision rehabilitation professionals. Both groups were reported to be largely in favour of involving significant others in rehabilitation programmes, while also highlighting a number of pitfalls. For the professionals, the advantages focused on improving significant others' understanding of low vision and learning strategies to support a person with low vision, as well as providing practical/emotional support and helping a person with low vision implement the strategies at home. Disadvantages mainly focused on disrupting the group bonding and interaction. Older people were reported to have differing preferences. The majority were in favour of involving significant others, but some preferred to attend alone. The authors concluded that clients should be given the choice to involve significant others in group-based rehab programs (p.165). However, they acknowledged that this was a small study and conclusions were therefore not generalizable. The Cimarolli (2012b) study, mentioned above, indicated that, while family members and friends can be instrumental in encouraging people to take advantage of occupational therapy, they do not necessarily influence therapy outcomes.

2.8.3 Reported gaps in services

Availability of/access to services

A survey carried out in 2002 discussed the type and location of low vision services within the UK, including community-based services (Culham, 2002). Services covered in the study included optical and non-optical aids and appliances and modifications to the visual environment, including the use of new lighting and contrast enhancement techniques. The provider groups included hospitals with eye departments, social services, opticians/optometry practices, local societies/voluntary organisations for people with visual impairment, specialist teachers and colleges/universities with optometry/optical dispensing courses.

The study found that only a third of potential providers made an active contribution to low vision services (including the prescribing of low vision aids and/or support, such as counselling or training). The majority either did not offer this service (41 per cent), or simply sold magnifying devices without professional support (33 per cent). The authors note that this is a massive underutilisation of potential resources and suggest that recruitment of professionals with appropriate expertise, either into the hospital or in close contact with medical ophthalmic care, would contribute to the service.

In terms of the geographical location of service providers, the study showed that services are unevenly distributed across the country with service providers being concentrated in urban areas where population densities are highest, while rural areas are less well served. The authors noted that lack of services in some areas meant that some people had to travel long distances to access services. Travelling could be difficult where mobility is restricted by medical problems. Difficulty in accessing services due to problems with transport is also highlighted by other studies. For example, a US study focusing on a community based intervention to older adults in public housing facilities (Chu 2009), reported that only 44 per cent of older adult residents had the opportunity to participate in the community vision seminar. Others had been unable to participate because of transportation issues. Unclear and pessimistic expectations of what an intervention can achieve for people with low vision were also identified in Rees 2007 as barriers to participation in low vision self-management programmes.

A report by RNIB, Facing Blindness Alone (Kaye and Connolly, 2013), revealed that between 2005 and 2013, there had been a 43 per cent decline in the number of blind and partially sighted people in England getting council care and support. The report showed that of 128 authorities that responded to the RNIB's freedom of information (FOI) exercise across local authorities, ten local authorities said that they did not offer a structured programme of rehabilitation to people who were registered blind or partially sighted or had lost their sight. Of those local authorities who had put in place a structured programme of rehabilitation, 33 councils did not offer it before community care assessments had been carried out, and 23 councils had restricted rehabilitation support to adults with sight loss who were registered as partially sighted or blind (p.30).

Limited attention to diverse life goals

Despite great importance attached by people with vision impairment to a range of life goals, evidence suggests that vision rehabilitation programmes place more emphasis on basic activities and daily functioning than any other domain. Reporting evidence from a small US based study, Boerner (2005) examined the importance of life goals among working-age adults with vision impairment and the way in which rehabilitation addressed personal life goals. They noted that vision rehabilitation programmes more commonly target functional life domains (such as finances, personal care and work) than relationship related goals (including the partner and family domains). Accomplishing daily tasks, and increasing motivation and emotional adjustment to vision loss are reported as the life goals most effectively addressed by rehabilitation services, whereas life goals relating to the work domain are reported as being addressed ineffectively. Reporting findings from the same study, Cimarolli (2006) noted that the poor quality of services and a mismatch between the client’s needs and the goal of the service are the key reasons why rehabilitation services are considered to address life goals ineffectively. Further, the authors suggest that although vision rehabilitation may focus on teaching functional skills, teaching clients how to apply these skills when pursuing goals may not be adequate.

Based on evidence from another US study mentioned above, Walter (2007) suggests that vision rehabilitation programmes might target social functions (such as adjustment to loss of independence, control, burdened and stressed social relations, and low self-esteem) more explicitly.

Staff training, awareness and confidence

A report by the Guide Dogs for the Blind Association estimated that there were just 550 specialised rehabilitation officers operating within adult services across the UK (Guide Dogs for the Blind Association, 2007). The report also stated that the number of vision rehabilitation officers was declining. To generate a diverse rehabilitation workforce, the report suggests that OTs could undertake some tasks currently undertaken by vision rehabilitation officers. However, as mentioned above, evidence suggests that most OTs in the UK would need further education and training to be confident and competent to take on this role.

Findings taken from a single study, reported in two papers (Ward, 2009; Campion, 2010) indicate that a significant proportion of OTs perceive their training as regards sight loss to be insufficient. Ward (2009) report that only two per cent of OTs felt confident to assess and give advice to people with sight loss when they first qualified, despite the fact that most had reported that their undergraduate programme had included sight loss training. Among participants who had undertaken additional training, 88 per cent said that generally they would refer on to a sight-loss specialist team for further assessment or intervention. The authors suggest that the

OTs' lack of confidence in working with people with sight loss may have been due to the type of education they had received at undergraduate level being mainly 'condition-based', with low priority given to the types of interventions that they might use with older people who had sight loss to improve their independence.

Furthermore, a small UK based study by Percival (2012) evaluating a programme of assistive technology demonstration projects, involving interviews with people with VI using sight loss services and focus groups with staff in four centres providing support to people with sight loss, found that the people with sight loss and the support staff had limited knowledge of assistive technology devices. Evaluation indicated that support staff would benefit from increased levels of confidence and training to maximise people's access to, and appropriate use of, assistive technology.

2.9 Conclusions from the qualitative review / limitations of the evidence

A number of key messages emerged from this element of our review. The findings suggest that people with sight loss attach great importance to different areas of their lives and that rehabilitation programmes have the potential to affect a number of outcomes positively, including functional and psychological outcomes.

The negative effect of vision impairment on both physical and mental health is well established in the literature. Research shows that people with sight loss have an increased need for emotional support (Gosney et al., 2010) and that the quality of life of people with vision impairment is more constrained by lost sources of pleasure and confidence than by constraints on their ability to perform essential activities (Reeves et al., 2004). Rates of depression among older visually impaired people are also reported to be at least twice those of the general population (Burmedi et al., 2002); yet people with depression are 64 per cent less likely to use any rehabilitation services (Horowitz 2003). There is also some evidence that people with visual impairment receive no offer of counselling and little or no information about equipment and community services at eye clinics (Murray et al., 2010) and this compromises people's short and long-term access to support (Thetford et al., 2009).

Despite a growing body of literature identifying the challenges facing people with visual impairment, most studies included in this part of the review reported that rehabilitation interventions more commonly target functional domains than other domains. The need for services to take account of individual's priorities in all areas, and address social functions and emotional adjustments to loss of independence more explicitly, was emphasised by a number of studies. A few studies drew attention to changes in the nature and intensity of vision-related challenges over time, highlighting the importance of having a regular assessment and a continuous review process to take account of possible changes. The shortage of vision services and the lack of sufficient training and low confidence among support staff who are not specialised in working with people with sight loss were other key messages emerging from the review.

While the studies reviewed have shed light on the value of community-based rehabilitation interventions for people with vision loss, no clear conclusion can be drawn from this part of the review about what model of care might maximise the self-care and independence of this group of people. Culham et al. (2002) argue that this is one of the main difficulties in determining the future rehabilitation needs. A number of important areas can be highlighted where further research may be valuable.

Focusing on a single component of rehabilitation intervention is a key limiting factor in the evidence base. As Lamoureux (2004) argues, quality of life draws from the interaction of several components including physical, social, functional and psychological; hence, ' a one-dimensional intervention program … may have limited success improving quality of life generally, such as self-care, mobility, activities of daily living, cognitive function, or emotional status' (p.265). Supporting this argument, Walter (2007) also notes that 'Research studies that focus on describing specific outcomes of low-vision rehabilitation rather than the entirety of outcomes may not be relevant in measuring rehabilitation services and their effectiveness' (p.104).

Another limitation of the evidence base arising from this part of the review is the failure of studies to take account of the context in which interventions take place. Factors such as general health, including physical and cognitive function and co-morbidities, level of visual impairment and availability of family and peer support are all important features to take into account when measuring the effectiveness of rehabilitation intervention as they may all have direct impact on the level of engagement with the intervention and therefore influence outcomes. However, most studies included limited data about participants' circumstances. The limited detail provided by some studies about the nature and content of the rehabilitation programme also leaves some unanswered questions about which aspects of the programme contribute to what outcomes.

The difficulty in making broad interpretations of the findings is another issue emerging from this part of the review. This is not only because the size of the samples used in most studies is small but also because participants are often recruited from a group of people with VI who are able to access services and therefore more likely to be motivated to look for and use services, raising the possibility of the findings being biased. Larger studies, with sufficient sample size and more robust methods are needed to assess the success and cost-effectiveness of different models of rehabilitation for people with visual impairment.

Chapter 3 Scoping Workshops with Professionals and Rehabilitation Service Users - Stage 2

3.1 Aims

The second stage of the study included four workshops – two with professionals and two with people with VI with the experience of rehabilitation support. The purpose of the workshops was to:

- Clarify a working definition of rehabilitation for people with VI.
- Explore the main features of good rehabilitation support and service arrangements.
- Identify examples of ‘good practice’.
- To use the findings to refine the survey questions.

3.2 Methods

The topic guides drawn up for the workshop discussions covered participants’ backgrounds, views on what constitutes rehabilitation support, whether they thought rehabilitation worked equally or differently for different groups of people, features of good rehabilitation support, and the main challenges in providing good rehabilitation practice (See Appendices 6 and 7). For each group, one workshop was held in York and one in London.

3.2.1 Workshops with professionals

In total, 15 professionals took part in the workshops (six in York and nine in London) including three partially sighted rehabilitation officers (ROs). Participants had a mixture of backgrounds, experiences and training and were from 15 different LAs. Two were senior ROs and two were managers from Sensory Impairment

Teams. Three people were representing services contracted out by LAs; others were from services provided by LAs. Participants were recruited through the Rehabilitation Workers Professional Network, members of the advisory group and snow balling.

3.2.2 Workshops with people using vision rehabilitation services

People using VR services were identified by the professionals taking part in the professional workshops. In total, 21 people were identified. We held a telephone conversation with all nominated people and selected participants to ensure that a range of experiences were included. We invited 15 people to participate in the workshops. Eleven people took part (four in York and seven in London), four people were not able to attend the workshops on the day. Participants included six men and five women, experiencing a range of congenital and acquired sight loss, from different age groups and with different experiences of using rehabilitation support. Documents used for the workshops were converted into Braille or large print where necessary.

All workshop discussions were recorded, with the consent of the participants, and transcribed fully. Data gathered were analysed using the framework approach and by a process of data reduction, data display and conclusion drawing and verifying (Miles and Huberman, 1994). This method enables summaries of data from each source to be presented and analysed by the type of study participants as well as by themes.

3.3 Views of the professionals

3.3.1 What constitutes rehabilitation support?

All participants reported that rehabilitation support is about empowering and enabling people to maintain or regain their independence. Whereas for some people rehabilitation involves learning new skills (for example how to cook), for others it is more about learning how to use old skills in a new way (for example, revisiting a route where the layout of the road has changed). An important part of rehabilitation support was said to be building up people’s confidence and making a positive change in their behaviour and attitude by ‘turning ‘I can’t’ into ‘how can I?’’.

The general feeling was that rehabilitation support should involve a whole range of interventions including information, advice and signposting; orientation and mobility training; emotional support and counselling; teaching communication (e.g. Braille) and independent living skills; providing equipment and teaching people how to use it, assessing risk and ensuring that the environments in which people live are safe. Providing emotional support and counselling was reported as an important part of rehabilitation, not only in addressing psychological issues experienced by people with VI, but also in motivating some people to engage in rehabilitation. Giving people magnifiers and teaching people how to use them was said to make a big difference to some people’s lives, but there was some concern that people did not always use the magnifiers provided by the hospital, either because they were not appropriate for their needs, or because they were not taught how to use them.

While all participants reported that rehabilitation benefited most people in one way or another, they felt that it worked differently for different people. For example, people with moderate learning difficulties may not benefit from mobility training, but there is value in them carrying a white stick to let others know that they are visually impaired; people with Alzheimer’s benefit from repetitive and regimented training. People’s cognitive and learning abilities, as well as their motivation and commitment to learning, impact on what rehabilitation can achieve for people and how long the process might take. Whereas some people may need one visit or even just a phone call, others may require a number of visits over a period of time. There was also a feeling that some people may resist becoming more independent for the fear of losing their social/family contacts, or access to a carer - ‘If I can go to the post office on my own, the person who takes me… all that might go’. It was therefore suggested that the scale and mix of intervention employed and the frequency/length of support should have no bearing on how rehabilitation should be understood; rehabilitation should be defined in flexible terms so that it can be applied to different circumstances.

3.3.2 Features of good rehabilitation support

Access to specialist skills

The commitment, enthusiasm, knowledge and skills of front-line staff were highlighted by all participants. The ideal rehabilitation worker was described by participants as someone with specialist knowledge, skills to motivate/encourage people to ‘do things for themselves’, rather than ‘having things done for them’, and the right mind-set with a positive and problem solving attitude. The shared view was that workers without specialist knowledge and skills are not trained to see ‘outside the box’ and may not recognise the rehabilitation potential in people with VI. Hence, they may miss opportunities for developing independent skills. For example, an OT may give people a liquid level indicator by default, thinking ‘that’s good to sort everything’, whereas people with VI may not even find the cup or see where to pour. Another example given was an OT not knowing that a person who is registered blind due to tunnel vision could still be able to read a newspaper.

High quality specialist assessment was considered essential in delivering the most appropriate rehabilitation support. A good assessment was said to be about asking people with VI the right questions:

'... if all you're asking is something like ..."do you get out of the house?" [or] "are you alright?" ... they might miss out on the whole emotional side of things'.

One participant had this to say:

‘… the Specialist Worker argument is one that’s always puzzled me, because if you’ve got a problem with your plumbing at home, you don’t call round an electrician. You call round a specialist plumber, unless you’re trying to do things on the cheap, and then it breaks and you go, … if … you’ve got a visual impairment, … they might get sent an OT who’s got a bit of awareness, or they might get sent a Rehab Assistant … They get sent who has been employed. And so, it’s just a really strange thing, why some areas, you always get Specialist Workers, but other areas, it seems okay to just have diluted services.’

Personalised support

All participants highlighted the importance of rehabilitation support being service user-led rather than worker-led. This means placing the person with VI in the centre of the assessment and identifying what people want to achieve and how they want to achieve it.

It shouldn't be the Rehab Worker saying, "I'm here to do this with you." It should be the Rehab Worker saying, "I'm here to find out what you need and do that with you."

An example given of a worker–led support was spending six weeks teaching someone to make a cup of tea if that was not something they would want to do. However, in a person-centred approach rehabilitation support should focus on the areas indicated by the assessment as being the result of his/her visual impairment, for example, the person becoming isolated or not being able to use a computer. There was a suggestion that younger people may prefer to have a taxi card or other means of travelling from A to B, rather than using a cane, as they may regard the latter as being not socially acceptable.

Participants considered group-based teaching programmes to be particularly effective in helping people adjust to vision loss, as it makes people feel that they are not the only ones going through ‘the journey’.

Flexible support

The importance of flexibility over the timing, content and duration of support and the ability to adjust inputs in response to users’ abilities, needs and preferences was highlighted by all participants. The general view was that rehabilitation support is a process and a ‘journey’ that can change directions. It is therefore essential for the support to be flexible and not time limited. Some people may need additional support over time as their sight loss levels and/or needs change. Other people might ‘reframe’ their goals as they restore confidence and get motivated to do more. Therefore, small interventions could turn into bigger plans over time; for example someone who has learnt the route to the school/doctor may decide at a later stage to learn the route into town.

Timely intervention

The timing of intervention was considered an important factor in the success of rehabilitation. Intervention offered in the early stages of sight loss was thought to be more likely to prevent further complications, reduce care packages in the long-term and contain costs. It was reported that people may lose essential skills, interest and motivation if intervention is offered years after they have lost their sight. One participant quoted a client telling her: “I haven’t made a cup of tea for 80 years; I’m not going to start now”.

Planning services for the future was said to be particularly important for people with learning difficulties. The best time to offer rehabilitation support to adults with learning difficulties was thought to be when they lived with their parents. Involving parents in rehabilitation was said to be more likely to result in better outcomes.

Close links/collaboration with other teams

Having close external links and collaboration with different teams, such as the Stroke Team, was thought to be essential for achieving maximum outcome for individuals. With an aging population, this was said to be particularly important as older people have other conditions that may impact on sight loss. There was a suggestion that understanding how professionals worked together was ‘a steep learning curve’, yet ROs received minimal training on inter-professional working. The value of networking, information sharing and continuous professional development opportunities was raised by all participants. However, there was some concern that budgetary restrictions had reduced continuing professional development (CPD) opportunities and that there was pressure on people to do networking in their own time, rather than during work time.

3.3.3 Challenges in current rehabilitation practice

The biggest challenge facing current rehabilitation services was said to be related to insufficient capacity in the service. A large number of people with VI was said to be either screened out or not receiving appropriate support. This was said to be because often people who carry out assessment of their support lack specialist knowledge and do not appreciate the value of rehabilitation. The waiting list and throughput was thought to put pressure on ROs to ‘get people moving’, impacting on the flexibility of responding to individual needs.

‘We are no longer treating visually impaired people as service users. They are a number, they are a target, and that’s all they are now… we have to … close a case as quickly as possible … more and more complex needs coming to our team and a lot of more generic work being dropped on our team ‘cause the word ‘vision’ is somewhere in the report…’.

The lack of professional registration was reported to be the key factor resulting in ROs not getting the same recognition and professional standing as, for example, social workers and OTs. Most participants felt this often led to other professionals not making referrals to rehabilitation teams.

While all participants reported that rehabilitation services tended to work flexibly, in terms of both the type and duration of support, there was some concern that certain outcomes appeared to be recognised as being more essential than others and it was therefore easier to justify an extension for these interventions. For example, it would be easier to make a case for people’s safety than ‘woolly stuff and less easily defined things’ such as emotional support, or support that is considered to be more time consuming - such as teaching Braille.

A service managed by specialist ROs was also thought to impact on service flexibility. The general feeling was that where services were not managed by specialist ROs they tended to become target-driven with quantity becoming more important than quality and ROs feeling more under pressure to cut corners to hit targets.

‘… we have to justify [extending the duration of support], obviously, but they [specialist managers] take our word as the word of a professional. Because we are qualified, they see – when we say that this client needs that time to regain their independence, they say, “You’re qualified. You have the knowledge to understand why this client needs that much extra time.” So, if you have understanding managers, I think they allow you that extra time to complete your work with the client.’

There was also a suggestion that contracted-out services were less flexible in terms of extending the duration of rehabilitation support because they are more restricted by the number of hours they are paid for than LA in-house services.

3.4 Views of people who use vision rehabilitation services

3.4.1 What constitutes rehabilitation

All participants had a shared understanding of what rehabilitation support was about. They described rehabilitation as the support that aimed to maximise people's independence rather than doing things for people; teaching people how to manage their daily activities on their own; helping people live a 'normal life'; and enabling people 'to access mainstream society'. This involves giving people the equipment they need and helping them learn and relearn skills to become as independent as they can be. It also involves encouraging people to be independent and giving people confidence - telling people that they 'can do it … [they] just have to do it in a different way'.

3.4.2 Features of good rehabilitation support

Holistic support
Sight loss was viewed by all participants as a 'serious bereavement' which can present itself in so many ways and completely change one's lifestyle. It was therefore considered essential for rehabilitation support to be holistic, covering a range of support; not only offering equipment and practical support, but also providing emotional support and counselling, learning/re learning skills, information and advice and help to maintain employment.

Personalised support
The importance of offering personalised support, listening to people and enabling people to engage in activities they want to engage with, rather than dictating to people what they should be doing and what they 'must find important' was highlighted by all participants. The general feeling was that the areas that people wanted

rehabilitation to focus on may vary from person to person. Whereas an older person may be particularly interested in making social contacts, for a younger person whose sight loss has caused the loss of his/her job, learning how to access a computer and getting back to work may be more important. It was also suggested that good rehabilitation support should have no time constraints as some people may take longer to respond to rehabilitation interventions.

Access to specialist knowledge and skills

As with the professionals, all people using rehabilitation services emphasised the importance of ROs having specialist knowledge, the right attitude for the job and being a good listener. Having personal experience of visual impairment was seen by some participants as an advantage for ROs. However, what mattered most to all participants was the workers' interest in vision impairment, flexibility of thought, the quality of work and ability to react to a situation and not 'just giving you a bath board to help you get in and out of the bath'. Training the partners of people with VI was also highlighted as an important feature of rehabilitation support; partners should be taught how to support a person's independence rather than to do things for them.

'My husband had to understand to wait until I said, "oh, give me a hand with this" ...They've got to learn to stand back a little bit, but to help enormously when necessary'.

Regular reviews

Regular reviews and follow-up sessions were said to be essential features of good rehabilitation interventions as they would enable the team to find out if the intervention has worked for people, detect any possible changes in support needs and/or identify new targets as people's abilities changed. A number of participants mentioned that they had learnt over time that if they did not ask for help, they 'would never get anywhere'. However, the general feeling among participants was that people with VI may not know what to ask for if they do not know what support is available. They felt that good rehabilitation support should not rely on people asking for help.

3.4.3 Challenges in current rehabilitation practice

A number of participants were concerned about ROs who lacked specialist training as they may not recognise what rehabilitation can help people achieve. Several participants felt that some managers, being deeply embedded in Social Services' ethos, tend to be more involved in 'caring' and safeguarding rather than thinking of rehabilitation as empowering and enabling people to find ways of doing things for themselves. For those managers, therefore, minimising risk tends to become an important element of rehabilitation support, hence focusing on providing liquid level indicators and white cane training.

There was a feeling among several participants that people with VI felt massively at the whim of their particular RO's interpretation of what might be the 'problem' and how it might be 'fixed'. One person considered it 'an institutional type attitude'. For example mobility training may be offered if the rehabilitation worker thinks mobility is a sign of independence, irrespective of what people think is important in their lives. Helping people with computer skills appeared to be very important to some people, particularly younger people, but most rehabilitation services were reported not to offer that.

'… the only way you can be a proper blind person is if you can walk around with your bus pass ... And it's like, … I hated going out when I was sighted. I like staying in and using a computer… it can, sometimes, I think, be a little bit of a battle of wills with a rehab officer about saying, "I'm not interested in going to the pub. I'm not interested in going shopping, because I use Tesco online, and they deliver it. I'm not interested in reading Braille," you know, which is an argument I've had on a number of occasions ...'

Part of the problem was seen to be related to rehabilitation services not having links with some services, for example Jobcentre Plus and Education. An assumption that people with VI did not work was thought to be the reason why there was little assistance with employment.

There were also some reports of rehabilitation intervention having time constraints. Examples were given of ROs saying to the client '"we've got to get done in 15 minutes", telling what they're going to do before you can even answer a question'. A number of participants reported that they were interested in learning Braille but they had struggled to get help from Social Services because it was said to be time consuming; a few people had relied on charities to learn it. Receiving no follow-up visits was a concern for many participants:

'... nobody said, "how are you coping? Has it worked? Are the things useful? They might be a waste of time for me, and they've spent all that money."'

The majority of participants thought information about what support was available and what people with VI might be entitled to was limited and fragmented. Some helpful information had been obtained by some participants only by accident (e.g. through a TV documentary or another person with VI). One person reported that when he was certified as blind, all he received at the hospital was a five minute chat. The inaccessibility of information was said to be particularly a problem for older people who tend not to ask for help:

'The hardest part for me was finding out what I was actually entitled to... the thing is there's nobody there to tell you... This is the trouble... The hospitals don't tell you any information ...When you want to find out what you're actually entitled to, what do you do next? There's none of that. No advisory service.'

The importance of peer support as a source of information was raised by most participants; there was a general feeling among some that people learn more from other people with VI than from ROs. While there were some examples of participants having received valuable advice from other people with VI, a few participants reported that they had no opportunity to meet other people with a similar condition.

3.5 Conclusion

This chapter reports findings from scoping workshops with professionals and people who use rehabilitation services. There was a shared understanding among both groups, of what constituted rehabilitation support. Both groups described rehabilitation as the support that aimed to enable people to become as independent as they can be and regain confidence. There were no noticeable differences between professionals and people who use services in terms of what they considered to be good features of rehabilitation support: access to specialist skills, personalised and flexible support, and timely intervention were highlighted by both groups as essential features of rehabilitation support. A key concern among professionals was shortages of specialist ROs as it impacted on their ability to respond effectively to individual needs; this was seen to be undermined by the lack of professional recognition of specialist VR skills. A key concern among people who use services, particularly younger people, related to assumptions being made by ROs for people with VI about the sorts of rehabilitation goals that were important to people with VI.

Chapter 4 The Survey – Stage 3

4.1 Aims

The aim of the national survey was to generate an overview of the prevalence, organisational models and capacity of VR provision currently available to people with visual impairment in England, and to identify where there might be gaps. This was to take place in two stages.

In stage 1, the aim was to contact local authority commissioners of adult VR services to identify services that are wholly- or part-funded by English local authorities (LAs).

In stage 2 the aim was to survey VR services identified in stage 1, to provide detailed information on the characteristics of the VR service.

4.2 Methods

Approval and support for the national survey was sought from the Association of Directors of Adult Social Services (ADASS) in two stages. Approval for stage 1 of the survey was received in June 2013. It was agreed that approval for stage 2 of the survey would be sought once the content of the questionnaire was finalised.

4.2.1 Stage 1

Directors of adult social care were emailed via the publicly available list of ADASS contacts. They were asked to forward the request for preliminary information about existing VR services to the appropriate person. Specifically, this requested baseline information on:

1. Whether the LA commissions/provides a structured programme of rehabilitation for people who are registered blind or partially sighted or have lost their sight?

2. Whether the VR service is provided:
    a. By local authority themselves i.e. ‘in-house’
    b. Jointly with health
    c. Contracted out to voluntary/independent sector organisation.

3. Contact details of the VR service(s) that the LA commissions:
    a. Name of providing organisation
    b. Name of manager of VR service
    c. Email
    d. Telephone Number.

Reminders were sent to those who did not respond to our initial request. Subsequently, as many routes and networks as possible were used to help fill in gaps in information, including: requests via Vision2020UK networks and Visionary newsletter, other networks suggested by members of the project advisory group and searches using RNIB’s sightline directory. In parallel, we searched LA websites and contacted adult social care services directly by telephone to try and gain the baseline information. A copy of the email invitation to participate in the stage 1 survey and accompanying information about the research is included in Appendix 8. A database was compiled of available information for all LAs and key contacts to be used in stage 2 of the survey.

4.2.2 Stage 2

Possible topic areas to be included in the questionnaire for stage 2 of the survey were identified, based on preliminary findings from the workshops and literature review. These were discussed by a meeting of the project advisory group. A draft questionnaire was designed using 'Qualtrics' software, a comprehensive online survey package supported by SPRU. This draft was circulated to the project advisory group and also discussed at a meeting of SPRU's adult consultation group. (The latter group comprises people who use health and social care services, or provide help from the voluntary sector, and meet regularly to discuss and advise on SPRU's current and future research.)

After incorporating comments, the questionnaire was piloted with three VR services, two in-house and one contracted-out service. Pilot services were also contacted by email and telephone to obtain additional feedback on the content and design of the questionnaire and its online performance. Further changes were made before submitting to ADASS. Approval from the ADASS research group was obtained 25th November 2013.

The final questionnaire comprised five sections which asked about the VR services funded totally or partly by local authorities.

Vision rehabilitation survey - questionnaire: section summaries

Section 1	Organisation and structure of the VR service and skill mix within the service
Section 2	Access, referral and assessment practices
Section 3	Type and reach of service provided
Section 4	Assessing and measuring outcomes of the service
Section 5	Costs and charges and experience of change

As far as possible the questions had closed responses, so that results could be compared across services to gain a national picture. Questions requiring a qualitative open response were confined to instances where more explanation might be required and questions designed to allow respondents to comment about their service.

The survey was distributed via ‘Qualtrics’ on 28th November with a request to complete responses by 23rd December 2013. A reminder was sent on 16th December. A final reminder was emailed to contacts on the survey database on 20th January and a reminder that the survey would close at the end of January was distributed via Vision 2020 UK (ltd), Visionary and London Visual Impairment Forum networks.

A copy of the final questionnaire, the email inviting people to participate in the survey and accompanying information sheet about the research in general and survey in particular, are in Appendix 9.

4.3 Results

4.3.1 Stage 1

Out of the 152 LAs with responsibilities for adult social care contacted, 100 completed a request for baseline information. This included one LA that replied that no structured programme of rehabilitation for blind or partially sighted people was commissioned or provided.

Baseline information about vision rehabilitation provision was obtained for a further 45 LAs using additional professional networks. By November 2013, a contact email address that could be used in stage 2 of the survey had been recorded for all LAs. For six LAs where information was incomplete, a generic contact address for the LA was used, rather than a personal or team email address.

Table 4.1 Type of vision rehabilitation provision for local authorities in England with responsibilities for adult social care

Type of vision rehabilitation provision	Number	Percentage
In-house	101	66
Contracted out	32	21
Combination in-house and contracted out	6	4
Joint health and social care	3	2
Joint health and social care - contracted out	1	1
Social enterprise	2	1
No VR service	1	1
Unknown	6	4
Total LAs	152	100

NB: percentages may not total 100 due to rounding.

4.3.2 Stage 2

A total of 89 survey responses were received including two refusals, thus providing information on VR services in 87 of the 152 LA areas. This represented a response rate of 57 per cent.

Responses to the questionnaire were analysed using IBM SPSS Statistics version 21, generating descriptive frequency tables for each section and further manipulating data to provide insight into the types of service models.

Section 1 Organisation and structure of the vision rehabilitation service

Participants were asked a range of questions relating to the main provider of VR services in their area, contractual arrangements, the type and location of the team and its mix of professional skills. A summary of the key findings are reported in Tables 4.2-4.4 below.

Table 4.2 Main provider of vision rehabilitation service and contractual arrangements

	Number of services	Percentage of services
Provider of core service:		
Local authority	53	61
Joint health and social care	3	3
Voluntary (not for profit) with LA funding	24	28
Pilot social enterprise	2	2
Private (for profit) with LA funding	2	2
Other	3	3
Total	87	
Core service contracted out:		
Nature of contract:		
Block contract	22	67
Outcome based	1	3
Spot purchasing	1	3
Via framework agreement	4	12
Other	5	15
Total	33	

NB: percentages may not total 100 due to rounding.

The main type of provision of VR services was that provided by LAs themselves in-house (61 per cent of services), with voluntary not for profit organisations providing a further 28 per cent of services (with LA funding). Models such as joint health and social care (3 per cent), pilot social enterprise (2 per cent), private (for profit) organisations (2 per cent) and other arrangements, such as a ‘LA trading company’ and a ‘partnership’ between the LA and ‘Royal Society for the Blind’ (sic) made up the remaining 11 per cent of services. There was a minority of LAs where, although they provided the core service in-house, some elements were contracted out via outcomes based contracts (three services), or framework agreements (two services). Such contracts were, for example, for home safety checks, maintaining the register, provision of basic equipment, and home visiting/befriending services. Where the core service was contracted out, the majority were via block contracts (67 per cent).

Table 4.3 Type and location of vision rehabilitation services

	Number of services	**Percentage of services**
Type of core team delivering vision rehabilitation:		
Specialist vision impairment team	28	35
Specialist sensory impairment team	33	42
Specialist physical and sensory impairment team	3	4
Multi-disciplinary re-ablement team	2	3
Other specialist multi-disciplinary team (including, for example, a stroke team) (please describe):	3	4
Part of generic adult social care team	5	6
Lone worker	3	4
Other	2	3
Total	79	
Where the core service is based:		
Local authority setting	47	60
Healthcare setting	2	3
Independent organisation setting	25	32
Other	5	6
Total	79	
Setting in which service delivered:		
Local authority	34	43
Healthcare	11	14
Independent organisation	23	29
intermediate care or re-ablement	13	17
Service user's home	67	85
Other	17	22
Total	79	

NB: percentages may not total 100 due to rounding or where more than one option can be selected.

The majority of services (81 per cent) described their core team delivering vision rehabilitation as ‘specialist’, either in vision impairment (35 per cent), sensory impairment (42 per cent) or physical and sensory impairment (four per cent). The majority of teams were based in a local authority setting (60 per cent), reflecting the type of provider. Services were delivered in a range of settings, typically in the service user’s home (85 per cent), but also reflecting organisational settings. Only two teams were described as re-ablement teams, but 13 (17 per cent) delivered their service, at least in part, within an intermediate care or re-ablement setting. ‘Other’ settings described were ‘out door’ or local community settings including adult education establishments.

Table 4.4 Professional skills within teams

	Number of services	Percentage of services
Manager of service (based on 79 responses):		
Specialist in vision impairment	28	35
Specialist in sensory impairment	14	18
Specialist in physical and sensory impairment	1	1
Occupational therapist (OT) – not specialist in vision impairment	10	13
Generic social worker	11	14
Other professional – not specialist in vision impairment	15	19
Total	79	
Skills represented in teams (in addition to manager):		
Senior ROVI	23	35
ROVI	60	92
Assistant ROVI	16	25
Assistive technology specialist	7	11
Social worker	16	25
Community care officer	14	22
OT	4	6
Eye clinic liaison officer	11	17
Other	12	18
Total	65	

NB: percentages may not total 100 due to rounding or where more than one option can be selected.

There were a range of professional skills represented in teams. Just over a third of managers (35 per cent) were described as being specialists in vision impairment and a further 18 per cent in sensory impairment. Managers included in the ‘other, not specialist in vision impairment’ included a speech and language therapist, specialist in strokes, ‘enablement’ manager, ’locality’ and ‘generic’ manager.

Within teams generally, rehabilitation officers for visual impairment (ROVIs[4]) were the profession most typically found (92 per cent of services). 'Other' skills in some teams included registration and equipment advisors, advocacy/welfare rights worker, dual sensory impairment workers, link-worker and independent living worker.

Section 2 Access, screening and assessment practices

Initial access to VR services may be by a number of routes, and referrals, assessments and reviews were dealt with in varying ways summarised in Table 4.5 below. Initial access to the service was most commonly by a referral from a health or social care professional (94 per cent of services), which could include a certificate of visual impairment (CVI), but 'open access' was a feature of 89 per cent of services. Other routes described were via voluntary organisations, education or housing, or following receipt of a CVI. Referrals were not necessarily screened initially by a person with specialist skills in vision impairment, but specialists were overwhelmingly involved in assessments (95 per cent). However, nine services (11 per cent) reported that assessments may be carried out by someone without specialist skills in vision impairment. Only one service reported this to be the predominant position. Assessments typically took place in the service user's home (97 per cent). A quarter of services required a FACS assessed community care assessment to determine eligibility.

The way in which people could access the service again was commonly by re-activating formal intake procedures (67 per cent), although a number of ways of prioritising need or by-passing formal processes were described. Review of service users' needs either at an agreed interval or more informally was a feature of most services.

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[4] The abbreviations ROVI and RO are used interchangeably.

Table 4.5 Access to service, screening of referrals, assessments and review

	Number of services	Percentage of services
Access to service:		
Referral from health or social care professional	73	94
Self-referral/open access	69	89
Other	21	27
Total	78	
Screening of initial referral by:		
Professional with specialist skills in vision rehabilitation	47	60
Professional without specialist skills in vision rehabilitation	19	24
Administrative staff	26	33
Other	7	9
Total	78	
Assessment carried out by*:*		
Professional with specialist skills in vision rehabilitation	75	95
Professional without specialist skills in vision rehabilitation	9	11
Other	4	5
Total	79	

FACS assessed community care assessment required:		
Yes	20	25
No	25	32
Sometimes but not a requirement	34	43
Total	79	
Where majority of assessments are carried out:		
Service user’s home	76	97
Health setting	4	5
Social care setting	4	5
Independent organisation setting	2	3
By telephone	2	3
Other	4	5
Total	78	
Re-accessing service:		
Re-activating formal intake procedures	52	67
Open access via waiting list	29	37
Open access (by-pass waiting list)	12	15
Other	14	18
Total	78	

Review of service users' needs (based on 76 responses):		
Formal follow-up at agreed time interval	48	63
Informal review	22	29
No review	16	21
Total	76	

NB: percentages may not total 100 due to rounding or where more than one option can be selected.

Sixty-six per cent of services responded that there was a waiting list for their service with caseloads, waiting list numbers and waiting times varying widely (Tables 4.6 and 4.7).

Table 4.6 Waiting list

	Number of services	**Percentage of services**
Waiting list for service:		
Yes	51	66
No	26	44
Total	77	

Table 4.7 Team caseloads and waiting lists

	Number of services	**Mean**	**Median**	**Mode**	**Range**
Annual case load	59	486	350	multiple modes exist	16-2000
Approximate number currently on waiting list	41	40	36	50	2-147
Approximate waiting time (in weeks)	47	10	8	multiple modes exist	2-50

(The mean and median are different measures of average. The mean is the simple arithmetic average of all values of the distribution i.e. the sum of all cases divided by the total number of cases. The median is the mid-point of the distribution, the value that splits the cases into two equally sized groups. The mode is the most frequent value in the distribution. The range indicates the lowest and highest values in the distribution.)

Section 3 Type and reach of vision rehabilitation services

The type of training and support, how inclusive teams felt they were, and how they worked with other organisations were of interest.

The majority of services (97 per cent) described the support they provided as open-ended, depending on need, rather than time-prescribed, for example, for a maximum of six weeks. There was greater uniformity over the type of training offered by different services, than the type of support. Independent living skills, orientation and mobility and training in the use of aids, adaptations and equipment were predominant types of training offered. Self-management courses were provided for service users in just over a third of services responding. Other types of training which services mentioned included low vision aid, confidence building and training in accessibility issues. In terms of support, provision of aids, adaptations and equipment (99 per cent), and an information/signposting role (100 per cent) were most commonly reported, followed by emotional support for service users (79per cent) and support for partners and carers (80 per cent). Counselling was less likely to be offered (24 per cent) and out-of-hours support, for example, over evenings and weekends was offered by a minority of services (12 per cent). Re-ablement support, arranging respite or 24 hour care, were included as the other types of support that some services offered.

Table 4.8 Length of time support provided

	Number of services	Percentage of services
Time prescribed (for example, maximum six weeks)	2	3
Open-ended depending on need	75	97
Total	77	

Table 4.9 Type of training provided to service users

	Number of services	Percentage of services
Independent living skills	76	100
Orientation and mobility	75	99
Use of aids, adaptations and equipment	75	99
Communication, for example, Braille, IT	68	90
Training for partners and carers	68	90
Self-management courses	26	34
Other	16	21
Total	76	

NB: percentages may not total 100 due to rounding or multiple responses are permissible.

Table 4.10 Type of support provided to service users

	Number of services	Percentage of services
Aids, adaptations and equipment	75	99
Managing personal budgets	27	36
Emotional support	60	79
Counselling	18	24
Employment advice	43	57
Benefits/financial advice	45	59
Housing advice	34	45
Training/education advice	45	59
Support for leisure/social activities	49	65
Support for social relationships	35	46
Facilitating peer support/group work	38	50
Information/signposting	76	100
Personal assistants (PAs)	19	25
Volunteer support	35	46
Support for partners and carers	61	80
‘Out-of-hours’ support (for example, evenings and weekends)	9	12
Other	12	16
Total	76	

NB: percentages may not total 100 due to rounding or where more than one option can be selected.

Participants were asked if there were any groups who did not use the service but who would be eligible to use it, or they felt may be under-represented and what the reasons for this might be. People with learning difficulties were thought most likely to be not accessing services (37 per cent), followed by those from ethnic minorities (31 per cent). Forty-five per cent of services did not feel that any groups were under-represented (Table 4.11). Other people mentioned were those in residential or nursing care and those who were not certified, but may be experiencing some difficulties.

Table 4.11 Potentially excluded groups

	Number of services	**Percentage of services** (based on 74 responses)
People with learning difficulties	27	37
People with dementia	22	30
People with acquired brain injuries	15	20
People who have experienced strokes	14	19
People who have multiple sensory impairments	7	10
People from ethnic minorities	23	31
People living in rural areas	6	8
Other	5	7
None	33	45
Total	74	

NB: percentages may not total 100 due to rounding or where more than one option can be selected.

The most likely reasons for exclusion were a lack of information about the service (86 per cent) or the lack of links with other services (48 per cent) (Table 4.12). Other reasons mentioned were a lack of knowledge within the adult care team, people who could potentially benefit from the service feeling that they did not need support, language and cultural issues and a lack of resources.

Table 4.12 Reasons some people may not access the service

	Number of services	**Percentage of services**
Lack of information about the service	36	86
Lack of specialist skills within the team	2	5
Lack of team time	4	10
Lack of links with other services	20	48
Other	8	19
Don't know	2	5
Total	74	

NB: percentages may not total 100 due to rounding or multiple responses are permissible.

How easy it was for services to work with other organisations and professionals that might be involved in supporting service users was explored. Participants were asked to rank how easy it would be if the team needed to work with other organisations on behalf of a client as 'difficult', 'neutral' or easy'. Employment services (25 per cent), followed by other health professionals, such as GPs (23 per cent) were most likely to be reported as 'difficult'. After other adult social care services (70 per cent) and eye clinic liaison officers (ECLOs) (68 per cent), voluntary/private organisations were cited as 'easy' to work with (65 per cent). Organisations or professionals included in the 'Other' category were 'health providers and commissioners of vision services' classed as 'difficult' and fire services, Guide Dogs, low vision and children's services reported as 'easy'.

Table 4.13 Ease of working with other organisations and professionals

Organisations including (Total numbers)	**Percentage of services including (Numbers)**		
	Difficult	**Neutral**	**Easy**
(Other) adult social care (74)	1 (1)	29 (21)	70 (51)
Eye clinic liaison officers (ECLOs) (71)	9 (6)	24 (17)	68 (48)
Health OTs (74)	11 (8)	41 (30)	49 (36)
Other health professionals (for example, GPs) (74)	23 (17)	54 (40)	23 (17)
Other specialist teams (for example, stroke team) (74)	11 (8)	45 (33)	45 (33)
Housing services (74)	10 (7)	57 (42)	34 (25)
Employment services (73)	25 (18)	47 (34)	29 (21)
Training/education services (72)	15 (11)	58 (42)	26 (19)
Benefits services (72)	8 (6)	49 (35)	43 (31)
Voluntary/private organisations (74)	1 (1)	34 (25)	65 (48)
Other (8)	13 (1)	25 (2)	63 (5)

Section 4 Assessing and measuring outcomes

Performance indicators (PIs) were a feature of the majority of services (76 per cent) (Table 4.14). Out of those services reporting that they used PIs, these were most commonly around referrals (for example, the number of referrals responded to within a specified time limit). A minority (14 per cent) reported other types of performance indicators that included numbers of assessments, rehabilitation training sessions, group training sessions completed in a year, contact hours and time taken to complete tasks.

Table 4.14 Performance indicators

	Number of services	Percentage of services
Are performance indicators applied to the service:		
Yes	57	76
No	18	24
Total	75	
Out of 57 services - Types of performance indicators (PIs):		
PIs around referrals	48	85
PIs around interventions	36	64
PIs around reviews	21	38
PIs 'other'	8	14

NB: percentages may not total 100 due to rounding or where more than one option can be selected.

As well as the use of PIs to assess the service, respondents were also asked if they measured the impact of their service on service users and if so, about the nature of their outcomes measurement (Table 4.15).

Table 4.15 Outcomes for service users

	Number of services	**Percentage of services**
Does the service measure its impact on service users:		
Yes	44	58
No	32	42
Total	76	
Does the service use a standardised outcomes measurement tool:		
Yes	19	43
No	25	57
Total	44	
If **not** a standardised outcomes measurement tool, was it developed in discussion with service users:		
Yes	4	18
No	9	41
Don't know	9	41
Total	22	

NB: percentages may not total 100 due to rounding.

Just over half (58 per cent) of services responding to this question replied that they measured the impact of their service on service users. However, less than half (43 per cent) of these used a standardised outcomes measurement tool. Standardised outcomes measurement tools mentioned were the ‘Action ladder’ developed by Action for Blind People, an adapted OT assessment tool and Likert scales. One service used ‘standard outcomes linked to local authority and UK vision strategy’ and another used ‘national service user outcomes’. Where other ways of measuring outcomes for service users were used, only four (18 per cent) of services replied that these had been developed in discussion with service users.

An open question explored how respondents felt that measuring outcomes on service users had influenced their practice. Responses varied from ‘no impact’, to ‘useful in seeing what the team achieves and why’. Some went further to describe how this helped them reflect on, or redefine their service and respond to service user needs quicker and was important in reviewing and developing their practice. It could ensure that the service focussed ‘more closely on what the service user felt was important to them, rather than what the service assesses as important’. Outcomes measurement could also be effective in demonstrating to commissioners the positive impacts on service users of rehabilitation. A drawback, or limitation, for one service was that their outcome measurement tool was very much linked to social care guidance and policy and not specific enough to people with visual impairment.

Section 5 Costs, charges and changes

The final section asked about costs and charges for the service and changes that the service might be experiencing. Data for overall budgets were poorly reported. Several services felt unable to provide the information as it was judged confidential and/or commercially sensitive. Some provided partial information on elements of the service, making comparisons for total budgets across services difficult. Others described how all or parts of their budget were combined with other services, making extracting information for the rehabilitation service difficult. Where data were submitted, based on 28 services, budgets ranged from £13,000 to £800,000, the median value being £133,000 (Table 4.16). The percentage split between different components of the services was examined. Other areas reported were costs associated with management of contracts, administrative support, accommodation, and training for service users. Budgetary data from the survey, along with case study data, were used in more detailed calculation of costs of rehabilitation services and are discussed in a separate chapter.

Table 4.16 Available budget for 2013-2014

	Mean	Median	Mode	Range
Total available budget 2013-2014 (based on 28 responses):	£220,624	£133,000	£96,000	£13,000 – £800,000
Approximate percentage allocation of budget:				
Staffing (including wages, salaries, on-costs, excluding training)	75%	75%	70%	27%-97%
Staff training	5%	5%	5%	1%-15%
Equipment	8%	6%	5%	1%-27%
Travel	7%	4%	multiple modes exist	0%-34%
Other	20%	13%	multiple modes exist	3%-100%

Charges to service users varied across services (Table 4.17). A minority charged for equipment (nine per cent), or courses (three per cent), but charges for sighted guides or personal assistants were split with approximately one-third of services charging, a third making no charge and the remaining third not offering the service[5]. Other charges reported included some social activities and equipment (costing under £100).

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[5] The survey question asked about charging for 'sighted guides/personal assistants' combined rather than for each type of support separately. Unfortunately this means it is not possible to say how many services charged for a sighted guide and how many for a personal assistant.

Table 4.17 Charges to service users

	Number of services	**Percentage of services**
Service users charged (fully or partly) for:		
Equipment		
Yes	6	9
No	62	91
Total	68	
Courses, for example, computer, braille, self-management:		
Yes	2	3
No	56	85
Not offered by service	8	12
Total	66	
Sighted guides/Personal Assistants:		
Yes	22	32
No	23	34
Not offered by service	23	34
Total	68	
‘Other’:		
Yes	3	16
No	5	26
Not offered by service	11	58
Total	19	

Continuing professional development (CPD) was not always easy to access, nor available equally to all levels of staff within services. Managers and those with existing specialist skills in vision rehabilitation were most likely to be reported as having opportunities for CPD available, although a majority of services (85 per cent) reported that ROVIs may find it difficult to access (Table 4.18).

Table 4.18 Availability of continuing professional development (CPD)

	Percentage CPD available including (Numbers)	**Percentage CPD available but difficult to access (for example, lack of courses locally) including (Numbers)**
Manager of rehabilitation service	66 (23)	35 (12)
Senior ROVI	43 (15)	35 (12)
ROVI	60 (21)	85 (29)
Assistant ROVI	43 (15)	27 (9)
Assistive technology specialist	23 (8)	21 (7)
Social worker	34 (12)	18 (6)
Community care officer	31 (11)	9 (3)
OT	11 (4)	3 (1)
ECLO	20 (7)	9 (3)
Other	20 (7)	12 (4)

NB: percentages may not total 100 due to rounding or where more than one option can be selected.

A majority of services reported that their budget had decreased (23 per cent) or stayed the same in the previous year (71 per cent) with only four services reporting an increase in their budget. Changes in staffing ratios showed a similar pattern (Table 4.19).

Table 4.19 Changes to budgets and staffing ratios compared with previous year

	Number of services	Percentage of services
Changes to budget:		
Increased	4	6
Decreased	15	23
Stayed the same	47	71
Total	66	
Reasons for decrease in budget:		
Changes in configuration of the service	5	33
Austerity measures/financial cuts	12	80
Other	4	27
Total	15	
Staffing ratios:		
Improved	6	9
Worsened	15	21
Stayed the same	50	70
Total	71	
Reasons for decrease in staffing ratios:		
Changes in configuration of the service	5	33
Changes in recruitment or retention of staff	3	20
Austerity measures/financial cuts	13	87
Other	2	13
Total	15	

NB: percentages may not total 100 due to rounding or where more than one option can be selected.

Where services had experienced an increase in their budgets (four services), this was attributed to changes in the configuration of the service or to changes in costs. Where budgets had decreased, 80 per cent cited austerity measures/financial cuts to services among reasons for budget changes. Similarly, a minority of services (six) reported improved staffing ratios. Reasons were equally spread between changes in configuration of the service, changes in service user demand and changes in recruitment or retention of staff. However, where staffing ratios had decreased, a majority of services (87 per cent) cited austerity measures/financial cuts among perceived reasons for the change.

The vast majority (90 percent) of services did not experience any problems in recruiting or retaining staff (Table 4.20).

Table 4.20 Problems with recruiting and retaining staff

	Number of services	**Percentage of services**
Service experiencing problems in recruiting staff:		
Yes	7	10
No	64	90
Total	71	
Service experiencing problems in retaining staff:		
Yes	7	10
No	65	90
Total	72	

Six out of seven services experiencing problems in recruitment blamed a lack of suitably qualified or trained staff. Out of seven services reporting problems in retaining staff, pay levels were seen as the reason by four services, and three services believed austerity measures/financial cuts had played a part. Other reasons cited were changes in contractual and funding arrangements.

Key differences

A comparison between specialist and non-specialist services was an area of interest to the project advisory group and one that had been raised during workshops with staff from VR services. Skills reflected in the management of teams were also identified as an area of interest linked to potential differences in type of provision and specialism. Data were therefore examined with expanded tables comparing firstly, the type of provider and the type of core vision rehabilitation team and then the type of provider and the management of the service. Data for these expanded tables appear in Appendix 10 - Tables A10.1 and A10.2.

Local authority in-house services showed the greatest diversity in the type of team delivering the service with examples across all categories (Appendix 10 - Table A10.1). The most common type of team found within LA in-house services was a sensory impairment team (57 per cent[a]). Three-quarters (75 per cent[b]) of voluntary sector (not-for-profit) providers were specialist vision impairment teams, comprising 64 per cent (c) of all such teams. The three services (d) provided jointly by health and social care were all part of multi-disciplinary teams or part of a generic social care team. Both pilot social enterprises were reported as specialist sensory impairment teams (e).

Table A10.2 (Appendix 10) provides a comparison of the management of teams across different types of provider. Overall, just over a third of managers (35 per cent) were described as specialists in vision rehabilitation. Within voluntary sector (not-for-profit) services two thirds of managers (67 per cent[f]) were described as a specialist in vision impairment, comprising over half of such specialist managers (g). This compared with 22 per cent (h) of managers in LA in-house services described as specialists in vision rehabilitation. Within LA in-house services, team managers were most likely to be drawn from a range of professions. Generic social workers were the most common professional group - almost a quarter (24 per cent[i]) of LA in-house managers. The managers of the three services provided jointly by health and social care were non-specialists in VR services, either an OT or other professional (not-specialist in vision impairment) (j).

Key differences between the two main types of provider – LA in-house or voluntary sector (not-for-profit) organisations were examined statistically. For categorical data, where respondents chose between two options, such as whether or not there was a waiting list for the service, statistical measures of association were generated where possible, appropriate to nominal, categorical data (Pearson chi square, contingency coefficient). In the case of continuous data, for example, caseloads or waiting times (and given that data were not normally distributed), a non-parametric test of association, the Mann Whitney U test, was used. Tables A10.3 and A10.4 in Appendix 10 report statistical data.

a. Specialist versus non specialist teams

As noted above there were clear differences between providers as to the type of team delivering VR including the degree of specialism in teams. Differences between the degree of specialism between LA-in-house and voluntary sector not-for-profit core teams was statistically significant when comparing teams specialising in VR or sensory impairment (Appendix 10 - Table A10.3). As noted above, 75 per cent of all voluntary sector not-for-profit teams were specialist in VR (20 per cent LA in-house) and 57 per cent of LA in-house teams were specialist in sensory impairment (13 per cent voluntary sector not-for-profit) (Appendix 10 - Table A10.1). However, there was no significant difference if teams specialising in sensory and/or physical impairment (as well as VR), or if those describing themselves as ‘other specialist teams’ were included in a ‘specialist team’ category and compared across main provider.

b. Management of teams

The differences in specialism between LA in-house and voluntary sector not-for-profit core teams extended to differences in management (Appendix 10 - Table A10.2); managers specialist in VR were statistically significantly more likely to be found in voluntary sector not-for-profit core teams. This difference remained significant if the degree of ‘specialism’ was extended to include sensory and physical impairment as well as visual impairment (Appendix 10 - Table A10.3).

c. Type of training or support offered to service users

The literature review in stage one of the research had suggested self-management courses were particularly effective in rehabilitation. Twenty-five per cent of LA in-house services delivered self-management courses compared with 39 per cent of voluntary sector (not-for-profit) providers. The difference in the type of provider delivering self-management courses was not statistically significant (Appendix 10 - Table A10.3).

d. Working with other organisations and professionals

When ease of working with other professionals or organisations was examined according to main type of provider, differences were not significant except for working with OTs from health services and links with housing services. Numbers were small, but out of those answering this question, eight out of 34 LA in-house services ranked working with Health OTs as difficult (as opposed to neutral or easy), compared with none of the voluntary sector (not-for-profit) services. The only other significant difference was in working with housing services, where again LA in-house services were more likely to rank working with housing as difficult (as opposed to neutral or easy) – seven services, compared with none of the voluntary sector (not-for-profit) services (Appendix 10 - Table A10.3).

e. Measuring outcomes for service users

Voluntary sector (not-for-profit) services were more likely to be measuring the impact of their service on service users (16 services or 70 per cent of voluntary sector (not-for-profit) services) compared with LA in-house services (19, or 46 per cent, of LA in-house services). However, this difference was not quite significant at the five per cent level ($p=0.07$) (Appendix 10 - Table A10.3). (Both pilot social enterprises and two out of the three joint health and social care services also measured outcomes.)

f. Budgets and staff changes

Voluntary sector (not-for-profit) services appeared to be experiencing pressures on budgets and staffing ratios disproportionately when compared with LAs. Although numbers of services were small, 27 per cent of voluntary sector (not-for-profit) services (six services) reported that budgets had decreased in the last twelve months, compared with 14 per cent of LAs (five services). Differences were not statistically significant. Similarly, 32 per cent of voluntary sector (not-for-profit) services claimed staffing ratios had worsened over the previous 12 months as against 18 per cent of LA in-house services. Again this difference was not statistically significant (Appendix 10 - Table A10.3).There was not the same disparity reported in changes in the recruitment and retention of staff.

g. Case loads and waiting lists

Responses were analysed for provider differences in annual case loads, waiting lists and their size and waiting times. Differences by type of provider were not found to be significant (Appendix 10 - Tables A10.3 and A10.4).

Open questions

The questionnaire ended with two open questions to managers of VR services:

1. What are you most proud of in your service?
2. What would you most like to change?

Information was analysed qualitatively to identify themes in responses, rather than numerically.

1. What are you most proud of in your service?

A number of themes emerged in the 65 responses returned.

Staff

The commitment and motivation of staff in enabling the provision of a quality service was a common theme in responses. The value of long-standing experience of some staff, along with the capacity to retain specialist staff and maintain training opportunities, was highlighted by some managers.

Specialism

Managers heading a specialist service were committed to maintaining specialist vision rehabilitation roles and input that could complement and work closely with other services. Specialist skills were seen as important in responding to the needs of people with visual and/or sensory loss. Inclusion of dual sensory loss within a service was seen as positive, especially given demographic changes.

Adapting to change and austerity

The ability to retain a specialist service was frequently seen as under threat due to cuts in services generally. Managers stressed the positive efforts made to be resourceful and continue to develop services within the context of static or diminishing resources.

Holistic services

Establishing good working relationships between staff and other services frequently had enabled ‘joined-up’ working and a more holistic service that could meet a range of needs.

Service user involvement

Listening to and involving service users in developing services contributed to providing flexible and responsive services and better outcomes for service users.

Processes

Having a service where access was easy and comprehensive specialist assessments were provided, being able to work with clients as long as required and offer open access after a specific input, were all processes seen as key in achieving better outcomes.

Outcomes for service users

The positive outcomes for service users and the differences staff made to both individual service users and to their family's lives were over-arching themes throughout responses.

2. What would you most like to change?

Sixty-two responses were returned to this question.

Visibility of and knowledge about vision rehabilitation services

This was a recurrent theme throughout managers' responses. There was a perceived need to raise the profile of VR services and improve awareness and knowledge of services. This was seen as enabling closer working with other services, and as key in establishing vision rehabilitation as part of a formal care pathway. There was a perception by some managers that the profile of VR services had deteriorated in restructuring processes, especially where specialist teams had been disbanded in favour of generic teams. The importance of the recognition of the role of specialist vision rehabilitation was seen as key to influencing the shape of services in times of huge change. A need to improve relationships with commissioners and health providers, in particular, was identified.

Financial cuts

A call for more funding was a frequent issue raised in responses. There was a concern that austerity and associated changes had a major negative impact on services in a number of ways. These included the loss of cohesion in VR services, pressures on numbers and type of staff, waiting times, the type of service that teams were able to provide and an increasing need to supplement gaps in other services. Examples of specific cuts in VR services, apart from freezing or losing posts, were the loss of group work and talking book services.

Specialist assessments

Linked to discussions about the status of VR services and concerns over budget cuts was a necessity to safeguard specialist assessments, especially in areas where rehabilitation via a generic team model was being adopted.

Bureaucracy

Several managers highlighted how the high levels of administration and local authority associated bureaucracy could become a burden and hindrance to providing a responsive and effective service.

Professionalisation and specialist training

It was felt that professionalisation of the rehabilitation officer’s role should be encouraged, with associated improved CPD opportunities specific to vision rehabilitation roles, prescribed training routes and registration of ROVIs.

Additional roles and support

Extra staff in existing roles, for example, ROVIs, were needed, but also managers expressed a need to incorporate roles within teams that currently may not be represented, for example, social worker, ECLO, community care officer. There was a desire to expand rehabilitation opportunities particularly in the area of emotional support and counselling, support to carers, group work and in meeting the needs of people in residential and nursing homes.

4.4 Discussion

Strengths and limitations of the survey

The survey element of the project took longer than we had originally planned. Stage 1 aimed to collect limited descriptive information about services which could provide a database for the main questionnaire in stage 2. The initial email to ADASS contacts and follow-up using additional professional networks provided baseline information for approximately two-thirds of LAs. The remainder required considerable effort that revealed difficulties in navigating LA websites and telephone systems that were complex and unhelpful for anyone attempting to identify whether a VR service exists in a locality, and particularly for potential service users. Although only one LA replied that no structured programme of vision rehabilitation was commissioned or provided, difficulties in obtaining an eventual response from six other areas suggests that this may also be true elsewhere.

The final response rate to stage 2 of the survey, 57 per cent, was deemed to be a good response rate for an online questionnaire that required considerable commitment to participate. Concerted efforts were made to increase participation in the survey, using professional networks and robust follow-up. Although disappointing in the context of professional interest in the future of VR services, it reflects a wider issue of the difficulties of obtaining information from LAs. The timing of the distribution of the questionnaire, before the Christmas/New Year period may have had an impact on responses, but was unavoidable within the constraints of the project timetable overall. The response rate of 57 per cent to stage 2 of the survey compared with, for example, a response rate of 46 per cent to the local government workforce survey 2012/13 (Local Government Association 2014) and a response rate of 60 per cent to the local authority youth services survey 2013 (Cabinet Office 2014).

There are, therefore, certain caveats in considering the survey findings.

- **Non-response***.* We know little about 43 per cent of LAs who did not respond to stage 2, beyond basic information that had been obtained in stage 1 of the survey, but might speculate that it may be ‘better’ services that have responded. However, there can be confidence in terms of representativeness of type of provider. The finding of 61 per cent LA in-house core service in stage 2 broadly corresponds to 66 per cent LA in-house recorded in stage 1, where the percentage of LAs for which baseline information was obtained was high (95 per cent).
- **Incomplete data***.* There were some questions that were not answered by all managers, or where data were incomplete.
- **Reporting errors***.* It became apparent in the later case studies and costing phases of the research that different services recorded caseload data in different ways that made comparisons difficult. For example, as discussed in the next section, caseload may be recorded as number of individuals or number of episodes, (which may lead to double-counting and inflate individual caseload figures).

Findings from the survey

It was not possible to identify a typical model of vision rehabilitation provision. There was wide variation in the type of team delivering vision rehabilitation compared across all types of provider and within the predominant LA form of provision. Services provided by voluntary sector (not-for-profit) organisations were most likely to be specialist in vision rehabilitation, including the management of their teams. The diversity of teams found within LA providers in particular and the range of management skills, coupled with the findings from the open questions, may reflect the wider changes in and pressures on adult social care more generally in recent years. Some LAs directly providing a VR service have responded to such changes by incorporating vision rehabilitation into existing or new models of delivery which have a more generic focus, or exist within other ‘specialist’ services. Hence, this is creating a diverse pattern of vision rehabilitation provision depending on local contexts of adult care delivery, with varying levels of specialism.

The wide variations included the composition of teams, how they operated and features such as caseloads and waiting times. The wide range in caseloads may be due in part to differences in recording and/or reporting contact with the team. Findings from the case studies suggest caseload data can be collected and interpreted as either number of individual clients, or number of episodes, and therefore may have been reported inconsistently in the survey. ROVIs were employed in the majority of teams, but were also highlighted as an area of staff shortages and where training and CPD opportunities and clear career pathways were lacking. This was sometimes linked to a lack of recognition of the importance of specialist vision rehabilitation skills in adult care and a declining profile for VR services generally. The importance of specialist assessments was an issue raised in earlier staff workshops and a concern that has been echoed in recent Royal National Institute for the Blind (RNIB) reports (Kaye and Connolly 2013, RNIB 2014). The current survey suggested that, although assessments tended to be carried out by someone with specialist skills in vision rehabilitation, this was not as common for the screening of the initial referral. Moreover, a quarter of LAs required FACS assessments to determine eligibility, which is contrary to current guidance (ADASS 2013) and in line with findings from the RNIB freedom of information exercise (Kaye and Connolly, 2013). With LAs restricting eligibility to ‘critical’ and ‘substantial’ care needs, this may be excluding many people with sight loss from receiving support, especially since the criteria applied often fail to address the issues important to them (Kaye and Connolly 2013, RNIB 2014).

Timely access to rehabilitation may be compromised by lengthy waiting lists for a service. The average waiting time of eight to ten weeks, with a maximum noted of almost a year, may risk care needs intensifying during this period. Since re-accessing the service was generally via re-activating formal intake procedures, timely ongoing support or capacity to respond to changing circumstances, may also be at risk.

The literature review in the first phase of the project suggested that self-management courses/ group work were particularly effective in vision rehabilitation. Self-management courses were offered by a minority (approximately a third) of services in the current survey and group work was noted as a casualty of financial cuts to services. The main focus of training and support for service users was around mobility, independent living skills and aids adaptations and equipment. A lack of information about VR services was reported as a key reason why people may not access services. This was also implied in the concern about the visibility of and knowledge of services, a dominant theme expressed in the final ‘open question’ comments. Linked to this concern was the issue of the importance of working with other organisations and professionals. The findings, suggesting difficulties around working with health professionals, housing (especially for LAs compared with voluntary organisations) and employment services, should be viewed with caution as numbers were small and, even where statistically significant, they may be due to chance in multiple comparisons. However, where difficulties were reported, this may reflect concerns about the profile/knowledge about the service. Furthermore, it was a concern raised particularly within LA core services, where a specialist vision rehabilitation team identity was more likely to have been eroded.

Measuring outcomes of the service for service users was not a universal practice and use of a standardised measurement tool was uncommon. Voluntary sector organisations and pilot social enterprises were more likely to be measuring the impact of their service, which may be linked to requirements of the commissioning process for these providers. There were differing views on the value of measuring outcomes, which may partly reflect the relevance and sensitivity of the measurement tools used by different teams, in capturing the specific needs of people with visual impairments.

There was a lack of transparency around budgets for VR services. Some managers viewed this as confidential or commercially sensitive information, while others indicated that extracting information specific to vision rehabilitation was problematic. Practices around charges to service users were variable, especially for sighted guides. There were no widespread problems identified in recruitment or retention of staff, but staffing ratios had deteriorated in some services and CPD, particularly for ROVIs, was reported as difficult to access. These changes and pressures on budgets reported by some services, coupled with the information from the open questions, suggests that adapting to wider financial cuts and diminishing resources was having a negative impact on VR service provision in some areas. The effects of financial cuts created challenges in all aspects of service provision, not only staffing levels, but the ways in which teams were able to work and the type of support they were able to offer.

Findings from the survey describe a diverse pattern of VR provision, in many areas under pressure from financial and structural changes within LA adult care. There are widespread concerns about raising the profile of vision rehabilitation and maintaining specialist skills, while responding to the challenges of developing services within a changing environment.

Chapter 5 Case Studies – Stage 4

5.1 Aims

The aim of this stage of the study was to examine whether the examples of ‘good practice’ identified at earlier stages were endorsed by those with direct experience of providing and using rehabilitation support and explore the factors perceived to promote or constrain the benefits of the service intervention for people with VI.

5.2 Methods

The findings from stages one, two and three were used to select three examples of VR services for in-depth study where different arrangements were being used. Two main criteria emerging from the findings were used to select the case study services: specialist versus non-specialist and in-house versus contracted-out arrangements. One focus group discussion with a sample of frontline staff and interviews with five rehabilitation service users were conducted in each case study site.

5.2.1 Focus groups with frontline staff

The purpose of these focus groups was to explore practitioners’ experiences of providing rehabilitation support, and their views on factors that facilitate or constrain the benefits of the service intervention for adults with VI. In total, 15 ROs took part in the focus group meetings (4, 6, 5). The focus groups were facilitated by two researchers. Each focus group discussion took two hours and was audio recorded, with the participants’ consent, and subsequently transcribed. Participants had a mixture of backgrounds and training and were considered most experienced members of the team in working with people with VI. All participants were recruited through the service managers. Telephone/email discussions with the managers of rehabilitation services in the study sites were held shortly after the focus groups in order to collect contextual information from the managers and verify the service profiles. See Appendix 11 for the topic guide used for these focus group discussions.

5.2.2 Interviews with people using rehabilitation services

The aim of these interviews was to explore service users' experiences of using rehabilitation support, including the types of advice and support they used/desired, the impact any support received had made on their lives and any problems they had experienced. Semi-structured interviews were conducted with 15 service users with VI, across the three study sites (five in each site). This included nine men and six women between the ages of 36 and 91. Interviewees experienced a range of congenital and acquired sight loss: nine with degenerative conditions, three with congenital conditions and three whose conditions had developed suddenly. Eleven interviewees lived alone, three lived with their partners and one lived with parents. Only one interviewee was working at the time of the interview. Fourteen interviews were face-to-face and one interview was conducted over the telephone to suit an interviewee who worked full-time. The people taking part in this research were identified by the ROs who had taken part in the focus groups but selected by one of the researchers in the team (PR) to ensure a range of experiences were covered, reduce the risk of bias in the recruitment and protect the identities of those who took part in the study. Two pilot interviews to refine the topic guides were conducted, one with a service user and one with a frontline member of staff. Those taking part in the pilot interviews were not from the sites that were participating as case studies. See Appendix 12 for the topic guide used for the interviews with service users.

5.2.3 Analysis of qualitative data

All interviews and focus group discussions in the study sites were recorded and transcribed fully (with participants' consent). The data generated from these interviews and group discussions were analysed using the framework approach. For further information see Chapter 3.

5.3 Rehabilitation services in the study sites

This section presents data collected from focus groups with frontline staff and telephone conversation and email discussions with the service managers in the three study sites. The focus group discussions with frontline staff focused on the key features of rehabilitation services and staff views on the factors perceived to facilitate or constrain the benefits of rehabilitation support for people with VI. Discussions with the service managers aimed at gaining some contextual information about the study sites and verifying data collected on service profiles.

5.3.1 Key features of rehabilitation services

Service profiles

This section summarises some of the main features of the rehabilitation services in each of the three study sites (Table 5.1). For more detailed information see Appendix 13.

Table 5.1 Key Features of Rehabilitation Services

	Site A	**Site B**	**Site C**
Who provides the service	LA providing the service	LA providing the service	Contracted out providing rehabilitation support to several LAs
Eligibility	Available to all groups, irrespective of whether or not registered Not dependent on FACS Community Care Assessment	Available to all groups, irrespective of whether or not registered Not dependent on FACS Community Care Assessment	Available to all groups, irrespective of whether or not registered Not dependent on FACS Community Care Assessment
Team delivering rehab	Dual Sensory impairment	Visual Impairment -situated within a Disability Service Team	Visual Impairment
Manager specialism	Social Work	Visual impairment, line managed by Disability Service Team manager specialised in OT	Visual impairment
Team composition	11, a mixture of FT/PT staff (including 4 ROs specialised in sight loss – all F/T)	7, a mixture of FT/PT staff (including 6 ROs – a mix of F/T and P/T)	11, a mixture of FT/PT staff (including 7 ROs – a mix of F/T and P/T)
Length of support	As long as required	As long as it is considered as a priority to maintain independence	Typically ROs can help clients to achieve a maximum of 6 tasks. They spend up to 8 hours on each task
Current case load	13 - 25	12 -26	15 -50
Current waiting list	59 people with waiting time of 28 days to 6 months	20/30 people with waiting time of 6/8 weeks	None. Clients contacted within 10-28 days

VI specialist input within the team

Sites A and B both work in-house. In site A, the core team delivering rehabilitation was reported to be a Dual Sensory Team with a manager whose background was in social work. The focus group participants in site A felt that the specialist input within the team was sufficient and that the variety of experience shared by the ROs was an advantage in helping the service users to get a service more quickly, while at the same time taking the pressure off other teams. For example, staff were able to get pieces of equipment such as bath/shower boards or a perching stool without having to wait, sometimes for months, for another team to issue them.

In site B, the rehabilitation team was reported to operate within a wider Disability Service Team (DST) with different layers of management. The rehabilitation team was led by a manager who was specialist in VI and was line-managed by the Disability Service manager with an OT background. There was some concern among focus group participants that having different layers of management was sometimes problematic. Unlike site A, participants in site B thought that the specialist input in the rehabilitation team was not adequate. While they were able to recommend simple adaptations (for example, lighting, handrails), anything more complex needed OTs' involvement. It was mentioned that the team had lost five ROs during the last 10 years, leaving the team with a backlog of 20 to 30 people with six to eight weeks of waiting time. As a result, participants felt under pressure to get through cases in order to meet the response times set by the Government (ADASS, 2002).

Site C had a contract to provide rehabilitation support to several LAs and was managed by two people sharing responsibilities; both managers were specialist in VI. Participants in that site reported that specialist input in the team was not adequate and that they were pressured to work within a certain standard time. There was some concern among participants that 'being pushed to do more in less time' did not give the ROs the time and flexibility to build up a relationship with the clients and be as motivating as they could be. The lack of flexibility was said to be particularly important for clients who needed more encouragement to become rehabilitated or who may not be ready to accept rehabilitation support at the time of the initial visit. The general view was that unless the ROs have sufficient time to build a rapport with clients, they may never hear back from some clients.

Types and balance of service duties

While no noticeable differences were reported between the sites in terms of the proportion of time spent on administrative duties compared to face-to-face contacts with clients, the balance did vary for different ROs. Across all sites, ROs reported spending between 35 and 50 per cent of their time on administrative duties. This included: making a referral, ordering specific equipment, writing up case notes and arranging visits. The time ROs spent doing duty (that is, answering the phone and taking new referrals) varied in different sites. In site A, ROs spent five days a week between them doing duty; in site B, they spent one and a half days a week and those in site C did not appear to do duty. The amount of time ROs spent on travelling varied in the three sites too. In site A, where ROs covered the whole area, travelling was reported to take a considerable time. In contrast, in site B, where ROs were assigned to different geographical areas, less time was reported to be spent on travelling. In site C, ROs had changed from being office-based to becoming remote workers (i.e. able to work out of the office); they felt that the move had improved the balance of their time – reducing the travelling time and increasing the time they spent with the clients. Being able to access the clients' data remotely was also felt to have helped ROs to manage their paperwork more effectively.

Coordinating/liaising with other services was not reported as taking a big part of the ROs' time in any of the three sites. All ROs taking part in the focus groups wanted to spend more time with the clients and less time doing administrative work.

Training and CPD opportunities

All participants reported that their training needs were identified through four to six weekly supervision sessions and annual reviews. However, opportunities for CPD and training were said to be limited across the three sites, restricting the teams' ability to deliver rehabilitation support.

In site A, a general absence of relevant courses was considered to be the main issue. Training courses on dementia and stroke were thought to be particularly beneficial to ROs as they received many referrals for clients with those conditions. However, it was mentioned that such courses either did not exist or were not designed to give ROs the specialist information they needed. An example given was a three-day stroke training course organised by the Stroke Association which was said to be too general and not cover the visual effects of stroke which would have been relevant to them.

In site B, budget restraint was considered to be the main issue undermining training and CPD opportunities. The team manager participating in the focus group reported that the rehabilitation service had not received a training budget for the last eight/nine years. For professional development, ROs relied mainly on attending the regional meetings held every three/four months. Those willing to pay for their own training would be given a day off without having to take annual leave. Participants felt that the shortage of a training budget suggested that their work was undervalued, unlike other professionals such as OTs and social workers who had a training budget to access specialist courses to keep them informed.

In contrast, site C was reported to have some contractual obligation to provide CPD opportunities to its staff. However, participants reported that in reality most training that they had been receiving was geared towards updating them on their general skills rather than offering specialist courses that they would want to do for their personal development.

Collaboration with other teams/organisations

All participants spoke highly about the benefit of interacting with other ROs particularly as training opportunities were limited. Participants in site A reported that they kept informed about the current trends through attending conferences and regional RO meetings. In contrast, participants in site B noted that there was no funding available for them to attend rehabilitation conferences and to interact with other ROs in the country; the lack of opportunity to network in conferences meant that they could miss out on new practices happening in the VI world. Unlike the other two sites, networking with other ROs was said not to be allowed in site C during work time because of a continuous pressure to keep up with the growing caseload.

Across the three sites, participants reported that they liaised with a range of professionals and services. Most regular contacts were made with the mental health teams, low vision clinics, the community stroke teams, children's services, social workers and OTs. Two of the sites (B and C) had access to eye clinic liaison/information officers within hospital.

Several participants in site A mentioned that they struggled to work with the mental health team because workers in that team had high and unrealistic expectations from the ROs as they tended to attribute people's mood to their eye sight and expected that someone who had been rehabilitated was suddenly going to become a happy person. Participants also reported that the mental health team did not seem to appreciate that not all people with VI would have the motivation to be rehabilitated; they occasionally had to redirect referrals back to the mental health team but it was sometimes difficult to explain to that team that people's low mood 'may not be just about the vision'.

Participants in site B reported that they were more likely to refer to other teams for assistance than receive referrals from other teams. They thought this was because the rehabilitation team did not have professional recognition; they felt that social workers thought of ROs as support workers who could take people out or act as a befriender rather than people with specialist skills in VI.

Types and scale of rehabilitation training and support

The range of interventions offered was more or less the same across the three sites. The main categories of intervention included:

- Mobility and orientation training.
- Daily living skills (for example, how to use the cooker, how to shop).
- Communication skills (including teaching Braille, electronic communication).

In addition ROs in all sites offered:

- Specialist equipment (for example, magnifiers, special lights, liquid level indicators).
- Housing adaptations (for example, lighting, handrails).
- Emotional support (through listening to people and building up their confidence).
- Information and advice (including advice on benefits).
- Signposting people to other services (for example, counselling, housing, social groups, training courses in the community, RNIB telephone support line).
- Filling in benefit forms.
- Advice on child care.

Participants in Sites A and B reported that while they offered some emotional support, they tended to refer clients to voluntary support groups or the mental health teams if they showed signs of distress. Site C was the only site that reported offering a befriending service.

All managers felt that self-management group work was as important as individual work. However, while they reported that such group work can have an effect on their caseload and that service users tend to get great support from peers, there was some concern among managers about service users having difficulties in transferring the skills they learn to their own environment.

Sites A and B appeared to have restricted their activities to one-to-one support. The manager in site A reported that their service was not able to offer any group activities, instead it signposted clients (with their permission) to various groups, mainly social groups but also a few that provided information and advice, run by small voluntary organisations in the area. Having no accessible space and access to transport were reported by the manager to be the key reasons why the service could not offer any group activities. Without such resources, she thought, the logistics of organising groups could outweigh the benefits.

Site B was reported to have run some group-based activities in the past. This included information days for people newly registered and their partners, courses on various aspects of rehabilitation, separate weekly social groups for men and women, a children's group, Braille and cooking classes, and IT courses. The manager of the service reported that the service had lost most of its group activities work to a private company about three years ago following the closure of the Blind Centre which had been run by a charity. The new provider currently runs some social groups including a men's group, a women's group and an older persons' group, and offers a general information course on benefits and support with IT. The rehabilitation team is currently teaching individuals Braille and cooking in their own home and has maintained some group activities for children at school.

In contrast, site C was reported to currently offer a range of group-based self- management rehabilitation programmes including: cookery courses, life skills courses for young people and information days on safety in the home. It also offers social events to help people to get out and reduce isolation. The service was also reported to provide Visual Impairment Awareness Training courses for staff, volunteers and external organisations.

The scale of interventions reported across the three sites varied from one or two visits (to carry out the assessment and provide equipment) to multiple visits that could continue for months or even years. Site C appeared to be more restricted than the other two sites in how long ROs could spend on a task, making it less likely for anyone to be perpetually on the caseload (more of this below). The scale of interventions was said to depend largely on clients' motivation and their learning abilities. The duration of visits also changed depending on the type of intervention. Typically sessions spent on mobility training took one to one and a half hours. All participants noted that some clients were perpetually on their caseload and seen by them periodically.

Assessment and monitoring progress

In all sites, full assessments were carried out in the initial visit to identify what the clients wanted to achieve and the areas of activity for the rehabilitation team to focus on. Rehabilitation intervention was described, across the three sites, as being open-ended, rather than being time-prescribed, as long as ROs could justify the benefit of it for the client. However, as mentioned above, there were some differences in the way the three sites operated. Whereas in the two sites where rehabilitation was provided in-house (A and B) the intervention appeared to be more flexible, the site that had a contract to provide rehabilitation (C) was reported to operate in a much more structured way.

Site A used a care plan on which to record clients' goals and progress. The care plan was reported to have no formal structure and no specific categories – it could be 'just a bullet point discussion'. For example, the goal recorded on the care plan could be independence in relation to mobility without specifying the route. If it became apparent at a later stage that the client learning one route wanted to learn an additional route, ROs were able to build that into the same care plan. This also meant that when helping a client with one task (for example, pouring hot drinks) ROs could identify and cover several other tasks. Such arrangements were thought to have given ROs a lot of flexibility.

Site B used the paperwork they had developed over years to record clients' goals and progress. The intervention in that site appeared to be more restricted to the clients' needs that had been identified at the time of the full assessment. For example, once clients had learnt one route they could not ask for a different route unless the work was considered as 'a priority' (for example, they had moved house, the child had moved school or the local shop had closed) otherwise they would need to go back into the waiting list to get additional help with that. Neither of these sites (A and B) used any other tool to measure clients' outcomes. There was a feeling among some participants in both sites that the rehabilitation intervention created a sense of dependency among some clients (that is, clients wanting to keep adding other targets once they had achieved some goals). Participants felt that having a simple outcomes tool would be helpful in preventing that from happening.

Site C was reported to use a different system. Following the assessment, ROs generated a re-ablement plan using a structured form. The form allowed the team to identify up to a maximum of six outcomes to be achieved, with a maximum of eight hours to achieve each outcome. The outcome categories included: improving quality of life, choice and control, improving health and well-being, economic well-being, making a positive contribution and personal dignity. Clients' progress would be reviewed half way through (that is, after four hours) and clients would be asked to fill in an evaluation form about their progress at the end of the re-ablement plan. Once a task was finished, ROs could not carry on teaching a different task unless they closed the initial task and created a new referral for an additional task. However, it was reported that ROs could work on two referral plans within the same re-ablement plan (for example, relating to mobility) simultaneously, as long as they were targeting different outcomes (for example, one referral for the route to the shop and one for the route to the community centre). There was said to be no limit in the duration of intervention for a particular client; what mattered was what work ROs carried out with clients and how long that work took. If the client's identified need for mobility training (for example being able to travel from home to a local shop) was long, the ROs broke it down to several referrals with 'reasonable segments' – for example 'how to use the cane', 'teach the route from their street to the next street' and 'teach the route from that street to the shop'. Breaking down the tasks to smaller segments was also thought to help clients to feel good about what they can achieve and get motivated to want to do more. There was a feeling among participants in site C that working in such a structured and outcomes-based approach was linked to requirements of the commissioning process for the service.

All participants highlighted that a big part of their involvement was focusing on preventative work, which was hard to measure. An example given was helping someone who was losing their sight to go out to the local shops, to socialise and to do exercise. This prevented people from becoming isolated and depressed. Using some additional lighting or colour contrast could also prevent people from having a fall and possibly having to spend weeks in hospital. All these were said to be cost saving for services.

5.3.2 Staff views on factors impacting on the benefits of rehabilitation support

The focus group discussions with the frontline staff identified a number of factors that participants considered enhanced the impact and effectiveness of rehabilitation services. This section reports the key common themes raised by all those who took part in the discussions.

Access to specialist knowledge and skills

High quality VI specialism at the start of and during rehabilitation intervention was considered essential in setting up appropriate goals for clients. The general view was that the screening carried out by social workers or OTs without specialist knowledge in VI would miss the potential for rehabilitation. According to one participant, social workers tend to ask questions like ‘can you make a cup of tea?’ and if the answer is ‘yes’ they close the case. They would not ask: ‘can you get up’, ‘get washed’, ‘get in your chair’, and ‘get dressed’. Some professionals were reported to be overprotective and overly concerned about safeguarding issues, but did not appreciate that someone with VI could be very capable and able to live on his/her own and look after a child. As a result, some clients were said to either fall through the net and end up with no support or get a care package to have things done for them rather than get the support and encouragement to do things for themselves. There was also a general feeling among participants that having managers with a social work background could act as a hindrance unless those managers had a positive understanding of rehabilitation work.

Participants in site A felt that having access to a dual sensory team was an advantage as it allowed the team to tap into each other’s expertise and knowledge when supporting clients with dual sensory loss.

The timing of rehabilitation support

The importance of offering rehabilitation intervention in the early stages of developing sight loss was highlighted by all participants. A general view was that ROs could achieve much better outcomes when the clients still had some vision. However, participants reported that they did not always get to know about the clients (for example, through the ECLO, the Eye Health personnel or a GP) at early stages of their sight impairment; sometimes clients were not referred until after they had been registered, by which time they could have suffered for a long time and lost a lot of vision and hope. A lack of understanding among consultants about what ROs could do was thought to be the main cause of such delays:

'…while they [consultants] were treating somebody, they wouldn't think about referring to our service…. One consultant said 'cause it was failure on his behalf to not be able to treat the person,... it was like to them we are the last resort, and all the consultants felt like that… They hadn't seen it that way round for the patient' (Site B).

Participants in site B mentioned that while social workers are concerned with the FACS eligibility criteria, ROs are more interested in prevention and stopping people becoming FACS eligible; however, getting that message across to social workers was said to be like 'a foreign language' to them.

The benefit for individuals of having access to rehabilitation before a care package was put in place was also raised by some participants. They felt that receiving a package of care prior to rehabilitation ran the risk of clients getting used to the care they received and so showing no interest in being re-abled:

'… so we go in…they've got carers going in…someone coming to help them to cook… they don't want you – they don't want it to be taken away,…they'll say "No, I don't want to learn to make a drink because I've got a carer coming in. I don't want any training because I've got someone taking me out" … we can't even try to re-able this person because … it's something easier for them…' (Site C).

Characteristics of people with VI using vision rehabilitation services

The general view among all participants was that rehabilitation worked differently for different people. One important factor impacting on the effectiveness of rehabilitation was said to be the characteristics of the person receiving the service. People who were motivated and who had come to terms with their visual impairment were thought to be likely to show greatest benefit; examples given were mobility training with a 90 year old person and teaching computer skills to an 80 year old person, both of which were said to have been very successful. Participants reported that while they did not exclude anybody from assessment, they might make decisions about certain things not being suitable for some people (for example, learning Braille, crossing the road). Working with people with limited memory capacity (for example, people with dementia and brain injury) was said to be more challenging because of difficulties in retaining information; however, participants felt that rehabilitation involvement could benefit this group in different ways, for example making them as safe as possible. This might include giving advice to family about falls prevention, improving lighting, removal of a door, putting the family in contact with the right service or playing a part in providing their future support.

5.4 The experiences of people using vision rehabilitation services

This section presents findings from semi-structured interviews with service users with VI in the three case study sites. The interviews explored difficulties service users experienced with daily living at the time of referral to rehabilitation teams, their experiences of using rehabilitation support (including the types of support they used and desired), the impact rehabilitation support had had on their lives and the perceived limitations of rehabilitation support.

5.4.1 People’s experiences before receiving vision rehabilitation support

As mentioned earlier, interviewees had experienced a range of congenital and acquired sight loss: nine had degenerative conditions, three had experienced a sudden onset of sight loss (two were related to stroke and one followed an eye infection) and three had congenital conditions. In terms of the difficulties they were experiencing at the time of referral, mobility, cooking, shopping, communication, getting on and off the bus and telling the time were key areas that all participants said they had been struggling with. Many people said they relied on family and friends for daily activities such as cooking and shopping.

Most referrals to rehabilitation teams were reported to have been made by hospital staff, after participants had registered as partially or severely sighted. A few people felt they had to be registered in order to have access to rehabilitation support. One person (B2) said he had to ‘make a fuss’ to be registered because the optician in the hospital thought he was making it up to get a bus pass:

‘If I didn’t make the fuss about it, I think I still wouldn’t be registered now. Don’t know how bad you need to be to be registered’ (B2).

While there were no noticeable differences reported between the sites in terms of the gap between the timing of diagnosis and the referral to rehabilitation teams, there were some variations between individuals’ experiences across the sites. The majority of service users with degenerative conditions reported that they had been referred to the rehabilitation team two to four years (in two cases 20 and 26 years) after they had been diagnosed. The referral was often said to have been prompted by either a rapid deterioration of eye sight or changes in family circumstances, for example the death of a partner/carer (A2). The general feeling among this group was that they knew they needed help but they did not know who to turn to and what help was available. Several people reported that the eye clinic had given them some equipment such as magnifiers, a white stick and a pair of glasses but they were not of much help to them. One person who had recently moved from another LA said the hospital in the previous LA had given him a long cane but he did not feel safe using it because he had no training to use it properly (A2). Another person reported that the hospital had offered to refer him to the Social Services without telling him what help they would be able to offer:

'…they were quite vague about it, … they just asked me. I could've refused to be … I had the choice to say no, but I did because, you know, 'cause I knew I would need help with certain stuff' (B4).

People who had experienced a sudden loss of their eye sight talked about the difficulties they had gone through in coming to terms with their condition – both physically and mentally. One person (C3) summed up how the sudden sight loss had affected him:

'… you try living your whole life with your eyes shut, it does change everything you have to do … there's nothing I do now that I did the same way when I could see, you know, regardless of what you do. And…So, you know, it did change my life quite considerably, and for a long time … everything I loved doing, it threw out the window… There was nothing I could continue doing that I used to enjoy doing before… I was in a dark place … physically speaking and metaphorically speaking' (C3).

Two of the participants (A4 and C3) said that they had to struggle on their own for a few years, with little input from the hospital; all they had been given by the eye clinic was a pair of glasses and a magnifier. One person had found his situation very stressful. He explained that his wife was diabetic and had a mental health problem; he had to regularly monitor her blood to see she needed to have insulin but he wasn't able to do that anymore. He said the hospital did not offer any help. His wife's Community Matron searched the internet and found a talking smart meter to help him with that and put him in touch with the rehabilitation team. He also mentioned that the help he received from his wife's carer with shopping, writing his cheques for him and reading his letters before rehabilitation support started was invaluable; without it he felt he would have had to move into a care home:

‘It felt as though I’d be thrown on the scrap heap, that’s how it felt. In fact, I was very resentful of it …I wanted to talk to somebody. I said, some therapy or something, I need to discuss it, … there was nothing… that was the situation for quite some time’ (A4).

Of the three people with congenital conditions, one had his condition recently diagnosed. The other two had moved to the research sites from other LAs and had been getting on and off support from various rehabilitation services throughout their lives; both reporting that the level and speed of the service they had received in different authorities were hugely different.

5.4.2. Negotiating rehabilitation goals and monitoring progress

Across the three sites the RO’s first visit was reported to have focused on assessments of service users’ capacity and home environments, what the service users wanted to achieve, what the rehabilitation teams could offer as well as providing information on what other services were available. All participants reported that rehabilitation goals were tailored around their individual needs.

The type of support and the frequency of the visits varied for different people and appeared to change over time across the three sites. The number of visits ranged from once to twice a week and continued for six weeks to six months depending on service users’ capacity to learn, ROs’ available time and the complexity of goals. Typically sessions spent on mobility training were said to last between one to one and a half hours. One participant who was in his 40s said he was relatively quick at picking up routes; he preferred to have a route completed in one longer session.

All participants in Sites A and B reported that they could receive help with additional tasks/training, over and above the agreed plans and the sessions could take as long as was needed. A few people had asked for additional mobility training to learn new routes or extra sessions on learning how to use their adapted computers. However two people in site B reported that they had to go onto a waiting list in order to get some extra training sessions. Participants in site C had been given some indication of the time restrictions on completing individual tasks. Two people in that site (C2 and C3) felt that the visits were rushed. One person commented that having a set amount of hours for learning one skill was not a problem for him as he was a fast learner but it could be a problem for other people:

‘It does seem a bit archaic that they [rehabilitation team] would do it like that, ‘cause everybody would learn differently and everybody has different levels of confidence’ (C3).

All participants reported that clients’ progress was monitored informally and the decision to end any particular intervention was made jointly with the RO when both parties thought the identified rehabilitation goal had been achieved. Re-accessing the rehabilitation team was reported to be easy across all three sites; all participants had to do was to call the RO and they would be able to arrange a visit within one or two weeks. None of the sites were reported to make any follow-up contacts with service users; instead service users were expected to contact the rehabilitation team as and when they needed extra help.

5.4.3 Rehabilitation interventions and activities

Help to get out and about

The majority of participants felt that mobility training had been the most beneficial aspect of rehabilitation support for them. All, except one, had either received or were in the process of getting long cane training. One person (B3) felt using a long cane would make him look vulnerable and that would not be safe in the area he lived in; he refused to have the training even though it meant that he could not leave home unless somebody accompanied him.

The common routes participants had covered were routes to the local shops, doctors and post office. Several younger participants had also learnt the routes to train stations and different sport centres. A number of people had received refresher training or additional training to learn new routes periodically. Three people with guide dogs had long cane training with the intention of not becoming too dependent on the guide dogs. They also thought it was easier to go to certain places (like sport centres and pubs) without the guide dog. One person had asked for mobility training to teach her sighted carer how to support her when using routes she was not familiar with.

Provision of aids and equipment

The supply of equipment appeared to be another main area that the rehabilitation team had helped service users with. The most common equipment given to service users free of charge included lamps, magnifiers, talking clocks, talking watches, liquid level indicators and markers. A number of participants reported that the ROs had been very helpful in searching websites to help them buy pieces of equipment that they would find easy to use (for example talking mobile phones, Dictaphones, big button phones, one cup kettles and Pen Friend audio labels) and taught them how to use the equipment. One person (B4) mentioned that the RO had accompanied him to a few technology fairs and helped him to get a grant to buy some assistive technology for his computer.

Communication

A few participants mentioned that what they had most missed following the loss of their sight was using their computer. As part of rehabilitation support, ROs had arranged for them to have a talking programme on their computers and some training sessions on how to use it. All felt this had opened up great opportunities for them to connect with the outside world, maintain contacts with their family and friends and feel less isolated.

Learning Braille did not appear to be a popular option. While several people reported that they had been offered the training, only one person said she had actually learnt how to use it (A3). A few people said they had started to learn it but they found it too hard, so they left the course. One person said all he was getting in terms of training to learn Braille was one session a week and some CDs that he had to listen to on his own. He would have preferred to have more regular sessions.

Information and advice

Giving service users information and advice on benefits, filling in the benefit forms, and helping them to get a blue badge, a disabled card and a bus pass appeared to be another main area of support that ROs provided. Most participants mentioned that ROs had signposted them to other services for information and advice including RNIB, the Macular Society, the Guide Dog Centre, Access to Work and Social Services.

Group-based activities

As mentioned above, rehabilitation teams in sites A and B did not provide any group-based support; instead they put service users in touch with other organisations in the area that provided such opportunities. In contrast site C offered a variety of group-based events, including social groups as well as information and advice sessions and self-management courses.

Almost half of the participants across the three sites reported that they had no experience of group activities organised for visually impaired people. Participants in site C appeared to have had wider experience of group activities than those in the other two sites. One person had been on a holiday organised for blind people. A number of older people reported that they were getting a lot of support from their families and they did not feel the need to join any social groups. Travelling was also said to be a barrier to participation in site A. In contrast younger participants across the sites reported that they were very interested in meeting people in similar situations but they had not come across any social activities that were suitable for younger generations.

5.4.4 Reported benefits of using rehabilitation support

Many participants described the support they had been receiving from the rehabilitation team as ‘second to none’. One of the most valuable aspects of rehabilitation support reported was the security of knowing that the support was there should they need it. Most people felt the rehabilitation team had helped them regain their confidence and believe that they would have a life again. One person described her RO as ‘her rock’ who knew exactly what she was going through and that ‘put her at ease straight away’

‘[The RO] helped me … get me out of that horrible, horrible hole I was in. The shock … was like being in a whirlwind…If I felt that I was panicking, I could get on the phone and speak to her. My husband tried to understand, but [the RO] was trained to understand … she knew why I was panicking and she knew – somehow, she knew the right words to say…Gave me my confidence back... I could get out. I could do things in here, by myself … I never thought about taking my own life to be honest, never in a million years, but I was very, very near to that… I hate to think where I would’ve been without her’ (A1).

All service users reported that rehabilitation support had improved their independence, made them feel safer and increased their confidence and motivation to make further gains. The greatest reported benefits of rehabilitation support related to mobility training and access to specialised equipment. Many felt that without rehabilitation support they would still be in a dark place and housebound. One younger participant who had experienced sight loss since she was a teenager and appeared to have a more active life felt that she would have had mental health problems had she not been taught the routes to different places she regularly visited. Another person (A4) explained that the assistance he and his partner (also visually impaired) had received from the RO after their son was born with a health condition was invaluable. They had to stay long hours at hospital and the RO had helped them with mobility to and within the hospital. Initially, he said, they relied heavily on nursing staff to go from A to B within the hospital, but the mobility training gave them the independence to move around when they wanted rather than when nurses had time to escort them (A5).

Other people described how rehabilitation support had impacted on different aspects of their lives:

‘Without [the rehabilitation team] there would be no training, there would be no equipment for me to use. I’d be relying on people to do things for me, not doing it myself. I’d be relying on somebody to cook for me, not doing it myself’ (C4).

One person explained why he thought he would feel ‘stuck’ without rehabilitation support:

‘I’d be in debt all the time. I wouldn’t be able to pay me bills and that, and I’d have no food. And I’d end up being with me self all the time… I’d probably be depressed … I wouldn’t be getting out and about’ (A2).

A few people mentioned that rehabilitation support had a tremendous impact on their families by giving them confidence that the support was there if the visually impaired person needed it. This appeared to have given one family more trust in their visually impaired son to move out and live independently.

Participants who had attended group-based activities felt such sessions had provided great opportunities to meet other people, increase their circle of friends and share experiences:

‘I thought it were a bit uplifting … it’s opened up a new world for me … it’s a little bit of hope … I felt - listening to people and how they have the pain and put up with things, you’re not on your own, are you?’ (B1)

Some participants mentioned valuable tips and advice they had picked up from other participants in such groups. For example, one person explained that she had not had the long cane training because the RO had told her she would find it difficult. The encouragement she got from a couple of participants made her take up the training and start using the cane. She felt that was like ‘opening the door to the world again’:

‘… he [another participant] passed his cane along … so I could feel the ball on the end … and he said, “If you ever get any chance of getting one of these, grab it with both hands”’ (C1)

5.5 Perceived limitations of rehabilitation support

Accessibility/timing of information
Several people across the sites felt that information about what help was available should be more forthcoming, timely and readily accessible. Expecting service users to ask for information assumes that service users always know what help they need.

The general feeling among people who had lived with their condition for a long time was that people often get help when it is too late or access a service when they have to have it. Several people said that the help they had received from the rehabilitation team had been tremendous but had they had the support sooner, they would have been better able to come to terms with their condition and be prepared for the future:

‘I think really from the beginning I should have been told, from ... having a sight problem that, ... I may need, you know, this service or I may need some training here or I may need help there .. could’ve been … advised on … how to cope with the condition… with work life, you know, and socialising … [I] would have been better prepared for it’ (A3)

Another participant talked about his experience at the eye clinic:

‘I had to make all the running myself. If I did not get up and go, … it got that bad I had to seek help … they should have prompted me to get help quicker, took a long time. If seen more regularly at the beginning, it could have been avoided may be’ (B2)

Participants who had some sight left were worried about losing all their sight. They felt they would benefit from a training course that taught them how to cope with having no vision in the future. One person reported that having the cane training with his eyes closed when he still had some sight was a great advantage to him as his remaining sight had made the training process much easier and quicker (C5). However, several service users said that they had not been mentally ready to receive help at early stages; some had resisted getting help from the rehabilitation team early on because they were still hopeful that things might improve:

'… [I] took the basic that I would need to get by, really, and didn't want anything to do with anything that I thought I was going blind. I mean, I didn't even want even to contemplate it, even though it was happening. So, I, sort of shunned [the rehabilitation team] for quite a while…I had made it blatantly clear to them that I didn't want anything else from them at the time' (C3)

In retrospect, they all thought having had more support at the beginning would have been very helpful.

Emotional support

Participants who acquired sight loss later in their lives described it as devastating. Some people, mainly older people, felt that the ROs' involvement was tremendous in helping them come to terms with it. Several people had mainly relied on their family members for emotional support. Two people (B4 and B5) had been referred to the mental health team by their GPs. However, a few younger people who had lost their eye sight at young age felt that their emotional needs had not been met effectively. One person explained that she had never discussed her emotional problems with the ROs thinking that they would not be able to help her as they were not counsellors. Another person felt that the rehabilitation team had only helped him to cope with the physical and not the emotional side of things.

‘People of my age would need more help mentally than other people ... Losing your sight at 70 may not be as devastating as somebody his age. They [ROs] should have pushed me to get some psychiatric help …most people who need psychiatric or psychological help would not ask for it’ (C3)

Access to social activities

As mentioned above, several younger participants reported that they were interested in joining social events and sport activities where they could meet other young people in a similar situation and with similar interests. However, they thought social activities appeared to be more geared towards older people. One young person reported that all he had been offered were coffee mornings and pottery classes. He said the only social meeting he had attended, which was supposed to be for younger people, was held in a church. He thought younger people would be more interested in going to more ‘youthful places’; having a meeting in a church would frighten a lot of young people off:

‘I think when you arrange social events, the younger generation needs to be thought through a little bit more. I can understand why the over-60s would go to a church ‘cause most of them probably are Christian or Methodists or so on and so forth, whereas the younger generation, we’re not quite as pious as they used to be’ (C3)

5.6 Conclusion

This chapter reports findings from focus group discussions with frontline staff, follow-up telephone/email discussions with the managers of rehabilitation services and interviews with service users in the three case study sites.

One of the key concerns among managers and ROs in two of the sites (B and C) was the shortages of specialist staff in the rehabilitation team and the time pressure it put on the workers, making it difficult for workers to get the flexibility needed to deliver effective rehabilitation support. This was considered to be particularly important for service users who needed more help to become rehabilitated. Having access to a dual sensory team in the other site (A) was said to be an advantage in supporting service users more quickly as it enabled staff to tap into each other's expertise when they came across clients with dual sensory loss. Other factors thought to restrict the teams' ability to deliver responsive rehabilitation support across the sites included inadequate training and CPD opportunities for ROs, limited opportunities to network with ROs outside the team as well as difficulties with collaborating with some external teams/organisations such as the mental health team. The general feeling among managers and ROs was that all these factors were linked to the shortage of the budget, undermined by the lack of professional recognition of specialist VR skills.

However, the findings show some differences between the three study sites in terms of the type and delivery of rehabilitation support. Firstly, the services provided by the local authorities (A and B) appeared to be less formally structured. This was thought to give workers some flexibility and continuity in supporting service users. In contrast, site C used a more structured and outcomes-based system, with some restrictions on the number of tasks service users received help with and the time spent on each task. Such arrangements appeared to be linked to the contractual arrangements. While some workers in that team felt under pressure to complete tasks within the specified time limit, the general feeling among the group was that such structured systems created less of a sense of dependency among service users. Secondly, unlike sites A and B where rehabilitation support was restricted to one-to-one interventions, site C offered a range of social events and group-based self-management programmes.

Most service users interviewed described the rehabilitation support as 'second to none'. The security of knowing support was there should people need it, regaining confidence, improving independence and increased motivation were reported as the most valuable aspects of rehabilitation support for the service users. Having access to group-based social and self-management activities were reported by most service users as great opportunities to socialise and learn from peers' experiences. However, as mentioned above, only one of the study sites (C) offered such opportunities.

Most service users across the three sites, particularly those with degenerative conditions, were concerned about having struggled for a long time before there were referred to the rehabilitation team. Lack of information about rehabilitation services was said to be the reason why people had not accessed such services earlier. There was a general feeling among service users that the main focus of rehabilitation support was on the physical aspects of people’s life and little attention was paid to their emotional well-being.

Chapter 6 Calculating the costs of visual impairment rehabilitation services

6.1 Introduction

The aim of this section of the project was to estimate the costs of typical models of rehabilitation services generated from the national survey data. We planned to base the estimates on published costs of community staff paid at similar grades to VI rehabilitation officers. The costs of each service model were to be combined with caseload data to produce a ballpark estimate of the cost per person using services and so an indication of which models appeared noticeably more or less costly than others (but with no account taken of outcomes). We anticipated a future full evaluation could include robust calculations of unit costs for the main types of VI rehabilitation services identified. Unit costs are the costs per unit of a service provided, for example, the cost per client[6] or the cost per hour of a service.

In fact, although data from the national survey showed the main differences in service models were whether they were provided by in-house teams versus contracted out services, and whether the VI rehabilitation teams were stand-alone specialist teams or based in generic teams, there did not appear to be any particular patterns to the makeup of teams. Thus it was not sensible to estimate the costs in the way we anticipated. Instead, we used the national survey data and additional data collected from the case studies to test the feasibility of estimating the unit costs of VI rehabilitation services.

This chapter summarises and discusses these calculations. Appendix 14 describes the detailed methods.

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[6] The term ‘client’ is typically used in describing unit costs (for example, client-related time), rather than terms such as ‘service user’ or ‘person using services’. For consistency with other publications on unit costs and for brevity in tables, the term client is used in this chapter to refer to people using vision rehabilitation services.

6.2 Costs of rehabilitation services in the three case studies

Detailed data on rehabilitation service team staffing levels, finances and caseloads were collected from the three case study sites. These data were used to test the feasibility of calculating detailed unit costs of VI rehabilitation services, specifically, the cost per hour of contact time with clients, the cost per hour of client-related work, the cost per hour worked and the cost per client. They were also used to calculate the amount of time spent on client-related work versus time spent on other duties.

Data were collected on two specially designed forms asking for information on (a) staffing levels and caseloads and (b) team finances. Completed forms were received from all three case study sites by 30th June 2014.

The forms requested detailed information about:

- The total number of hours worked per typical week by staff in the team.
- The total number of clients supported by the service in the previous 12 months.
- The typical weekly mileage accumulated by the team.
- The numbers of hours (or percentage of time) spent by the team on activities such as face to face contact with clients and client-related administrative duties.
- Staff salaries and on-costs, direct and indirect revenue costs and capital charges.

Copies of the forms are included in Appendix 15.

Time spent on different activities

The manager of each case study team completed a form showing the number of hours worked by the team in a typical week and the hours per week spent on different activities (such as time spent in face to face contact providing support to clients or time spent on general office duties). Table 6.1 presents these data for each case study individually and the average across all three.

Table 6.1 Hours per week worked and percentage of time spent on different activities

	Case study A	Case study B	Case study C	Average
Total hours a week	190 hours	225 hours	348 hours	254 hours
Face to face contact with clients	35%	46%	51%	44%
Other client-related time	30%	32%	32%	31%
Non-client-related time	35%	22%	17%	25%

Table 6.1 shows that the rehabilitation team in case study C is almost twice the size of case study A when measured in hours worked per week. The number of hours worked includes that of management and administrative staff as well as ROs.

Table 6.1 also shows that all three case studies spent about a third of their time on other client-related work (which includes preparing for visits, writing up case notes, travel time and client-related meetings with other professionals). On average, the sites spent 44 per cent of their time in face to face contact with clients, although this varied from 35 per cent in case study A to 51 per cent in case study C. The more detailed tables (Tables A14.1, A14.5, A14.9) in Appendix 14 show that when considering ROs' time only, those in site C spend around 85 per cent of their time in face to face contact with clients; this is higher than the other two sites that spend 42 per cent and 53 per cent of their time with clients. The administrative staff in site C, however, spend 83 per cent of their time on client-related work compared to none in the other two sites. Discussion in the focus groups (see Chapter 5) also showed that the ROs in case studies A and B did duty work (that is, answering the phone and taking new referrals); whereas they did not do so in case study C (a contracted out service). Time doing duty has been classified as non-client-related time in Table 6.1 as this work is not associated with clients already allocated to an RO. These differences in doing duty may account for at least some of the variation in the percentages of time spent on different activities. That is not to say, however, that case study C is a more efficient service because proportionately more time is spent with clients; it merely suggests that the costs of doing duty are being borne elsewhere, probably by local authority-based staff undertaking the duty that is done by ROs in case studies A and B.

Costs per hour worked

In addition to data on staff hours worked, each case study provided details on their annual budget. Annual budgets and the number of hours worked per year were combined to give estimates of the cost per hour worked, the cost per hour of face to face contact time and the cost per hour of client-related contact time.

Table 6.2 shows these costs per hour for each case study and the average across all three. It also gives the ratio of time spent on different activities; these ratios simply present the information from Table 6.1 in a different format.

Table 6.2 Ratios of time spent and costs per hour

	Case study A	**Case study B**	**Case study C**	**Average**
Ratio of direct to indirect time - face to face contact - client-related work	 1 : 1.85 1 : 0.54	 1 : 1.16 1 : 0.28	 1 : 0.97 1 : 0.21	 1 : 1.33 1 : 0.34
Cost per hour worked by the team	£28	£26	£22	£25
Cost per hour of face to face contact with clients	£80	£56	£43	£60
Cost per hour of client-related time	£43	£33	£26	£34

The ratios of direct to indirect time show that, on average, for every one hour spent by rehabilitation teams in face to face contact with clients, a further 1.33 hours (approximately one hour and 20 minutes) is spent on other client and non-client-related work. Also, on average, for every hour spent on client-related work, a further 0.34 hours (about 20 minutes) is spent on non-client-related work. These ratios include work undertaken by all members of the rehabilitation teams, not just ROs.

On average, the cost per hour of work across the teams is £25. However, it is often more useful to consider the cost per hour of face to face contact time or per hour of client-related time; these costs are, on average, £60 and £34 respectively. These costs take into account the fact that each period of time spent with a client involves a further period of time in preparation and follow-up work or other office duties.

Annual budgets and caseloads

Table 6.3 gives the annual budgets and caseloads for the three case studies, plus the average across all three.

Table 6.3 Annual budgets and caseloads

	Case study A	Case study B	Case study C	Average
Total annual budget	£237,985	£256,276	£336,241	£276,834
Annual caseload	282	2951	3322	n/a

The average annual budget was £276,834. Case study C reported a substantially larger budget; this is probably related to the larger number of hours worked by the team (see Table 6.1). Indeed, the cost per hour worked (given in Table 6.2) is similar in the three case studies.

The reported annual caseloads vary substantially, with case studies B and C having ten times the volume of case study A. The reason for this variation is the way in which caseloads are measured. In case study A, the 282 cases refer to individuals allocated to an RO, but do not include telephone calls by or on behalf of potential clients who were signposted elsewhere. In case study C, caseload was recorded as episodes of support. Therefore the caseload of 3322 refers to the number of episodes of support provided by ROs over the year. Clients could receive a number of episodes of support, each episode lasting up to eight hours. Thus the number of separate individuals receiving support in case study C is likely to be substantially less than 3322. This figure, however, was not available. The unit of measurement was less clear in case study B.

The intention was to calculate the cost per client based on the annual budgets and caseloads of the three case studies. Because of these differences in the measurement and recording of caseload, neither the cost per client nor an average caseload has been calculated.

6.3 Costing rehabilitation services using national survey data

The national survey collected data on the total annual budgets of services, staffing levels and caseloads. In response to the question about total available budget for vision rehabilitation in the financial year 2013/14, respondents were asked to include all costs/charges associated with delivering the service, including rehabilitation assessments and inputs, and any elements of the service that may be contracted out, for example, equipment. For the question about staffing levels, respondents were asked to provide the whole time equivalent number of staff and their salary grades. Staffing levels were used to build up a picture of the staff costs of services for comparison with reported annual budgets. Full details of the methods are given in Appendix 14.

Table 6.4 presents the annual budgets as reported by respondents to the national survey and estimated annual budgets calculated from data on staffing levels provided in the national survey.

Table 6.4 Actual and estimated annual budgets from the national survey data

	Number of services	Mean	Median	Minimum	Maximum
Reported total budget	28	£220,624	£133,000	£13,000	£800,000
Budget estimated from staffing levels					
Estimated salary costs	66	£173,026	£134,274	£25,716	£683,166
Estimated salary on-costs*	-	£53,638	£41,625	£7,972	£211,781
Estimated non-salary costs**	-	£75,555	£58,633	£11,229	£298,316
Estimated total budget	-	£302,219	£234,532	£44,917	£1,193,263

*assumed to be 31% of salary costs (allowing for national insurance and employer pension contributions) (Curtis 2013)

**Table 4.16 in chapter 4 on the national survey shows that salary costs account for 75 per cent of total budgets. Thus, non-salary costs are approximately 33 per cent of salary costs.

The mean total annual budget reported was £220,624. The mean total budget estimated from information provided about staffing levels was £302,219. These budgets are both similar to the average of £276,834 reported by the three case studies. This suggests that a typical rehabilitation team budget is probably in the region of £200,000 to £300,000 per year. However, the median budgets are slightly lower and there is a huge range from under £50,000 to around one million pounds.

Information on annual caseloads was collected in the national survey. Fifty-nine services provided caseload data. Annual caseloads ranged from 16 to 2000, with a mean of 486 and median of 350. In theory, these figures could be used to calculate a cost per client. However, it is likely that these caseloads are subject to the same measurement differences as caseload data from the case studies, that is, some of the 59 services will have reported the number of people allocated to an RO and some will have reported episodes of care[7]; there may also be other mechanisms of measuring and reporting caseloads. These unknown differences in the way caseload has been measured mean that calculating a cost per client based on these figures would produce a misleading result. Cost per client has therefore not been calculated.

6.4 Discussion

This section has presented data on the unit costs of VI rehabilitation services. The original aim of this part of the research was to use data from the national survey to provide a ballpark figure for the costs of different service models. As this was not feasible, we used survey data plus additionally collected data from the three case study sites to undertake more detailed calculations of unit costs.

Limitations

One obvious limitation of the unit costs calculated using the national survey data is that not all services provided complete data. In particular, few services provided information on both total annual costs and caseload, or on staffing levels and caseload. Furthermore, in relation to caseload data, it is clear that annual caseload is not recorded consistently across all services. For example, the minimum caseload recorded in the national survey was 16 clients per year and the maximum 2000, and in the case studies was 282 and 3322. Because of these differences, the cost per client has not been presented in this report.

A further limitation in the calculations is that no account was taken of the cost of initial VI rehabilitation officer qualifications or ongoing training.

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[7] The caseload data were not split into two distinct groups that clearly reflected numbers of people or number of episodes.

These costs are important as they are an integral part of becoming an RO. As an example, Curtis (2013) includes £25,430 per year for initial qualification costs for social workers but no costs for ongoing training as these were not available. Including qualification costs of £25,430 per year adds around 40 per cent to the unit costs of adult social workers (see Curtis, 2013, Table 11.2). The published unit costs given in Table 6.5 below exclude qualification and ongoing training costs to ensure the comparisons are valid.

The detailed bottom up calculation of unit costs is based on only three case study sites. To be more confident in the generalizability of the costs, these calculations should be repeated for a larger number of sites. They should also be repeated for in-house and contracted out services separately, especially if tasks such as doing duty are carried out by team members in some services and not in others.

Finally, and perhaps most importantly, the unit costs reported give an estimate of the costs of services only; no information is given about the outcomes for clients. Therefore these costs tell us nothing about the cost-effectiveness (the value for money) of the services.

Summary and discussion of findings

The unit costs calculated vary according to the methods used and by case study site. Cost per hour of contact time in the case studies ranged between £43 and £80. Cost per hour worked by the teams ranged from £22 to £28.

From Table 6.4, the mean annual budget (£220,624) reported by the 28 services that responded to this question in the national survey is lower than the annual budget estimated from staffing levels given in the national survey (£302,219). However, both are comparable to the range of total annual budgets reported by the case studies (£237,985, £256,276 and £336,241). The similarity of each of these results (at around £220,000 to £340,000 per year) suggests they are reasonably reliable.

Tables 6.1 and 6.2 showed the time spent by case study site teams on client and non-client-related activities varied, perhaps in part due to the time spent doing duty in case studies A and B. To test the impact on unit costs of doing duty, the time and salary costs of doing general admin tasks in case studies A and B were excluded. Details are given in Appendix 14. In summary, unit costs in sites A and B reduced by between £2 and £4 an hour. The percentage of time spent on client-related activities increased in both sites, as would be expected, with percentages in case study B closely mirroring those in case study C. The issue of doing duty (and its associated costs) should be revisited in any future evaluation.

To place the unit costs of VI rehabilitation teams in context, Table 6.5 gives a range of related costs to which they can be compared. The unit costs in Table 6.5 are all reported in *Unit Costs of Health and Social Care 2013* (Curtis, 2013). Table 6.5 includes unit costs of re-ablement services, occupational and physiotherapists, and mental health nurses. For example, the average cost per hour of contact time with a home care re-ablement service is estimated as £43, compared to an average for VI rehabilitation teams of £60. The ratio of face to face contact time to other client and non-client-related duties for re-ablement teams is 1:0.94 (not shown in the table) compared to an average ratio for the case study sites of 1:1.33. VI rehabilitation service and re-ablement service costs in Table 6.5 include the costs of all team members (that is, management and administrative staff as well as front-line workers) whereas those for occupational and physiotherapists and the mental health nurse are based on the costs of that member of staff only. Once again, these unit costs take no account of effectiveness and so are not a comparison of the relative cost-effectiveness of services.

Table 6.5 Comparison of unit costs of VI rehabilitation services and other community services

Type of service	Unit of service	Unit cost 2012/13	Unit cost 2013/14*
VI rehabilitation service	Per hour	-	£25
	Per hour of contact time	-	£60
	Per hour of client-related work	-	£34
Re-ablement service	Per hour	£22	£23
	Per hour of contact time	£42	£43
Community OT (LA)	Per hour	£41	£42
Community OT (NHS)	Per hour	£30	£31
Community physiotherapist	Per hour	£30	£31
Nurse (mental health)	Per hour	£35	£36
	Per hour of contact time	£65	£66
	Per hour of patient-related work	£46	£47

All costs reported exclude qualification and ongoing training costs

* 2012/13 prices and pay uprated by 3.3 per cent and two per cent respectively. Using the same methods as Curtis (2013, page 251), percentages for inflating costs are calculated from an average of the past three years available in Table 16.2 The Hospital & Community Health Services (HCHS) Index.

There are a number of lessons for a future full evaluation that can be drawn from the experience of calculating the unit costs presented in this chapter. These lessons are discussed in Chapter 7. In brief, care should be taken over the measurement of caseload and simple data collection forms can provide sufficient detail to calculate basic unit costs. These unit costs can then be applied to data on the staff time spent with study participants.

Chapter 7 Summary, Discussion and Conclusions

7.1 Aims and design of the study

This study aimed to provide an overview of the evidence base for specific models of rehabilitation interventions for people with VI. The study focused on rehabilitation services funded by local authorities to find out what services are currently doing to support people with VI, what possible outcomes services might achieve for people with VI and identify gaps in the evidence base about current service arrangements.

The study involved:

- A review of existing literature (both UK and international) on rehabilitation interventions for people with VI, published since 2000, to establish the size and robustness of the evidence base;
- Scoping workshops with professionals and people with VI who had experience of rehabilitation support, to clarify a working definition of visual impairment rehabilitation and explore the main features of good rehabilitation support and service arrangements;
- A national (England) survey to map out rehabilitation services for people with VI that currently exist;
- Case studies to examine whether the examples of ‘good practice’ identified at earlier stages were endorsed by those with direct experience of providing and using the services; and
- Scoping the potential costs and effects of rehabilitation services for people with VI.

The findings from the literature review, the scoping workshops and the survey were used to select three case study sites where different arrangements were being used in order to gain an in-depth understanding of how rehabilitation services operated and delivered support. This was also an opportunity to obtain the views of the front-line staff on factors that help or hinder the effectiveness of rehabilitation support and explore service users’ experiences of using the service. In two of the sites, VR was provided by the local authority in-house team, in the other site it was provided by a contracted-out service. The case studies involved focus group discussions with the front-line staff, followed by telephone/email discussions with the service managers and semi-structured interviews with people with VI using rehabilitation services.

While there is some evidence that rehabilitation can be an important contributor to the quality of life for people with VI, much of the existing research in this field is on low vision rehabilitation which is mostly hospital based, focusing on personal physical limitations and functional ability. Robust evidence around VR services that are community-based and managed outside the health service has hitherto been lacking, but is seen as a priority for further research (Boerner et al., 2005). This report describes the first major piece of research in this area and is the first step towards a full evaluation study to determine the cost effectiveness of rehabilitation services for people with VI.

7.2 Main findings of the study

7.2.1 Current state of vision rehabilitation provision

The survey showed a diverse pattern of VR provision across all types of provider and also within LA provision. The two main types of providers were LAs themselves i.e. in-house (61 per cent of services) and voluntary (not-for-profit) organisations (28 per cent of services). The most common type of team found within LA in-house services was a sensory impairment team (57 per cent); services provided by voluntary sector (not-for-profit) organisations were most likely to be specialist in VR (75 per cent); this included the management of their team. Team managers within LA in-house services were most likely to be drawn from a range of professions, with the most common professional group being generic social workers (almost 24 per cent). The wide variation of teams was extended to how different teams operated and features such as waiting times, and caseloads. Such variation, coupled with the findings from the open questions in the survey, may reflect the wider changes in and pressures on adult social care more generally in recent years, such that some LAs have incorporated VR into other ‘specialist’ services or services that have a more generic focus.

Moreover, the survey showed a quarter of services required a FACS community care assessment to determine eligibility. This is contrary to current guidance (DH, 2010; ADASS, 2013), and with LAs restricting eligibility to ‘critical’ and ‘substantial’ care needs, this may be excluding a large group of people with VI from receiving support, especially since the criteria applied in FACS assessments often fail to address the issues important to them (Kaye and Connolly, 2013; RNIB, 2014). The finding that initial screening of referrals may be undertaken by professionals without specialist skills in VR (40 per cent) also suggests that visually impaired people may miss out on rehabilitation services. A lack of information about VR services and lengthy waiting lists for a service may also compromise timely access to services and risk care needs intensifying. A concern among managers participating in the survey was that financial cuts have created challenges in all aspects of service provision, not only staffing levels, but also the types of support that rehabilitation teams are able to provide. This concern was echoed in the views of managers and frontline staff participating in the case studies.

The survey also showed that measuring outcomes for service users was not a widespread practice for all services; those that did measure outcomes did not commonly use a standardised measurement tool. The voluntary sector (not-for-profit) organisations and pilot social enterprises were more likely to be measuring the outcomes of their services (70 per cent of voluntary sector (not-for-profit) services) compared with LA in-house services (46 per cent of LA in-house services); this may be linked to the commissioning requirements for these providers. This finding was mirrored in the case study sites as the contracted out service was the only site that used a structured tool to measure service users’ outcomes; the two LA in-house services measured service users’ progress more informally.

7.2.2 Types of rehabilitation interventions

The majority of services taking part in the survey described the support they provided as open-ended. The findings from the survey show greater uniformity over the type of training offered by different services than the type of support. The main focus of training was around orientation and mobility, independent living skills, aids, adaptations and equipment and communication. The majority of services also offered training for partners and carers (90 per cent) and just over a third provided self-management courses. In terms of support, provision of aids, adaptations and equipment and information/signposting were most commonly reported in the survey; facilitating group work was offered by half of the services responding and counselling was offered by less than a quarter. Data from the case study sites show a similar pattern.

The literature review suggests that self-management courses and group activities are particularly effective in VR; this was confirmed in discussions with managers and frontline staff in the case study sites. However, the survey showed that self-management courses were offered by 25 per cent of LA in-house services and 39 per cent of voluntary sector (not-for-profit) organisations. Group work was considered to have suffered a decline as a result of financial cuts to services. This finding was echoed in data gathered from the case study sites which showed that the contracted out service was the only service offering group-based social and self-management activities. The other two sites sign-posted service users to the voluntary or private organisations that offered such activities. However, transport was reported to be a barrier to participation for a number of service users in those sites.

Other areas highlighted in the literature review as being important for supporting service users with VI were emotional support and counselling. However, the findings from the survey and the case studies suggest that these types of support were less likely to be offered by services.

7.2.3 Staff experiences of providing rehabilitation services

While all managers and ROs participating in the case studies demonstrated commitment and enthusiasm to helping people with VI to become as independent as possible, in practice they felt that there were restrictions impacting on the teams' ability to work more effectively with service users.

The proportion of time ROs spent on administrative duties compared to face to face contacts with service users appeared to be similar across the three study sites, according to discussions in the focus groups. However, data collected from team managers for calculating the costs of services suggested ROs in site C spent around 85 per cent of their time in face to face contacts with service users compared to about 40 to 50 per cent in the other sites. This could, in part, reflect the fact that ROs in case studies A and B did duty (answering the phone and taking new referrals) whereas in case study C they did not. What is not clear from the findings is how essential ROs (or managers) felt it was to do duty. Did they feel that it was an integral part of the service that contributed to team knowledge and perhaps outcomes for people using the service, or was it seen as a role that others (without training as vision rehabilitation officers) could fulfil, thus freeing time for trained staff to spend supporting visually impaired people?

From the group discussions, those who worked in the contracted out service (site C) felt more under pressure to complete tasks within the specified time limit than those who worked in the other two LA in-house services (sites A and B). Having said that, ROs in site C felt the outcomes-based system was helpful in preventing service users from becoming dependent on the service. Being assigned to different geographical areas (site B), or working as remote workers (site C), was considered an advantage in improving the balance of time for ROs working in those sites.

As mentioned above, a major concern among managers and ROs was that financial cuts had put pressure on numbers and types of staff, as well as the types of support that workers were able to provide. Inadequate opportunities for CPD training, networking with other ROs and difficulties with collaborating with some external teams/ organisations, in particular the mental health team, were highlighted as other key areas of concern by both managers and ROs.

The timing of rehabilitation support was also considered to be an important factor in what rehabilitation could achieve for people with VI. There was consensus among all managers and ROs that delays in referral to the rehabilitation team risks care needs intensifying and service users getting used to the existing care and support they receive, and thus not being motivated to learn how to be more independent. There was a feeling among all ROs that they could achieve better outcomes for service users before they lost all their vision - which for some people meant losing their hope as well. However, all managers and ROs felt there was a tendency among professionals to see rehabilitation as the last resort. Lack of awareness among professionals as to what rehabilitation is about and what it can achieve for people was reported to be the main reason why professionals did not make timely referrals.

7.2.4 People’s experiences of using rehabilitation services

All the people interviewed in the case study sites who used VR services were positive about the impact of rehabilitation on their independence and confidence, with many feeling more motivated to make further gains. Many described rehabilitation support as ‘second to none’. In line with the findings from the survey, service users felt that the greatest benefits of rehabilitation intervention related to mobility training, independent living skills and the supply of aids, adaptations and equipment. Learning communication skills was considered an important part of the rehabilitation training for some service users, particularly the younger generation. Filling in benefit forms was regarded by all service users as a key element of support they had received from the rehabilitation team.

A key concern among interviewees using services across the three sites, particularly those with degenerative conditions, was the delay in being referred to the service. Many reported that they had struggled for a long time, with little input from hospital staff. Lack of information about rehabilitation services was said to be the main reason why people had not approached services earlier. The lack of follow-up visits was also a concern for some interviewees. Most interviewees wanted information about rehabilitation services to be more timely and readily available; they felt that expecting service users to ask for information assumed that they always knew what help they needed. However, a few interviewees reported that they had rejected the support offered to them earlier by the rehabilitation team because they did not feel ready for it, as they had not yet come to terms with their sight loss. In retrospect, however, all felt they should have had the help sooner.

In line with the findings from the literature review, people who had some experience of group-based activities felt the sessions had provided valuable opportunities to meet other people with similar conditions, share experiences and pick up valuable tips and advice from peers. However, most younger adults felt that the group activities they had been offered were geared towards older people. They felt in particular that the main focus of rehabilitation support was on the physical aspects of their life and little attention had been paid to their emotional well-being. This was not said to be a problem for some older people who relied on their family members for emotional support.

7.2.5 Key features of a model of 'good practice' for rehabilitation services

Drawing evidence from different sources of data involved in this study including the literature review, scoping workshops with professionals and service users, the survey and case studies, the key ingredients of a model of 'good practice' for rehabilitation services funded by social services for people with VI can be summed up as follows:

- Staff with specialist knowledge, the right attitude and skills to motivate and encourage people to 'do things for themselves' rather than 'having things done for them'. This requires specialist training and CPD opportunities for ROs as well as opportunities for networking and information sharing.

- High quality assessment, including the initial screening of referrals, to recognise the rehabilitation potential in people with VI.
- Listening to service users and offering personalised and service user-led support rather than making assumptions about which rehabilitation goals are important to service users.
- Holistic support offering a range of inputs including emotional support and counselling. Where the rehabilitation service does not provide a particular type of support/activity (for example computer training, emotional support, social groups and self-management courses), having access to professionals and skills outside the rehabilitation team that do offer such support/activities is particularly important. Having access to transport is essential for user participation in group activities.
- Flexibility to adapt the timing of the duration and content of support as users' abilities, needs and preferences change. This requires the rehabilitation support to be open ended rather than being time prescribed.
- Timely intervention to prevent care needs intensifying and potentially reduce future care costs.
- Clarity among all health and social care staff about the aims, potential and limitations of the VR service. This enables staff in the rehabilitation team to make and receive appropriate referrals. Collaboration with some teams/organisations including the mental health team, housing and employment are considered to be particularly essential.
- Regular reviews and follow-up visits to assess progress, monitor outcomes and identify new targets for service users.
- Providing people with VI with timely and accessible information about VR services.

The individual characteristics (such as their types and level of support needs and/or motivation) of people using services are also considered important factors impacting on the effectiveness of rehabilitation intervention. While there was a consensus among managers and ROs participating in the workshops and focus group discussions that everybody would benefit from rehabilitation in one way or another, they all agreed that rehabilitation worked differently for different people.

People who are motivated to become rehabilitated and who had come to terms with their visual impairment were thought to show greatest benefit.

7.3 Strengths and limitations of the study

7.3.1 Strengths of the study

As mentioned earlier, robust evidence around community-based VR services that are managed outside the health service has hitherto been lacking. Little was known about the state of current evidence, prevalence of rehabilitation provision and current service arrangements, specific service characteristics that might maximise people’s ability to live independently in the community and outcomes that should be measured. As the first stage in the full evaluation of such services, the current study makes a significant contribution to filling this gap.

The study design and methods have a number of important strengths. First, the literature review established the size and robustness of the state of current evidence around VR services that are not exclusively clinical in their focus, both nationally and internationally. Secondly, the study has provided the key factors that are likely to impact on service effectiveness and an indication of what impact VR services could have on people’s lives. Thirdly, the study had multiple strands (including scoping workshops, the national survey and case studies) and examined rehabilitation services from multiple perspectives (including the perspectives of the managers, frontline staff and service users). The evidence reported in this report is strengthened by triangulating data gathered from all these different sources to identify features that are likely to optimise outcomes for service users. Being able to use professional networks to ensure we reached a wide range of different providers (for the survey) and ROs (for the workshops) was another strength.

7.3.2 Limitations of the study

Despite these strengths, there are a number of limitations that affect the interpretations of the findings from this study.

The most significant limitation of this study is the lower than expected response rate (57 per cent) to the survey, despite the intensive efforts made to increase participation. While the response rate was disappointing given the professional interest in the future of VR services, it is reasonable for an on-line questionnaire. However, it may be that 'better' services responded to the survey and we know little about non-responders.

Furthermore, the study aimed to identify typical models of rehabilitation interventions for people with VI. However, it was not possible to do this because of the wide variation in the type of team delivering VR across all types of provider and within the predominant LA form of provision. Similarly, we were hoping to identify three examples of VR services for the case studies with different service models. Although we selected services that appeared to use different practices (based on the findings from the literature review, scoping workshops and the survey), they may not be as diverse as we had hoped. This suggests that we need to be cautious about generalizing from the findings from the case studies.

A further potential shortcoming of the study arises from the inclusion and exclusion criteria that determined recruitment of service users in the case study sites. Staff in those sites were asked to exclude anyone who they considered unable to give consent to participation in the study. This means that some service users with mental health problems may have been excluded. As pointed out in Chapter 2, this limitation is also true about the nature of the samples that are included in the more robust evaluations.

The review section of our work included both a 'review of reviews' and a review of primary studies, both qualitative and quantitative. Inevitably, some of the primary studies we included had also been included in the earlier reviews. Moreover, there was also some overlap of studies between the earlier reviews. This is an almost inevitable outcome when different research groups are using similar sources to address different review questions. If we had been carrying out a formal systematic review with the intention of directly informing practice or commissioning decisions, it would have been crucial to ensure that we did not put unwarranted weight on such ‘duplicate’ studies.

However, our aim was to assess the size and robustness of the evidence base on a number of topics, only one of which was about effectiveness. By assessing both existing systematic reviews and primary studies that met our inclusion and exclusion criteria, we have been able to establish the size of the evidence base. By reviewing primary studies relevant to our specific focus of community-based rehabilitation, we have been able to say something about the robustness of that evidence base. As we point out in chapter 2, the evidence base, and therefore the conclusions that can be drawn from it, remains very under-developed, both in scope and quality. In relation to calculating the costs of VR services, the different ways in which caseload data were measured and recorded meant that it was not possible to estimate the cost per client receiving the service from national survey data or case study data. In addition, the study was not designed to measure outcomes for service users and so, despite being able to estimate the unit costs, the study findings say nothing about the cost-effectiveness or value for money of services.

7.4 Recommendations for policy and practice

The findings from this scoping study suggest that VR intervention has the potential to have a positive impact on the independence of people with VI. The study has been able to identify some of the features that are likely to enhance the success of VR services (see Section 7.2.5). A number of areas in which existing practice might be developed can also be identified.

As mentioned in chapter one, a number of policy documents (DH, 2010; UK Vision Strategy Advisory Group, 2013; and ADASS, 2013) clearly explain that **rehabilitation should not be dependent on FACS eligibility criteria**. However, as the current survey shows, a quarter of

LAs required FACS assessments to determine eligibility, which is in-line with the finding from the RNIB freedom of information exercise (Kaye and Connolly, 2013). The finding clearly demonstrates that services in some areas are not following recommended practice. With LAs restricting eligibility to ‘critical’ and ‘substantial’ care needs, many people with VI living in those areas may be excluded from receiving support. While the Care Act 2014, coming into force in April 2015, has replaced FACS criteria with a national eligibility criteria, it now requires local authorities to take steps to prevent, delay or reduce individuals’ needs for care and support, whether or not people are assessed as meeting the new eligibility threshold (DH, 2014b). It remains to be seen how the new Act will facilitate people with VI accessing specialist VR services.

Similarly, **the importance of specialist assessments** was highlighted by staff participating in earlier workshops and case study sites. This was also a concern echoed in recent RNIB reports (Kaye and Connolly, 2013; RNIB, 2014) and highlighted in the Care Act 2014. The current survey showed that although the majority receive specialist assessments, screening of the initial referral is sometimes undertaken by a non-specialist. This also suggests that some people with VI may not receive the support they need and may therefore run the risk of their care needs intensifying. Greater consideration is needed to safeguard specialist assessments (including the initial screening of referrals), especially in areas where vision rehabilitation via a generic team is adopted.

A clear message from the study was that **timely intervention**, before people lose all their vision and hope, could help achieve better outcomes for users. However, findings from this study show that timely access to rehabilitation may be compromised by a lack of recognition of the importance of specialist VR skills in adult social care and a declining profile for VR services generally. Greater consideration could therefore be given to **raising the profile of specialist VR skills** and a better awareness among professionals as to what VR is about and what it can achieve for people with VI. **Providing accessible and timely information** about rehabilitation services might also help users to access such services earlier, before their condition becomes more complex. Drawing on findings in table 4.11, greater attention is needed to raise awareness of VR services and make them more accessible to the full range of people who might benefit from them. Another practice recommendation emerging from the literature review and echoed in case study findings is that **VR services need to be flexible** and **take account of individual priorities in all areas**, not only daily functioning, but also social functions and emotional adjustment. A high prevalence of depression among people with VI also suggests that the workforce in services of all types needs to be **skilled and confident enough to recognise and address psychological issues** in its client group, or to refer on to specialist services.

Finally, this study has shown that **self-management courses** as well as providing opportunities to re/engage in valued social activities can contribute to users' confidence, independence and social participation. However, as mentioned above, self-management courses were offered by only a minority of services (approximately a third), particularly within LA in-house services, and group work was reported as a casualty of financial cuts to services. Service providers need to assess current practice and give further consideration to extending the scope of VR services, to include such **group-based activities**.

7.5 Lessons for a full scale evaluation

This scoping study was designed as the first stage in the process of developing a full scale evaluation in the future. The study has provided an overview of the prevalence, organisational features, capacity and skill mix of VR provision currently available to people with VI and an indication of the costs of such services. It has also identified ingredients of a model of 'good practice' for VR services funded by social services for people with VI and explored factors that are likely to enhance positive outcomes for this group of people. Future research is needed to evaluate which types of service delivery and models of vision rehabilitation interventions are more effective in improving outcomes, for whom and at what cost. Such an evidence base will be valuable for commissioners when making decisions about developing VR services within the current financial constraints. The findings from this study have produced important lessons for the feasibility of carrying out a future full evaluation.

On the basis of this study, carrying out a full scale evaluation appears to be technically feasible. However, a number of important issues should be taken into account.

Firstly, given the current variation in VR service landscape and capacity within individual teams, we do not believe that a randomised controlled trial (RCT), where people are randomly allocated to intervention or control arms, would be feasible at this stage. However, a quasi-experimental design could be appropriate. A key distinguishing feature of quasi-experimental designs is the gathering of information about outcomes for different groups of individuals at a number of points. A decision would need to be made about what models of service interventions are to be evaluated in the future study. Moreover, the number of people with VI using VR services recruited to take part from each model should be sufficient to ensure the generalizability of the results. The work of Horowitz and colleagues (2000; 2003; 2005), reviewed in Chapter 2, also shows the value of large-scale surveys over time, coupled with sophisticated statistical analysis.

Secondly, our survey shows that not all VR services measure outcomes of the service for people with VI using the service and that the use of standardised measurement tools is uncommon. The literature review also points out the difficulty in using some existing instruments to measure certain types of outcomes. Therefore a future study will require the identification or development of appropriate measurement tools that are easy to use and that measure a range of outcomes that are meaningful to people with VI, across all services participating in the study. Willingness of practitioners to use such tool/s would be a key factor in collecting outcomes data.

Thirdly, lack of data in some sections in the survey, especially details of staffing levels within teams and budgetary information, also meant that extracting information specific to VR was problematic. However, our experience of estimating the unit costs in the three case study sites has shown that, with the goodwill of the team and finance managers, it would be feasible to use the same specially designed, short forms to collect and analyse these data from a larger number of sites in a full evaluation. Keeping the forms short and simple, but detailed enough to provide information about how staff spent their time, meant the data were detailed enough to calculate unit costs, but not too onerous for team managers to complete. Enabling team managers to choose whether to complete the details about how staff spent their time in a typical week as either number of hours worked or percentage of time also appeared to help make this task acceptable. However, far more detailed data collection forms are used in some studies that have a primary focus on calculating unit costs. Reporting time spent doing duty separately from other non-client-related activities is particularly important. In any future evaluation, a decision would need to be made about the level of detail required. In addition, the number of sites from which unit costs are calculated should be sufficient to be confident that the results are generalizable.

Finally, the term ‘annual caseload’ should be clearly defined in any future evaluation. It was evident from our analyses that some rehabilitation teams recorded caseload as the number of clients supported and others as the number of episodes of support provided. As some people with VI had a number of episodes of support in a year, annual caseloads appeared to vary hugely. There is no simple solution to this problem in relation to data collection as services cannot be expected to change their recording mechanisms for the purposes of research studies. However, this is an issue that would need to be addressed in a full evaluation.

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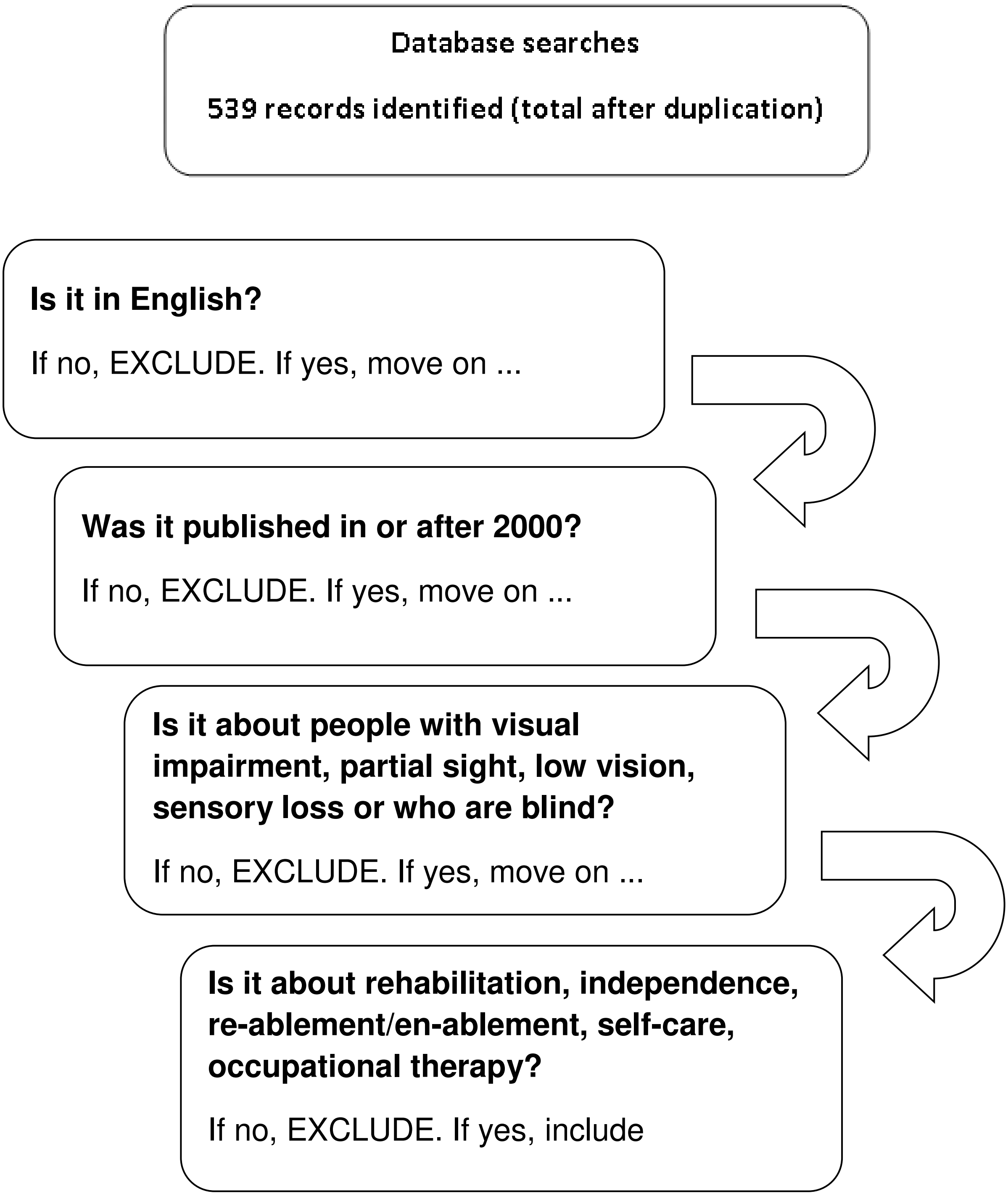
Appendix 1

VI Rehabilitation Services: algorithm for selection for relevance using title and abstract (where possible)



Database searches

539 records identified (total after duplication)

Is it in English?

If no, EXCLUDE. If yes, move on ...

Was it published in or after 2000?

If no, EXCLUDE. If yes, move on ...

Is it about people with visual impairment, partial sight, low vision, sensory loss or who are blind?

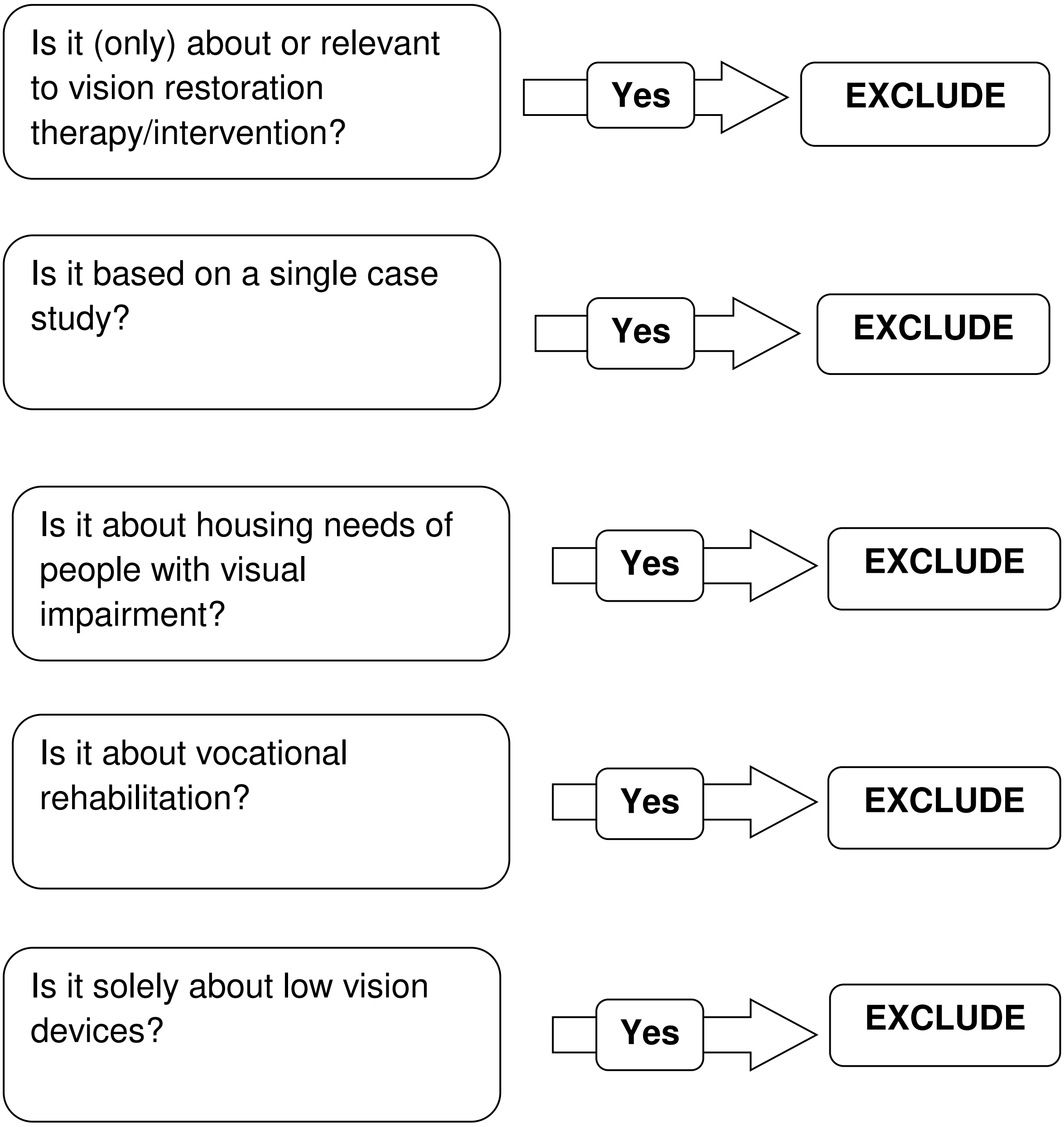
If no, EXCLUDE. If yes, move on ...

Is it about rehabilitation, independence, re-ablement/en-ablement, self-care, occupational therapy?

If no, EXCLUDE. If yes, include

Appendix 2

97 articles/books identified for relevance and full-text versions obtained
VI Rehabilitation Services: algorithm for selection for review



55 publications included for review

Appendix 3

Data extraction headings

Systematic reviews data extraction headings

Study details

- Publication details
- Focus of review
- Dates of literature reviewed
- Number of studies included
- Number and design of studies
- Review question related to low vision rehab
- Quality assessment technique used
- Synthesis methods

Results

- Quality of Life
- Visual functioning
- Other function
- Coping/adaptation/self-efficacy
- Mental health
- Dose/response/timing findings
- Cost-effectiveness
- Comparison of different models

Practice recommendations

- Recommendation 1
- Recommendation 2
- Our comments on strength of recommendations

Research recommendations

- Research recommendation 1
- Research recommendation 2

- Research recommendation 3

Qualitative study data extraction headings

Study details

- Publication details
- Study Location
- Description of programme/intervention/service
- Descriptive study
- Study population
- Aims of the study
- Design and methods

Data on features of ‘good’ rehabilitation

- Type of service delivery
- Service organisation and structure
- Access to equipment
- Access to specialist support
- Duration of intervention
- Family involvement
- Access to rehab support
- Leadership/management support
- Support for staff
- Staff training
- Person-centred support (attention to all personal needs/life goals)
- Holistic approach (e.g. focusing on rehab, education, environment)
- Reviews (recognising changes in needs)

Qualitative assessment of outcomes

- General well-being outcomes (including psychological/mental outcomes)
- Improved functional independence
- Aspects of coping and adaptation
- Accessing services
- Costs

- Other/general

Evidence on gaps in rehabilitation services

- Availability of/access to services
- Goals not addressed (e.g. relationship and leisure goals)
- Staff training, awareness and confidence
- Low number of rehab officers
- Issues raised for further investigation

Conclusions

- Authors' conclusions
- Suggestions for improvement/practice implications
- Authors' views on limitations/challenges of research
- Our views on limitations and strength of conclusions

Quantitative study data extraction headings

Study details

- Publication details
- Design
- Methods
- When were outcomes measured?
- Definition/measure of VI used
- Where was study carried out?

Sample

- Sample details - inclusion and exclusion criteria
- Size of sampling frame and achieved sample
- Sample characteristics

Intervention details

- Description of intervention or service
- Components of intervention
- Where delivered?

Impairment outcomes

- Visual impairment
- How measured
- Results
- Other impairment
- How measured
- Results

Employment and occupational outcomes

- Vocational activities/employment
- How measured
- Results

Social or leisure outcomes

- Social activities
- How measured
- Results
- Leisure activities
- How measured
- Results

ADL or IADL outcomes

- Type of ADL/IADL 1
- How measured
- Results
- Type of ADL/IADL 2
- How measured
- Results

Mental health or emotional outcomes

- Type of MH or emotional outcome
- How measured
- Results
- Type of MH or emotional outcome
- How measured

- Results

Any other outcomes reported

- Other outcomes assessed 1
- How measured
- Results
- Other outcomes assessed 2
- How measured
- Results

Conclusions

- Authors' conclusions
- Our comments on this

Appendix 4

Table A4.1 Included in Systematic Reviews: Review Details

First author and date	Focus of review	Dates of literature reviewed	N of studies included	N and design of studies	Review question related to vision rehabilitation
De Boer 2005	Evidence-based guideline that used SR techniques to identify evidence	1991-2003	No details given	No details given	What is current evidence on available interventions for various groups of visually impaired people?
Hooper 2008	Low vision rehabilitation and AMD	1980-2006	72 studies selected meeting inclusion criteria	10 randomised and 62 non-randomised. However, best evidence approach meant only 32 studies were actually included in the review. No details about the cut-off point for inclusion. Also looked at 5 SRs	How effective are low vision rehabilitation programmes and interventions for people with AMD?

				of studies that included AMD patients undergoing low vision rehabilitation.	
Lee 2008	Self-management education programmes and AMD (adults 60+ as sole or majority of participants).	1980-2006	12 articles passed title and abstract screening. Of these, 7 met all inclusion criteria, reporting on three different interventions.	3 RCTs and 1 pre/post-test with control group. In total, three author groups reported on three interventions, using four different samples (one intervention with two different samples)	What is the effectiveness of health education programmes on emotional status, performance of ADL and self-efficacy in older adults with AMD.
Binns 2012	Low vision services overall, with sub-section about rehabilitation specifically.	1950-2010	58 met inclusion/exclusion criteria. 52 relevant to general effectiveness of LV services, 4 to children or minority groups, 2 to health economic evaluations. Multiple papers from some studies, so 52 studies in total.	'Majority' were before and after without controls. 7 RCTs but most with 'significant' design or reporting flaws.	Not formally stated but appears to be about establishing 'the effectiveness and cost-effectiveness of the various types of rehabilitation' (p.37).

Nyman 2010	Review of grey literature on needs and interventions in relation to emotional well-being in people with sight loss.	Jan 2001 to September 2008	Nine studies (9 papers) identified.	Six were cross-sectional (post-test only), 2 were pre/post-test, and 1 was longitudinal.	Assess how best to provide emotional support for people with sight loss.
Rees 2010	Psychological outcomes after low vision rehab interventions	1950-Feb 2010	120 potentially relevant, 30 studies (35 papers) included. Most were focussed on older adults, with mean age of 70+	10 RCTs, 6 non-randomised CTs, 14 pre/post-test without controls (one of these was about residential rehabilitation and one about LV aids following vision assessment, so are not included in our synthesis).	Not formally stated as a question. Says article 'aims to outline current evidence for the impact of low-vision rehabilitation programs on psychological well-being' and 'to describe and summarize the effects of novel interventions designed specifically to address psychological needs in people with vision impairment' (p.386).

Orellano 2012	Impact of occupation and activity-based interventions on IADLs among community-dwelling older people. Includes material on people with visual impairment.	1990-November 2008, plus recommended articles published 2009-11.	38 studies included overall,	31 at quality level I; 3 at level II, 3 at level III, and 1 at level IV.	What is the effectiveness of occupation or activity based interventions targeted at improving or maintaining IADL performance in community dwelling older adults?

Appendix 5

Table A5.1 Included in Quantitative Studies: primary study details

First author and date	Design	Methods	When were outcomes measured?	Definition/measure of VI used	Where was study carried out?
Alma 2012	Pilot single group, pre-test, post-test.	Face to face interviews carried out by trained interviewers.	Before and immediately after intervention and then at 6m.	Person with visual acuity ≤0.5 Snellen with probs in daily life or those with visual field <30 degrees.	Netherlands
Birk 2004	Pre-test, post test pilot intervention study using standardized assessment of intervention and non-intervention groups.	Standardized interview carried out by group trainers, thus not blind to treatment assignment. T2 assessments were both face-to-face and telephone.	1 week before programme began and the week after it finished.	Bilateral macular degeneration, defined by assessment of ophthalmologists involved in the study. Remaining visual acuity in better eye < 20/70.	Germany

Brody 2002 and 2005	RCT. Random assignment to one of two intervention groups or a waiting list control group.	Interviews a clinical psychologist and trained research assistants using standardized measures. Interviewers not aware of treatment assignment and participants did not know the study hypotheses. Trained personnel tested visual acuity.	Baseline (not otherwise specified) and post intervention (not entirely clear when this was) and then at 6m follow up.	Visual acuity of 20/60 or worse in better eye and 20/100 or worse in the other, with habitual correction.	USA
Christy 2010	RCT. This paper described the design and baseline characteristics of participants.	Questionnaire administration by trained interviewer masked to design, protocol and intervention.	Baseline (not otherwise specified) and nine months.	Best corrected visual acuity <6/12 to light perception, or visual field <10 degrees from the point of fixation, but uses or is potentially able to use vision for planning and/or execution of a task.	India

de Boer 2006	Non-randomised, follow-up study comparing patients referred to two different models of visual rehab.	Participants referred to either one of two different models of visual rehab - in one to a low vision optometrist, in the other to a regional multi-disciplinary visual rehab centre. Methods of data collection not described at all.	Baseline, defined as before contact with service, 1-4 weeks for some of sample, 5 months later and 12 months later. This paper reports baseline and 12 month follow-up data.	Not defined. Clinical assessment of visual impairment - distance visual acuity assessed by projection and with habitual correction for both eyes separately - was carried out by opthalmologist at baseline and 12 months.	Netherlands
Eklund 2004, 2005, 2008; Dahlin Ivanoff 2002	Randomised longitudinal study evaluating the ADL-based Health Education Programme 'Discovering new ways' compared to usual care.	Random assignment using random number tables. OTs collected data when clients attended low vision clinic. They were not masked to allocation but were not part of the programme. Used structured interview protocol and made an assessment of perceived security in performing daily activities.	1,4,16,and 28 months after intervention was completed.	Distance visual acuity in the better eye, with own glasses and best refraction, no lower than 0.1. Tested with a letter chart, graded 0.1 to 1.0 at a distance of 5m.	Sweden

Engel 2000	Pre-test, post-test.	Face to face and telephone interviews initially, then telephone interviews alone. Questionnaire developed and piloted by the directors of the three agencies involved in the project. Interviews of between 15 and 30 minutes.	Baseline (at referral to service) then every two months up to a maximum of five interviews. Few completed four or five interviews so respondents' 'postintervention responses' were averaged.	Not defined. Table reports 'vision with glasses' using six categories but no indication of how assessed.	USA
Girdler 2010, Packer 2009	RCT comparing 'usual care' from a third sector provider with usual care plus a vision self-management group intervention.	Random assignment via computer-generated random numbers table. Face-to-face, structured interviews in participants' own homes. Assessor masked to participants' group allocation but participants often inadvertently revealed this during interviews.	Baseline, immediately after completion of rehabilitation, and 12 weeks later.	Best corrected vision at the Snellen equivalent of 6/12 or less in both eyes.	Australia
Hinds 2003	Pre-test, post-test evaluation of impact of multi-disciplinary LV rehab service.	Interview at home 2 weeks before first appointment. Reassessment 6m after first appointment - not clear where this was done.	2 weeks before appointment and 6m after.	Not defined.	Scotland.

Horowitz 2000	Pre-test, post-test evaluation of impact of group model of vision rehab - Adaptive Skills Training Programme (AST)	Questionnaire developed to cover demographic s, information on services received and measures of psychosocial and functional status. All interviews done 'in person' by service providers. Had been trained in questionnaire administration by researchers. Training manual and training sessions done via conference calls.	Before service receipt (during assessment or before group began) and shortly after last training session.	‘Legally blind', not otherwise described. Later reports proportions with 'low vision' and 'totally blind'.	USA
Horrowitz 2003, 2005	Pre-test, post-test exploration of impact of range of factors, including rehabilitation, on depression. Second paper explores this in more detail.	Face-to-face interviews in participants' own homes. Covered socio-demographics, self-rated health , functional vision loss, change in vision impairment (since first interview), measure of functional disability, social support indicators, rehab service use, and depressive symptoms. Main focus was on depression and	Baseline interview prior to service use. Follow up was 20 to 27 months after baseline.	Not defined.	USA

		its relationship to change over time.			
Kirkcaldy 2011	Mixed methods study of an RNIB peer support programme. One element was pre-test post-test evaluation of impact on QoL.	Telephone administration of QoL measure. Not clear who did this.	Baseline during fortnight before attendance at the programme. Follow-up around 3 months after attendance.	Not defined.	UK
Campbell 2005, La Grow 2006	Three arm RCT evaluating a home safety programme designed to prevent falls in older people with severe VI. Second paper reports same results but with more detail about the nature of falls and explores why home safety programme worked.	2x2 factorial design. Independent assessor did baseline assessments at participant's home. Randomised using computer generated random numbers, masked to investigators. Assigned intervention then delivered within next two weeks, where possible.	Baseline before randomisation. Follow-up at one year.	Poor vision defined as visual acuity of 6/24 or worse in better eye after best possible correction.	New Zealand

Langelaan 2009	Prospective cohort study evaluating impact of comprehensive rehabilitation service for VI adults.	Face-to-face interviews. No other details.	Baseline was during 'observational programme' and 7m and 16m after baseline (roughly 3m and 12m after finishing rehab).	Not defined, but visual acuity was assessed as part of the research by a functional vision score that 'integrates visual acuity and visual field into one comprehensive score', ranging from 0 to 100, with 0 representing total blindness and 100 normal vision.	Netherlands
Margrain 2012	RCT evaluating Problem Solving Therapy compared to referral to GP requesting treatment according to NICE 'stepped care' recommendations and waiting list control. Focus was impact on	Attendees at LV services in SE Wales and London who screened positive on GDS-15 (score of 6 or more). Low vision assessment and information about the study and given copies of the measures. Informed consent. Baseline telephone interviews, completion	Baseline, 6 weeks, 3 and 6 months for all arms. Additional qualitative follow up but not clear whether this was for everyone or just waiting list control group.	Not defined in this paper.	UK

	depression.	of instruments. Randomisation. People scoring 2 or 3 on suicidal ideation scale excluded and referred to GP.			
McCabe 2000	Pre-test post-test evaluation of multi-disciplinary rehab, delivered either with individual or family focus.	All eligible patients informed and told participation would involve random assignment to one of two interventions. Functional assessment questionnaire done over the phone by research assistants masked to allocation. Functional vision performance test done by OT or technician (not clear where this was done). Randomisation process not described.	At baseline (before randomisation) and at conclusion of rehab.	Best corrected vision in better eye of 20/100 or worse.	USA

Russell 2001, Reeves 2004	Three arm RCT comparing standard clinic-based rehab (CLVR), enhanced rehab with supplementary home-based rehab (ELVR), and standard rehab with non-rehab home visits from a 'community care worker'.	Unequal block randomisation with computer generated allocation codes before start of study. Concealed in opaque envelopes. Outcomes assessed by researcher masked to allocation.	Before 'first hospital assessment' and 'about 12 months later'.	Primary diagnosis of AMD and visual acuity worse than 6/18 in both eyes and equal to or better than 1/60 in better eye.	UK

Appendix 6

THE UNIVERSITY of York

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Vision Rehabilitation Services

Topic guide for workshops with professionals

1. Introduction

- Researcher introduction/aims of the workshop
- Consent form
- Confidentiality within the group
- Ground rules about conduct of workshop

Group introduction: Ask each participant to say their names, their job title, training/expertise, and how long they have been in the vision rehab team.

2. Background

- Who do they work for? How is the service funded?
- What support do they offer?
- What is their current caseload?
- Who is in their client group?

3. General views on rehabilitation

- ➢ What do they think constitutes rehab support? (Explore any problems/challenges with it)

- The scale/mix of intervention employed - How big does intervention have to be? (e.g. single intervention/multiple interventions)
- What sort of process/over what length of time? (one-off, over several sessions, on-going process)
- The balance between learning skills maintenance vs. rehabilitation/special skills?

➢ What outcomes should rehab help people achieve?

➢ Do they think that rehab works equally/differently for different people? Are there any groups of service users who they think rehab would work better or worse for? (Ask for details)

4. Good practice

➢ What are good features of rehab support?

Possible prompts:

- What type of support should be provided (e.g. the balance between practical help, emotional support and supply of equipment)
- When would it be good to offer the support?
- How long should the support last?
- Who should provide it? (probe for importance of staff training, attitude, personal experience of SL)
- What external links/collaboration would be necessary in order to achieve maximum outcome for the service user?
- Any examples of good rehab practice?

➢ What do they think are the main challenges in providing good rehab support as described above?

5. Suggestions for improvement – how could rehabilitation services be improved?

- Is there anything that they think would improve rehab services?

- Is there anything that they think could help any particular areas of their practice (e.g. braille)?

6. Anything else not covered?

Appendix 7

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Vision Rehabilitation Services

Topic guide for workshops with service users

7. Introduction

- Researcher introduction/aims of the workshop
- Consent form
- Confidentiality within the group
- Ground rules about conduct of workshop

Group introduction: Ask each participant to introduce themselves and say how long they have had a sight loss.

8. Personal experience of using rehab services

- Description
  - What did the rehab service help them with? Length of the service?

- Views on using the service
  - What experiences (good or bad) have they had with it? (Probe for reasons)
  - Was there any area of their life (e.g. functional, social and emotional) that was not addressed but they would have liked it to be addressed when they were receiving rehab support? (Probe for what/reasons for not receiving the support)

- Outcomes
  - What differences (if any) do they feel rehab support has made to their lives? (Ask for details – probe for improvements in ADL, IADL, social activities, emotional well-being, mobility, independence, feeling safe, employment opportunities, and impacts on their family members).

9. General views on rehabilitation

- What do they think rehab is/should be?

- What aspects of the rehab support do they think are most beneficial to people?

- Has their view about it changed over time?

- Are there any individuals/groups that they think rehab would work better or worse for? (Ask for details)

10. Good practice

- How do they describe a good rehab support?

  Possible prompts:
  - What type of support should rehab services provide? (e.g. the balance between practical help, emotional support and supply of equipment)
  - How long should the support be available to people?
  - Who should provide the support? (probe for staff training/attitude/personal experience of SL)
  - What outcomes should rehab help people achieve?
  - Any examples of good rehab practice?

11. Suggestions for improvement

- How do they think rehab services should improve?

12. Anything else not covered?

Appendix 8

Survey stage 1 documents: email invitation to participate in the stage 1 survey, accompanying information about the audit and questionnaire to collect baseline data

Dear Colleague

Vision Rehabilitation Services: increasing the evidence base

As you will be aware from the recent ADASS circular, the Social Policy Research Unit at the University of York are carrying out a study of adult vision rehabilitation services, funded by the Thomas Pocklington Trust.

As part of this research, we are carrying out a survey of vision rehabilitation services nationally that are funded, or part-funded, by local authorities. We now have ADASS support for the first phase of the survey, which is to contact commissioners to obtain the contact details of adult vision rehab services commissioned within each local authority area. We appreciate that these services may be either in-house or contracted out.

We would be grateful if you could forward this email with the attached information sheet and contact form to the appropriate person in your authority.

In the second phase of the survey, we plan to contact the services that we identify with a more detailed questionnaire about their provision. We will consult with ADASS Research Support Group about the content of the final questionnaire, before it is sent out to these vision rehab services. The main survey is scheduled to be sent to vision rehab services in August/September 2013.

If you would like any more information, or have any questions relating to this research, please contact Sylvia Bernard, Email: sylvia.bernard@york.ac.uk Tel No 01904 321978.

Thank you for your help.

Kind Regards

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Vision Rehabilitation Services: Increasing the Evidence Base

Information sheet for audit of vision rehabilitation services

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You are being invited to take part in a survey conducted by the Social Policy Research Unit at the University of York. This is part of a wider project funded by the Thomas Pocklington Trust to understand more about adult vision rehabilitation services in England. The research has the approval of the Social Care Research Ethics Committee (SCREC) and the support of the Association of Directors of Adult Social Services (ADASS). Before you decide whether or not you wish to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Please ask if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

The number of older people in England is set to rise significantly. As age-related eye conditions are the most common causes of visual impairment, the number of people with visual impairment is also expected to rise considerably. Rehabilitation services could play an essential role in enabling people to live independently. Little is known about what services are doing actively to support people with visual impairment. It is important that people with visual impairment are not excluded from receiving appropriate rehabilitation interventions that could improve their quality of life and promote their independence.

We want to find out what rehabilitation services are currently doing to rehabilitate adults with visual impairment and what outcomes they are likely to achieve for this group. Providing such an evidence base is crucial to the development of rehabilitation interventions that can target support better. The research is in five stages. It includes a literature review; workshops and focus groups with adults with visual impairment and a range of professionals concerned with people with visual impairment and a national audit of vision rehabilitation services. This information sheet refers to stage three of the project: the audit of vision rehabilitation services.

How we would like your help

You have been invited to take part in this study because you are involved in commissioning and/or providing rehabilitation support to adults with visual impairment. The purpose of the survey is to map out the prevalence, location, capacity, organisation and content of rehabilitation services for adults with visual impairment that currently exist.

As a first step we need to identify existing services and collect baseline information on adult vision rehabilitation services that are funded or part-funded by local authorities. We will then contact services to collect more detailed information.

Participation in this audit is entirely voluntary. We anticipate that this phase will take no longer than 10 minutes of your time. If you decide to take part, please provide the **initial service type and contact information only** as requested in the attached ‘Vision Rehab Services’ document. We will then approach service providers separately for more detailed information. If you choose not to take part, it would be very helpful if you would let us know, stating the local authority you are representing, so that we do not contact you again. You do not have to provide a reason, but doing so would enable us to understand your reasons for declining to participate, which might help when planning future projects.

Confidentiality

Your involvement in the audit, and the information that you provide, will be kept confidential. A unique identification number will be used throughout the audit for each local authority and all data will be anonymised. Data will be held in accordance with the 1998 Data Protection Act and University of York Ordinances.

Ethical review

This research has been reviewed by the Social Care Research Ethics Committee and has been given a favourable opinion for ethical conduct. As this phase is simply collecting information about what services your local authority commissions, it is designated as a service audit and exempt from requiring ethical review.

We do not anticipate any risks to you or your organisation as a result of taking part in the research. If you have a concern about any aspect of this study, please speak to a member of the research team who will do their best to answer your questions (01904 321950).

Outputs

We will write reports and articles on the findings of the research during and after the project. We will make sure that the reports are distributed widely to people who provide services and people who work in local authorities and government departments. We will send you a summary of the results after completion of the study and let you know how the final report can be accessed.

Funding

This study is funded by the Thomas Pocklington Trust. It will be completed in June 2014.

For further information, please contact:

Sylvia Bernard, Becky Thompson or Parvaneh Rabiee

Social Policy Research Unit

University of York

Heslington, York

YO10 5DD

Telephone 01904 321950, 01904 321978 or 01904 321974

Email sylvia.bernard@york.ac.uk
rebecca.thompson@york.ac.uk or parvaneh.rabiee@york.ac.uk

Website http://php.york.ac.uk/inst/spru/research/summs/tpt.php

Concerns or complaints about any aspect of the study can be addressed to Sally Pulleyn by ringing 01904 321951 or emailing sally.pulleyn@york.ac.uk

Thank you for taking time to read this sheet and considering taking part.

THE UNIVERSITY *of York*

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Vision Rehabilitation Services: Increasing the Evidence Base

Details of Vision Rehabilitation Services

If you have read the accompanying participant information, and are able to participate, please could you provide the following information about vision rehabilitation services that **your local authority may fund or part-fund**:

1. Name of local authority :

2. Does your local authority commission/provide a structured programme of rehabilitation for people who are registered blind or partially sighted or have lost their sight?

☐ Yes

☐ No

3. If you answered yes to question 2, in your local authority area, is the vision rehabilitation service provided:

☐ 'In-house' by local authority,

☐ **Jointly** with health

☐ Contracted out to voluntary/independent sector organisation

(Please tick all that apply)

4. Please can you provide contact details of the vision rehabilitation service(s) that your local authority commissions.

Name of providing organisation:

Name of manager of vision rehabilitation service:

Email:

Telephone Number:

Thank you for your participation

If you would like any further information, please contact:

Sylvia Bernard, Becky Thompson or Parvaneh Rabiee

Social Policy Research Unit

University of York

Heslington, York

YO10 5DD

Telephone 01904 321950, 01904 321978 or 01904 321974

Email sylvia.bernard@york.ac.uk
rebecca.thompson@york.ac.uk or parvaneh.rabiee@york.ac.uk

Website http://php.york.ac.uk/inst/spru/research/summs/tpt.php

Concerns or complaints about any aspect of the study can be addressed to Sally Pulleyn, by contacting 01904 321951 or emailing sally.pulleyn@york.ac.uk

Appendix 9

Survey stage 2 documents: email invitation to participate in the stage 2 survey, accompanying information about the research and copy of questionnaire

Dear Colleague

Vision Rehabilitation Services: increasing the evidence base

As you may be aware, the Social Policy Research Unit at the University of York are carrying out a study of Vision Rehabilitation Services, funded by the Thomas Pocklington Trust.

As part of this research, we are carrying out a survey of adult vision rehabilitation services nationally that are funded, or part-funded, by local authorities. We have ADASS support for this survey, and are now contacting vision rehabilitation services with a questionnaire about their provision. We appreciate that these services may be either in-house or contracted out.

Please click the link below to find out about the research and specifically about the survey.

Link – information sheet

If after reading this you are able to take part, you can access the survey via the web link:

www.etc.

The questionnaire should take approximately 30-45 minutes to complete and we would be grateful if you could submit your responses by 23rd. December 2013. If you would prefer a hard copy or Braille format, please let us know.

If you would like any more information, or have any questions relating to this research, please email Sylvia Bernard, sylvia.bernard@york.ac.uk Becky Thompson, rebecca.thompson@york.ac.uk or Parvaneh Rabiee parvaneh.rabiee@york.ac.uk or telephone 01904 321950.

Thank you for your help.

Kind Regards

Vision Rehabilitation Services: Increasing the Evidence Base

Information sheet for audit of vision rehabilitation services

---

You are being invited to take part in a survey conducted by the Social Policy Research Unit at the University of York. This is part of a wider project funded by the Thomas Pocklington Trust to understand more about vision rehabilitation services for adults in England. The research has the approval of the Social Care Research Ethics Committee (SCREC) and the support of the Association of Directors of Adult Social Services (ADASS). Before you decide whether or not you wish to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Please ask if there is anything that is not clear or if you would like more information.

Why is the research important?

The number of older people in England is set to rise significantly. As age-related eye conditions are the most common causes of visual impairment, the number of people with visual impairment is also expected to rise considerably. Rehabilitation services could play an essential role in enabling people to live independently. Little is known about what services are doing actively to support adults with visual impairment. It is important that people with visual impairment are not excluded from receiving appropriate rehabilitation interventions that could improve their quality of life and promote their independence.

What is the purpose of the study?

We want to find out what rehabilitation services are currently doing to rehabilitate adults with visual impairment and what outcomes they are likely to achieve for this group. Providing such an evidence base is crucial to the development of rehabilitation interventions that can target support better. The research is in five stages. It includes a literature review; workshops and focus groups with adults with visual impairment and a range of professionals concerned with people with visual impairment and a national audit of vision rehabilitation services. This information sheet refers to stage three of the project: the audit of vision rehabilitation services.

How we would like your help

You have been invited to take part in this study because you are involved in providing rehabilitation support to people with visual impairment. The audit will collect information on adult vision rehabilitation services in order to map out the prevalence, location, capacity, organisation and content of rehabilitation services for people with visual impairment that currently exist.

The survey is designed to be completed electronically, but if you would prefer a hard copy format please let us know. The survey can be accessed via the web link in the email.

If you are providing a service for more than one local authority, please can you complete the survey for each local authority separately. (You can re-access the survey using the same link.)

The questionnaire should take 30 to 45 minutes to complete. It may be helpful to have information about your service to hand before you start the survey, including basic overall budget information.

Participation in this audit is entirely voluntary. If you choose not to take part, it would be very helpful if you would let us know, so that we do not contact you again. You do not have to provide a reason, but doing so would enable us to understand your reasons for declining to participate which might help when planning future projects.

Confidentiality

Your involvement in the audit, and the information that you provide, will be kept confidential. A unique identification number will be used throughout the audit for each service and all data will be anonymised. Data will be held in accordance with the 1998 Data Protection Act and University of York Ordinances.

Ethical review

This research has been reviewed by the Social Care Research Ethics Committee and has been given a favourable opinion for ethical conduct. As this phase is simply collecting information about what services your local authority commissions, it is designated as a service audit and exempt from requiring ethical review.

We do not anticipate any risks to you or your organisation as a result of taking part in the research. If you have a concern about any aspect of this study, please speak to a member of the research team who will do their best to answer your questions (01904 321950).

Outputs

We will write reports and articles on the findings of the research during and after the project. We will make sure that the reports are distributed widely to people who provide services and people who work in local authorities voluntary organisations and government departments. We will send you a summary of the results after completion of the study and let you know how the final report can be accessed.

Funding

This study is funded by Thomas Pocklington Trust. It will be completed in June 2014.

For further information, please contact:

Dr Parvaneh Rabiee, Dr Sylvia Bernard

Social Policy Research Unit

University of York

Heslington, York

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Telephone 01904 321950

Email parvaneh.rabiee@york.ac.uk or Sylvia.bernard@york.ac.uk

Website http://php.york.ac.uk/inst/spru/research/summs/tpt.php

Concerns or complaints about any aspect of the study can be addressed to Sally Pulleyn by ringing 01904 321951 or emailing sally.pulleyn@york.ac.uk

Thank you for taking time to read this sheet and considering taking part.

Vision Rehabilitation Survey

Note: The questionnaire was designed to be answered on-line. The following copy is a downloadable version that includes (in bold) commands, generated by the software, to route participants through the questionnaire, according to their answers to particular questions.

The following survey is conducted by the Social Policy Research Unit at the University of York. It is part of a wider project funded by the Thomas Pocklington Trust to understand more about adult vision rehabilitation services in England that are funded totally or partly by local authorities. The questionnaire is divided into five sections and should take approximately 30 to 45 minutes (maximum) to complete. You do not have to complete the whole questionnaire in one session: you can close the webpage at any time and your answers will save automatically. You can come back to the webpage and add more answers for up to two weeks after starting the questionnaire, as long as you are using the same computer. If you wish to edit your responses, you can move back through the survey by clicking the back button in the bottom left corner of the page. You are able to download a summary of your responses at the end of the survey. If you are providing a service for more than one local authority, please can you complete the survey for each local authority separately. (You can re-access the survey using the same link.) The information sheet accompanying the introductory email provides further details about the research. If you have read the information and are happy to participate in the survey, please check the box below and proceed. Thank you for taking part.

☐ Yes, I have read the information sheet and wish to take part

☐ No, I do not wish to take part

If ‘No, I do not wish to take part’ Is Selected, Then Skip To End of Survey

Please confirm the name of the local authority that funds or part funds this service.

____

Section 1. The first section asks about the organisation and structure of the vision rehabilitation service and the skill mix within the service.

Who provides the core vision rehabilitation service?

☐ local authority social care (in-house)

☐ joint health and social care

☐ voluntary (not-for-profit) with local authority funding

☐ pilot social enterprise

☐ other (please describe) ____________________

☐ private (for-profit) with local authority funding

Answer If ‘Who provides the core vision rehabilitation service?’ local authority social care (in-house) Is Selected

Although the core vision rehab service is provided in-house, are there any elements of the service that are contracted out?

☐ Yes

☐ No

If No Is Selected, Then Skip To ‘How would you describe the team delivering vision rehabilitation?’

Answer If ‘Although the core vision rehab service is provided in- house, are there any elements of the service that are contracted out?’, Yes Is Selected

Which elements of the vision rehab service are contracted out (and receive local authority funding) (for example, equipment)? (Please describe)

____

Answer If ‘Although the core vision rehab service is provided in-house, are there any elements of the service that are contracted out?’, Yes Is Selected

What is the nature of the contract(s)? If you have a different type of arrangement to those listed, or more than one type of contract exists, please select 'other' and describe.

☐ block contract
☐ outcome based contract
☐ spot purchasing
☐ via a framework agreement
☐ other (please describe) ____________________

Answer If ‘Who provides the vision rehabilitation service? Local authority social care (in-house)’ Is Not Selected

What is the nature of the contract? If you have a different type of arrangement to those listed, or more than one type of contract exists, please select 'other' and describe.

☐ block contract
☐ outcome based contract
☐ spot purchasing
☐ via a framework agreement
☐ other (please describe) ____________________

How would you describe the core team delivering vision rehabilitation?

☐ specialist vision rehabilitation team
☐ specialist sensory impairment team
☐ specialist physical and sensory impairment team
☐ multi-disciplinary re-ablement team
☐ other specialist multi-disciplinary team (including, for example, a stroke team) (please describe)

____

☐ part of generic adult social care team
☐ lone worker
☐ other (please describe) ____________________

Where is the core service based (that is, where does the core team work from)?

☐ local authority setting
☐ healthcare setting
☐ independent organisation setting
☐ Other (please describe) ____________________

In which of the following settings is the service delivered? (that is, where do the team carry out their work with clients) (Please select all options that apply).

☐ local authority setting
☐ healthcare setting
☐ independent organisation setting
☐ intermediate care or re-ablement setting
☐ service user's home
☐ other (please describe) ____________________

Who is the team manager of the vision rehabilitation service?

☐ specialist in vision impairment
☐ specialist in sensory impairment
☐ specialist in physical and sensory impairment
☐ occupational therapist (OT) - not specialist in vision impairment
☐ generic social worker
☐ other professional - not specialist in vision impairment (please describe) ____________________

Which professional skills are represented within the core team delivering vision rehabilitation? Please calculate as whole time equivalent (WTE) for each category of staff (including the manager), (exclude time devoted to other services) and enter number (for example, 1, 1.5, 2) in the appropriate box for the NJC scale level (or equivalent grade). If you do not know the scale level (or equivalent), please enter the total WTE in the 'scale level not known' box. If a particular skill is not represented in the team, please enter 0 in 'not applicable'). WTE for Scale 3 (or equivalent)(£15,882-£16,998) WTE for Scale 4 (or equivalent) (£17,333-£19,317) WTE for Scale 5 (or equivalent)(£19,817-£21734) WTE for Scale 6 (or equivalent) (£22,443-£23,945) WTE for SO1 (or equivalent) (£24,892-£26,539) WTE SO2 equivalent) (£27,323-£28922)

- team manager
- senior rehabilitation officer (vision impairment)
- rehabilitation officer (vision impairment)
- assistant rehabilitation officer (vision impairment)
- assistive technology specialist
- social worker
- community care officer (CCO)
- OT
- eye clinic liaison officer (ECLO) or other hospital advice and information officer
- other (please describe)
- other (please describe)

Section 2. This section asks about access, referral and assessment practices.

How do people access the service? (Please select all options that apply)

☐ referral from health or social care professional

☐ self-referral/open access

☐ other (please describe) ____________________

Who screens the initial referral?

☐ professional with specialist qualification in vision rehabilitation

☐ professional without specialist skills in vision rehabilitation

☐ administrative staff (including initial council contact centre)

☐ other (please describe) ____________________

Do adults with sight loss have a FACs assessed community care assessment before being offered vision rehabilitation?

☐ Yes

☐ No

☐ sometimes, but not a requirement

Who carries out assessments for the vision rehabilitation service? (Please select all options that apply).

☐ professional with specialist skills in vision rehabilitation

☐ professional without specialist skills in vision rehabilitation

☐ other (please describe) ____________________

Where are the majority of assessments carried out?

☐ service user's home

☐ health setting (for example, eye clinic)

☐ social care setting

☐ independent organisation setting

☐ by telephone

☐ other (please describe) ____________________

When you have finished working with a client, how can they access the service again, if they need to?

☐ via re-activating the formal intake procedures
☐ open access via the waiting list
☐ open access (by-pass the waiting list)
☐ other (please describe) ____________________

How does the service review service users' needs?

☐ formal follow-up review at agreed time interval
☐ informal review
☐ no review

What is the approximate annual expected case load for the service?

____

Once a referral has been made, is there a waiting list for the service?

☐ Yes
☐ No

If No Is Selected, Then Skip To End of Block

Approximately how many people are currently on the waiting list?

____

What is the approximate waiting time (in weeks) for the service?

____

Section 3. This section asks about the type and reach of the service provided.

Is the support that the service provides:
☐ time-prescribed (for example, maximum 6 weeks)
☐ open-ended depending on need

Answer If Is the support that the service provides: time-prescribed (for example, maximum 6 weeks) Is Selected
How long is support offered? (Please enter maximum number of weeks)

____

What type of training for service users does the rehabilitation team provide? (Please select all options that apply).
☐ independent living skills
☐ orientation and mobility
☐ use of aids/adaptations/equipment
☐ communication, for example, braille, IT
☐ training for partners/carers
☐ self-management courses
☐ other (please describe) ____________________

What type of support for service users does the rehabilitation team provide? (Please select all options that apply).
☐ providing aids/adaptations/equipment
☐ support in managing personal budgets
☐ emotional support

☐ counselling

☐ employment advice

☐ benefits/financial advice

☐ housing advice

☐ training/education advice

☐ support for leisure/social activities

☐ support for social relationships

☐ facilitating peer support/group work

☐ information/signposting

☐ personal assistants (PAs)

☐ volunteer support

☐ support for partners/carers

☐ 'out of hours' support (for example, evenings and weekends) ____________________

☐ other (please describe) ____________________

Are there any groups who do not use the service but who would be eligible to use it, or you feel may be under-represented ? (Please select all options that apply).

☐ people with learning disabilities

☐ people with dementia

☐ people with acquired brain injuries

☐ people who have experienced strokes

☐ people who have multiple sensory impairments

☐ people from ethnic minorities

☐ people living in rural areas

☐ other (please describe) ____________________

☐ none

Answer If Are there any groups who do not use the service but who would be eligible to use it, or you feel may be under-represented? None Is Not Selected

Do you think some people may not access the service because of: (Please select all options that apply)

☐ lack of information about the service
☐ lack of specialist skills within team
☐ lack of team time
☐ lack of links with other services
☐ other (please describe) ____________________
☐ don't know

If your team needed to work with other organisations on behalf of a client, how easy would it be? (You may wish to consult with other team members to answer this question.)

Select Difficult, Neutral or Easy

- (other) adult social care (including for example, low level intervention teams such as 'well-being team', 'outreach travel trainers')
- eye clinic liaison officers (ECLOs)
- health OTs
- other health professionals (for example, GPs)
- other specialist teams (for example, stroke team)
- housing services
- employment services
- training/education services
- benefits services

- voluntary/private organisations' support
- other (please describe) ____________________

Section 4. This section asks how you assess and/or measure the outcomes of your service.

Q35 Are performance indicators applied to this service?

☐ Yes

☐ No

Answer If ‘Are performance indicators applied to this service?’ Yes Is Selected

Please select the type of performance indicators (PIs) that apply to this service. (Please select all options that apply).

☐ PIs around dealing with referrals, for example, number of referrals responded to within a specified time limit

☐ PIs around interventions, for example, time taken to complete an intervention

☐ PIs around reviews, for example, percentage of rehabilitation plans reviewed annually

☐ other (please describe) ____________________

Do you measure the impact of your service on outcomes for service users (for example, quality of life)?

☐ Yes

☐ No

If No Is Selected, Then Skip To End of Block

Do you use a standardised outcomes measurement tool?

☐ Yes

☐ No

Answer If Do you use a standardised outcomes measurement tool? Yes Is Selected

What standardised outcomes measurement tool do you use?

____

Answer If Do you use a standardised outcomes measurement tool? No Is Selected

Was your outcomes measurement tool developed in discussion with service users?

☐ Yes

☐ No

☐ Don't know

How do you feel the outcomes measurement tool has influenced your practice?

____

Section 5. The final section asks about costs and charges for the service and changes that the service might be experiencing.

In the current financial year, (2013-2014), what is the total available budget for vision rehabilitation support (in £s)? (Please leave blank if you do not know.) (Please include all costs/charges associated with delivering the service in your estimate, including rehabilitation assessments and inputs, and any elements of the service that may be contracted out, for example, equipment.)

____

How is this budget allocated (approximate percentage allocation)? (Click on slider and pull across). (If you describe several elements in the 'other' category, please enter percentage as total 'other'.)
______ staffing (include all wages/salaries and on costs, but exclude training)
______ staff training
______ equipment
______ travel
______ other (please describe)

Are service users charged (fully or partly) for any of the following types of support? (Charges may be subject to financial assessment.) Please select all options that apply: Yes, No, Not offered by service.

- equipment
- courses, for example, computer, Braille, self-management
- sighted guides/personal assistants
- other (please describe)____________________

Are continuing professional development (CPD) opportunities available to different staff within the service to provide and/or maintain specialist skills around vision rehabilitation? (If the service does not include a particular category of staff, please select 'not applicable'.) Select from: CPD available, CPD available but difficult to access (for example, lack of courses locally), CPD not available, not applicable.

- manager of rehabilitation service
- senior rehabilitation officer (vision impairment)
- rehabilitation officer (vision impairment)
- assistant rehabilitation officer (vision impairment)
- assistive technology specialist
- social worker
- community care officer (CCO)
- OT
- eye clinic liaison officer (ECLO) or other hospital advice and information officer
- other (please describe) ____________________
- other (please describe) ____________________

We are interested in recent changes to the service and possible reasons why they may have happened. In the last year, has the budget for this service,

☐ increased
☐ decreased
☐ stayed the same

Answer If ‘We are interested in recent changes to the service and possible reasons why they may have happened.’ If ‘stayed the same’ Is Not Selected

What are the reasons for these budget changes? (Please select all options that apply).

☐ changes in the configuration of the service
☐ changes in service user demand
☐ changes in costs of services
☐ austerity measures/financial cuts
☐ other (please describe) ____________________

In the last year, have staffing ratios for the service changed (that is, number of WTE staff per person with vision impairment),

☐ improved
☐ worsened
☐ stayed the same

Answer If In the last year, have staffing ratios for the service changed (that is, number of WTE staff per person with vision impairment). If ‘stayed the same’ Is Not Selected

What are the reasons for these staffing changes? (Please select all options that apply).

☐ changes in the configuration of the service
☐ changes in service user demand
☐ changes in recruitment and/or retention of staff
☐ austerity measures/financial cuts
☐ other (please describe) ____________________

Is the service experiencing problems in recruiting staff?

☐ Yes

☐ No

Answer If Is the service experiencing problems in recruiting staff? Yes Is Selected

Are the problems in recruiting staff due to: (Please select all options that apply)

☐ lack of suitably qualified/trained staff

☐ lack of recognised career path

☐ lack of continuing professional development (CPD)

☐ pay levels

☐ austerity measures/financial cuts

☐ other (please describe) ____________________

Is the service experiencing problems in retaining staff?

☐ Yes

☐ No

Answer If Is the service experiencing problems in retaining staff? Yes Is Selected

Are the problems in retaining staff due to: (Please select all options that apply)

☐ lack of recognised career path

☐ lack of continuing professional development (CPD)

☐ pay levels

☐ austerity measures/financial cuts

☐ other (please describe) ____________________

Finally, what are you most proud of in your service?

What would you most like to change?

Appendix 10

Tables A10.1-A10.3: Key differences between teams

Table A10.1 Type of core team delivering vision rehabilitation by type of provider

			Provider						Total
			LA (in-house)	Joint health and social care	Voluntary (not-for-profit) with LA funding	Pilot social enterprise	Other	Private (for-profit) with LA funding	
Type of core VR team	Specialist vision rehabilitation team	Count	9	0	18	0	1	0	28
		% within type of core VR team	32%	0.0%	64%[c]	0%	4%	0%	100%
		% within Provider	20%	0%	75%[b]	0%	33%	0.0%	35%
		% of Total	11%	0%	23%	0%	1%	0%	35%
	Specialist sensory impairment team	Count	26	0	3	2	2	0	33
		% within type of core VR team	79%	0%	9%	6%	6%	0%	100%
		% within Provider	57%[a]	0%	13%	100%[e]	67%	0%	42%
		% of Total	33%	0.%	4%	3%	3%	0%	42%

	Specialist physical and sensory impairment team	Count	3	0	0	0	0	0	3
		% within type of core VR team	100%	0%	0%	0%	0%	0%	100%
		% within Provider	7%	0%	0%	0%	0%	0%	4%
		% of Total	4%	0%	0%	0%	0%	0%	4%
	Multi-disciplinary re-ablement team	Count	1	0	1	0	0	0	2
		% within type of core VR team	50%	0%	50%	0%	0%	0%	100%
		% within Provider	2%	0%	4%	0%	0%	0%	2%
		% of Total	1%	0%	1%	0%	0%	0%	3%
	Other specialist multi-disciplinary team (including, for example, a stroke team) (please describe)	Count	2	1	0	0	0	0	3
		% within type of core VR team	67%	33%	0%	0%	0%	0%	100%
		% within Provider	4%	33%[d]	0%	0%	0%	0%	4%
		% of Total	3%	1%	0%	0%	0%	0%	4%
	Part of generic adult social care team	Count	3	1	1	0	0	0	5
		% within type of core VR team	60%	20%	20%	0%	0%	0%	100%
		% within Provider	7%	33%[d]	4%	0%	0%	0%	6%

		% of Total	4%	1%	1%	0%	0%	0%	6%
	Lone worker	Count	1	0	1	0	0	1	3
		% within type of core VR team	33%	0%	33%	0%	0%	33%	100%
		% within Provider	2%	0%	4%	0%	0%	100%	4%
		% of Total	1%	0%	1%	0%	0%	1%	4%
	Other	Count	1	1	0	0	0	0	2
		% within type of core VR team	50%	50%	0%	0%	0%	0%	100%
		% within Provider	2%	33%[d]	0%	0%	0%	0%	3%
		% of Total	1%	1%	0%	0%	0%	0%	3%
Total		Count	46	3	24	2	3	1	79
		% within type of core VR team	58%	4%	30%	3%	4%	1%	100%
		% within Provider	100%	100%	100%	100%	100%	100%	100%
		% of Total	58%	4%	30%	3%	4%	1%	100%

NB: Superscript letters are referenced in text below.

Table A10.2 Manager of vision rehabilitation service by type of provider

			Provider						Total
			LA (in-house)	Joint health and social care	Voluntary (not-for-profit) with LA funding	Pilot social enterprise	Other	Private (for-profit) with LA funding	
Manager of the VR service	Specialist in vision impairment	Count	10	0	16	0	1	1	28
		% within Manager of VR service	35.7%	0.0%	57.1%[g]	0.0%	3.6%	3.6%	100.0%
		% within Provider	21.7%[h]	0.0%	66.7%[f]	0.0%	33.3%	100.0%	35.4%
		% of Total	12.7%	0.0%	20.3%	0.0%	1.3%	1.3%	35.4%
	Specialist in sensory impairment	Count	9	0	3	1	1	0	14
		% within Manager of VR service	64.3%	0.0%	21.4%	7.1%	7.1%	0.0%	100.0%
		% within Provider	19.6%	0.0%	12.5%	50.0%	33.3%	0.0%	17.7%
		% of Total	11.4%	0.0%	3.8%	1.3%	1.3%	0.0%	17.7%
	Specialist in physical and sensory	Count	0	0	0	0	1	0	1
		% within Manager of VR service	0.0%	0.0%	0.0%	0.0%	100.0%	0.0%	100.0%

	impairment	% within Provider	0.0%	0.0%	0.0%	0.0%	33.3%	0.0%	1.3%
		% of Total	0.0%	0.0%	0.0%	0.0%	1.3%	0.0%	1.3%
	OT - not specialist in vision impairment	Count	8	1	1	0	0	0	10
		% within Manager of VR service	80.0%	10.0%	10.0%	0.0%	0.0%	0.0%	100.0%
		% within Provider	17.4%	33.3%[j]	4.2%	0.0%	0.0%	0.0%	12.7%
		% of Total	10.1%	1.3%	1.3%	0.0%	0.0%	0.0%	12.7%
	Generic social worker	Count	11	0	0	0	0	0	11
		% within Manager of VR service	100.0%	0.0%	0.0%	0.0%	0.0%	0.0%	100.0%
		% within Provider	23.9%[i]	0.0%	0.0%	0.0%	0.0%	0.0%	13.9%
		% of Total	13.9%	0.0%	0.0%	0.0%	0.0%	0.0%	13.9%
	Other professional - not specialist in vision impairment	Count	8	2	4	1	0	0	15
		% within Manager of VR service	53.3%	13.3%	26.7%	6.7%	0.0%	0.0%	100.0%
		% within Provider	17.4%	66.7%[j]	16.7%	50.0%	0.0%	0.0%	19.0%
		% of Total	10.1%	2.5%	5.1%	1.3%	0.0%	0.0%	19.0%
Total		Count	46	3	24	2	3	1	79

	% within Manager of VR service	58.2%	3.8%	30.4%	2.5%	3.8%	1.3%	100.0%
	% within Provider	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%
	% of Total	58.2%	3.8%	30.4%	2.5%	3.8%	1.3%	100.0%

NB: Superscript letters are referenced in text below.

Table A10.3 Tests of association with provider (LA in-house vs voluntary sector not-for-profit) (categorical data)

	Total cases	**Pearson chi square**	**df**	**Contingency coefficient,C**	**Asymp. Sig. (2-sided)**	**Significance at 5% level**
Team specialist in VR	70	20.46	1	0.48	0.000	S
Team specialist in sensory impairment	70	12.60	1	0.39	0.000	S
Manager specialist in VR	70	13.64	1	0.40	0.000	S
Manager specialist in VR, SI, PI	70	9.11	1	0.34	0.003	S
Self-management courses provided	67	1.44	1	0.15	0.23	NS
Working with Health OTs ‘difficult’ Working with	65	5.0	1	0.27	0.03	S

housing services ‘difficult’ vs ‘easy’ or ‘neutral’	65	4.3	1	0.25	0.04	S
Measuring outcomes for service users	64	3.20	1	0.22	0.07	NS
Budgets ‘decreased’ vs ‘increased’ or ‘stayed the same’	57	1.46	1	0.16	0.23	NS
Staffing ratios ‘worsened vs ‘improved’ or ‘ stayed the same’	62	1.67	1	0.16	0.20	NS
Waiting list exists for service	68	0.01	1	0.01	0.91	NS

Table A10.4 Tests of association with provider (LA-in-house vs voluntary sector not-for-profit) (continuous data)

	Total cases	Mann Whitney U	Standard error	Standardised test statistic	Asymp. Sig. (2-sided)	Significance at 5% level
Case load	52	286.00	52.58	-0.52	0.60	NS
Approximate number on waiting list	38	114.50	32.47	-1.48	0.14	NS
Approximate waiting time in weeks	42	178.50	37.20	-0.47	0.64	NS

Appendix 11

Vision Rehabilitation Services: Increasing The Evidence Base

Topic guide for focus groups with frontline staff – (Stage 4)

Aim

The purpose of these focus groups is to explore practitioners' experiences of working with adults with visual impairment using rehabilitation services, and their views on factors that facilitate or constrain the benefits of the service intervention for adults with visual impairment.

Introduction

- Information sheet and consent form
- Aims of the focus group
- Confidentiality within the group
- Ground rules about conduct of focus group

Group introduction: Ask everyone to say their names, their job title, background, current caseload and how long they have been in the rehabilitation team.

A. The team organisation

1. **Describe the service model (e.g. composition of team, location of service, organisational/management features, contractual basis, any charges for service users)**
    - Is there adequate specialist input to the work of the team and at what level? - Explore what criteria they are using to make the judgment of adequacy.
        - If not adequate, what problems arise?

2. What types of service duties do staff carry out and what percentage of staff time is typically spent on them?

- Face to face / telephone contact with people
- Single / group activities
- Office/admin duties that are to direct benefit to client (e.g. completing benefits claims with clients, making a referral, ordering specific equipment for a client) and general service duty (e.g. writing up cases notes, arranging visits and record keeping (computer-/paper- based))
- Travel time (patch-based areas of work or other)
- co-ordination/liaison with other services)
    - Is the balance right?
    - If not, what would they want to do more/less of? Explore the constraints.

3. Which groups of people do staff work with? (e.g. people with dementia, younger/older people, people with learning difficulties, people who have had stroke)

- Are there people who could benefit from rehab support who staff think are not currently included? Are there people who are included who staff think perhaps should not be?

4. Opportunities for training:

- How are staff training needs identified?
- What opportunities for post-qualification/CPD training do staff have (in-house/professional)?
    - How adequate is it?
    - If not adequate, what problems arise?
    - What improvements could be made?

5. What links/collaboration do staff have with other teams <u>within</u> the organisation? With <u>external</u> individuals/organisations (e.g. ECLO, OTs)?

- Which services/professionals do staff tend to have <u>most</u> contact with? Why?
- Do staff network with other rehab workers outside the service (e.g. through the Facebook group)
- Are opportunities for joint working adequate?
    - If not adequate, what problems arise?
    - What improvements could be made?

B. Support of rehabilitation (what do staff do?)

6. What types of support does the service provide? What types of intervention are more/less common? For any particular group (e.g. age/condition/ethnic group)?

For example:

- Communication & IT use
- Mobility & orientation
- Independent living skills
- Emotional
- Boosting confidence
- Employment/benefits
- Increasing social engagement/contacts/networks
- Supply of equipment
- Information/signposting

7. What scale of intervention is employed? Explore:

- Single intervention/multiple interventions?
- Over what length of time? (e.g. one-off, over several sessions, on-going process)
- Single/group-based programme?
    - (Specifically) self-management programme?
- Prevention/early interventions?

8. Assessment and monitoring progress:

- How do you go about goal setting for clients?
- How is progress towards achieving the agreed goals monitored? (e.g. is there a written down documentation of goals that is agreed/signed by the service user?)
- Are there any on-going assessments (setting new goals) during rehabilitation?
- Are there any formal (or informal) assessments of individual outcomes at the end of rehabilitation? Assessment of outcomes for the service as a whole?
- Do current outcomes assessments adequately capture what the team does and what service users value?
- Is re-accessing the service based on evidence or informal?

C. Impact

9. Ask for any actual (anonymous) examples of immediate and long-term benefits/impacts specialist rehab support has made to service users' lives (e.g. improvements in a service user's levels of functional ability, independence, social life, emotional well-being, mobility, feeling safe and employment opportunities).

- Any impact on other people in service users' family?

10. What factors facilitate or constrain the benefits of rehab support for people with visual impairment?

Possible probes:

- Features of the rehab service (e.g. skill mix of the staff, specialist assessment, length of time spent with the client on each visit, duration of intervention, access to specialist equipment, management issues, flexibility of the service, capacity within the team, service charges).
- What do they see as the advantages/disadvantages of their particular service model? (Explore in-house vs contracted-out, location, links, impact on service users).
- Staff issues (e.g. attitude/'mindset', commitment, training/supervision, personal experience of SL).
- Liaison with specialist skills/organisations outside the team (e.g. expertise in dementia, mental health, learning difficulties).
- User characteristics - Are there any groups of service users who staff think rehab would work better or worse for? (e.g. people with different conditions/motivation/ living circumstances, younger/older people, people who come into the service at different stages of sight loss, and people with dementia)?

D. Finally, suggestions for how rehabilitation services could be improved?

11. Is there anything that staff think would improve the service?

12. Is there anything that staff think could help any particular areas of their practice (e.g. Braille)?

Thank you very much for your time and for taking part in this interview

Appendix 12

Vision Rehabilitation Services: Increasing The Evidence Base

Topic guide for interviews with rehabilitation service users – Case studies

Introduction

- Aim – The aim of these interviews is to explore service users' experiences of using rehabilitation services, including types of advice and support they used/desired, the impact any support received has made on their lives and any problems experienced.
- Explain what we mean by a rehab service.
- Information sheet and consent form.

Switch on the recorder

1. Background information

- How long have you had a sight loss?
- When were you referred to the rehab service? Who referred you and why? How long did it take you to be seen/assessed?
- Have you had any help from a rehab service before? If yes, what?
- Have you been offered help before but refused? Why?
- Can you tell me about your situation just before receiving rehab support [focus on the most recent intervention]? What difficulties were you experiencing at the time? [Probe for aspects of daily living e.g. personal care and shopping]
  - Were you receiving any help from family members, friends or anybody else? Who? How long for?

2. Personal experiences of using rehab support

Description of rehab support

- How was it decided what the rehab service would help you with? Did anyone tell you what kinds of things you could get help with? Who was that? What did they say?

    - Have you been restricted to learning one thing at a time? How do you feel about that?

- What has the rehab service helped you with? Possible probes:

    - Help you how to do things for yourself – independent living skills
        - Personal care(e.g. dressing, toileting, bathing)
        - Practical skills (e.g. shopping, cooking, cleaning)
    - Communication and IT use
    - Talk to you to help you get your confidence back
    - Give you emotional support
    - Give you information and advice
    - Increase your social contacts/not to feel lonely (e.g. by putting you in touch with community activities)
    - Help you to manage your health (medication, depression)
    - Make you feel safer
    - Getting out and about
    - Help using the phone
    - Discussing lighting and magnifiers
    - Supply of equipment
    - Help to maintain employment
    - Help to access other services/activities (e.g. falls clinics, counselling)
    - Other

- Has the support you have been receiving involved any group activities? Explore.
- How many visits have you had each day or week? How long have the visits been? How long have you been receiving this support for? How long do you expect to go on receiving this help?

Views on using the service

- Do you think what you have been offered is what you needed? [Probe for any expectations and resistance].
- What experiences (good or bad) have you had with using the rehab support? Possible probes:

    - Access to the rehab service
    - Access to specialised staff
    - Staff attitude
    - Access to specialised equipment (e.g. any difficulties/delays in getting or using equipment
    - Having control over the goals / how to achieve them
    - Time constraints – Probe for any benefits from longer or shorter visits
    - Access to information
    - Monitoring progress (including any feelings about completing service monitoring/outcome assessments)
    - Flexibility in duration of support
    - Length of time staff spend with the client on each visit / frequency of visits
    - Flexibility of visit times/ease of fitting visits around other commitments
    - Contacts made with other organizations
    - Single vs group-based activities
    - Involvement of family and friends – impact and attitudes

- Has the type of help given to you / the frequency of visits changed over the period of receiving the service? Who decided what was to happen? How do you feel about that?
- Has your views about rehab support changed over time?

Thinking about the duration of the service

- Do you feel you have had/will have the service for long enough?
- Would you have preferred the support to go on for longer? How much longer? How do you think that would have helped you?
- Do you think you can re-access the service in the future? How do you feel about that?

Thinking about the benefits rehab support has made to people's lives

- What differences (if any) do you feel rehab support has made to your life [probe for both immediate and long-term benefits]? Has it had any impacts on:
    - Doing activities you want to do (including personal care, shopping, cooking, cleaning)
    - Social activities
    - Emotional well being
    - Getting out and about
    - Doing things independently
    - Feeling safe
    - Employment opportunities
    - Managing own health
    - Feeling better about yourself/the quality of your life

- What aspects of the rehab support do you think have been most/least beneficial to you?

- What benefits or difficulties (if any) do you think rehab support has had for your family members, friends or anybody else who might have been involved in your care before?

3. Outstanding unmet needs

- Overall how much do you think the rehab support has helped you?
- What other support would you have liked to get (e.g. functional, social and emotional)?
    - What were the reasons for not getting the support?

Thank you very much for your time and for taking part in this interview

Appendix 13

Key features of rehabilitation services

Site A

1	**Current service model**	• Service provided by local authority. • The initial screening is done by the ROs within the team. • The full assessment is carried out within the team. • The support can go on for as long as it can be justified. • Each RO covers the whole of the council (rather than being assigned to a geographical area). • The Pathway – A FACS Community Care Assessment (CCA) is undertaken, as part of the holistic assessment, before rehabilitation is started to identify any basic needs to be met. However, rehabilitation is not dependant on FACS CCA.
2	**Eligibility criteria**	• The service is available to all groups including children/young people, people with dementia, people with learning difficulties and people who have had a

		stroke. - As long as a significant sight loss is evident rehabilitation is undertaken whether or not the client is registered partially sighted or blind.
3	**Core team delivering rehab**	- Dual Sensory Impairment team – working with people with visual impairment and hearing loss.
4	**The team composition**	The team consists of: - One team manager (social work background) - One deputy team manager (social work background) - One dual sensory loss worker - One well-being officer covering both, the VI and the hearing sides. On the VI impairment side: - Four qualified ROs (full-time). On the hearing side: - One social worker - Two assessment officers. There are no OTs in the team. Referrals can be made to the council or NHS OT services.
5	**Caseloads for ROs**	It varies. Currently ROs' caseloads are between 13 and 25.

6	**Current waiting list**	Fifty-nine people are currently on the waiting list. This number has recently increased due to a vacancy in the dual sensory loss post and other factors like an office move and new database requiring extra training. Although most people are seen within 28 days some have been waiting for six months.
7	**Referral routes**	The service takes referrals from various routes including: Low Vision Clinic, Optometrists, other health agencies, service users, carers, other social care workers, Specialist Teachers, and so on.
8	**Current charging policy**	People are not charged for the service.

Site B

1	**Current service model**	• Service provided in-house . • The Certificate of Visual Impairment (CVI) referrals are screened by the rehabilitation team but other types of referrals are screened by the duty social workers who have no VI knowledge. • The full assessment is carried out within the rehabilitation team. • The support can go on for as long as it can be justified and is considered as a priority to maintain independence. • The team covers three different regions of the city with each RO being assigned to a particular geographical area. • The Pathway – rehabilitation is not dependant on FACS Community Care Assessment (CCA). Rehabilitation can be delivered with or without a FACS CCA as the team is able to work under FACs criteria as a ‘preventative measure‘. Re-ablement is carried out (often for six weeks) and is offered to everyone - not only people with visual impairment. If the person still needs care after the re-ablement, an RO would be asked for a report to identify if any rehabilitation from the team would benefit the person.
2	**Eligibility criteria**	• The team works with all people, adults and children (no matter what other

		illnesses/impairments they have); whose sight loss is significantly affecting their daily living. • People with visual impairment do not need to be registered to receive rehabilitation support.
3	**Core team delivering rehab**	VI rehabilitation team, situated within a Disability Service Team.
4	**The team composition**	The Disability Service Team operates in three localities. Each of three DST team comprises: • One Disability Team manager (OT background) • Six to eight OTs • Four to six OT assistants • One or two specialist social workers (for all disabilities) – • Two assessment officers • One to two administrative support. The rehabilitation team consists of: • One manager (VI background) – city wide • Six qualified ROs - a mixture of two part-time and four full-time workers • Team split into three localities. The manager of the rehabilitation team is line-managed by one of the Disability Service managers.

5	**Caseloads for ROs**	It varies. Currently ROs’ caseloads are between 12 and 26.
6	**Current waiting list**	Six to eight weeks for 20-30 people.
7	**Referral routes**	The service takes referrals from all routes – for example, all hospital clinics, GP, self, friends, relations, housing, high street opticians, care homes.
8	**Current charging Policy**	People are not charged for the service.

Site C

1	**Current service model**	• The service is contracted out. The contract specifies the hours of work to deliver rehabilitation support. • The team provides rehabilitation support to several LAs. • The manager and her deputy (the senior RO) screen the initial referrals. They are both qualified ROs. • The full assessment is carried out within the team. • The length of the support provided varies. Typically ROs can help clients to achieve a maximum of 6 tasks. They spend up to 8 hours on each task. Any additional task to be carried out will be considered as a new referral. • ROs are remote workers (not office-based). • The Pathway – rehabilitation is not dependant on FACS Community Care Assessment (CCA). FACS CCA is not undertaken before rehabilitation is started.
2	**Eligibility criteria**	• The team works with adults and children. This includes people with dementia, people with learning difficulties and

		people who have had a stroke. - The team provides an assessment to all people and addresses any health and safety issues people may have whether registered or not. However, the team is not contracted to do any additional/in-depth work for people who are not registered. The service also offers some courses that are just for the registered people.
3	**Core team delivering rehab**	Visual impairment team situated within re-ablement services.
4	**The team composition**	The team consists of: - One manager (background in VI) - One deputy manager- senior RO (background in VI) (The manager and the senior RO oversee the rehabilitation team) - Seven qualified ROs - a mixture of part-time and full-time workers - One assistant - One administrative support
5	**Caseloads for ROs**	It varies. Currently ROs' caseloads are between 15 and 50.
6	**Current waiting list**	There is no current waiting list. The team has to contact clients within 10 days and visit them within 28 days.

7	**Referral routes**	The team gets referrals from different routes, including: hospital/eye clinics, opticians, First Contact and self-referrals.
8	**Current charging Policy**	There are no charges for people (whether registered or not) needing a few sessions to address their health and safety needs. However, if people want more help and they are not registered they get charged.

Appendix 14

Detailed calculations of costs

This appendix gives the detailed methods for calculating the costs of rehabilitation services presented in Chapter 6. There are two sections. Section 1 covers the methods and detailed costs for the three case study sites and section 2 describes how costs were calculated from data in the national survey.

(1) Case studies

In each of the following sub-sections, details are given for each case study on the makeup of the team, the number (and ratios) of hours spent on client and non-client-related activities in a typical week, the annual cost of the rehabilitation service, and the unit costs of the service.

Case study A

Case study A is a local authority-run service comprising one 50 percent WTE manager (18.5 hours a week) and one 25 percent WTE deputy manager (9.25 hours a week). Three full time and one part time ROs together worked 144 hours in a typical week. A 50 percent WTE member of administrative staff supported the team.

Ninety six percent (270/282) of clients allocated to a care worker during 2013/14 were adults.

In total, the team travelled about 250 miles in a typical week.

Table A14.1 shows the number of hours spent on client and non-client-related activities in a typical week. Contact time represents face-to-face and telephone contact delivering support to clients. Other client-related time comprises client-related administrative tasks such as preparing for visits or writing case notes, client-related meetings with other professionals, and travel to and from client visits. Non-client-related time is all other duties, such as general administrative tasks like doing duty/taking new referrals, general meetings with other professionals or agencies, and providing or receiving training or supervision.

Table A14.1 Case study A – Number (%) of hours per week spent on client/non-client related activities

	Contact time		**Other client-related time**		**Non-client-related time**		**Total**	
	Hrs	**%**	**Hrs**	**%**	**Hrs**	**%**	**Hrs**	**%**
Managers	1.5	6%	0.8	3%	25.5	92%	27.8	100%
Rehab officers	60.3	42%	56.4	39%	27.3	19%	144	100%
Admin support staff	5	27%	0	0%	13.5	73%	18.5	100%
Totals	66.8	35%	57.2	30%	66.3	35%	190.3	100%

Table A14.1 shows that ROs in case study A spent 81 percent of their time in direct contact with clients or other client-related duties. Managers and administrative support staff spent 92 and 73 percent of their time respectively on non-client-related duties.

Presenting these figures as ratios shows that, for the team as a whole, for every hour spent in direct (face to face or telephone) contact with clients, a further 1.85 hours is spent on other duties. Likewise, for every hour spent on client-related activities, a further 0.54 hours is spent on other non-client-related duties.

The hours per week presented in Table A14.1 were converted to hours per year for comparison with the annual cost data. Table A14.2 gives the hours per year.

Table A14.2 Case study A - Number of hours per year spent on client/non-client related activities

	Contact time	**Other client-related time**	**Non-client-related time**	**Total**
Hours per year*	2966.81	2538.79	2941.50	8447.10

* calculated by assuming a 222 day working year (5 days a week for 52 weeks, minus 30 days annual leave and 8 statutory holidays).

Table A14.3 gives the annual cost of the rehabilitation service. Direct revenue costs include items such as utilities, cleaning, equipment, consumables and other operating costs. Indirect revenue costs include costs such as human resources and finance. Capital charges represents building and land costs.

Table A14.3 Case study A – staff and other team costs per year (2013/14)

	Expenditure	Comments
Salaries and on-costs	£200,097	
Direct revenue costs	£14,821	Includes equipment, telephone & printing
Indirect revenue costs	£10,045	50% team corporate recharge for HR, legal, ICT etc.
Capital charges	£13,022	Pro rata rent for office
Total costs	£237,985	

Units costs were calculated using the total cost of the service presented in Table A14.3 and the hours per year spent on different duties given in Table A16.2. Table A14.4 gives the unit costs of the service in case study A. The cost per hour of client-related work includes contact and other client-related time.

Table A14.4 Case study A – Unit costs

Unit of service	Unit cost
Cost per hour worked by team staff	£28
Cost per hour of contact with clients	£80
Cost per hour of client-related work	£43

Case study B

Case study B is a local authority-run service comprising one full time manager, four full time and two part time ROs (working 185 hours a week in total), and three hours a week of administrative support.

Ninety nine percent (2919/2951) of clients were adults.

The team typically travelled between 400 and 500 miles a week.

Table A14.5 shows the number of hours spent on client and non-client-related activities in a typical week.

Table A14.5 Case study B – Number (%) of hours per week spent on client/non-client related activities

	Contact time		Other client-related time		Non-client-related time		Total	
	Hrs	%	Hrs	%	Hrs	%	Hrs	%
Managers	5	14%	10	27%	22	60%	37	100%
Rehab officers	98	53%	62	36%	25	14%	185	100%
Admin support staff	1	33%	0	0%	2	67%	3	100%
Totals	104	46%	72	32%	49	22%	225	100%

Table A14.5 shows that ROs in case study B spent 89 percent of their time on direct contact or other client-related duties. Managers and administrative support staff spent 60 percent and 67 percent of their time on non-client-related activities.

Considered as ratios, these figures show that for the team as a whole, for every hour spent in direct (face to face or telephone) contact with clients, a further 1.16 hours is spent on other duties. For every hour spent on client-related activities, a further 0.28 hours is spent on other non-client-related duties.

Table A14.6 gives the number of hours worked on client and non-client-related activities annually.

Table A14.6 Case study B - Number of hours per year spent on client/non-client related activities

	Contact time	Other client-related time	Non-client-related time	Total
Hours per year*	4617.60	3196.80	2175.60	9990.00

* calculated by assuming a 222 day working year (5 days a week for 52 weeks, minus 30 days annual leave and 8 statutory holidays).

Table A14.7 gives the annual cost of the rehabilitation service.

Table A14.7 Case study B – staff and other team costs per year (2013/14)

	Expenditure	Comments
Salaries and on-costs	£215,466	
Direct revenue costs	£15,965	Data on non-salary costs unavailable so estimated to be same percentage of salary costs as case study A
Indirect revenue costs	£10,819	
Capital charges	£14,026	
Total costs	£256,276	

Table A14.8 gives the unit costs of the service calculated from information in the preceding tables.

**Table A14.8	Case study B – Unit costs**

Unit of service	Unit cost
Cost per hour worked by team staff	£26
Cost per hour of contact with clients	£56
Cost per hour of client-related work	£33

Case study C

Case study C is a contracted out service provided by a voluntary organisation. One part time manager worked 30 hours a week, supported by a senior RO working 22.5 hours a week. Six full-time and one part-time RO worked 252 hours a week in total. A part time administrator and an assistant worked 21 and 22 hours a week respectively.

Eighty seven percent (2901/3322) of clients in 2013/14 were adults.

In the week taken as an example, the team travelled 941 miles.

Table A14.9 shows the number of hours spent on client and non-client-related activities in a typical week. Table A14.10 gives the hours per year.

**Table A14.9	Case study C – Number (%) of hours per week spent on client/non-client related activities**

	Contact time		Other client-related time		Non-client-related time		Total	
	Hrs	**%**	**Hrs**	**%**	**Hrs**	**%**	**Hrs**	**%**
Managers	3	11%	6	19%	21	70%	30	100%
Senior rehab officer	8	35%	9	40%	6	25%	23	100%
Rehab officers	151	85%	9	5%	18	10%	178	100%
Admin support staff	3	3%	83	83%	14	14%	100	100%
Other core member	11	66%	4	25%	1.5	9%	17	100%
Totals	177	51%	112	32%	59.5	17%	348	100%

Table A14.9 shows that ROs in case study C spent 90 percent of their time in direct contact with clients or other client-related work. The senior RO and administrative support staff spent about 40 percent and 83 percent, respectively, of a typical working week on client-related activities in the office. The majority of the manager's time (70 percent) is spent on non-client-related activities.

These figures show that for the team as a whole, for every hour spent in direct (face to face or telephone) contact with clients, a further 0.97 hours is spent on other duties. Likewise, for every hour spent on client-related activities, a further 0.21 hours is spend on other non-client-related duties.

Table A14.10 gives the hours per year spent on different activities.

Table A14.10 Case study C - Number of hours per year spent on client/non-client related activities

	Contact time	Other client-related time	Non-client-related time	Total
Hours per year*	7837.71	4951.49	2639.80	15429.00

* calculated by assuming a 222 day working year (5 days a week for 52 weeks, minus 30 days annual leave and 8 statutory holidays).

Table A14.11 gives the annual cost of the rehabilitation service.

Table A14.11 Case study C – staff and other team costs per year (2013/14)

	Expenditure	Comments
Salaries and on-costs	£263,981	
Direct revenue costs	£7,708	
Indirect revenue costs	£44,552	
Capital charges	£20,000	
Total costs	£336,241	

Table A14.12 gives the unit costs of the service calculated from information in the preceding tables.

Table A14.12 Case study C – Unit costs

Unit of service	Unit cost
Cost per hour worked by team staff	£22
Cost per hour of contact with clients	£43
Cost per hour of client-related work	£26

Sensitivity Analysis

A sensitivity analysis is a method of testing how sensitive results are to changes in the underlying data. Sensitivity analyses are undertaken where the accuracy of underlying data is uncertain.

(a) Working days per year

Each case study gave details of the typical number of hours worked per week across all staff in the team. In Tables A6.2, A6.6 and A6.10, the number of hours worked per year was calculated by multiplying the hours worked per day by 222 working days (44.4 weeks) per year (allowing for 30 days leave and eight statutory holidays).

To test the sensitivity of the unit costs to the number of working days assumed per year, unit costs were recalculated assuming a 41 week and a 43 week working year. The Personal Social Services Research Unit report *Unit Costs of Health and Social Care 2013* (Curtis, 2013) calculates unit costs assuming a 41 week working year for social care staff. Forty one weeks is derived by taking an average working time across all social work sectors to give 29 days annual leave, 8 days statutory leave, 10 days for study/training and 8.6 days sickness leave.

Training and supervision time is already included in the allocation of hours in a typical week for the case studies in the current study (under non-client-related time). We therefore removed the 10 days for study/training included in the *Unit Costs of Health and Social Care* calculation to give a 43 week working year.

Tables A14.13 and A14.14 present the number of hours spent on client/non-client related activities and the unit costs respectively for the three case studies, assuming a 43 and 41 week working year.

Table A14.13 Sensitivity analysis - Number of hours per year spent on client/non-client related activities assuming 41 and 43 working weeks per year

	Case study A	Case study B	Case study C
Original analysis (44.4 weeks)			
Contact time	2967	4618	7838
Other client-related time	2539	3197	4951
Non-client-related time	2941	2176	2640
Total	8447	9990	15429
Sensitivity analysis (43 weeks)			
Contact time	2873	4472	7591
Other client-related time	2459	3096	4795
Non-client-related time	2849	2107	2557
Total	8181	9675	14943
Sensitivity analysis (41 weeks)			
Contact time	2740	4264	7238
Other client-related time	2344	2952	4572
Non-client-related time	2716	2009	2438
Total	7800	9225	14248

Table A14.14 Sensitivity analysis – Unit costs assuming 41 and 43 working weeks per year

	Case study A	**Case study B**	**Case study C**
Original analysis (44.4 weeks)			
Cost per hour of contact with clients	£80	£56	£43
Cost per hour of client-related work	£43	£33	£26
Cost per hour worked by team staff	£28	£26	£22
Sensitivity analysis (43 weeks)			
Cost per hour of contact with clients	£83	£57	£44
Cost per hour of client-related work	£45	£34	£27
Cost per hour worked by team staff	£29	£26	£23
Sensitivity analysis (41 weeks)			
Cost per hour of contact with clients	£87	£60	£46
Cost per hour of client-related work	£47	£36	£28
Cost per hour worked by team staff	£31	£28	£24

Table A14.14 shows, as would be expected, a slight increase in unit costs associated with a reduction in the working year from 44.4 to 43 and 41 weeks.

(b) Time spent doing duty

Teams in case studies A and B, according to discussions in focus group meetings, spent five and 1.5 days a week, respectively, doing duty, that is, spending time in the office answering the telephone and taking new referrals. Participants in the focus group in case study C reported that they did not do duty. This may account, in part, for the lower percentage of time that ROs in case study site C spent in non-client-related work.

To explore how doing duty impacted on the unit costs of the teams, the ROs' time (and equivalent salary costs of) doing duty were taken out of the calculations for case studies A and B. The results are given in Tables A14.15 and A14.15.

Table A14.15 Hours per week worked and percentage of time spent on different activities (excluding duty)

	Case study A	**Case study B**	**Case study C**	**Average**
Total hours a week	173 hours	215 hours	348 hours	245 hours
Face to face contact with clients	39%	48%	51%	46%
Other client-related time	33%	33%	32%	33%
Non-client-related time	28%	18%	17%	21%

Table A14.16 Ratios of time spent and costs per hour (excluding duty)

	Case study A	**Case study B**	**Case study C**	**Average**
Ratio of direct to indirect time				
- face to face contact	1 : 1.59	1 : 1.07	1 : 0.97	1 : 1.21
- client-related work	1 : 0.39	1 : 0.22	1 : 0.21	1 : 0.27
Cost per hour worked by the team	£29	£26	£22	£26
Cost per hour of face to face contact with clients	£76	£54	£43	£58
Cost per hour of client-related time	£41	£32	£26	£33

Table A14.15 gives the total number of hours a week worked by the vision impairment rehabilitation teams, excluding duty. For case studies A and B, total hours have been reduced by 17.5 and 10.5 hours a week respectively. For case study A, the reduction is far less than the reported five days spent doing duty. This is because the time spent per week on general admin tasks including duty, reported by team manager on the forms requesting details of staff activities, was less than the time doing duty that ROs reported in the focus group. Therefore, all of the time spent on general admin tasks was excluded from the revised calculations. If the ROs' estimates were right, this is an underestimation of the impact of doing duty. However, it is also possible that the managers' calculations were accurate, and so this is a true or over-representation of the impact of doing duty. This issue needs to be explored more fully in a future evaluation.

Despite this limitation, both tables show that excluding an amount of non-client-related time affects the percentages and ratios of time spent on different activities. For example, in case study A, the percentage of time spent on face to face contact with clients increased from 35 percent (Chapter 6, Table 6.1) to 39 percent (Table A14.15). Percentages of time spent on different activities in case study B mirrored those in case study C more closely after time doing duty was removed.

The impact on the unit costs was small. The cost per hour worked by teams in case study sites A and B barely changed; the costs per hour of face to face and of client-related contact time reduced by between £2 and £4 an hour (see Table A14.16). These changes reflect the fact that proportionately more time was spent on these activities compared to non-client-related tasks.

(2) Using national survey data on staffing levels to calculate annual budgets

A 'bottom up' approach uses detailed data to build up a picture of the costs of a service. In this study, we used the staffing levels and salaries reported in the national survey to build up a picture of the staff costs of vision rehabilitation services. It is important to note that the salary costs are just one element of total costs, therefore using only these data gives an underestimate of the costs of services.

The national survey asked respondents to report the number of whole time equivalent (WTE) staff and their salary grades. These data were collected about the following types of staff:

- team manager
- senior RO (vision impairment)
- RO (vision impairment)
- assistant RO (vision impairment)
- assistive technology specialist
- social worker
- community care officer (CCO)
- eye clinic liaison officer (ECLO) or other hospital advice & information officer
- other

In the ‘other’ category, the following staff types were reported:

- administrative and business support
- equipment & adaptation officers/advisers
- dual sensory impairment workers/co-ordinators
- information and advocacy
- telephone assessors
- social work assistants
- link worker
- club co-ordinator
- rehabilitation assistants
- independent living coordinator
- speech and language therapist

For the purposes of calculating service costs, we assumed that the staff about whom details were given in the national survey were core members of the vision rehabilitation teams. Information about which budgets covered staff costs was not collected in the survey. The staff costs calculated are therefore the costs of vision rehabilitation service teams, with no account taken of the sources of funding of these teams. One respondent reported that their eye clinic liaison officer was funded by the Clinical Commissioning Group, and another that the team had access to specialist counselling funded from another source; neither included details of the WTE of these staff.

In addition to reporting the WTE number of staff, respondents were asked to report which of the following staff salary scales each type of staff received:

- Scale 3 (or equivalent) (£15,882-£16,998)
- Scale 4 (or equivalent) (£17,333-£19,317)
- Scale 5 (or equivalent) (£19,817-£21734)
- Scale 6 (or equivalent) (£22,443-£23,945)
- SO1 (or equivalent) (£24,892-£26,539)
- SO2 (or equivalent) (£27,323-£28922)
- PO (or equivalent) (£29,538-£42,032)
- Salary scale not known

These data were used to calculate the cost of each type of staff for each service by multiplying the WTE number of staff by the midpoint of their salary scale. For example, 2.5 WTE ROs at SO1 level (midpoint of scale £25,715.50) gives a salary cost of £64,288.75 per year.

The salary scale was reported in the majority of cases, but where it was not known, the midpoint of the most commonly reported scale was used as a proxy measure. For example, the salary levels of 15 ROs (across five services) were not known. Across other services, the salary scales of 148 ROs were reported; more of these (53.5 WTE) fell into the SO1 scale than any other scale. Therefore the 15 ROs for which the salary scale was not known were costed as if they were paid at the midpoint of the SO1 scale. This system of allocating salary costs was repeated for all staff types where the salary was not known.

In addition, in 20 cases the salary scale was reported but the WTE number of staff was not reported. For these cases, the WTE was assigned according to the mode or, if there was more than one mode, the median of reported WTEs at that grade. For example, the WTE for three ROs on salary scale SO1 was not reported. Sixteen services reported the number of WTE staff at this salary scale; the most commonly reported WTE was one (reported by seven of the 16 services). Thus the three missing WTEs were each assigned as one

WTE. Again, this system of allocating WTE staff numbers was repeated for all staff types and salary scales where the WTE was not known.

The total cost of each staff type per service was calculated by summing the costs of staff on each salary scale. Table A14.17 shows the mean, median and range of costs of each type of staff and the total costs of all staff.

Table A14.17 Salary costs of staff members in visual impairment rehabilitation teams

Type of staff on team	N=89		Mean	Median	Minimum	Maximum
	Valid	Missing				
Team manager	46	43	£36,829	£35,785	£0	£286,280
Senior RO	31	58	£39,029	£28,123	£0	£143,140
RO	61	28	£79,183	£56,245	£0	£488,595
Assistant RO	26	63	£21,288	£10,380	£0	£107,355
Assistive technology specialist	18	71	£10,873	£0	£0	£62,327
Social worker	28	61	£32,534	£28,123	£0	£178,925
Community care officer	24	65	£28,448	£20,776	£0	£107,355
Occupational therapist	13	76	£36,180	£0	£0	£255,630
Eye clinic liaison officer	20	69	£12,995	£8,439	£0	£53,678
Other 1	17	72	£24,025	£16,440	£0	£102,862
Other 2	12	77	£16,997	£4,110	£0	£82,200
Total (all staff types)	**66**	**23**	**£173,026**	**£134,274**	**£25,716**	**£683,166**

Therefore, the mean salary costs for a VI rehabilitation team were £173,026. It is important to remember that this figure does not include on-costs such as superannuation or payroll tax. There may also be administrative support costs that are not included. Non-salary costs such as equipment and travel, direct and indirect overheads and capital charges are not included. Therefore, these figures give a low estimate of total team costs.

Appendix 15

Staffing/caseload and team finances questionnaires

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Vision Rehabilitation Services:

Increasing the evidence base

Team staffing and caseload questionnaire

The purpose of this questionnaire is to collect information about staffing levels and caseload to help estimate the unit costs of Visual Impairment Rehabilitation Teams, such as the cost per client supported.

1. Please indicate in the table below **the total number of hours worked per typical week** by staff in the team. For example, five rehabilitation officers might work 151 hours (three at 37 hours a week plus two at 20 hours per week). This question gives us a baseline which we can use to work out percentages of time spent on different tasks.

	Managers	**Rehabilitation officers**	**Admin support staff**	**Other core team members**
Total number of hours worked per typical week				

2. During **the last 12 months/latest financial year available**, what was the total number of clients supported by your service? (This includes face to face contact at a client's home or elsewhere, and telephone or any other support with a client.)

Children ………………………………….
Adults ………………………………….

3. In a **typical week**, approximately how many miles does the team accumulate in travelling to and from locations where clients are supported?

…………………………………………………………

4. In a **typical week**, please estimate **the number of hours (or percentage of time)** spent by the team on the activities listed in the table below.

	Managers	**Rehabilitation officers**	**Admin support staff**	**Other core team members**
Face to face contact with clients delivering support				
Telephone contact/ telephone support to clients				
Client-related admin tasks (e.g. preparing for visits, writing case notes)				
General admin tasks (e.g. doing duty/taking new referrals)				
Travelling to and from client visits				
Client-related meetings with other professionals/ agencies				
General, non-client-related meetings with other professionals/ agencies				
Providing or receiving training/supervision				
Other (please specify)				

Thank you very much for taking the time to fill in this questionnaire.

If you have any queries, please contact Kate Baxter on

01904 321950 or kate.baxter@york.ac.uk

Vision Rehabilitation Services:
Increasing the evidence base

Team finances questionnaire

The purpose of this questionnaire is to collect financial information about the Visual Impairment Rehabilitation Team to help estimate unit costs such as the cost per client supported.

1. Where is your service located? (please tick)

☐ Local authority building

☐ Voluntary organisation building

☐ Other (please specify): ………………………………………………………..

2. **Please complete the table below about expenditure during the latest financial year available.**

Which year is this? …………………

	Expenditure (£)	Comments/explanations
Team managers' salaries		
Team managers' salary on-costs		
VI rehab officers' salaries		
VI rehab officers' salary on-costs		
Team admin support staff salaries		
Team admin support staff salary on-costs		
Other salaries		
Other salary on-costs		
Direct revenue costs (over and above staffing costs): e.g. utilities, cleaning, equipment, consumables, other operating costs		
Indirect revenue costs (over and above staffing costs): e.g. finance, human resources		
Capital charges e.g. land, buildings		

Thank you very much for taking the time to fill in this questionnaire.

If you have any queries, please contact Kate Baxter on

01904 321950 or kate.baxter@york.ac.uk

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

END OF REPORT