

# Independence and well-being in sight:

## Investing in the potential of blind and partially sighted adults in England



Moving forward together





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**Guide Dogs**

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# Glossary

Within the text, a number of abbreviations or acronyms are used. The glossary below provides the full descriptors of the main abbreviations or acronyms to assist the reader.

<b>CPD</b>	Continuing Professional Development
<b>ECHR</b>	The European Convention on Human Rights
<b>EHRC</b>	Equality and Human Rights Commission
<b>FHEQ</b>	Framework for Higher Education Qualifications
<b>Guide Dogs</b>	The Guide Dogs for the Blind Association
<b>ILS</b>	Independent living skills
<b>JSNA</b>	Joint Strategic Needs Assessment
<b>LAA</b>	Local Area Agreement
<b>LVSCs</b>	Low Vision Services Committees
<b>LSP</b>	Local Strategic Partnership
<b>NALSVI</b>	National Association of Local Societies for Visually Impaired People
<b>NOS</b>	National Occupational Standards
<b>NQF</b>	National Qualification Framework
<b>O&amp;M</b>	Orientation and mobility
<b>ODI</b>	Office for Disability Issues
<b>OTS</b>	Office of the Third Sector
<b>RNIB</b>	Royal National Institute of Blind People
<b>SfC&amp;D</b>	Skills for Care and Development



# Foreword

**In 2005, The Guide Dogs for the Blind Association (Guide Dogs) set out on an important journey. It jointly established a Rehabilitation Project Group (RPG) and country steering groups with all of the major voluntary organisations and key statutory agencies throughout the United Kingdom. Their primary purpose has been to help bring about significant improvements in the provision of rehabilitation services to blind and partially sighted people.**

In the course of intense and rigorous research and debate, there has been a gratifying level of like-minded agreement with statutory agencies and Government representatives in England about the nature and pace of the changes required.



This policy paper presents a series of recommendations based on a review of the strengths and weaknesses of existing services, evidence obtained from empirical research and discussion with service users which, together, clearly highlight that many blind and partially sighted people are unable to fulfil their potential due to a lack of appropriately targeted services. A model for future practice is outlined which, we believe, will result in more person-centred and integrated health and social care services.

We are deeply indebted to all the organisations and individuals who contributed to this work. Most of all, we wish to thank all the blind and partially sighted people who participated, either through surveys or in focus groups, and provided vital feedback from the service user perspective.

*Bridget Warr*

Bridget Warr  
Guide Dogs' Chief Executive

# Executive summary

## The origins and progress of the Rehabilitation Project Group

In 2005 the Rehabilitation Project Group (RPG) was established jointly by The Guide Dogs for the Blind Association (Guide Dogs), the Royal National Institute of Blind People (RNIB), Action for Blind People and the National Association of Local Societies for Visually Impaired People (NALSVI). It also included a wide range of other voluntary and statutory organisations involved in the delivery of services to blind and partially sighted people throughout the United Kingdom. The aim of the RPG is to enable significant improvements for blind and partially sighted people through the provision of better rehabilitation services.

Guide Dogs, on behalf of the RPG, undertook extensive research into the needs of blind and partially sighted people, and established three sub-committees across the UK to co-ordinate the work to be undertaken: adult services; education and training; and services to children and young people. Country-specific steering groups were established in Scotland, Wales and Northern Ireland. To build the evidence base, both quantitative and qualitative research was undertaken, including telephone interviews with practitioners; UK-wide and country-specific empirical surveys of blind and partially sighted people; analysis of key policy drivers;

and service user focus groups.

The RPG and its country steering groups discussed these findings and developed recommendations for change, and four consultation documents were issued for wider discussion at the beginning of 2007. These included, in England: 'Independence and well-being in sight: Developing the vision. A consultation on the future of rehabilitation services for visually impaired adults in England'.

The feedback from the consultation has confirmed the need to explore further and pilot a Middle Step approach to service delivery. This initiative adopts the direction of travel of health and social care as set out in the White Paper 'Our health, our care, our say', and promotes a multi-agency approach to bridging the gap between health and social care services through coordinated provision of assessment, emotional support, accurate and timely information, and prompt and effective delivery of rehabilitation services. Overall, the consultation has helped to give shape to the recommendations and principles of service delivery that are being proposed across the UK.

## Chapter summary

This policy paper commences in Chapter 1 with an account of the evolution of human rights conventions and the domestic law applying in England related to disabled people.

It is emphasised that the rights of blind and partially sighted people of all ages to equal citizenship and a reasonable quality of life are now enshrined in legislation. Modest improvements following the introduction of non-mandatory service standards are acknowledged, and current services for people with sight loss are described.

Chapter 2 highlights the significance of the growing proportion of people over 75 in population projections, and the likely increase in overall numbers of blind and partially sighted people. A major service user survey is analysed and provides evidence for many of the recommendations below. The development of policies which acknowledge the importance of well-being and place the user at the heart of integrated and more responsive health and social care services is applauded. The importance of the UK Vision Strategy and its relationship with this paper is highlighted.

Chapter 3 makes the argument for the social and economic benefits of change which would help blind and partially sighted people to realise their potential and contribute to the social capital of society. Managers and users of services were invited to comment on the ideal shape and structure of future services, and strong support was expressed for the logic of the proposed Middle Step

in making services more integrated and accessible.

In Chapter 4, the findings of a survey of rehabilitation workers are examined. The creation of a diverse rehabilitation workforce is discussed, including a case for the employment of rehabilitation assistants or support staff. The current situation and future education and training needs for rehabilitation workers are explained. Regulation and registration are discussed. The budget and resource implications for the proposed changes are identified.

### **Recommendations of the Rehabilitation Project Group**

- Policy-makers must better demonstrate their commitment to the rights and entitlements of everyone with a visual impairment to equal citizenship and a reasonable quality of life. (Chapter 1)
- The delivery of services should secure entitlement to outcomes designed to improve independent functioning and generate well-being for blind and partially sighted people. (Chapter 3)
- Blind and partially sighted people should be entitled to an agreed level and quality of service, equitably provided regardless of the domicile of the service users. This service should help the individual to respond to the impact of sight

loss, to maintain or facilitate independence and well-being, and to achieve the optimum quality of life. (Chapters 2 and 3)

- Future services should be based on a Middle Step model underpinned by key practice principles including: timely contact and provision of information and emotional support; an outcome-based assessment; and services that are user-led and emphasise entitlement. (Chapters 2 and 3)
- The implementation of the Middle Step model of service will require a multi-disciplinary rehabilitation workforce, provided by a variety of practitioners in different team settings and with other professional staff from the health, social care and voluntary sectors. It is anticipated that staff will have a combination of generalist skills and specialisms. (Chapters 2 and 4)
- The Middle Step should take place as near to local communities as practicable, and should foster multi-disciplinary co-operation. Pilots currently being undertaken may inform decisions about optimum location but it is anticipated that the model could be run within health, social care or voluntary sector facilities. (Chapter 3)
- To support a multi-disciplinary workforce, it will be necessary to establish a flexible diet of training courses including National Qualification Framework (NQF) Level 2, NQF Level 5, Degree and Postgraduate Diploma and Masters, provided and validated by colleges and universities in partnership with employers, including those in the voluntary sector. These courses should have an element of work-based learning, and should offer flexible modules, and accessible progression and transferability between Levels. NQF Level 2 should be the minimum qualification for rehabilitation assistants/support staff; NQF Level 5 should be the minimum recognised qualification for a rehabilitation worker. All rehabilitation workers should have the opportunity to pursue Continuing Professional Development (CPD) through participation in postgraduate courses. (Chapter 4)
- A steering group should be established to consolidate and expand training for the rehabilitation workforce including representation from Skills for Care and Development (SfC&D) and from Government. (Chapter 4)

- The registration of the rehabilitation workforce should be pursued as a matter of urgency in conjunction with SfC&D and the General Social Care Council. (Chapter 4)
- Historically, services for blind and partially sighted people have not had the benefit of discrete budgets and consistent long-term planning. Consequently, they have tended to be vulnerable in certain circumstances; such as around the time of Comprehensive Spending Reviews. However, the new Concordat between the third sector and Government, and the move towards personalisation as laid out in the Department of Health report 'Putting People First' (2007) suggest a tangible commitment to resource plans for short and long term improvements.

We call upon local authorities and the Government to ensure that sensory services are recognised in Local Area Agreements and other planning systems and in subsequent monitoring processes and, furthermore, that visual impairment services are adequately funded and fully integrated into long-term planning cycles. (Chapters 2 and 4)

- Future Government health and social care policy should draw upon the service principles and recommendations of this paper to ensure that the planning of both specialist and mainstream health and social care services has a reasonable chance of meeting the needs of blind and partially sighted adults. (Chapter 4)



## Chapter 1

# The implications of domestic law and policy initiatives for service provision

### The legal context: human rights

The European Convention on Human Rights (ECHR) is a treaty which was ratified by the United Kingdom Government in 1951. In England, the Human Rights Act of 1998 came into force in October 2000 and incorporates most of the rights of the ECHR into our domestic law. Among the pertinent substantive rights included in the Human Rights Act are: the right to life; the right to respect for private and family life, one's home and correspondence; prohibition of discrimination; prohibition of abuse of rights; and limitation on the use of restrictions on rights. In addition, the Act incorporates the rights in Protocol 1 Article 1 which guarantee the right to peaceful enjoyment of property, and Protocol 1 Article 2 which guarantees the right to education.

Section 3 (1) of the Act states that:

“So far as it is possible to do so, primary legislation and subordinate legislation must be read and given effect in a way that is compatible with the Convention rights.”

Under section 4, if a court is satisfied that the provision (of primary legislation) is incompatible with a Convention right, it may make a declaration of that incompatibility. Where a court is

considering whether to make such a declaration, the Crown is entitled to notice and the appropriate Minister of the Crown is entitled to be joined as a party to the proceedings. Section 19 (1) requires that a Minister of the Crown in charge of a Bill in either House of Parliament must, before second reading of the Bill, make a statement to the effect that in his view the provisions of the Bill are compatible with the Convention rights (a ‘statement of compatibility’) or, if unable to make such a statement, to state whether the Government nevertheless wishes the House to proceed with the Bill.

Section 6 of the Human Rights Act states that it is unlawful for a public authority to act in a way which is incompatible with a Convention right, and section 7 allows victims of breaches to bring legal proceedings against the authority.

Consequently, it is now firmly an expectation of blind and partially sighted people, embedded in domestic law, that they have human rights entitlements as citizens to live independently, to feel valued, and to contribute to society.

On 16 February 2006 the Equality Act received Royal Assent, creating a single British Equality and Human Rights Commission (EHRC) after majority

support for the idea in a consultative process. The EHRC has taken on the work of existing Commissions including the Disability Rights Commission (DRC).

The Equality Act (2006) has two major impacts:

- It makes it unlawful to discriminate in the provision of goods, facilities and services, education, the use and disposal of premises, and the exercise of public functions.
- It promotes equality of opportunity regarding gender, race, disability, age, religion or belief and sexual orientation.

The Commission, which has been operational since October 2007, also has responsibility for monitoring all new laws to ensure that they are compliant with the Human Rights Act. For the first time in the United Kingdom, there is now an institutional support for human rights.

In a parallel process, the Convention on the Rights of Persons with Disabilities and its Optional Protocol were adopted by the United Nations General Assembly in December 2006 and opened for signature in March 2007, the UK being one of the signatories. The purpose of the Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all disabled people, and to protect respect for their inherent dignity.

The Convention has not yet been ratified by the UK Government, but it could, if ratified, have a very significant and beneficial impact on the efforts of blind and partially sighted people to assert their rights to properly resourced support services, equality of opportunity, and an enhanced quality of life.

Further details of the Convention are provided in Appendix A.

**“Sensory loss is extremely frightening and devastating to individuals. The impact needs to be fully appreciated from the Government down.”**

*Consultation response from individual service user*

### **Legislation, regulations and initiatives relevant to disabled people**

New rights to prevent discrimination in employment, goods, facilities, services and property were introduced under the Disability Discrimination Act 1995. Specific actions must now be taken by service providers to address the particular needs of users, including blind and partially sighted people.

Building on this earlier Act of 1995, the Disability Discrimination Act 2005 created a Disability Equality Duty requiring public authorities to have due regard to the need to:

- eliminate discrimination against, and harassment of, disabled people;
- promote greater equality of opportunity for disabled people;
- promote positive attitudes towards, and participation in public life, of disabled people; and
- recognise that achieving equality for disabled people will at times require adjustments that will mean treating a disabled person more favourably.

Implicit in these duties is a requirement that blind and partially sighted people must be fully consulted about the future policies and services which are going to affect the quality of their lives. In effect, the Disability Equality Duty is intended to mirror and have equivalent weight to the similar equality duty in the Race Relations Acts of 1976 and 2000.

Under the Disability Discrimination (Public Authorities) (Statutory Duties) Regulations of 2005, the power was given to the Disability Rights Commission (whose responsibilities have since transferred to the EHRC) to enforce specific duties by means of the issue of compliance notices which are enforceable through the Courts. In accordance with a Statutory Code of Practice, public authorities listed in the regulations are now required to prepare, publish and review their Disability Equality Schemes and to demonstrate the effectiveness or otherwise of their plans.

Under the Disabled Persons Act of 1989, carers were also granted entitlement to separate assessment and to have their ability to continue caring taken into account. These rights were strengthened further by the provisions of the Carers (Recognition and Services) Act 1995.

In essence, the legislation in England now recognises the right of blind and partially sighted people to lead a rich and full life with equality of opportunity to develop themselves without discrimination. Whether the services relate to education, support services, social, recreational or general consumer retail, providers are required to work towards providing an environment which is fully accessible and free from discriminatory practices.

### **Development of service standards**

Inspection reports published ten years apart, 'A Wider Vision' and 'A Sharper Focus' (Social Services Inspectorate 1988 and 1998), were critical of the quality of support available to blind and partially sighted people in England. One of the main findings referred to inconsistent and poor communication between health and social work that often left blind and partially sighted people without support for long periods.

In October 2002 the Association of Directors of Social Services (ADSS) published the first ever standards of social care for blind and partially sighted adults.

The document set out a total of 16 standards within four themes:

- Planning integrated services;
- Managing integrated services;
- Providing person-centred services; and
- Improving performance.

The standards were not mandatory, but represent in effect a set of benchmarks against which to measure performance. Evidence collected up until and including 2005 suggested that a significant number of authorities (but by no means all) used the standards to drive up performance, involving and engaging with blind and partially sighted adults in the process. ('Improving Lives: Raising Standards', 2005).

### **Provision of rehabilitation services**

The range of services provided to adults with visual impairment in partnership with carers and agencies includes the following: risk assessment; care and service provision and co-ordination; individual assessment; emotional support; individual training/rehabilitation; protection of vulnerable adults; provision of equipment; provision of communication support; training in the use of environmental aids; information advice; advocacy; awareness raising; and benefits advice.

With their specialist knowledge and training, the skills of the rehabilitation

worker are utilised across a wide range of care programmes and external organisations and agencies.

Rehabilitation workers identified the key tasks they provide as:

- orientation and mobility (O&M) tasks (e.g. long cane training, mapping skills, developing auditory senses);
- independent living skills (ILS) tasks (e.g. aids and equipment instruction; use of kitchen utilities; personal care);
- communication tasks (e.g. basic IT skills; telephone usage; Braille, talking books/newspapers and tapes; advice on formats);
- low vision tasks (e.g. use of magnifiers; advice on residual vision; lighting advice; CCTV demonstration; screen enlargement; specialist low vision clinics);
- other tasks (e.g. referrals; grant applications; group work; emotional support; training and advice on social activities/leisure pursuits/transport; information on eye conditions; awareness training).

There is no single authoritative source of data on the level of rehabilitation provision throughout England. A survey was conducted by the Tavistock Institute at the end of 1998 into the level and nature of local authority provision for blind and partially sighted people in 199 councils/boards with social services

responsibility in England, Wales and Northern Ireland. Just over 51 per cent (102) of authorities responded.

As would be the case today, the researchers found a great deal of diversity between teams with some staff working within local authority sensory or visual impairment teams, others in more generic physical health and disability teams, and others in teams based in local societies for blind and partially sighted people.

Type of central/local team	Authorities responding	
Visual impairment team	19	19.5 per cent
Sensory impairment team	34	34 per cent
General disability team	19	19.5 per cent
Other type of team	13	13 per cent
No information	12	12 per cent

Today, as then, the staffing permutations of teams vary but are generally drawn from social workers, rehabilitation workers, and assistants. However, not all teams feature all three roles and not all authorities have qualified rehabilitation workers. Of the authorities that provided data at the time, 12 employed no full-time rehabilitation workers. Of those that did, 46 employed just one or two, 31 employed between three and five and 12 employed six or more. It was noted

by the researchers that:

“Because it was difficult to measure the amount of staff time available for work with visually impaired clients, and the overall number of clients, it was not possible to carry out more sophisticated analyses of staffing. Such analyses might be seen to be desirable in the future: for example, to provide ratios of staff to clients, of staff to overall population of visually impaired people, or mapping service provision using computer GIS (Geographic Information System) mapping. However, this will have to await both further developments in the sophistication of the questionnaire and, in some authorities, improvements in the ability to collect relevant information within social services departments.”

**Declining numbers of specialists**

According to a report published in 1995 by the Visual Handicap Group, there were 699 home teachers working in England in 1958, when the population of blind and partially sighted people was arguably smaller than today. The post of ‘home teacher of the blind’ was a forerunner of today’s rehabilitation worker. A mapping exercise in the field of visual impairment conducted on behalf of the National Council of Voluntary Organisations estimated that there were just fewer than 1,250 practitioners undertaking rehabilitation work in 1994.

In 2006, the people who run the rehabworker.co.uk website canvassed everyone on their database, all Social Service (Sensory Impairment) Departments and most relevant voluntary organisations in the UK. From the responses they received, a list was compiled showing not only how many qualified rehabilitation workers were employed, but also where they were based. At that time the figures suggested that there were 459 rehabilitation specialists with a recognised qualification operating around the UK. A more recent online poll towards the end of 2007 yielded a figure of 395.

Guide Dogs estimates that the number of rehabilitation workers operating within adult services across the UK today is in the region of 550. With what is known about approximate numbers in Wales, Scotland and Northern Ireland, this suggests that fewer than 500 are employed in England.

Whatever the staffing levels have been in the past, today there is a growing mismatch between the incidence of visual impairment (increasing) and the number of qualified rehabilitation workers (in decline). Research undertaken by Guide Dogs has revealed a number of issues which suggest some worrying trends: the average working life of qualified rehabilitation workers is around eight years, leading to concerns about the sustainability of

the workforce; the majority of workers chose rehabilitation as a second or third choice career; and the current lack of career development opportunities means that many workers choose either to specialise in work with children, to train in related areas such as social work or to leave the field altogether. Evidence appears to indicate that many local authorities struggle to fill vacated posts.

In the absence of an official register of rehabilitation workers, surveys and estimates provide only rough measures. All evidence suggests, however, that the rehabilitation workforce suffers from systemic problems of staff recruitment and retention, and is insufficient to meet the needs of today's blind and partially sighted adults – let alone those who will lose their sight over the coming years.

### **Additional contribution from the voluntary sector**

Beyond traditional statutory rehabilitation provision, many voluntary organisations provide additional services such as information, sign-posting, emotional support, support at eye clinics, a wide range of social and leisure activities, locally produced newsletters and magazines, assistive technology training, a range of services to children and young people and their families, advice, advocacy and casework on benefits and concessions, and employment retention or retraining. The voluntary sector also works to promote and campaign for

improvements in social care service provision, access to employment, access to alternative formats, and access to transport and the built environment.

**“Partnership should mean what it says and explore local solutions and value for money, and not exploit competition to reduce service delivery through the pricing mechanism. Good ‘standards’ will ensure a level playing field and consistent values.”**

*Collective local voluntary organisations’ consultation response*

Guide Dogs provides a range of mobility and other rehabilitation services that increase the independence, well-being and dignity of blind and partially sighted people; district teams based throughout England have developed good working relationships with social services departments and local societies for visually impaired people to identify individuals whose mobility would be enhanced by the provision of a guide dog; additional mobility services are offered to those who apply for a guide dog or who may be unable to train with a guide dog; and mobility training services are provided to children, young people and adults under contract to local education authorities. Guide Dogs also supports and carries out research and

campaigns for improved rehabilitation services, and for unhindered access for blind and partially sighted people within the built environment and to transport services.

RNIB also provides some statutory social care services under contract across England, and supports blind and partially sighted people who wish to remain in or obtain employment. It offers transcription services and manages a vast talking book library. The organisation campaigns on issues such as improved employment opportunities for blind and partially sighted people; access to information and transcription services; benefits rights; and on the prevention of sight loss. On behalf of Vision 2020 UK and the sight loss sector as a whole, RNIB recently led the development of the UK Vision Strategy, which is covered in more detail in Chapter 2.

Many other voluntary organisations, both national and local, operate across England, but are too numerous to list here. It is evident that, for the positive advancement of services for blind and partially sighted people in the future, there must be a cohesive partnership between the voluntary sector, the statutory services and both national and local government policy makers, guided by the expressed needs of service users themselves.



## Chapter 2

# The drivers of change

It is evident that services for people with sensory loss are entering a dynamic period of change. There are several significant factors acting as the main drivers of this change. In this chapter, consideration will be given to: trends in the make-up of registered blind and partially sighted people; the expanding number of people living beyond the age of 75; the views of service users on their own quality of life and their level of satisfaction with existing services; and the implications of and opportunities provided by recent policy initiatives.

### The impact of demographic trends and implications for services

#### Registered blind and partially sighted people in England

The Information Centre, Social Care Statistics, published the most recent statistics on registered blind and partially sighted people in England for the year ending 31 March 2006. These statistics are derived from triennial returns based on registers maintained by the Councils with Social Service Responsibilities (CSSRs) in England as required by the National Assistance Act (1948). It is notable that, predominantly at the request of service users and patients, the terminology used for registration has now changed to severely sight impaired (blind) and sight impaired (partially

sighted). However, since the criteria for certification have not changed, this will not affect comparisons over time periods.

The main findings from the 2006 statistics are as follows:

- 152,000 people were registered with their local authorities as severely sight impaired: a reduction of 4,000 from 2003.
- There were 11,000 'new' registrations of severely sight impaired people during the 12 month period from 1 April 2005 to 31 March 2006, representing a reduction of 17 per cent compared with those joining the equivalent registers during the year ending 31 March 2003.
- 155,000 people were on registers of sight impaired people: similar to the number in 2003.
- New registrations of sight impaired people amounted to 14,000: a fall of 13 per cent compared with 2003.
- 66 per cent of severely sight impaired people and 68 per cent of sight impaired people were aged 75 or over, similar to recent years.
- 41,000 (29 per cent) of those people registered severely sight impaired and 39,000 (27 per cent) of those registered sight impaired

were also recorded as having an additional disability. Not all councils could provide additional disability information.

- Of those people registered as severely sight impaired with an additional disability, 64 per cent and 24 per cent have a physical disability and hearing impairment, respectively.
- Of those people registered as sight impaired with an additional disability, 70 per cent and 22 per cent have a physical disability and hearing impairment, respectively.

The above statistics should be viewed with caution. Even though it is a precondition for the receipt of certain financial benefits, registration is voluntary and there are no records available of the numbers of people who decline to register either through lack of awareness of the benefits of registration or by personal choice linked to concerns about 'labelling'. Furthermore, since registration is not a prerequisite for social services support or some concessions, this may also reduce its attraction; especially for sight impaired people. There are uncertainties too about the regularity with which councils review and update their records, which casts doubts on the reliability of the figures and, subsequently, comparisons between years.

In summary, therefore, the triennial publication of registration statistics cannot be deemed to represent the definitive number of blind and partially sighted people in England. Figures for 'new' registrations are believed to be more accurate than total numbers on a local authority's registers, particularly where no routine arrangements exist for removing people from the register if they die or move away from the area. Whilst the overall accuracy of the statistics could be improved, the registers of those who are severely sight impaired or sight impaired are an invaluable planning tool.

### Estimates of significant sight loss

According to RNIB, just over two million people in the UK have significant sight loss. This estimate is based on a literature review by a team of epidemiologists which RNIB commissioned (Tate et al 2005). The estimates by age groups (including those with registrable sight loss and those with sight loss using  $<6/12$  as a measure of acuity) are as follows:

**Table 1: Estimates of significant sight loss in UK by age groups**

Age group	Numbers
0-16	25,000
18-64	80,000
65-74	797,631
75+	1,178,962
Total (rounded up)	2,100,000

As indicated in Table 1, the vast majority of people with sight problems are aged 65 or over; over 50 per cent of their sight problems are estimated to be due to untreated refractive error or cataracts. Moreover, there is an increasing incidence of the key underlying causes of sight loss, including obesity and diabetes. This suggests that the number of people with sight problems will increase substantially unless appropriate action is taken to encourage people to have healthier diets and to improve eye health screening so that sight threatening conditions are detected earlier.

**Projected population in England**

It is timely at this point to examine the long term population projections for England by age group. Published in September 2007, these projections are based on the revised 2004 mid year population estimates released in August 2007. In these projections it is assumed that life expectancy at birth in the UK as a whole will rise from 77.2 years in 2006 to 82.7 years in 2031 for men and from 81.5 years in 2006 to 86.2 years in 2031 for women. They do not take into account any future policy changes. Nonetheless, the projections, particularly for older age groups, are revealing and inject an urgency into the debate.

**Table 2: Projected population in England by age group and year (thousands)**

Age group*	Year	
	2008	2029
0-4	2,991.60	3,046.90
5-9	2,858.70	3,090.00
10-14	3,065.40	3,073.50
15-19	3,308.50	3,061.30
16-64	33,382.30	34,333.40
65+	8,287.80	12,305.50
75+	3,988.30	6,320.80
85+	1,112.70	1,974.50
All ages	51,220.50	56,456.80

As indicated in Table 2, the number of people in England aged 65 years and over will rise by 48.5 per cent over the next two decades. Over the same period, the number of people aged 75 years and over will increase by 58.5 per cent, and as Sir Derek Wanless notes below, there will be an even greater rise in the number of people aged 85 or over. These substantial proportional increases in the older age groupings will occur during a period when the overall population increase will only be about 10.2 per cent. With the prevalence of sight loss increasing substantially in older age (the over 75s make up around 66 per cent of local authority

\* For illustration purposes, the working age population projections (16-64) are given, even though there is an overlap with the age group 15-19. The overall age groupings in the Table do not therefore represent exact aggregate totals.

registers of blind and partially sighted people), and the disproportionate increases in the numbers of people in the population aged over 75 and over 85 will lead to a dramatic rise in the number of blind and partially sighted people requiring services in England over the next twenty years.

### **Implications for future social care**

In his 2006 report 'Securing Good Care for Older People: Taking a Long-term View', Sir Derek Wanless noted how the population of England is ageing significantly and speculates on the likely impact of this over the next 20 years. In a detailed and penetrating analysis, Wanless reached the following conclusions:

- While there is an estimated 10 per cent growth in total population by 2026, he emphasised the disproportionate increase in the number of people aged 85 years and over, which is expected to rise by 66 per cent.
- Over the same period, Wanless predicted a 53 per cent increase in the number of older people with "some need" and a 54 per cent increase in those with a "high level of need".

- The total number of older people with disabilities, and potentially in need of care, will be significantly higher, particularly arising from conditions common in old age such as heart disease and stroke, sensory problems (vision and hearing), arthritis, incontinence, dementia and depression.
- In contrast, however, a future is foreseen where population health could be improved due to moderate reductions in obesity and other lifestyle conditions, in addition to the introduction of effective new treatments and technologies.
- Expectations are changing and the growing cohort of 'baby-boomers' (born between 1945 and 1954) is likely to be much more vociferous in their objections to age discrimination and to insist on greater choice and quality.

His warning to policy-makers and service providers is clear:

"Overall, the number of people with impairment and dependency will increase significantly over the next 20 years. This will increase the demand for social care, putting pressure on available resources and funding."  
(Wanless, 2006)

### **Future projections – a summary**

It is important to recognise that not all of those people predicted to be living with sight loss over the next 20 years will necessarily meet the medical criteria to be registered as severely sight impaired (blind) or sight impaired (partially sighted), or be eligible to receive help from their local authorities.

Furthermore, it is difficult to predict accurately whether the prevalence of conditions such as macular degeneration will rise significantly due to the ageing population, or will fall if the medical community improves the effectiveness of treatment for this and other eye conditions. Nonetheless, if our citizens are to realise their true potential, the implications of the demographic changes outlined above in Table 2 alone present a compelling case for increased investment in the future provision of sensory services in England.

**“Rehabilitation workers are being bought in to do an assessment when a dependency has already been created on services like home care or meals on wheels. They need to be looking at outcome based assessments in the initial stages of the Single Assessment Process and to include rehabilitation workers in that process, and not as an afterthought.”**

*Local authority response from SE of England*

However, efficient planning is dependent on accurate collection and collation of statistics of registered blind and partially sighted people, their age groupings, gender, geographical locations and any additional disabilities they may have. The accuracy of overall visual impairment population statistics in England has been increasingly questioned. Despite efforts on the part of some local authorities to improve data collection, a recent significant fall in the number of ‘new registrations’ suggests that many people who would meet the criteria for registration are not being registered.

Suspicion is falling on changes made in September 2005 when the BD8 medical certificate used by ophthalmologists to confirm eligibility for registration was phased out and replaced with an updated version of the Certificate of Vision Impairment (CVI) that was launched but not universally adopted in November 2003. It is widely felt that the withdrawal of the BD8 halfway through the 12 month period for which the last ‘new registration’ statistics were collected, suggests that the fall in those numbers is more than just coincidence. Whether this reduction in new registrations is a temporary blip, caused by confusion over the changes to the medical certificate used to confirm eligibility for registration, may be seen once the next set of figures for new registrations is released.

Responding to concerns over the apparent decline, the Department of Health agreed to bring forward the data collection exercise by 12 months, and so comparative data for the 12 month period ending 31 March 2008 should be available by autumn 2008. Whether temporary or longer-term, it is unlikely that the decline in new registrations reported in 2006 is simply the result of a fall in the numbers of people going blind or declining registration.

Over the next two decades, the emerging needs and expectations of blind and partially sighted people, coupled with the increasing proportion of those aged 75 and over, will add significantly to the social challenges faced by the Government.

There is a perception amongst blind and partially sighted people (shared by those who work with them) that they have traditionally been deemed to be a marginal or minority group. Whilst it has never been appropriate for planners or policy-makers to regard sight loss in this way, given the huge demographic changes we face such views are becoming increasingly untenable, as all families could be affected in the future. It is vital, therefore, that service planners and those shaping policy make innovative decisions so that resources are targeted most effectively to cope with the increased demand for rehabilitation and other specialist

community and social care services.

### **The views and expectations of blind and partially sighted people**

Official records only tell a limited story about the extent of increasing support needs in the community, especially among older people who are living well beyond their seventies.

**“The current move to ‘tick box’ social care against lacklustre targets overlooks other key issues that seasoned rehabilitation workers already know. For example, a person who turns down eccentric reading training or mobility training at first can be encouraged to move on and give it a try – the result is invariably positive. But it takes time and careful nurturing that may in future be all too rarely available.”**

*Collective local voluntary organisations’ consultation response*

Some blind and partially sighted people, particularly those in older age groups, do not identify themselves as having needs: they accept their sight loss as a natural part of ageing and as something with which they simply have to cope. However, those blind and partially sighted people who do identify themselves as having needs are also demonstrating higher expectations of the services provided.

Particularly, but not exclusively, among younger people, technological advances have revolutionised communication, and modern rehabilitation services should enable blind and partially sighted people to make greater use of IT equipment such as personal computers, laptops and various electronic reading and talk-back devices.

Should services fall below a satisfactory level, users now have much more clearly defined complaints procedures, and, in serious cases of discriminatory practices, they ultimately have the right to take the service provider to court. As the Government seeks to improve the information flow about the services that people receive, it is becoming easier for anyone who wants to compare and contrast provision across different geographical regions. As a result, it is nowadays more feasible to detect the negative effects of a postcode lottery which result in some users having to endure a lower quality of service either because it is poorly managed or their particular authority is relatively under-resourced.

### **Research undertaken by Guide Dogs**

In 2007, Guide Dogs published the results of a major piece of research, 'Functionality and the Needs of Blind and Partially Sighted Adults in the UK – A survey'. The specific research objectives were twofold:

- To describe the experiences of the registered population of blind and partially sighted people, and specifically how they function in a range of life situations; and
- To understand the factors that enable or act as barriers to the achievement of individual priorities.

A structured questionnaire of 292 questions was administered by telephone. A total of 1,428 people were interviewed, of whom 881 were resident in England.

All respondents were registered – 60 per cent as blind and 40 per cent as partially sighted. 56 per cent were women, and 44 per cent men. The responses specific to England were analysed and presented in a separate report. Among the major findings were the following:

- 38 per cent of people registered within the last five years were not offered a service on the basis of a needs assessment.
- Only 18 per cent of people had received any training in independent living skills (ILS). When asked to rate the level of difficulty experienced in performing routine tasks, those reported as most difficult were: identifying food and medication labels (79 per cent); going shopping (62 per cent); dealing with mail (60 per cent); setting controls on

appliances (52 per cent); making a hot meal (41 per cent); organising possessions (44 per cent); finding clean matching clothes (43 per cent); and doing housework (44 per cent).

- Mobility is a crucially important area of functionality. The ability to move around independently in our environment facilitates almost all of our regular activities. 38 per cent of people who do not have any other mobility-limiting condition are going out less than once a week. Their 'quality of life', 'physical health' and 'mental health' scores tend to be lower than those who go out more often.
- 35 per cent of people in the sample reported having received some mobility training. Comments were offered on the requirement for refresher training.

The opportunity to have a voice, to express one's needs and to feel assured that, once heard, those needs will be addressed is crucial in empowering service users to engage proactively with their service providers. The word 'forum' was used in the survey to encompass the concept of somewhere or someone to turn to for help or advice.

- 30 per cent of people said that they did not have a forum.

- Where people reported having access to a forum, in 24 per cent of cases this need was met by local societies for blind and partially sighted people, in 13 per cent it was met by local authority social services departments, and in four per cent by family.

### **Quality of life**

The Guide Dogs survey has demonstrated a clear link between well-being and functionality – how well a person copes with a range of tasks. An enhanced quality of life for blind and partially sighted people should therefore be the ultimate desirable outcome in the provision of rehabilitation services. The aspirational quality of life of service users must remain the central focus in the development and provision of services.

The survey asked six questions designed to measure various components of quality of life. These were concerned with likelihood of injury; ease or difficulty in coping with demands of life; ease or difficulty in making friends; ease or difficulty in organising needed assistance; ease or difficulty in fulfilling desired roles; and effect of visual impairment on confidence levels.

- The people who have the highest quality of life scores tend to be older (average age 67 years), have better physical and mental health, report less social isolation, be more confident and have less difficulty with independent living skills activities.
- There is a demonstrable link between suitable transport and mobility and social engagement. Consequently, there is an onus on public authorities and providers of other key services to ensure that transport is readily available and accessible, and that information about it is up-to-date and widely circulated.
- Employers' attitudes and personal confidence levels are deemed to be the main barriers to finding and retaining work. The question is raised as to whether suitable jobs actually exist for blind and partially sighted people. The survey confirms that many blind and partially sighted people are underachieving and not using their talents to the full.
- 58 per cent of respondents are mobile phone users and report this as either very useful or invaluable in their everyday lives. 43 per cent of respondents use a personal computer (PC), which is slightly less than the figure for the rest of the UK (47 per cent). Of those who use a

PC, 52 per cent have one in their own homes, which is a higher figure than the General Household Survey (GHS 2000) UK general population figure of 42 per cent computer ownership. Technology usage has an increasingly positive impact on the lives of blind and partially sighted people.

This research indicates gaps in services or absence of support for many blind and partially sighted people. A correlation between quality of life and better mental health and self-confidence has been demonstrated. It is a matter of concern that an unacceptable level of depression and anxiety among some respondents has been highlighted, and there is unquestionably a need to consider provision of professional counselling as part of the essential services.

Despite efforts to improve the quality of careers advice, guidance and education, and to make training available in the world of work, evidence points to continuing lack of awareness among employers, and the constant struggle faced by blind and partially sighted people, not only to get jobs, but also to retain them or develop their careers.

As highlighted above, another key priority must be the availability of suitable and accessible transport,

as the extent of transport services dictates the degree of mobility that can be achieved to make use of community services and keep up a positive and healthy level of social engagement.

This feedback points to significant priorities for improving or filling gaps in services. Failure to address these in future planning will incur a heavy social and economic cost, and deny blind and partially sighted people the right to engage in society and have a reasonable quality of life.

It is important that society as a whole takes ownership of the issues highlighted in this research. The needs of blind and partially sighted people should no longer be marginalised or pigeon-holed. The social and economic costs of failing to provide adequate services are clearly borne by blind and partially sighted people and those close to them, but they also have a negative impact on the wider community. Historically, disabled people have been directly or indirectly discriminated against because they have been compartmentalised as ‘other’, serving no economic use and therefore not commanding any priority. This has been exemplified by the fact that, at times of economic stringency, disability services have never benefited from a stable or planned budget allocation. Future policy and provision

affects all of our lives. In the remainder of this chapter, Government and third sector policy initiatives which demonstrate a gratifying awareness of the need for extensive and integrated change will be examined.

**“The paradox could be that, whereas in the past, blind and partially sighted people may have had a long wait, but got a quality service, with new developments, they may be contacted immediately, but not offered a quality service! For example, merely being provided with information and contact numbers for other agencies.”**

*Local authority consultation response from SW England commenting on the consequences of tighter eligibility criteria*

## **Government and third sector policy initiatives**

### **The NHS Eyecare Services Programme**

Established in 2002 with a £4 million award from the Department of Health, the Eyecare Services Programme facilitated and co-ordinated a number of pilots in England to develop and test ‘Eyecare Pathways’ – to ease the transition for an individual from primary or secondary eye care through to low vision and rehabilitation support. In addition to clinical aspects of the pathways, the role of the rehabilitation

worker was seen as crucial to the success of the pilots, particularly in relation to those focusing on Age Related Macular Degeneration and low vision. Efforts were made not only to involve rehabilitation workers but also to improve links with wider, more generic aspects of local social care provision where appropriate.

These innovative pilots explored new ways of working to utilise the skills of rehabilitation workers more effectively. Protocols were developed to allow for rehabilitation assistants and low vision therapists to undertake some of the more routine tasks, freeing up rehabilitation workers to concentrate on the more complex issues and supervision of the system.

The results of the pilots were the subject of a national conference organised by RNIB on behalf of the Department of Health in York on 17 and 18 January 2007. This event included the publication of a set of 'Recommended Standards for Low Vision Services' and a 'Commissioning toolkit for community based eye care services'. The latter provides PCTs and practice based commissioners with practical advice on commissioning community based eyecare services. It draws on evidence that has emerged from the pathways and also fits within the wider commissioning framework and, amongst other things, sets out the

links between wider health and well-being and visual health. The importance of including rehabilitation workers within integrated low vision services is spelt out and the potential role of the third sector is explored.

More information on the Eyecare Pathways can be found at:

<http://www.eyecare.nhs.uk>

where descriptions of the pilots and the particular pathways they developed are also available. The Eyecare Services Programme came to an end on 31 March 2008.

### **Low Vision Services Implementation Group**

The development of integrated low vision services as part of the Eyecare Services Programme was a welcome addition to an earlier and ongoing initiative. In 1999, the Low Vision Services Consensus Group published 'Low vision services: Recommendations for service delivery in the UK'. This laid out a clear set of definitions and standards for integrated and holistic low vision services, with the purpose of enabling those with low vision to make optimum use of their remaining sight and maximise their potential. It covered issues such as emotional support as well as more practical dimensions such as the provision of magnifiers or other low vision aids.

One of the big successes of the document was the subsequent development of local Low Vision Services Committees (LVSCs) in many parts of England. These multi-disciplinary, multi-agency bodies (often including users of services) take responsibility for low vision strategy, usually in conjunction with Local Optical Committees and local authority social services departments. There are currently 80 LVSCs operating in England.

### **Choice, prevention, independence, well-being and other priorities**

The Department of Health's 'Choosing Health' White Paper (2004) set out key principles for supporting the public in making healthier and more informed choices with regard to their health. The stated aim was to provide information and practical support to get people motivated, and improve emotional well-being and access to services so that healthy choices are easier to make.

Three principles underpin the Government's approach to public health:

**Informed choice** – The Government believes strongly that people want to have control over the health choices they make, but can only do so meaningfully if they are presented with adequate information.

**Personalisation** – One size does not fit all. People may need flexible services that are convenient and sensitive to their particular needs.

**Working together** – Real progress in promoting good health depends on effective partnerships across communities, including local government, the NHS, the private and voluntary sectors, communities, the media, faith organisations and many others.

The Department of Health's 2005 Green Paper 'Independence, well-being and choice: Our vision for the future of social care for adults in England' proposed seven outcomes for adult social care services:

- Well-being
- Improved quality of life
- Making a positive contribution
- Choice and control
- Freedom from discrimination
- Economic well-being
- Personal dignity.

These were confirmed in the subsequent White Paper 'Our health, our care, our say', published in January 2006. Both documents place greater emphasis on:

- Prevention;
- Emotional well-being; and
- Outcomes.

An ambitious programme to transform health and social care has been set in train and is gathering pace. These developments are welcomed, as is the review being undertaken by the Commission for Social Care Inspection (CSCI) into the effectiveness of current Fair Access to Care Services (FACS) eligibility criteria (a report is anticipated in September 2008), and the six-month public debate initiated by the Department of Health into the future funding of adult social care. The debate, stimulated by the document 'The case for change – Why England needs a new care and support system' is expected to lead to a Green Paper early in 2009.

**“The new framework for Local Area Agreements brings some major changes which are very welcome – much greater clarity about the relationship of national and local priorities, a reduction and rationalisation of national performance monitoring, and greater financial flexibility.”**

*Cllr Simon Milton, Leader of the Local Government Association*

### **Local planning and commissioning systems**

The approach taken by Government to modernising joint planning and commissioning frameworks is intended to promote health, well-being and

independence by using contracts, pooling budgets and using the flexibilities of direct payments and practice based commissioning.

Strong and Prosperous Communities (2006) and the Commissioning Framework for Health and Well-Being (2007) set out requirements (and a legal basis) for the formation of Local Strategic Partnerships (LSPs) covering a range of themes, including one focusing on health and well-being. LSPs bring together representatives of all sectors (public, private, voluntary and community) to agree targets for Local Area Agreements (LAAs).

In essence, an LAA is a three-year agreement between a local area and central Government. The LAA sets out how local priorities will be met through locally based solutions, but also contributes to national priorities set out by the Government. The first LAAs were established in 2004, but were updated in 2008 to place more emphasis on area-based service delivery, giving more freedom in spending decisions and with fewer central targets and reporting requirements. New LAAs include provisions laid out in the Local Government and Public Involvement in Health Act 2007.

Directors of public health, primary care trust commissioning directors and directors of adult social services are

expected to work together to manage the process of producing a Joint Strategic Needs Assessment (JSNA) focused on local health inequalities and improving health and well-being. The JSNA informs commissioning priorities on a three year cycle.

The JSNA is based on: a joint analysis of current and predicted health and well-being outcomes; an account of what people in the local community want from their services; and a view of the future, including potential new or unmet need.

Guidance emphasises that there should be a strong focus in the JSNA on neighbourhoods and people with the lowest levels of well-being. It is worth underlining the emphasis on people with the lowest levels of well-being, as this is a key issue explored in the research undertaken by Guide Dogs on behalf of the RPG referred to earlier in this chapter and in more detail in the 'Functionality and Needs' survey report.

### **The Compact between Government and the voluntary and community sector (the third sector)**

The Compact was established in England in 1998 and represents the agreement between Government and the voluntary and community sector to improve their relationship

for mutual advantage and community gain. Operating at national, regional and local levels, the Compact contains a set of principles. For instance, the Government undertakes to respect the independence of the voluntary and community sector, consult effectively and recognise the cost of doing business when funding public service delivery. For its part, the third sector undertakes to be open and accountable, involve all members, and contribute constructively to public policy.

There are five codes of practice associated with the Compact. The funding and procurement code refers to the importance of transparent accountability and strong effective systems. It recognises the legitimacy of inclusion by the voluntary and community organisations of all relevant elements of overhead costs in estimates; and accepts that longer term funding arrangements should be implemented where these represent good value for money. In the community groups code, the values leading the community sector are defined as: being able to make decisions themselves; mutuality; equality; social justice, co-operation; and the importance of local delivery at a personal level.

In the code relating to consultation and policy appraisal, emphasis is placed on: consultation being built into the regular planning cycle and starting at an early point; new policies and procedures being appraised, particularly at the development stage, and the implications arising for the voluntary sector at national, regional and local level being identified; and making the consultation process as accessible as possible. The other two codes refer to black and minority ethnic issues and volunteering. ([www.thecompact.org.uk](http://www.thecompact.org.uk))

The working of the Compact has been further strengthened by The Transfer of Functions (Third Sector, Communities and Equality) Order 2006 No. 2951, and a new Department of Communities and Local Government, created in May 2006, bringing together for the first time responsibilities for local government, social exclusion and neighbourhood renewal, in addition to new responsibilities for communities, race, faith and equalities.

Important underlying themes of Government policy are social mobility and economic inclusion. Inter alia, the then Prime Minister, Tony Blair, expressed the view that it was time to build on the challenges of tackling social exclusion and developing the role of the voluntary sector. ([www.opsi.gov.uk/si/si2006/ukSIem\\_20062951\\_en.pdf](http://www.opsi.gov.uk/si/si2006/ukSIem_20062951_en.pdf))

A new Office of the Third Sector (OTS) was formed in the Cabinet Office at the same time, to represent the Government lead for the third sector, including the voluntary and community sector, charity law and regulation, volunteering and charitable giving issues, and social enterprise. The main purposes of the OTS are to drive forward the Government's role in supporting the thriving third sector, to co-ordinate third sector related policy work across Government, and to report to a dedicated Minister for the Third Sector in the Cabinet Office. The importance of the OTS in maintaining and improving the legal, regulatory, fiscal and funding framework in which the third sector operates has also been emphasised. (Ibid)

The transfer of functions to the Cabinet Office includes responsibility for the funding and overview of the following bodies:

1. Capacity Builders. This was set up in 2005 to administer the Change Up funding programme designed to increase voluntary and community sector infrastructure and capacity.
2. Commission for the Compact. A new organisation also established in 2005, the Commission is charged with strengthening the Compact in its aim to foster good partnership relationships to

the mutual advantage of Government and the third sector. The Commission is an independent organisation which works with representatives of the views of the third sector (the Compact Voice) and the OTS, and constructs the annual national action plan.

The Compact Annual Meeting is held in Parliament between the Compact Voice, Government Ministers and the Local Government Association. This meeting reviews progress in development of the National Compact and Local Compacts and agrees the proposed action plan to take forward the Compact over the next year.

### **Towards personalised services**

An important stepping-stone towards person-centred services was the Department of Health protocol 'Putting people first: a shared vision and commitment to the transformation of adult social care' (10 Dec 2007). That report reflects the Government's shared aim across all departments to put people first through a radical reform of public services, in order to strengthen the rights of citizens to services of high quality, and personal safety, independence, well-being and dignity.

In effect it is a ministerial concordat to promote collaboration between central and local government, social care providers and regulators.

It describes the key elements of a personalised adult social care system as:

- Local authority leadership accompanied by authentic partnership with local NHS services, other statutory agencies, third and private sector providers, service users and carers, and the wider local community, in order to create a new, high quality care system which is fair, accessible and responsive to the individual needs of service users and their carers.
- Agreed and shared outcomes which should guarantee a quality of service and responsiveness, whatever the illness or disability.

To achieve this, a Joint Strategic Needs Assessment (JSNA) is required (as described earlier in this chapter), combined with other plans such as local housing strategies. In combination, these plans will inform a Sustainable Community Strategy, the specific outcomes of which will include: preventative public health policies; hospital discharge arrangements; adequate intermediate care; packaging of individualised nursing and health support; management of long term conditions; co-located social and primary care; effective community equipment services; and universal information, advice and advocacy services.

Where appropriate, LAAs will operate to ensure consistency. Third sector innovation will also be actively sought as part of the JSNA. All relevant community resources will be utilised to ensure that prevention, early intervention and enablement become the norm. The alleviation of loneliness and isolation will be a major priority, as will supporting people to remain in their own homes as long as possible. A first stop shop will be introduced, accessible by phone, letter, email or within local community settings for information, advice and advocacy services. Personal advocates will be made available if no carer is present.

**“I have no doubt that for some people individual budgets would give choice, control and flexibility to their service needs. However, it may also leave them prey to untrained providers. I also worry that the very highly skilled service providers, who rely on a volume of service users to fund their appropriately trained staff, could be forced out of the market.”**

*LA Sensory Team response, NE of England*

Practitioners will be expected to help people to achieve individually tailored support packages, with greater emphasis on self-assessment. Essential elements will be made available to promote self-determination, including:

personal budgets for everyone eligible for publicly funded adult social care support; direct payments on an increasing basis as part of the targets set in each local authority area; and the development of programmes to help carers develop their skills and confidence.

Local workforce development strategies will be actively pursued to raise practitioner skill levels and provide career development opportunities across all sectors, produced and co-developed in partnership with the private and voluntary sectors. The Department of Health has pledged funding over a three year period to bring about transformations in the systems employed in all local authorities. It is a prerequisite that each local authority must agree with all relevant partners on the best ways to employ this funding in order to develop a truly personalised system. By March 2011, there is an expectation that significant progress will have been made in all local authority areas, including clear bench-marking and designated delivery responsibilities. The protocol itself is described as a catalyst for innovation. However, success will be judged through service user feedback, measurable progress in adult independent living, other objective performance measures, and levels of job satisfaction among staff.

## Summary of Government policy initiatives

For more than a decade, there has been a Government commitment to work in partnership with the voluntary and community sector in order to achieve mutual advantages and ensure that all available resources are being utilised at an optimal level. The Compact, which provides the framework for this collective effort, has been further strengthened by re-organisation within Government, clearer reporting and accountability, and the establishment of an independent Commission to co-ordinate efforts and activate and review annual action plans.

Regarding social and health care, the protocol published by the Department of Health in 2007 outlines the essential ingredients of a personalised care system which requires a radical transformation of local authority structures. Inherent in the model is a commitment to partnership with the voluntary and community sector in the context of locally defined strategies.

Gratifyingly, the aspirations of Government are entirely complementary to the recommendations which have emerged in this policy paper, derived from our own lengthy and detailed consultations and research. The ground is therefore rich and fertile for collaboration between the representatives of blind and partially

sighted people and Government at national and local levels in order to achieve the outcomes which we all seek.

### The UK Vision Strategy

The work of the RPG is very timely, dovetailing with and influencing the work of the UK Vision Strategy. The UK Vision Strategy, launched on 18 April 2008, sets a clear direction for eye health and sight loss services. It represents the UK's response to the World Health Assembly Resolution of 2003, urging the development and implementation of plans to reduce avoidable sight loss and improve services for those whose visual impairment is unavoidable. Government representatives from across the UK were involved in its development.

Similar to the work programme and documentation emanating from the RPG, the UK Vision Strategy has been drawn up by a "strong and united alliance of statutory health and social care bodies, voluntary organisations, eye health professionals and service users" (page 9 of the UK Vision Strategy).

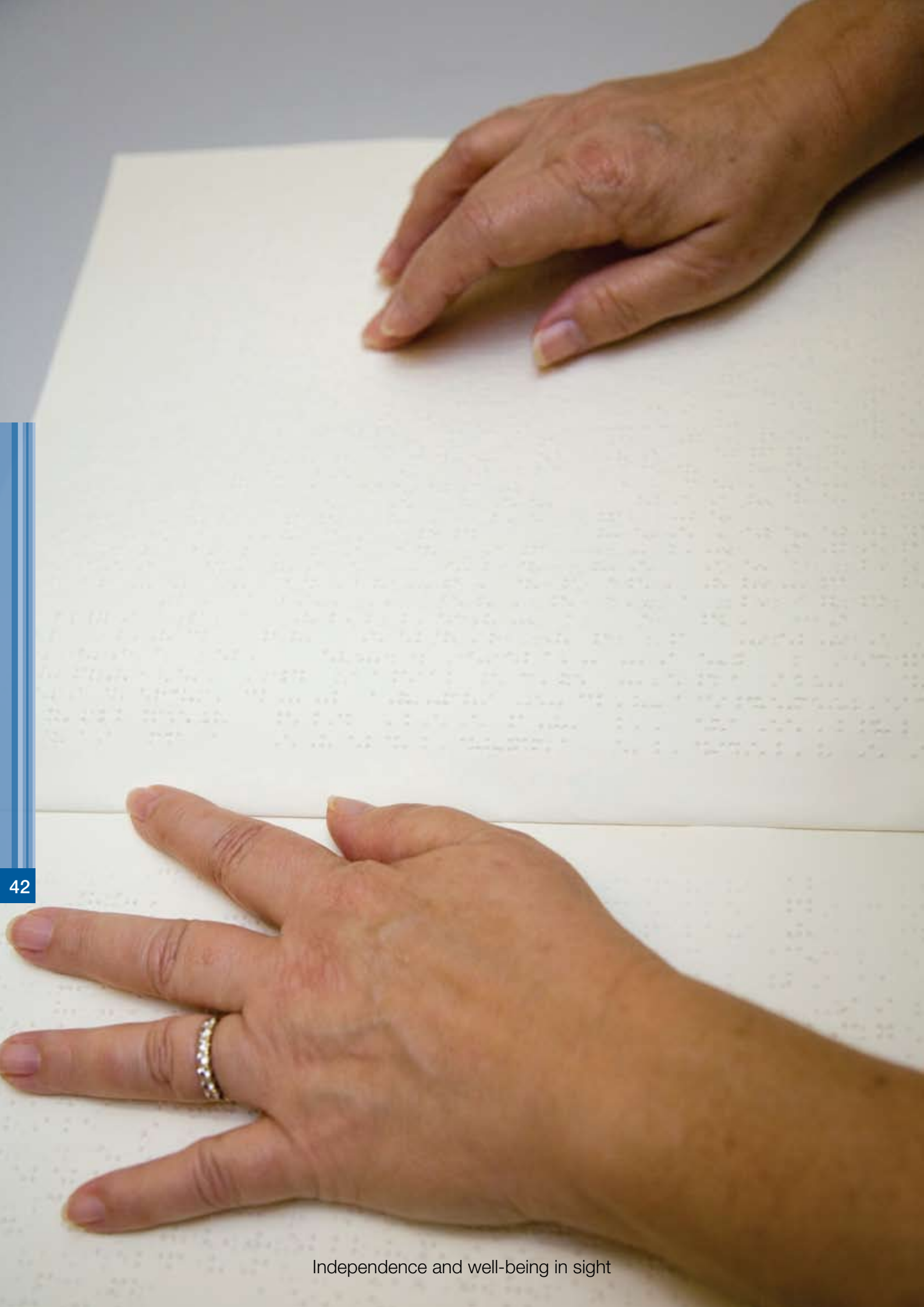
The work of the RPG reflects the aims and values of the UK Vision Strategy, which amongst other things aspires to:

- Enhance the inclusion, participation and independence of blind and partially sighted people;

- Achieve person-centred delivery of excellent services and support in the most appropriate way for each individual; and
- Establish evidence-based policies and services to guide resource allocation and effective services.

**Some key observations of the UK Vision Strategy that chime with the recommendations of this paper and the research undertaken by the RPG in developing and refining them:**

- Health, education and social care services for adults and children with sight loss are very variable and links between health, education and social care can often be poor. This leads to a failure to adequately support individuals and their families.
- Emotional support, including counselling, is almost non-existent, despite the acknowledged trauma of sight loss. The absence of such support often means that people will be much slower to regain their confidence and learn new skills. The prevalence of depression is at least twice as high in visually impaired older adults as in older people with good vision.
- Eye care and sight loss services should include emotional support as an integrated part of the service. Counselling should be available from the point of diagnosis to service users and those supporting them. Links to peer support networks should also be encouraged.
- The wider impact of blindness on independence and quality of life is not sufficiently acknowledged. Assessments, from the initial stage onwards, should consider daily living, mobility needs and communication needs, and should be followed up at regular intervals.
- The traditional model of rehabilitation should be reviewed to ensure that the support package provided meets the needs of modern living.



## Chapter 3

# Tackling the challenge

### The main aim of change

The main aim of the RPG is to ensure entitlement to services which deliver on outcomes designed to improve independent functioning and generate well-being. Among the main principles of an outcome-based approach are: consistency of support; optimum quality of life; and provision which is user-led and person-centred.

### The benefits of change

A focused and strategically planned service for blind and partially sighted people, based on outcomes, and involving in-depth partnership between health and social care services and between statutory and voluntary sectors, can achieve the following benefits:

- A better focus for key practitioner skills;
- Greater accountability and measurement of effectiveness;
- Economic use of resources;
- Breaking down of professional barriers.

Blind and partially sighted people can be described as part of the social capital of our society. Failure to provide appropriate support and enable independence as far as practical incurs a social and economic cost. When human potential is prevented from being fully realised, the wealth

of society is diminished in the sense that individuals are not employing their whole talents for the public benefit, and additional public expenditure may be incurred in trying to sustain the avoidable dependency into which those individuals are forced. This applies as much to the older person facing social isolation because of a lack of transport and communication facilities as it does to an adolescent facing unemployment or under-achievement because of employers' attitudes or lack of constructive guidance.

However, aspirations have to be coupled with specific ideas about the nature of desired changes. The RPG has therefore consulted widely among people who either use the current services, or are practitioners involved in their delivery.

### Achieving consensus

A consultation exercise was conducted by the RPG across the UK on a range of issues, using a structured questionnaire. There were 116 formal submissions from across the UK, 63 of which were in response to 'Independence and well-being in sight: Developing the vision. A consultation on the future of rehabilitation services for visually impaired adults in England'. These were received from a range of individuals and organisations including blind and partially sighted

people themselves (independently or collectively following group consultation exercises); local and national voluntary organisations of and for blind and partially sighted people; local authorities (a mixture of sensory teams and other departments); other national or local bodies; and from practising rehabilitation workers.

**Consultation question: “If you had the power to change the way in which services for visually impaired people are provided – what three changes would you make that you believe would bring about the biggest improvements?”**

**Response:**

- 1) A system that breaks down the triple waiting time to access low vision, social care assessment and rehabilitation follow-up, i.e. a system that allows multi-disciplinary assessment on one site.**
- 2) A stronger recognition of the value of peer-support services in overcoming social and emotional barriers to well-being.**
- 3) A greater awareness by service commissioners of a) the relatively low-level cost of early intervention, and b) the serious implications of sight loss and the cost of non-intervention.**

*Local authority consultation response from N of England led by rehabilitation worker and the sensory team*

Highlighted below are the main areas of agreement among the respondents which have informed the work of the RPG in considering the future structures proposed in this policy paper:

- Confirmation of the positive effects of the promotion of integrated multi-agency pathways, and the role they play in present and future planning and delivery of health and social care services. There is consensus on the need to build upon this work and develop further rehabilitation services within this framework.
- Agreement that an outcome-based approach to assessment and delivery of service (which places the focus on the end result) is the most cost effective way forward, as long as it is measurable.
- Support for the development and use of an outcomes framework to help to bring about standardisation to services across the country and to make provision person-centred. The framework should include: managing health; emotional well-being; transport; work; leisure and spiritual pursuits; education; information; communication; outdoor mobility; enjoyment of safety of the home; family and carer; financial advice; and personal safety.

- Recognition of the importance of piloting the proposed Middle Step model (which is detailed later), as a further development of the integrated multi-agency eye care pathways. The Middle Step model should include emotional support. The use of group work, while not being suitable for everyone, was seen as a good means of encouraging peer support. Family and carers' needs should be included.
- Acknowledgement of the need for the definition of roles, remits, and skills mix of rehabilitation staff. Confirmation that some tasks currently undertaken by rehabilitation workers can be safely undertaken by staff with other qualifications and/or training. Suitable training provision is required for present roles and any future roles.
- Wide agreement that registration and regulation of the rehabilitation workforce is needed.
- Anticipation that there will be an increase in demand for services, as indicated in the changing age profile of the population, and that this will have major implications for planning and resourcing of services.
- Wide agreement around personal and organisational barriers to achieving successful rehabilitation. The emotional impact of sight loss,

loss of confidence and isolation were particularly highlighted as personal barriers. The limited rehabilitation workforce, its ability to carry out follow-up and to re-open cases and the inadequate provision of longer-term training programmes were mentioned as key organisational barriers.

- General recognition of and support for the need to develop the rehabilitation workforce further, but as part of the wider visual impairment workforce; and to establish and define the skills mix, roles and remits that are required to meet the rehabilitative needs of blind and partially sighted people. It was also agreed that attention should be given to an appropriate assistant role.

### **Consultation conclusion**

In summary, there was majority support for the Middle Step across all groups of respondents, in order to provide information, structured emotional support and early intervention, and address many of the personal and organisational barriers to successful rehabilitation that were consistently cited by consultation respondents. Greater communication and inter-agency working, particularly between the medical and community based professions, was also seen as a major benefit.

**Responses to the consultation question “Do you agree that the Middle Step described would be an effective and efficient method of addressing the needs highlighted (in the consultation paper)?”**

Strongly agree	23
Agree	30
No opinion	4
Disagree	4
Strongly disagree	0
Total	61*

\* Not all 63 respondents explicitly answered the question.

**“To what extent do you agree with the statement that some tasks currently undertaken by rehabilitation workers could be safely undertaken by staff with other qualifications and/or training supervised by adequately and appropriately qualified staff?” (Responses broken down into those received from rehabilitation workers and from others.)**

**Rehabilitation worker responses**

Strongly agree	3
Agree	10
No opinion	1
Disagree	0
Strongly disagree	0
Total	14

<b>Other (non-rehabilitation worker) responses</b>	
Strongly agree	17
Agree	22
No opinion	3
Disagree	2
Strongly disagree	3
<b>Total</b>	<b>47</b>

Development of outcomes-based services was welcomed as long as the outcomes were quantifiable and the services provided to achieve them truly person-centred. There was considerable support, including from within the rehabilitation worker profession, for drawing upon the skills of a range of other personnel to meet the needs of some people with moderate vision loss and 'lower-level' needs.

A much more detailed analysis of the consultation responses received can be found in 'Refining the vision – Collation of feedback from the independence and well-being in sight consultation in England' (2007).

### **The shape of change**

#### **Implementing the Middle Step**

Pilot projects are being established in a range of settings to evaluate the components of the Middle Step and the effectiveness of the techniques and services employed, and to inform the

skills mix required to deliver the model. Some are underway, and a programme specification has been constructed to inform both practitioners and participants. An integrated approach between health and social care is of primary importance here, and this depends on a true belief in person-centred services and professionals working hard at developing and maintaining positive working relations to achieve this.

The aim of the Middle Step is to provide a structured and supportive transition from the detection and diagnosis of sight loss through to a range of beneficial outcomes, including positive engagement with rehabilitation services and, ultimately, to enhanced independence and emotional well-being. In doing so, it sets out to emphasise the importance of meaningful choice and independent functioning for every individual and utilises a person-centred planning approach. This allows participants to take greater control of their sight loss journeys and

steer a course towards self-identified goals or outcomes.

### **Middle Step pilots**

The structure of all Middle Step pilots will comprise the components of assessment, appraisal and evaluation, although the detail of how these are carried out will vary between sites.

Referral encompasses how individuals will be recruited, is underpinned by effective communication between health and social care service providers and participants, and needs to include diagnostic information. Early intervention is required to mitigate against a loss of confidence which often follows the first detection and formal diagnosis of sight problems. Thus, participants of the Middle Step should not be left for unduly lengthy periods between diagnosis and the start of the Middle Step.

Given that blind and partially sighted people live in a variety of locations where the availability and proximity of facilities varies from area to area, the Middle Step model must be flexible enough to be conducted in a range of settings. Effective communication between individuals, health professionals and social care professionals is essential to ensure that the effectiveness and coherence of the model is not eroded or contradicted.

Where Middle Step services are located alongside established hospital-based services, this will enable health care staff to become more actively involved in promoting the benefits of the Middle Step to their clients. The involvement of these key professionals in the follow-on care of their patients should mean that they no longer have to deliver the message that “nothing more can be done”. This is likely to have an impact on eye care service design and delivery as a result.

### **Well-being**

Research has shown the clear link between sight loss and depression: Burmedi et al (2002), Hanson et al (2002), Horowitz et al (2003), Mitchell et al (2004). Many people who took part in the Guide Dogs survey suggested the loss of confidence at the time of diagnosis prevented them making the progress and adaptation necessary to maximise their independence.

Using recognised instruments, the Middle Step will make a formal appraisal of a participant’s well-being to identify the impact of sight loss on the participant and determine how and when to proceed with further support.

### **Functionality and outcomes**

Using the principles established in the International Classification of Functioning (ICF) and promoted by the World Health Organisation (WHO), Middle Step

returns the focus of service provision for blind and partially sighted people to the outcomes which will meet the needs that they themselves have identified.

The individual will be supported in identifying their own desired outcomes for greater independent functioning. Although exploratory, this initial self-assessment will be formal and likely to provide the first opportunity to establish the individual's initial aspirations though recognising that they may grow in confidence and develop more ambitious targets as they progress through the Middle Step.

**“Emotional support should be first offered during the treatment process, as the diagnosis of sight threatening conditions can often be devastating, making patients extremely vulnerable. The link between serious medical conditions and emotional support is well recognised in areas such as cancer care and we need to develop similar approaches for sight loss.”**

*National voluntary organisation consultation response*

A pre-intervention assessment has been developed to enable an appraisal of an individual's current capacity in a number of key aspects such as well-being, mobility and independent living skills. The aim at this stage is to reveal the level of need each individual has in key

life skill areas, and to help in determining the content and priorities of a tailor-made rehabilitation programme to meet the individual's chosen outcomes.

### **Programmed intervention**

Once the individual's diagnosis, self-assessed outcomes and functionality are clear, a programmed intervention can be prepared to address each in turn. Emphasis will be placed on the individual's readiness to engage in such a programme and their likelihood to benefit from it, and consideration will be given to the key issue of timing. If one has not already been conducted, a low-vision assessment may be required to inform the programme. This will be conducted by a suitably qualified professional.

It is widely recognised that the provision of emotional support must be both timely and appropriate. Peer support has been shown to be an effective vehicle for this and group work practice, facilitated by suitably skilled practitioners will play a central role in the provision of emotional support, development of self-confidence, and exchange of information at this stage. Using objective functionality measurements to demonstrate the need for intervention in particular areas and the agreed outcomes as targets, individuals will be provided with accurate information about their eye condition, likely prognosis and its implications, and details of services and skill training

opportunities available to them. This will lead to an appraisal of outcomes and an explanation of how they can be achieved most effectively for each individual. Suitable resources will have to be identified locally and carefully managed. It is important to emphasise that practitioners with counselling skills should play a central role in responding to emotional support needs.

Programmes of training may also take place during this phase. These will be designed to introduce participants to key areas of training aimed at helping them to achieve their desired outcomes. As such, they will focus on the rationale behind rehabilitation, providing in-depth explanation and consideration of each topic as well as some basic training in key skills. The aim in doing so is to maximise the progress each participant can make in the time available with access to dedicated resources.

This is also a formal opportunity to involve family and carers (if requested) in the Middle Step model. Often, these key people will have different needs and aspirations from the individual. They too can benefit from, and bring benefits to, the Middle Step intervention through their involvement in and active support of the programme. This will be an opportunity to learn about the nature of their partner's or family member's sight loss, what the impact of the prognosis might be and how to play an ongoing

part in the rehabilitation process.

### **Post intervention and action plan**

As the individual completes the Middle Step, they will be at the point of moving forward with agreed outcomes for the future, built on their achievements. A post-intervention assessment will be conducted repeating the questionnaire used prior to the intervention, to determine improvements in the individual's level of functioning. This will also assist in the preparation of an Action Plan describing the ongoing support and services the individual requires from community based services to achieve the outcomes identified.





## Chapter 4

# Rehabilitation services: into the future

Having considered the shape and the potential benefits of change, this policy paper now attempts to define and examine the skills that are required within a multi-disciplinary workforce to meet the needs of blind and partially sighted clients most effectively.

Ultimately, services will have no real validity if they are not anchored in a person-centred approach, which reinforces client autonomy and choice, and which responds to specific feedback given by the individuals about the support they feel they need.

However, emphasis throughout will be on the fact that the rehabilitation profession – like all professions in the health and social care sector – only retains the right to such resources if it can demonstrate effective outcome-based delivery of services, properly appraised and evaluated, which consistently meets the existing and changing needs of blind and partially sighted people.

### Rehabilitation worker survey

In order to examine the existing role of the rehabilitation worker and identify the pressures and challenges they face, a survey was carried out across the UK involving 110 rehabilitation workers, 56 of whom were based in England.

The survey highlighted many of the difficulties and frustrations that rehabilitation workers experience, but also their willingness and desire for change in their roles and responsibilities, and their enthusiasm for Continuing Professional Development (CPD) to meet better the needs of blind and partially sighted people.

### Assessment, administration and time constraints

Rehabilitation workers indicated that on average in any given month they spend 35 per cent of their time on assessment.

They believe that on average they spend 40 per cent of their time on administrative tasks.

Although both assessment and administration tasks are essential to the provision of services, this only leaves 25 per cent of their time to undertake rehabilitation training. The difficulty this creates is confirmed by the rehabilitation staff, who identified that tasks such as orientation and mobility (O&M), and independent living skills (ILS) were the most demanding tasks to provide due to time constraints.

### Met and unmet needs

While most respondents to the survey mentioned that the tasks they had to carry out were dependent on the needs of their clients, as identified from the

initial assessment, they mainly fell into the categories of coming to terms with sight loss, confidence building, O&M and ILS.

Whilst a small number of respondents felt that they could carry out any task requested, a significant number said it was difficult or impossible for them to provide expensive equipment, and that there was limited availability of IT training. Time constraints did not allow for the development of skills in O&M or ILS.

### **Creating a diverse rehabilitation workforce**

Respondents to the consultation exercise expressed the view that some tasks currently undertaken by rehabilitation workers could safely be undertaken by staff with other qualifications and training.

The consensus over the need to develop the rehabilitation assistant role, to undertake many of the less specialist tasks that rehabilitation workers currently do, came with qualifying comments around the need to define roles and remits of rehabilitation staff, and to establish clarity about core skills and tasks to be retained by the rehabilitation worker. There was strong feeling that an assistant role should never be considered as a substitute for the rehabilitation worker, and blind and partially sighted respondents

commented that training programmes should be retained by rehabilitation workers. A few respondents who were managers of services commented that forms of the assistant role already existed to a certain level within their own areas, although they wished it to be recognised that there was, as yet, no defined education and training for such roles.

The idea that an assistant role could be effective across visual impairment, hearing, and dual sensory loss, was one of the most significant areas of debate to emerge from the consultation. Views ranged from those citing successful use of such roles already, through to those warning of the potential risk of dilution of specialist skills. Some pointed to the prevalence of moderate hearing and vision loss amongst many older people, and expressed the view that this type of role would build relevant knowledge into teams, thus allowing for flexibility, but that there may need to be an expansion of the workforce. Comments were well made that there is more work needed on this topic, in conjunction with existing specialist organisations.

## **Current and future training needs for rehabilitation workers**

In both the rehabilitation worker survey and consultation exercises, comments were offered on the need for CPD opportunities to be made available for rehabilitation staff. There was evidence of an appetite for opportunities to undertake modules in working with children and young people, clients with acquired brain injury, and older people, amongst others.

It is evident that at present career development opportunities for rehabilitation workers are very restricted.

The findings of the survey and consultation suggest that the development of modular and post qualifying training would not only have a significant impact on the future professional development and career opportunities for rehabilitation staff, but would also create a multi-disciplinary rehabilitation workforce, able to respond more appropriately to the needs of all blind and partially sighted people.

Rehabilitation workers have a key role in the provision of current services which will be further emphasised when, subject to thorough evaluation of the pilot projects, the Middle Step is implemented in full. This multi-agency model presents an ideal opportunity to continue to ground the role of the rehabilitation workers in existing and

future eye care pathways and build on the recommendations of the Department of Health and the Eyecare Services Steering Group initiative outlined in Chapter 2. Fundamental to the future recruitment of suitably skilled people will be the provision of appropriate training courses.

## **Training qualifications and professional development**

At present, the only tailored courses available throughout the United Kingdom are: DipHE in Rehabilitation Work (Birmingham City University, formerly the University of Central England), Foundation Degree in Health and Social Care (Visual Impairment) (Canterbury Christ Church University), and BSc in Health Care Practice (Visual Impairment) (York St. John University). An MSc in Mobility and Independent Functioning of Children and Young People with a Visual Impairment has also been established at York St. John University, and a postgraduate option for suitable first degree holders is pending validation at Brunel University. Another course has emerged, a BTEC Certificate provided by Provisions Solutions, as a pragmatic effort to make skills training available to employers in the absence of a national strategic approach to training and qualifications in rehabilitation.

Discussions are underway, initiated by Guide Dogs, with third level colleges and universities throughout the United

Kingdom to test out the feasibility of a tiered diet of courses which would incorporate progression and transferability, and would suit the needs of workers in a pan-service sensory setting. Such workers would include rehabilitation assistants, rehabilitation workers and specialists in the fields of rehabilitation and therapy. Ideally, staff involved in work with both visually impaired and hearing impaired people will be able to register on common base generic courses which also provide specialist electives. A principle underpinning the new training provisions would be the importance of CPD.

It is essential that training needs are located clearly within the National Qualifications Framework (NQF) and the Framework for Higher Education Qualifications (FHEQ). ([www.direct.gov.uk/en/EducationAndLearning/QualificationsExplained](http://www.direct.gov.uk/en/EducationAndLearning/QualificationsExplained)).

Rehabilitation assistants/support staff would be expected to progress to at least Level 2 within two years of commencing employment. The NQF defines the benefits of Level 2 as: good knowledge and understanding of a subject; and ability to perform a variety of tasks with some guidance and supervision. Being largely 'on the job' training, it would best take the form of a National Vocational Qualification (Level 2) or a BTEC First Diploma, and would be provided through a local

further education college. Flexibility would have to be built into the training programmes to ensure that entrants could join modules at various points and accumulate credits. In addition to rehabilitation assistants involved in domiciliary support services, this training could also be made available to the many day and residential care workers who, hitherto, have been reliant on relatively informal induction training within their agencies.

The minimum appointment qualification for a rehabilitation worker would be at Level 5 in the NQF, which offers the opportunity to increase the knowledge and depth of an area of study, so that the person can respond to complex problems and situations; involves a high level of work expertise and competence in managing and training others; and prepares the individual for a particular professional role. The format could be a Higher National Diploma (HND), a BTEC Professional Diploma, or a Foundation Degree in Health and Social Care, which would have course and practice placement content approved by the General Social Care Council and Skills for Care and Development (SfC&D). A Foundation Degree is described in the FHEQ as an intermediate level of higher education qualification, equivalent to a Higher National Diploma, a Diploma of Higher Education, or an ordinary Bachelor's Degree, and has

the explicit benefit of being tailored to suit employers' needs. Provided through local colleges, these would be recognised by universities for entry into the second year of a suitable Honours Degree course.

The minimum qualification for a senior rehabilitation worker with supervisory responsibilities would be the BSc (Hons) Rehabilitation Studies, a three year course provided by a university. Entrants could either: study relevant sciences in a common base first year, largely campus-based, or enter the second year having successfully attained NQF Level 5. The second and third Degree years would have substantial components of supervised practice in sensory service settings. This Honours Degree would be equivalent to Level 6 on the NQF and could be offered in full-time or part-time modes. It will be important to articulate the common ground between this Degree and the Social Work Degree, which has emerged as the minimum professional qualification for social workers, and there will be obvious opportunities for common base teaching of some subjects. In a similar spirit, it should be possible to offer the BSc (Hons) Rehabilitation

Studies as a professional qualification to practitioners working with deaf and hard of hearing people, through the provision of specialist electives and appropriate training placements.

Postgraduate courses should be provided by a university or a college in association with a university. The minimum requirement for entry would be NQF Level 5, the BSc Degree or a previous recognised qualification in rehabilitation. These courses would be tailored to the CPD needs of practitioners in specialist skills enhancement or organisational management. A Postgraduate Diploma would be awarded after one year (full time equivalent) of successful study. Outstanding candidates would also be offered the opportunity to complete a one year (full time equivalent) MSc in Rehabilitation Studies which would require an empirically based thesis. It would be an expectation that senior rehabilitation workers would pursue their education and training to at least a Postgraduate Diploma level in order to meet the continuous professional development requirements of professional registration.

It is anticipated that all existing qualifications such as those validated in conjunction with Guide Dogs and RNIB would continue to be recognised retrospectively. Holders of such qualifications would also be entitled to apply for the Postgraduate Diploma or Masters courses for the purpose of continued professional development. All new appointees to rehabilitation teams would be expected to have the new minimum qualifications appropriate to their area of work, or to acquire them within a time limit as part of their conditions of appointment.

It is timely, too, that a new Qualifications and Credit Framework (QCF) for the whole of the United Kingdom, based on cumulative units of learning, is currently being piloted and will take final shape before the end of 2008. Within this national framework, it should be possible for a flexible and progressive model of training for rehabilitation workers to establish itself.

The recommendations emerging from this policy paper should also be complementary to the work currently being undertaken by SfC&D in developing national occupation standards and a qualification strategy for the sensory services workforce throughout the United Kingdom.

In the early 1980s, the Government introduced national standards of

occupational competence in its desire to improve the effectiveness of British organisations. The Manpower Services Commission required these standards to be explicit, agreed, widely accessible, flexible, progressive and testable. Representative bodies were established to set effective standards appropriate to each sector and relevant to the current and future needs of the competent practitioner. Consequently, most industrial and professional sectors now have National Occupational Standards (NOS) agreed and in place. ([www.train4publishing.co.uk/content/occsta/intro.doc](http://www.train4publishing.co.uk/content/occsta/intro.doc))

**“The vision for 2020: CPD will be available to all, regardless of professional status or employer. Members of the workforce will be supported in developing skills and producing personal development plans which promote lifelong learning and career progression.”**  
*Options for Excellence*

NOS are organised into units of competence, each unit describing an area of work, with activities separated out into elements with appropriate performance criteria and knowledge base. There are different levels of standards which are used to benchmark and differentiate the skills, knowledge

and responsibilities associated with roles of varying complexity.

SfC&D is part of the Sector Skills Council which came into being in 2002, licensed by the Government, and works in consultation with 60,000 employers and 1.6 million practitioners and service users, with the aim of modernising adult social care in England. To achieve this, it seeks to ensure that qualifications and standards continually adapt to meet the changing needs of people who use the services, by the following methods:

- Developing national standards and a qualification framework for the adult social care sector;
- Collecting skills data and carrying out research;
- Establishing a national workforce development strategy;
- Building employer-led regional support networks.

The emergent Health and Social Care National Occupational Standards (NOS) are jointly owned by the alliance partners SfC&D and Skills for Health. Any reviews of NOS are undertaken jointly by all UK alliance partners. NOS reviews are carried out incrementally so that changes can be made responsively should any problems arise regarding the definition of specific standards. Currently, the skills and knowledge base of practitioners in rehabilitation have been subsumed within Level 2 of the SfC&D standards

framework which has evolved. However, national occupation standards for sensory impairment services specifically are still being developed.

As training courses which are mapped to national occupational standards have a greater chance of attracting external funding, it is obviously crucial that the recommendations in this policy paper are seen to be compatible with and complementary to the ongoing work of SfC&D. This being so, it is recommended that a steering group be established, including SfC&D, major organisations representing blind and partially sighted people, key institutions of further and higher education, and the Department for Innovation, Universities and Skills, to consolidate and expand training courses leading to rehabilitation qualifications which are consistent with agreed national occupational standards for rehabilitation workers at different levels of responsibility within the sensory services.

### **Options for Excellence**

It is gratifying that the concerns in this policy paper about developing a strong skilled workforce fully complement the aspirations of the Department of Health and the (then) Department of Education and Skills in the joint workforce review, Options for Excellence, published in 2006. ([www.dh.gov.uk/en/socialcare/workforce/DH\\_4131862](http://www.dh.gov.uk/en/socialcare/workforce/DH_4131862))

That report reflected a recognition that a vibrant and committed social care workforce is needed to deliver the aspirations outlined in a range of health and social policies. Setting the context, it described the diverse scope of the social care workforce in the form of 30,000 provider organisations, one third of the workforce being employed by local authorities and 62 per cent employed by the private and third sectors; the latter consisting of a wide range of large corporations, small local enterprises, not-for-profit voluntary organisations, self-employed carers and practitioners, and service users who have individual budgets or direct payments and in effect have become employers.

By the year 2020, the main characteristics of the social care workforce are anticipated as:

- Making full use of CPD;
- Being supported in the workplace whether as new entrants or new managers;
- Using personal development plans to engage in lifelong learning and career progression;
- Having a capacity for research in social care;
- Seeking improvements which are evidence-based;
- Integrating the views of users into workforce development priorities;

- Pursuing new ways of working;
- Using new technology to full benefit;
- Including social care assistants who have access to tailor-made workforce development;
- Having regular opportunities to improve leadership and management;
- Having the requisite commissioning skills to elicit essential elements of service from private or third sector organisations, while ensuring minimum quality standards;
- Having clear procedures for registration and accountability for all social care staff.

The inevitable caveat is included that some options would be dependent on funding being available.

Nonetheless, this is a positive vision for a purposeful and skilled workforce. Clearly some practitioners within social care such as qualified social workers are already a substantial distance down the road in realising these expectations. However, it is equally evident that rehabilitation workers, because of a lack of focus on their professional development needs in previous years, have to be given special priority in the deployment of resources and access to training opportunities to enable them to deliver the outcome-based services of consistently high quality that are required.

## Registration and the creation of a professional body

There have been repeated calls for registration of rehabilitation workers, on the basis that this would more clearly delineate their areas of professional work and expertise and assist in future resource planning. The number of qualified workers required annually across the UK could then be more easily defined. Service users would also benefit from the clarity of role definition which would emerge. They would have access to 'one-stop shop' services of a guaranteed quality.

**“Registration of the workforce was also perceived as important to provide a proper reassurance to the public that people not fit to practice would not be allowed to. Registration also reassures the public that staff have an appropriate qualification for the job they do and that they are continually challenged to improve.”**

*Dame Denise Platt, The Status of Social Care – A Review 2007*

The General Social Care Council is responsible for registering people who work in social services in England and regulating their education and training. Its role is to increase the protection of people who use social services, to raise standards of practice and to increase public confidence in the sector

([www.gsccl.org.uk](http://www.gsccl.org.uk)). The register of social workers in England opened on 1 April 2003 and protection of title came into force two years later, on 1 April 2005.

Determination of sensory service workforce skills needs, training place quotas and human resource planning and deployment relating to rehabilitation workers are likely to come within the ambit of SfC&D in the future. However, it remains to be determined how and when a register of rehabilitation workers will be created which will have the same beneficial effects as in the social work profession. This being so, the feasibility of establishing a specific professional body for rehabilitation workers which would be responsible for setting registration criteria should be investigated further, in collaboration with SfC&D.

## Budget and resource implications

The proposals for a Middle Step as part of a continuum of integrated multi-disciplinary services would, of course, have to be underpinned by a coherent planning strategy for the future of effective rehabilitation services and workforce.

It is clear that if services, including workforce issues, are to be effective and develop to meet the growing needs of blind and partially sighted people, then they need to be given a certain level of priority within local planning frameworks and processes.

Resourcing priorities must include: workforce planning; the continued development of effective multi-agency working; creation of a clear framework for assessing need and unmet need that includes both quantitative and qualitative outcome indicators; a formal statement of purpose that includes a list of key elements of service provision; involvement of all stakeholders, including voluntary organisations and service users in ongoing consultation; establishment of an equipment policy; and identification of a recurrent budget specifically for specialist equipment.

Within England the voluntary sector plays a vital role in the delivery of rehabilitation services to blind and partially sighted people, with many local authorities commissioning service provision from local societies. (Examples can be found at [www.nalsvi.cswebsites.org](http://www.nalsvi.cswebsites.org).) The voluntary sector needs to be properly funded with full cost recovery for those services commissioned. Unlike much of current reported practice, there should be no hidden subsidies. It is noteworthy that the principles outlined in the Compact between Government and the third sector include an acknowledgement of the importance of the true cost being identified and met in any collaboration.

### **The case for change – towards a Green Paper**

It is acknowledged that the investment in the potential of blind and partially sighted

adults for which this paper is arguing is competing with other priorities.

The review conducted by Sir Derek Wanless referred to in Chapter 2 confirmed what most commentators had already been saying for some time. Demand for health and social care is set to continue to outpace the financial resources that fund it, despite increased investment in this sector. It was no surprise, therefore, when the Government announced its intention in 2007 to publish a Green Paper to consider further reform of the social care system, with an emphasis on independence, choice and control on the part of the users of the services, but also society's views on future financing arrangements for care. The Green Paper is probably due in early 2009 but an open debate which will inform its content has already begun with publication of 'The case for change – Why England needs a new care and support system'. This document invites views on a number of key questions:

What more do we need to do to make our vision of independence, choice and control a reality?

What should the balance of responsibility be between the family, the individual and the Government?

Should the system be the same for everybody or should we consider varying the ways we allocate

Government funding according to certain principles?

Should there be one system for everyone or different systems depending on the type of need for care and support that somebody has?

Which is more important to us: local flexibility or national consistency?

What should the balance be between targeting Government resources at those who are least able to pay and having a system that supports those who plan and save?

The consultation takes place until November 2008, and the debate will inform Government plans for the funding arrangements for adult social care.

### **Government commitment to improving life chances**

A joint interdepartmental report issued in 2005 through the Prime Minister's Strategy Unit, called 'Improving the life chances of disabled people', seemed to be a heartening signal of the Government's commitment to ensuring improvements in the quality of life of disabled people. It set a target that by 2025 disabled people in Britain should have full opportunities and choices to improve their quality of life and be respected and included as equal members of society. Practical measures were outlined to make this possible:

- Helping disabled people to achieve independent living by moving progressively to individual budgets in the form of cash and/or direct provision of services.
- Improving support for families with young disabled children.
- Facilitating a smooth transition into adulthood by putting in place improved mechanisms for effective planning for that transition.
- Improving support and incentives for getting and staying in employment by ensuring that support is available well before a benefit claim is made; reforming the gateway to benefit entitlements; and providing effective work-focused training for disabled people.

### **Independent Living: A cross-Government strategy about independent living for disabled people**

This initiative has been driven forward by the Office for Disability Issues (ODI), which commenced a consultative process in July 2006 during which the views of disabled people were sought in some depth. Subsequently, in March 2008, a five year plan was published entitled 'Independent Living: A cross-Government strategy about independent living for disabled people'.

Its statement of aims outlined the Government's commitment:

“The Government wants every locality to have a single community based support system which focuses on all aspects of what people need to maximise their health and well-being and to participate in family and community life. The right of the individual disabled person to determine the kinds of services and support that they need will be at the heart of this reformed system.”

In practice, the objectives of the five year strategy will be a vital part of the realisation of the 2025 vision of full and equal partnership. In essence, it is hoped that disabled people will have more choice and control over the ways in which their needs for support and equipment are met. The strategy expresses a determination to tackle barriers to access to health, social care, housing, transport, education and employment opportunities. In doing so, the Government wishes to respond to the criticism in the consultation feedback and close the gap between its policy formulation and the real experiences of disabled people. Targets have been set to address a wide range of issues, including:

- Transition to adulthood – through support programmes, post-16 learning packages, and piloting of individual budgets.
- Transport – through accessibility

planning in local transport plans, more participation of disabled people in policy development and implementation, confidence training in the use of transport, and training for transport providers in the needs of disabled people.

- Housing – through improvement in the Disabled Facilities Grants System, adherence to Lifetime Homes Standards in all new housing construction by 2013, and promoting the adoption of accessible housing registers.
- Employment – through a cross-Government national strategy in job retention, and a review of the Disability Living Allowance and Attendance Allowance to foster greater independent living.
- Personalisation – through individual budgets and direct payments, and investment in early intervention and preventative measures.
- Advocacy and brokerage – through better representation of views and training in communication skills.
- Older people – through, in particular, one-stop information resources on independent living for the benefit of older people at national, regional and local level. A regional initiative will consider investment in independent living for older people in residential/nursing care or at risk of moving into care.

- Family – through improvement in preventative support for parents and children.

**“While our politicians have adopted the language of the Independent Living Movement, users receiving services are lucky to get anything extending beyond being washed and fed.”**

*Baroness Jane Campbell,  
The Guardian 30 April 2008*

There will be a strengthening of the evidence base to inform future policy development and investment, and illustrate the best ways to promote choice and control within available resources.

Concern has been expressed by RADAR about the absence of any definite legislative change. Instead, the strategy states that:

“...the Government considers that there should be no change to primary legislation unless the current legislative framework poses insurmountable barriers to implementing current policy...”

(Independent Living, 2008)

It is intended that the strategy will be reviewed annually over the five year period in the form of an ODI report to the Life Chances Ministerial Group. This group will appraise the effectiveness of delivery of these objectives before the

completion of the next Comprehensive Spending Review 2011-2014. The need for legislation will be reviewed if it is concluded that insufficient progress has been made in meeting targets by 2013.

### **Disabled Persons (Independent Living) Bill**

In 2006 Lord Ashley of Stoke introduced a Private Member’s Bill to the House of Lords with intentions that are similar to the cross-Government Independent Living Strategy but on a formal legislative basis. On 22 March 2007 Lord Ashley accepted an amendment to include a right for blind and partially sighted people to receive rehabilitation skills training. Clause 14 (3) (b) (i) includes the right to the provision of mobility training, communication skills training, low vision training and equipment.

The Bill has been through the House of Lords on two occasions and the ‘Our Lives, Our Choices’ coalition (which is supported by RPG member organisations) continues to campaign for its adoption. However, despite intensive lobbying, the Bill has failed to receive a Second Reading in the House of Commons and is unlikely to become law in the 2008 parliamentary session. It has become increasingly clear that the Bill is unlikely to gain the endorsement of the Government, which seems to have chosen instead to pursue its own Independent Living Strategy.



## Postscript

In this modern era, all citizens have fundamental rights to equality of opportunity and a reasonable quality of life. These rights are enshrined in the European Convention and incorporated in our domestic legislation.

One of the most significant opportunities for any human being is the development of personal potential to the full. Society as a whole benefits when all its citizens are afforded such opportunities. It is timely therefore for policy-makers and planners to address the unmet needs of blind and partially sighted people in England so that they can fully participate in and enrich their communities.

This will require specific budget allocation, deployment of skilled practitioners in Middle Step services as part of the integrated health and social framework, and the initiation of a variety of professional training courses in rehabilitation. The benchmarks for evaluation of progress after, say, 10 years, should be the requirements of the Equality and Human Rights Commission (EHRC).

The reward for this investment will be a healthier society which can truly claim that it celebrates social diversity and enables its blind and partially sighted citizens to reach their full potential.

## Appendix A

# United Nations Convention on the Rights of Persons with Disabilities (2006)

Principles underpinning the United Nations Convention (2006) on the Rights of Persons with Disabilities are as follows:

- Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons.
- Non-discrimination.
- Full and effective participation and inclusion in society.
- Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity.
- Equality of opportunity.
- Accessibility.
- Equality between men and women.
- Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

Under its general obligations, States are obliged to take all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities. States are also exhorted to consult with and actively involve disabled people, including children with disabilities, through their representative organisations.

The Convention calls for States to take measures to ensure access on an equal basis to transport, information and communications, technologies and systems, and other facilities open or provided to the public, and identification and removal of obstacles or barriers to accessibility.

Disabled people should be recognised as having equal rights to live in the community with full enjoyment of amenities and full inclusion and participation. Intrinsic in participation should be the facilitating of personal mobility in the manner and at the time

of their choice, and at affordable cost. Access should also be possible to quality mobility aids, devices, assistive technologies and technical support, again at affordable cost. There should also be an inclusive education system at all levels and lifelong learning directed to the full development of human potential and sense of dignity and self-worth. With regard to health, access should be ensured to health services that are gender-sensitive, including rehabilitation. Early identification and intervention as appropriate should be provided, with services designed to minimise and prevent further disabilities, among both children and older persons. Health services should be as close as possible to people's own communities, including in rural areas.

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