



information on eye care and vision
for people with learning disabilities

www.lookupinfo.org

Collected research on eye care and visual impairment in adults with learning disabilities

This document was previously available via RNIB Information & Practice Development Service on Multiple Disability. We are often asked for reports and statistical information about adults with visual and learning disabilities. This is a short collection of material which may be helpful. The statistical information in this document refers to information current to 2001 – we will be adding to this information in due course.

Please note: We have **not** edited this material, except in **Registered blind and partially sighted people year ending 31 March 2000, Department of Health, January 2001 (page 8 and pages 32 - 41)**, where only part of the tables have been included.

Registered blind and partially sighted people year ending 31 March 2000, Department of Health, January 2001 (page 8 and pages 32 - 41)

Data reliability

10. The statistics relating to blind persons who have an additional disability is likely to understate the true numbers, especially in respect of those aged under 16.
11. Because of the difficulties described above, the statistics in this report should be used and interpreted with care.

Table B3 Number of registered blind people with an additional disability by category of disability (1)

England, as at 31 March 2000

| Area | Total | Learning disabilities only | Learning disabilities and other disabilities |
|--------------------------|--------------|-----------------------------------|---|
| England | 25,070 | 1,468 | 600 |
| North East | 1,102 | 97 | 21 |
| North West | 3,308 | 156 | 84 |
| Merseyside | 705 | 26 | 17 |
| Yorkshire and the Humber | 3,597 | 230 | 60 |
| East Midlands | 987 | 92 | 29 |
| West Midlands | 1,775 | 123 | 41 |
| South West | 4,537 | 182 | 131 |
| Eastern | 3,383 | 251 | 130 |
| London | 2,702 | 96 | 36 |
| South East | 1,927 | 217 | 51 |

Source: SSDA 902

(1) England total will not agree with Table B4 as some authorities were able to provide disability totals but not age breakdowns.

Table B4 Number of blind people registered who have disabilities by age group (1)

England, as at 31 March 2000

| | Blind people registered with additional disabilities who are aged: | | |
|---------|---|----------------|-------------------|
| | All ages | 18 - 64 | 65 or over |
| England | 23,990 | 4,970 | 18,390 |

Source: SSDA 902

(1) England total will not agree with Table B3 as some authorities were able to provide disability totals but not age breakdowns.

A report about services from 1996 to 1999 for people with learning disabilities from the Service Planning and Research Database 2000, Swindon Borough Council / Wiltshire and Swindon Health Care NHS Trust (page 42 - 43, and 61)

Eye care

Eyes tested in the last year in England:

| People with Learning Disabilities in England, Centre for Disability Research, May 2008 | |
|---|-----|
| • Mild or moderate | 51% |
| • Severe | 55% |
| • Profound and multiple | 41% |
| • All people | 52% |

The number of adults who have their eyes checked with an Optician has gone up over the last few years. In 1999, 4 out of 10 adults regularly got their eyes checked. That is 43%.

The same is for children aged 14 to 17 years. Nearly 5 out of 10 (49%) children had their eyes regularly checked by an Optician. 57% of adults do not have their eyes checked, that is 348 people. This number includes people who are registered partially sighted or blind. It is important for everyone to have regular eye checks.

These are the age groups of people who don't go to the Opticians:

- 163 people are aged between 31 and 50 years (47%)
- 139 people are aged between 18 and 30 years (40%)
- 46 people are aged 51 and over (13%)

In 1999 the number of children aged 14 to 17 years and adults who wore glasses went up to 16 children and 242 adults. That is 28% of children and 39% of adults. But 1 in 4 people who have glasses do not wear them.

Out of the adults who wear glasses there are 114 people who have not had their eyes checked in the last 3 years. (47%). Over half of these people are aged 40 or under.

Children aged 14 to 17 - since 1997 the number of children who were either partially sighted or registered blind has doubled each year. 3% in 1997 to 12% in 1999.

The biggest rise has been the number of children who are registered blind. In 1997 there were 2 children and in 1999 there were 5 children.

Adults - since 1997 the number of adults who were either partially sighted or registered blind has got bigger each year. 7% in 1997 to 9% in 1999.

The biggest rise has been in the number of adults who are registered as partially sighted. In 1997 there were 23 adults and in 1999 there were 31 adults.

Table 31 Eye care for adults 1997 to 1999

| | 1997 | | 1998 | | 1999 | |
|---|-------------|-----|-------------|-----|-------------|-----|
| Total number of adults each year | 571 | | 576 | | 614 | |
| Regularly see an Optician | 194 | 34% | 216 | 38% | 266 | 43% |
| Have visual problems | 208 | 36% | 211 | 37% | 231 | 38% |
| Wear glasses | 199 | 35% | 214 | 37% | 242 | 39% |
| Are registered partially sighted or blind | 36 | 6% | 37 | 6% | 35 | 6% |

Recording in detail started in 1997

Community Care, issue 25 February - 3 March 1999

Incidence of learning difficulties

| People with a learning difficulty per 100,000 of population | |
|---|-------------|
| • with a mild learning difficulty | 2,000 |
| • with a moderate/severe learning difficulty | 300 - 400 |
| • with significant challenging behaviour | 115 - 360 |
| • with additional mental health problems | 115 - 1,200 |
| • with impaired sight | 690 - 720 |
| • with impaired hearing | 920 - 960 |
| • with epilepsy | 230 - 260 |
| • with cerebral palsy | 230 - 260 |

Source: Department of Health, 1998

The NHS - Health for all? People with learning disabilities and health care, a Mencap report (June 1998)

Chapter 1 Primary health care

1.11 Optometrist

1.11.1 Eye Health and people with learning disabilities

People with learning disabilities are known to be more likely to have sight problems, particularly people with Down's syndrome or Cerebral Palsy, with a reported incidence of 63% in one study (Lavis 1994). As people with learning disabilities are living longer, they are also developing visual problems as part of the usual ageing process.

Undetected sight problems can lead to a lack of confidence, impaired ability to communicate, difficulty moving about, disturbed behaviour and may eventually lead to blindness. Levy (1996) notes neglect of the sight and hearing of people with learning disabilities through lack of awareness and inadequate testing.

Early detection can minimise the problems, and increase the chance of the person coping with glasses if needed:

'My daughter was not tested until she was 11 years old, and now she does not feel the need to wear glasses'.

Optometrists may be unwilling to prescribe glasses to someone with a learning disability who they think may not wear them. It is possible to support people to get used to glasses, and clinically the impact can be enormous. Improved vision is also known to enhance learning.

While some people with learning disabilities may be able to use a high street optometrist, it is clear that others will need to access specialist services, usually hospital-based. For the sake of continuity, both are discussed in this section.

1.11.2 Optometrists and people with learning disabilities

The survey of optometrists showed that, for the majority, people with learning disabilities constitute less than 1% of their work load. One in eight had received some training in learning disability, mostly post-qualification, though over half would welcome further training, particularly in communication and learning disability. This is being developed by some local optical committees. Most are unaware of local services for people with learning disabilities, including the community learning disability team.

It is not surprising, then, that there was variable awareness amongst optometrists in the survey, of the particular eye conditions which can threaten the sight and health of people with learning disabilities. More than half thought there were not specific visual conditions associated with learning disability, and only 5% were able to name some of them. The adaptations to practise made by optometrists were: the use of more objective methods, clear language and taking more time, though no-one seemed to have access to different test cards. These are a considerable expense for practices, and are more likely to be found in a hospital practice.

Most of the optometrists surveyed thought that the health care of people with learning disabilities, though vastly improved, fell below that of the general population, through lack of time and lack of appropriate services. A support service to facilitate eye examinations was thought to have some value.

1.11.3 Visits to the optometrist

53% of people with learning disabilities have not had a sight test in the last two years, either at a 'High Street' optometrist or with a specialist, though 57% recorded wearing glasses. Again, people living more independently seem to attend to their health less: 62% of those living alone had not made a visit to the optometrist in the last year.

As with other health services, the survey found a difference in access according to the age of people with learning disabilities, recording higher sight testing rates for those 19 years old or younger. 69% of those not attending for a sight test are 40 years or over - the general recommended age for sight testing every two years. People commented on a lack of publicity about the importance of eye tests and how to obtain them.

1.11.4 Optometrists, waiting areas

One in 10 carers said that the optometrist waiting area presented difficulties for the person they support, whether through hazards, lack of space or something to pass the time.

1.11.5 Optometrist communication

In terms of communication with their patients with a learning disability, it seems that optometrists are somewhere between doctors and dentists in talking to the person they are examining - 30% of carers responded positively. As well as creating a rapport with the person for the purposes of the test, the optometrist needs to gain information about their lifestyle and visual functioning, usefully supplemented by the carer. 50% of carers said that the optometrist talked to them and the person they support.

However, one in 10 thought that optometrists explained poorly or inadequately. Service users said how hard it was to understand the optometrist, because they talked too fast, too much, and in difficult language:

'If they listened to the carer they would know the best way to ask questions'.

Optometrists themselves said they are often worried that the information they are trying to convey has not been understood, and usually rely on carers to facilitate, while recognising the need for more training and more time.

Going to the optometrist is a less frequent occurrence than many other health checks, so there is less opportunity for both parties to become familiar with each other. Those people surveyed suggest optometrists should gain a better understanding of learning disabilities during training, as well as giving better explanations, working on their communication with the person and taking time. Optometrists would value information before the appointment about the person's vision and how the examination is likely to proceed.

1.11.6 Sight testing strategy

The survey found around 50% of people with learning disabilities cannot identify the alphabet and so are unable to participate in a sight test in the usual way.

Although some named alternative sight-testing strategies - including techniques usually available at specialist centres - there were others who said there had been no accurate assessment or that the assessment was approximate. It may be that the practitioner is doing the best they can with the equipment they have, but carers lack the understanding of how tests work to be convinced of the result:

'I'm not sure how valuable the test was as my son does not have a means of communication'.

'There needs to be a follow-up to see that the glasses are right for the person'.

Optometrists and carers need to be aware of the specialist vision assessment services they can access, where comprehensive testing can be carried out. Optometrists also noted the value of carers preparing someone for what is to happen at the appointment.

Signposts for success in commissioning and providing health services for people with learning disabilities, Dr Mary Lindsey, NHS Executive, (January 1998, page 98).

Sensory disabilities

- About 30% of people with learning disabilities have a significant impairment of sight and 40% have significant hearing problems. The prevalence of these problems increase with age. Sometimes both are present resulting in a complex disability.
- Sometimes these impairments progress over time.
- There is a very high rate of under-detection of sensory impairments, most of which can be treated.
- Sensory disabilities are often associated with challenging behaviour.

Prescription for Change, a Mencap report on the role of GPs and carers in the provision of primary care for older people with learning disabilities, June 1997.

Chapter 2 The health of people with learning disabilities

The following tables show how long ago unpaid and paid carers in the survey estimated that the person they care for received a sight test.

| Unpaid carers, estimate of the last time the person they care for received a sight test | |
|--|-----|
| In the past 12 months | 60% |
| Over 1 year and under 3 years | 13% |
| Over 3 years and under 5 years | 4% |
| Over 5 years and under 10 years | 9% |
| Over 10 years ago | 9% |
| Never | 5% |

| Paid carers, estimate of the last time the person they care for received a sight test | % |
|--|----------|
| In the past 12 months | 62% |
| Over 1 year and under 3 years | 21% |
| Over 3 years and under 5 years | 11% |
| Over 5 years and under 10 years | 3% |
| Over 10 years ago | 3% |

The tables show a similar trend to that of health checks and hearing tests but a much larger proportion of people with learning disabilities are receiving more frequent sight tests. Almost three-quarters (73%) of people living at home with their family and in residential care had received a sight test in the past 3 years. However, whilst 14% of people living with their families had either never received a sight test or it had been over 10 years since the last one took place, this was the case for only 3% of those living in residential care.

An explanation for the higher levels of sight tests compared to hearing tests may be the greater availability and easier access to tests, particularly with the growth of high street opticians in recent years. Research by Wilson & Haire (1990) also found a lack of sight tests. In a sample of 75 people attending a day centre, 42 had not had their medication reviewed for over 5 years.

The vast majority of carers, 92% of unpaid and 91% of paid, thought that people with learning disabilities should receive regular hearing and sight tests. However the results have shown that not as many people with learning disabilities benefit from this belief amongst their own carers.

Previous research indicates that many people with learning disabilities have undetected illnesses or medical conditions. This may be the result of the lack of communication between people with learning disabilities and their carers or professionals in the field of primary or secondary health. Wilson & Haire (1990), for example, found in their survey that 44% of people with learning disabilities failed an eye test, including those who were already wearing spectacles.

A research review by Turner & Moss (1996) highlights the variety of studies that have indicated a high prevalence of vision problems among people with learning disabilities (Aitchinson et al 1990; Jaworski 1993). Children with Down's syndrome show a high incidence of vision and hearing problems, and deterioration of vision and hearing during adulthood is likely (Pueschel & Gieswein 1993). Hearing problems are also common, both because of congenital abnormalities and chronic or recurrent conditions such as otitis media (Hagerman et al 1987) or impacted earwax (Brister et al 1986). Crandell & Roeser (1983) report a prevalence of conductive hearing loss of 28%, compared with 2 - 6% in the general population. In a Danish study, Parving and Christensen (1990) reported a prevalence of 33 - 40% of defective hearing, largely uncorrected, among people with learning disabilities living at home.

The Health of People with Learning Disability - Steve Moss and Steve Turner, Hester Adrian Research Centre, University of Manchester (1996)

Vision and Hearing p.17

Vision problems in the Down's syndrome and fragile X syndrome populations have been reviewed and the high prevalence of problems in these groups is reflected in studies of the learning disabilities population as a whole. Aitchinson et al (1990) found that 59% of 367 patients in two mental handicap hospitals in Bristol, England, had one or more eye abnormalities, and this figure only reduced to 54% when the Down's syndrome group were excluded. Jaworeski (1993) reports that exposure corneal disease (keratopathy) due to incomplete blinking was a significant problem among people with learning disabilities, affecting 18% of 210 patients.

In a Danish study, Parving and Christensen (1990) report a prevalence of 33 to 0% of defective hearing among people with learning disabilities living at home. Of the 17% judged to require a hearing aid, none were using one. Two US studies report a high level of conductive hearing loss due to impacted earwax among adolescents and adults with learning disabilities (Brister et al, 1986; Crandell and Roeser, 1983). In the latter study, prevalence of conductive hearing loss due to this cause was 28%, compared with 2 - 6 % in the general population.

Learning Disabilities: The Fundamental Facts, Mental Health Foundation 1996

Learning Disabilities in the UK

Official figures on the extent of learning disabilities in the UK population are virtually non-existent. The most reliable information is derived from locally-based case registers which are combined to estimate figures for the population as a whole.

Learning disabilities affect all social classes and all races. It is estimated that 2% of the UK population - over 1 million people - have learning disabilities. The majority of these are mild. Less than half of these individuals will ever have been identified by educational or other authorities as suffering impaired intellectual ability. For the purposes of this report we shall concentrate on those with more severe conditions.

Recent research suggests that in every 100 consecutive live births, up to six babies are born with severe learning disabilities. This approximates to 4500 births in the UK. This figure appears to have remained relatively constant since the 1960s although it hides the fact that the declining incidence of some conditions (due to better prevention) has been off-set by increasing survival rates for babies with Down's syndrome.

Within the general population (all ages) it is estimated that 4 in 1000 people - over 200,000 - have severe learning disabilities of whom approximately 50,000 are under 16. Proportionately more males (54%) than females (46%) are affected. By comparison, the sex ratio of men to women in the UK is 49.51%.

Studies suggest that up to 25% of those with severe learning disabilities are profoundly affected, often with multiple disorders, for whom the availability of expert and intensive care is essential at all times.

Who do learning disabilities affect?

| UK Population | Males | Females |
|---|-------|---------|
| 57m | 54% | 46% |
| 200,000 people have severe learning disabilities 50,000 are under 16 25% are profoundly affected | | |
| 793,000 live births in the UK in 1991 4,500 babies born with severe impairments of mind - 6 in 1,000 | | |

2 in 100 people in the UK have learning disabilities, the majority mild. 4 in 1000 are severely affected, of whom 1 in 4 are children under 16. 54% of people with learning disabilities are male, 46% female. 4,500 babies were born with severe impairments of mind in 1991.

Sensory impairment project 1993 - 1997, Invicta Community Care (NHS) Trust, Phase I: Jane Frankel and Brenda Halls, Phase 2: Francis D. Harvey, pages 7 - 9 and pages 31 - 42

Background:

Visual impairment

In a study of 2,421 people with an IQ of less than 50 Mittler and Preddy (1981) found a prevalence of 4.6% blind and 11.0% partially sighted. Mitchell and Woodthorpe (1981) studied 282 people with an IQ of less than 50 or who were in receipt of "mental handicap services" and found a prevalence of 5.4% blind and 9.6% partially sighted. Ellis (1982) surveyed 30,020 people with a learning disability living in National Health Service residences using a functional questionnaire. Ellis found a prevalence of 3.6% blind and 4.4% partially sighted.

Hearing loss in people with a learning disability

Brannan, Sigelman and Bensberg (1975) conducted a postal survey of 111 institutions in Maryland US with a total population of 98,034 people. 19% of this population were found to have some degree of hearing loss with 9.5% being classified with hearing impairment, 7.2% classified as hard of hearing and 2.3% classified as deaf.

A similar postal survey in the UK (Kropka, Williams and Clements 1984) was circulated to all National Health Service Hospitals and Hostels in England and Wales and generated a response of 18,657 people (approximately one third of the potential population). 21.4% of this population were found to have some degree of hearing loss with 10.7% classified as hearing impaired, 3.4% classified as deaf and 7.3% classified as partially hearing.

Hearing impairment levels for people with a learning disability living in the community can be gathered from the mental handicap registers for England and Wales. In a review of these registers Kropka and Williams (1986) give a range of 3.1% to 10.1%, the average being 6.1% which is lower than the prevalence found within NHS residential establishments.

In a sample of 300 people in Lewisham, Yeates (1992) found a prevalence of hearing loss sufficient to require amplification for 39.6% of the sample.

Dual sensory loss

In a review of five Mental Handicap Registers across England and Wales, Ellis (1986) identifies a broad categorising of sensory loss into blind, partially sighted, deaf and partially hearing and finds that "between one quarter and one third of clients with hearing handicaps also have visual handicaps".

A survey carried out for the charity SENSE (National Deaf-Blind and Rubella Handicapped Association) by Best (1982) identified a group of 288 deaf blind children being educated in schools dedicated to learning disability. More than half of the group were partially sighted and partially hearing with one in ten being profoundly deaf and blind.

Some of the findings of project:

Audiology assessment

A total of 109 people completed audiological assessment, although it was not possible to obtain recordable results for three of these people. A total of six

hearing aids were prescribed as a result of the ENT and Audiology assessments.

Table 8 Audiological assessment

| | Number of people |
|---|-------------------------|
| Satisfactory completion of standard Audiological testing | 85 |
| Further testing required for Brain Stem Evoked Response without anaesthetic | 5 |
| Further testing required for Brain Stem Evoked Response under general anaesthetic | 16 |
| Unable to obtain satisfactory audiology assessment | 3 |
| BSER recommended but unable to complete due to ill health | 2 |
| Failure to complete BSER test due to lack of consent | 1 |
| Failure to attend for audiological examination | 1 |

Ophthalmology assessment

Ophthalmology assessments were carried out by two Optometrists from the Kent County Ophthalmic and Aural Hospital over the timescale of the project.....Identified ophthalmic pathologies and conditions (which are not mutually exclusive) were as follows:

Table 10 Ophthalmic pathologies and conditions

| Condition | Number of clients |
|------------------------------|--------------------------|
| Cataracts | 14 |
| Glaucoma | 2 |
| Corneal scarring | 2 |
| Proptosis | 1 |
| Posterior capsule thickening | 1 |
| Optic Atrophy | 5 |
| Immature Development | 1 |
| Nystagmus | 3 |
| Retrolental Fibroplasia | 1 |
| Convergent Squint | 14 |
| Divergent Squint | 22 |
| Alternative Squint | 10 |
| Tunnel Vision | 2 |

At the commencement of the project, eight people of the sample were registered blind and four of the sample registered partially sighted. Through the screening processes of the study, a further five people were registered blind and a further four people registered partially sighted.

Several people were issued with spectacles as a result of ophthalmic assessment. In total, 32 people were in possession of glasses at their initial assessment, of whom seven people required a new prescription for lenses. 15 people were prescribed and issued with glasses where they had not worn these before and a further three people were recommended for glasses but chose to consider for this period. In these cases, the client was given a written record of their suggested prescription.

Dual sensory loss

Dual sensory loss was determined when an individual was assessed as having a moderate or greater visual loss in both or their worst eye as well as a moderate or greater hearing loss in both or their worst ear.

The number of clients gaining successful assessments for both vision and hearing were 100, and of these people the following levels of dual and sensory loss were found:

Table 14 Levels of single and dual sensory loss

| Level of sensory loss | Number of people | % of population |
|-----------------------|------------------|-----------------|
| No impairment | 30 | 30 |
| Visual loss only | 44 | 44 |
| Hearing loss only | 9 | 9 |
| Dual sensory loss | 17 | 17 |

Table 15 Levels of sensory loss by residence

| | No sensory impairment | Visual loss only | Hearing loss only | Dual sensory loss |
|-----------------------|-----------------------|------------------|-------------------|-------------------|
| MPCT residential | 13 | 16 | 3 | 9 |
| MPCT home support | 2 | 8 | - | 2 |
| Private and voluntary | 11 | 17 | 5 | 5 |
| Living alone | 2 | 3 | - | - |
| Living with family | 1 | 1 | 1 | 1 |

Primary health care for people with a learning disability: a keynote review.

Mike Kerr, William Fraser and David Felce, Welsh Centre for Learning Disabilities, University of Wales College of Medicine, Cardiff, British Journal of Learning Disabilities Vol. 24 (1996), p.3.

People with severe learning disabilities have high levels of specific organic impairments and other diseases (see below). Sensory impairment is common. The OPCS (1988) showed that 48% of people with a learning disability have impairment in one sensory domain and 18% are doubly impaired.

Prevalence of medical conditions commonly seen in people with a learning disability, a keynote review*.

| Condition | Average Occurrence | Range of occurrence |
|----------------------|---------------------------|----------------------------|
| Sight Problems | 40% | 23-57% |
| Hearing problems | 25% | 5-60% |
| Dental disease | 20% | 11-29% |
| Epilepsy | 20% | 16-34% |
| Psychiatric problems | 12% | 10-14% |
| Behavioural problems | ** | 17-56% |

* Compiled from a range of surveys worldwide.

** No figure is given due to variation in definition between studies.

Investigating the needs of people with a learning disability and visual impairment

Ann Lewis, Development Officer at Kent Association for the Blind, Focus 15 p.17/18 June 1995

Ann Lewis' project was to identify and promote the needs of people with visual and learning disabilities. The 'target group' were people who had an identified visual impairment and people whose visual ability was unknown - usually because no-one had assessed their sight recently. 300 adults attending day centres were surveyed. It was found that only 46% had regular sight tests.

The report found a high level of un-met need - people whose lives might have been substantially different if they had received appropriate help:

- 14% of people had a visual impairment, which was sufficiently severe to make them eligible for registration as blind or partially sighted, and entitled to benefits and concessions
- some people were not registrable but had a significant degree of visual loss which affected their daily lives
- almost 25% of people with a visual impairment were identified as having some degree of hearing loss.

A total of 148 students were prescribed glasses to correct a refractive error (short sight, long sight and astigmatism). This represents 56% of the survey:

- 50% were to wear spectacles at all times
- 3% were prescribed two pairs of spectacles - for close work and distance
- 4% of wearers were prescribed specs for distance only
- 40% of wearers were prescribed specs for close work only
- 1% of wearers are querying their spectacle prescription as the benefits are not apparent
- 2% of people prescribed spectacles refuse to wear them.

Di Lavis, Advisor for Sensory Impairment - North Warwickshire NHS Trust

One step ahead: Aspects of sensory impairment and the ageing process, Focus 13, p.1/2 September 1994

Life expectancy for people with learning difficulties has increased considerably over the past 50 years. Records show that in the period between 1930 and 1980 life expectancy has risen from an average of 18.5 to 59 years. The survival rate for people with Down's syndrome is particularly dramatic - having risen from a life expectancy of 9 years in 1929 to 54 in the period 1976 to 1980.

Learning disabled adults living at Brooklands, a 'treatment facility' for 150 people in North Warwickshire, were surveyed.

After full audiological and ophthalmic assessment, 43% of service users over the age of 50 had significant deafness and the majority of the remainder had 'functionally adequate' rather than acute hearing.

A further 63% were found to have visual perceptual difficulties; cataracts were the commonest cause representing two thirds of those with sight loss. A total of 19% of people had both sight and hearing loss.

The Prevalence of Cerebral Visual Disturbance in Children with Cerebral Palsy

An article from A.J.F Schenk-Rootlieb et al (1992), Developmental Medicine and Child Neurology, Volume 34: 473 - 480.

Ophthalmological examination of children with cerebral palsy often reveals disturbances in eye movements such as squint and tracking defects. Abnormalities in refraction are also frequently seen. The present study sought to discover whether deficits in the visual acuity of a large group of children with cerebral palsy were due to these sorts of problems or instead might be related to neurological deficits in the area of the brain responsible for vision.....Analysis of results showed that 71 per cent of patients had low

visual acuity, but only a small proportion of the visual defects could be explained by ophthalmological abnormalities. It was concluded that approximately 84 per cent of the cases of low visual acuity probably represented cerebral visual disturbance. The authors suggest that awareness of visual disability is essential when compiling programmes of visual stimulation for children with cerebral palsy.

Primary Care for People with A Mental Handicap - report of Working Party on the Interface between the Primary Care Team and People with a Mental Handicap.

Occasional Paper 47 published by The Royal College of General Practitioners - London, November 1990.

Chapter 3 - The Medical Needs of Adults, Martin Barker, FRCGP and Gwyn Howells, RD, MRCGP

Sensory Impairment

It is important to prevent the development of secondary handicaps; because mentally handicapped people are in a continuing learning situation, sight and hearing tests are particularly important. The incidence of visual problems is increased in this group; as many as 30% - 40% may have refractive errors. The prevalence of cataract, glaucoma and squint falls within the range of the normal in non-specific mental handicap, though in Down's syndrome the prevalence of visual problems is extremely high. Apart from an increased prevalence of minor problems such as wax and otitis externa, as many as 60% - 70% of these patients will have measurable hearing loss and many will be amenable to correction by the use of hearing aids.

Chapter 7 - Down's syndrome and the General Practitioner, Gwyn Howells, RD, MRCGP

Sensory Impairment

Impairment of hearing and/or vision can lead to an erroneous diagnosis of mental handicap even in normal children. It is not surprising then that in Down's syndrome such impairments, which occur with alarming frequency, can lead to a gross distortion in the perceived potential of an affected individual. Furthermore, unrecognised deafness may result in behavioural disorders or even apparent psychotic features, especially among those with a poor level of communication.

Common eye problems

Virtually all adults and children with Down's syndrome suffer problems relating to the eyes, but fortunately many of these are amenable to treatment. Blepharitis occurs frequently and may be the result of an abnormality of the tears (Allerhand et al, 1963).

Constant rubbing of the eyes often produces ectropion, entropion and trichiasis. Frequent gentle cleansing of the eyelids using warm water is helpful, and acute flare-ups can be controlled by topical antibiotic eye ointments.

Most authors state that by the age of 12 or 13 years, 50% of children with Down's syndrome have cataracts, but these are usually flake-like opacities which do not affect vision significantly until later life (Lowe, 1949). Congenital cataracts are uncommon in the general population but affect 1% - 5% of babies with Down's syndrome (Lowe, 1949) which, because of their extent and density, often require early removal.

Myopia, hypermetropia and astigmatism are very common in those with Down's syndrome. Vision can usually be tested using standard charts, but when this is not possible retinoscopy using homatropine can detect myopia. The pupil with Down's syndrome appears to be sensitive to atropine, dilating quickly and remaining dilated for longer than normal. In addition, nystagmus is common and can make sight testing difficult. It often occurs only when one eye is closed so the patient should keep both eyes open during examination.

Squint, almost invariably of the convergent type, is common among those with Down's syndrome, and is usually managed by correction of the refractive error. When this is not possible, surgical correction is necessary. Improved vision is relatively easy to achieve, but binocular function and a satisfactory cosmetic result are more difficult.

Keratoconus occurs in 5% of people with Down's syndrome (Cullen and Butler, 1963). The incidence is higher than in any other condition and it often appears at puberty when it may be associated with cataract and glaucoma. The acute type is painful and requires admission to hospital. The chronic form presents in a less dramatic way as increasing astigmatism.

The possibility of a visual problem should always be considered when a child or adult with Down's syndrome loses interest or becomes frustrated with daily activities which require a reasonable level of visual acuity. Ideally all babies with Down's syndrome should be seen by the ophthalmologist within the first year of life and again before they start school.

Social Services Inspectorate (SSI), Inspection of day services for people with a mental handicap: individuals, programmes, plans, (HMSO, London, 1989) p.12, 2.18

The Social Services Inspectorate (SSI) survey found that there were 8% of ATC clients and 34.5% of SCU clients with visual impairments. 9% of ATC and 14% of SCU clients had hearing impairments. These figures may well be an under-estimate in the light of the comments of some local authorities that screening programmes are still underdeveloped and that a client's sensory handicap may be overlooked. SSI found only limited use of special programmes or facilities for these clients; there was little reference to access to mobility officers or to specialist social workers and there were few examples of assistance being sought from RNIB, RNID etc. There was little evidence of any adaptations to the environment of the units to meet the needs of clients with sensory handicaps, nor to any adaptations to assist clients with dual handicaps.

Sons and daughters with profound retardation and multiple handicaps attending schools or social education centres: final report, J. Hogg, L. Lambe, (Mencap Profound Retardation Multiple Handicap Project, Manchester, July 1988). p.18

| | Children | Adults |
|---|-----------------|---------------|
| 'No sight at all' | 7% | 4% |
| 'Great difficulty in seeing' | 10% | 6% |
| 'Some difficulty in seeing' | 22% | 17% |
| Total | 39% | 27% |
| Note: 'Respondent not aware if he/she was visually impaired' | 9% | 8% |

From the same report as above:

Visual Impairment - Percentage of school (N = 591) and ATC attenders (N = 195) reported as having auditory impairment

| | Children | Adults |
|----------------------------------|-----------------|---------------|
| No hearing at all | 3% | 4% |
| Great deal of difficulty hearing | 3% | 0% |
| Some difficulty hearing | 13% | 6% |
| No difficulty hearing | 77% | 85% |
| Do not know | 4% | 4% |

Innovations in Health Care for People with Intellectual Disabilities, Vision and Hearing in People with Intellectual Disabilities, Alison M. Kerr

This chapter aims to share the experience of providing systematic assessments of vision and hearing to 600 people in a large institution in the process of discharging its residents to the community.

Many large institutions in Britain were established at the turn of the century to protect disabled people from exploitation and abuse. Although the intention was humane and the outcome satisfactory in some cases, separation from the mainstream of society has allowed standards of health care to drift below acceptable levels.

Our institution was no exception to the general experience and in 1990 a limited review of health needs indicated that although crisis medical care was being provided and general practitioners carried out the regulation annual examinations, few residents had been offered specialist diagnosis or assessment of their neurological or genetic problems nor testing of their vision and hearing (Kerr 1994). At this stage there was scepticism about the value of proactive assessments, and concern regarding the quality of health care was curbed by anxiety about the cost. It was therefore necessary to provide further evidence on the prevalence and significance of health problems.

A vision screen programme for two wards was carried out voluntarily by final year students at the Caledonian University (McCulloch, Sludden, McKeown, Kerr 1996). This culminated in a Vision Week at which Professor Mette Warburg from Copenhagen conducted ophthalmic clinics on several wards and delivered the Halliday Lecture on 'Visual Impairment among people with developmental delay' as the centre piece of a 1993 Symposium in the Royal College of Physicians and Surgeons of Glasgow. At the same event our initial health review was presented, and contributions on the nutritional and genetic needs of the residents were provided by consultants from other Glasgow hospitals who had been serving the learning disabled population (Kerr 1994).

The group of senior specialists who contributed to the Symposium agreed to form a Working Party on the Medical Needs of Learning Disabled people, thus providing a multidisciplinary advisory body at medical consultant level which has continued to offer advice to the Health Board and Trust. The Working Party has supported the health initiatives.

In January 1995 we received the promise of sufficient funding from the Greater Glasgow Health Board and Community Mental Health Trust to provide vision and hearing assessments for the residents over a four year period. It was agreed that the primary physician for each ward would retain the responsibility for acting on reports. Our request was refused for a clinical psychologist or occupational therapist to be appointed to assist in clinical audit and liaison. However, a speech and language therapist, already fully employed by the hospital, was invited to liaise with the project to encourage implementation of the specialists' advice.

The box below summarises the steps involved in undertaking a health assessment and the specific actions undertaken in our project, and the box overleaf gives our recommendations for a vision and hearing team.

Steps in Health Assessment 1 (what we did in brackets)

- Establish the range of identified health problems (for 60 people).
- Choose specific health problems to be assessed (vision & hearing).
- Persuade the physicians and administration of the need to assess.
- Find specialists with the appropriate skills (optometrist & audiologist).
- Agree project duration (4 years for 600 people) & cost per test (£25).
- Agree format and circulation of reports (in plain English to all carers).
- Ensure that health providers accept responsibility for follow-up action.
- Encourage therapy departments to allocate time for liaison.
- Agree the place & requirements for testing (quiet room on wards).
- Ensure that key workers attend appointments with residents.

Recommended Vision and Hearing Team

- Physician co-ordinator (paediatrician in our project).
- Secretary (computer skills invaluable).
- Two audiologists.
- Two optometrists.
- Liaison speech and language therapist.
- Liaison occupational therapist.
- Senior clinical psychologist (not appointed).

Team members were asked to give one or two sessions weekly to the project.

Methods

We began work in January 1995 as a small team consisting of one doctor, two audiologists, one - later two - optometrists (opticians), a secretary and a liaison speech and language therapist. Each team member allocated half or one day weekly to the project.

All the tests of vision and hearing are planned to take place on the wards with an experienced nurse in attendance. The specialists arrange each visit flexibly to suit themselves and ward routines; visiting first the wards due for early closure. Wards provide a quiet room for the tests.

The project office is furnished with a computer, independent of the hospital recording system and 'Access' relational database software on which to record data and generate cumulative reports for clinical audit. However paper records are kept also.

The physician begins the process by recording, from the medical case notes and nursing care plans, precise statements of family and developmental history and reports from neurologists, geneticists, hearing, vision and nutrition specialists giving name, date and diagnosis. Other stated medical diagnoses and current medications are listed separately.

Staff opinion is requested regarding each person's level of physical and intellectual impairment and whether visual or hearing impairment, feeding difficulty or seizure disorder are present. This 'Health Check' summary provides pre-test information for the optometrists and audiologists, and the data is entered on the computer database for clinical audit. A copy is provided for the primary physician with the recommendation that it be copied for the new general practitioner when a resident moves into the community.

The two audiologists visit together using as far as possible the same instruments as when testing able people. If pure tone audiometry is not possible they use ability related distraction and performance tests looking for responses to sounds of known pitch and intensity. We attach great importance to the attendance of the chief carer with the resident to the specialist and to pass on practical advice from the audiologists to the other members of staff.

The optometrists have visited the wards separately although we have come to feel that it is best if they visit together. They have used conventional vision

testing equipment as far as the co-operation of the residents allows but have adapted their methods to suit the clientele. Cardiff cards have been used for testing visual acuity.

The audiometricians and optometrists discuss their findings and advice with the ward staff to ensure that the final recommendations will be acceptable.

In addition to traditional reports, the vision and hearing specialists provide reports in 'plain English', technical terms being used when necessary but explained in lay terms for the benefit of the abler residents and for carers who may be members of the family or from another caring profession. Such a report states any diagnosis which has been made, the likely outcome or prognosis, recommended treatment and the time interval after which the examination should be repeated. Each report gives the name, qualifications and contact address for the specialist and the date of the examination.

The vision and hearing reports are photocopied and delivered to each of those for whom they have been written, namely the primary physicians, therapists and social work teams who are currently placing people in the community. We suggest that a photocopy of the plain English vision and hearing reports may be included, unaltered, in the 'life style' log books which are provided for those moving into the community. A copy of each report is also placed in the medical case file which is kept in the ward.

Additional funding has been obtained to purchase a supply of polyvinyl folders 22x15cm in which to present the plain English reports to a pilot group of residents. These personal 'Health Watch' books are intended to remain with each resident after resettlement in the community and the key carer is advised to take the book with the individual when he or she attends future health specialist appointments. In this way we hope to ensure that the relevant health information is at hand at the next appointment.

We advise that specialists who are consulted in future should be routinely invited to record their advice in plain English for their patient and his or her carer, following the style of the vision and hearing reports. Since this is now becoming accepted as good medical practice for the general population we consider it appropriate that those with intellectual disability should enjoy the same advantage, particularly since they are peculiarly dependent on the carer to provide background health information, and carers are apt to change in the community, as in many institutions. The style of report is illustrated in Figure 1.

The liaison speech and language therapist visits the ward after the tests have been reported to discuss the reports and encourage and assist the making of arrangements to obtain aids. She advises key workers when adjustments in ward management are found to be desirable.

Data from the vision and hearing reports is entered by the project secretary into a series of databases related to the health check database.

Periodic written audit reports are circulated to the staff giving the findings of the project in its progress through the hospital. Six-monthly seminars are arranged addressing health issues with ward staff taking an active part. By sharing information with all the caring professionals and teaching the principles of health care we aim to encourage good practice in the hospital and in the community as relocation of residents and staff is achieved.

The box below summarises further steps in health assessments and the actions taken on our project.

Steps in Health Assessment II (what we did in brackets)

- Establish free-standing relational database to store the data (Access).
- Preliminary review of medical records (team physician).
- Ward tests offered in agreed order (30 minutes per person).
- Plain English reports delivered to team physician.
- Immediate copies to primary physicians, therapists & carers.
- Plain English reports delivered as property of resident (pilot stage).
- Seminars highlight and discuss health issues (6-monthly).
- Information sharing through reports and publications.
- Provide argument and prototype for regional health database.

About your vision

page 1

Your eyesight was tested on.....

Your eyes are healthy but not well focussed for distance and we have supplied you with spectacles which will let you make out the numbers on a car atpaces.

Your eyes are not well focussed for near vision and your spectacles will help you to see near objects better. The figure below shows the size of object which you can see clearly with spectacles.

A

Your lenses are hazy due to cataract and your central vision is not good although your side vision is good. You will find it helpful to move close to things you want to see and a bright light will help you to do close work. You will need assistance in traffic and possibly on stairs.

We have supplied you with one pair of spectacles for both near and distant vision and your name is engraved on them.

You are advised to request another vision test in one year.

The lens powers are with a near addition of

Lost or broken spectacles can normally be replaced or repaired without cost.

This report is supplied by Mr (optician) address telephone.....Glasgow.

This report was supplied to Jean Smith date of birth.....address.....

About your Hearing

page 2

Your eyesight was tested on

You have severe hearing loss in both ears and it will help if you are spoken to on the left. It will help if the wax is gently removed from your ears by your doctor or clinic nurse. It will also help if you are able to use a hearing aid and this can be arranged through your doctor and clinic.

You are advised to request another hearing test in.....

Severe bilateral hearing loss means 70-90 decibels of hearing loss.

This test was carried out by audiologist address telephone

This report was supplied to Jean Smith date of birth address

Figure 1

Results

At the midpoint of project 'Health Check', summaries have been completed for 450 of the almost 6000 residents and vision tests for 200 (January 1996). The population is ageing as every effort is made to keep disabled young people in the community and the mean ages for the residents are 55 years for men and 57 years for women with a range from 26 to 90 years.

Forty per cent of residents cannot walk unsupported, 35 per cent cannot use their hands without physical assistance in simple self care tasks and 62 per cent cannot express themselves in sentences.

The health check reviews found that only 8 per cent of records contained a neurologist's report on the condition underlying the intellectual disability. Some form of genetic screening had been offered to 34 per cent; however family and early medical histories indicated that a genetic cause was unlikely in only 14 per cent, probable or certain in 36 per cent, and possible in a further 50 per cent, so that screening would be appropriate in 86 per cent of residents.

Seizures have been recorded at some time in 45 per cent of residents and in 32 per cent this remained an active problem. Feeding difficulties or other nutritional problems were present in 56 per cent of residents. Virtually all residents had been recorded as having other medical conditions and many of these were for long-standing irritating or painful conditions such as varicose eczema, peptic ulceration and tinea pedis.

At the beginning of the project ward staff thought that hearing and visual impairments might affect about ten percent of residents. However as the testing programme progressed, with staff observing the results, the level of awareness increased. About ten per cent of residents were unable to cooperate satisfactorily in the test situation. However with a knowledgeable key worker in attendance it was usually possible to reach an estimate of impairment and provide practical advice.

Of those in whom the level of hearing could be tested, 25 per cent had normal hearing and 75 per cent some reduction in hearing. In 34 per cent of the population tested the hearing loss was mild (30-50 decibels' loss) and in 41 per cent it was moderate, severe or profound (decibel loss of 50-70, 70-90 and over 90 respectively). In 12 per cent of the testable group the level of loss was such as to justify a hearing aid, although difficulties in understanding might limit its use and lead to modified recommendations. The advice to

remove ear wax was frequently given but this was not considered a major contributor to the hearing losses detected.

The preparation of the vision report has lagged behind the rest of the programme. However earlier vision testing initiatives which spearheaded the current project have supplemented information, giving 200 test reports to date. As with hearing tests about 10 per cent have been unable to co-operate. Ninety five per cent of those able to co-operate have shown some degree of visual defect or were considered likely to benefit from correction with spectacles. The optical diagnoses ranged through simple defects amenable to spectacle correction, to complex malformations resulting from the original neurological disorder and its complications. Treatable conditions were common and included conditions of the eyelids, infections and glaucoma. In 11 per cent of residents cataracts required surgery.

It was common to find that an individual had both hearing and visual impairments. Table 1 shows the results of vision and hearing tests in a typical group of residents who were consecutively assessed.

Practical observations and local issues

Although the final audit of the project is still to come there have been obvious benefits to the residents and ward staff. Spectacles, lens implants for cataract, relief from impacted wax and chronic ear infections, and hearing aids have improved health and quality of life for the residents. There has been heightened staff awareness of the importance of vision and hearing for the residents. Nurses have enjoyed being included in the testing situation and noticed improved communication after treatment of deafness and poor vision. The teaching seminars have introduced ideas from other areas of the country and encouraged cross-disciplinary discussion within this area.

| Case No | Right Ear | Left Ear | Left Deafness | Right Deafness | Visual Diagnosis |
|----------------|------------------|-----------------|----------------------|-----------------------|---------------------------|
| 1 | wax | wax | mild | mild | spectacle for distance |
| 2 | intact | reddened drum | Severe/ profound | Severe/ profound | Toxoplasmosis retinitis |
| 3 | wax | intact | moderate | moderate | strabismus |
| 4 | intact | intact | normal | normal | bilateral cataract |
| 5 | wax | thickened drum | normal | normal | lens implants |
| 6 | wax | wax | mild | moderate | spectacles prescribed |
| 7 | wax | wax | mild | mild | bilateral cataract |
| 8 | intact | infection | severe | severe | myopic astigmatism |
| 9 | intact | wax | mild/moderate | mild/moderate | cataract & keratoconus |
| 10 | intact | wax | inconclusive | inconclusive | hypermetropic astigmatism |

The Vision and hearing reports have been well received and found useful, particularly by the therapy and social work departments, in planning future accommodation and care in the community. Demand for information outstrips our capacity for provision of health information. Twenty-five pilot 'Health Watch' booklets have been enthusiastically received by carers in the hospital and community with suggestions that use of further symbols would be welcomed by some people who cannot read but are eager to understand the content. The information was not seen as duplicating health information from other sources.

Ward testing has been a great success, indeed in our situation it presented the only realistic way to proceed. Some adaptations of methods and equipment were necessary but have not generally been problematic. In general the vision and hearing specialists have found that they require twice the usual time allotted for an able person in order to test residents adequately.

Time is needed for familiarising the residents with the testing procedures, for repeat tests when co-operation has been problematic, for discussions with

the key carers and for preparation of the plain English reports which require careful thought and effort from specialists who may be in the habit of communicating in writing only with other health disciplines.

It was agreed at the start of this project that implementation of advice would remain the responsibility of the primary consultants of the wards. Traditionally these have been consultant psychiatrists while the junior medical staff are registrars in psychiatry and clinical assistants. With the intention to transfer residents into the community, there have been major changes in medical staffing. The consultant psychiatrists have been transferred to clinics in the community and general practitioners from surrounding practices have been appointed to supplement the reduced clinical assistant cover. Most general practitioners therefore spend little time in the hospital and do not carry overall responsibility for medical care. It remains to be seen whether continuity of primary medical care can be achieved and whether this will lead to improved primary health care and appropriate specialist referrals.

The liaison speech and language therapist with one half-day weekly, has found it necessary to restrict her efforts to just a few of the twenty-three wards. She has been concerned at delays in making referrals and offering of hospital ENT (otolaryngology) appointments. It has been difficult to ensure that key workers accompany residents and bring the appropriate information to consultations. The ENT consultant has suggested that the Project audiologists should be invited to supply and support the introduction of aids and this seems likely to prove acceptable to the NHS Trust. The Project optometrist already supplies and provides advice on spectacles, recommending referral to the ophthalmologist for more complex disorders and for surgery.

When aids have been supplied, poor understanding of their use by the resident and lack of supervision by the key carer has led to their loss or damage in several cases. Active encouragement has been necessary to ensure that even the simplest measures are carried through. Perhaps the most important factor in the success or failure of the project with regard to each individual has been the interest, insight and permanence of the key carer and the relationship which develops between the resident and the key carer. We have been dismayed to find how frequently this relationship is broken by organisational changes. It is clear that a person who cannot understand his past and present health problems or recount these in speech is highly vulnerable to a change of carer. Arriving at a hospital clinic without someone who is able to provide a clear account of their past history and present problems, residents are unlikely to receive the help they need. The

hospital administration is now responding by increasing therapy and training time for ward staff and residents.

Entering the health information from these 600 people into a relational database and learning how to present and analyse the data is a challenge for which our computer skills are developing gradually. Regular advice from an administrative assistant with wide experience of databases would be of value. Because of the interest of caring staff and departments in the hospital and the community, we deal with ever-increasing requests for information which might be answered by a telephone 'health help-line' which could become part of the monitoring role. The database itself is the potential core of a permanent regional health register.

Comments and Recommendations

Delivery of quality health care to multiple disabled people may be obstructed by certain attitudes which are common at the present time. These include:

1. ignorance of the brain disorders which lead to disability
2. failure to understand that these may be prevented and treated effectively
3. scepticism that this knowledge may benefit the individual and society
4. fear of the responsibility of knowing, since knowledge dictates action
5. fear of the cost of health care

When these attitudes are allowed to dictate policy, the result is a system of containment in which it is tacitly agreed that, while obvious health crises will receive treatment, underlying medical conditions will not be acknowledged.

In choosing to assess vision and hearing we selected the most obvious argument to demolish this illogical and unethical stance. Poor vision and hearing may be corrected in many disabled people and can be satisfactorily accommodated in others provided that it has been truly understood. The cost of such care is not great.

On the other hand, the cost of neglecting the vision and hearing of disabled people is very great. Failing eyesight and hearing lead to increasing dependence, distressed, 'challenging' and 'self-injurious' behaviours, unnecessary medications, iatrogenic illnesses, low morale and a high sickness rate among carers with inevitably escalating expense.

It is not only neglect of visual and hearing loss which carries these consequences. Failure to diagnose and understand underlying neurological and genetic conditions is also disastrous since each specific diagnosis

carries possibilities for treatment and each has its own characteristic profile of impairments and skills within which therapists and careers must learn to work. Each disorder is associated with specific risks to be avoided or planned for.

By recording previous diagnoses and assessments in key areas of health, we have drawn attention to existing deficits in the programme of regular medical assessments for adults with learning disabilities, and indicated the multiplicity of complex health problems which may coexist in one individual. The box summarises the anticipated outcomes of our project.

It is clear that people with learning disability are likely to require advice from a range of senior medical specialists in neurology, ophthalmology, audiology, genetics, psychiatry, psychology, orthopaedics, paediatrics, nutrition and general medicine. Many medical specialities must therefore co-operate to provide the advice required by this multi-disabled population.

Anticipated Outcomes of Vision & Hearing Project

- Vision & hearing assessments achieved for all residents.
- 'Plain English' reports provided to explain needs to carers.
- Increased awareness of the value of accurate health advice.
- Increased carer insight into how to look after health.
- Establishment of realistic concepts supporting access to health care.
- Development of realistic concepts supporting access to health care.

The primary physician or general practitioner is competent to detect and treat a range of medical disorders, the strength of this position lying in the fact that he knows the whole family and its environment and can manage episodes of illness within this context. Routine annual medical examination by the general practitioner should detect such disorders as diabetes and hypertension. When complex neurological, genetic, psychiatric, nutritional or surgical problems are present which are beyond his or her competence, the general practitioner's role becomes that of gateway to specialist services (Kerr, Dunstan and Thapar, 1996).

Since learning disabled people suffer a high incidence of complex and multiple impairments which are easily overlooked on routine examination and, because they cannot independently gain access to the appropriate assistance, it is clear that the provider must offer periodic specialist assessments in those areas of outstanding medical importance. In our view a record of health needs, of which such specialist assessments will be part, should be made for each person and reviewed at intervals of no less than five years.

There are several ways in which such a quality service can be achieved and providers of health care should be responsible for consulting with the full range of senior clinicians in order to decide how best the service can be integrated and monitored (see box).

Essentials for a Community Health Care Service

- Continuing instruction on health issues for carers, therapists & physicians.
- Habitual health surveillance by carers and professionals.
- Annual review and medical examination by the general practitioner.
- Community liaison nurses attached to specialist clinics.
- Routine provision by all specialists of plain English reports for carers.
- Automatic five-year specialist health assessments of mobility, nutrition, vision, hearing, communication, seizure, neurological and psychiatric state.
- Regional Health database linked to paediatric care.

However for this to be achieved, it will necessarily include several 'first-line' service elements:

1. a general surveillance system which registers all multiple disabled people, whether or not they have approached the health services. This system should be linked to the regional paediatric register.
2. primary medical care (through general practitioner services)

3. a local disability service (with community nurses and therapists)

Any of these systems may accept the responsibility for co-ordinating the periodic specialist medical assessments. The family and the chief carer should be welcomed during the recording of needs and the specialist assessments, and invited to participate in decisions which follow. The general practitioner, the family and chief carer should receive a full copy of the completed assessment.

The hospital-based, specialist medical services which are most often consulted to advise intellectually disabled people will find it necessary to set aside extra time at clinics, provide additional staff and develop facilities to provide an effective specialist service. Special expertise may be most readily developed and most effectively used when it is concentrated in special units of advice on complex disabilities as has been done successfully by paediatric assessment units and a growing number of 'University Affiliated Programmes' (Welsh Health Planning Forum 1992). This is particularly helpful for people who require specialist advice from many departments since a single day in the unit can include several appointments with the same specialists as for the able population, but with additional support.

Assessment of severe and complex epilepsies may require short periods of residential assessment for which a specialist unit has great advantages. Expensive equipment which must service an entire region may be justified only if it is in frequent use in experienced hands.

Delivery of health care to the general public depends upon the affected person actively seeking help and explaining the present symptoms and how they have arisen. Adults with severe intellectual impairments cannot do this and as they grow older they are increasingly unlikely to have a life-long advocate who has known them sufficiently long or well to act as a substitute. Long-term relationships, whether with family, friends or carers should be highly valued and protected. When a health specialist provides advice, a copy of this should be routinely provided for the chief carer - explained when necessary - as well as for the general practitioner.

This project has shown a need for continuous in-service health education for a growing number of carers from many professions including the families of multiple disabled people and the disabled themselves. In order to be effective in health surveillance and implementation of health advice, carers need to be well informed on a wide range of health issues. There will be a growing need for truly informative medical literature which can serve these groups of people, and there will be an important role for a regional centre

which can combine first-hand knowledge of the multiple disabled people in the area and their health needs with a service capable of teaching, advising on the development of services, and providing library facilities and other resources.

References

Kerr, A.M. (1994). Medical Concerns in people with severe learning difficulties: report on a vision week and symposium at the Royal College of Physicians and Surgeons of Glasgow, Scotland, 8-12 March 1993. *Journal of Intellectual Disability Research*, 38, 85-95.

Welsh Health Planning Forum (1992). *Mental Handicap (Learning Disabilities) Protocol for Investment in Health Gain*, Welsh Office. NHS Directorate, Cardiff.

Kerr, M., Dunstan, F. & Thapar, A. (1996). Attitudes of general practitioners to caring for people with learning disability. *British Journal of General Practice*, 46, 92-94.

McCulloch, D.; Sludden, P., McKeown, K. & Kerr, A. (1996). Vision Care Requirements among intellectually disabled adults: a residence based pilot study, *Journal of Intellectual Disability Research*, 40, 140-150.