



Manchester Learning Disability Partnership
&
Community Orthoptic Service
2004

“Right to Sight”

Accessing Eye Care for Adults who are Learning Disabled

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Abstract

People who are learning disabled have a high incidence of visual problems, which can lead to further disablement. This study was carried out to determine best practice in providing equality of eye care and to improve communication between the eye care and learning disability services.

A telephone questionnaire was used to investigate the existing uptake of eye care services by 146 learning disabled adults. Following this, 74 learning disabled adults attended eye examinations. Satisfaction questionnaires were completed following the examinations.

39% of the total sample were found to be receiving less eye care than the general population. People living with families or independently were significantly less likely to have had an examination than people living with paid support staff. 30% of those previously examined had been diagnosed with eye problems, the most common being cataracts. 43% of those previously prescribed glasses could not tolerate them.

Eye examinations were possible for all 62 who attended with the Orthoptist (assesses vision and identifies disorders), 40 went on to see the Optometrist (tests vision and can prescribe glasses) and 14 were referred to the Ophthalmologist (diagnoses and treats all defects and diseases). Following their appointments, five people were prescribed glasses for the first time and a further four were given revised prescriptions. Four people were prescribed with treatments and a further four were referred for surgery. Two people were registered blind for the first time.

High levels of satisfaction were reported for the testing locations and with the eye care professionals. However, fewer people were as satisfied with the waiting times, waiting areas and reception staff.

The authors recommend that eye care should be promoted amongst learning disabled adults. Eye care professionals as well as supporters of learning disabled people should be aware of barriers to eye care and be trained accordingly. There should be structured and adequately resourced Ophthalmic provision to the learning disabled population. The establishment of follow-up support services could increase levels of tolerance of glasses. The screening should be repeated for the remaining areas of the city.

Section A. Introduction

Background

People who are learning disabled have a high incidence of sight problems, and prevalence increases dramatically with the severity of the learning disability and with age, (Warburg, 2001a). Reports of incidence of visual impairment vary from 25% (Janicki and Dalton, 1998), to 63% (Lavis, 1994). A recent compilation of surveys worldwide reported an average occurrence of 40% (Kerr et al, 1996).

Warburg (2001b) reports that the most widespread eye condition for people who are learning disabled is cerebral visual impairment. Optic atrophy, high myopia, cataracts and keratoconus (see Appendix 5) are also particularly common (Warburg, 2001b).

High prevalence rates are thought to be due to the close association between brain and eye development. Where damage has occurred to the brain during foetal development, vision is likely to be affected (Aitken, 1992). Several syndromes are also recognised as being prone to developing eye problems e.g. Down's, Usher's, Fragile X, Rubella, hydrocephalus and cerebral palsy. People who are learning disabled develop visual problems as part of the ageing process too, and the high prevalence rates reflect the fact that they are living longer. In addition, people who are learning disabled generally experience these problems ten years earlier than the general population (College of Optometrists, 2000).

Visual problems in people who are learning disabled can lead to further disablement and lowered self-esteem (Stanford and Shepherd, 2001). O'Hara and Sperlinger (1997) state that vision testing should precede any assessment of mental ability. Without a thorough understanding of vision it is impossible to make accurate judgements about co-operation or functional ability within task performance. 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. Whereas early identification can lead to prevention of visual deterioration and infection, a reduced possibility of developing behavioural consequences of coping with vision loss (Speechley, 2002), and increase the chance of coping with glasses (Mencap, 1998). Awareness of vision needs can also help staff and carers assist the person appropriately. For example, environmental changes such as lighting alterations can be made (RNIB, 1998).

“People's quality of life can be greatly improved when their sight problems have been identified and they receive appropriate help to take more control over their lives.”

RNIB

“The more people can see, the easier it is for them to make sense of their world and acquire skills.”

RNIB

Most people who are learning disabled first come into contact with the Orthoptist (See Appendix 4: "Who's Who in the Ophthalmic World") within the school environment, where they are regularly tested (Speechley, 2002). It is following the transition from childhood to adulthood that access to eye care becomes problematic. At present little medical information, including Orthoptics, is transferred from the children's learning disability services to the adult learning disability services and valuable information that is essential to enable continuity of care is lost. As adults, people who are learning disabled are often left to consult the high street Optician / Optometrist (see Appendix 4).

Although a range of literature about accessing services exists for learning disabled adults (including RNIB Focus factsheets, British Institute of Learning Disability booklets and, in Manchester, the Eye Care Pack is available from the Central Manchester Primary Care Trust Orthoptic Department and from MLDP) the complex world of eye care often seems inaccessible or inappropriate. It may also be wrongly assumed that it is impossible to test the sight of this client group due to an inability to read, sit still, communicate; or that there is no perceived benefit from having glasses prescribed.

Lewis (1995) found a high level of un-met need when she surveyed 300 adults attending day centres – only 46% had regular sight checks. In addition, whilst frequency of testing for the general population is approximately every two years (RNIB advice, see Appendix 6), the Mencap "Health for All?" (1998) report states that 53% of people who are learning disabled had not had a sight test in the last two years, though 57% wore glasses. Living situation was found to be a factor as people living independently were found to be less likely to attend to their vision; 62% had not seen the optometrist in the last year (Mencap, 1998). It was also found that whilst 14% of people living with their families had either never received an eye test or it had been over ten years since the last one took place, this was the case for only 3% of those living in residential care (Mencap, 1997).

"It is a scandal that so many people have unidentified visual problems which may cause pain, lower potential and undermine successful participation in a range of activities."

RNIB

Indeed, 50% of people with a learning disability cannot read the alphabet (Mencap, 1998), making the traditional Snellen chart an inappropriate testing method. However, a large number of alternative assessment methods exist, including use of pictures and preferential looking. A study by Woodhouse, Griffiths and Gedling (2000) demonstrated that eye examinations are possible for the majority of individuals as they found that screening was successful for 148 out of 150 learning disabled adults.

"No one is too disabled to have his / her sight tested."

RNIB

Kerr (1998) discussed knowledge and attitude of health professionals, as well as communication and behaviour of people who are learning disabled, as

barriers to health care in general. The Mencap “Health for All?” (1998) survey revealed that people who are learning disabled constituted only 1% of the Optometrists’ workload and that only 12.5% had received some training in learning disabilities, mostly post-qualification. Over half of the Optometrists surveyed thought there were no specific visual conditions associated with learning disability, and only 5% were able to name some of them. None had access to alternative tests. To summarise, difficulties for the practitioner may include: lack of training, inability to communicate well, and perceived lack of equipment (College of Optometrists, 2000). Problems for people who are learning disabled undergoing eye examinations may include: inability to read the alphabet, no verbal communication, support unavailable to accompany the person, eye care not seen as a priority for the person, difficult behaviours and being frightened of the procedure (College of Optometrists, 2000).

“Valuing people” (2001) identifies four key principles: rights, independence, choice and inclusion; eye care is cited in all. An aim of the paper is that everyone with a learning disability will have a Health Action Plan by 2005 and the HAP will specifically highlight the vision needs of the individual. In addition, section 21 of the Disability Discrimination Act (1995) requires that service providers take all reasonable steps to ensure that the services are as accessible to disabled people as they are to the general population.

Despite recommendations from the large number of government initiatives and from studies published by RNIB, BILD and Mencap, there is evidence that vision is an un-met area of health need. The literature confirmed the importance of vision testing for people who are learning disabled and exposed a need for local research.

Service Setting

This study was carried out in the large British city of Manchester where services for approximately 1200 learning disabled adults are provided by a partnership between Health and Social Services. The Manchester Learning Disability Partnership (MLDP) has three local Community Learning Disability Teams that correspond with the three areas – North, South and Central Manchester.

The MLDP highlighted a need for multi-disciplinary and multi-agency working to encourage better services (Burton, 1998) and this has been instigated with the establishment of the Learning Disability Eye Care Group made up of members of the Community Orthoptic Service and MLDP. The Group launched the Eye Care Pack in May 1998 in order to:

- Raise awareness of eye problems
- Enable staff to support people who are learning disabled to obtain better eye care
- Give guidance on how to access the appropriate service
- Highlight the importance of both written and verbal communication.

A survey following the promotion and circulation of the pack found that only 39% of learning disabled adults or their support staff had seen the pack; that the use of the Visual and learning disability checklist and Eye Examination Report was inconsistent; and that there were clear discrepancies in standards of frequency of eye testing between the learning disability service standards, advice from RNIB and what professionals were prepared to do. The survey also found that the number of learning disabled adults prescribed with glasses had increased from 63% to 75%, but that 25% did not wear them (Learning Disability Eye Care Group, 1998).

The Eye Care Group has recently made the following conclusions from a benchmarking exercise in the region:

- The experience of Orthoptists in testing vision in patients with communication / behavioural problems is essential
- Access to written information is poor
- Guidelines / recommendations need to be developed
- There is a distinct lack of training in eye care for care workers (Learning Disability Eye Care Group, 2000).

This study, two years on, follows on from the above conclusions.

Aims and Objectives

Aim: To determine best practice in providing equality of eye care and to improve communication between the eye care and learning disability teams.

Objectives:

To determine:

- Number of learning disabled adults who have / have not had access to eye care
- Quality of eye care already received
- Incidence and type of problems found
- Amount of ophthalmology input required

To establish:

- Provision of eye care to those with no previous history of eye care
- Communication to and understanding of results by carers in terms of treatment need and use of functional vision

To assess:

- Suitability of testing locations
- Additional training needs of health care professionals and carers

To improve:

- Transfer of clinical information from child to adult learning disability services.

Section B. Methods

Sample Selection

The convenience sample was obtained using the Social Services Information System (SSIS) database for Central Manchester. Fifteen people could not be contacted due to changes of addresses / telephone numbers, two people were found to be recently deceased and four people refused to take part. A total of 146 learning disabled adults agreed to take part in the study.

Data Collection

The study had three phases:

1. Telephone questionnaire

A telephone questionnaire was used to investigate the existing uptake of eye care services by people who are learning disabled in Central Manchester, and to identify any barriers. The method was chosen as a result of a previous unsuccessful audit in the field, where few postal questionnaires were returned. The questionnaires, accompanied by the information sheets and consent forms were sent out to participants with the letters of introduction in March 2002. The letters contained a specified time when one of the two Orthoptists would be telephoning the participants at home in order to obtain their answers regarding:

- Living situation
- Severity of disability
- Existence of difficult behaviour
- Date and location of last eye test
- Whether glasses / contact lenses worn and tolerance
- Diagnosed eye problems
- Medication or surgery for eyes
- Satisfaction with previous eye tests
- Whether they would like an eye test
- Preferred location of eye test.

2. Eye test

The eye test formed the intervention part of the study, based on Warburg's (2001) finding that professional assessments disclosed a higher prevalence of visual impairment than questionnaires. The participants who requested an eye test were given an appointment with the Orthoptist who gathered information regarding:

- History (eye conditions, previous treatment, general health, family history, carers' concerns)
- Vision result
- Presence of squints or nystagmus
- Ocular movements

- Binocular vision
- Confrontational fields.

Testing began in April 2002. Following the appointments with the Orthoptist, if necessary, participants were referred to the Optometrist for prescriptions for glasses and then to the Ophthalmologist who prescribed treatments or surgery (See Appendix 4).

3. Satisfaction questionnaire

Finally, satisfaction questionnaires were given out at / after the last appointment attended, to the person attending / person accompanying, to gather data on suitability of location and satisfaction with staff and treatment.

Ethics

Ethical approval for the study was obtained from the Central Manchester Local Research Ethics Committee.

Statistical Analysis

Data was entered onto a Microsoft Excel database and imported into the Statistical Package for the Social Sciences (SPSS, 2001) for statistical analysis. Statistical tests were carried out to investigate:

- Relationship between living situation and last eye test
- Relationship between the severity of disability and last eye test
- Relationship between difficult behaviour and last eye test
- Relationship between local area group (LAG) lived in and last eye test
- Relationship between location of previous eye test and satisfaction with the test
- Relationship between incidence of problems and wards.

Descriptive information was used to describe: the number who had previous access, quality of previous eye care, how many tolerate glasses, location of previous eye test, incidence and type of problems found, suitability of testing locations, tests used, how many confrontational fields able to do, and amount of ophthalmology input required.

Section C. Results

Demographic Details

The sample was made up of approximately 50% of the learning disabled adults that are known to the service, in the following areas: Fallowfield, Rusholme, Moss Side, Longsight, Ardwick, Levenshulme, Hulme and Gorton (see Table 1). Three people who had moved to addresses in other areas were also included.

Table 1: Learning disabled adults (excludes 3 in other areas)

Area	Eye care Sample		JCT / MLDP Database*	
	Frequency	Percentage	Frequency	Percentage
Ardwick	3	2.1	17	5.7
Longsight	28	19.6	45	15.1
Fallowfield	12	8.4	22	7.4
Rusholme	20	14.0	46	15.4
Gorton	47	32.9	81	27.2
Levenshulme	21	14.7	46	15.4
Moss Side	9	6.3	30	10.1
Hulme	3	2.1	11	3.7
Total	143	100.0	298	100.0

*The Joint Commissioning Team / Manchester Learning Disability Partnership Database was used for comparison because it gives a more accurate population breakdown than the Social Service Information System database, which has since been superseded.

The sample was representative in terms of gender: 55.9% males, 44.1% females compared with 56.4% males and 43.6% for the total number of learning disabled adults in the areas studied. The mean age of participants was 40.5 years with a range of 19 – 94 (standard deviation = 18.9).

Table 2a shows how representative the sample was in terms of ethnicity. Whilst the percentage of British White people is higher by 8.7% for the Eye Care Sample, there may be no real difference as the percentage of not recorded is 8.9% higher for the JCT/MLDP database and these people are likely to be British White. Regardless of these differences, it can be said that overall, the sample included a representative distribution of ethnic groups. (See Appendix Table 2b for a more detailed breakdown of ethnic groups included in the sample.)

Table 2a: Ethnicity

Ethnicity	Eye Care Sample		JCT/MLDP Database	
	Frequency	Percentage	Frequency	Percentage
British White	116	79.5	211	70.8
Black	11	7.5	19	6.4
South Asian	10	6.8	24	8.1
Middle Eastern	1	0.7	1	0.3
Not Recorded	8	5.5	43	14.4
Total	146	100	298	100

In terms of the living situation distribution, differences between the sample and the JCT / MLDP database were no greater than 8% for each type of situation (see Table 3). The sample was therefore, representative. The largest proportion of the sample was living with families (50%) followed by those living in MLDP Network Homes (20%) and those living in Independent Sector Homes (17%).

Table 3: Living Situations (excludes 3 in other wards)

Living Situation	Eye Care Sample		JCT / MLDP Database	
	Frequency	Percent	Frequency	Percent
Adult Placement	5	3.5	14	4.7
Living with Family	71	49.6	172	57.7
Living Independently	14	9.8	8	2.7
Independent Sector Home	24	16.8	34	11.4
MLDP Network Home	29	20.3	70	23.5
Total	143	100	298	100

The majority of the sample was made up of people with either moderate or severe learning disabilities (see Table 4).

Table 4: Level of Learning Disability

Level of Learning Disability	Frequency	Percent
Mild	14	9.6
Moderate	60	41.1
Severe	62	42.5
Profound	7	4.8
Not Known	3	2.1
Total	146	100

Previous Eye Care

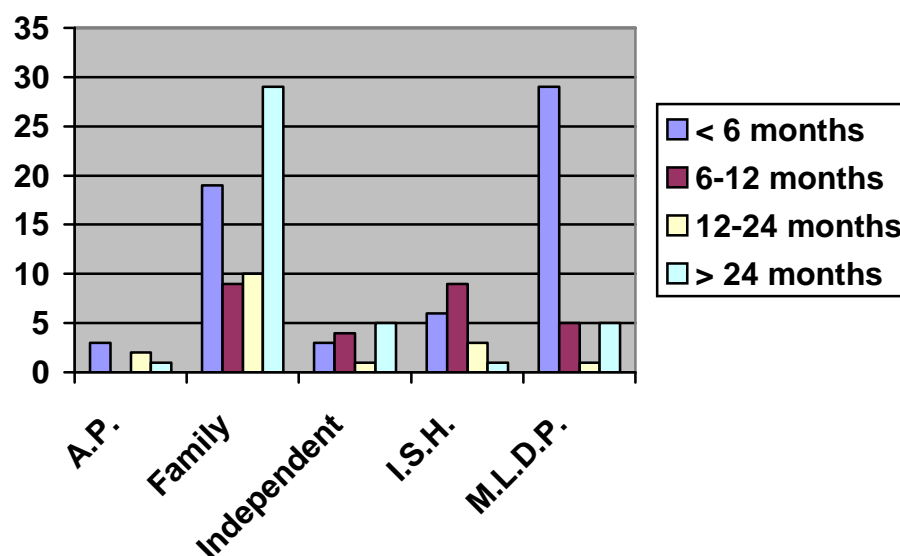
Of the 146 learning disabled adults contacted, 129 (88.4%) reported having had an eye test, 16 (11%) had not, and one person was not sure. Of the 129 tested, 27.1% were tested less than 6 months ago, however, 31.8% had their eyes tested over 24 months ago (See Table 5).

Table 5: Time since last eye test

Time since last eye test	Frequency	Percentage
<6 months	35	27.1
6 – 12 months	29	22.5
12 –24 months	19	14.7
>24 months	41	31.8
Not sure	5	3.9
Total	129	100

People living with families or independently were significantly less likely to have had a test within the last 24 months than people living with paid support staff ($2(2) = 12.691, p < 0.05$). However, whilst the people living with families were significantly less likely to have been tested in the last 24 months than people in any other living situation ($2(1) = 11.369, p < 0.05$), the graph shows that a large proportion of people living with families nevertheless had received a test in the last six months (26.8%, $n=19$).

Graph: Living situation and previous access



Statistical analysis (Chi Square) found no statistically significant relationship between the severity of a person’s learning disability and whether they had received an eye test ($\chi^2(1) = 0.146, p > 0.05$). Also, statistical analysis (Chi Square) found no statistically significant relationship between the presence of “difficult behaviour” and whether the person had received an eye test ($\chi^2(1) = 0.320, p > 0.05$).

Statistical analysis (Chi Square) found no statistically significant relationship between L.A.G. lived in and receipt of eye care ($\chi^2(3) 3.428, = p > 0.05$).

Of 129 tested, 29 (22.5%) reported being very satisfied with their last eye test, 77 (59.7%) were satisfied, and 11 (8.5%) were not satisfied. The most common location for the last eye test was found to be the high street optometrist (55.8%), followed by the hospital (18.6%). (See Table 6.) A Kruskal Wallis test showed no statistically significant difference in levels of satisfaction for each location ($\chi^2(4) = 6.453, p > 0.05$).

Table 6: Location of last eye test

Location	Frequency	Percentage
High Street Optometrist	72	55.8
Hospital	24	18.6
Local Clinic	14	10.9
School	8	6.2
Other	5	3.9
Not known	6	4.7
Total	129	100

74 (50.7%) of the 146 learning disabled adults requested an eye test. Of the 74, 7 (9.5%) requested a home visit. All of these people had either severe (3) or profound (4) learning disabilities. Five had challenging behaviour including “anxious in strange places” and “will not sit still”. Three had never had their eyes tested and the other four were tested over 24 months ago.

Comments

A number of the carers who completed the telephone questionnaire, on behalf of the person with learning disabilities, made positive, enthusiastic comments about the upcoming eye examinations:

“I am very pleased to have received your letter and (participant 19 is) very keen to have an eye test”.

Father of participant 19

“Dealing with learning disabled adults needs to be part of training in all aspects (of health care). I am very keen and happy that something is being done”.

Mother of participant 3

“I would like to know what he can see”.

Mother of participant 16

Some of the carers expressed concerns:

“He is very uncooperative. He does not sit still for long. He needs to be not kept waiting”.

Carer of participant 142

“He is very difficult to test because he does not like bright lights. Are there any alternative tests?”

Mother of participant 7.

Visual Impairment

Of the 129 previously tested, 77 (60%) were prescribed glasses. 43 (56.6%) people tolerated the glasses, whilst 33 (43.4%) could not tolerate them. 39 (30%) of those previously tested, had been diagnosed with eye problems, the most common being cataracts (11% of the entire sample) and squints (9.6% of the entire sample). (See Appendix Table 7: Diagnosed Conditions).

Statistical analysis showed no statistically significant relationship between area lived in and incidence of eye problems ($\chi^2(3) 0.341, = p>0.05$).

Intervention

Out of the 74 who requested an examination, 62 (83.8%) attended with the Orthoptist. The most used test by the Orthoptist was the Snellen / Linear test (54.8%) followed by the Cardiff Cards test (22.6%) and the Single test (11.3%). (See Table 8.) 65.6% of those who saw the Orthoptist had their confrontational fields tested.

Table 8: Tests used

Test	Frequency	Percentage
Linear / Snellen	34	54.8
Single	7	11.3
Pictures	2	3.2
Cardiff Cards	14	22.6
Other	5	8.1
Total	62	100

40 of the 62 (65%) went on to see the Optometrist for refraction. Five were prescribed glasses for the first time and a further four were given revised prescriptions. Fourteen (23%) were then referred to the Ophthalmologist where four people were prescribed with treatments and a further four were referred for surgery. Two participants were registered blind following the intervention.

Evaluation of Intervention

36 satisfaction questionnaires were completed. No problems whatsoever were reported with the accessibility of the clinics, the eye care professionals or their explanations. In fact, a considerable majority (>85%) reported very high levels of satisfaction with most aspects of the intervention. Slightly less people were as satisfied with waiting areas (54.3%), waiting times (77.8%) and reception staff (80.6%). (See Appendix Table 9: Satisfaction).

All comments given were positive including the following:

“Delighted by the efficient service provided by the receptionist, waiting time minimum, very good examination”.

“Superb service, very friendly and professional staff”.

“Excellent service (the person with learning disabilities) enjoyed it all”.

Section D. Discussion

Study Limitations

The confidence with which the results can be interpreted may be affected by a number of limitations with the study methodology:

- The sample did not include all of the learning disabled adults living in Central Manchester that the service is aware of and included none that the service is unaware of (although there will be few or no people in the latter category). It may have also been the case that those who agreed to take part regarded eye care as more important than those who refused, who might have felt that eye care was a low priority. Therefore, the people missing from the study could include the most disadvantaged group.
- The retrospective nature of the telephone questionnaire means that the study relies on memory for dates, location and outcome of last eye test. Diagnosed conditions may have been particularly difficult to remember due to perplexing medical terminology. The study was also reliant on judgements about level of learning disability, and challenging behaviour that may have not been entirely accurate. Furthermore, some people accompanying the learning disabled adults to the appointments knew nothing about the person, which made it more difficult for the eye care professionals to make accurate diagnoses.
- Regarding time since last eye test, participants were only required to indicate whether this was less than six months ago, between six and twelve months ago, between twelve and 24 months ago or over 24 months ago. It would have been more useful to collect estimates of how long over 24 months their last eye test was, in order to gain a fuller picture of access.
- The satisfaction questionnaires were completed anonymously and information on the location of the appointments or on the staff seen was not recorded. Therefore, the researchers were unable to make any conclusions regarding suitability of location or competency of staff. However, the overall high levels of satisfaction with all aspects of the appointments suggest that individual locations and staff were unrelated to satisfaction. The high levels of satisfaction with the eye care professionals may reflect the fact that they were aware of the study and adjusted their practice accordingly.
- Some of the statistical analyses required that some categories had to be merged in order to meet test assumptions: some information was therefore 'lost'. For example, for the evaluation of the relationship between living situation and previous access, the five categories of living situation were collapsed into three (MLDP, ISH, other) and then into two for further analysis (Family and other).

Despite the study limitations, a number of conclusions can be drawn from the analysis regarding previous uptake and quality of eye care services, visual impairments, tolerance of glasses and professional input.

Conclusions

Previous Uptake

The results show that only 11% of the sample had no previous eye examination, which reflects the fact that problems with access for most people begin in adulthood. Of those who had been tested, 30% were tested over 24 months ago and so 39% of the total sample were found to be receiving less eye care than the general population, compared to 54% in Lewis' (1995) study and 53% in the Mencap "Health for All?" survey (1998).

Living situation, as well as severity of learning disability and challenging behaviour, was found to be unrelated to whether or not someone had received an eye test and this was probably due to widespread testing in schools. However, the people living with families or independently were significantly less likely to have had a test within the last 24 months than people living with paid support staff. This was the expected finding based on the existing evidence (Mencap "Health for All?" survey, 1998) and the fact that the Eye Care Pack was only distributed to people living in either MLDP network homes or independent sector homes.

No significant differences in service delivery between the four local area groups were found.

Quality of Previous Eye Care

Whilst only 9% reported that they were dissatisfied with their last eye examination, 50% of the sample requested an eye test, which suggests a higher level of discontentment than reported. Comments made by carers with regards to feeling relieved that something was finally being done, also indicated that they had been less than satisfied with previous experiences. Satisfaction was found to be unrelated to location of the test.

Visual Impairments

26.7% of the sample had been previously diagnosed with eye health problems, the most common being cataracts (11%), consistent with Warburg's (2001b) findings, and squints (9.6%). Ophthalmologist input was required for 18.9% of those tested in the intervention phase of the study, four were prescribed treatment, four were prescribed surgery.

Glasses Tolerance

60% of those tested had been prescribed glasses, consistent with Lavis's (1994) finding that 63% of learning disabled adults were visually impaired, but a smaller proportion than the 75% found to have been prescribed with glasses by the Eye Care Group (2000). However, over 40% were found to be unable to tolerate their glasses, a proportion much higher than the 25% previously recorded by the Eye Care Group (2000). The authors believe that this finding is a result of the lack of follow-up support services.

Intervention

Eye examinations were found to be possible for all of the participants who attended appointments and this finding reflects previous claims by eye care professionals (Woodhouse et al, 2000; RNIB). Some people were examined without the use of conventional tests, but nevertheless some assessment was possible for everyone. For example, Cardiff Cards have been found to over-estimate vision (Geer & Westall, 1995), yet they are still useful in that some measure of vision can be taken and, from this, any improvements or deterioration can be seen. Whilst confrontational fields could only be measured for 65.6% of those who attended the Orthoptist, it was felt that more could have been measured if two Orthoptists were in attendance instead of just one. The researchers stress the importance of support from carers / family members at appointments.

Home Visits

Of the 12 people who requested but did not attend appointments, seven people requested home visits due to carer concerns regarding challenging behaviour including “anxious in strange places” and “will not sit still”. In addition, all seven had either severe or profound learning disabilities. Three of the seven had never had their eyes tested and the other four were tested over 24 months ago. Despite the findings that severity of learning disability and existence of challenging behaviour were statistically unrelated to uptake of eye care, this suggests that the most severely impaired learning disabled adults are the group most likely to be missing out on eye care.

It was decided to trial a joint home visit with both the Orthoptist and the Optometrist in a MLDP network home where two learning disabled adults lived together with 24 hour paid support. Both clients had profound learning disabilities and, according to their carers, had never had an eye test. The following conclusions were made from the visit:

1. Use experienced staff where possible.
2. Joint visit with the Orthoptist and the Optometrist is useful for support and administration of certain tests.
3. Important for an experienced carer to be present during testing, especially if the people might present challenging behaviour.
4. Assessment in a known, safe environment leads to better cooperation and compliance with tests.

Evaluation of Intervention

The satisfaction questionnaires revealed generally high levels of satisfaction with all aspects of the intervention eye tests. Waiting times, waiting areas and the reception staff were the aspects of the intervention that people were least satisfied with.

Section E. Recommendations

On the evidence provided by the sample used in this study, we would like to put forward the following recommendations:

For Practice

- Continue to utilise present resources in the form of the Eye Care Pack, but recurrent additional funding is required to biannually update, print and extend distribution to people living with families or independently and also to all GP practices city wide.

For Service Development

- Staff/carer training is essential. Training should include the understanding of certain eye conditions and their effect on living and social skills, accompanying a person to an appointment and assisting with certain treatments. The present arrangement is by annual seminar but this is dependent on staff/speaker resources. There have been discussions on including some form of training at induction but again this will require resources.
- Structured and adequately resourced Ophthalmic provision to this group of the population.
To expand on this recommendation:
- Clinic sites in Central Manchester – one East and one West of the City – using mostly existing Orthoptic equipment and regularly booked clinic rooms. Sessions to be for adults with learning disabilities only with service specific stationary.
- Ophthalmic service provision to include:
 - Two Orthoptic clinics per month using two Orthoptists.
 - Named orthoptist for access and continuity of care.
 - One Optometry clinic bimonthly with orthoptic support.
 - Direct access to Ophthalmologist at Manchester Royal Eye Hospital (MREH).
- Patient caseload would be:
 - New referrals.
 - Follow-up appointments for assessment, support and advice.
 - Follow-up appointments for those who are in transition from special education service, where they have already had Orthoptic input.
- Utilise existing service level agreements and professional links with the Optometry department at the MREH and local Optometrists respectively.
- Utilise access to Ophthalmologist at the MREH which has already been agreed.
- Orthoptist to attend any MREH appointments for continuity of care.

- Build on existing communication links with other health professionals / carers.
- Monitor and audit this new service provision and agree changes if necessary.
- Extend service provision to North and South PCTs
- Given the risks of undiagnosed and untreated visual problems, and the prevalence levels found in this study as well as in previous ones, it is important to repeat the screening exercise for the rest of the city. This will require allocation of modest funding by each Primary Care Trust.

For Future Research

Future research could usefully include:

- Name location on satisfaction questionnaire – continued evaluation of practice in order to identify areas for improvement and examples of good practice.
- Qualitative interviews with learning disabled adults / carers and with eye care professionals about their experiences could provide examples of good practice as well as identify problems and barriers. Further qualitative information regarding why such a high proportion of learning disabled adults are unable to tolerate their glasses would be particularly useful to Orthoptists providing follow-up support. Furthermore, qualitative information on how the intervention has benefited participants would complete the picture that the study paints.

Final Comment

The evidence gathered has provided an excellent opportunity to address an existing inequality of service to this vulnerable population. Addressing such a basic “right to sight” has a considerable impact on their quality of life and consequently on that of the families / carers. To extend existing resources in order to provide the recommendations is cost effective, local and desirable.

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APPENDIX 1

Table 2b: Ethnicity

Ethnicity	Number	Percent
African	1	.7
Afro Caribbean	3	2.1
Arab	1	.7
Asian	1	.7
British	33	22.6
British African	1	.7
British Black	1	.7
British Jamaican	2	1.4
British White	80	54.8
Bangladeshi	1	.7
Caribbean	3	2.1
Irish	3	2.1
Pakistani	7	4.8
Sikh	1	.7
Missing	8	5.5
Total	146	100.0

APPENDIX 2

Table 7: Diagnosed Conditions (7 people diagnosed with more than one condition)

Diagnosed Conditions	Frequency
Cataract	16
Squint	14
Blind in one eye	2
Detached Retina	3
Astigmatism	2
Bilateral Aphakia	1
Blepharitis	1
Conjunctivitis	1
Myopic	1
Astigmatism	1
Riet Pigment	1
Keratoconus	1
Nystagmus	1
Tunnel Vision	1
Total	46

APPENDIX 3

Table 9: Satisfaction

	Very	Fairly	Not at all
How suitable was the waiting area?	54.3%	40.0%	5.7%
How happy with the waiting time?	77.8%	19.4%	2.8%
How friendly were the reception staff?	80.6%	16.7%	2.8%
How friendly was the Orthoptist's manner?	97.2%	2.8%	0%
How friendly was the Optometrist's manner?	96.4%	3.6%	0%
How friendly was the Ophthalmologist's manner?	85.0%	15.0%	0%
How clear was the explanation?	97.0%	3.0%	0%
How able felt to ask questions?	85.7%	11.4%	2.9%
How necessary was the written information?	63.2%	31.6%	5.3%
How easy was it to understand the written information?	86.4%	9.1%	4.5%