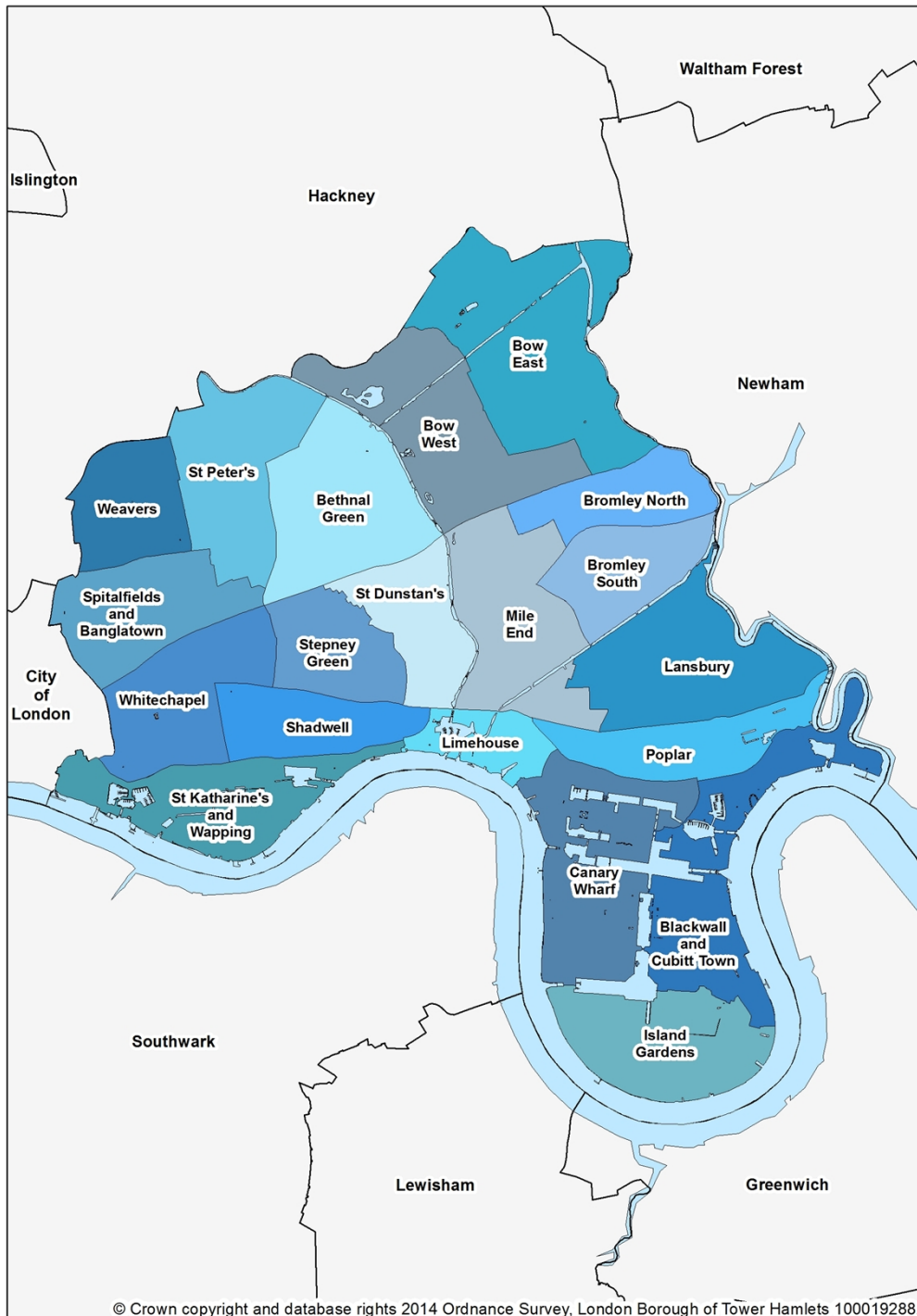


Vision for Tower Hamlets: A Plan for Eye Care & Inclusion 2013 – 2016



Contents

Executive Summary 4

1. Introduction 6

Evidence Base

2. Costs, Trends, and Prevalence of Visual Impairment 10

3. Main Diagnoses of Visual Impairment 12

4. Socio-Economic Factors 14

5. Life and Lifestyle Factors 15

6. Other Conditions Linked to Visual Impairment 20

7. Health, Wellbeing and Visual Impairment 22

8. Patients, Service Users and Carers 26

Mapping The Sector

9. [The Vision Pathway](#)

10. [Services on the Visual Impairment Pathway in Tower Hamlets](#) 27

11. [Wider Avenues of Support](#) 45

In Conclusion

12. Conclusion 48

13. Service Development Priorities 49

Appendix

Executive Summary

Tower Hamlets Vision Plan sets out the current landscape for eye health and visual impairment support provision in the Tower Hamlets identifies service and delivery considerations and sets out recommendations for current and future service provision.

The Plan brings together professionals across hospitals, health agencies, the council, voluntary sector, patients and service users to evidence current and future service requirements, resulting in a cross sector plan of action that supports the implementation of Outcome Frameworks for the NHS, Public Health and Adult Social Care.

The main challenges facing Tower Hamlets in its provision of eye health and visual impairment support services are:

- The population of visually impaired people in Tower Hamlets is expected to increase from 3,340 to 3,950 by 2020 ¹
- In 2010/11 £9.34 million was spent by Tower Hamlets Primary Health Care Trust on 'Problems of Vision'. With an expected increase in visual impairment by 2020, this could rise significantly over the next 7 years².
- 50% of visual impairment, and expenditure, is avoidable. Greater awareness of eye health, improved sight loss pathways, more timely detection of eye disease and changes to individuals' lifestyles are some of the factors that can reduce this.

Reducing unnecessary sight loss can potentially lead to cost savings within local areas as well as helping to maintain good health, wellbeing and independence for individuals through the modification of lifestyle and increased awareness of visual impairment.

While there is some great work happening to support those with a visual impairment in Tower Hamlets there are also some critical gaps. The most critical main gaps in the provision of vision services are:

- **Health and Wellbeing:** Embed the Vision Plan into the Health and Wellbeing framework, and achieve a user led partnership approach to the planning, delivery and evaluation of eye health and sight loss support services (Action Plan 1)
- **Prevention:** Maximise the uptake of eye examinations and raise awareness of eye health to ensure that avoidable sight loss is prevented wherever possible (Action Plan 2)
- **Joined up data:** Ensure that comprehensive cross sector data on sight loss and local demographics is collected and shared to inform resource allocation across

¹ RNIB Sight Loss Data Tool (Nov 2013)

² 2010-11 Programme Budgeting Benchmarking Tool Version 1.1 27.01.12

Public Health, NHS, Optometry, Social Care and Voluntary organisations (Action Plan 3)

- **Joined up services:** Ensure that an effective and efficient service provision is available, resulting in a clear pathway for people experiencing sight loss from diagnosis through to independent living. This will include optometrists, GPs, eye clinics, social care teams and voluntary services (Action Plan 4)
- **Social inclusion and independence:** Ensure that people with sight loss have good access to key local services - information, transport, leisure, employment, education and welfare rights to obtain and maintain independence and not experience social exclusion, inequality or isolation (Action Plan 5)
- **Children's services:** Develop and embed into the main Vision Plan considerations for children and young people, including evidence of current and future need, sight loss pathway, arrangements for transition to adult services and an action plan to address gaps and need (Action Plan 6)
- **Visually Impaired people with complex needs:** Ensure that the needs of people with visual impairment as a secondary presenting condition are recognised. Visual impairment is often overlooked in those with, for instance, Dementia, Parkinson's, Learning Disabilities, etc. (Action Plan 7)

The immediate priorities, identified through consultation with visually impaired people in Tower Hamlets are:

- **Health and Wellbeing:**
 - Embed the Vision Plan and Eye Health JSNA (2009) into the Health and Wellbeing framework and Commissioning Plan,
 - Ensure links with Tobacco Control, Healthy Weight, Healthy Lives (Obesity), Diabetes, Falls strategies are in place.
- **Prevention:** Maximise the uptake of eye examinations and raise awareness of eye health, through targeted campaigns, to ensure that avoidable sight loss is prevented wherever possible.
- **Joined up data:** Implement method of identifying agreed accurate cross-sector figures for the number of local people with sight loss or low vision.
- **Joined Up Services: Improved guidance on existing services:**
 - **Referral Systems:** Ensure referral systems between the sectors (Health, Social Services (Adults and Children) and Voluntary) are in place and being used effectively.
 - **Community Optometry:** Re-address and re-commission the Learning Disability Service, Low Vision Service and Direct Cataract Referral Scheme
- 1. **Eye Clinic Liaison Officers:** Provide an Early Intervention/Advice and Information Service at all Eye/Low Vision Clinics

2. **Ongoing Support:** Maximise the opportunities for both those with sudden sight loss and long-term degenerative conditions to access on-going rehab and emotional support services at any and multiple points in their life.
- **Social inclusion and independence:**
 - **Accessible formats:** Increase availability of information on services, social activities and appointments (GP and hospital) in accessible formats
 - **Visual Awareness Training:** Increase visual awareness training for staff who provide public services (esp. with regard to transport, employment services, life-long learning, leisure services)
 - **Navigation:** Address street furniture, uneven pavements, barriers and beepers at road crossings, to enable Visually Impaired people to travel safely

[Back to Contents](#)

1. Introduction

The Tower Hamlets Vision Plan aims to provide a single portal for the planning, commissioning, delivery and evaluation of services for eye health and visual impairment support in the Tower Hamlets. It also aims to ensure that Tower Hamlets is able to implement national outcomes linked to eye health and visual impairment set out in the Government's outcomes frameworks for the NHS³, Public Health⁴ and Adult Social Care⁵. References to the relevant outcomes are made throughout the document.

The Plan sets the stage for the development of seamless, cost effective and joined up prevention initiatives and service provision in Tower Hamlets that puts patients and service users at the heart of their delivery. The Plan and its accompanying Action Plan is clear opportunity to respond to the Public Health Outcome Framework aim of having a comprehensive agreed inter agency plans for responding to public health incidents (3.7). An accompanying action plan will ensure that the recommendations are owned and implemented across all key sectors.

The Plan and action plan have been developed by a cross sector planning group, whose members includes patients and service users, clinicians, professionals, senior managers and advisory agencies representing the Local Authority, Health and the Voluntary Sector.

The implementation of the recommendations contained in this document and its accompanying Action Plan will be regularly reviewed by the Tower Hamlets Vision Strategy Group and revised as local policy, strategy, priorities or service considerations in the Tower Hamlets change.

The Tower Hamlets Vision Plan implements the UK Vision Strategy⁶; the UK Vision Strategy's three outcomes are:

- Everyone in the UK looks after their eyes and their sight.
- Everyone with an eye condition receives timely treatment and, if permanent sight loss occurs, early and appropriate services of support is available and accessible to all.
- A society in which people with sight loss can fully participate.

Visual impairment impacts our community on many different levels; on a personal level it can be a deeply traumatic life event. On an economic level, it is estimated that in 2008 visual impairment cost the UK £22 billion. Yet, the number of visually

³ http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_131723.pdf

⁴ http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_132559.pdf

⁵ http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_133335.pdf

⁶ <http://www.vision2020uk.org.uk/ukvisionstrategy/page.asp?section=32§ionTitle=About+the+Strategy>

impaired people living in the UK is set to double from 2 to 4 million by 2050. Therefore, the issues that surround the support and prevention of visual impairment need to be urgently tackled.

“I could not believe it. It was like somebody had ripped the rug from underneath my feet. I was in no man’s land.”⁷

The development of a visual impairment can be an upsetting and disrupting experience. It can lead to the loss of one’s employment, hobbies and leisure activities, routines need to be adapted, and everyday tasks become harder to achieve without outside help. Depression is also a common consequence of visual impairment in later life. However, these consequences can be eased with the right kind of rehabilitation, support, and enablement. The right support at this time can be crucial in helping individuals regain independence and to re-engage in a social and economic context. In essence, with the appropriate rehabilitation, the costs associated with visual impairment can be eased on a personal, social and economic level.

[Back to Contents](#)

Evidence Base

2. Costs, Trends, and Prevalence of Visual Impairment

There are 1,225 registered with a visual impairment in Tower Hamlets; 615 are registered as Severely Sight Impaired (blind) and 610 as Sight Impaired (partially sighted). Of these 105 are under 16 years old.⁸

However, for a number of reasons, not everyone with a visual impairment affecting their day-to-day life is registered as sight impaired or severely sight impaired.⁹ Therefore, a much more accurate estimate would be about 3,340 blind or partially sighted people living in Tower Hamlets¹⁰.

Clearly, a more comprehensive registration process would help service providers plan their services more effectively, it would also help empower people living with a

⁷ Blind female aged 30, ‘Executive Report for the Thomas Pocklington Trust: Emotional Support to People with Sight Loss’, 30th June 2010, p322.

⁸ RNIB Sight Loss Data Tool (Nov 2013)

⁹ This is based on the fact the while 360,000 are registered as blind and partially sighted it is estimated that 2,000,000 people in the UK live with sight loss that affects their day-to-day lives. See <http://www.rnib.org.uk/aboutus/research/statistics/Pages/statistics.aspx> for more information.

¹⁰ RNIB Sight Loss Data Tool (Nov 2013)

visual impairment to push for better low vision services by illustrating their widespread need in Tower Hamlets.

In 2011 £9.34 million was spent by Tower Hamlets Primary Health Care Trust on 'problems of vision'¹¹.

NB: this refers to the cost of low vision services such as hospital admission for cataract surgery or glaucoma treatment. This does not include the associated costs to the NHS for accidents that arise from visual impairment.

There are 254,100 people living in Tower Hamlets,

- 18,700 are age 0-4
- 43,300 are aged 5-19
- 125,500 are aged 20-39
- 50,900 are ages 40 - 64
- 15,500 are aged 65+. ¹²

The ratio of men to women in the Tower Hamlets is 49.6:50.4.

51.2% are from black or ethnic minority backgrounds.

The 3 largest migrant groups are from:

Bangladesh	20.1%
India	2.7 %
China	1.9 % ¹³

2.1 Future trends in visual impairment and predicted costs

Figure 1 - Predictions of the number of people who will be living in the Tower Hamlets broken down by eye-condition type.

Source: Sight Loss Data Tool (Nov 2013)

Condition	Current Prevalence
Age Related Macular Degeneration (AMD)	930
Cataracts	1,250
Diabetic Retinopathy	2,950
Glaucoma	1,690

¹¹ NHS programme budgeting PCT
http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_132501.zip

¹² 2011 Census Population Figures

¹³ GLA Intelligence: London Borough Profiles 2011/12

It is estimated that there are 3,340 people currently living in Tower Hamlets with a visual impairment. This is projected to increase to 3,950 by the year 2020. This would be an extra 610 people living in the community with visual impairment that impinges on their day-to-day life.¹⁴

The reasons for this increase will be discussed in detail below but the main reasons for this increase are; an aging population, ethnicity and certain lifestyle factors that place people at increased risk of visual impairment.

[Back to Contents](#)

3. Main Diagnoses of Visual Impairment

Public Health Indicator for Eye Health

The first ever Public Health Indicator for eye health came into force on April 1st, 2013.

As part of the new Public Health Outcomes Framework, the Indicator will track changes in the numbers of people who are certified as blind or partially sighted and have lost their sight from one of the three major causes of preventable sight loss: glaucoma, wet age-related macular degeneration and diabetic retinopathy.

The Public Health Framework Data Tool, detailing prevalence in each region can be accessed here:

<http://www.phoutcomes.info/search/eye%20health#gid/1/par/E12000007/ati/102/page/0>

3.1 Age Related Macular Degeneration – this is the most common form of sight-loss in the UK and mainly affects people aged 50 and over.

Estimates suggest that there are roughly 930 people in Tower Hamlets living with Age Related Macular Degeneration.

3.2 Glaucoma - this is caused by optic nerve damage, although early diagnosis and regular treatment can halt its progression.

Estimates suggest that there are roughly 1,690 people in Tower Hamlets living with Glaucoma.

3.3 Diabetic Retinopathy - is a complication of diabetes, and is also the leading cause of blindness in people under the age of 65. Estimates suggest that there are roughly 11,859 people in Tower Hamlets who suffer from diabetes (with 2,950 currently experiencing background Diabetic Retinopathy) and 80% of people living with diabetes for longer than 10 years will develop some degree of diabetic retinopathy. Consequently, without even accounting for an increase in the number of diabetics, within 10 years there is likely to be a further increase in people living with impaired vision in Tower Hamlets.

3.4 Cataracts – are also common in older people, but can be treated through surgery.

Estimates suggest that there are roughly 1,250 people in Tower Hamlets living with Cataracts.

3.5 Accidents - changes in vision can also result from optic nerve damage caused by brain injuries. The most common cause of brain injuries is a blow to the head during car and motorcycle accidents. Research from the US has also suggested that visual impairment tends to be higher amongst veterans given the higher likelihood of bodily injury, this phenomenon has become known as 'blast trauma'.¹⁵

3.6 Cancer - there are several cancers that can cause problems with vision. The most direct cause is eye-cancer, which can necessitate the removal of one or both eyes. Regular eye check-ups can help spot the problem early and prevent the need for major surgery. Nasal and sinus cancers may also cause problems with vision, as can cancer of the nasopharynx (the tube that connects the nose to the back of the mouth) and brain tumours.¹⁶

3.7 Neurological Conditions - There are also several neurological conditions that are closely associated with visual impairment, the most common of which is Multiple Sclerosis (M.S.). This is a condition where the immune system attacks the brain, spine and optic nerves. One of the first symptoms of M.S. can be the loss or blurring of vision, therefore it is important that eye-health professionals are able to recognise symptoms and refer patients is necessary.

3.8 Strokes – are similarly a risk factor in the development of visual impairment. Around 60% of stroke survivors have some form of visual impairment, such as loss of visual field, blurred vision, double vision and 'tunnel' vision.¹⁷

There were 2044 strokes in 2012 in Tower Hamlets. The 2006/7 incidence of Stroke emergencies was 151.8, which in 2008/9 increased to 153.5.¹⁸

3.9 Genetic Eye Conditions - In addition to the above sight loss condition there are a diverse range of eye disorders which can result in blindness; (eg Retinitis Pigmentosa – RP) these conditions can have a genetic origin, in many cases the deterioration is a gradual erosion of sight, taking decades and may remain undiagnosed until a significant impact on an individuals sight is experienced. These conditions are rarely treatable, making the need for direct access to consistent levels of support and rehabilitation services essential throughout a person's life as adaptation to the loss of vision takes place.

[Back to Contents](#)

¹⁵ <http://www.aao.org/publications/eyenet/200811/woundsofwar.cfm>

¹⁶ For more information on sight loss and cancer consult: <http://www.cancerresearchuk.org/home/>

¹⁷ For more information see <http://www.rnib.org.uk/eyehealth/eyeconditions/eyeconditionsoz/pages/stroke.aspx>.

¹⁸ Tower Hamlets Stroke: factsheet :
https://www.google.co.uk/url?sa=t&rct=j&q=&esrc=s&source=web&cd=7&cad=rja&ved=0CFYQFJAG&url=http%3A%2F%2Fwww.towerhamlets.gov.uk%2Fidoc.ashx%3Fdocid%3D2fd81f12-8ee3-45d7-9b83-c7754d61bae2%26version%3D-1&ei=OBSnUYmDM8S_Oe3dgMgB&usq=AFQjCNE1zo7gj0r5cK_Zyj5YYde3SdSdDg&bvm=bv.47244034.d.ZWU

4. Socio-Economic Factors

4.1 Deprivation - Tower Hamlets is a deprived borough. It is ranked 3rd out of 32 for levels of deprivation in London, and 7th out of 346 in England.

Research has shown that three out of four people with visual impairment live in, or on the margins of, poverty.¹⁹ This means that those living with a visual impairment are also more likely to be the some of the most economically vulnerable in the Tower Hamlets. Those with a low life expectancy are also more likely to develop a visual impairment later on in life, due to poorer health indicators throughout their lives.

4.2 Ethnicity - also affects one's chances of developing a visual impairment.

Glaucoma - is more common in people of African, African-Caribbean, South-East Asian, or Chinese origins.

Cataracts – are more common in people of Asian origin.

Diabetic Retinopathy – is more common in people of African, African-Caribbean, or Asian origins.

Tower Hamlets has a black and ethnic minority (BAME) population of 51.2%

The three largest groups are:

Bangladeshi 20.1%

Indian 2.7%

Chinese 1.9%²⁰

Research by Sight Loss UK has suggested that information campaigns targeting black and ethnic minority populations can be highly cost effective in prevention campaigns.²¹

[Back to Contents](#)

¹⁹ Unseen: neglect, isolation and household poverty amongst older people with sight loss, RNIB, March, 2004,

²⁰ London Borough Profiles 2012

²¹ Darwin Minassian and Angela Reidy Future, Sight Loss UK 2: An epidemiological and economic model for sight loss in the decade 2010-2020, Epivision and RNIB, 2009.

5. Life and Lifestyle Factors

Lifestyle factors have a significant bearing on the prevalence of visual impairment in a local area. The main factors are listed below with an indication of how we might expect their relevant importance to increase (or decrease) in the next few years.

5.1 Aging – on a positive note, improved public health, nutrition, and lifestyle means people in the UK are living longer. This is no exception in Tower Hamlets, where the number of people aged 60 + is estimated to increase from 15,570 to 19,293 by 2015.

Unfortunately, 80% of those who are blind or partially sighted are aged 60+. As a consequence, the number of people who suffer from visual impairment will increase by 15,434 within the next 2 years. Aging increases the likelihood, of Macular Degeneration, Cataracts, and Glaucoma.

This will represent a significant challenge for providers of low vision services in the immediate future; an increase in older people in the community will not only increase the number of people seeking help from services, but also alter the needs of those seeking help. Rehabilitation for visual impairment in older people may well need to be done in with reference to other age related health problems, such as poor mobility or dementia.

There is a specific Public Health Outcome indicator for preventable sight loss (4.12). However, there are additional Public Health, NHS and Adult Social Care Public Indicators that can be addressed as part of this Vision Plan

The Adult Social Care Indicators for aging include the proportion of older people (65+) who are at home 91 days after discharge from hospital into re-enablement/rehabilitation services (2B)

5.2 Smoking - the link between smoking and macular degeneration is well documented. Not only are smokers 50% more likely to develop macular degeneration, but they are also likely to develop it at an earlier age. On the other hand, the cessation of smoking (for a period of 20 years) has also been shown to reverse the damage caused by smoking.²² Tower Hamlets smoking prevalence rates stands at 27%, compared to a national prevalence of 21% in 2011.²³

²² 'Further Observation on the Association Between Smoking and the Long-term Incidence and Progression of Age-related Macular Degeneration: The Beaver Dam Eye Study', Ronald Klein, Michael D. Knudtson, Karen J. Cruickshanks, Barbara E. K. Klein, *Archive of Ophthalmology*. 2008, vol. 126, no. 1, pp.115-121.

²³ Statistics on Smoking: England, 2011, Health and Social Care Information Centre, Lifestyle Statistics, 2011.

5.3 Obesity - has been shown to be a risk factor for all four major eye-diseases, macular degeneration, Glaucoma, Diabetic Retinopathy and Cataracts.²⁴

Given recent trends in obesity, this is a particular point of concern. It is estimated that 20-30% of the adult population in Tower Hamlets is clinically obese indicating that obesity related eye problems will increasingly become a major eye-health issue.²⁵ In regards to childhood obesity nearly 1 in 7 children aged 4-5, and over 1 in 4 children aged 10-11 are obese in the borough. The obesity rates are the fifth highest proportion of obesity aged 10-11 in London and the sixth highest in the country.²⁶

5.4 Alcohol - there is clear association between excessive consumption of alcohol over a sustained period of time and the development of all four main eye-diseases, although, the reason for this is not currently clear. In addition, alcohol consumption by women during pregnancy has also been linked to ocular abnormalities in children.²⁷

Tower Hamlets JSNA shows that use of alcohol within the community is moderate, with 63% consuming alcohol in the borough.

Binge drinking in Tower Hamlets has been shown to be increasing. Again, it is likely that this trend will lead to increased pressure on low vision services in the area. Also, accidents resulting in visual impairment are often linked to intoxication.

Recent research on alcohol use amongst older people also suggests that alcohol use amongst older people tends to be higher despite a lower tolerance to its effects. Many health conditions and hospital admissions are also related to alcohol use, which may in turn reflect social isolation, bereavement and loss of status in older age.²⁸

5.5 High Blood Pressure - the restriction of blood to the eye can cause damage to the retina and result in the deterioration of eye health. Heart health and good circulation is therefore essential to maintaining good eye health.

In Tower Hamlets, instances of high blood pressure have reached 15,000 people of the borough's population. Again, it is likely that this will strain of the provision of local visual impairment services.

²⁴ 'Obesity and Eye Disease', Cheung and Wong, Survey of Ophthalmology, vol.52, issue. 2, pp. 180-195.

²⁵ NHS Tower Hamlets Adult Obesity <http://www.towerhamlets.nhs.uk/about-us/public-health/our-priorities/adult-obesity/>

²⁶ NHS Tower Hamlets Childhood Obesity <http://www.towerhamlets.nhs.uk/about-us/public-health/our-priorities/childhood-obesity/>

²⁷ 'Alcohol and Eye-Disease: A Review of Epidemiologic Studies', Hiratsuka and Li, Journal of Studies on Alcohol and Drugs, 2001, May, Vol.62, issue 3.

²⁸ <http://www.ias.org.uk/resources/factsheets/elderly.pdf>

5.6 Strokes – As previously referred to in the ‘Main Diagnosis of Visual Impairment’ section, strokes are similarly a risk factor in the development of visual impairment, and will have an impact on the provision of local visual impairment services.

There are approximately 2000 people living in Tower Hamlets who have had a stroke and each year there are approximately 350 incidences of stroke admissions to secondary care each year.²⁹

5.7 Diabetes - Diabetes is the leading cause of blindness in working age people. As such, it could be considered one of the most economically damaging factors leading to visual impairment.

There are currently 11,859 of people in Tower Hamlets living with diabetes³⁰. National trends have suggested that the number of people living with diabetes has increased by 25% since 2006, and if trends were to continue (given that 80% of diabetics develop retinopathy within ten years³¹) diabetic related visual impairment will become a major pressure on local low vision and rehabilitation services.

Aside from the strong associations between obesity and type 2 diabetes, there are also some important demographic links; people of South Asian origin are six times more likely than white people to develop type 2 diabetes, and those of African-Caribbean origin three times more likely. Members of ethnic minorities are also more likely to develop complications of diabetes at an earlier stage. It is particularly important, therefore, for people within ethnic minorities to be aware of the potential effect of diabetes on their sight.

National guidelines suggest children will not get screened for Diabetic Retinopathy until they are at 12 years old. Therefore it is important that children and their parents are made aware of the impact of diet, lifestyle and condition management before they reach the age of screening to avoid the early onset of Diabetic Retinopathy.

Tower Hamlet’s eye screening programme takes place in the diabetes centre in Mile End Hospital. The service provided offers a wide range of services from screening and testing to support and education. One of the services available is HAMLET (Hands-on Approach to Motivation and Lifelong Empowerment Training) is a structured diabetes education for people with type 2 diabetes, which is designed to help people manage their diabetes on a day-to-day basis. DIANA (Daily Insulin dose Adjustment to Nutrition and Activities) is another service that provides an educational course for people with type 2 diabetes, teaching people how to use the tools needed to accurately adjust their insulin to match their carbohydrate.³²

²⁹ Stroke JSNA Factsheet 2010-11

³⁰ Diabetes Fact Sheet Tower Hamlets JSNA 2010-2011 http://www.towerhamlets.gov.uk/lgs/701-750/732_jsna.aspx

³¹ Klein BE. Overview of epidemiologic studies of diabetic retinopathy. *Ophthalmic Epidemiology*. 2007 Jul-Aug, vol. 14, no. 4, 179-83.

There are clear indications that the number of people experiencing visual impairment will strain local resources in the coming years as the projected health demographics of Tower Hamlets develop. Therefore, measures that tackle the above factors, such as improved sight loss pathways, better public awareness and increased eye screening could reduce future eye care costs, help to eliminate avoidable visual impairment, and could also improve the overall health and wellbeing of the local community.

[Back to Contents](#)

6. Other Conditions Linked to Visual Impairment

Delivering a smooth, joined-up and holistic service for those with a visual impairment requires a consideration of additional health and wellbeing factors that are most common in people with visual impairment.

6.1 Learning Disabilities – 1 in 10 people with a learning disability have some form of visual impairment.³³ This means that out of the 1,000 adults in Tower Hamlets with learning disabilities, roughly 100 will also be experiencing some form of visual impairment³⁴.

Diagnosis of visual impairment in people with severe learning disabilities presents several problems for the health care professional. People with learning disabilities can struggle to use the traditional sight tests, which are based on reading and letter recognition. Those with learning disabilities may also be less able to express to others that they feel that their eye-sight is deteriorating.

Yet, research conducted by the Centre for Disabilities Research in 2008 suggested that only half of people with learning disabilities had received an eye test in the past twelve months. It also showed that the proportion relieving regular eye examinations declined as the severity of the disability increased.³⁵

6.2 Dementia - visual impairment is most likely to develop in older people. Therefore, it often accompanies other medical conditions that are more prevalent later in life - such as dementia. Research by the Thomas Pocklington Trust conservatively estimated that 2% of the population aged 75+ are visually impaired and suffer from dementia. This equates to 148 people in Tower Hamlets.

The relationship between dementia and visual impairment is particularly problematic as patients may struggle to remember how their vision has deteriorated over time.

Some forms of dementia have a direct impact on vision, and may cause the loss of functional vision even when a person's eyes are healthy. Recent research has also suggested that some forms of dementia and visual impairment share a common causal pathway. Although this research is still in its infancy, the higher rate of visual impairment in those with dementia certainly suggests a strong link between the two.³⁶

³³ http://www.seeability.org/our_services/knowledge_base/eye_2_eye_campaign.aspx

³⁴ Learning Disabilities Tower Hamlets JSNA 2010-11 http://www.towerhamlets.gov.uk/lgsi/701-750/732_jsna.aspx

³⁵ Hemmerson & Hatton, People with Learning Disabilities in England, Centre for Disabilities Research Report, May, 2008, p.14.

³⁶ Pham T, Kifley A, Mitchell P, Wang JJ (2006) Relation of age-related macular degeneration and cognitive impairment in an older population, *Gerontology* 52, 353-358; Uhlmann RF, Larson EB, Koepsell TD, Rees EB, Duckert LG (1991) Visual

6.3 Deaf blindness – dual sensory loss requires specialist care to enable both communication and mobility. However, despite the need for highly specialised support, Sense UK has suggested that the deaf blind population are significantly underestimated. In January 2014 there were 86 people in Tower Hamlets living with deaf blindness on the Sight and Hearing Service’s database. The Centre for Disability Research has estimated that the population for deaf blindness will increase by 60% in the next 18 years.³⁷

[Back to Contents](#)

impairment and cognitive dysfunction in Alzheimer's disease, Journal of General Internal Medicine 6, 126-132.

37 <http://www.sense.org.uk/Resources/Sense/Publications/Documents/Sense%20of%20Urgency.pdf>

7. Health, Wellbeing and Visual Impairment

7.1 Depression – there is a well established link between depression and visual impairment, as discussed earlier. This can result in a reluctance to actively seek help, or respond to help when offered; it has also been shown that those who are depressed have poorer health outcomes from rehabilitation. This is particularly true of older people with visual impairment who are three times more likely to suffer from depression than their peers without visual impairment.³⁸

7.2 Social Isolation – Research by the Thomas Pocklington Trust has shown that visual impairment can lead to social isolation because, as mobility becomes harder, one's opportunity to socialise outside the home decreases. It also highlighted that an inability to pick up on important visual cues in social settings makes communication with others difficult thereby increasing social isolation. Finally, visual impairment increases one's dependence on friends and family, this can in turn result in social relationships becoming tense as family members and friends feel the strain of looking after loved ones.³⁹

7.3 Falls – can be both physically and psychologically damaging. Physically, blind and partially sighted people are 1.7 times more likely to fall and 1.9 times more likely to have multiple falls leading to injury, such as fractured hips.

The cost of falls to the NHS in Tower Hamlets in 2010-11 was estimated to be £1,146,000. ⁴⁰21% of this total is estimated to have been spent on those with a visual impairment, this equates to £240,660.

There is no falls strategy for Tower Hamlets available online. Tower Hamlets does have a Falls Prevention Team that consists of a physiotherapist, occupational therapist, a nurse and rehabilitation support workers. They offer a one to one therapy to improve strength, balance, mobility, confidence and overall function. There is also a twelve week balance and strength training programmes at various centres within Tower Hamlets including a group at Mile End Hospital. ⁴¹

Better planning of public space, transport, and rehabilitation could help prevent the need for resources being spent further down the line on treatment for the physical injuries, as well as improving the psychological wellbeing, of those with visual

³⁸ Burmedi, Becker, Heyl, Wahl and Himmelsback, "Emtional and Social Consequences of Age-Related Low Vision: a narrative view", Partial Sight and Blindness Research, Vol. 4, No. 1, pp. 47-71.

³⁹ 'Emotional Support to People with Sight Loss: Research Findings', September 2009, no.26.

⁴⁰ Falls in Tower Hamlets 2011 http://www.towerhamlets.gov.uk/lgs/701-750/732_jsna.aspx

⁴¹ Community Health Services Tower Hamlets http://www.towerhamlets.gov.uk/lgs/701-750/734_community_catalogue/staying_healthy/community_health_services.aspx#Falls

impairment. Psychologically, a severe fall causing physical injury can lead to fear of leaving known environments, thereby increasing social isolation.

The additional factors, outlined above, underline the diverse and varied ways that visual impairment can impact upon the everyday life of visually impaired people. It also highlights the need to consider how visual impairment may be part of the wider needs of the individual. It is a strategic aim of Tower Hamlets that the care and treatment provided for individuals is considered in this holistic manner.

[Back to Contents](#)

8. Patients, Service Users and Carers

8.1 Patients and Service Users - In 2012 a national consultation of thousands of service users across the UK was undertaken as part of an initiative called 'Seeing it My Way'⁴². The consultation identified 10 key expectations of patients and service users with visual impairment:

1. That I have someone to talk to
2. That I understand my eye condition and the registration process
3. That I can access information
4. That I have help to move around the house and to travel outside
5. That I can look after myself, my health, my home and my family
6. That I can make the best use of the sight I have
7. That I am able to communicate and to develop skills for reading and writing
8. That I have equal access to education and life long learning
9. That I can work and volunteer
10. That I can access and receive support when I need it

8.2 Carers

Tower Hamlets has two carers strategy the 'Carers Plan 2012 – 2015' and the 'Young Carers Strategy'. These plans do not specifically outline the strategy for carers of those with visual impairments.

[Back to Contents](#)

Mapping The Sector

9. Introducing the Vision Pathway

The chart below illustrates the ideal path that a service user should experience during the initial process of diagnosis and rehabilitation. It is hoped that this will highlight how service gaps can interrupt the process of rehabilitation, prolonging, or even impeding progress towards an active, independent, and fulfilling life.

Stage 1

Local eye-health campaigns promote eye-health awareness amongst GPs and encourage individuals to visit their local Optician.



Stage 2

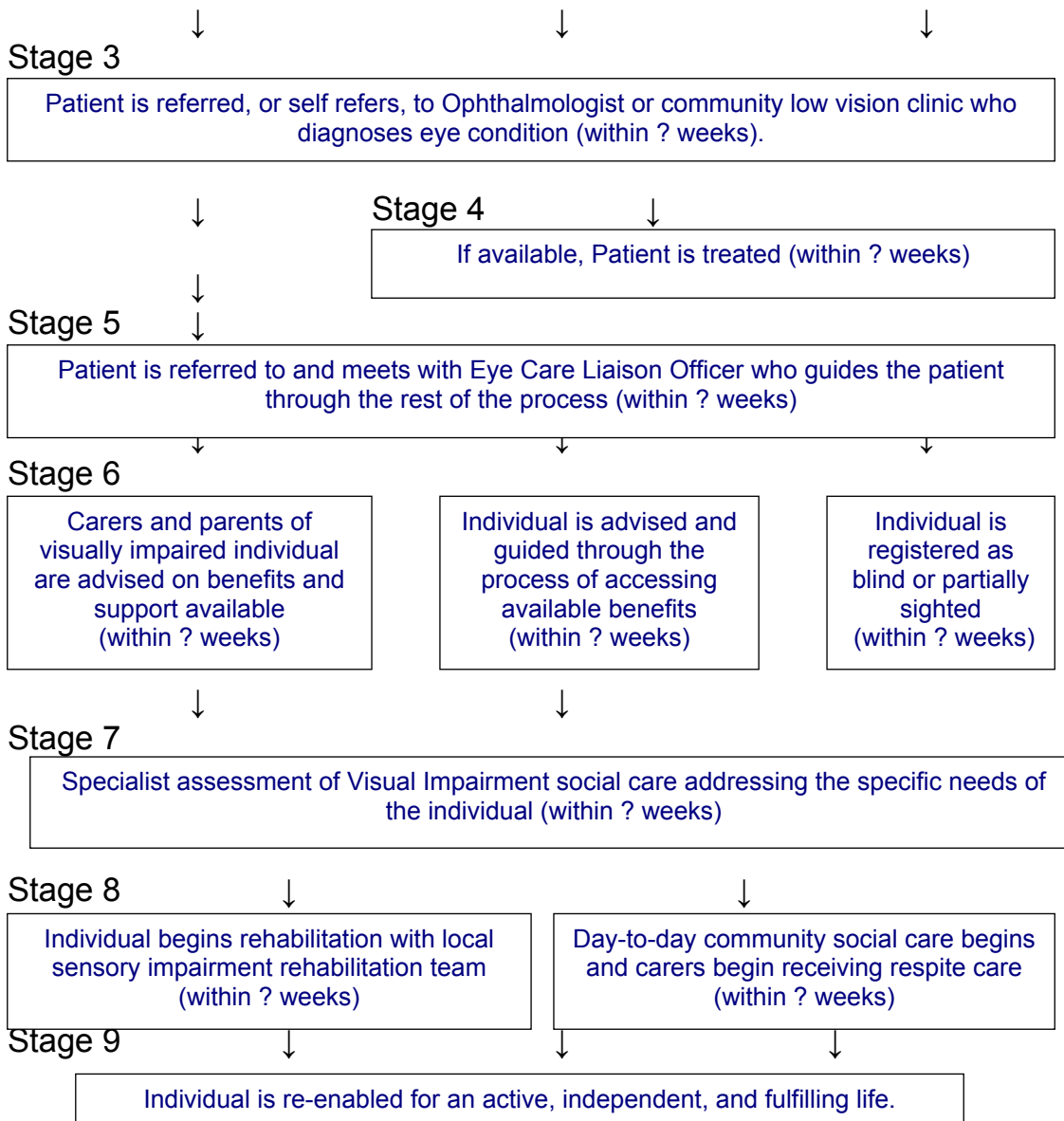
Individual, family member or carer refers patient.

Optometrist notes abnormality during regular eye test

GP suspects loss of vision

⁴²

<http://www.actionforblindpeople.org.uk/get-involved/campaigns/seeing-it-my-way/>



(Total ? weeks)

[N.B. in the ideal pathway a patient can withdraw at any time and re-enter the pathway when they are ready to complete the process

The steps below describe the ideal path that a service user should experience during the initial stages of prevention, diagnosis, treatment and rehabilitation. It is hoped that this will highlight how service gaps can interrupt, prolonging, or even impede early diagnosis, treatment or progress towards an active, independent, and fulfilling life.

Stage 1: Promoting Eye Health

- Implementation of the Public Health Outcome Indicator for sight loss
- Cross sector eye-health and lifestyle campaigns to promote eye-health awareness and the impact of lifestyle on vision with the general public
- Activities to increase knowledge and awareness of local service provision and referral mechanisms across service providers and professionals

Stage 2: Spotting the Problem

- Individual, family member, carer or professional refers patient to Optometrist, GP or Hospital
- Optometrist notes abnormality during regular eye test.
- GP suspects loss of vision

Stage 3: Diagnosis

- Patient is referred, to Primary Eyecare Acute Referral Scheme (PEARS) service (if available)
- GP, Optometrist or PEARS service refers to an Ophthalmologist. Eye condition is diagnosed
- GP, Optometrist, Ophthalmologist or PEARS service refers to a community low vision clinic, who assesses patient (within **8** weeks)

Stage 4: Treatment

- Ophthalmologist treats patient (within maximum of 18 weeks), who advises whether sight is recoverable, will further deteriorate or is untreatable. Patient advised whether eligible for Certificate of Visual Impairment (CVI) and if so this is issued within 5 days of patient's agreement.
- Community Low Vision Clinic provides support with visual aids and adaptations

Stage 5: Introduction to Support

- Where available, patient is referred to and meets with Eye Clinic Liaison Officer (ECLO) or equivalent
- Patient receives information on emotional and psychological support options available
- Individual is signposted to voluntary sector organisations options for information and support

Stage 6: Emotional and Practical Support

- ECLO/equivalent advises and supports the patient, their carer or parents to access benefits and support (within **1** week)
- Individual is registered as blind or partially sighted (within **1** week)
- Individual begins emotional and practical support options via formal or informal counselling, and support from Voluntary Sector organisations
- Local Authority or contracted agency contacts to begin social care assessment

Stage 7: Assessment and Rehabilitation

- Specialist assessment of individual by social care or contracted agency to address the specific needs (within **5** weeks)
- Individual begins rehabilitation with local sensory impairment rehabilitation team or contracted agents (within **16** weeks)
- Day-to-day community social care begins and carers begin receiving respite care

Stage 8: The Road to Independence

- Individual's health and social care needs are reassessed at regular intervals and programme of care is adjusted accordingly
- Individual is advised of the level of care to be provided by the sensory team and purchase of services (within 1 week)
- Individual accesses Voluntary Sector support, activities, events, training and other services
- Individual is supported to undertake independence activities (accessing transport, leisure, education, employment)

Stage 9: Independence

- Individual is able to live an active, independent, and fulfilling life.

[Back to Contents](#)

10. Services on the Visual Impairment Pathway in Tower Hamlets

This section has been organised to follow the ideal path that a person might experience in relation to prevention, or on identifying eye health problems or visual impairment might follow

10.1 Stage 1 – Promoting eye-health

Local public health campaigns that promote the eye-health of the local community, especially those that target 'at risk' groups, are an essential in sparking the process of diagnosis and rehabilitation.

There is currently no public awareness campaign focusing on eye-health in Tower Hamlets.

It is important that practitioners and professionals across the eye health and sight loss support pathway are aware of services that may complement or overlap their own service provision, which will improve the seamlessness of services (which also has the potential to reduce costs).

[Back to Contents](#)

10.2 Stage 2 - Spotting the Problem

The agencies described below are crucial in Tower Hamlets eye-care system; it is through visits to a local high street Optometrist, or to the GP, that early signs of eye-sight deterioration will be picked up. This means that these agencies tend to be the

first point of contact that individuals losing their sight will have with eye-care professionals.

Local Optometrists - Optometrists play a vital role in the maintenance of eye-health, whether they are based on the high street or in local hospitals. Therefore, it is important that members of the community are able to access local Optometrists. There are 19] high street optometrists in Tower Hamlets, who serve a population of 254,096 - this equates to one optometrist per 13,373 of the population.

Research by RNIB has shown a tendency for people to visit their local high street optometrist only when they sense a problem with their sight. This lessens the ability of local optometrists to act as an early warning system for potential eye-disease, by finding and noting abnormalities before they become a problem. This is important in conditions such as glaucoma where the deterioration is not reversible but can be halted by the right treatment at the right time.⁴³ It is also suggested that both ease of transport to a high street optometrists and their optometrist's perceived independence from the need to sell spectacles both influenced the likelihood of individuals attending eye tests.⁴⁴

With numerous competing companies, and patients not limited to a specific locality to access an eye-test, service provision is somewhat fragmented. Therefore, it is not possible to provide statistics for the number of people who had an eye-test within the last year.

Eye tests for users with specific needs

Optometrists who offer low vision assessments or enhanced eye tests for people with a learning disability:

G Bleetman

347 Bethnal Green Road, E2 6LZ

Tel: 020 7739 2356

Eye Society Opticians

94 Whitehorse Lane, E1 4LR

Tel: 020 7702 8253

Gore Opticians

130 Roman Road, E2 ORN

Tel: 020 8980 3872

L A Sackwild Opticians

⁴³ The barriers and enablers that affect access to primary and secondary eyecare services across England, Wales, Scotland and Northern Ireland: A Report to RNIB by Shared Intelligence, Carol Hayden, RNIB Community Engagement Projects, January, 2012.

⁴⁴ The barriers and enablers that affect access to primary and secondary eyecare services across England, Wales, Scotland and Northern Ireland: A Report to RNIB by Shared Intelligence, Carol Hayden, RNIB Community Engagement Projects, January, 2012.

237 Whitechapel Road, E1 1DB
Tel: 020 7247 4442

Watney Eyecare
Watney Market, E1 2PP
Tel: 020 7702 8256

Local GP Services - It is also possible that problems with a patient's eyesight might be picked up by their GP. However, the most common role for the GP is to refer patients to their local eye hospital for further testing and diagnosis. This can often be a slow and frustrating experience for patients concerned about deterioration of their vision.

There is currently no information on any GP's with a special interest in Optometry or Ophthalmology in Tower Hamlets.

There is currently no information on any actions that are being taken to ensure Doctors Surgeries are accessible.

[Back to Contents](#)

10.3 Stages 3-4 – Diagnosis and Treatment

The NHS Framework identifies several outcomes that relate to the diagnosis and treatment of long term conditions. These include Ensuring that people feel supported to manage their condition (2.1), Improving people's experience of outpatient care (4.1) and improving people's experience of accident and emergency services (4.3).

The Adult Social Services outcome Indicator relating to diagnosis and treatment states that 'earlier diagnosis, intervention and re-enablement mean that people and their carers are less dependent on intensive services' (2A). Note: Indicator (2A) also relates to health and wellbeing indicator referred to at stage seven in the pathway.

Services available in Tower Hamlets include the following:

PEARS - Many areas are now operating a Primary Eyecare Acute Referral Scheme (PEARS), where accredited optometrists are able to carry out further tests themselves without the need to refer to doctors or local eye hospitals. This saves the NHS the costs of treating individuals in secondary care settings and the patient time and anxiety while they wait for further tests.

Community Low Vision Service – Tower Hamlets does have a community low vision service that picks up on individuals who have a visual impairment that does not require hospital treatment, and those who have completed a course of treatment

by an Ophthalmologist, but do not need further hospital treatment. Low vision services are an important method of early detection of new eye conditions, in discharged patients and the early onset of eye conditions in patients who have not yet been referred to an Ophthalmologist.

The Community low vision service is held on the first Monday of the month at LBTH Sight and Hearing Service, Albert Jacob House, 62 Roman Road, London E2 0PG. For more information contact Mary Ellis or Carol Excell on 020 7364 6953

Orthoptists - Orthoptists specialises in defects in binocular vision and eye movement abnormalities. Although Orthoptists work with patients of all ages, because of their profession tends to specialise in areas such as lazy eye or squints, many have a specific role of preventative screening and treatment of children, in addition to the work they undertake in hospitals and local communities.

Ophthalmology Provision – The main hospital with specialist Ophthalmology departments serving Tower Hamlets is Moorfields and The Royal London Hospital.

In The Royal London Optometry department there are facilities to treat Glaucoma, Diabetic Retinopathy and Cataracts. They do not offer treatment for ARMD, for which patients would need to travel to Moorfields to receive treatment.

For those living furthest away from The Royal London Hospital in Tower Hamlets, travelling to the hospital (via public transport) takes, on average, 35 minutes.

[Back to Contents](#)

10.4 Stages 5-6 – Emotional and Practical Support

Eye Clinic Liaison Officer (ECLO) - The role of an ECLO (is to provide practical support for newly diagnosed patients. For instance, an ECLO should be able to signpost social services and local voluntary organisations that can provide additional support or information on benefit entitlement and other forms of support.

ECLO's can also provide initial emotional support for patients coming to terms with their diagnosis, which has been identified as a service not always offered by time-pressed Ophthalmologists. Ideally, an ECLO will remain with a patient throughout their journey towards re-establishing independence life.⁴⁵ Research by City London University suggests that a majority of professionals (90% of clinical staff and 63% rehabilitation officers) believe that ECLO's significantly improve patient experience.

Eye Clinic Liaison Officers may also be known by other job titles, but will be providing similar role in support and signposting of the newly diagnosed and those undergoing treatment for eye conditions.

Most people are referred to Moorfields Eye Hospital and The Royal London Hospital. Moorfields has an ECLO. The Royal London Hospital used to have an ECLO service, but does not currently.

The role is key to ensuring that early registration takes place, that the newly diagnosed are provided with and signposted to early support and that there are accurate figures to inform the Public Health Outcome Indicator.

Ensuring Early CVI Registration – it is important that all those who are eligible to be CVI registered are identified at the earliest opportunity. The role of the ECLO or the voluntary sector is one key aspect that enables this to happen. However, Optometrists, Ophthalmologists, Social Care and the Voluntary sector need to work together more closely to share information and statistics, and develop cross sector working practices that will ensure the early identification of all those who are eligible for registration, even if they are not currently at any stages of the vision pathway. (Action Plan Action 3).

Psychological, Emotional and Practical Support – the ECLO and/or local voluntary organisation is able to signpost to or provide initial support at the time of diagnosis or need. In addition to this support, other emotional and psychological support includes:

45 http://www.mib.org.uk/aboutus/research/reports/2011/eclo_role_report.doc Cost implications for the ECLO role - The average price of the ECLO training course is £760.00 based on information collected from the ECLO survey. The average annual cost of employing an ECLO is £38,170 pro rata. This includes salary costs, employer national insurance and superannuation contributions, overheads such as telephone, heating and stationary, capital overheads such as building and fittings costs and one time training and set up costs. The cost of an ECLO per patient per contact is £17.95 assuming an average of 9 patients are seen per day, in a 42 week year. The costs involved are likely to rise every year in line with inflation and this must also be borne in mind. Costs are also likely to be 15%-20% higher in London.

Tower Hamlets Improving Access to Psychological Therapies (IAPT) service and is known as Community and Primary Care Psychology Counselling Service. Within service is the Disability Counselling Service (DCS) that provides a specialist clinical counselling service to newly disabled people or people with acquired disabilities their families and carers. The service offers counselling in a variety of languages: English, Sylheti, Bengali, Hindi, Urdu and British Sign Language.⁴⁶

There are also a variety of voluntary sector organisations that offer information about the emotional and practical support. See 10.5.3 below

[Back to Contents](#)

10.5 Stage 7 – Assessment and Rehabilitation

There are several Adult Social Care Outcome Indicators that relate to the assessment and rehabilitation stages of the pathway. These include:

- Everyone has the opportunity to have the best health and wellbeing throughout their life, and can access support and information to help them manage their care needs (2A) Note: This indicator also refers to the earlier diagnosis indicator at stage 5 in the pathway
- People know what choices are available to them locally, what they are entitled to and who to contact when they need help (3C)
- People, including those involved in making decisions on social care, respect the dignity of the individual and ensure support is sensitive to the circumstances of each individual (3D)
- The proportion of people who feel safe (from harm, injury, abuse and able to manage risk (4A)
- The proportion of people who use services who say those services have made them feel safe and secure (4B)

10.5.1 Sensory Loss Teams – The Sight and Hearing Service in Tower Hamlets deal with people who are aged 18 and over with either visual or hearing impairment, as well as people with dual sensory loss. It is unclear what number of people in the sensory loss team who specialise in visual impairment. The main tasks and responsibilities of the sensory loss team are to provide:

- Social work support
- Information, support and advice
- An assessment of needs with regard to sight loss, hearing loss and dual sensory loss.
- Support services to meet eligible needs following assessment, this may include home help and specialist equipment.
- Rehabilitation training and equipment to encourage independent living skills.

⁴⁶ <http://www.towerhamlets.nhs.uk/your-services/mental-health-services/online-directory-of-services/?entryid101=39251&p=11>

- Mobility training
- Classes in Braille and advice on IT equipment
- Communicator guides, BSL interpreters, a BSL video link and interpreters in community languages
- Links with local community groups and the NHS who work with adults that have sensory loss.

The Sight and Hearing Service is located at:

Albert Jacob House,

62 Roman Road

E2 0PG

Tel: 02073646953

Email: sensory@towerhamlets.gov.uk

The referral of patients to the Sight and Hearing Service is done via self-referral, GP, hospital the average waiting time for patients to begin rehabilitation is **40** working days.

10.5.2 Children's Sensory Loss and Rehabilitation Services

Tower Hamlets Vision Impairment Service forms part of the Sensory Support Team, alongside the Service for Deaf and Partially Hearing. These teams lie within the Borough's Support for Learning Service.

It works with visually impaired children, young people and their families from the age of diagnosis until 19 years of age (depending on educational setting). It is a team of 6 qualified teachers of the visually impaired (adding to 5.1 full time posts) and 2 full time specialist V.I. instructors. The main focus is raising educational attainment. It also prioritises wider and long term issues such as independence, mobility, family engagement, social and emotional wellbeing. One of the team is bilingual to aid our liaison with families.

The Early Years teachers provide a service for pre-school babies and youngsters with a vision loss. They support in the home, introducing families to the Developmental Journal, which tracks the child's progress. They run a weekly group called DOVES, a parent and child drop-in session. This allows families to meet and teachers to model good practice with V.I. children during play and light stimulation.

For pupils educated within the Borough at mainstream and special schools, they have a core offer and provide interventions at a low, moderate and high level depending on pupil need. The support pathway generally begins with a hospital referral to the service. The team has strong working relationships with the Royal London Hospital, Moorfields and GOSH. Schools and other professionals can refer to Tower Hamlets Vision Impairment Service via CAF if there is a visual diagnosis.

A team member will then carry out a functional vision assessment and a SERSEN Needs Analysis to determine the level of intervention needed for that child.

Tower Hamlets Vision Impairment Service supports and monitors over 200 youngsters with vision impairment in Tower Hamlets across homes, nurseries, schools and during transition to college. Tower Hamlets is an inclusive borough, so parents of a V.I. child can be assured of support in any school. However, there are currently a number of visually impaired pupils educated at Morpeth secondary school where resources and staff specialisms have been built up to enable curriculum modification, adaptation of materials and Braille Teaching. Mulberry Secondary School for Girls also has a number of V.I. Pupils and a breadth of experience in this area.

The team writes reports and advice sheets which schools find invaluable. These help explain eye conditions and their implications, give information on the periodic eye tests they have carried out and advise on issues such as lighting, print size, position in class, modification, resources and access technology. Team members attend annual reviews and help set targets. They liaise regularly with pupils so that they can represent their views and help with social and emotional difficulties.

In special schools, the team's focus is to create small step increase in the child's use of vision. They encourage classroom staff to join them in assessments, set workable targets and stimulate the child's residual vision. Light work in optimum dark room conditions can spark the first realization that looking brings rewards and information.

Youngsters who are resident in Tower Hamlets, but educated out of borough are monitored by Tower Hamlets Vision Impairment Service service at annual reviews.

They buy in the services of a senior MSI consultant to provide specialist assessment and advice for dual sensory (deaf/blind) pupils. They also provide mobility and habilitation training for pupils to increase their independence and self-help skills.

The service set up a weekly Braille class to train teaching assistants in the borough as qualified and nationally accredited Braillists. Parents are also welcome at this class.

Where necessary, they support families at their specialist eye clinic appointments.

They have formed the Children's Sensory Team with Social Care colleagues to find solutions for visually impaired pupils and their families using joint professional expertise. They also attend multi agency meetings on a child's behalf and take part in cross agency groups with the intention of promoting VI issues in the borough.

Vision Impairment Service

Team Leaders: Philippa Moody and Lorna Paterson

020 7364 6321

10.5.3 Third Sector Organisations – Blind Society/Voluntary Sector
Organisation can offer additional support for sensory loss and rehabilitation which includes:

Beyond Barriers

Chairperson: Ashrafia Choudhury Mobile Number: 07956510008 Email: ashrafia1@btinternet.com

Secretary : Mahendra Rastogi Mobile Number: 07850000095 Email mahendrarastogi@gmail.com

User led peer support group, which runs a monthly programme of meetings and outings/activities.

The overall purpose of Beyond Barriers is to assist visually impaired people, living or working in Tower Hamlets and surrounding boroughs, combat social isolation, increase self dependence and enhance the quality of their lives. Beyond Barriers aims to enable visually impaired people to live a valued life and participate fully in society socially, economically and politically.

BlindAid

020 7403 6184

enquires@blindaid.org.uk

Home visiting service, telephone befriending and annual events for people with a visual impairment in the 13 inner London boroughs, including Tower Hamlets.

Deafblind UK

Tel/Textphone: 01733 358 100

Email: info@deafblind.org.uk

Address: Deafblind UK Head Office, National Centre for Deafblindness, John & Lucille van Geest Place, Cygnet Road, Hampton, Peterborough, PE7 8FD

Deafblind UK - Our overarching goals

To work towards a more equal society by raising awareness and understanding of deafblindness by engaging with people who have a sight and hearing loss, the Government and other organisations, individuals and communities.

To enable people with both a sight and hearing loss to remain in their own homes and participate in their local communities.

To provide relevant, high quality **Peer Support, Befriending** and **Information and Advice** services to people with a dual sensory loss, helping them to; live independently, interact with others, understand their rights and access their entitlements

Deafblind Tower Hamlets group meets monthly

Mobility Support Services

5 Clove Crescent

E14 1BY

Tel: 02073645003

Email: mobility@towerhamlets.gov.uk

Provides a wide range of concessionary travel and parking schemes to give residents with disabilities greater opportunities for independent travel.

RLSB (Royal London Society for Blind People)

Telephone: 02078086170

Email: enquiries:rlsb.org.uk

Address: London office, Royal London Society for Blind People (RLSB), Victoria Charity Centre, 11 Belgrave Road, London, SW1V 1RB

RLSB - focuses particularly on supporting the education and skill development of blind and partially sighted young people in London.

They run a peer support group in Tower Hamlets for young people up to the age of 25.

[Back to Contents](#)

10.6 Stage 8 - Independence and Accessibility

To help inform services that facilitate independence, Tower Hamlets has surveyed [number] local venues for accessibility, which is available on the Tower Hamlets pages of the Disabled GO website. The aim of the site is to identify local businesses and services that are disabled accessible.

(Note: To find out information in your Tower Hamlets click on link below)

<http://www.disabledgo.com/en/search>

10.6.1 Transport

Tower Hamlets has a Transport Planning Strategy 2011-2032 is available on the Tower Hamlets website at: http://www.towerhamlets.gov.uk/lgsl/451-500/493_planning_policies_for_tran.aspx The strategy does now specifically outline the plan for those with a visual impairment.

Buses – There are 28 bus routes and 10 night bus routes running through Tower Hamlets. The area does have talking buses however does not have talking bus stops.

(Note – specific Tower Hamlets information on buses can be sourced via <http://www.tfl.gov.uk/tfl/businessandpartners/buses/TowerHamletsreports/>)

Dial a Ride – Dial a Ride is a Transport for London initiative specifically for people with a disability who cannot use public transport to go shopping, visiting and access leisure activities.

TaxiCard – The Tower Hamlets TaxiCard scheme is for people who have serious mobility and sight impairment resulting in difficulty in using public transport. The service is subsidised by Tower Hamlets. For each trip taken the user must pay the first £1.50, the council will then pay a maximum of £10.30 per trip. Tower Hamlets has a banding system for taxicard usage which is determined by the LBTH criteria.

Band 1 gives up to 4 journeys a month

Band 2 gives up to 8 journey a month

Band 3 gives up to 12 journeys a month

Band 4 gives up to 16 journeys a month.

Any unused journeys can be carried forward for use in subsequent months. Users are allowed to swipe their card twice during one journey, allowing two trips and two subsidies to be used to cover one long journey.

Taxis and Mini Cabs – Black taxis in the borough mainly operate in accessible locations across the borough.

The Disabled Go website does not explore whether the staff of mini cab companies have undertaken specific visual impairment training (as opposed to being equalities aware). This could be an additional barrier to independence, as service users have cited examples of mini cab drivers sitting in their car tooting the horn despite being advised that the passenger has a visual impairment, rather than escorting an individual from their door to the taxi, and dropping them at the entrance of their destination.

Trains, Trams and Underground – Tower Hamlets has 31 train stations providing links to major destinations across London. Trains are operated by 3 providers, and platform staff have undertaken training to support people with a visual impairment and can provide support with travel and escort whilst in the train station for people with a disability on request.

Public Riverboat Services – There are 2 waterway services in offering public transport in Tower Hamlets, Canary Wharf pier and Masthouse Terrace Pier.

10.6.2 Streets and Street Furniture

Tower Hamlets has a highway assets management plan (HAMP) setting out the vision for managing Tower Hamlets 'assets': streets, lighting, road surfaces, markings, structures (such as bridges), street signs, trees, hedges and planted areas. The plan feeds into the London Transport Strategy and is an important part of Tower Hamlets local implementation plan. There is no information available on Tower Hamlets HAMP online.

10.6.3 Leisure and Shopping

There are **[number]** leisure centres all of which can accommodate an assistance dog, and 2 of which provide information in Braille and large print.

There are 4 theatres in Tower Hamlets that can accommodate an assistance dog and 1 provides information in Braille/large print.

In terms of Libraries, there are 6 libraries in the Tower Hamlets which can accommodate an assistance dog and 6 of these provide information in large print, and provide audio books and large print books.⁴⁷

Of the 70 supermarkets in Tower Hamlets, 17 are on the disabled go website stating that they can accommodate an assistance dog.

⁴⁷ Disabled GO <http://www.disabledgo.com/en/org-results/tower-hamlets-council>

[Insert any issues about barriers to shopping and leisure in the Tower Hamlets through consultation or local forums]

10.6.4 Employment

Evidence shows that 66% of people with a visual impairment of working age are not in employment, and that Government schemes fail to place blind and partially sighted people in work and that training and employment opportunities for those furthest from the labour market are dwindling.⁴⁸ Providers of support into employment in Tower Hamlets including the following:

Job Centre plus, is one of the main sources of employment in the Tower Hamlets. They provide support into work, access to benefits and provide specialist support for those who are disabled.

Job Enterprise and Training (JET) is a specialist service for people with a disability or long term health condition in Tower Hamlets. It provides information, advice and guidance on finding work, keeping a job, developing skills and making adjustments for work. JET is located at: Tower Project Job, Enterprise and Training Service Candy Wharf, Unit 2, 22-23 Copperfield Road, E3 4RL. They can also be contacted via telephone on: 02089803500

Disability Information training Opportunities (DITO) provides IT training, one to one support with finding/applying for jobs and benefits advice. They are located at The resource Centre, 40-50 Southern Grove E3 4PX or contacted via email:

infor@ditoh.org

Action for Blind People is an organisation that supports people with a visual impairment with job retention (but not support in seeking work), self employment work experience opportunities and provides careers guidance across the UK. They also provide advice on support for travelling to work and support available in the workplace. However, they can be contracted to provide tailored support into employment for people with a visual impairment.

It is unclear how many other voluntary sector organisations are providing support into employment in Tower Hamlets, or how many are able to support people with a visual impairment to obtain work opportunities. It is also not clear how many of these are Department of Work and Pension primary or secondary contractors.

[Insert any issues relating to barriers to employment in the Tower Hamlets through consultation or local forums]

⁴⁸ <http://www.rnib.org.uk/aboutus/research/reports/employment/Pages/employment.aspx>

10.6.5 Education

Children’s Education – Tower Hamlets has a visual impairment teaching service. The policy of the local authority is to have children with a visual impairment taught in mainstream schools and specialist centres.

Tower Hamlet’s has a vision impairment special needs support for the ages of 0-19 years old. The service provides support for hearing impaired and visually impaired pupils in both mainstream and special schools. For children below school age, support is provided in the home and in nurseries. They can be contacted via telephone on: 02073646468⁴⁹

There are 3 mainstream schools in Tower Hamlets that have experience and support skills for pupils with a visual impairment.

Harbinger Primary School, that is located in the Isle of Dogs where they have a resource room where Braille can be produced electronically and used for other pupils in the borough. They can be contacted via Telephone: 02073871924.

Bangabandhu Primary School in Bethnal Green is a mainstream school that provides high quality learning opportunities for all children whatever they need. They have a variety of facilities and learning materials as well employing a large number of teaching assistants who are there to support pupils needs. The school can be contacted via telephone on: 020980 0580.⁵⁰

Halley Primary School is located in Stepney. They have a large and experienced ‘inclusion team’ who are dedicated to giving everyone the same opportunities and educational support. They can be contacted via telephone on:02072658061.⁵¹

Stephen Hawking School in Tower Hamlets is small school with 75 students aged 2-11 years old. The school works with pupils that generally have profound and multiple learning difficulties with a significant number of children who have additional sensory impairments.⁵²

Further Education – Tower Hamlets has 1 main centre for further education, Tower Hamlets College.

[Add description, accessibility information and equalities impact assessment].

Higher Education – Higher education in Tower Hamlets is offered by London Metropolitan University and Queen Mary University. London Metropolitan has a variety of assistive-technologies available as well as teaching support if needed. Queen Mary University provides learning support in the form of scanning text or reading books onto tape, taking notes in lectures and tutorial support if it's wanted.

Adult Education/Lifelong Learning – Idea Store offers a diverse range of vocational and practical courses for adult learners in Tower Hamlets. The Idea Store is located in various places across Tower Hamlets, Bethnal Green, Whitechapel, Shadwell, Bow and Canary Wharf. No courses are tailored towards people with a visual impairment but there are a variety of learning resources and support available.

10.6.6 Welfare Rights

Understanding the entitlement to welfare rights and benefits and access to benefit entitlement is an important way of ensuring independence for people with a visual impairment.

[Insert text on voluntary sector providers operating in Tower Hamlets and any cross referral or co delivery of services]

10.6.7 Accessibility

A recurring theme that runs through the all stages of the pathway is the need to ensure that information is produced in an accessible format and imparted to patients and service users in a timely and accessible way. Examples of this include when accessing the GP, receiving information about appointments, understanding eye conditions, accessing benefits/seeking advice, dealing with household bills, etc.

Therefore, work needs to be undertaken to ensure that as many statutory, voluntary and commercial organisations in Tower Hamlets are providing both accessible information and accessible services.

[Back to Contents](#)

11. Wider Avenues of Support

There are numerous national bodies that also provide support to people living with sight loss in Newham. Many of these charities provide practical information and community spaces where people can seek advice or support from other people living with sight loss.

ACTION for Blind People:

Telephone: 020 7635 4800

Or RNIB helpline: on 0303 123 9999

Email: helpline@rnib.org.uk

Address: Action for Blind People, 53 Sandgate Street, London, SE15 1LE

Action for Blind People - provides practical information for people with visual impairment, as well as information and the contact details for local groups and services. It is part of the RNIB Group.

Blind Veterans UK

Telephone: 020 7723 5021

Email: enquiries@blindveterans.org.uk

Address: Blind Veterans UK, 12-14 Harcourt Street, London, W1H 4HD

Blind Veterans UK - a specialist charity that provides physical and emotional support for ex service men and women to enable them to live as independently as possible.

BlindAid

020 7403 6184

enquires@blindaid.org.uk

Home visiting service, telephone befriending and annual events for people with a visual impairment in the 13 inner London boroughs.

Deafblind UK

Tel/Textphone: 01733 358 100

Email: info@deafblind.org.uk

Address: Deafblind UK Head Office, National Centre for Deafblindness, John & Lucille van Geest Place, Cygnet Road, Hampton, Peterborough, PE7 8FD

Deafblind UK - Our overarching goals

To work towards a more equal society by raising awareness and understanding of deafblindness by engaging with people who have a sight and hearing loss, the Government and other organisations, individuals and communities.

To enable people with both a sight and hearing loss to remain in their own homes and participate in their local communities.

To provide relevant, high quality **Peer Support, Befriending** and **Information and Advice** services to people with a dual sensory loss, helping them to; live independently, interact with others, understand their rights and access their entitlements

Guide Dogs

Telephone: 0118 983 5555

Email: guidedogs@guidedogs.org.uk

Address: The Guide Dogs for the Blind Association, Burghfield Common, Reading, RG7 3YG

Guide Dogs - organises and trains dogs for the visual impaired, as a charity their primary interest lies in enabling the mobility of the visually impaired.

London Visual Impairment Forum (LVIF)

Telephone: 07875 541133

Email: sharon.schaffer@lvif.co.uk

Website: www.lvif.co.uk

Links organisations for the blind and partially sighted in London.

Macular Society

Telephone: 01264 350 551

Email: info@macularsociety.org

Address: Macular Society, PO Box 1870, Andover, Hampshire, SP10 9AD

Macular Society – offers support and information on macular disease and central vision loss, and has branches throughout UK

The Partially Sighted Society

Telephone: 0844 477 4966

Email: info@partsight.org.uk

Address: The Partially Sighted Society, 7/9 Bennetthorpe, Doncaster, DN2 6AA

The Partially Sighted Society - provides equipment (such as magnifiers) and information (on matters such as lighting) for individuals to make the most of their remaining sight.

RNIB:

Telephone: 0303 123 9999

Email: helpline@rnib.org.uk

Address: RNIB Headquarters, 105 Judd Street, London, WC1H 9NE

RNIB - offer a telephone counselling service for those having difficulties coming to come to terms with their sight loss, as well as a wealth of practical information for parents, carers and the visually impaired.

RLSB

Telephone: 02078086170

Email: enquiries:rlsb.org.uk

Address: London office, Royal London Society for Blind People (RLSB), Victoria Charity Centre, 11 Belgrave Road, London, SW1V 1RB

RLSB - focuses particularly on supporting the education and skill development of blind and partially sighted young people in London.

They run a peer support group in Tower Hamlets.

SeeAbility

Telephone: 01372 755 000

Email: enquiries@seeability.org

Address: SeeAbility House, 1a Hook Road, Epsom, Surrey, KT19 8SQ

SeeAbility is a national charity that provides support for people who are visually impaired but also have other disabilities, such as mental health problems, mobility impairment or learning disabilities.

Thomas Pocklington Trust

Telephone: 020 8995 0880

Email: info@pocklington-trust.org.uk

Address: Pier House, 90 Strand on the Green, Kew, London w4 3NN

Housing and support for people with sight loss, including Research & Befriending (Tele, Email & Buddy Befriending schemes)

[Back to Contents](#)

In Conclusion

12. Conclusion

There is some very positive work being done in Tower Hamlets to help those who are blind or experiencing a visual impairment. These, identified through consultation with local service users, include:

- The Eye Health JSNA 2009 and legacy of the Low Vision Committee
- A well resourced Sight & Hearing Service, that delivers excellent support services
- Recently commissioned peer led support group, Beyond Barriers
- Barts Charity funding for Information & Advice Officer at Royal London Hospital, Children's Eye Clinic
- A good sense of community

Nonetheless, in Tower Hamlets the number of older people is growing, as is the number of people with obesity, heart disease, and diabetes. As a consequence, by 2020 there will be 22% more visually impaired people in need of support and care from the community.

However, as 50% of visual impairment is thought to be avoidable, prevention will need to become a central part of the Tower Hamlets Vision Plan. In particular attention will need to be focused on accessing 'at risk groups'. Successful targeting of these key audiences could significantly reduce the pressure on low vision services in the future.

There are also some important gaps in the provision of services for people already experiencing visual impairment; these gaps are focused on the following key themes:

- Embed the Vision Plan into the Health and Wellbeing framework and achieve a user led partnership approach to planning, delivery and evaluation of eye health and visual impairment support services
- Prevention: Maximise the uptake of eye examinations and raise awareness of eye health and lifestyle to ensure that avoidable visual impairment is prevented wherever possible
- Ensure that comprehensive cross sector data on visual impairment is collected and disseminated
- Ensure that comprehensive service provision is available, resulting in a clear pathway for people experiencing a visual impairment

- Ensure that people with a visual impairment have good access to information, transport, the environment, leisure, education, employment and welfare rights, and so do not experience social exclusion, inequality or isolation
- Develop and embed into the main Vision Plan considerations for children and young people, including evidence of current and future need, sight loss pathway, arrangements for transition to adult services and an action plan to address gaps and need

[Back to Contents](#)

13. Service Development Priorities

Based on the above gaps in service provision in Tower Hamlets the following service priorities have been identified. These service priorities have been arranged into the categories of prevention, services and inclusion, to reflect the objectives of the UK Vision Strategy with a note of the desired outcome.

13.1 Health and Wellbeing (Action One of the Action Plan)

Outcome: Ensuring that the Vision Plan and Action Plan are an integral part of local planning and service delivery

Indicators:

- Health and Well Being Board (either directly or via another forum to be agreed) is signed up to this Vision Plan and it is informing the implementation of its Action Plan
- Engagement of other decision making structures so that they are part of the implementation of the strategy and can help shape the future direction of the action plan, in particular:
 - HealthWatch
 - Clinical Commissioning Groups
 - Council Social Care and Commissioning Teams
- Opportunities for cross sector learning, information sharing and/or joint working are developed between relevant health sector, social care and voluntary sector agencies

13.2 Prevention (Action Two of the Action Plan)

Outcome: a reduction in avoidable sight loss.

Indicators:

- Cross sector Public Health campaigns, which include the impact of priority health conditions such as diet, lifestyle and health conditions on eyesight and vision
- Activities to engage locally identified or hard to reach groups in the area is undertaken
- Cross sector activities are implemented and evaluated to increase the number of Eye Examinations (general or targeted group)

13.3 Joined Up Data (Action Three of the Action Plan)

Outcome: comprehensive cross sector data on sight loss and local demographics is collected and shared to inform resource allocation across Public Health, NHS, Optometry, Social Care and Voluntary organisations.

Indicators

- A method of collecting and collating data on eye health and sight loss support services is developed, implemented and evaluated, and can inform current and future needs
- Accurate information can inform the Public Health Outcome Indicator
- A cross sector system is implemented and evaluated to detect early changes in vision in those who already have sight conditions or low vision to enable treatment and early registration
- CVI information is accurate, processed effectively and is of use to all relevant parties

13.4 Joined up Services (Action Four of the Action Plan)

Outcome: individuals are empowered so that they can access the type of support and information they require at the time of need to maximise their independence.

Indicators:

- An evaluation of the ECLO post is carried out and a cross sector business case for continuation of the post is undertaken
- Health sector organisations and services are mapped, recommendations for change are made if appropriate and an effective communication system is created
- Statutory rehabilitation resources are increased to ensure relevant support is available on an ongoing basis
- Voluntary sector services are mapped, rationalised if appropriate and funding is made available to sustain high quality and effective delivery

13.5 Social inclusion and independence (Action Five of the Action Plan)

Outcome: individuals with visual impairment are able to lead active and independent lives, where they are able to fully engage in social, economic and educational opportunities

Indicators:

- Access (physical access and accessible information) is developed to enable people with sight loss to excel in education and undertake leisure activities
- Employment support and back to work agencies have developed and implemented policies to support people with sight loss into employment and training
- People experiencing sight loss are clear about, and supported in their rights and options in relation to their health, social care and independence needs
- Activity to ensure that information in accessible formats in the commercial, statutory and voluntary sectors results in service users being noticeably more satisfied in this area
- Action to explore how access can be improved via public transport links between all parts of the borough and Hospital, to ensure that people are able to access treatment and are not at risk of avoidable sight loss

13.6 Children's Services (Action Six of the Action Plan)

Outcome: Tower Hamlets Vision Plan identifies and addresses considerations relating to children and young people

Indicators

- Children's considerations are firmly embedded into the main Vision Plan and Action Plan to ensure that service providers are joined up and service considerations are identified, addressed and monitored for impact
- Evidence that diet and lifestyle prevention awareness has been undertaken with young diabetics and their parents/carers, and that they are adequately prepared for annual Diabetic Retinopathy screening when it begins at age 12 to prevent the early onset of Diabetic Retinopathy
- A clear transition pathway from children to adult services (both clinical and social care) is developed and communicated to partners, children and their parents/carers
- The process of children's registration is investigated and, if required, amended, or good communication ensures that the process is understood by all

13.7 Visually Impaired people with complex needs (Action Seven of the Action Plan)

Outcome: People whose primary condition is not related to their vision will have their eye health and sight loss support needs addressed

Indicators:

- Cross sector commissioning protocols are developed to address conditions where sight loss is a known factor (Diabetes, Strokes, Learning Disability, Elderly, Deaf-Blindness)

- Cross sector service provision is developed to address the treatment and rehabilitation needs of both the primary and secondary conditions
- Training is developed and delivered to ensure that carers (temporary and respite carers) including those in care homes are sight loss aware and are equipped to support those in their care

13.8 Involve local People in Sight Loss Priorities (Action Eight of the Action Plan)

Outcome: Local People are actively engaged in defining local priorities and providing local feedback on eye health and sight loss support services

Indicators

- Active engagement by patients and service users who have input and own the Vision Plan and the accompanying action plan, and active engagement at the implementation and evaluation stages
- Consultation on service provision and its impact has been undertaken
- An active forum is in place to look at eye health and sight loss support needs from a local perspective, which is able to feed into Healthwatch, local campaigning and local decision making processes

Tower Hamlets Vision Action Plan

An action plan has been developed to accompany the Vision Plan, giving further details of the areas outlined in the Outcome Indicators. This will enable the delivery of the Tower Hamlets Vision Plan to be monitored and its impact assessed over time.

It will be necessary to periodically revisit the Vision Plan and action plan to reflect the changes resulting from its delivery and the ongoing needs of blind and partially sighted people living in Tower Hamlets.

[Back to Contents](#)

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