



Access to Health Services for People with Learning Disabilities

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Foreword by the task group

People with learning disabilities* experience worse health than the general population and often experience a poor service from health providers. The need for improvement has been recognised by seven national reports in the last ten years. Despite so much attention being given to this problem little noticeable improvement has been made.

It is, therefore, vitally important that something is now done, that is why the overview and scrutiny committee have agreed to commission this task group. Councillors believe that there has been enough talking and strategy development, and concerted action needs to take place.

The recommendations set out in this task group are practical and can be achieved without excessive financial cost to Brent. It is in many cases a matter of making practical adjustments to the systems used by clinics and hospitals, and of educating all staff in the use of better communication techniques, for people with learning disabilities.

The Task Group has been assisted by many experts and we would like to thank everyone who has spent time preparing reports and attending meetings, to advise us.

We would also like to give particular thanks to the carers we met at both Hay Lane School and Wembley Centre for Health and Care, who shared their personal experiences of the obstacles encountered by them, when accessing health services.

We intend to continue working to ensure that the recommendations of this task group are realised, and that Brent has systems for people with learning disabilities to be proud of.

*The suitability of the word 'disabilities' was considered briefly by the task group. It is currently being reviewed by various professionals in the UK and may also be usefully reviewed by Brent Council.

Executive Summary

This review was commissioned because Brent Carers spoke to local councillors about the difficulties they faced when using general health services with the person that they cared for, who also happened to have a learning disability.

The task group met with Brent carers who reported a number of on-going difficulties when using primary care services in the borough such as Dentistry, GP's and Opticians. Many relate to an overarching lack of awareness about learning difficulties issues and failure to implement reasonable adjustments which would make these services accessible to all patients. Our evidence found that there are variable standards for patients across the borough.

At the national level there is a strong body of evidence highlighting failures across health and social care to provide adequate healthcare services for people with learning disabilities, who are among the most vulnerable adults in society.

There has been recognition within NHS Brent that further progress needs to be made in implementing government guidance on services for people with learning disabilities. NHS Brent has recently recruited an Acute Liaison Nurse. This role works across a number of hospitals and is based in the community team. They have a specific duty to support PWLD in hospital, they are alerted when a patient with learning disabilities is admitted and they ensure that their needs are met while they are in hospital. The Trust has expressed its commitment to achieving these aims and has agreed a number of important self assessment framework targets with NHS London.

The task group were concerned about the transition from children to adult services. Members were informed by the Chief Executive of Mencap and the Head teacher at Hay Lane School that this is an important area for the task group to focus on. Members were informed by the Assistant Director for Community Care that a project looking at this area had already been scoped and is awaiting the go-ahead. The task group believe that this project must start as a matter of urgency.

The task group also considered the 'invisible community'. It refers to the residents of this borough who have mild to moderate learning disabilities yet we do not know who they are, if they are prevalent among the groups who do not have regular health checks. Nor do we understand whether they are accessing the services that they need. We do know that they are a vulnerable group and early investment can provide longer term savings to the council.

There is a project in the London Borough of Ealing called Treat Me Right! which has developed a range of measures to improve patients with learning disabilities experience in the acute care sector. They have produced information in easy to read formats, such as the complaints policy and admission information as well as provide staff training. One of the main recommendations of the task group is that NHS Brent develops a similar model for Brent Hospitals.

As a result of their investigations, recommendations from the task group included that the Health select committee monitor the implementation of NHS Brent targets to improve services for people with learning disabilities and that specific reference should be made to the needs of this group within health promotion strategies and the obesity strategy which is currently being developed by the council and its partners.

Introduction

One of the main roles of the overview and scrutiny function is to look at issues that are of concern to local residents. This review was commissioned because Brent Carers spoke to local councillors about the difficulties they faced when using general health services with the person that they cared for, who also happened to have a learning disability.

On the whole, carers felt that their views and opinions were ignored when dealing with medical professionals although they are best placed to provide information about the people that they support. Medical professionals often have limited knowledge about people with learning disabilities which has a big impact on the patients experience and treatment. There were also barriers around some practical issues; carers felt that they were not catered for in hospitals when they are providing support to their loved one, even though this has benefits for hospital staff. Appointments at hospital or the GP's surgery posed a real difficulty, as people with learning disabilities often need extra time and can find waiting for appointments difficult.

The Overview and Scrutiny Committee were asked to set up this task group to consider if the concerns raised by carers were more broadly felt across the borough and if local health services are meeting the needs of people with learning disabilities as required in equalities legislation.

During the course of the task group investigation, Members also became aware that accessing health services for people with learning difficulties is not just a local issue but is a major problem across the UK, which has prompted national government to develop a targeted, strategic response.

The difficulties faced in accessing health services by this group are exacerbated by the fact that many people with learning disabilities are also more likely to have poorer health. Also, the number of people with this condition is on the increase, currently around 2.5% of the population in the UK has a learning disability depending on definition. A report entitled *Healthcare For All*¹ highlights that advances in medical care leading to longer life expectancy will mean that this figure is likely to rise. Rates are likely to go up by around one per cent per annum for the next ten years and grow overall by over ten per cent by 2020.

Recommendations

1. That NHS Brent implements a project – similar to the Treat me Right project developed by Support for Living in Ealing Hospital.
2. That there are specific actions to address the needs of people with learning disabilities in the Brent Obesity Strategy and other health promotion strategies.
3. That the Health Select Committee monitor the implementation of the NHS Brent learning disability self assessment framework and improvement of statutory functions such as dentists.
4. That information is gathered on residents that have a learning disability to ensure that they receive targeted appropriate services.

¹ Healthcare for All, Independent Inquiry into access to healthcare for people with learning disabilities, Sir Jonathan Michael, July 2008.

5. That the go-ahead is given to the council project to look at transitions from children's to adult services for people with disabilities - as a matter of urgency. The appropriate Overview and Scrutiny Committee should monitor the progress of this work.

Membership/scope

The members of the task group were:

- Councillor Eddie Baker
- Councillor Ruth Moher
- Councillor Emily Tancred

Methodology

The aims of the task group were to:

1. Identify what specialist services are available to meet the health needs of children and adults with a learning disability
2. Identify gaps in specialist health service provision for people with learning disabilities
3. Review the effectiveness of the mainstream health related provision for children and adults with a learning disability
4. Identify what reasonable adjustments have been made or need to be made to services to enable people with learning disabilities to access health services
5. Review the plan to meet the Valuing People Now health related targets with Brent NHS

The task group consulted as widely as possible and carried out the following activities:

- Met with the Chief Executive, Brent MENCAP
- Met with Assistant Director for Community Care, Brent Council
- Met with Head of Service for People with Learning Disabilities
- Visited Head teacher, Hay Lane School
- Met with Head of Diversity, Brent Council
- Met with Brent Carers
- Met with Deputy Director, NHS Brent
- Met with Deputy Director Partnership Commissioning NHS Brent, Brent Council.
- Met with Support for Living Project in Ealing.

National Context

At the national level there is a strong body of evidence highlighting failures across health and social care to provide adequate healthcare services for people with learning disabilities, who are among the most vulnerable adults in society.

The Department for Health defines learning disability as “a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence) with a

reduced ability to cope independently impaired social functioning which started before adulthood, with a lasting effect on development.”²

A report by National Mencap in 2004 entitled *Treat me Right* drew attention to this problem. The report highlighted that this group are more likely to have poorer health than the rest of the population with a higher prevalence of medical conditions such as epilepsy and thyroid problems. Despite their greater reliance on healthcare, this group are more likely to receive a poorer service. The report highlighted that many medical professionals are not being trained to deal with patients with learning disabilities. This can lead to poor quality of care as the staff are not able to communicate with patients effectively and understand their needs. This was also reinforced by a report commissioned by the then Disability Rights Commission called *Mind the Gap* which highlighted the high level of health inequalities experienced by people with a learning disability and also those with mental health problems.

The 2006 Government White Paper “ Our Health, Our Care, Our Say” stated that many people with learning difficulties have a poor experience of using health services and can find it difficult to access mainstream services.

A further report by MENCAP in 2007 entitled *Death by Indifference* featured six case studies where the patients suffered fatal consequences due to the poor services they had received. In some cases, the inability of healthcare professionals to take into consideration the patients learning disabilities was highlighted as a contributory factor.

In 2008, the Secretary of State for Health set up an independent inquiry chaired by Sir Jonathan Michael to review these issues. His report *Healthcare For All* identified a range of barriers experienced by people with learning disabilities including:

- People with learning disabilities find it much harder than others to access assessment and treatment for general health problems which has nothing to do with their disability.
- Carers of adults with learning disabilities often find their opinions and assessments ignored.
- Health staff often have limited knowledge about learning disability. As a result people with learning disabilities are less likely to receive pain relief and palliative care. There was some evidence of belief amongst some staff that people with learning disabilities have a higher pain threshold.

Valuing People Now, an updated version of the 2001 Strategy for people with learning disabilities was issued in early 2009 and lays down much clearer expectations on both councils and Primary Care Trusts to address the continuing poorer health of people with a learning disability highlighted in the above mentioned reports. It also includes more compulsory performance management indicators to be met by statutory providers within defined timescales which include health, employment and housing.

Local Context

Brent MENCAP estimates that there could be as many as 7,000 people with a learning disability in Brent, based on an assumption that around 2.5% of the population have some form of learning disability. That said, at present only 573 adults with learning disabilities are

² Valuing People Now, Department of Health 2001

in receipt of council services. Council services for people with learning disabilities (PWLD) are provided by the Brent Learning Disability Partnership Unit (BLDP). This is a statutory organisation and was established on 1st April 2002 as an integrated Brent Council, NHS Brent learning disability service with the Council as the lead organisation. This multi agency unit is responsible for the provision of comprehensive health & social care services for adults with learning disabilities ranging from assessment, care management, specialist community health services, placement services, crisis intervention, community outreach services, residential services, and various day care services. The service users range from those with a mild learning disability to those with profound learning and physical disabilities, including people with autism and or challenging behaviour.

One of the outcomes from Valuing People Now is that the Primary Care Trusts must transfer the commissioning of services for PWLD to the council. In Brent this will involve at least £7m worth of care costs. The council is in the process of reviewing services for people with learning disabilities to ensure that they are of a high quality and meet the objectives within Valuing People Now.

At the time of writing this report the council is undergoing a major transformation programme as part of its Improvement and Efficiency agenda. A number of services have been identified which need to be modernised and will deliver efficiency savings for the council. The Learning Disability Service currently has two projects as part of this agenda;

- A wide scale review of the Learning Disability Community team
- In-house review of day services including how to position them in future in line with personalisation guidance

NHS Brent progress

NHS Brent has an important role in commissioning services for people with learning disabilities. A report went to the NHS Trust Board in July 2009 setting out how they would implement the latest Valuing People Now strategy and the recommendations for addressing Healthcare for All and Six Lives Reports. The progress with this will be discussed later in this report.

NHS Brent has recently recruited an Acute Liaison Nurse. This role works across a number of hospitals and is based in the community team. They have a specific duty to support PWLD in hospital, they are alerted when a patient with learning disabilities is admitted and they ensure that their needs are met while they are in hospital.

Key findings

We met with the Chief Executive of Brent Mencap who gave us a general overview of some of the issues that people with learning disabilities and their carers are faced with when accessing health services. PWLD may not understand simple instructions; might find some activities difficult such as time keeping, travelling and navigating their way around a hospital. Some PWLD may not be able to read and write. People with autism don't understand standard rules and conventions therefore if they have to wait for an appointment they can shout and get agitated.

It was further reported that careful consideration must be given to service planning otherwise PWLD could find it almost impossible to use public services. For example, If they are invited for a smear test they could be given a five minute appointment which could be difficult if they do not understand what is happening. Some reasonable adjustments can be made to this

process including allowing more time for the appointment, writing to people in simple English and using pictures. As a result of the current failures to plan for the needs of PWLD there is a lower level of basic check ups and they have a higher level of cardiovascular disorders and high blood pressure.

Primary care

We met with Brent carers who reported a number of on-going difficulties when using services such as Dentistry, GP's and Opticians. Many relate to an overarching lack of awareness about learning difficulties issues and failure to implement reasonable adjustments which would make these services accessible to all patients. Our evidence found that there are variable standards for patients across the borough.

We were told by Brent Carers that GP's can be over cautious when dealing with issues of consent between a patient with learning disabilities and their carer. In many instances there is a great disparity between the physical and mental age of a patient with learning disability. Therefore a patient can resist an injection or dental treatment as they do not understand the longer term benefit.

Carers told us that although they try to explain this to the medical professional in some instances they still refuse to carry out the procedure. Many of the carers believe that there is fear within the medical profession about being sued by an adult who has to be restrained to receive treatment. For a carer this will mean that they have to face a battle with medical professionals time and again even if they have been with the same GP over a number of years. This is an additional burden upon a family who are dealing with the everyday challenges of supporting someone with a learning disability.

Waiting for appointments can be a big issue as PWLD can find this difficult and can become disruptive – one carer told us that as a coping mechanism her husband will wait outside with her son and she will call them when it is time for their appointment. The hospital had refused her requests for fast tracked appointments. This view was reiterated by another carer who told us that when waiting for appointments her child is more likely to become restless and engage in challenging behaviour such as spitting at people.

Carers also told us GP's can often try and get them out of the surgery as soon as possible therefore lower priority conditions are often not addressed as the focus is on their more complex needs. A mother told us that she wanted to talk to the doctor about her son's acne but since there was limited time she had to focus on the bigger issues.

The Chief Executive of Mencap told us that appointments need to be longer and there may need to be two slots. One to explain to the patient what will take place then the procedure to take place on the second visit. Another option is to make appointments at the beginning or end of the day. All the carers that we spoke to felt that these options needed to be implemented as a matter of urgency.

A carers experience at the optician also highlighted a lack of awareness amongst the wider medical profession about how to deal with PWLD. An optician was trying to get a patient with learning disabilities to read the eyesight testing board and carer had to highlight that although the person looked like an adult they have a child's mentality and needed to go to the children's side and use pictures. Carers would like to see greater awareness and urgent training for the medical profession.

There also needs to be continuity with GP's who have a good knowledge of the case history, many carers reported seeing a number of GP's within a short period of time.

We met with the Head Teacher at Hay Lane School which is designated for pupils with severe, profound and multiple learning difficulties and all have statements of special educational need. It was reported that many pupils in the school have problems with their teeth however the difficulties posed by getting a pupil to the dentist and sit in a chair with their mouths open means that dental issues are often neglected unless it becomes acute. The Head Teacher confirmed that this issue affected the majority of pupils within the school.

We were informed that the law requires that dentists need to provide a service to all members of the community making reasonable adjustments where necessary. In this instance it could mean that dentists would be required to go to the patient's home or school to carry out basic check-ups. NHS Brent informed us that they are considering the appropriateness and feasibility of offering dentistry services from a school base. The Health Select Committee will monitor dentist services for this group.

Acute Care

The Chief Executive of Mencap told us that there are difficulties with the interface between primary and acute care and some health professionals are unable to meet the needs of PWLD. Patients can arrive at hospital without adequate handover, therefore staff are not equipped to deal with the often unique needs that PWLD have. The task group hope that the newly employed acute care nurse will help to tackle some of these issues. Although there are concerns that it would be impossible for one individual to meet the needs of all PWLD in the borough.

The Chief Executive of Brent Mencap reported that inadequate training amongst health professionals means that they can assume that that behavioural changes for PWLD are a result of disability not a sign of pain, this is known as 'diagnostic overshadowing'. It can be very serious in relation to detecting illnesses such as breast cancer as late diagnosis makes it difficult to treat and the treatments more invasive. Medical Professionals can also have an apathetic attitude towards PWLD who often take carers along to medical appointments, health professionals are known to address the carer and act as if the patient with learning disability is not there.

Brent carers told us about the difficult situations that they faced when staying in hospital with the person that they support. Firstly many carers didn't feel confident in the ability of the hospital staff to provide the necessary care which led to decisions to stay with them. Many found that although they were in effect doing the work of hospital staff by interpreting the needs of the patient, providing encouragement and a comforting presence, their needs were totally ignored. This often meant that they were not provided with adequate eating or sleeping facilities. A carer told us of her experience of staying with her sister at a hospital in the borough. She stayed at the hospital for 5 days and slept on the floor. She did everything for the patient but was refused a cup of tea. The hospital only agreed to relieve her for half an hour to go home and freshen up.

The carers raised issues around screening for breast cancer. One carer explained that she looks after someone with a chronological age of 53, mental age of 5 and the body of a 70 year old. However she didn't qualify for screening as the programme is for the over 60s. Due to the complexity of the health issues that PWLD face their bodies age differently, this needs to be taken into consideration when developing screening programmes. Furthermore, as many PWLD have limited communication skills it may mean that carers don't always realise when there is a problem.

Carers are often not allowed to go into the screening room with the patient. This can make the screening process distressing for the patient as the carer can provide reassurance and

help with communication. For some PWLD going for mammograms is just too difficult because the procedure is painful and people are required to stand up. We raised these issues with NHS Brent who agreed that we need to strengthen the role of carers in the acute sector.

Health Promotion

Given the health inequalities and prevalence of health issues that PWLD face such as obesity we felt that specific reference should be made to this group within health promotion strategies. We are aware that the council and its partners are currently developing an obesity strategy and it is important that there explicit references to the needs of PWLD and how they will be met, based on the fact that there are higher levels of obesity amongst PWLD due to sedentary lifestyles and restricted access to healthy diet and exercise.

Recommendation

That there are specific actions to address the needs of people with learning disabilities in the Brent Council Obesity Strategy and other health promotion strategies

Health Action Plans

The White Paper, Valuing People 2001 highlighted the need for Primary Health Care to ensure that all people with a learning disability had a health action plan to ensure their health needs were met by primary, secondary and acute health care providers. This document sets out information about what a person with learning disability needs to do to stay healthy. It lists any treatment needed and the support that individuals require to get it. Local research undertaken by Brent PCT, Brent Mencap and Brent Learning Disability in 2007 could only find evidence of about 40 health action plans being completed out of a population of about 1250 people with a learning disability.

NHS Brent has put in place an enhanced scheme where GP's are paid a sum of money for every Annual Health Check completed. During our investigations the task group found a number of problems with Annual Health Checks and Health Action Planning:

- Many GP's are still not signed up to the scheme as it is perceived as little remuneration for the work that it entails.
- Conversely, some carers felt that GP's can be faced with a perverse incentive to complete health action plans.

Carers told us that they were approached and asked to complete one as a tick box exercise rather than real concern for the patient's welfare. NHS Brent are aware of these challenges, they informed us that so far 53% of GP's are signed on to the scheme. Other GP's have asked for more training. The recent data submitted from NHS Brent to the Department of Health has showed that the number of Annual Health Checks completed in 2009-10 has risen to 289.

Transitions for young people from children to adult services

Overall the task group found that in reviewing services for both adults and children, young people with learning disabilities often benefitted from the fact that they were in statutory education which is attached to specialised medical provision. This was the case at Hay Lane

school where it was reported by the head teacher that there is a good structure in place that is currently working well. A team of nurses' work between Hay Lane and Grove Park Schools there is also a paediatrician attached to the school. There are a number of medical professionals involved with the pupils but as it is within the context of the school, they work together and share information about the pupils.

The concern for young people lies in the transition from children to adult services. We were informed by the Chief Executive of Mencap and the Head teacher at Hay Lane School that this is an important area for the task group to focus on. The Assistant Director for Community Care informed us that a project looking at this area had already been scoped and is awaiting the go-ahead. We believe that this project must start as a matter of urgency.

Recommendation

That the go-ahead is given to the council project to look at transitions from children's to adult services for people with disabilities - as a matter of urgency. The appropriate Overview and Scrutiny Committee should monitor the progress of this work

NHS Progress

There has been recognition within NHS Brent that further progress needs to be made in implementing the Valuing People Now recommendations. The Trust has expressed its commitment to achieving these aims and has agreed a number of important self assessment framework targets with NHS London. It has outlined a number of important actions within primary care that will enhance services for people with learning disabilities including;

- That GP's surgeries have a register of patients with learning disabilities and their carers.
- That PWLD have annual health checks
- That PWLD receive disease prevention, screening and health promotion activities to the same extent as the rest of the population
- Work to ensure that better health outcomes for PWLD is promoted across primary care

The council, through the Health Select Committee can play an important role in monitoring the self assessment targets to ensure that they are being implemented within the given time scales.

The task group welcomes the news that Brent Mencap has been commissioned to provide training from admin staff to director level to ensure healthcare staff understand the issues and that reasonable adjustments are addressed through strategic plans. This training focuses on commissioning services, to ensure that patients have a better experience with providers.

Recommendation

That the Health Select Committee monitor the implementation of the NHS Brent learning disability self assessment framework and improvement of statutory functions such as dentists.

The Invisible community

We were informed by officers in the council and the Chief Executive of Mencap that only 20% of people with learning disabilities are known to local specialist services provided by the council and its partners. The other 80% have a learning disability but do not meet the eligibility criteria which are critical and substantial needs, therefore they do not become known to the council unless there is a crisis such as their carer dies.

We defined this group as the 'invisible community'. It refers to the residents of this borough who have mild to moderate learning disabilities. The council and local partners' needs to draw together a comprehensive understanding of this group, to determine if they are prevalent among the groups who do not have regular health checks and if they are accessing the services that they need and whether they need further investment and support. We know that they are vulnerable group and early investment can provide longer term savings to the council.

The Chief Executive of Brent Mencap shared our concerns. She told us that as 60% of PWLD live at home this will be a time bomb as very few families are putting support in place. When carers pass away they will be an additional responsibility for the council. Many of the PWLD do not have the skills to live independently, this needs to be addressed at an earlier stage. There needs to be long term planning and preventative work to ensure that PWLD can gain the skills to live independent lives.

We asked our witnesses if they had put any provision in place to care for their loved ones in the event that they were not able to and none were in the position to do so. We raised this with the Assistant Director for Community Care who agreed that preventative care can stop the need for high level services. The council does what it can but is subject to financial constraint.

The task group were keen to find ways to identify this group to monitor the services that they are accessing. The Head of Diversity informed us that it is possible to find out more information about people with learning disabilities in the borough. If we had the resources to map every statutory agency that has information, such as council tax, police and job centre plus records. We could work with statutory agencies to find out what they know. However there may be some concerns within some agencies about sharing this type of information.

We were also informed by the Head of Diversity that they had received some funding to do some targeted work with the Muslim community in Brent. Consultants were commissioned to do some research to provide more information such where they live, ethnic background, as little was known about this group. The results from this work gave the diversity team a detailed understanding of the group and they were able to develop targeted projects. However the project was funded by national government.

A practical way to resolve this issue was found through a new project set up by the housing and community care department. The Assistant Director for Community care informed us that the invisible community can be identified through a new project that the team had recently received funding for. The council and NHS Brent and other partners put in a bid and received £100,000 from the social exclusion workforce for a project starting in April 2010. The project focuses on developing training and work opportunities for people with learning disabilities.

It was recognised that there is a lack of co-ordination and capacity in the voluntary sector, although they are best placed to work with these groups and support them to access services. The project will pump prime and build the capacity of the voluntary sector to get PWLD into specialist services.

The Assistant Director assured us that the project will focus on employment and training for PWLD and through this process they will be able to identify this group and ensure that they are accessing the services that they are entitled to.

The task group welcome this project and congratulate officers for securing funding for this piece of work. We would like to emphasis the importance of using this opportunity to map the wider group of PWLD in order to ensure that they are accessing the services that they need.

Recommendation

That information is gathered on residents that have a learning disability to ensure that they receive targeted appropriate services.

Leading by example

The task group also investigated the councils support for PWLD. In reviewing this issue we thought it important to ensure that our own house was in order as well as challenging our partners to improve services. We met with the Head of Diversity to discuss the work of the team and the extent to which learning disabilities features as a priority within equalities issues. We were informed that the council has already gone beyond the statutory requirements of race, disability and gender and includes age, faith and sexuality. Brent is one of the most diverse boroughs in the country with a majority BME population. The council celebrates its diversity as it adds to the richness of the area. However the Chief Executive of Brent Mencap argued that PWLD are marginalised by the council in important strategic documents like the corporate strategy which make no reference to the needs of this group. The Head of Diversity said that the council's strategic documents generally refers to the six strands of equality and diversity as an umbrella term and within each strand there is a great deal of difference. This does not mean that we disregard learning disability. In the Brent Council Single Equality Scheme there are a number of targeted activities for people with learning disabilities. For example one of the targets was to meet the housing support needs of people with learning disabilities. As part of this the diversity team carried out a strategic review of learning disability and housing support services tendered for new providers and reconfigured the service. The Brent Council Single Equality Scheme had been consulted upon widely and Mencap were a member of the council's Disability Equality Liaison Group (DELG) who had helped to shape the document.

In Brent Council, 4% of the workforce has a learning disability. However it is thought that the real figure is much higher as the declaration rates for PWLD among staff is low. Some find it uncomfortable to discuss and others do not want to declare it but there are requests for support needs from staff. So discussions are taking place with managers about needs. If we were to gather this information it would present a far clearer picture about the extent of learning disabilities in the council.

We were concerned by reports that PWLD are still stared at in the street by the general public. We believe that the council can play an important role in promoting positive images of PWLD in everyday activities and not only in relation to their disability. We were told by the Head of Diversity that the council uses a mix of people in promotional material and does try to avoid it being contrived. For example we use pictures of people in wheel chairs and images of other types of disability including people with learning disabilities in all sorts of articles not just those about disability.

We also spoke to the Head of Diversity about terminology. The chair of this task group was particularly keen to understand the policy around how language was framed as there was

concern that some people found the use of the word 'disabled' offensive. We were informed that the term disabled is used because of the legislative framework. The chair argued that the use of the term 'special' should be adopted, however the Head of Diversity argued that though she was supportive of this, careful consideration needs to be given to use of euphemisms because as there are 130 languages spoken in Brent and this may cause confusion.

The Chief Executive of Brent Mencap was concerned that we do not use diversity monitoring as an opportunity to drill down into types of disability, this could be useful in identifying the needs of residents and contribute to service planning. The Head of Diversity informed us that the council's diversity monitoring guidance uses the Disability Rights Commission recommended format and definitions and in the case of disability it does drill down into different types of learning disability.

Treat Me Right! – Support for Living project with Ealing Hospital

Desk top research conducted for this review led the task group to become aware of a project being carried out by Support for Living³ in conjunction with Ealing Hospital. Support for Living set up a project called Treat Me Right! This project came about because clients complained about the difficulty in accessing Ealing Hospital. Support for Living (SfL) approached Ealing Primary Care Trust and made a proposal for funding to help staff gain a better understanding of challenges faced by people with learning disabilities. The project received £70,000 in funding and has been able to implement a whole host of measures to improve services for PWLD. The funding has enabled them to produce information in easy to read formats, such as the complaints policy and admission information.

We met with the Treat Me Right project team who gave us an overview of the work. We were informed that senior level buy-in is essential to make this model successful. The project team met with the Chief Executive of Ealing Hospital to talk about the Treat Me Right project including expectations and legal requirements. The Head Nurse for Improvement and Development acts as a link person. She has proved very useful and ensures that staff take part in the training. There is a steering group in the hospital which includes service users, carers, and commissioners. This group helps to drive the project forward.

We found that in the Treat Me Right project they are developing a new approach to health action plans. The aim is to empower the patient or the carer to complete the forms so that they are in control of it. The underlying thinking is that this is not a medical document. When people take responsibility for ensuring that they are completed, it will help them to understand their needs and explain this to medical professionals.

As an alternative to Health Action Plans they have developed a hospital passport which provides a summary of the most important information about people with learning disabilities when they go into hospital. Patients, carers and hospital staff have found the hospital passports very useful, which has resulted in lots of positive feedback. The SfL team works with patient to fill in the passport. For example a small adjustment was agreed for a patient with learning disabilities who was prone to leaving their hospital bed and 'wandering off'. This was recorded in the hospital passport and the patient was placed near the nurse station and familiar items were provided to help him relax.

³ Support for Living is a not for profit organisation providing support for people with learning disabilities across Ealing, Hillingdon, Hounslow, Harrow and Brent.

We believe that a similar model to the Treat Me Right project should be implemented in hospitals in Brent. We shared our findings about this work with NHS Brent who immediately contacted Support for Living to ask them to develop a proposal for Brent. During our meeting with NHS Brent we were assured that they agreed with our view that this is the type of model we need to implement in hospitals in our borough as a matter of urgency.

There was a concern that there would be overlap between the Support for Living model and the Mencap training however it was agreed that the two activities were different. Mencap would be focussing on commissioned services while Support for Living would be looking at staff training and reasonable adjustments within the hospital. The Ealing model is the logical next stage as it is about putting things into practice in order to commission services.

NHS Brent is also interested in Ealing's concept of trying to ensure that everyone within the hospital understood the needs of PWLD and spread good practice across the hospital rather than having one designated nurse. The task group were informed that it is important that this agenda is seen as everyone's responsibility rather than one individual.

Recommendation

That NHS Brent implements a project – similar to the Treat me Right project developed by Support for Living in Ealing Hospital

Conclusion

The underlying thrust of the issues within this review is about equal opportunities, based on the premise that everyone should have equal access to public service irrespective of age, race or disability. It involves looking beyond the narrow focus on physical access which is often associated with disability issues to focus on the importance of clear targeted communication, challenging prejudice, assumptions and ensuring that the needs of this group is embedded in service planning and are consistent across the board.

The task group found many of the issues raised in this review disturbing. The idea of young people having to endure dental pain, carers having to sleep on the floor and a general lack of understanding the needs of people with learning disabilities is wholly unacceptable. As a task group we recognise that this review is the beginning rather than the end of the piece of work. The overview and Scrutiny function must prioritise this issue to ensure that the recommendations in this review are implemented. NHS Brent must also deliver on its commitments within the agreed timeframe.