

Brent Health Action Project

People with learning disabilities - healthcare for all?

December 2011

The national picture - healthcare for people with learning disabilities:

Health inequalities experienced by people with learning disabilities are well documented within the literature (ref 1-8). Research also shows that despite having considerably greater health needs, people receive poorer support from mainstream health services (Elliot et al, 2003). Formal reports and government strategy have served to highlight these inequalities and proposed new ways of working to address these. Nationally, an independent inquiry into access to healthcare for people with learning disabilities was established under Sir Jonathan Michael's leadership in May 2007, following the publication of the (Royal) Mencap report 'Death by Indifference' (2007), which described the experiences of six people who died whilst under the care of the NHS. A further report, 'Six Lives' (2008)- the Health Ombudsman and Local Government Ombudsman's report into these six deaths, are a damning indictment of NHS care for people with a learning disability. They confirm the findings in the 'Death by Indifference' report of the widespread failure by health professionals to provide the proper level of care and highlight an appalling catalogue of neglect of people with a learning disability', Mark Goldring, Chief Executive, Royal Mencap. The Disability Rights Commission Formal Investigation into equal treatment had also raised questions about the quality of healthcare for people with learning disabilities who were physically ill.

The inequalities evident in access to health care, in the view of the recent study by Emerson et al (2011) are 'likely to place many NHS Trusts in England in contravention of their legal responsibilities defined in the Equality Act 2010, the Mental Capacity Act 2005 and the Health and Social Care Act 2008 (Regulated Activities) Regulations 2010. At a more general level, they are also likely to be in contravention of international obligations under the UN Convention on the Rights of Persons with Disabilities.'

Organisational barriers

A range of organisational barriers to accessing healthcare (nationally) have been identified, cited in Emerson et al (2011) These include:

- scarcity of appropriate services;
- physical barriers to access;
- failure to make 'reasonable adjustments' in light of the literacy and communication difficulties experienced by many people with learning disabilities;
- lack of expertise and disablist attitudes among healthcare staff;
- 'diagnostic overshadowing' (e.g. symptoms of physical ill health being mistakenly attributed to either a mental health/behavioural problem or as being inherent in the person's learning disabilities).

The project:

In the light of the above national picture, Brent Mencap has campaigned locally to reduce health inequalities, promote understanding of the particular needs of people with learning disabilities and engage with their health service partners. Funding was secured from the Learning Disability Development Fund through the Learning Disability Partnership Board to continue and expand existing training across primary and acute healthcare settings. The project ran from January to December 2011 with the aim to remove barriers to Brent people with learning disabilities receiving the right healthcare and support from local NHS services by providing information, specialised training and advice.

The project covered a number of areas:

- Learning disability awareness training for Brent NHS senior managers, General Practitioners (GPs) and practice staff
- Training including consumer trainers (with a learning disability) for acute hospital, community and mental health trust staff
- Participation in the local Health Action Group, and leading the group from August 2011
- Regular information stalls at NHS sites
- Focus groups to gather patient stories, and learn from people's experience of local healthcare
- Mystery patient visits to acute healthcare settings
- Evaluation of the effectiveness of the project, in terms of training outcomes, action plans implemented and changes in attitude and working practice.

Three types of training have been given:

- **GP training, involving GPs and practice staff.** This has focused on giving information and statistics about learning disabilities, highlighting current good practice and legislation, and outlining the expectations for this service user group in the Learning Disability Health Action plan of the local Brent NHS.
- **Hospital training, involving clinical and non clinical staff.** This has been delivered in partnership with consumer trainers, raising learning disability awareness, highlighting good practice and promoting action planning to change current practice.
- **Training at Community Health Centres, involving clinical and non clinical staff** (as above).

Healthcare in Brent for people with learning disabilities - the patients' voice.

Now, we hear the patients' view at first hand:

Visiting the Doctors: The main issues are about **communication**: "The doctor should ask the right questions." "The wording is hard to understand." "They won't explain medical words or write them down" - "oh, you won't know what it means". "Doctors explain on their terms rather than our

terms.” “Doctors may talk nicely – in the end nothing happens.” “Some people are not very good explaining in plain language.”

Issues of **respect** and **understanding of learning disability**: “In my childhood I felt like a piece of meat. I saw a lot of Doctors.” “When I saw the doctor she made me angry as she thought I only wanted the sick note. I was in pain. She did not take me seriously. It’s really horrible when they don’t take you seriously.”

“At the Work Capability Assessment they commented on how well dressed I was. They make assumptions that people with learning disabilities can’t dress or do things for themselves.”

“I got upset with the diagnosis of mental retardation. It upset me a lot.” (It’s the wording). “People don’t understand certain disabilities.”

Making appointments at the Doctors: Issues include the **booking systems** and **length of time** needed to get a reply: “If you ring up you must call early.” Some people felt it can take a long time before someone answers the phone. People did not like that the call is expensive- an issue if you are on benefits.

Outpatient and inpatient hospital visits: Issues again include **communication, understanding of learning disability** and treating people with **respect**: “Staff often speak with a loud voice in hospital. This is patronizing and makes you feel upset.” “They don’t always keep up-to date records. The nurses ask (the same questions) all the time.” “Different hospitals should pass on notes to each other.” “I broke my toe, had to wait a long time. They seemed annoyed because it was something minor to them at Central Middlesex but not at Northwick Park. They made you feel welcome not made me feel like an idiot.” “In lots of cases the doctors don’t seem to believe me. It’s really annoying. I once had an electric shock, they thought I meant heart attack.” And a comment that sums up the frustrations and feeling of powerlessness:

“Slow, slow (lots of waiting around) but the doctor – quick, quick, quick and he is gone.”

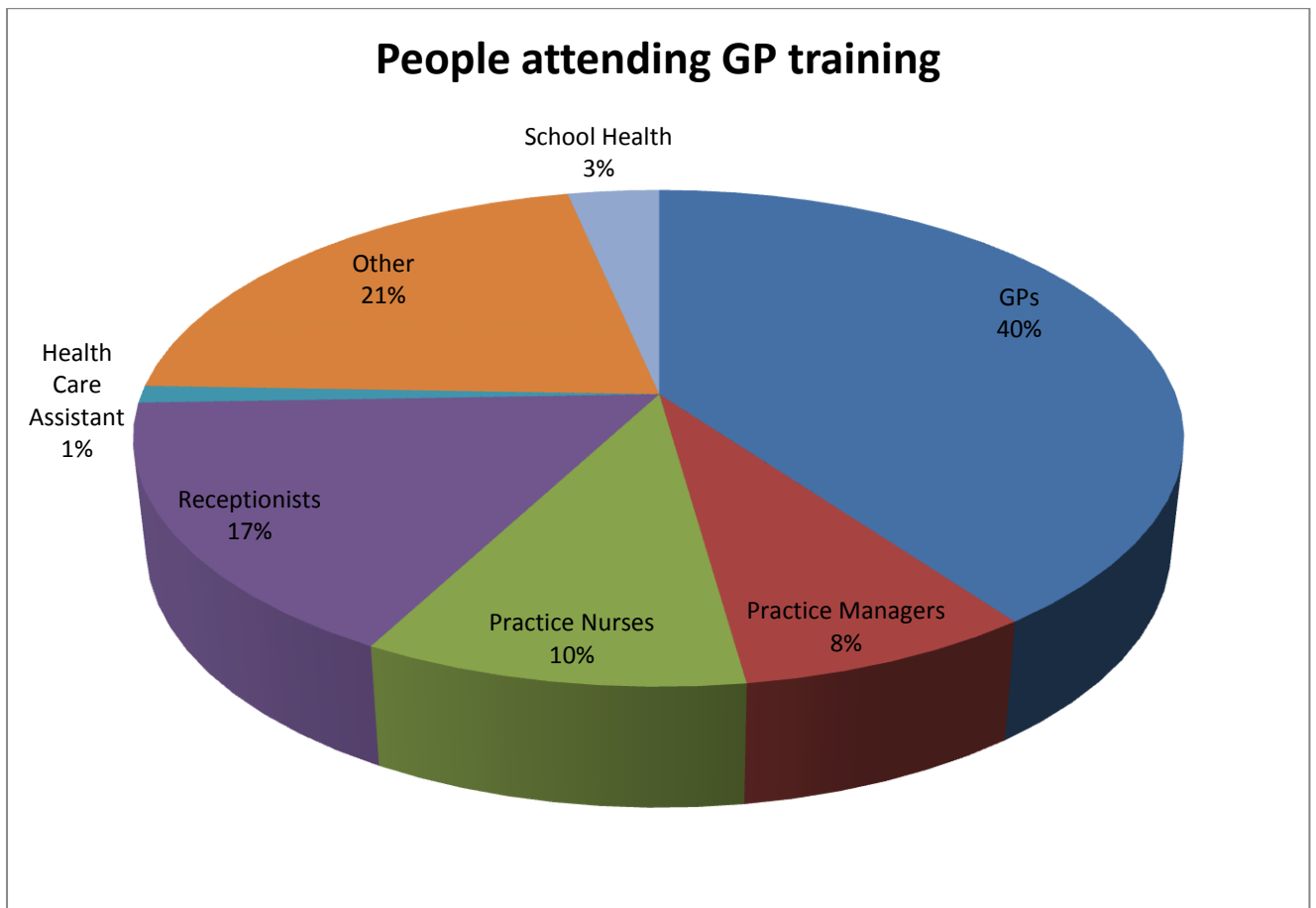
The training- GPs and practice staff

Who has done the GP training?

104 people have attended GP training on Learning Disability awareness. In addition 30 GP registrars attended a shorter workshop. Just under half of these people have been GPs, with other staff from the practices broken down as follows, (Table 1). Considering there are around 70 GP practices in Brent, this is roughly an average of one person attending per practice. In reality, the picture is of course, more varied, with some practices embracing the training and sending a good number of staff, and others, not represented at all. There has been a reasonable representation from all areas of the practice which should promote team understanding of the issues raised. Trained Practice

Managers can make a difference in how the surgery runs, and how appointments are made. Front line staff such as receptionists can be aware of communication and other issues for people, and the nurses and doctors, can have an understanding of what they can do to support people to get good health care. The good number of GPs is encouraging as with their time commitments, they can be difficult to access for training.

Table 1

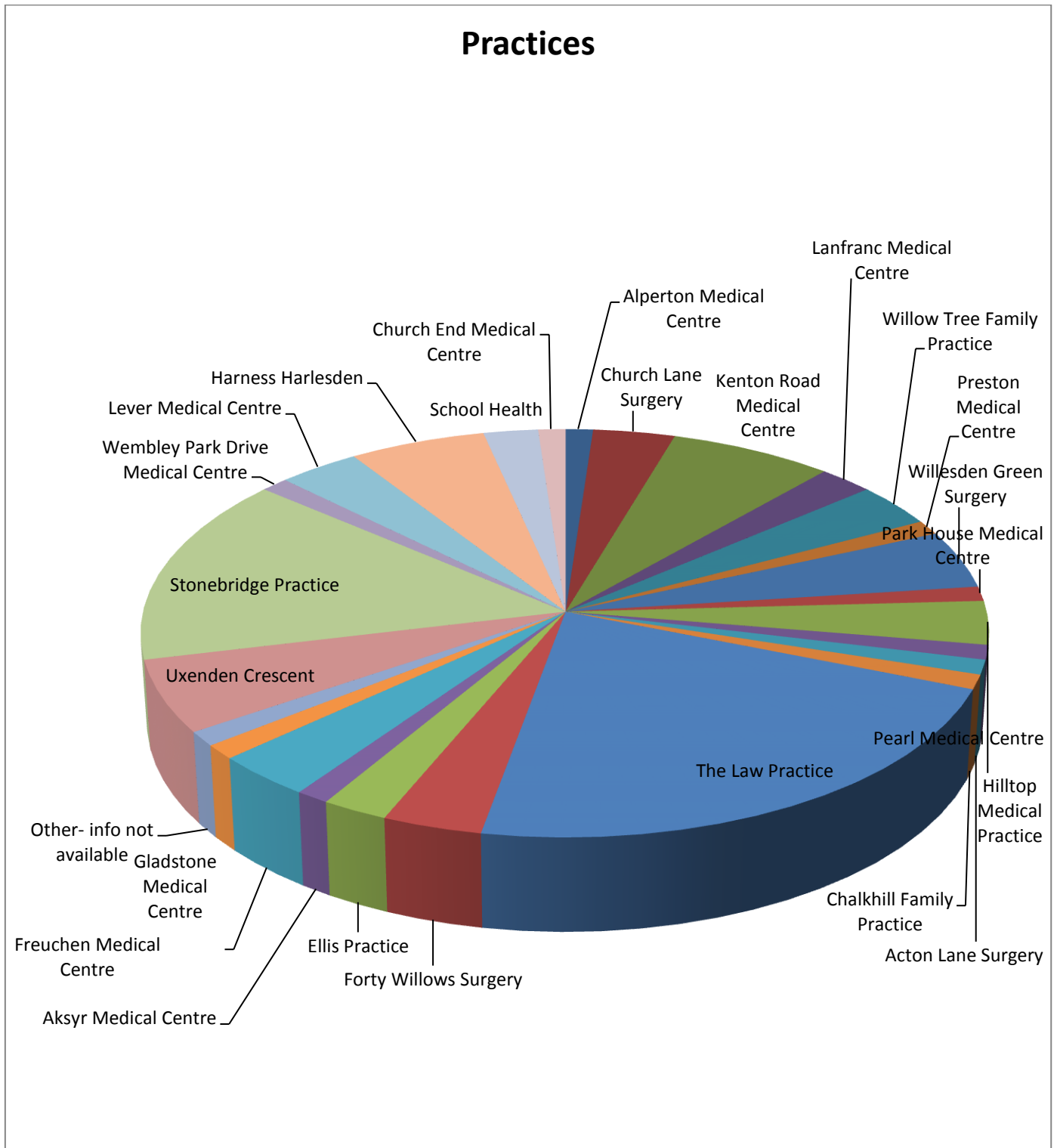


N=80

Where are people from?

The people attending training are from the following GP surgeries and medical centres (Table 2).

Table 2

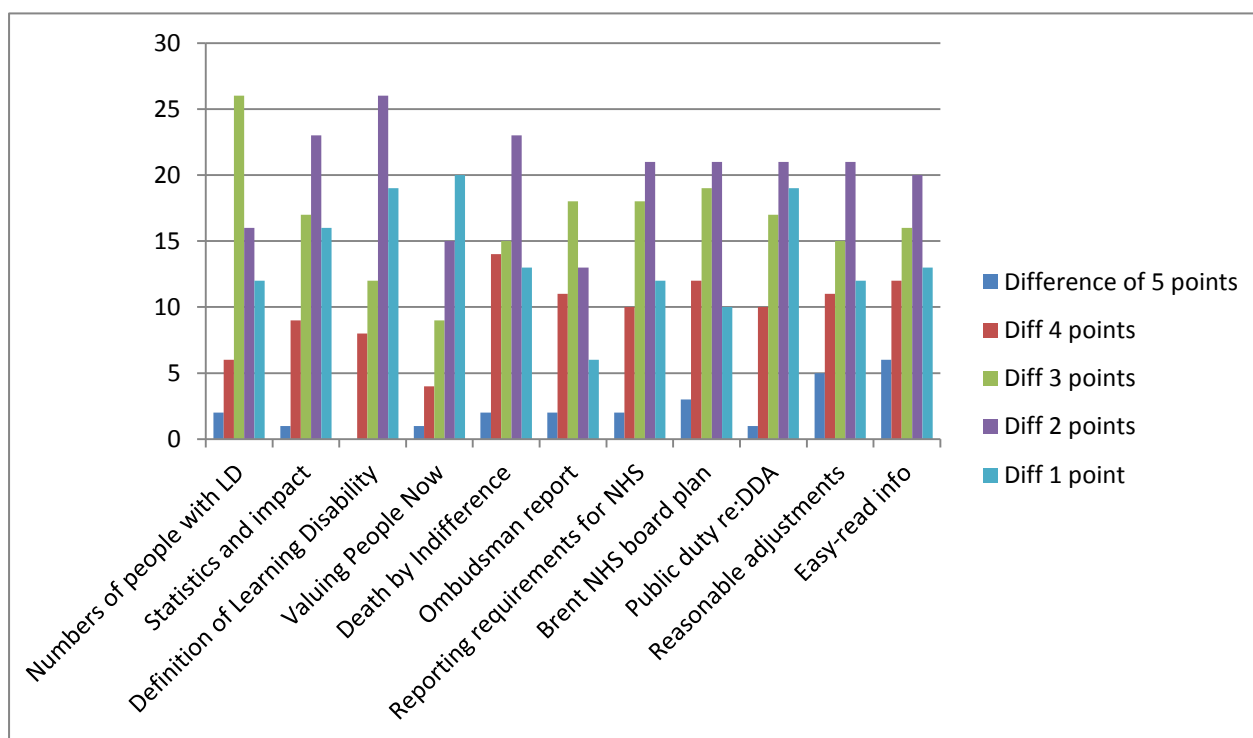


Results:

The staff were asked to complete a brief questionnaire comparing their knowledge before and after the training. There are differing results which show people starting with different amounts of knowledge and experience. This means that those starting from a point of ‘reasonable knowledge’ may move to ‘full knowledge’ by the end of the training- a difference of two points. The majority of the participants show an increase in their scores after training, particularly for specific learning disability reports e.g. Ombudsman report, and ‘Death by Indifference’, and also in practical suggestions about ways to make ‘reasonable adjustments’ and easy-read information.(Table 3).

Changes pre and post training: Table 3

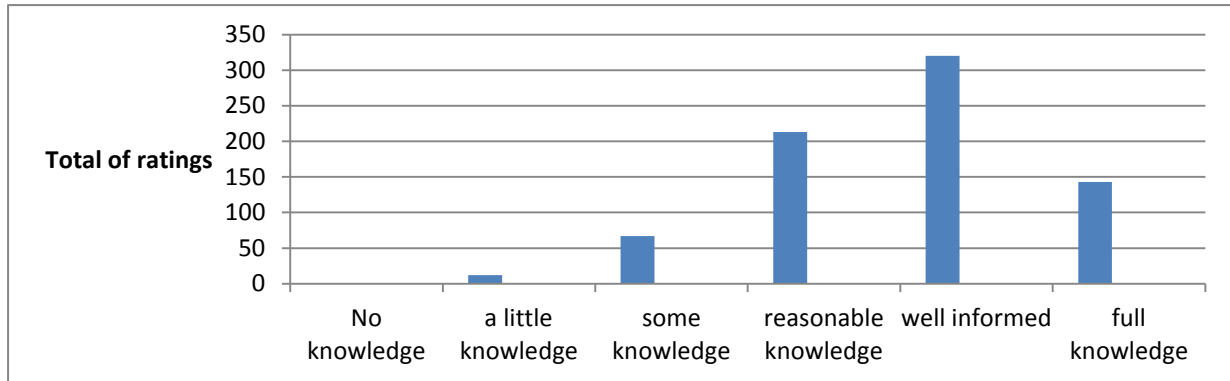
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¹ LD –Learning Disability
DDA -Disability Discrimination Act

80 participants were asked to rate 11 areas of the training (total 880 ratings) and the majority of scores at the end of training show that they had ‘reasonable’ to ‘full knowledge’. (Table 4) This is very encouraging and shows that the training has been well targeted and presented.

Final scores at end of training: Table 4



Follow up to GP training:

Ten participants were followed up by telephone after their training to assess the value of the training and to ask if they had made any changes as a result of the training (environmental or communication). The follow up included reception staff, Practice Nurses, GPs, and Practice Managers.

All participants felt that the training had been useful and had covered what they wanted. The most helpful areas were highlighting awareness of people with learning disabilities, how to communicate well, ensuring that a proper range of services are offered, ensuring that people’s health needs are not overlooked. Following the training, reception staff reported changes to appointment bookings, booking an early appointment, or one at the end of surgery, ensuring people are ‘fast tracked’, if anxious in the waiting room, or given a quiet area to wait. A Practice Manager explained that they were developing longer, more specialist appointments. This is encouraging and works towards the benchmark ***‘Flexible appointment systems’²***

All participants spoke of modifying their communication, giving examples such as not asking leading questions, finding out what people would like to be called, and generally giving more time. When asked if they had changed anything in the workplace, some said that they hadn’t yet! A few talked about ordering easy-read literature and changing their entrance and exit signs for clearer ones. When asked who they would contact for learning disability advice, some spoke of the Learning Disability team although one practice expressed frustration about not being able to be put through to a LD liaison nurse when requested. This had taken some persistence and repeated phone calls, but they now had a named contact with whom they were very happy .

² Healthcare for vulnerable people, NHS London: benchmark of Best Practice. September 2010.

It became apparent on the training that not all GPs were aware of Safeguarding issues³ and some have since completed training in this area. Brent Mencap also sends regular information and updates to GP practices by email.

Who has done the hospital and community training?

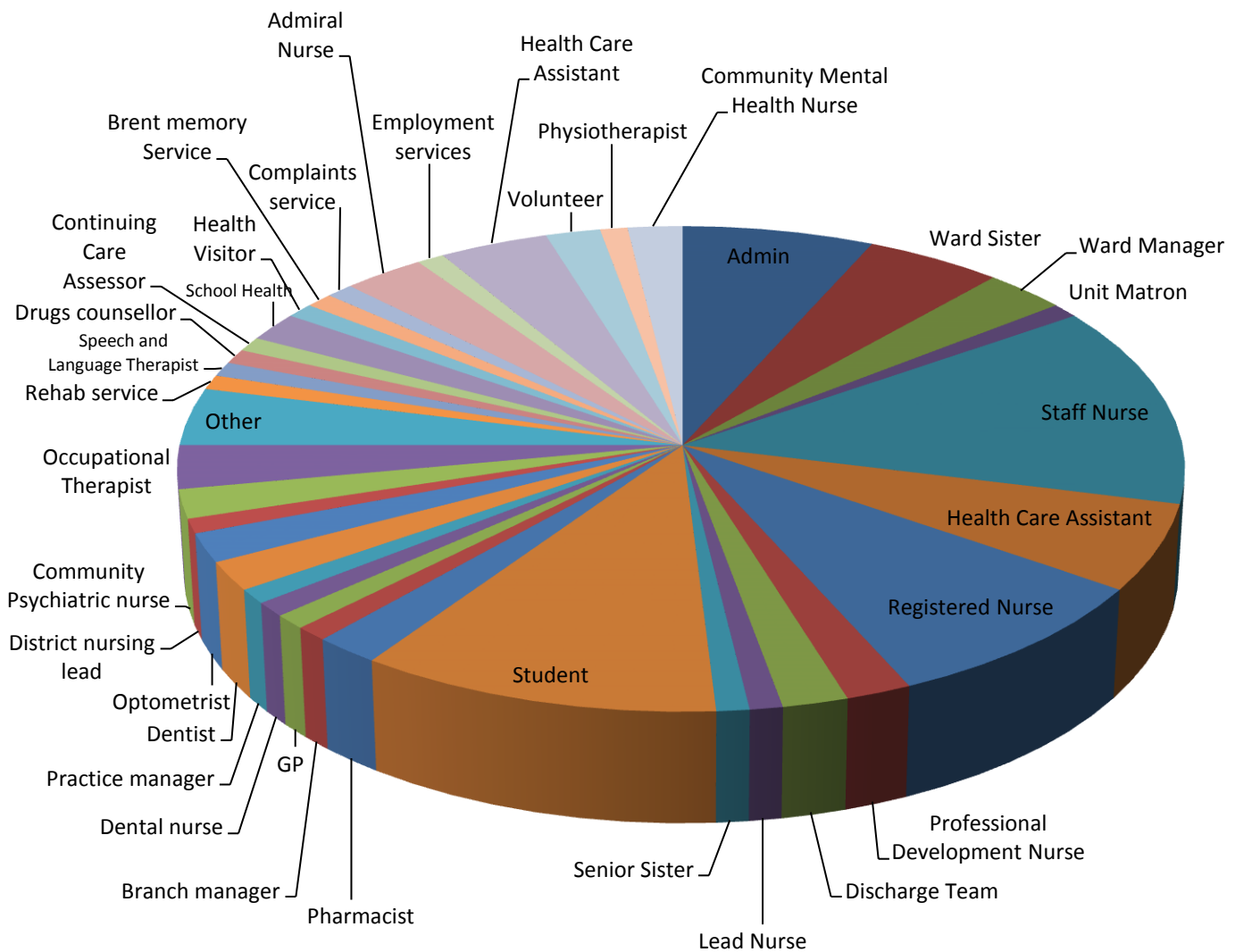
A total of 115 people have attended training at both Central Middlesex and Northwick Park Hospitals and community centres for health and care. Their roles can be broken down as follows: (Table 5.)

This is in some ways an encouraging sample as it includes a good mix of staff at all levels including both those delivering front line care and those in management positions. Senior clinical/managerial staff can lead and influence others and be at the forefront of changing the way that things work, while those in daily contact with patients, need to have the awareness and information to prevent people being disadvantaged. In terms of numbers however, it is a poor representation, considering the number of employees in these services. Further training needs to continue to involve people at all levels. The highest proportion of attendees were staff nurses, registered nurses and students. The training does show a lot of gaps in community staff, e.g. therapists, dentists, optometrists etc due to the very slow pick up rate of training within Brent NHS and very low attendance. There is also a significant gap in medical hospital staff and consultants.

³ Safeguarding Vulnerable Adults. Sept 2006.

Table 5

People attending hospital and community training



What did people think of the training?

An almost total majority described the training as either 'good' or 'very good', being satisfied that the course covered what they wanted. They highlighted particular areas such as the involvement of people with learning disabilities as trainers as very useful, and enjoyed the role play situations in particular. Many gave particular mention to hearing the user experience at first hand, and how powerful this was. Practical suggestions such as the 'Getting It Right' User Charter and Hospital Passports were thought to be good ideas as well as an Acute Nurse Liaison role.

In this training, participants were asked to identify an action plan that they could carry out back in the workplace. The action plans contained the following themes:

Information – making use of the information learnt on the course, further study, passing on information to colleagues, encouraging others to attend the course and making sure that carers had relevant information.

Environment- changing waiting space, displaying accessible information, safety issues e.g. increasing lighting, offering a choice of seating, making sure wheelchair is available, and displaying the Getting It Right charter as a positive message.

Communication- adapting own and others communication, using easy words and pictures, providing communication tools, e.g. symbols, picture menu cards, accessible complaints leaflet, allowing time for people with learning disabilities to express themselves and make choices

Procedural- adapting booking systems e.g. end of session appointments, double appointments, booking regular doctors, use of hospital passport (when finalised), knowing who to contact for specialist advice.

Rights and respect- ensuring people's needs are understood, ensuring enough information is given for person to consent, (or not), assessing people's needs well and responding immediately, being more aware of different factors that contribute to a person's behaviour.

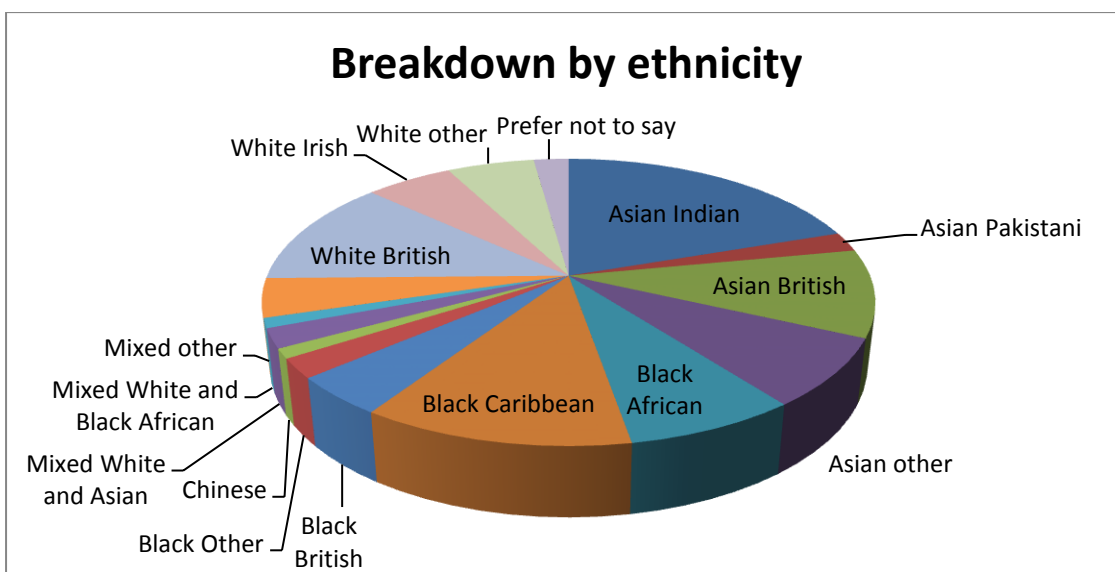
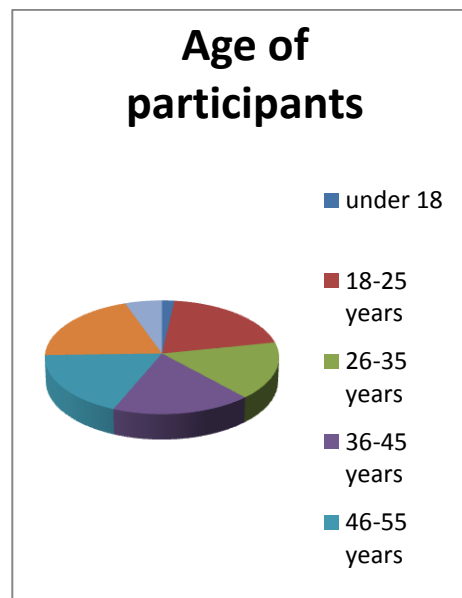
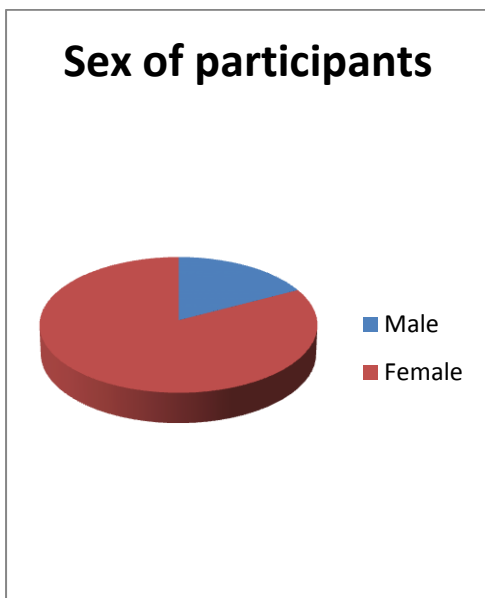
Other- making people aware of Learning Disability Liaison Nurse.

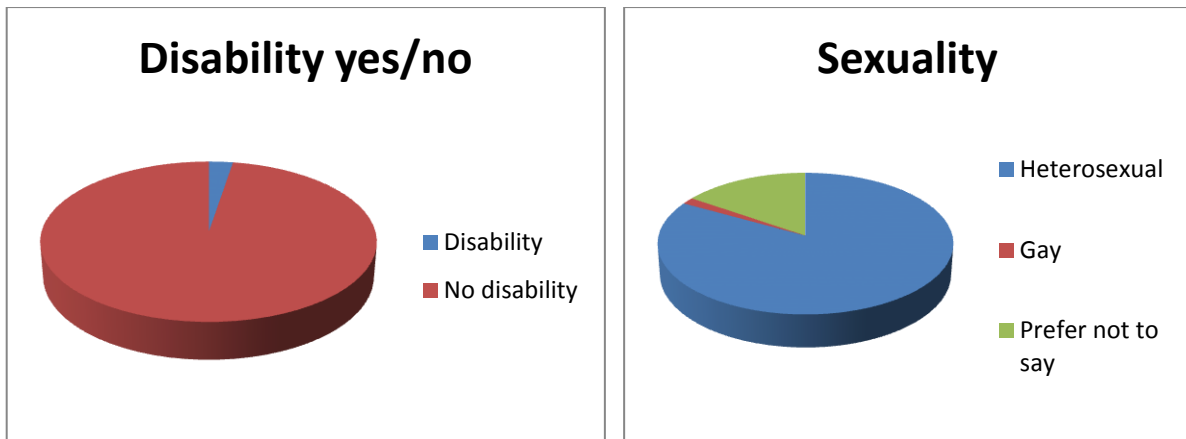
Follow up by telephone to 20 participants produced a varied response. Where quick practical tasks had been suggested, e.g. putting up the 'Getting It Right' charter, these had, in the most part, been actioned. In one case, the manager had set up a specific notice board area for information which staff had been accessing. They also talked of having information available for carers. Two managers had sent staff on further training, although one had not received further training dates through the hospital. One respondent who agreed to set up picture menu cards was waiting for another colleague to attend the training and to do a joint project. A pharmacist had identified people with a learning disability and spent extra time going through their medication with them and using pictures where appropriate and also passing this on to colleagues. Some reported not having day to day contact with patients, but encouraging colleagues to attend the training and passing on skills learnt. Some talked of adapting their own communication and being generally more aware of issues facing people with learning disabilities.

Time to follow through good ideas and goodwill from the training seemed to be a recurring theme, with dental staff reporting looking for easy read information relevant to their area and not being able to find any. (The project was able to provide links to this.) Another respondent talked of visiting the Mencap offices to look at resources, but again time was given as a reason for actions not being completed. Some of the more recent training participants (November and December 2011) had action plans with action dates after the end of the project.

In conclusion, those who have attended the training all talked of the positive impact it had. There seems to be some progress in highlighting awareness of learning disability but actions requiring planning time and searching for resources are definitely losing out to competing priorities and time pressures. The use of Learning Disability ‘champions’ in departments, given appropriate time through Continuing Professional Development (CPD) to move forward practical and resource based projects specific to that department could be a way forward. In hospitals, the Acute Learning Disability Liaison Nurse could be an important link for these ‘champions’.

Breakdown by diversity data (total training)





Challenges to the project

There have been considerable difficulties in take-up of the training offered. Administrative issues such as room booking and availability of staff have significantly limited how many have been able to attend so far. Sessions have been cancelled due to there being insufficient numbers, and at times, the trainers have presented for the training to find no participants at all. This has had a significant effect on the project, and in particular on the consumer trainers' morale. For some, this is their first experience of paid work, for which they have been well trained and have made a considerable commitment of their time and effort. It is difficult not to interpret this as 'not being important enough'.

It has proved difficult, particularly within Brent NHS to gain responses from those responsible for training programmes, and to secure commitment even to publicise events, and to ensure attendance. There is interest to attend from ground level staff, but the commitment is needed from first line and senior managers to release staff, and training leads to support the training. The ability to affect this situation remains within the organisations themselves and will continue to affect the raising of awareness for this group of people and ultimately, their healthcare outcomes.

Mystery patient experiences:

Two 'mystery patient' visits took place during the project at Central Middlesex (CMH) and Northwick Park (NWP) hospitals. Information was also collected from individual experiences, at the GP, as inpatients and from outpatient visits. Themes from these will now be highlighted in relation to the standards expected in the Benchmark of Best Practice document: Healthcare for vulnerable people, (2010)⁴ *highlighted in italics*.

'Healthcare environmental signage is clear and unambiguous'

Hospital signage relies almost entirely on reading the written word, also the use of specialist terms, e.g. maxillo-facial, audiology. A few symbols are available for non clinical areas e.g. toilet and cafe, and helpfully, tube stations. This lack of easy-read information excludes people who do not read

⁴ Healthcare for vulnerable people, NHS London: benchmark of Best Practice. September 2010.

from accessing the same information as everyone else. In one instance at CMH, the mystery patient was given reasonable (verbal) directions from reception to 'blood tests', but on exiting the lift, was confronted by a barrage of written signage, with no symbols or explanation. The mystery patients reported feeling 'confused', 'lost' and 'left out'.

Explanations for waiting procedures at both hospitals in the departments visited, (outpatients and blood tests) were written only, without pictures, symbols or even arrows to assist understanding. E.g. *'To help maintain patient confidentiality please queue here at the blue barrier and wait to be called.'* Our mystery patient commented: "you would be embarrassed not knowing what to do next." "You wouldn't be able to come here on your own." A person who does not read is immediately at a disadvantage, and may even miss their appointment due to a lack of understanding of the system. In an already potentially stressful situation, this can unnecessarily raise anxiety levels. People with learning disabilities will not be the only people disadvantaged by such reliance on written information.

'All information provided for the public domain has an agreed accessible version designed in partnership with self advocates and Speech and Language Therapists.'

On requesting information at the blood tests clinic (CMH), although members of staff were helpful, we were told that there was no such material available. In general, patient information on the walls was mostly in writing only, some pictures were available in some areas e.g. diabetic clinic. Although this was a good start, and made our mystery patients feel a bit more included, the pictures did not conform to 'easy-read' principles, e.g. giving the same information as the words.

The PALS service (CMH) was a helpful contact, operating an accessible, open door policy. We asked if there were any easy-read leaflets with pictures available about a hospital stay. The staff member took our details and got back to us, unfortunately saying that there was not anything available specific to that hospital but directed us to other nationally produced information, appropriate to people with learning disabilities. This is clearly a gap in hospital resources, particularly as the hospital website talks about a leaflet 'Your stay' - which provides an ideal opportunity for an accessible version using pictures, with information local to the hospital.

A highlight of one of the visits was the Macmillan Cancer Care advice and support service (NWP). Helpful staff and volunteers knew about and provided appropriate, learning disability specific easy-read information on cancer.

'All staff receive learning disability focused training.'

This is obviously the aim of this project. While there are examples of particular areas achieving good attendance on the training, in other areas, attendance has been poor, with sessions cancelled. There has been no representation from (hospital) medical staff and consultants, a significant gap. This standard is currently not being met.

Positives from the mystery shopping:

- **Proactive volunteer helpers at reception at Northwick Park.** These people approached the 'mystery patient' before they reached the reception desk and asked if they needed any assistance. They spoke to the person with a learning disability and not just the carer, and

gave clear and helpful directions to the department needed. The mystery shopper commented, “ they were friendly, polite and reasonable”. “It was a lovely welcome.”

- **‘Reasonable adjustments’ made at the cafe (CMH).** When asked to pour away some of the mystery patient’s hot drink as it was too full for them to manage without spilling, the staff member suggested a larger cup and went to find one.

Mystery patient feedback: (questionnaires) This is a very small sample size, but each experience is a valued one and provides feedback as a patient story.

Doctor’s surgery (5 questionnaires)

All participants found reception staff helpful.

50% of the Doctors introduced themselves by name.

3 participants had a health action plan that the Doctor used.

The majority of people felt that the Doctor spoke to them, as well as their carer.

The majority felt that the Doctor explained treatment before giving it.

The majority explained the choices available about their treatment.

Not all patients felt they were given time to ask any questions they might have.

Only one patient was given written information in a format that they could understand.

Half of the respondents said that there was no pictorial information on the walls at the surgery.

Hospital (outpatients) covering ACAD, ENT, Orthopaedic (4 questionnaires)

The majority found their way to the appointment

Some pictures were seen on hospital wall signs e.g. toilet

Some people were helped with directions, particularly the receptionist

Most people felt that their carer was talked to, and not them.

Most people were told who people were and what job they did.

Most people had treatment explained before it was given, but with one exception.

Most people did not use long words to explain things, with one exception.

All people felt they were given a choice about their treatment.

Not everyone was given the chance to ask questions

No one received easy-read information about their condition or treatment.

Specialist hospital (outside Brent)

A very negative experience was reported, with a person experiencing poor communication, lack of understanding of disability, no opportunity to ask questions, no explanation of options or consent to treatment. This is being followed up as a formal complaint.

Dentist (1 questionnaire)

Overall, this was a fairly positive experience, although there was a lack of preparation or explanation before treatment and no time to ask questions. Again no easy-read information was available.

In conclusion:

There have been many strands to this project, starting with the patient voice, implementing the training across different parts of the local NHS, and reviewing the impact, from individual NHS staff

and from mystery patient one-off visits. There has been a patchy response, with some practices and wards committing strongly to the programme, ensuring a majority of their staff attend, and others where there is less commitment. Where training is provided free of charge, and using 'expert patient'-type models, (consumer trainers) and there is commitment in the board plan (NHS Brent)it is difficult to understand the lack of take up of the training.

Although some patient stories provide an encouraging view of people's experience of their local healthcare, which we celebrate, there are other examples that demonstrate that there is still some way to go. Attitude change is always difficult, particularly across large and disparate organisations, but it begins with knowledge, information and understanding, and in this case, inclusion of the expertise of people with learning disabilities themselves.

Good beginnings have been made in this project, but commitment at senior and commissioning level within local healthcare organisations is needed to build on this positive start. It is important that individual gains and small changes in practice are rolled out more widely, with senior support and endorsement, and the resources necessary to effect change.

Recommendations:

- Secure commissioner and senior management commitment to further training within Brent NHS and across GP practice and hospital settings (including medical staff and consultants) with targeted expectations for staff to attend
- Consider use of LD 'champions' in wards and departments with dedicated time (through CPD) to ensure availability of appropriate resources and implement projects to ensure 'reasonable adjustments' are made.
- Review signage at hospitals and healthcare centres together with service user groups, to include pictures and symbols where possible
- Identify funds to review healthcare leaflets and work together with service user groups and speech and language therapists to provide accessible versions, e.g. 'Your stay'
- Continue to build on links between primary and acute and specialist Learning Disability services. There are encouraging signs with the GP practice LD link nurse model and the new Acute Liaison Nurse role in North West London Hospitals trust.
- Continue to build links with service user and self advocacy groups and organisations for specialist resources and advice.
- Encourage people with learning disabilities to take part in patient forums, with appropriate support.

Cathy Lenton

Project Evaluator

December 2011

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