

# Healthwatch Oxfordshire and My Life My Choice – research into GP provision for people with Learning Disabilities

**“Every Voice Counts”**

**March 2014**

**“The health and strength of a society can be measured by  
how well it cares for its most vulnerable members.”**



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## Summary

“Every Voice Counts” was a project funded by Healthwatch Oxfordshire and facilitated by the Oxfordshire-based self-advocacy charity My Life My Choice (MLMC). One hundred and six MLMC Members across eleven Groups took part in this report. This included a case study, as well as one focus group made up of carers and the people they support. A DVD presented by four of the Charity’s Health Champions and an Easy Read report was also part of the final project.

The Report found that there are still areas within GP provision which are lacking for those with Learning Disabilities, predominantly in relation to preventative measures such as annual health checks. Just over half those taking part were satisfied with the level of GP services and a similar quantity felt that health service staff, particularly those working in general healthcare, had little or no understanding of Learning Disabilities.

There have been some marked improvements, most specifically with regards to ‘reasonable adjustments’ in physical accessibility to buildings for example and, in cases where the GP knows the individual well, good practice is commonplace.

It is hoped that the findings in Every Voice Counts will inform and continue to improve on the work that has already been done.

Ruth Shaw-Williams, Groups Coordinator, My Life My Choice – March 2014

## Background

MENCAP's "Death by Indifference" (2007), the Sir Jonathan Michael led independent public inquiry "Health Care for All" (2008) and the Department of Health's "Six Lives" progress reports (2010 and 2013) found "convincing evidence that people with learning disabilities have higher levels of unmet need and receive less effective health treatment." In 2008 Sir Jonathan Michael identified 5 key areas of concern in health care (including GP surgeries) for people with learning disabilities:

1. People with learning disabilities find it much harder than other people to access assessment and treatment for general health problems that have nothing directly to do with their disabilities.
2. There is insufficient attention given to making reasonable adjustments to support the delivery of equal treatment, as required by the Disability Discrimination Act.
3. Parents and carers of adults and children with learning disabilities often find their opinions and assessments ignored by healthcare professionals, even though they often have the best information about, and understanding of, the people they support. They struggle to be accepted as effective partners in care by those involved in providing general healthcare; their complaints are not heard.
4. Health service staff, particularly those working in general healthcare, have very limited knowledge about learning disability.
5. Care, between services of difference age groups, and across NHS primary, secondary and tertiary boundaries is poor in relation to services for adults with learning disabilities.

These were the five points that our project collected evidence on in relation to Oxfordshire's GP surgeries. The purpose of this project was to help Healthwatch Oxfordshire and My Life My Choice (MLMC) to identify areas of improvement and good practice in health care at GP surgeries for people with learning disabilities (PWLD).

We asked our MLMC Group Sessional Workers to facilitate a discussion around these five issues across our eleven self-advocacy groups. There was a need to simplify these points due to the high range of differentiation amongst our Membership. These were broken down into the following questions:

1. How good is your GP service?
2. Does your GP give you the treatment you need? Have you had a health check? Is so, was it any good?
3. How easy is it to book an appointment to see your GP
4. Does your GP service make reasonable adjustments?
5. Do you think that your GP listens to what your family carer/support worker has to say?
6. Do you think that your GP knows much about learning disability?
7. Do people with learning disabilities get treated as well by their GP as other people?

Additionally, our MLMC Groups Coordinator worked with one couple with learning disabilities, as a case study as well as a small focus Group comprising of carers and those they support.

MLMC has committed a considerable amount of work on health over the past five years, these projects include, amongst others:

- Partnering Oxfordshire PCT to train 74 out of the 83 GP Practices on the need to give comprehensive health check to PWLD. The uptake increased from 413 to 848 over a two year period, but after our work ceased progress stalled.
- Completing research into health checks with Professor Jan Walmsley of the Open University, "Checking up on DES: An investigation into the implementation of Annual Health Checks for people with learning disabilities in Oxfordshire." Jan Walmsley Ltd with My Life My Choice. Articles published in the BMJ, Learning Disability Practice and British Journal of Learning Disability.
- Delivered Conference Presentations for Department of Health supported, "Improving Health and Lives (IHAL): Learning Disabilities Observatory.
- Led a campaign by lobbying MP's and decision makers to persuade South Central SHA and Oxfordshire PCT to develop a comprehensive action plan to improve take up of health checks in the region.
- Had our Charity Health Champions act as consultants for Norah Fry Institute research into the effectiveness of health checks.
- Developed health training of Oxfordshire's trainee GP's (20 per annum) at the John Radcliffe Hospital, Oxford.
- Our Charity training team (Power Up) were cited in the Department of Health's Six Lives report (2010) as best practice example.

MLMC had previously carried out a project in 2013 comprising of nine digital stories of health experiences of PWLD (<http://healthtalkonline.org/peoples-experiences/disability-impairment/learning-disability-and-health.>)

These stories and the background research pointed to the continuation of serious unmet needs for PWLD, some of which directly related to GP surgeries. Clearly, this emphasized the need for further investigation into the healthcare experiences of PWLD. These are factors which have sadly been highlighted most recently following the inquiry findings that eighteen year old Connor Sparrowhawk, whilst in the care of Southern Health at Slade House in Oxford, died of 'preventable causes' on 4 July 2013:

<http://www.southernhealth.nhs.uk/news/report-into-death-sparrowhawk>)



## Methodology

My Life My Choice (MLMC) operates eleven monthly self-advocacy groups across Oxfordshire. The Members of these groups represent a cross section of PWLD across the county accessing healthcare provision. During the month of February the MLMC Groups Coordinator and five freelance Sessional Workers ran eleven separate focus groups within the self-advocacy meetings. Additionally, the Groups Coordinator met with a small focus group consisting of three PWLD and their two carers and one young woman with a learning disability who is a full-time carer for her disabled mother. For the case study, the Groups Coordinator met with a couple in their home, one of whom has much experience of the healthcare system and her partner, who is also her full-time carer. All of the one hundred and six people who were in attendance at our groups during the month of February took part in this project.

Due to the range of differentiation across our Membership a variety of methods were utilized to collect the information gathered for this report. The nature of learning disability means that many of our Members have pre-entry levels of literacy and numeracy. These limited skills around basic reading and writing rendered questionnaires ineffectual in this study. In addition, some Members have limited verbal communication skills, as well as sensory impairments such as deafness and blindness. This resulted in several approaches being taken. These included:

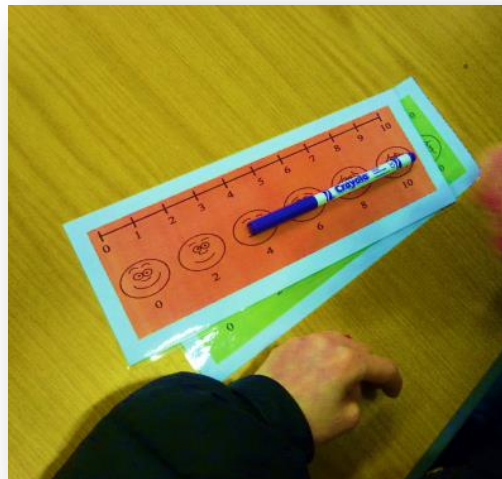
- Breaking down the seven questions into more manageable points for discussion

- Group discussion/signing with flip chart
- Post-it notes (yes/no - tick or cross)
- Thumbs up, thumbs down
- Easy-read imagery
- Scale of 1 - 10
- Show of hands
- Selection of 'emotion' pictures
- Role play
- PowerPoint presentation
- Smiley faces – happy = 'yes' or positive

Neither happy nor sad = non-committal; not good/bad

Sad = 'no' or negative

(These detailed resources may be found in the appendices available under separate cover from this report)



## Findings & Analysis



### Question 1: How good is your GP service?

“When I go to the GP I go with my sister and the GP treats me with respect.”

**Banbury Group Member**

“My doctor gave me false information and I ended up in hospital with a viral infection.”

**Blackbird Leys Group Member**

This question, when broken down and discussed, met with a mixed response from our Members. Just over half of those questioned scored their GP with a 10/10, but there was an overall sense that there is still room for improvement and that much depended on who it was that they saw on the day.

Members of a couple of MLMC Groups expressed the fact that they were anxious and nervous before they visited their GP, with a couple of people saying that they were very confused, as they did not understand why they had to go. The remaining Members of one of these two Groups did not give a view; this is because several of them either do not speak or are unable to follow a conversation.

Comments included:

“I haven't been to the GP for such a long time, I don't really know.”

“Sometimes it is okay. Sometimes in the middle, it depends as you don’t know what it is going to be like and how happy you are.”

“They are helpful and give you pills and check you.”

“Our GP service is really good with lots of support; they are trying to get me some more support at the moment from the learning disability services. He always checks about my diet and my prescription and that my prescription is up to date. My Doctors are brilliant because they help me out. They check me out with everything.”

“The doctor doesn’t always tell you what is wrong or give any explanation.”

**Didcot Group Member**

One Member scored her GP practice 0/10 “because there is only one GP who talk about themselves and not the patient. I take medicine for my epilepsy and they don’t give me the right amount.”

Three Members of our Group for young PWLD agreed that “they often leave the GP’s feeling confused. They all feel things aren’t explained to them properly.”



### **Case Study Jane and Simon**

Jane has been with her fiancé, Simon, for ten years now. He is her full-time carer. Jane has a Learning Disability, but also has complex health problems. Having been diagnosed with cancer aged 29 after which she spent 18 months in a hospice. The cancer and subsequent treatment for it left Jane

with weakness to her bones, resulting in several joint replacement surgeries. She is currently undergoing a shoulder joint replacement.

### **Before we began, Jane outlined some of her health history:**

“My carer, before I knew Simon, found a lump under my arm. I had been feeling ill. It was just before my 30th birthday. Mum was organizing a party for me and she thought that I would not make it because I was so ill with the cancer. My GP at the time didn't believe me; thought I was attention seeking, but mum said I wasn't like that. The first night I was in hospital because my legs didn't work and I couldn't feel anything below the waist, I had an accident in the night and kept ringing the bell for someone to come and help me, but no one came all night. When mum came back the next day and saw me in that state, she made them move me to a different hospital. I had surgery, but it (the cancer) went to my lungs next, so I was sent to the hospice. Everyone was amazed that I came out of there after 18 months, that doesn't usually happen. Because of the treatment I had, I now have lots of weakness with my bones. I've had a knee replacement and now have to have my shoulder done. I'm really scared, not of the operation, but about afterwards.”

### **How would you rate your GP service?**

“I would rate my GP service at 6/10. They could sort out my health better. When I first got my cancer, my support worker found the lump under my arm and mum took me to the GP. I could barely see and my legs wouldn't work, but they thought I was 'attention seeking.' Mum insisted that I wasn't and they got me into hospital.”

“I'm having problems at the moment, again, I've had such a lot of pain in my elbow, but they keep on saying that the problem is with my shoulder and once I have my surgery that will be sorted out. I've been in a lot of pain since I've been waiting.”

"I don't always see the same GP, so sometimes they listen and sometimes they don't. I don't ask questions, as I can't put into words what I want to ask, so I find that hard."



## Focus Group

"Yes, we are very happy with our GP service, we'd give them a 10/10."

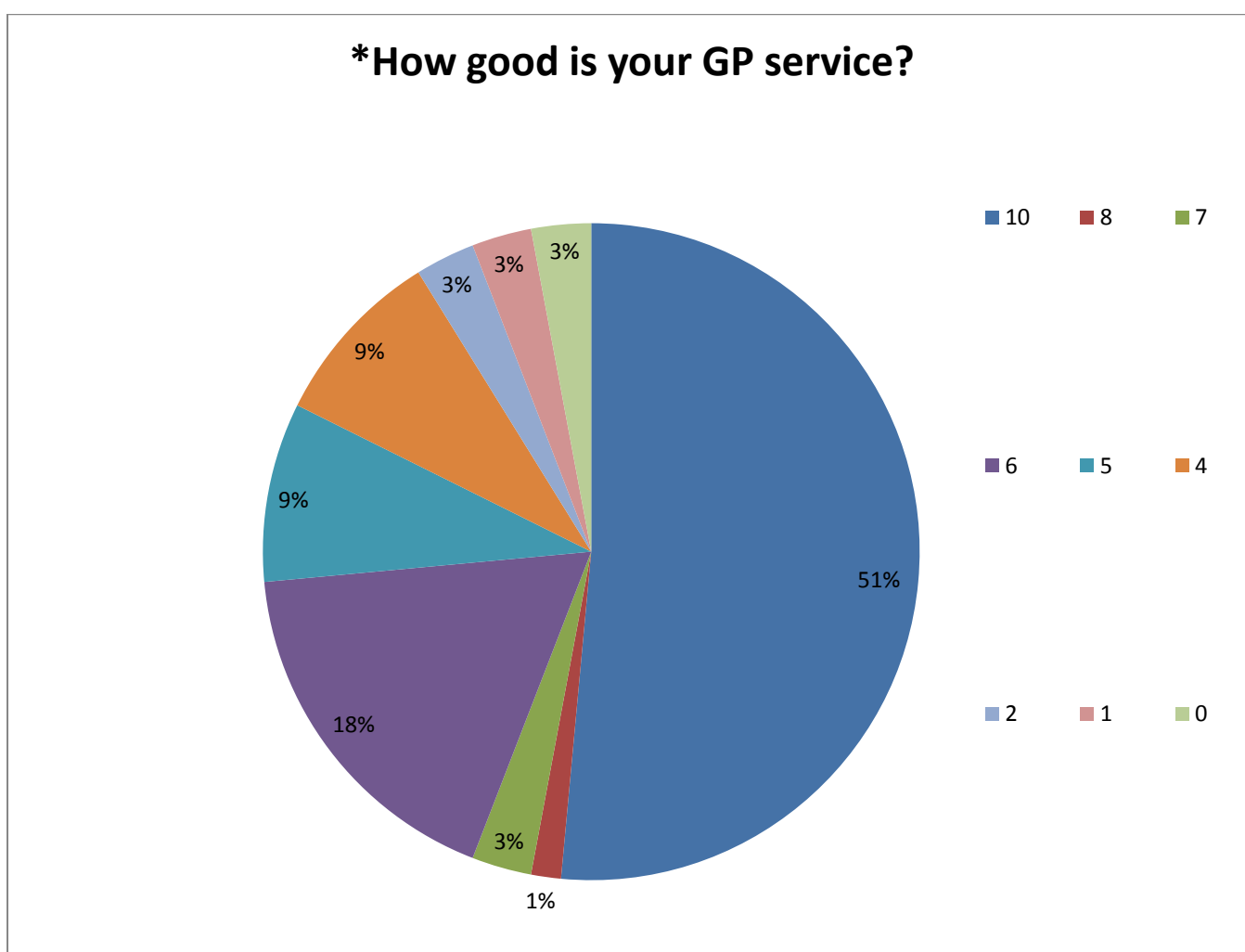
One Member of the focus Group stated:

"I'm not quite sure, I don't like injections, he looks at my face and he gives me things, he asks me if I'm alright"

The carers explained that because one of the women they work with has Downs Syndrome, she is more likely to experience blood problems and potential difficulties with her heart; she therefore has blood tests every three months. Out of all of them, she is the only one who needs extra support from their GP throughout the year. They felt that her treatment was exceptionally good.

**Fig I**

\*Due to the range and nature of differentiation across our Membership the results on the pie chart shown here are representative of 86 out of the 106 PWLD taking part. Results shown are scores out of 10, thus 51% of our Members scored their GP service at 10/10, 18% gave a score of 6/10 etc. Each Member was given a sheet with a scale of 1 – 10 to record their individual results.





## Question 2:

**Does your GP give you the treatment you need? Have you had a health check? If so, was it any good?**

“I have one every year and once a year my medication is reviewed and I have some blood tests. Health checks are important as they can detect something you might not know about.” **Banbury Group Member**

This question was broken down into three parts. As previously stated, MLMC has striven to improve the rates of health checks for PWLD across Oxfordshire. In many of the Groups it was necessary to explain exactly what a health check is and how it differs from a standard visit to the GP.

In one of the Groups, all initially said that their GP did give them the treatment they needed. On reflection three Members said they couldn't really answer the question as they had no way of knowing what treatment they needed. Regarding health checks, 8 people out of the 16 had received a health check in the previous 12 months and were happy with it and comments included “thorough” and “checked just about everything.” One person was not sure and the remaining members were unaware that they were entitled to an annual health check.

All Members in another one of the Groups said that their GP did give them the treatment they needed. With regards to health check, however, none of them had received a health check in the previous 12 months, and indeed they were not aware they had ever had one. One Member with Diabetes had regular check-ups for that condition, but not for anything else. None of the Members was aware that they were entitled to an annual health check.





## **Case Study Jane & Simon: Does your GP give you the treatment you need? Have you had a health check? If so, was it any good?**

“Sometimes I feel as if I am treated with respect, but sometimes I get the sense that they think I’m putting it on for attention.”

“I get the right treatment and I have a health check every six months. The last one I had was very good and my medication is checked regularly.”



### **Focus Group**

“I’ve had a health check and he checks my heart and blood pressure and checks to see if I’ve got high and low cholesterol. I have excellent health; we never ask for a health check, they send one in the post every year.”

“My GP checks that I am fit – I can carry suitcases for my holiday – I am strong and healthy, nothing wrong with me. When I came to live with P and F, I was very poorly, but I’ve got better and better.”

“My GP’s alright, checked my arm and pumped it up with the cuff.”

“She has all the tests, R gets checked for everything and gets all the different kinds of scans she needs – she really likes her GP.”

**Fig II** – Figure shown here represent how many Members of each Group have received a health check within the past twelve months

<b>Group</b>	<b>Health Check Figures</b>
Abingdon	10/11
Banbury	7/8
Blackbird Leys	1/3
Carterton	8/16
Chipping Norton	4/5
Henley	7/7
Oxford	5/7
Oxford City College	10/18
Wantage	9/11
Witney	0/4
Case Study	1
Focus Group	3/4
<b>Health check total</b>	<b>65/95 = 68%</b>



### **Question 3: How easy is it to book an appointment to see your GP?**

“On the whole, it is easy to get an appointment when I want.”

**Banbury Group Member**

The answers to this question were varied across the Groups and were wholly dependent on the surgery concerned and the appointment systems in place. Around half of our Members do not actually book their own appointments with the GP and this is done by family or support workers on their behalf. This is particularly the case with our younger Membership, as well as those with more profound and complex Learning Disabilities.

In five of the Groups a role play methodology was adopted with Members taking turns at attempting to book appointments. One Group adopting this methodology all booked their own appointments and comments included:

“Booking appointments is okay, but when I get to the surgery, because of my sight problems I can't see the screen, but I also can't understand the voice on the machine.”

“It's difficult for me to reach the screen in the reception area because I am in a wheelchair.”

“I think that GP's take on too many patients and this is what makes it difficult to get an appointment, especially with the more popular GP's.”

“I think that the receptionists try to block you, they promise that someone will call back and they never do. At one time, a GP I really liked had left the practice and I didn't find out for a year.”

Another Group found it quite easy to get appointments and they also felt that the reception staffs were helpful and friendly. Three Group members had support staff who booked appointments and the mother of one Member always did this, everyone else booked up for themselves. A couple of people struggle with the screen in reception. With regards to the phone system, one Member of this Group found it complicated and didn't like the fact that:

“It plays music at me!”

In one of our smaller Groups, one Member, who is quite articulate and confident, said it was easy to book an appointment, and the person who answered the phone was always helpful and polite. One Member never booked an appointment as they did not feel confident. They felt very shy speaking to someone over the phone and consequently their mother always booked their appointments. Another Member, who can neither read nor write, got their mother to book the appointments. She told us how worried she was because her mother was very old and would not be around for ever. The 4<sup>th</sup> Member got their carer to book the appointments because they had difficulties making themselves understood (the person has a speech impairment.) Also the Member could not deal with numbers and dates and had to be supported by their carer. He did say that he liked to visit his GP on his own, and explained that he thought his GP was cute! All four Members said that normally it was possible to see their GP within 3 days.

Reasons cited for family members or carers making appointments include the following:

“I can’t write.”

“I’m not confident.”

“Can’t do numbers or dates.”

“I can’t get them to understand me.”

“Too complicated – wouldn’t know what to do or say.”



### **Case Study Jane & Simon: How easy is it to book an appointment to see your GP?**

“I book my appointments myself by phone. The reception staff are nice and friendly, if I ever go to the surgery on my own, they talk with me and will even come in with me, if I ask them to, and Simon is not there.”

“I think that the booking system is quite straightforward and usually I can get an appointment when I need one.”



### **Focus Group**

“I like to speak to a person straight away, so I always go in.”

Carer – “This is difficult, because it’s all changed now, we get a healthcare person assigned us, they phone you back and say ‘I’m not medically trained ...’ but there are lots of changes at our surgery. Receptionists are not helpful, it’s not easy if you want to see a specific GP, you have to see who is there and it’s much better to see the GP you know. We do the screen when we take them along to the GP.”

“They put you on hold – it doesn’t feel nice – not happy.”

**Abingdon Group Member**





#### **Question 4: Does your GP service make reasonable adjustments?**

Many of the MLMC Group Members were not aware of this term, therefore images showing various 'reasonable adjustments' were passed round the Groups, as well as health leaflets which had been picked up from local surgeries.

Overall there was a good response to this question, with many surgeries having made adjustments to the surgery building such as ramps, wider doors, automatic doors, disabled toilets and some information in larger text or easy read.

During a discussion, one Group made the following observations. (In this Group one Member is a wheelchair user and two Members have visual impairment):

"Sometimes the desk in reception can be too high. I also think that GP's need to tell you about the possible side-effects of medication. I had to ask the chemist about some tablets I was taking."

"I agree, the GP gave me some cream yesterday, but they didn't tell me how many times a day to put it on, so I had to ask the chemist."

Carer - "J cannot use the touchscreen in reception, as she can't reach it. The GP's always ask how much J weighs, but they do not have any scales for wheelchair users. They tried weighing her once by supporting her under her

arms, but this didn't give an accurate weight, as her feet were not on the scales properly."

"I can't get up on the couch in the surgery, as it is too high. Also, there is only one disabled toilet; I can't use the other ones very easily, as they are a bit too high."

"At my school, we had weighing scales with a seat on them. I'm blind so I can't read leaflets; it would be good to have stuff on tapes."

"Some of the leaflets are easier to read than others, this can be difficult, especially if the writing is too small."

Other comments included:

"My GP checks my ears, because I have hearing aids, it is difficult for me to hear what the GP says, but he speaks clearly."

"I like being met in the waiting room and taken in."

"There is a touch screen computer for registering at the surgery but they didn't tell me what it was for."

"Sometimes it's not easy to understand leaflets, larger type would be better."

"It doesn't matter what form it's in, it doesn't make much sense to me, my brain doesn't engage."





## Case Study Jane & Simon: Does your GP make reasonable adjustments?

We looked at some images of reasonable adjustments, as Jane and Simon were not clear about what this term meant.

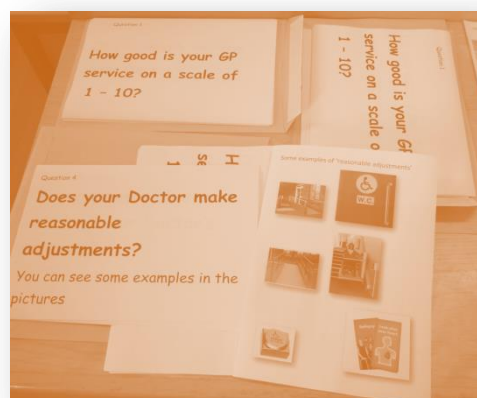
“They have disabled toilets, a door button to open the door. There are no ramps at the surgery, as it is all level. We leave our scooters outside and walk in and it is linked to the health centre.”



### Focus Group

“Getting in and out is fine, we don't really do any easy read stuff, because we usually know what we have gone in for they have push buttons on the door and they have made reasonable adjustments. And they are having a new building put up which will be very modern.”

D who is a full-time carer for her mother sometimes struggled to get her mother's wheelchair into the building: “It can be difficult, because there is a bit of groove where the step used to be, I can't always get the chair in, but there is a button there for assistance.”





**Question 5: Do you think that your GP listens to what your family carer/support worker has to say?**

“Sometimes it is difficult to talk over my mum and get the GP to listen to me.”

**Didcot Group Member**

This is a question which often comes up in MLMC self-advocacy Groups. In the past we have had feedback from the Membership which ranges from a sense that the person with the Learning Disability is not heard or given an opportunity to voice their own opinion, as all questions are directed at the family carer/support worker, through to Members feeling that significant information has been missed due to the family carer/support worker not being invited to contribute to the conversation

For example, in one of the Groups, a Member who is usually accompanied by her mother and/or sisters said that the GP listens to them, but makes no effort to explain things to her. She said that sometimes she almost felt as if she did not really need to be there. In another Group, all those in attendance felt that the GP listened to their carer and family member, but often did not listen to them. Conversely, others felt the GP listened to the support staff and allowed them time to talk too and that as well as listening to their carer, the GP was very supportive.

One Member expressed the importance of having a family member in attendance:

“If I go on my own and I have to explain the problem to my GP I get very nervous. If my sister comes with me she will explain everything to the GP. At

one time my mother was my only carer, but she died two years ago. They are very good at helping me understand.”

In the Henley Group all of those attending thought that their support worker was listened to.

In the group for young people, there was a sense that the families were listened to, however the young people did think that they wouldn't be listened to in the same way as their parents because of their age. They also thought that their parents would be able to fight for them in ways that they couldn't.

It was noted that one Member had increased confidence since attending his MLMC self-advocacy Group which had led to him attending GP appointments unaccompanied.



**Case Study Jane & Simon: Do you think that your GP listens to what your family carer/support worker has to say?**

Simon – “I think that they do listen to me. I always visit with Jane and even if I don't always go in, I will wait in the waiting room.”

“They listen to any helpful information I might have and I can give examples. I did get told off yesterday by Jane's mum for talking for Jane.”



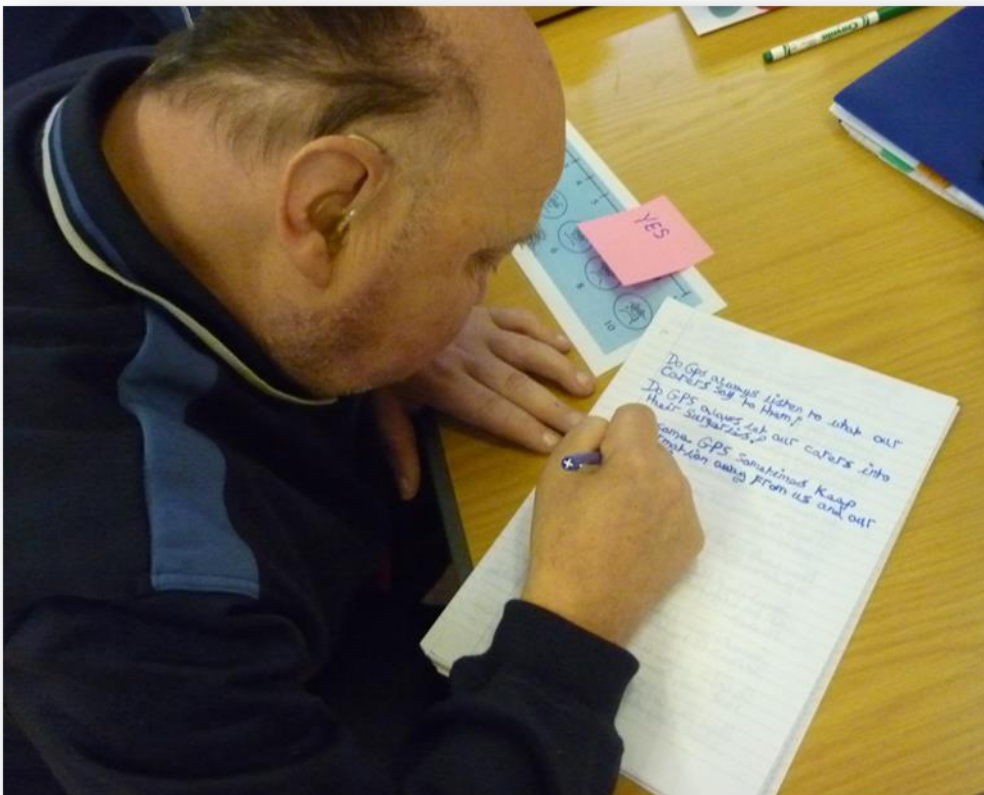
## Focus Group

“My mum or my sister comes to the GP and sometimes they can't always come with me. When I go on my own, some things get missed. Last time I went, I found she did not register what I said.”

“Yes, he listens to me and to my carers when they come with me. He gives me tablets sometimes if I've got a cold.”

“My GP is good to me too.”

Carer – “When it comes to R, it can be difficult due to communication problems and she doesn't know where it hurts sometimes. However they do listen to what I say and it is never rushed.”





## **Question 6: Do you think that your GP knows much about Learning Disability?**

“Me and H trained nurses at Brookes University for My Life My Choice.”

Delivering training to Health Care professionals in working with PWLD is a key aspect of the work carried out by My Life My Choice. This is user led, with all of our Trainers being experts by experience. This is therefore an important question to put to our Membership in relation to their experiences of GP services.

When we asked the Oxford Group to discuss this they had the following positive comments:

“Definitely, yes, they are getting me the support I need now.”

“Yes, my GP knows a lot about Learning Disabilities.”

“I feel sure that my GP does, they have got some bungalows over the road where lots of PWLD live and they attend that surgery.”

“Certainly, my GP has worked with MLMC in the past and attended workshops. She always talks to people with Learning Disabilities about different things like health checks and diabetes.”

However one Member commented that he had: “been on an advisory Group at our GP’s and I asked them a question about how many people they have with LD on their records, they could not answer so they don’t know how many people with Learning Disabilities go into their surgery.”

“Sometimes it doesn’t feel that they understand about Learning Disabilities, it feels like they don’t recognize that I have one.”

**Banbury Group Member**

Across half of our Groups, there was a sense that most GP’s know something about Learning Disabilities, particularly the GP they see on a more regular basis. There were more problems inherent with seeing different GP’s or locums. However, some Members felt sure that there was room for improvement with regards to further training:

“The minute you say you have a disability; everyone assumes that you need help with everything.”

“The GP had no idea how to be around my brother, who has high support needs, as well as autism.”

“Sometimes too much written information is given which is difficult to read and therefore confusing.”

In the Witney Group, three people felt that their GP’s knew a bit about Learning Disabilities and two of them felt that their GP’s tried very hard to understand more about LD. Another Member of the group said he felt that his GP knew very little about LD and was not good at explaining things. This Member explained that up until the age of 15, he did not realize that he was not the same as other people and when the GP told him he had Autism, he made no effort to explain what that meant. It was only later that the member’s mother explained things to him.



## Case study Jane & Simon: Do you think that your GP knows much about Learning Disability?

Jane – “No – I don’t think mine understands, they haven’t asked, although Dr N. knows, it just depends on who I see.”

Simon - “I’ve said, but I feel that it’s not my place to say.”

Jane – “Sometimes they take me seriously, my own GP does, not the locums though. My own GP treats me with respect.”



### Focus Group:

Carer – “This is a difficult question – but R and MC came with very little information when they moved in with us, there wasn’t much on record, so the GP has had to start from scratch really. I think that there are some things that they can’t know. V came to us with all her records so that was fine.”







## **Question 7: Do People with Learning Disabilities get treated as well by their GP as other people?**

This was perhaps the most difficult question for many of the MLMC Group Members to answer; many struggled with the concept of being treated differently from others. Those facilitating the sessions where this question was tackled found that they had to use a variety of approaches in order to make it a less abstract construct. Feedback from the Sessional Workers included:

“All who expressed a view answered “yes” to this question, but several Members said they had no way of knowing how their GP treated other people.”

“No individual responses but a general consensus that this was an ‘unfair’ question because you don’t really know how other people get treated.”

“The final question which asks people if they think they are treated as well by their GP as other people, I did not ask because I do not feel that this is a very valid question. It is asking people to speculate on something they could not possibly know.”

“The Group felt that this was too difficult a question to answer, that they couldn’t know how other people get treated by GP’s.”

“No individual responses but a general consensus that this was an ‘unfair’ question because you don’t really know how other people get treated.”



“One said that GP’s must treat people with LD fairly and with respect. Although their own treatment was fine, they had heard from friends who had not been treated well. Most of the rest agreed with this.”

Group feedback included the following:

“I think so” – everyone said yes. No one had any stories of other people getting treated better.

“It depends how seriously ill the other patient is. We were waiting once when all the GP’s and nurses were running haywire, because someone had collapsed, so they had to see them first.”

I asked the Members at supplementary question – “What’s the one thing that needs to be done to make things better for PWLD when they visit their GP?”

“GP’s needed to know a lot more about what it was like to live with a Learning Disability.”

“GP’s must treat people with LD fairly,” although their own treatment was fine, they had heard from friends who had not been treated in an equal way.

“I’d like GP’s to be friendlier, if they were, I would be able to go along without my mother.”



## Case Study Jane & Simon: Do people with Learning Disabilities get treated as well by their GP as other people?

“My GP treats me with respect, but when I am out in the street I get called ‘spastic’ by other people.”



### Focus Group

“My GP always used to talk to my mum as if I wasn’t there, which really used to p\*\*\* me off.”

Carer - “When I go and get treated I get treated really well and I think that the girls get treated just as well as us. We can only go by how well we are looked after and judge it on that. “

“I think it’s people’s attitudes when they go to the GP. It can be a good session or a bad session and I also think that people that live in adult placement or in supported living perhaps do get treated better because there is someone there for them, whereas when someone lives independently, they are treated differently.”



## Recommendations:

- With just over half those questioned being satisfied with the service provided by their GP's, there is room for improvement. User-led training in working with PWLD would be one way to ameliorate this situation.
- 68% of those questioned said that they have received an annual health check. This is a far higher figure than NHS statistics for 2012/13 (see page 36) and should be treated with caution. It is not known when respondents had their last health checks and many respondents have difficulty in differentiating between a health check & a regular GP visit. Further and **continuing** MLMC involvement in partnerships with Health Care professionals, and much greater priority given to health checks by Health Care professionals would be highly desirable (see message from Health Champion page 36).
- The appointments system is fraught with difficulty. User-led training for administrative staff could help them improve on this & would potentially encourage PWLD to book appointments on their own behalf.
- Much work has taken place with regards to 'reasonable adjustments' and the Report found favourably in this respect. However, more could be done in respect of developing accessible (Easy Read) printed information and instructions for medication.
- On the whole there is some very good practice around PWLD feeling 'heard' by their GP's and the family carer/support worker being involved in the process. There is still some room for improvement around communication and inclusion of the person with the LD in these discussions. This, coupled with the fact that around half of our Group Members feeling that their GP's could know more about Learning Disabilities would also indicate that user-led training would be highly desirable.



## A message from our Health Champion

There needs to be more effort put in by GPs, carers, the local authority commissioners and health services to make sure more people have a health check.

Last year's Confidential Inquiry into premature deaths of people with learning disabilities found that three times as many people with learning disabilities die before the age of 50 compared to the general population. In addition, men with learning disabilities die on average 13 years younger than the general population, while women die 20 years younger.

An article in the British Medical Journal (2010), adding to already convincing evidence, stated that the "Annual Health Check is the most significant attempt yet to address the unacceptably poor health care provided for patients with learning disabilities."

In Oxfordshire only 45% of those eligible had a health check in 2012/13 compared to the national average of 53%. The target set by Oxfordshire's Joint Health and Wellbeing Strategy was 50% for 2012/13 and 60% for 2013/14. The 2012/13 target has been missed and there is no reason to be optimistic about the 2013/14 target being met. We need to do better than this.

Other areas around the country have done much better but Oxfordshire has failed to learn from and/or implement examples of good practice.

Indeed after consistent work by MLMC and Ridgeway Partnership health checks were increased from 26.1% to 45% over a three year period up until 2012. Unfortunately, the then PCT took exception to our campaigning methods (raising awareness of Oxfordshire's poor performance), and complained to our main funders (Oxfordshire County Council). The Trustees of MLMC decided to give the PCT an opportunity to improve the take up of health checks without the support of MLMC; the results seem to suggest that this was a poor decision by the MLMC Trustees.

## Conclusion

This is by no means an exhaustive study of the views of those with Learning Disabilities in receipt of GP services in Oxfordshire; it does however represent a cross-section of the Learning Disabled community in the county.

Improvements to this provision have, and indeed are still being made, but there are still areas for concern in relation to the five issues flagged up by the report 'Healthcare for All' (Michael 2008)

There is still a lack of knowledge surrounding Learning Disabilities amongst those working in general healthcare and more needs to be done in relation to preventative measures, such as annual health checks. PWLD deserve to be treated as active protagonists in their own healthcare; listened to and respected. Only then will they gain parity with the rest of society in this area, if indeed "the health and strength of a society can be measured by how well it cares for its most vulnerable members" (Michael 2008) taking these measures will ensure that this society will have good reason to be proud.

