

Access to Health Services for People with Learning Disabilities Report

PATIENT EXPERIENCE REPORT

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1. Acknowledgement

Healthwatch Derbyshire would like to thank the many groups and services who supported and cooperated with this engagement activity. We would also like to thank the many participants who gave up their time to talk to us about their experiences.

2. Disclaimer

The comments outlined in this report should be taken in the context that they are not representative of all patients, family, friends and carers who have cared, or care, for someone with a Learning Disability, but nevertheless offer a useful insight. They are the genuine thoughts, feelings and issues that patients, family, friends and carers have conveyed to Healthwatch Derbyshire. The data should be used in conjunction with, and to compliment, other sources of data that are available.

3. Background

Healthwatch Derbyshire is an independent voice for the people of Derbyshire. We are here to listen to the experiences of Derbyshire residents and give them a stronger say in influencing how local health and social care services are provided.

Healthwatch Derbyshire was set up in April 2013 as a result of the Health and Social Care Act 2012, and is part of a network of 148 local Healthwatch organisations covering every local authority across England. The Healthwatch network is supported in its work by Healthwatch England who build a national picture of the issues that matter most to health and social care users and will ensure that this evidence is used to influence those who plan and run services at a national level.

We listen to what people have to say about their experiences of using health and social care services and feed this information through to those responsible for providing the services. We also ensure services are held to account for how they use this feedback to influence the way services are designed and run.

Information about the prevalence of Learning Disabilities can be found in the East Midlands Public Health Observatory.

DERBYSHIRE OBSERVATORY. (2013) *'Derby & Derbyshire Learning Disability Needs Assessment'*, [Online] Available from: http://observatory.derbyshire.gov.uk/IAS/Custom/resources/HealthandWellbeing/HealthNeeds_Assessments/Derbyshire_LD_needs_assessment_final1.pdf [Accessed: December 2015].

The assessment states that:

"The prevalence of people with Learning Disabilities reflected in health and social care data is likely to be a significant under-estimate of the true number of people in the population with some degree of learning disability."

- Approximately 0.5% of the population in Derbyshire County are known to have a Learning Disability, similar to the national average. It is however estimated that the likely true prevalence is just over 2%, equating to approximately 15,250 people.

- The number of people on GP registers in Derbyshire is 2,904 individuals, and those with Learning Disabilities known to local authorities is 1,875 individuals.
- The percentage of the practice population recorded as having a Learning Disability by Clinical Commissioning Group (CCG) vary from 0.7% in Hardwick CCG to 0.55% in Southern Derbyshire CCG.
- **2008/09 - 2011/12** - There was a decrease in the percentage of people with a Learning Disability receiving GP health checks in Derbyshire County. This may however be due to greater numbers of people with Learning Disabilities being registered, and the proportion is significantly higher than the national average.
- Overall there is a higher prevalence of males with a Learning Disability than females, and in younger and middle aged adults.
- The median age of death for people with a Learning Disability in Derbyshire was 59 years; this is similar to the England average.

The draft 'Services for Derbyshire People with a Learning Disability Joint Commissioning Strategy 2009 - 2014' predicted: *"Between 2009 and 2029 the number of Derbyshire people with a learning disability is predicted to grow by 18%, but this hides a much bigger increase for those aged 65 plus. The number aged 65 plus is projected to grow by 67%, whilst those aged 18 - 64 are predicted to grow by some 7% over this period."*

People with Learning Disabilities - Co-morbidities

- In Derbyshire, as a whole, there are a significantly higher proportion of patients with Learning Disabilities who have diabetes compared to the practice population as a whole.
- The percentage of people with Learning Disabilities who have epilepsy is significantly higher across all Derbyshire CCGs than the practice population.
- The data also shows that across Derbyshire as a whole there are significantly more people with Learning Disabilities who have asthma, schizophrenia, bipolar disorder or psychosis than the general practice population.
- Across all of the Derbyshire CCGs the rate of women with Learning Disabilities receiving cervical screening was significantly lower than the rate in the practice population.
- People with Learning Disabilities are less likely to have regular contact with dental services meaning that their oral health is often poorer than that of the general population. Dental work is also more likely to be reactive than preventative and is more likely to require general anaesthetic, meaning conditions may take longer to treat.

Learning Disability Health Self-Assessment

The Assessment also published findings from the Learning Disability Health Self-Assessment, revealing significant similarities to the comments made to Healthwatch Derbyshire.

Positive Comments

- The most common area commented on was that staff were nice/friendly/helpful.
- The opportunity to discuss concerns and worries, to receive advice and information and to be allowed adequate time also featured highly.
- Appointments being on time.

Negative Comments

- Appointments being late/waiting for other reasons was the most commonly cited negative aspect and the most common suggestion for improvement. Increased waiting times lead to increased anxiety for patients.
- Health services included staff being unfriendly or not explaining procedures so that the patient understood, including a lack of adapted materials.
- Difficulties in making appointments and consultations being rushed.

Suggested Improvements

Suggestions for improvements to health services to meet the needs of Learning Disabled clients centred around:

- Increased awareness of the issues faced by people with Learning Disabilities.
- More flexibility and adaptations in services.
- Additional time being given to ensure patients are receiving the services they need and that they understand what is happening during consultations.

4. Rationale for the Report

In order to enable a diverse range of people to share their views and concerns about their local health and social care services, Healthwatch Derbyshire aim to pay specific attention to those who struggle to be heard.

For this reason during May - July 2015 we agreed to focus our engagement activity on people with Learning Disabilities, and in particular their experience of 'accessing' health services.

By law, under the Equality Act 2010, all health services are required to make reasonable adjustments to make sure they are accessible to all. This duty requires organisations and services to anticipate the needs of disabled people and, where possible, make adjustments to provide the same level of service as for non-disabled patients.

The adjustments have to be made if it is reasonable to do so. This depends on such things as how practicable the changes are; the size of the organisation; if the change would overcome the disadvantage disabled peoples' experience and the cost of making the changes.

There are three different things organisations may need to do to make it easier for people to access or receive services. This includes changing the way things are done (e.g. allowing longer appointment time at the GP/dentist); changing a physical feature (e.g. installing a ramp or widening doors) or provide an extra aide or service (e.g. provide hearing induction loop or information in large print, braille or providing a BSL translator).

Hence, the onus is on the service to remove or reduce factors which may mean that people with Learning Disabilities do not receive health services which are as good as other people.

The comments given during this engagement activity give useful first hand feedback from participants with a Learning Disability about how it feels to access and use health services, and includes their ideas as to what could be better. Some comments were also received from friends, carers and professionals.

5. Methodology

In order to collect consistent information from people with Learning Disabilities, a series of questions were developed to provide a framework for discussions with individuals. These questions can be found in Appendix 1.

The primary focus of these questions was collecting experiences of accessing health services, in particular doctors, dentists and hospitals, and capturing sufficient detail to ensure that this feedback would be useful to service providers. Where possible, we have identified the service provider associated with the feedback given, in order to allow services to respond to specific comments. The report also features more general comments, likes, dislikes and ideas for improvement that cannot be attributed to a specific service. These findings are all organised under appropriate headings at the end of the findings section in this report.

The questions could be completed by the individual alone, as part of a small focus group or with support from a Healthwatch Engagement Officer, care worker, friend, family member or carer.

Not all participants responded to all questions, and some questions were not applicable depending on the experience recounted.

A series of visual aids and symbols were also used to support communication with people with Learning Disabilities.

Engagement activities took part across Derbyshire. To protect the identity of individuals we are not able to provide a detailed list of these activities. However, it is possible to see the number of participants who took part in each district of Derbyshire by looking at 7.1 in the Findings section.

A total of 171 responses were collected.

6. Summary of Findings

There are several positive themes that have emerged from the findings, these relate to:

- Flexibility to allow the patient to attend appointments at a time of day that suits them.
- Clear communication to explain why and when appointments are running late or are cancelled.
- Allowing extra time to take conversations slowly.
- Health professional speaking to both the patient and their carer.
- The support given by Specialist Learning Disability Nurses in acute hospitals.
- The provision of easy read information.
- Health professionals listening, giving additional explanation and gaining understanding in plain English.
- Staff that are friendly and personable.
- Continuity with the same health professional.

Negative themes that emerged included:

- The positive themes reversed:
 - Not being talked to directly.
 - Professionals not talking slowly or steadily enough or checking understanding.
 - No communication as to why individuals were having to wait.
 - Use of complex language that individuals can't understand.
 - Lack of Easy Read information.
- Some staff lacking understanding/awareness about Learning Disabilities on some acute wards.
- Lack of agreed 'stop' sign that someone with a Learning Disability can use when treatment is painful/uncomfortable e.g. dental treatment.
- Problems with managing or paying for footcare.
- Lack of time for additional explanation/conversation when a single GP appointment is booked.
- Audio and visual announcement are required by some individuals, as they may not be able to see or read.

7. Findings

7.1 Where do participants live?

For this question, a total of 166 responses were collected. It was not possible to establish a response from 5 of the 171 participants.

District of residence	Number of participants	% of total
Amber Valley	26	15.2%
Bolsover	24	14%
Chesterfield	42	24.6%
Derby City	2	1.2%
Derbyshire Dales (North)	5	2.9%
Derbyshire Dales (South)	3	1.8%
Erewash	16	9.4%
High Peak	20	11.7%
North East Derbyshire	11	6.4%
South Derbyshire	17	9.9%
Unknown	5	2.9%

7.2 Age of participants

For this question, a total of 135 responses were collected. It was not possible to establish a response from 36 of the 171 participants.

Age range	Number of participants	% of total
16-24	10	5.8%
25-34	20	11.7%
35-44	32	18.7%
45-54	41	24%
55-64	22	12.9%
65+	10	5.8%
Unknown	36	21%

7.3 Findings by Service Provider

The comments reported below have been organised by service provider and are categorised as either positive, mixed or negative/ideas for improvement. All comments come from participants with a Learning Disability, unless stated otherwise.

Appletree Medical Practice

Positive

- The practice knows me well and works around me, like they don't give me early morning appointments.
- The practice will put a message up on the television screen if running late.
- They explain things, and go slowly.

Negative/Ideas for Improvement

- I'd like it if when my name comes up on the screen there is a voice to say it's my turn.
- When Lloyds pharmacy from the surgery delivers my medication, they say which day it will be delivered but they don't say what time. It drives me mad; it would help if they said morning or afternoon as I can't go out. It drives me bananas.

Brimington Surgery

Positive

- The doctors come to see me at home.
- (Named Doctor) comes to see me, she listens to me.
- She explains what my tablets are for.
- The doctor spoke to me really clearly.
- We do have home visits from the GP, they do the health check. The doctors at Brimington send us a form two weeks before they come and we can put any of our concerns down. (Comment from professional).

Chesterfield Royal Hospital

Positive

- They do explain everything, they have told me about the side effects of an eye operation so I am wondering if I should have it done. I am due to go back to see them again when I can ask other questions.
- Explained everything and I understood what they said.
- I had to go into Chesterfield Royal Hospital before Christmas to have a blood transfusion, the nurses were really nice.
- I was on (named ward) for five days, it was good because they let my support worker stay with me. The nurses talked with me and they were really nice. I went to A&E and there was a nurse there on work placement, she was really good and explained everything.
- We have been able to stay with people overnight in the hospital. We do liaise with (named professional) before individuals are admitted. This professional offers support by talking to other nurses on the ward. They offer them the traffic light system and we take in care plans. One of our residents broke his hip, I spoke to (named professional) and they were able to offer me some advice and they sorted things out with the Emergency Department and the ward. We have only just recently found out about this named professional. (Comment from professional).
- I went to Chesterfield Royal to have some teeth out under general anaesthetic, the dental consultant was absolutely fantastic, and they explained things really well.
- The dermatologist was very good as he spoke to me and my guardian but he asked me questions and he gave me time to answer them and I understood what he was saying.

Negative/Ideas for Improvement

- Doctors and clinical staff do speak directly to individuals but they speak with complex language that sometimes the support workers don't even understand. (Comment from professional).
- The nurses at the hospital will just leave us to it, sometimes that it a good thing and sometimes they leave us to do the personal care. (Comment made by professional).
- Parking problems make me worry.

Derbyshire Community Health Services

Mixed

- The Hydropool has been over prescribed for a while but he has recently got 12 sessions, the physio (name provided) has been great, she goes over sensory tips, she helps with him scrunching his hips up, and we have all had a good experience as they have had a lot of input into a number of services. Parents have struggled with wheelchair services but they have now got to see someone at the wheelchair clinic in Derby. (Comment from carer)
- There needs to be more support for people with a Learning Disability in community hospitals. My daughter was in Bolsover for three months, there wasn't very many people that could interact with her but the staff did treat her well and she did get

treated with dignity and respect. Two male nurses had to shower her but they did do it in a very dignified way.

- We get to hear a lot about some people when they are in hospital and sometimes nurses will not communicate with us because of confidentiality issues. Some of our residents do not have close family so we are the only ones that deal with them. We have set up passwords but communication isn't consistent across the hospital and things get lost in translation. Some nurses are very good with people whilst others seem very nervous to engage with residents, I feel there is still a stigma around Learning Disabilities. More often than not, our residents don't get washed when they are in community hospitals, especially Clay Cross, we are quite concerned because they don't have the same system as acute hospitals, they don't have acute liaison nurses. But on the other hand staff do communicate better, they ring us if they have any concerns and they do seem to have more time with the patients. There is an inconsistency with visiting times sometimes they will let us go at any time at the community hospitals while others will only let us go at visiting times. (Comment from professional).

Negative/Ideas for Improvement

- The receptionists mainly talk to my mum and dad. I would like them to talk to me.

Derbyshire Health United

Negative/Ideas for Improvement

- This participant had difficulties communicating his answers, so the support workers answered for him. The support workers said, 'We rang 111 at lunchtime but they didn't ring back until 3am. We have also contacted 111 at 7:30pm but the doctor didn't come round until 4am.'

Elmwood Surgery, Buxton

Mixed

- There is an automatic keyboard/check in that I can't get my head around so I speak to the receptionist. The receptionist is nice, I have to wait 20 minutes but I am happy to wait. There are magazines in each corner and a play area.
- Sometimes I understand what they say, sometimes I don't, my mum has to explain it to me and the doctor goes over things.

Negative/Ideas for Improvement

- Could there be a coffee machine and a water machine for while you are waiting?

Eyre Street Dentist

Positive

- The dentist does speak to me and explains everything he also speaks to my carers.

Negative/Ideas for Improvement

- No easy read information but I would really like that information so I could understand things.

Jessop Medical Practice, Ripley

Positive

- The surgery always tries to get her seen within two hours which is very good, and we feel fortunate to have this service. The surgery has known her all her life. (Comment from family member).

Newhall Surgery

Mixed

- When I have an emergency appointment, the doctors talk with medical words. They use long words, swivel their chair and go back to the computer. If my appointment is with my doctor, he is good, will explain and will say, 'Did you understand, do you want me to go over anything?' I like my doctor, he tries to help me.

Parkside Surgery, Alfreton

Positive

- The doctors are very good, I like talking to them. The doctors do not upset me.

Queen's Hospital, Burton-upon-Trent

Positive

- I know where to go. The signs are big and easy to understand. There are arrows too.
- Doctor speaks to me and my mum and dad which I like, and I'm told to say if don't understand, so they can explain.

Mixed

- Doctor speaks to me, and then my mum when I don't understand. They were talking fast; I wanted him to talk a bit slower. I like it when they talk to me slowly and steadily.

Negative/Ideas for Improvement

- I got fidgety and nervous because had to wait too long.
- They used big words.

Rectory Medical Centre, Staveley

Positive

- Doctor spoke to me and the support worker, they are very polite.
- They weighed me and I had put some weight on so they explained things to me.

Mixed

- It was an easy read letter, but I still can't understand it because I can't read.

Royal Derby Hospital

Positive

- Spoke to me and my carer.
- My mum always lets (named professional - a specialist learning disability nurse) know that we have an appointment, she is very good because she speaks to me and my mum. She is a great help because she speaks to other nurses to make them understand about Learning Disabilities.
- (Named professional) came to see me; she came before and after the operation. I like (named professional) because she talks to me, others don't. She smiles, and is funny.
- They gave me leaflets about what was wrong with me and I did understand the leaflet better than I had understood what the doctors said.
- When I went to the hospital at Derby they had very friendly nurses and they went to get me a cob and cup of tea.
- At Derby I enjoy going there for my appointments as I get a special nurse who sits with me whilst we wait and go to see the doctor. This really helps and I find it much better now as I do not like to be left on my own in a strange place. Before I used to go to another hospital and there was no help there. Even though it is further for me to go to I would rather go to Royal Derby as it means I stay calm rather than getting very upset. The nurse is very good.

Negative/Ideas for Improvement

- Whilst in hospital I had to keep asking to be covered up as I was cold. They did not cover me up properly, they did give me more blankets but I was still cold. I was near a window and I asked them to close it but they did not.
- I was really worried I would miss my appointment because we couldn't park.
- When I went into hospital to have my teeth out there was no TV in my room. I would prefer this as I had to go into the dining room to watch TV and I did not want to do this as I did not know anyone else there.
- No easy read.

Sawley Medical Centre, Sawley

Negative

- Sometimes the doctor confuses me by using big words and talking fast. Sometimes I understand, sometimes I don't understand.

St Phillips Drive Surgery, Hasland

Positive

- I speak to the doctor, he explains things well and speaks to my mum.

Swadlincote Surgery

Positive

- My sister makes all my appointments for me on-line and then emails me the details. She does this all on-line and this is done from abroad, where she lives. It is much better for her now as it used to cost her a lot of money to ring and make appointments for me. I only like to see one GP and so I will wait as long as I need to make sure I see them.

The Springs Health Centre

Positive

- I don't tend to go often but I have had a health check, they check my blood pressure, weight, the doctor explains things well, the doctor speaks to my relative as well, I take my health file in with me.

Wheatbridge Surgery, Chesterfield

Positive

- I like the Footcare and Dentistry at Wheatbridge, I am very happy they have helped me with my oral health.
- Wheatbridge are absolutely fantastic, they always make sure that individuals are OK and they are very person centred. (Comment from professional).

Mixed

- I rang up; first time I rang was on Thursday afternoon. I asked for an appointment and they told me to call back in the morning, I tried to ring the next day and the line was busy until 8:20am and then there were no appointments, I explained that it was urgent and they booked me in that day.
- The receptionist, she makes me feel OK. I don't have to wait long, my name is on a screen but I can't read it.

Negative/Ideas for Improvement

- No easy read but I am partially blind. I am learning to read braille, audio tapes would be good.
- They need to tell me why they haven't got any appointments when I have to wait a while to see a doctor; it is a worry for me. I need things explaining to me.

Woodville Surgery

Positive

- The doctor spoke to me and asked how I felt, instead of asking my relatives who were with me. I liked that. All the treatment I have received has been really good.

Negative/Ideas for Improvement

- I have not had a health check but my mum has had one so I am worried about that, also I have been wanting a flu jab, I don't understand why my mum can have one free because she is my carer but I can't have one. I have to pay privately for mine.

7.4 General Findings

The comments stated below are general likes, dislikes and ideas for improvement that cannot be attributed to a specific service. All comments come from participants with a Learning Disability unless stated otherwise.

Positive

- The receptionist checks me in, she is friendly and talkative and she always takes the time to have a chat.
- They always chat with me and ask me how my health is; they talk to me to ask how I am feeling.
- They speak to me and my parents because there are some parts that I don't understand.
- I like the receptionists because they call me by my first name.
- The dentist explains things really well and when I raise my hand they stop the treatment.
- When I had my scan last year I had some leaflets explaining what it was and what to expect. I understood some of it. I also have leaflets about my epilepsy which I like.
- I like it when I go to the dentist. It is a lady dentist and she uses something to clean my teeth and she gave me a pink tooth brush to take home.
- I get more time as I have Learning Disabilities. I get more time to talk and to allow me to think. This is good.
- The dentist explained what he was going to do before they did it so I do not get nervous.

Note: There were 20 separate comments about 'friendly reception staff'.

Mixed

- I told the doctor that I did not like them using the word 'sex' during my health check, and he apologised.
- I got very anxious at the dentist and it brought me out into a rash and they thought it was because I was allergic to the rubber gloves. Actually the rash was due to anxiety and they are trying to find something for me to take as I get it when I get upset.
- I have leaflets but it builds my anxiety levels because I read them too much before appointments.
- Neurology is a difficult one for us, recently an individual has had a couple of appointments that have been cancelled at the last minute, this causes a great deal of anxiety because there hasn't been an explanation to go with it and the next appointment isn't reorganised for another 3-4 months leaving the individual feeling very worried. More things to be in easy read so our residents could understand things better, the easy read breast screening is good but I don't know if it is sent out to people. To have easy read consent forms for procedures in hospitals,

sometimes they don't tell us much but we are expected to consent to treatment, the individual needs to understand it. (Comment from professional).

Negative/Ideas for Improvement

- A letter with symbols/easy read would be helpful (x 11).
- Fifteen participants mentioned that they can't cut their own toe nails, they aren't able to use cutting equipment and using a chiropodist is expensive and takes money out of their budgets.
- I hate waiting because it makes me feel worried I find it hard to understand why I have to wait. Services don't tell us why appointments have been cancelled.
- The doctor was rushing and I did not understand (x 5).
- They hurt me when they were cleaning my teeth. I didn't tell them to stop. They should give a sign to say stop because you are hurting me.
- Dislike being rushed (x 15).
- We have never come across an acute liaison nurse before and we support a lot of people in hospital. Some nurses are great whilst others seem to have limited knowledge/experience of caring for people with a Learning Disability. (Comment from professional).
- For my carer to come into the Ambuline patient transport ambulance with me.
- The doctor just spoke to my mum.
- A book to read that is easy read in the waiting room.
- I would like to see the same doctor so he could get to know me better (x 12).
- Talking too fast (x 8).
- Less waiting time on the telephone (x 4).
- Less waiting in the waiting room (x 17).
- The letters about the health check are sent to my son and daughter individually but it would be good if there was a health check letter done in easy read.
- A professional suggested that a double appointment should always be provided due to the length of time needed for communication, explanation, reassurance etc and this should be 'standard' practice.
- A comment from parent carer suggested that health records could be adapted to cover more areas and that there should be facility to add pages.
- We don't have blister packs with our own medication, I have to be given it by someone else but I would like to be able to take my tablets on my own.
- My carer isn't recognised as a carer because he has a Learning Disability I think they just look at him as a service user.

Specific comments about the Annual Health Check

- I can't remember when I had it. The appointment is quite short.
- The nurse takes my blood pressure, she checks my heart, weighs me and explains everything to me.
- Take my blood pressure, I didn't ask many questions and I wasn't given any information.
- They do blood pressure, physical check, blood, hernia check and they ask how I am feeling.
- The mental health question always panics service users at the health checks causing anxiety because they think they have a mental health condition. (Comment from professional).

- They look at medication, general physical health but they don't look at feet. We can refer them to a chiropodist at Brimington or Clowne for free treatment. (Comment from professional).

8. Recommendations

This report recommends that health services should review their ability to identify patients with a Learning Disability and make reasonable adjustments to their needs as highlighted in the patient feedback given, to include:

1. Registering and accommodating a preference regarding appointment times, when possible.
2. Developing communication systems that explain when and why appointments are running late or are cancelled.
3. Creating systems to allow extra time in appointments, such as the routine use of double appointments in General Practice.
4. Reviewing training/awareness for staff to build skills, techniques and confidence in dealing with Learning Disability patients and their carers.
5. Highlighting the specialist role of learning disability nurses in acute hospitals to ensure maximum awareness and usage of the service.
6. Reviewing the availability of appropriate easy read information.
7. Promoting continuity with the same health professional when possible.
8. Introducing an agreed 'stop' sign for painful/uncomfortable treatment when necessary.
9. That due consideration is given to the availability and provision of appropriate and affordable footcare.
10. That every reasonable effort is made to maximise the take up of the Annual Health Check.

9. Service Provider Responses

Response from Deborah Jenkinson, Service Manager - Learning Disabilities and Autism Derbyshire County Council

Whilst the report focused specifically on health services Adult Social Care work in partnership to promote the health and wellbeing of people with a learning disability and welcome the report and its findings. As your report highlights, the findings are similar to the Joint Learning Disability Self-Assessment Framework and improving access to healthcare has been a priority for a number of years.

Whilst there is further work to be done it is gratifying to see that many people have had good experiences and improvements have been made. Colleagues in health services have worked hard and the health facilitators and hospital liaison nurses are positive initiatives to support services to make the required changes and better meet the needs of people with a learning disability.

The report will contribute to the 2016 Joint Self-Assessment Framework submission, and the Learning Disability Partnership Board are looking forward to receiving the report later in the year. The recommendations will be considered as part of the LD SAF action planning process.

Response from Sarah Todd, Patient Experience Manager - Derby Teaching Hospitals Foundation Trust

The Trust would like to thank our colleagues at Healthwatch Derbyshire for preparing and sharing their report on healthcare services for patients with Learning Disabilities. We found the feedback regarding our services here at Derby Teaching Hospitals very reassuring and it shows us we are providing a good service for those with Learning Disabilities. We are very proud of the work of Debbie Edwards in particular; without whom we would not have achieved what we have done.

However, we are not complacent and have taken on board each of your recommendations. We appreciate your recommendations were to the health community as a whole and not just acute Trusts. Nevertheless, we have detailed point by point our responses to your recommendations, including details of actions we already have in place:

1. Appointment times and lengths can be adjusted for those that need reasonable adjustments to be made. For example, where patients need more time to relieve anxiety and aid better communication, double-length appointments are made and set at times suitable to them. Patients with particular needs can also be prioritised so that they are not waiting for long lengths of time.
2. As above.
3. As above.
4. In terms of training staff in LD awareness, there is mandatory training as part of the Safeguarding module plus there is ad-hoc training available as and when staff require it (e.g. if a ward is expecting to care for a person with LD and needs to prepare). Therapy staff also have a package of training, as do student nurses.
5. Our LD Specialist Nurse provides her details to staff and promotes the value of the role at carers groups as well. We are also considering doing some awareness raising as part of the Carers Week. Internally, we recognise we can always do more to promote staff accessing the services of the specialist nurse and will consider how we can continuously remind staff about the service.
6. There are a range of easy read leaflets and information packs the Trust uses - there are lots of condition-specific leaflets online (e.g. for cancer), therefore, we haven't had a need to create our own. We instead access existing resources. Furthermore, every ward has a Hospital Communication Book, which includes guidelines, and we used nationally recognised pain indicators and a 'Traffic Light Assessment' to help staff identify a patients' needs. We also have a number of videos on our website showing patients certain common procedures such as having a blood test.
7. We can make arrangements so that the patient sees the same health professional, but it can be difficult as it is on an availability basis. However, as all LD patients can have our specialist nurse with them, which goes some way to offering

continuity. Patients often see different doctors (consultants, registrars in same team) but will frequently have a named nurse practitioner they see in clinic. This also offers some continuity.

8. It is standard practice with all patients receiving painful or uncomfortable procedures to agree a 'stop' signal.
9. We don't believe this applies to us - we are presuming this is relating to a podiatry service. If you have any suggestions for us regarding foot care, please get in touch.
10. Although we are not General Practice so don't provide the Annual Health Check ourselves, our specialist nurse routinely asks her patients if they've had their check and when they haven't and will be due one, she encourages them to book one with their GP.

We also note that there were 4 negative comments about our services and would like to apologise that those patients did get the full service they needed/desired. We have the following responses for you:

- In response to the first negative comment about the lady who was cold, we note she was given more blankets but was still cold and the window was open. The window may well have been open to keep the temperature down as our wards can get very warm and other patients may have been uncomfortable but without knowing the exact time and ward, it's difficult to comment. Our staff always endeavour to make patients as comfortable as possible so we apologise she wasn't kept comfortable during her stay.
- In response to the car parking issue, we recognise this is an issue across the Trust and at peak times there are queues for the car parks. Unfortunately there aren't enough spaces at peak times but we have taken some actions to try and reduce the volume of cars entering at those times. We have reduced priced car parking after 5pm (£1) to encourage ward visitors to come then instead of in the afternoon at 2pm. Many of our clinics are now offering evening and weekend slots to encourage people to come outside of peak times but this is dependent on the individual service's staff availability and some that have offered these slots have then had poor uptake. We are also in the process of applying for permission to build another car park.
- In response to the lack of TV access, at present, not all side rooms have TVs in them and they are being under-utilised where we do have TVs in bays and side rooms. We believe this is mainly because people watch videos and TV on their own devices a lot more now and people don't want to pay to watch TV in hospital. We will review the provision of TV and entertainment across our wards and departments. Clearly there is a cost implication in providing such services so they need to meet the demand of most patients rather than a small minority of patients.
- In response to the final comment about there being no easy read information, as already detailed in our response to recommendation number 6, we do have access to a whole range of resources so the patient should have been offered access to the required easy read information. It is possible staff weren't aware of the need and this is why easy read was not provided. We cannot have easy read and

translated formats of every leaflet out on display in clinics as this would be impractical, but these are made available on request.

Chesterfield Royal Hospital NHS Foundation Trust

The Trust welcomes this report and is very pleased that the majority of the findings are positive. The recommendations have been responded to below.

Overall Recommendations - The Healthwatch report recommends that health services should review their ability to identify patients with a Learning Disability and make reasonable adjustments to their needs as highlighted in the patient feedback given, to include:

1. Registering and accommodating a preference regarding appointment times, when possible.

Alerts are put on the Medway system at the Trust to identify patients that have a Learning Disability (LD). Specific care pathways for complex patients can be agreed that accommodate a patient's needs. There is an alert facility on Medway to highlight those patients who have a specific agreed care pathway.

Royal Primary Care (RPC) have a database that includes carers information and the clinical system also links family relationships and households, so where consent has been gained, RPC can communicate with family members so they can then relate the information to the patient.

2. Developing communication systems that explain when and why appointments are running late or are cancelled.

This is an issue that is highlighted by the Friends and Family survey, therefore something that the Trust is aware of. For patients with learning disabilities, as mentioned previously, specific care pathways can be put in place to minimise the disruption to them e.g. first appointment or first on the list on the day for surgery.

Within RPC there are private rooms available for patients if they need a more relaxed waiting area and they have a robust DNA procedure that ensures they contact patients with LDs if they fail to attend their appointment.

3. Creating systems to allow extra time in appointments, such as the routine use of double appointments in General Practice.

The Trust is currently looking at the feasibility of this. However, the breast screening unit already have a system which routinely allows ladies with learning disabilities extra time (30 minute slot rather than the standard 6 mins) when they attend their appointments at the hospital.

40 minute appointments are offered at RPC for LD health checks as standard.

4. Reviewing training/awareness for staff to build skills, techniques and confidence in dealing with Learning Disability patients and their carers.

Training is regularly reviewed and delivered as follows:

- face to face training
- at the point of care
- mandatory training on safeguarding and MCA/DoLS also includes elements with regards to patients with Learning Disabilities.

The Care Certificate training for all unqualified clinical staff, has a session on Learning Disability which is delivered by the Learning Disabilities Lead.

RPC is currently looking at e-learning as an option to raise awareness. Training for RPC clinicians is bi-annually with a strategic health facilitator and all other staff have annual online training. Consent and Chaperoning training is also attended once a year.

5. Highlighting the specialist role of learning disability nurses in acute hospitals to ensure maximum awareness and usage of the service.

The role has been highlighted internally for example Learning Disability Lead nurse role has been highlighted on information stands in the main concourse. Externally, flyers have been sent to GP practices and various other meetings/forums e.g. the Learning Disability Partnership Board meetings

6. Reviewing the availability of appropriate easy read information.

Easy read information is available on the Trust website:

http://www.chesterfieldroyal.nhs.uk/patients/easy_read/index

RPC provide different letter formats to help promote communication and there is a Makaton trained clerk to further enhance this. All staff has online access to websites containing letter formats for LD reviews. Practice handbooks are also available in differing formats and prints.

7. Promoting continuity with the same health professional when possible.

Each LD patient's case is looked at individually and where possible the same health professional will care for the patient.

All RPC patients are offered the opportunity to see the nurse/GP of their choice as standard.

8. Introducing an agreed 'stop' sign for painful/uncomfortable treatment when necessary.

This is something that the Trust would be happy to sign up to but feel it needs to be agreed Derbyshire wide; the same "stop" sign needs to be used for all healthcare services. Also it needs to be discussed with people with learning disabilities. This is something that we would work with the Learning Disability Partnership Boards to take forward.

9. That due consideration is given to the availability and provision of appropriate and affordable footcare.

N/A

10. That every reasonable effort is made to maximise the take up of the Annual Health Check.

This is something that the LD lead nurse highlights to LD patients and RPC offer different letter formats to invite patients for their Annual Health Check.

Response from David Gardner, Hardwick CCG

Hardwick CCG supports the four Derbyshire CCGs with their commissioning of learning disability services and coordinates the Joint Commissioning Board for learning disabilities. Our response is on behalf of all 4 CCGs.

This was a very helpful report which is consistent with the reports and comments we have received through the self-assessment process, Good Health Group and Learning Disability Partnership Boards.

It has been good to read of the positive experiences of care, and we feel this demonstrates how services have improved over the last few years. We feel that the report also shows how and where we need to continue to make efforts to improve.

All GP practices have received training regarding the Learning Disability Annual Health Check, they have been provided with a pack of easy read information which includes a template for an easy read letter and a link to a site to make their own easy read invitation.

We have launched webpages this year to enable this easier for practices to access this information via a web link: <http://www.derbyshirehealthcareft.nhs.uk/services/learning-disabilities/annual-health-check/inviting-people/> (recommendation 4 and 10)

Our Strategic Health Facilitation team have conducted a series of quality checks with GP Practices in 2015 and have visited 34% of practices to check on the quality and content of the Annual Health check. The minimum time allowed for the check was 20 minutes with the Nurse (plus additional if required with GP) and maximum 60 minutes. A report is currently in the process of being written (Recommendation 10).

We had already raised concerns regarding access to chiropody and podiatry services at the Good Health group following feedback from the Learning Disability Self-Assessment. A presentation was subsequently delivered to the group by the Podiatry Services Manager and easy read podiatry leaflets were circulated in order to improve availability and provision of appropriate and affordable foot care (recommendation 9)

We have also recommended that during the assessment process for support, foot care needs are taken into account. Social workers who complete the assessments are being provided with a schedule of expected health appointments. Checking feet is also part of the Annual Health check and GPs can refer for further treatment (recommendation 9).

Carers can be registered as carers with their GP and support can be provided by Derbyshire Advocacy and Derbyshire Carers. We recognise that people with learning disabilities can be carers and try to extract this information annually from our GP

practices. Last year GPs recorded 168 patients with a learning disability across Derbyshire as also being a carer.

All Main Hospitals in the East Midlands have a Learning Disability Liaison Nurse. Through the Good Health group and local Learning Disability partnership Boards, the specialist role of learning disability nurses in acute hospitals has been consistently promoted in order to maximise usage and awareness of the service. We have also promoted the role of the liaison nurses through web information, at events, provider forums and in Health Action Plan training. The hospitals are improving at telling people about the Learning Disability Liaison Nurses and Derby Teaching Hospital is including contact details of the nurse in letters to patients (recommendation 5).

The availability of annual health checks is also promoted through the Good Health group, local Learning Disability partnership Boards and additional meetings attended by Strategic health Facilitators (i.e. Taskforce events) (Recommendation 10). Individuals with Learning Disabilities have also regularly supported us in the development of easy read information (recommendation 6.) for wider circulation across Derbyshire and Derby City.

Communicating with individuals is emphasised in the Learning Disability Annual Health Check training for GP practices and we have provided toolkits to support communication across health services. We have also supported some services to develop easy read booklets for their services e.g. what happens at Ripley/ Ilkeston Hospital and we have given 3,000 symbols based 'My Health' files out across Derbyshire to enable people with Learning Disabilities to enable them to keep their own health records. There are additional pages that can be added, and bespoke sections can be made by individuals (Recommendation 2, 4, 6 and 10).

We will be asking the Strategic Health Facilitator team to take forward the points raised in relation to appointment times, communications systems and training (recommendations 1, 2, 3, 4, 7 and 8).

In 2016 the Accessible Information Standard will mean that healthcare providers will all be required to record people's communication needs and respond to them. We have made contact with Communication Teams across Derbyshire NHS community about this and suggested that they attend events in the East Midlands to help them to learn more about implementing the law. Health services will also be expected to sign up to the Dignity campaign which includes respecting people by keeping them informed (Recommendation 1 and 2).

In addition to the packs currently provided to GP practices, which support health care appointments and health checks, we have provided all our local and main hospitals and clinics with a pack to help them to communicate with people who have learning disabilities. This is called 'My next patient has a learning disability.' We will ask the Equality leads at the Hospitals and clinics to remind their staff teams to use the packs (Recommendation 1, 2, 3, 4, 6 and 8).

Practices have been asked to send a pre health check questionnaire to patients.
| However, we have found through the quality checks that few do so. This is something we

will be emphasising in the training. There is also a section in the annual health check which covers mental health; we will add comments from the assessment regarding the mental health question causing anxiety into the GP updates for 2016.

We will also be ensuring that through our commissioning arrangements with health providers they continue to make progress in being responsive and making adjustments for people. The Learning Disability Clinical Professional reference group have planned in an agenda item to will focus on reasonable adjustments at their meeting in March 2016.

We are pleased that the Learning Disability Liaison nurse professional approach has worked well in Chesterfield Royal and Royal Derby Hospitals and we wish to support their continued efforts to improve services. We will particularly pay attention to training and support to staff in the smaller hospitals. We do note that there is a differential in health checks and the support offered by practices and we will continue to ask practices to work with our health facilitators on the points patients raised.

Our understanding is that most dentists do suggest that people put up their hands if they want to stop. However, we are planning to offer training to high street dentists this year and will make sure that this is emphasised (Recommendation 8)

In particular we wish to ensure people with a learning disability have access to cancer screening services. This has been piloted in Hardwick practices and CCGS and Public Health are working to see this being adopted elsewhere.

Response from Derbyshire Health United (DHU)

DHU found aspects of the report useful. The overall summary of the report findings will help to guide DHU to deliver better care for people with Learning Disabilities within Derbyshire. The specific comments regarding DHU makes it very difficult to investigate or provide specific feedback without patient details and date/time of contact with NHS 111 / Out of Hours GP.

DHU had already made some adaptations to the services they provide in order to make them more accessible for people with Learning Disabilities but since this report has been issued DHU is re-addressing some of their approaches. For example, DHU recognises that individuals with a learning disability may require longer consultations with medical staff to give them the time in which to communicate their needs or symptoms. DHU will allocate double appointments to anyone with a learning disability in order to improve the quality of the consultation.

This was implemented some time ago but DHU feel that this needs to be communicated again to all DHU staff to improve awareness of this facility.

DHU plan to make the following changes - to produce an up to date leaflet to inform and educate all clinical and non-clinical staff regarding national and local healthcare issues for people with a learning disability. This leaflet will include the best ways to adapt approach when communicating with a patient with a learning disability and issues to avoid (as highlighted within this report).

DHU will continue to provide information in easy-read format whenever possible.

Response from Queen's Hospital Burton NHS Foundation Trust

Thank you for sharing the findings of this report. Although there were few comments relating to this Trust it is heartening to see the positive comments and we recognise that the issues raised for other Acute Trusts are relevant to our services and patients. It is also true that many of the issues raised are relevant for all patients regardless of disability. The recommendations promote how we want to deliver our services and they will contribute to our continued striving to improve patient experience for our most vulnerable patients.

We are currently reviewing how information about communication needs in relation to a learning disability or sensory impairment are recorded, shared across the hospital and acted upon. We expect that this will address several of the recommendations of the report and will include the reviewing of the availability of easy read information and accommodating preferences for appointment times where possible. We are committed to improving staff awareness of learning disability. Staff professional development days include awareness-raising and in April a Learning Disability Conference is being held for staff.

Our Safeguarding Vulnerable Adults Lead Nurse works closely with Primary Care Clinical Nurse specialists to promote her supporting role to patients, in addition to visiting community based groups and forums to help ensure that people with learning disabilities and carers are aware of the support available when they need to come into hospital. Referrals through the PALS team also help support this. Where possible we try to accommodate patients on the same ward for repeat visits so that they can be cared for by familiar faces.

Response from Derbyshire Community Health Services NHS Foundation Trust

We have found this report to be very useful. Where our service users have identified a need for improvement we will now be able to focus on developing our skills to meet that need. DCHS is committed to Healthcare4all and we are working hard to ensure that wherever people with learning disabilities access our services they will have the positive experience that all of our patients should expect. Our eight Caring Always promises describe what the experience should be like. We are very sorry to hear that some people who have used our services have not had an experience that meets those promises.

Since reading this report, we have already:

- Provided feedback to the staff providing the Hydrotherapy service at Ashgreen about how highly valued this is. The service is available as part of a planned specialist programme.
- Discussed with leaders the importance of understanding what each service user's needs are - and the importance of identifying each person's preferences and communication abilities.
- Agreed a commitment to improve our ability to communicate with all people with learning disabilities and to support staff in developing their skills.

- Agreed the ongoing need to identify every person with a learning disability and make reasonable adjustments, especially in relation to their communication needs.

We will be making the following changes:

Skills and awareness:

- Making sure that our staff are equipped with the skills and resources to offer the best standards of personal care regardless of need or ability. We will ensure that we improve levels of awareness around the needs of people with learning disabilities, especially to equip them to make adjustments to their usual communication style. A training package will be developed on wards at Clay Cross and Bolsover initially, in conjunction with our specialist LD team.
- Involve Clay Cross hospital in providing internships for people with learning disabilities, as we believe this will help to increase awareness amongst our staff.
- Ensure that there is ongoing support for staff working in our community hospitals from our specialist LD team.

Resources and information:

- Establish systems that will capture the communication needs and adjustments needed for people using any of our services.
- Focus on meeting Accessible Information Standards and Inclusive communication across all services

Patient Experience and involvement:

- Ensure that people with learning disabilities are able to fully participate in our Access to Healthcare Forum.
- Making a more accessible patient feedback form (piloted in our specialist services) available to people using any of our services.

This valuable feedback has ultimately helped us to bring about positive changes within our services. We are an organisation that takes equality and diversity matters very seriously and we will continually strive to fulfil our commitment to a positive patient experience, regardless of need or ability.

10. Appendix I



Learning Disability
Prompts.pdf

Your Feedback

Access to Health Services for People with Learning Disabilities Report

Healthwatch Derbyshire is keen to find out how useful this report has been to you, and/or your organisation, in further developing your service. Please provide feedback as below, or via email.

1) I/we found this report to be: Useful / Not Useful

2) Why do you think this?

.....

.....

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3) Since reading this report:

a) We have already made the following changes:

.....

.....

.....

b) We will be making the following changes:

.....

.....

.....

Your name:

Organisation:

Email:

Tel No:

Please email to: karen@healthwatchderbyshire.co.uk or post to FREEPOST RTEE-RGYU-EUCK,
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