

healthwatch
Bracknell Forest

healthwatch
Windsor, Ascot and
Maidenhead

local healthwatch
working together

Report on the
experiences of local
people with a learning
disability when using
hospital services

July 2018



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Introduction to our report



Every local authority area has a Healthwatch service.



Healthwatch asks people what it is like to use health and social care services.



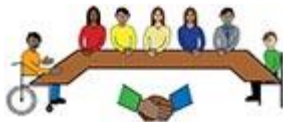
It listens and collects people's feedback and ideas about how services could be better.

It shares these with people who make decisions about services.

It does this by:



- Writing reports



- Going to meetings



Every year National Mencap, a charity that works with and supports people with a learning disability, organise Learning Disability week.



The week raises awareness in the community about the issues and problems people with learning disabilities can face.



This year, 18th – 24th June 2018, the focus was on health – in particular promotion of the Treat Me Well campaign.



Healthwatch Bracknell Forest and Healthwatch Windsor, Ascot & Maidenhead decided to work together during Learning Disability Week to support the Treat Me Well campaign and find out more about how people with a learning disability are treated and supported when using hospital services.

We did this by:



- Collecting the views about hospital services from local people with a learning disability.
- Collecting the views from unpaid carers (family and friends) and from support workers about how they think the person they help and support was treated when using hospital services.



- Contacting local hospitals to ask them how they support people with learning disabilities to get good care and to ask them to encourage their staff to sign up to the Treat Me Well campaign.

Why work together?



People that live in both areas use the same hospitals and services.



Both areas are covered by East Berkshire Clinical Commissioning Group (CCG) who help to monitor (keep an eye on) local hospital services.



Collecting people's views



We produced a survey for people to fill in. A copy of this is found in [Appendix A](#) of this report.

Before Learning Disability Week we sent copies of this survey to local groups and services working with and providing activities for people with learning disabilities:

- The Ark Trust, Bracknell
- Wokingham, Bracknell & Districts Mencap
- Maidenhead Mencap Society
- Windsor Mencap
- Waymead Centre and short-term care service, Bracknell
- Oakbridge Centre, Windsor
- Boyn Grove Community Resource Centre, Maidenhead

People could also contact us and we would send them a survey by post or email. We made sure that this information was on our website and it was sent to contacts in both Community Teams for People with Learning Disabilities.

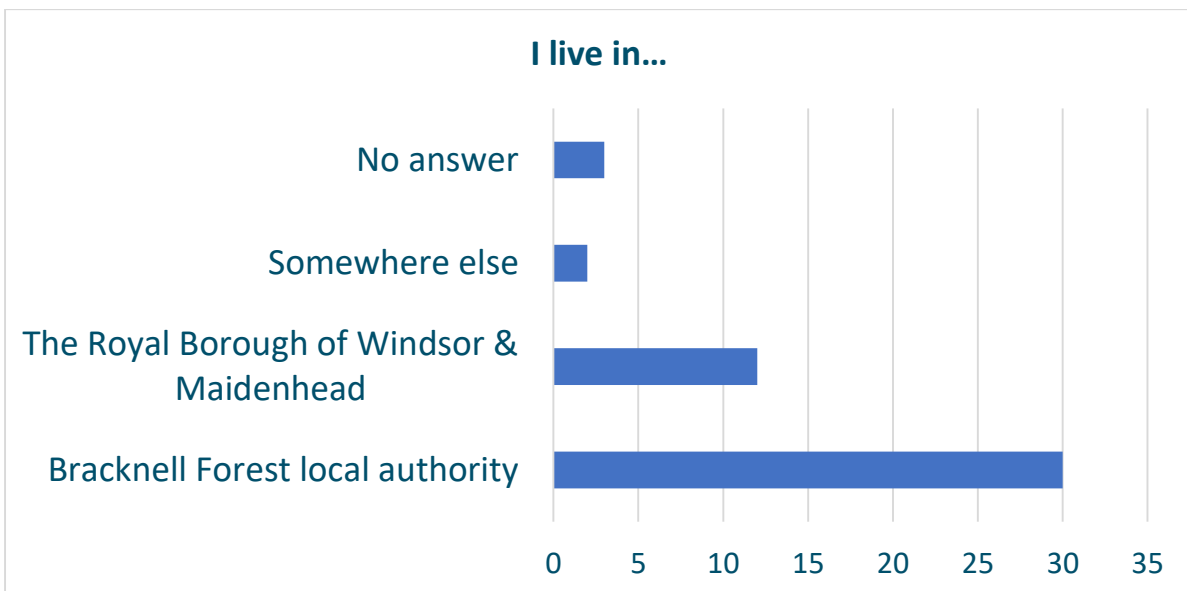
During Learning Disability Week we visited groups and, with Wokingham, Bracknell & Districts Mencap, went out in the Mobile Information Bus to hand out surveys in the community and promote the Treat Me Well campaign.

We asked people to return the surveys to us by the [9th July 2018](#).

Survey results

47 surveys were completed

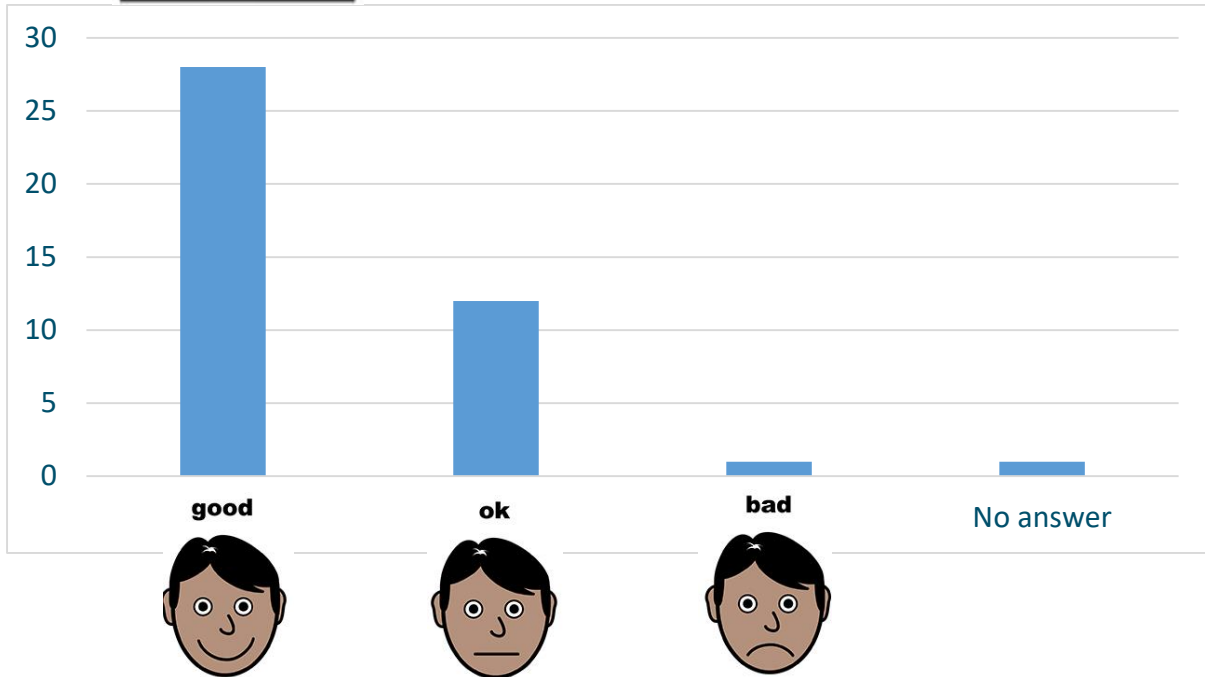
Information about the people who filled in the survey



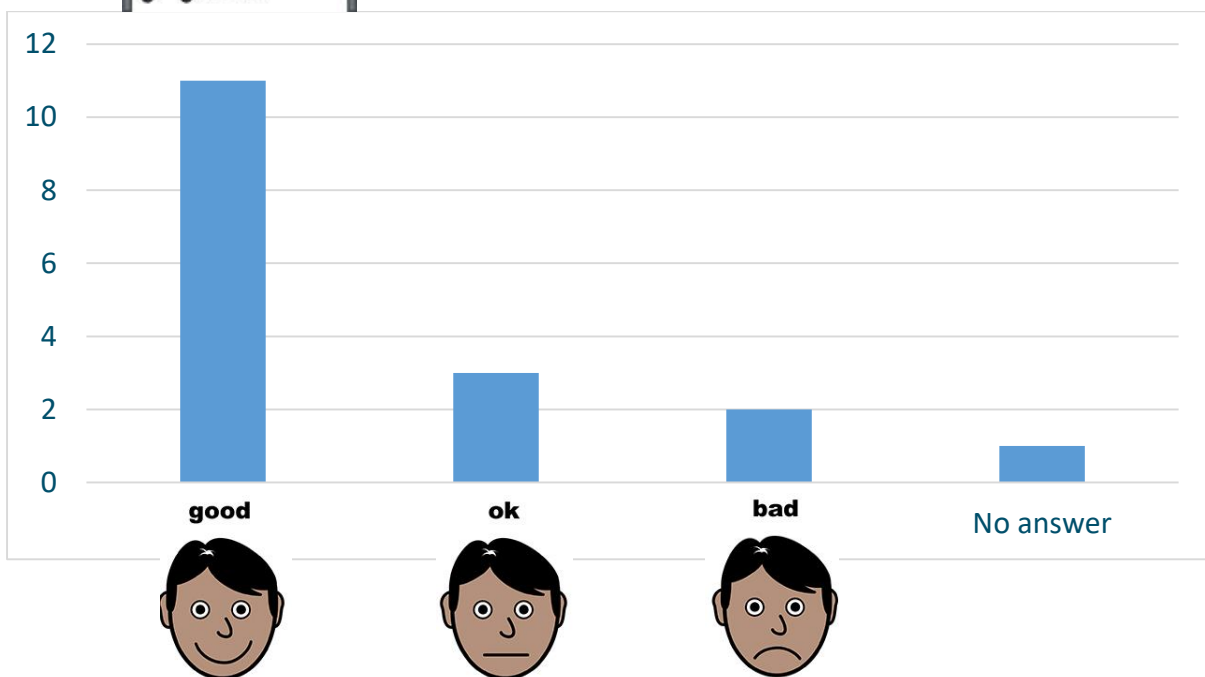
We then asked people what hospital services they (or the person they support) had used in the last year and how good or bad they felt the service was.



Outpatient Clinic (to see a doctor or nurse)

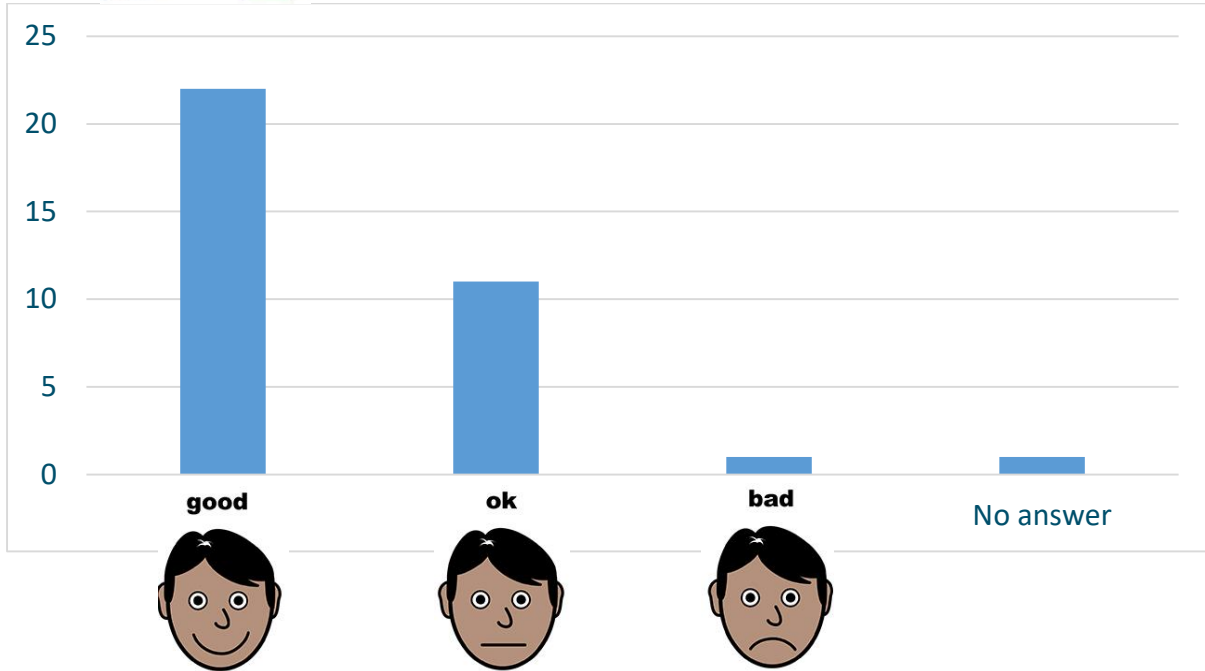


Radiology

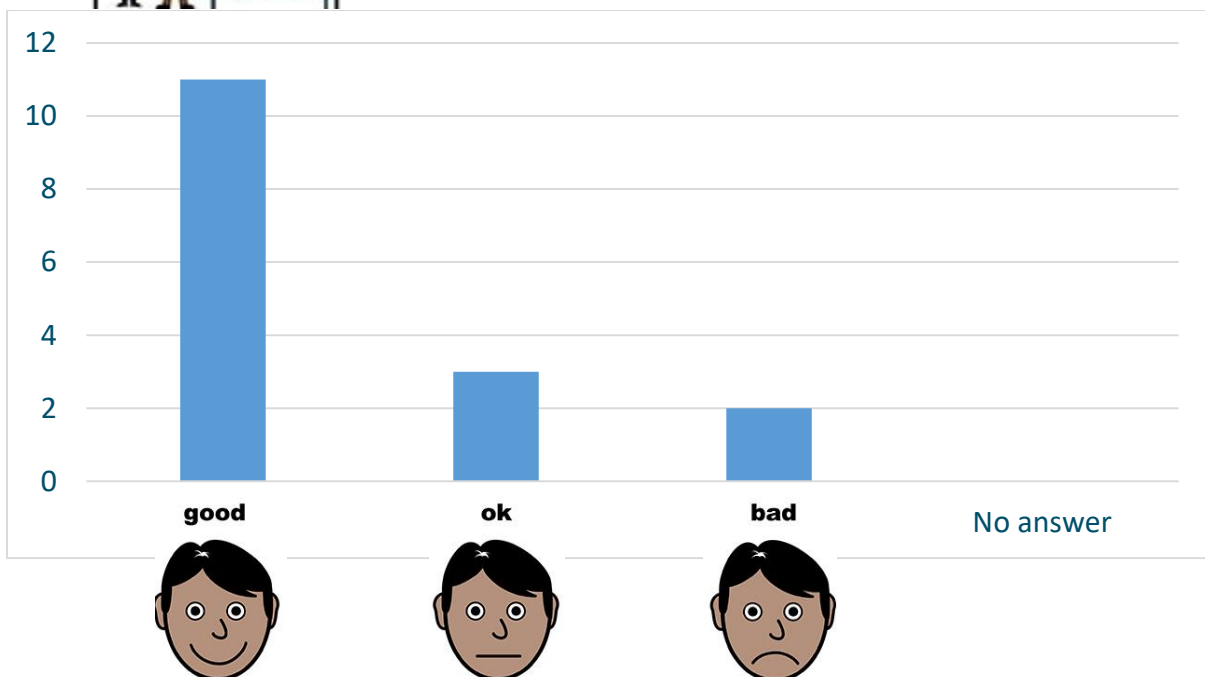




Phlebotomy (blood tests)

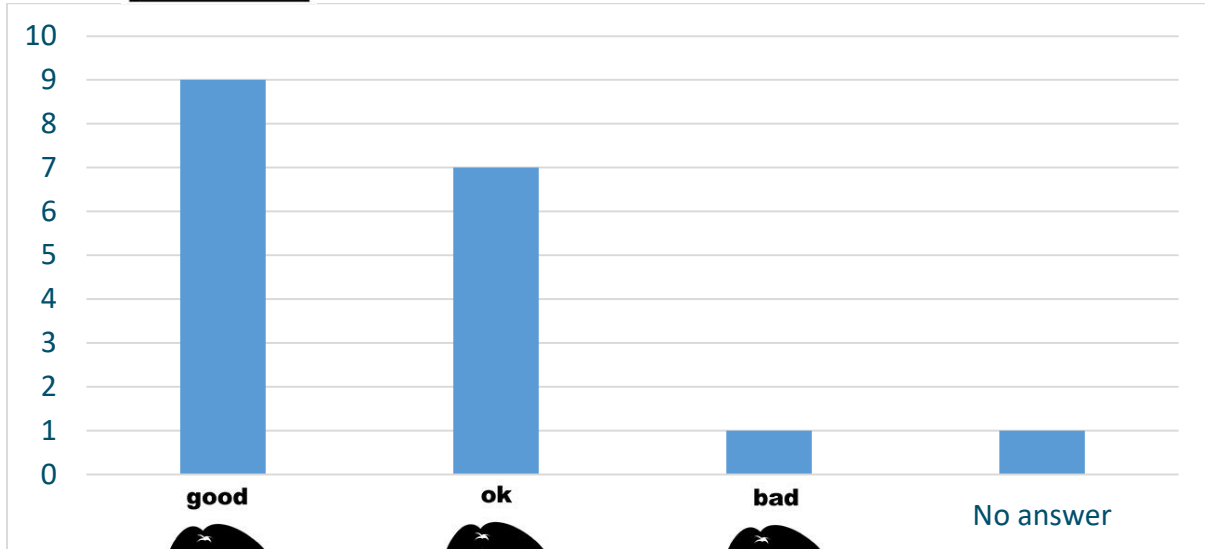


Inpatient (stayed overnight or all day because you have had an operation or treatment)

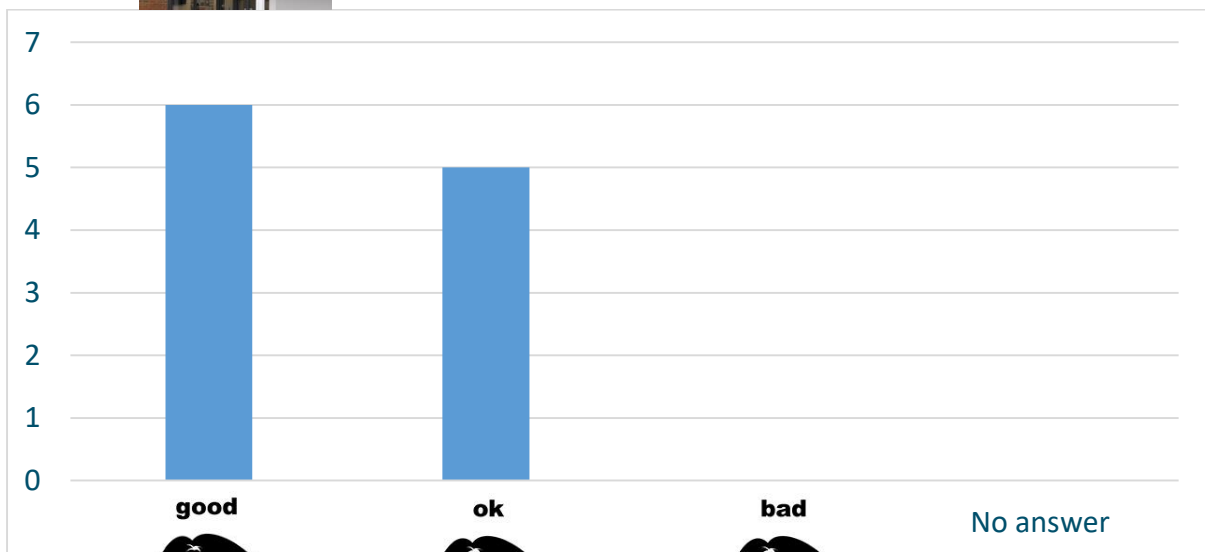




Accident & Emergency

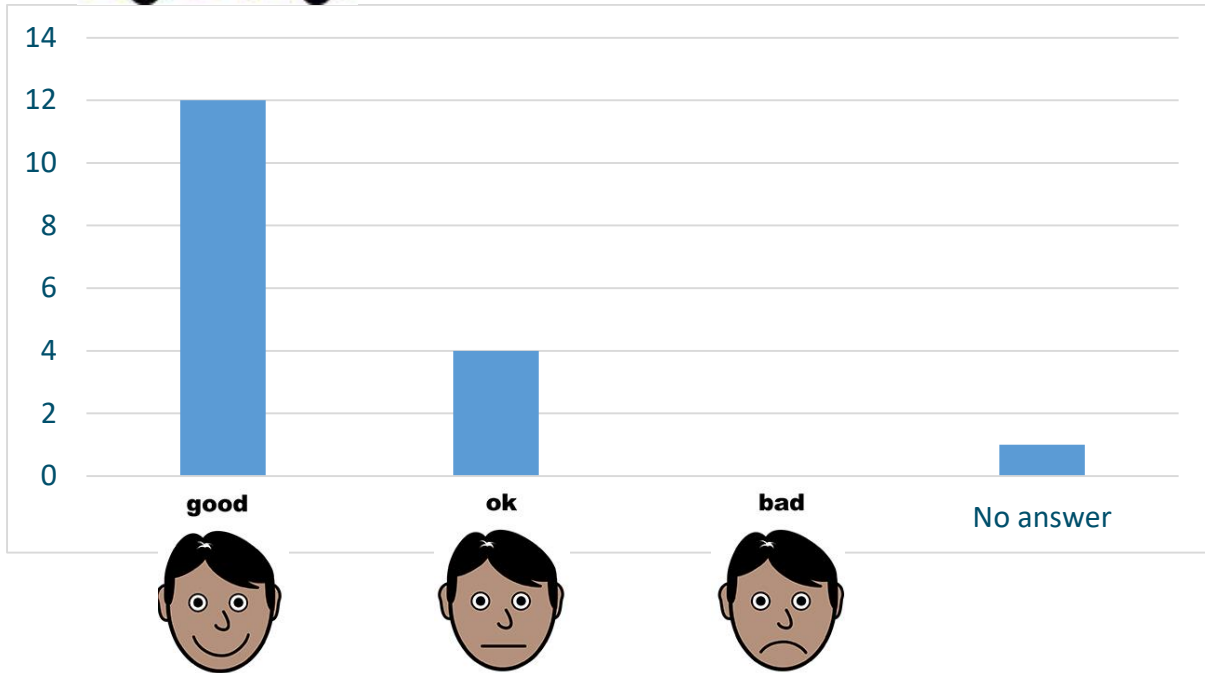


Urgent Care Centre

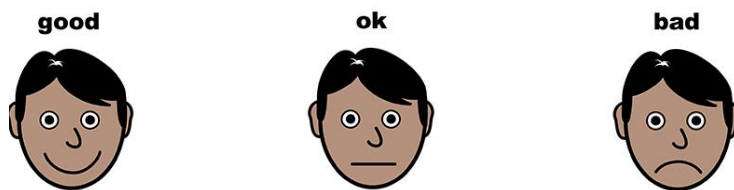




Ambulance Service



We then asked people if they had used any other services and, if so, what it was and how good they felt it was



	good	ok	bad
GP	3	0	1
Audiology	2	0	0
Dentist	3	2	0
Service not identified	3	1	1

It is just hard because of all the waiting around. People with learning disabilities shouldn't have to wait as long.

All excellent!

In A & E, handed nurses the traffic light form containing personal information, communication abilities, likes & dislikes - they read it and brought him something that was on his like list.

Appalled by treatment at Royal Berks.

I felt the nurse rushed me; I didn't know what they were doing to me.

First class care and post-operative care, no complaints.

It was ok because I was asleep. The nurses were fine.

Please tell us more about your experiences of hospital services.

Most staff were professional and good listeners. Felt really ill after operation and they really helped me to feel better.

More care and attention should be given to disabled people who are not verbal and cannot express themselves.

Very good eye laser doctor.

Excellent.

All the doctors and nurses told me about the exercises I have to do every day to straighten my arm.

As a general rule my daughter has been treated well when she has needed to attend the hospital.

I didn't understand the doctors and nurses, they mumbled, I wear hearing aids.

PW at KE7th, excellent care and tests, ENT at FPH excellent and helped with my ear problems.

Carers (professional) should not go to often for minor things, they err on the side of caution (Health & Safety).

Use Makaton, use small words, ask someone else to explain.

If we had a nurse with more time to explain things to me.

Helping us to feel less anxious in a stressful environment.

Write documents in big print.

Please tell us if you have any ideas to make hospital services better for people with learning disabilities.

Being able to choose an appointment at the beginning or end of the day when it's not so busy.

Be more understanding, speak slowly & clearly, understand that not all disabilities are visible.

Not making us wait too long, explain things better, don't give us wrong information.

Would be nice if the opportunity was in place to let professionals know a patient has learning difficulties without having to do it in front of them.

One-person advocate from start to discharge to help support the person with a learning disability.

Summary

From the 47 surveys people told us about **172** interactions (uses) of services.

good



64% of people rated their experience as good.

ok



28% of people rated their experience as ok.

bad



5% of people rated their experience as bad.



3% of people did not tell us about how they rated their experience.

The services people used most were:



- Outpatient Clinic (to see a doctor or nurse)

67% of people rated their experience as good.



- Phlebotomy (blood tests)

63% of people rated their experience as good.

When we asked people to tell us more about their experiences the main themes of the comments were:

- Medical care is very good.
- Communication and information could be improved especially when explaining conditions, treatment and procedures.
- Long waiting times and busy clinics can be difficult.

When we asked people if they had any ideas to make hospital services better for people with learning disabilities, the main themes were:

- Improving communication and accessible information
- Providing a consistent person to help the person through the process (admission, treatment, discharge etc.)
- Reducing stress and anxiety by reducing waiting times and accessing clinics when they are not busy.
- Identifying additional communication and support needs beforehand.

Contacting local NHS Trusts

The NHS Trusts that provide the majority of hospital services in the area are:

- Berkshire Healthcare NHS Foundation Trust
- Frimley Health NHS Foundation Trust
- Royal Berkshire NHS Foundation Trust

We wrote to the Chief Executives of these trust's on the 13th June and asked them:



- To encourage their staff to sign up to the Treat Me Well campaign online
- How do they make sure that people with learning disabilities are treated well and fairly when using their hospital and services
- Do they make any of the simple changes that Treat Me Well have identified as making a big difference to people with learning disabilities



Better communication



More time



Clearer information

Only one trust replied; Berkshire Healthcare NHS Foundation Trust.

They said:



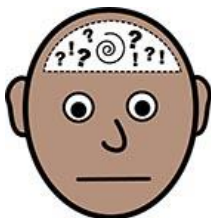
- Their community based and inpatient services for people with learning disabilities are currently rated “Good” by the Care Quality Commission (CQC). *These are specialist services only for people with a learning disability*



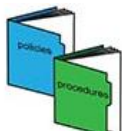
- They provide Learning Disability awareness training to staff across all their services.



- Their clinical records system can be flagged to alert people that someone has a learning disability.



- Their Learning Disability services and the Mental Health Crisis Team have been working together to improve support for people with learning disabilities during a mental health crisis.



- They have an accessible complaints procedure.



- They follow the NHS Accessible Information Standard.



- They have been making a short film with members of EBE² (part of Healthwatch Bracknell Forest) for their staff to help improve the experiences of people with learning disabilities when using services.



- Their staff from Community Teams for People with Learning Disabilities help hospital staff support individuals.



- Members of staff take part in Learning Disability Mortality Reviews (as do Healthwatch)



- Working to recruit their own Experts by Experience.

Their full reply can be found in [Appendix B](#) of this report.

Action plan



- We will publish this report on our websites and will send it to NHS trusts, East Berkshire CCG, Healthwatch England, the heads of Adults Social Care in Bracknell Forest and the Royal Borough of Windsor & Maidenhead and also to National Mencap.

We will also send copies to all the groups and organisations who we sent surveys to.



- We will write to the NHS trusts who did not reply and request the information under our statutory (legal) powers – which means they will have to reply.

When they reply we will publish these and link them to this report.

- We will continue to offer our services to help make services better for people with learning disabilities.



In the past we have helped to produce easy read health information, reviewed signage in hospitals and supported EBE² to make videos and to do reviews of health and social care services.

- We will continue to promote the Treat Me Well campaign.



EBE²



- EBE² is a group of people with learning disabilities who are supported by Healthwatch Bracknell Forest. They are Enter and View representatives and community champion volunteers. They will help to establish a similar group linked to Healthwatch WAM.
- We will continue to collect feedback on services from people with learning disabilities and make sure their voice is heard.
- We will help people with learning disabilities to speak up directly to services and NHS trusts when they are not happy with their care and refer them to advocacy services who can support them to make complaints.
- To undertake further work looking at how people with learning disabilities feel they are treated when they use primary care services (GPs, Dentists) and if they are being offered and taking up annual health checks – East Berkshire CCG reported that only 60.21% of people with a learning disability received one in 2017/2018. *
- *Figure provided by Quality Support Manager, East Berkshire CCG*

Contact information

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@HealthwatchWAM



HealthwatchBF



HealthwatchWAM



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Berkshire
RG12 1JG



The Space
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RG12 1JG

Appendix A

Learning Disability Week 2018 health survey

(Please tick one box)

I am:

A person with a learning disability

A friend or family member of a person with a learning disability

I am a support worker / professional working with people with learning disabilities

I live in:

Bracknell Forest local authority




The Royal Borough of Windsor and Maidenhead

Somewhere else

In the last year please tell us what hospital services you (or the person you support) have used and how good / bad you feel this service was.




Outpatient Clinic
(to see a doctor or nurse)



good	ok	bad
		
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>




Radiology (x-rays and scans)



good	ok	bad
		
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>




Phlebotomy (blood tests)



good	ok	bad
		
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>




Inpatient (stayed overnight or all day because you had an operation or treatment)



good	ok	bad
		
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>




Accident & Emergency



good	ok	bad
		
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>




Urgent Care Centre



good	ok	bad
		
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>




Ambulance Service



good	ok	bad
		
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Other service

(Please tell us what in the space below)

good	ok	bad
		
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please use the space below to tell us more about your experiences of hospital services (good and bad).

Please use the space below to tell us if you have any idea to make hospital services better for people with learning disabilities.

Please return this questionnaire, by the 9th July 2018, to:

The Space, 20/21 Market Street, Bracknell, Berkshire, RG12 1JG

If you need more space to say more, please use the other side of this page

Appendix B

Dear Chris

Further to your email to Julian Emms, Chief Executive, Berkshire Healthcare NHS Foundation Trust, I am responding on his behalf to the following two questions:

How do you make sure people with learning disabilities are treated well and equitably?

We provide community based and inpatient services for people with learning disabilities – to help support people to remain well and active in their community – and to receive timely inpatient care if required – these services are currently rated “Good” by the CQC across all key lines of enquiry

We have LD awareness training available to our wider staff teams – to ensure team members are more aware of the additional needs, challenges and risks that people with learning disabilities experience, and examples of reasonable adjustments that can be made to improve that experience for people.

We use an alert/flagging system within our clinical record system to help identify people with learning disabilities – and this helps all our staff consider what reasonable adjustments might be necessary for people to help them get the best care.

Our Learning Disability services and the Mental Health Crisis Team have been working together to increase awareness, confidence and skills in how to support people with learning disabilities during a mental health crisis – and how our LD services can also help ensure there are effective contingency plans in place for those people at increased risk out of hours.

We have an accessible complaints and compliments procedure to enable people to give us feedback

We participate in benchmarking to compare our learning disability services with other similar services nationally.

Our inpatient service was recently accredited under the Quality Network for Inpatient services for people with learning disabilities (QNLID) by the Royal College of Psychiatrists

National Mencap have highlighted that simple changes in hospital care can make a big difference – better communication, more time and clearer information. What are you doing to achieve this?

We adhere to the NHS Information Standard – to make help identify for whom and how information needs provided differently to be accessible to people, and we continue to work to develop more easy read information and materials for people.

We have been working with self-advocates and Bracknell Healthwatch to develop a short video highlighting the experience of people with learning disabilities of visiting the GP/hospital services – and how this can be improved. Our CTPLD staff offer person centred advice and support to staff from the local acute hospitals at an individual level in how best to support someone while in hospital/outpatients.

At a wider system level we support the national Learning Disability Mortality Review (LeDeR) process – with members of our staff undertaking reviews and participating with other stakeholders in learning from the deaths of people – seeking to positively act on this learning (e.g. raising awareness of the risk of sepsis and pneumonia).

We are working with NHS Professionals to support us in recruiting Peer Support Workers/Experts by Experience to help support the further development of our learning disability services

Helen

Helen Mackenzie

Director of Nursing & Governance

Berkshire Healthcare NHS Foundation Trust