



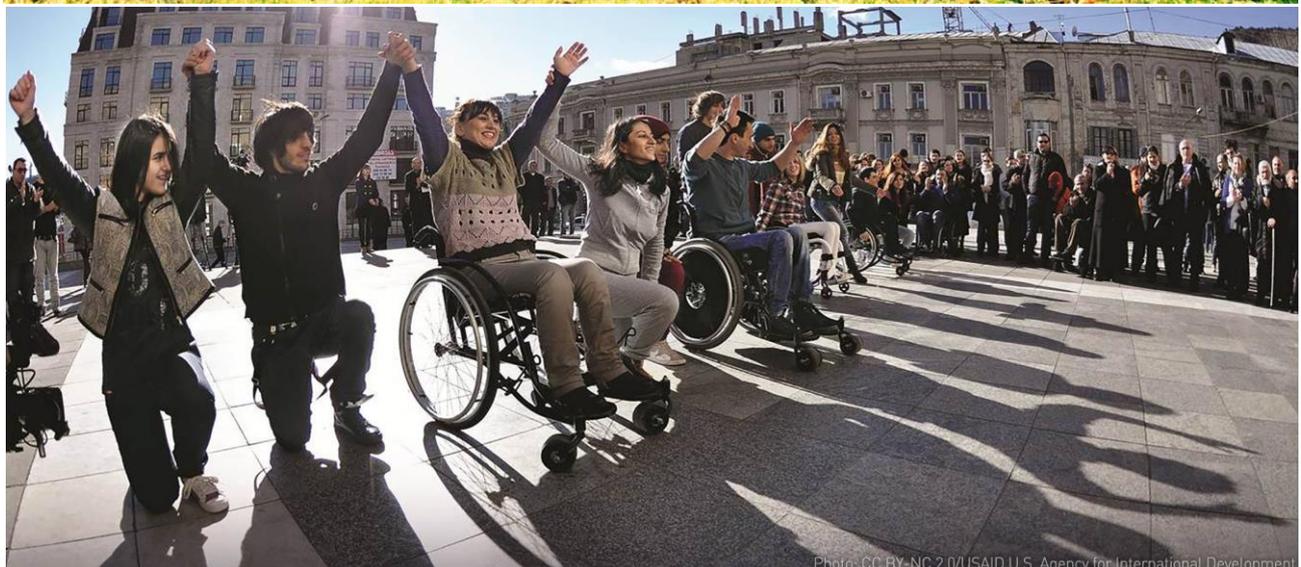
healthwatch
West Berkshire

VOICE OF DISABILITY

A Healthwatch fact-finding
conference

Workshop Report

15th November 2018



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INTRODUCTION

Healthwatch is an independent, statutory organisation responsible for ensuring the patient /public voice is heard as well as monitoring health and social care services on behalf of patients



The most important part of our role is listening to the views, experiences and thoughts of West Berkshire residents. We want to know what you have to say about local health and social care services, where things are going well as well as where they are not. We want everyone to be able to use us and especially groups that are hard to reach or those who are isolated by where they live, their age, medical condition, ethnicity, disability, traumatic event or poverty.

Co-produced events, like the Voice of Disability (VOD) are key to helping Healthwatch find out what you think. It is our way of gathering your views and taking it to those who deliver and commission services. We are committed members of the community who have the authority to make your views heard and campaign for change.

The Voice of Disability is such an event and was designed to seek the views across a range of disabled people, including individuals, carers and various agencies. It was arranged jointly with West Berkshire Independent Living Network (WBLIN), the Volunteer Centre and with support from West Berkshire Council Adult Social Care (WBASC), Berkshire West Clinical Commissioning Group (BWCCG), Department for Work and Pensions (DWP) and the Care Quality Commission (CQC).

This report contains the views of individuals and carers and information from key bodies. The appendices include points expressed and the Executive Summary tries to bring these points together. Where points are duplicated, they have not been included further times in the appendices although this emphasis is indicated in the main text.

This report is compiled under the headings of the workshop but organised under relevant questions and with relevant quotes from delegates added for support.

AUTHOR'S NOTE

The quotes that appear in this document are those of the participating delegates. Although some are mentioned in the appendices they may not be included in the body text. This is because an individual or group of individual's experience may not represent what is evidenced in general about a service.



EXECUTIVE SUMMARY AND RECOMMENDATIONS

It is widely accepted that there are a lot of good things about West Berkshire for people with disabilities. The open spaces, the accessibility of the town centre and the number of voluntary services and support agencies are much appreciated. A number were mentioned specifically (see appendices)

1. In general, the NHS and local GP services were felt to be positive. Although clearly this is not the case for everyone and what came out very strongly were the difficulties that people had in making appointments at an appropriate time of day and in an appropriate timescale.

Recommendation – GP surgeries review accessibility of appointments with recognition that bus passes can only be used after 9.30 and some people with disabilities have fluctuating conditions that require a timely consultation.

2. There appears to be a recurring theme that people with disabilities do not know what services/activities are available to them. Regarding services, GPs are sometimes thought to know all and signpost people appropriately. However, in the current climate where recruitment and retention of GPs and lack of available appointments is problematic, other ways of bringing information to the fore are necessary.

Recommendation – West Berkshire Council and the Health and Wellbeing Board put efforts into publicising / marketing the West Berkshire Directory and having a hard copy in relevant public places that are fully accessible, eg library.

People were vocal in wanting to meet others and socialise. However, lack of information about what is available is resulting in people feeling lonely and isolated. This is particularly evident in rural locations.



3. Secondary health services and specialists appear less understanding of disabilities than GPs.

Recommendation – The Health and Wellbeing Board considers how disability training for secondary care services is carried out and how this can be monitored, including consultants.

4. Waste disposal has mixed reviews. Some people felt that their assisted bin collection is good whilst for others this has been difficult to organise. There is a difficulty of insufficient capacity where a person uses incontinence supplies. Also, where bins are left on the pavement after collection, this can be obstructive for wheelchair users.

Recommendations - West Berkshire Council considers:

- how the service can be better publicised
- whether integrated Health and Social Care services can work together so that additional bins can be provided where incontinence supplies are used.

5. People also commented on the difficulty in following through a complaint.

The energy needed to complete the complex process means that complaints are often dropped.

Recommendation - West Berkshire Council considers how making complaints can be made easier and fully accessible.

6. CAMHS (Child and Adolescent Mental Health Service) attracted a great deal of criticism with some carers becoming desperate. It is unreasonable that the need for a diagnosis and thence support and medication if appropriate, requires a waiting time of up to two years.

Recommendation – The Health and Wellbeing Board undertakes an URGENT review of CAMHS waiting times, with special reference to children with a disability and how this affects the carer and the family, and looks at priority funding.

7. Referrals to Health and Social Care are often problematic and waiting time can be up to a year.

Recommendation – The Health and Wellbeing Board undertakes an URGENT review of integrated services (Health and Social Care) referral waiting times in relation to people with disabilities and considers priority funding.

8. People generally feel that those with disabilities are accepted in the area, that there is support from peers and support in crisis is good. There are many voluntary groups and the Volunteer Centre is appreciated. However, in contrast the lack of respite care is of particular concern.

Recommendation – The Health and Wellbeing Board undertakes an URGENT review of respite in line with the Local Offer.

9. Parking is a known issue at Royal Berkshire Hospital and must be mentioned, but it is recognised by Healthwatch that there may be development planned at the site. However, the lack of access for large wheelchairs to toilet facilities is of concern as is the availability of **appropriate** wheelchairs.



Recommendation – Royal Berkshire Hospital undertakes an updated access review of the Hospital, including toilet facilities, and ensures that there is appropriate wheelchair access and signage to locations- in light of the size of modern powered wheelchairs. As this may highlight expensive capital requirements, short term mitigation of issues highlighted should be considered. For example, a greeter with specialist knowledge to aid wheelchair users and people with disabilities.

10. Transport is the area where people have the most difficulty even though there is acknowledgement that the town pedestrianisation has been very positive. The three aspects that were positive included volunteer drivers, all buses now announcing the next stop audibly / on screen and Reading to Newbury buses ability to carry wheelchairs.



However, access to other buses is problematic with little or no wheelchair provision and scheduling to rural areas often at inappropriate times, resulting in residents feeling cut off. The location of 'dropped' kerbs not being adjacent is also a problem.

Bus drivers also come under criticism, particularly moving off too quickly before people are seated. This is a safety issue and should be addressed urgently. Drivers are also often unaware of the difficulties that disabled people have.

Vegetation around bus stops can also presents a problem for access and safety and restricts the view so bus driver misses the person at the bus stop.

Recommendation – West Berkshire Council assist with representation to local bus companies to review:

- scheduling to rural areas
- carry out URGENT staff training regarding disabled passengers
- cutting back vegetation that restricts access to bus stops .

Additionally, if passengers experience problems they could be encouraged to ask for a driver's name, number and the person to whom to report issues and this publicised. The person is believed to be Julia O'Brien, West Berkshire Council Licensing.

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11. There is generally a lack of wheelchair taxis with some drivers refusing to take a wheelchair even if they have the facility to do this. One person said they must book all their trips a month in advance to ensure they can get to appointments. This is a key issue as are the lack of suitable drivers.



Recommendation - West Berkshire Council jointly undertake a service user review to ensure services are operating appropriately in line with the Equality Act 2010 and look to ease issues with lack of suitable drivers (recruitment, training, etc).

12. Financial difficulties remain a serious difficulty for disabled people. When claiming a Personal Independence Payment (PIP), it is felt to be fairer for a person to be assessed on what they are unable to do rather than what they can do. This is because people have good days and bad days and difficulties fluctuate. There is also a feeling that the Department of Work and Pensions (DWP) needs to fit people into a category so that forms can be filled in, so people are known by their diagnosis not as a person.

Additionally, a disability reduction in Council Tax is difficult to get. The cancellation of home to school transport for anyone with SEND is causing hardship to some families and Housing Associations are not always felt to be helpful or sympathetic.

Recommendation – Healthwatch West Berkshire requests the local DWP to look at how a more accurate view of a person’s condition can be assessed and the whole person considered. Healthwatch West Berkshire requests the local MP to take this back to the relevant Ministers to ask for a ‘sea-change’ on looking at the whole person as the client not the condition.



13. Of major concern is the inaccessibility of one of the DWP offices in Reading where some PIP reviews are heard. The room is located on the second floor with no lift and there is no notification before attending. If a person is then late for an appointment because of these access problems an immediate sanction is applied.

Additionally there is a lack of disabled parking nearby.

Recommendations - The Health and Wellbeing Board request that the DWP undertake an immediate review of accessibility at the Reading office, as this was highlighted as far back as 2003 by a member of the West Berkshire Disability External Scrutiny Board (WBDES). Additionally, that the DWP undertake an accessibility review of their local offices and consider the following:

- making alternative arrangements and/or moving the office without lift access to one that complies with the Equality Act 2010 (previously known as DDA 1995)
- offering accessible alternatives or home visits as a matter of policy .

14. The lack of support for people whose disability fluctuates is a problem as the support needs are only necessary when there is an episode. The system does not accommodate this fluctuation.

Additionally the long wait for repairs from the wheelchair clinic means that a person whose only way of community access is removed becomes isolated and their life restricted.

Recommendation - The Health and Wellbeing Board urgently locates the responsible service and requests a review of its compliance with the Equality Act 2010 (previously known as DDA), its procedures and waiting times. This to be reported back to the Board.

15. There was great enthusiasm to use good assistive technology and many good ideas were proposed including 'talking' utility meters and talking aids such as Google Home.



Recommendation – The Health and Wellbeing Board support the roll out of assistive technology from its partners to aid the quality of life for people with disabilities and ensures that key staff are trained appropriately i.e. 'Tech Savvy' Occupational Therapists.

16. West Berkshire External Disability Scrutiny Board currently only reports to West Berkshire Council. It covers a range of issues that are covered in this report, including health/well being/transport/access issues.

Recommendation – The Health and Wellbeing Board requests reports from the West Berkshire External Disability Scrutiny Board.

17. It is clear there are still many challenges for those with disabilities in West Berkshire though currently there is no co-ordinated response or if the Health and Wellbeing Board (H&WBB) even has sight of the disabled.

Recommendation – The Health and Wellbeing Board (H&WBB) assesses how it manages disability issues and reviews the successes and/or challenges with particular reference to issues affecting health and wellbeing inequalities.

RESPONSES

Adult Social Care



In response to recommendation 7:

'From an Adult Social Care perspective, waiting times are an area of focus because we know that the sooner people can access support the better it is for them and for the services which support them. There has been significant progress over the last year, with a 40% reduction in the number of people waiting for an assessment by the community teams. There is too much variation in waiting times depending on where people live and this is something that we are working to address. Teams do prioritise their response based on the perceived level of risk so people with an urgent need are seen more quickly than others.'

In response to recommendation 8 :

'Adult Social Care does commission respite care for people with a range of needs, but agrees that it can be difficult to source. Providers are often reluctant to offer respite because it is a less predictable source of income than permanent placements. Another challenge is that some people want to plan respite far in advance but others may need respite on an emergency basis, creating another practical challenge. Our experience this year is also that we saw a large amount of scheduled respite for people (based on assessments) which was still unused at year-end and this makes the picture more complex.'

Paul Coe - Service Manager - Adult Social Care

Royal Berkshire Hospital



Royal Berkshire
NHS Foundation Trust

'The RBFT recognises the challenges encountered by our patients, caused mainly by our patchwork of old estate built to a different code and challenging to alter.'

As recommended by the VOD report we will undertake an access review across our site during 19/20. Due to the age and restrictions of our current site making the hospital fully accessible may be challenging. We will ensure that signage and information regarding facilities are improved and made available at key points such as the reception and welcome desks. During 19/20 we are working on a long term Master plan to develop our estate that will consider the needs of our services and our patients. As we develop designs for our new and refurbished hospital buildings we will be keen to engage with patients and visitors to ensure that our buildings meet their needs as far as is practical.

In addition, this year we have a focus on reducing the need for patients to attend the RBH site through the use of technological solutions as well as more clinics at our modern estate in Townlands, Bracknell and West Berkshire.'

Caroline Ainslie - Executive Director of Nursing

Richard Benyon



'Richard has noted the three points you raise – and should the H&WBB want him to raise these issues with the appropriate bodies at some point he would be happy to do that.'

Catherine Haig - Senior Researcher for The Rt Hon Richard Benyon MP

WHAT IS GOOD AND WHAT CHALLENGES ARE THERE OF SERVICES FOR PEOPLE WITH DISABILITIES IN WEST BERKSHIRE HEALTH AND SOCIAL CARE?

It is widely accepted that there are a lot of good things about West Berkshire for people with disabilities. The open spaces, the accessibility of the town center and

the number of voluntary services and support agencies is much appreciated. A number were mentioned specifically (see appendices).

Health

In general, the NHS and local GPs came out well.

I am exceedingly thankful for the NHS. In all probability I would have died by now without the many ways they have helped me. This is a burning issue because there is so much negative talk about it"

Healthcare good – I feel very supported and receive good care.

West Berks community Hospital and Red Cross Ambulance Service very good

GP atmosphere very good (Thatcham Medical Centre)

Thatcham dentist very good

Pain clinic is starting to treat people holistically

Empathy of practitioners and staff generally

There are highly trained professionals in adult social services

Clearly this is not the case for everyone and it came out very strongly the difficulties that people had in making appointments at an appropriate time of day and in an appropriate timescale.

GP surgeries only open a few days a week (rural locations)

Waiting times for appointment is poor, three weeks is too long

No support from GP to manage meds reviews (long term condition) – advised to make appointment three months in advance to see own GP

There is also concern about on-going health provision and services following on from GPs.

Good relationships with local GPs, for clients with LD. But not so good when you get into specialist services and consultants

Beyond GP and broader health services, specialists are less understanding

No after care after seeing NHS professionals, I called an ambulance, they treated me, then I was left alone

Challenge to see a psychiatrist at Hillview House community hospital. I got diagnosed and was told to see a psychiatrist on a regular basis and that my GP would follow-up, but GP knew nothing and said he would investigate it but didn't. I am now lost back in the system. I have suffered from mental health issues since 16 and now at 31 a carer for a disabled child and I can't get help

Child and Adolescent Mental Health Service (CAMHS) are severely criticised with people informed that there is a waiting time of two years and some carers struggling to cope

CAMHS waiting list. Been told to wait 2 years

Waiting times for mental health in young people poor

My children are on the CAMHS waiting list and I have been told to expect a wait of approximately two years.

I am having a nightmare and will continue to do so until my kids receive some sort of diagnosis. This is NOT acceptable. We as a family are struggling. Medication cannot be prescribed without a diagnosis through CAMHS

Referrals to Health and Social Care are often problematic and waiting time can be up to a year. The list is based on need, so anyone added to the list with a greater need takes priority. There is a wish that the way things used to be would return. People used to phone in and speak to a social worker who made an immediate appointment.

When I was 16, I had mental health problems. I am now 32. I have tried to commit suicide. There was no help. I was taken by ambulance to Prospect Park but the referral back to the GP never arrived

Carers / Support

People generally feel that people with disabilities are accepted in the area, that there is support from peers and support in crisis is good. There are many voluntary groups and the volunteer centre is appreciated

General acceptance in the local community of disabled people

Once under crisis, the support is good

Thatcham Volunteer Bureau

Goodwill. People making a difference in voluntary groups

However, in contrast the lack of respite care is of concern.

Lack of respite options for adults. Funding has been cut for short stay respite

But everyone on this table said lack of respite for carers or mental health support for them

We need support for parents with children that have poor mental health

I don't get any respite as I can't buy it in, can't afford it. The direct payment rate is £10 an hour but Mencap charge £18 per hour. I want a two-week holiday, which is what I'd get if I was an employee

The Local Offer sets out provision which is available for children and young people with Special Educational Needs and Disabilities (SEND), aged 0 to 25, including education, health and social care services, but some people find accessing this difficult.

I can't access respite. I get a carers allowance of £50 a week and for overnight care it costs £900. I want some sleep.

Personal Independence Payments for carers with health issues are poor. No income or support for medications and dentist

Payments for carers and lack of information are real problems. Additionally, agency carers often have a lack of language skills or training for complex communication needs. This can mean there is a lack of empathy and can have major time issues for carers. For example, a lack of understanding can result in food / drinks being left out of reach.



It is accepted that there is a lot of help (other than respite) but people are not informed and don't know what information they need. People don't know what they don't know.

I need carer training – how to lift safely, First Aid – updated regularly

I lack knowledge about what to do as a carer

I don't know what is available – no support to sort out mobility scooters and wheelchairs, GP has no information

Access

West Berks Community Hospital is a valued service as it means less travelling. Where hospital visits are further afield there is transport support although this is not known by everyone and there is a cost.

CAB is fantastic. I pay £12.50 for transport to RBH when I need to get there



The built environment is felt to be good in Newbury with the pedestrianisation of Northbrook Street and trip hazards removed, but this is not the case in villages and people can feel isolated. The town disabled facilities are generally good.

The Kennet Centre has good changing facilities in toilets

Vue is ok with spaces but can't book online

Parking is a known issue at Royal Berkshire Hospital, however it is a further difficulty for people with disabilities as there is limited parking and no prior information about whether the disabled spaces are full. Late arrivals at appointments are often the case. Changes to South Central Ambulance Service (SCAS) bookings for hospital

transport to/from out-of-area are problematic. People with disabilities are often told to use public transport or drive themselves when this is inappropriate, impossible or dangerous for the patient.

Not enough disabled parking at RBH and you must enter the car park to find out disabled spaces are full – you then have to pay to get out of the car park

The toilets at RBH are also difficult to access in a wheelchair and there are also issues with the accessibility of ward shower rooms



Took my relative to RBH. I can't manage a large wheelchair but had to transfer to a large wheelchair at the hospital. Large chair won't go into the toilets for the disabled so had to transfer to smaller one just for the toilet. Made a complaint. Letter back saying thanks for bringing to our attention. then nothing.

RBH changing facilities, difficult for LD and wheelchair user

There is an acknowledgement that West Berks is trying to get better with sensitivity to people with autism, but there is more needed in shops etc.

Some GPs appear to have no knowledge of their patients. Do not know their medical history. Do not offer support regarding a child with special needs or help with regards to mental health.

There is often an expectation that GPs should have the knowledge of all services and be able to signpost. One person pointed out that she had difficulty with being examined by her GP because of lack of equipment.

A specialist will recommend talking to a GP regarding services (nappy pickups) but GP's do not know what services are available or how these can be requested / put in place

There are no hoists at GP surgeries, so I can't be examined

Other access problems

Signs are written rather than any images, for people who can't read

Communication aids are necessary for children and should be more accessible. Our 9-year-old child cannot talk. We do not have the money to pay for different apps (£300 - £400) to "try" and buying communication aids that can cost £1000's

I'm registered blind and have a walking stick. Get vehicles parking on the pavement (cars, vans, lorries, motorbikes) so I must get off the pavement then get the driver shouting at me for being on a road. When I speak to WBC Highways, they say, 'I don't know what we can do'. Same with police: they say I have to speak

to WBC. Hit my head against a brick wall every time. Can't usually walk from my house to the bus stop. Would like to see a law, that people parking on pavement are fined.



Changes within West Berkshire Council and legislation means that disabled people cannot now attend Planning Meetings, Transport Meetings or many other statutory public meetings. Therefore, representation has been reduced, or is no longer available.

Transport

Transport is one area where people have the most difficulty even though there is acknowledgement that the town pedestrianisation has been very positive.

The three aspects that were positive included volunteer drivers, all



buses now announcing the next stop audibly and, on a screen, and Reading to Newbury buses ability to carry wheelchairs.

However, access to other buses is problematic with rural areas feeling cut off and buses that do run scheduled at inappropriate times.

Handy Bus difficult to access

Large wheelchairs don't fit on buses

Buses to college no good I need to use 'mum's taxi

In Mortimer there is no transport on Sundays and Bank Holidays, they have been removed

No transport to WB Council offices at Calcot

Public transport from Cold Ash v poor

There is a bus service to the rural areas. But only 3 buses a day at not the most convenient of times / within the school day

No late-night buses generally and assistance service problematic

Lack of public transport in West Berkshire, ie Compton has limited service. Does not help with employment

Bus drivers come in for criticism:

Bus drivers don't give people a chance to sit down (Jet Black 1). As a result, passengers have fallen over

Drivers often not aware of disabilities, e.g. don't put ramp down

Drivers make excuses not to take disabled people

Bus drivers don't park close enough to the pavement

There is a need for training for bus drivers and taxi drivers in the requirements and show of respect to disabled people

Bus drivers drive past even when a disability is visible

Buses have a seat where a disabled person should have priority. However, they are more often occupied by people, mostly women, and most of them use the seat for their shopping and don't move although they can see you need the seat

However, there are two sides to most things!

There are two sides to the issue re bus drivers. It is true that some drivers are rude and inconsiderate, however (a) so are passengers and (b) the employer puts constraints on the driver which puts makes for difficult situations for him. Eg I was a bus driver in Bristol for two years and was allowed 28 seconds for a stop. Taking on a woman with a pram and toddler takes over the allocated time.

Physically accessing buses when they do run at convenient times can then be difficult. Getting on and off with walking aids can be difficult and kerbs are difficult to traverse if a person uses a wheelchair or is unsteady on their feet. Dropped kerbs can help but are often in the wrong place and/or don't line up with similar on the other side of the road.

I tried to get dad on a wheelchair taxi but he said he couldn't take that wheelchair. He said he'd been on a course, there needed to be hard back and attachment points. Means everyone will have to change their wheelchair.



No drop curbs and some pavements rough especially on A4 between Church Hall and ½ mile East

Any complaints or suggestions relating to bus difficulties should be directed to the bus company in the first instance and then to the council (details on website). 90% of bus services are operated by Reading buses. Mathew from West Berks Transport services will feed back on issues raised at the workshop.

Taxis are also sometimes problematic:

Wheelchair users – booking a taxi is a nightmare – availability, cost, refusal to take – West Berks are investigating incident where a taxi driver refused to take my dad in a wheelchair

Lack of wheelchair taxis



Trains have issues too:

Theale Station is inaccessible to wheelchair users such that disabled users need to travel to Basingstoke and return to the other Theale platform, incurring additional cost, more inconvenience and is discriminatory.



I can't use public transport unless I book 24 hours in advance if a ramp is needed

Trains – access for disabled people, ie not have to go to the next station to have help to get off the train with the right help

Other points relating to transport include:

My husband was dying of cancer. Had to get to RBH. Not nice conversation to book in. Dr said could have transport. Person on the desk said needed to fit box. 'Isn't dying enough?'

Disability Living Allowance recipients and Blue Badge holders in the future

Loss of companion bus passes for carers

Barrier to getting Blue Badge – I receive a care package but no badge

Hospital transport – I was recently told it is NOT available to Personal Independence Payment /

Thatcham football club - not disabled friendly - no parking and no covered area for wheelchair users. Toilet has a slight step too

Social

There are a number of clubs and social groups for people with disabilities (see appendices). People were vocal in wanting to meet others and socialise. However, there appears to be a general

lack of information getting to people and people living in rural villages felt isolated. There is also a lack of age appropriate activities for those with complicated needs.

Education

Views were expressed for Newbury College to have more activities with animals and sports and a need to have access to working computers. There are also allegations of 'bullying' behaviour towards people with learning disabilities from other students were expressed- but not felt serious enough to warrant immediate action at the event.

Financial

Financial difficulties remain a serious difficulty for people with disabilities. When claiming a Personal Independent Payment, it is felt to be fairer to be assessed on what they are unable to do rather than what they can do. This is because people have good days and bad days such that difficulties fluctuate.

There is also a feeling that the Department of Work and Pensions need

to fit people into a category so that forms can be filled in, so people are known by their diagnosis not as a person.

Additionally, a disability reduction in council Tax is difficult to get. The cancellation of home to school transport for anyone with SEND is causing hardship to some families and Sovereign Housing is not always felt to be helpful.

Disability reduction on Council Tax is hard to get

Of note is the fact that one of the DWP offices in Reading where PIP reviews are heard is on the second floor with no lift.

This is not known prior to attending. If a person is then late for an appointment, because of access problems, there is an immediate sanction applied.

PIP waiting times for assessments and appeals cause real difficulties

Technology

There appears to be an assumption that everyone has a computer or can navigate sites easily. Several people (particularly those over 60) may not have a computer and may feel they can't learn IT skills or simply may not wish to.

WBC rely too much on people having access to email for information. Not everyone has or can use a computer

Carers Rights day needs webinar access, so I can attend

Services / Facilities

When known about people generally feel that charities and services are positive

However, there appears to be a recurring theme that there are a lot of services/activities for people with a learning disability but that these are not known about.

Information is not available re voluntary service

When accessed, charities and services encountered are positive

Making sure there's information about where to get support. E.g. cancer charity could give lifts but only found out about it ad hoc with 3 Frogs

A central resource where it is easy to find voluntary and statutory services in your local area. There are lots of services that people aren't aware of. I have just found out about a directory – westberks.gov.uk. Make sure that ALL services are listed

Waste disposal has mixed reviews.

Some people felt that their assisted bin collection is good whilst for others this has been difficult to organise. There is also a difficulty where a person uses incontinence supplies and replacing bins after collection can be obstructive.

Assisted bin collection, will go to back door. But [another group said] people emailed about it and then had a large form to fill in and it takes 12 weeks to get in place

Bins are needed if an adult is incontinent

Langley Hall Drive is often blocked by waste operatives' replacements of bins

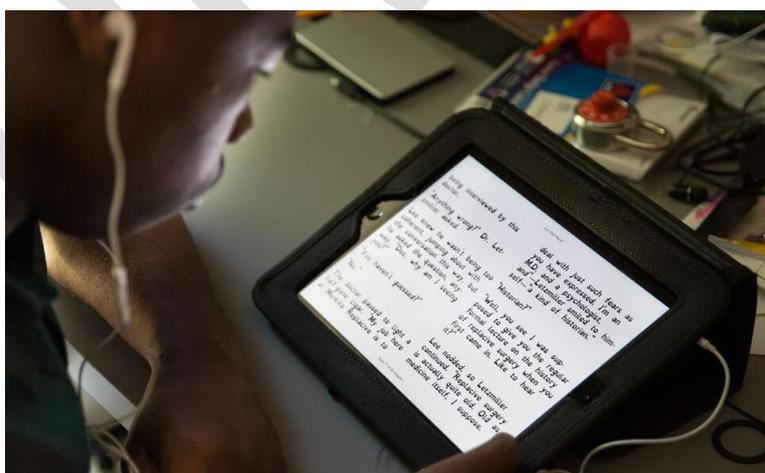
People also commented on the difficulty in complaining about a service. The energy needed to carry on following through with a complaint meant that they are often dropped.

West Berks complaints procedure is awful – you get no results

The lack of support for people whose disability fluctuates is a problem and the long wait for repairs from the wheelchair clinic means that a person whose only way of community access is removed become isolated and their life restricted.

There is no home help for occasional need. I am told to go to hospital, but I can be looked after at home when needed

Children's wheelchair clinic – a long wait to be seen; a long wait for repairs; a reluctance to give wheelchairs at the level needed resulting in people being restricted and isolated



Adult Social Care – How does it work with you?

Mike Harling (Principal Social Worker for Adult Social Care) and Alex Barrow (Social Care Practitioner from West Team)

West Berks has reorganised the support teams. Where previously teams were organised by condition, ie a disability team, a dementia team, now they are organised by locality. This means each team is responsible for all needs in their area and there is a one-stop-shop to get in touch.

There are offices at West Street, Hillcroft and Turnhams Green where parking is a problem. It is routine that social workers visit people in their own home or other convenient place. There is a carers assessment and a current push to support carers as the council is aware of the vital role that they play.

However, someone commented: **“not everyone knows about the assessment or the Carers Hub.”**

A local resident disclosed in a conversation with her social worker that she was being treated badly by her husband. The social worker was able to work discretely and supported the woman to move to her own safe accommodation with support.

Social Care make sure carers have all the information and support they need as a carer.

Carers not supported by GPs. Heard about carers hub by accident. Had been caring for mother-in-law for 11 years. Only found out as stamped my feet and shouted

There is now also a West Berks Directory of groups, clubs, societies, organisations, etc. An internet search for West Berkshire Directory should get you there.

Currently loneliness is a big issue for the Council, as it is nationally.

50-year-old Alex presented at the Council distressed. His wife had a stroke and had difficulty walking meaning that going out was problematic for them both. Alex also had health problems, and both felt isolated. An adult care social worker visited the couple and, through conversation, found that Alex's wife had a long interest in horses and riding. The social worker arranged an hour of riding each week and this improved her walking and wellbeing and support was arranged for Alex.

Some don't know about carers hub



When I have a bad episode there is no one to help me. My GP says I must call the paramedics, but they don't want to take me to hospital. They get me downstairs but must leave me. My children live away. I do not have constant problems but episodes, so I can't have a carer. I don't know what to do. I have tried incontinence pads when I can't get to the toilet, but they don't work. I am not considered disabled enough to get PIP.

Anyone who rings in to the Council who is a carer is given information in compliance with Care Act requirements.

Reading and West Berkshire Carers Hub provide information and advice to unpaid carers to help support their physical and emotional wellbeing. They offer carer-specific advice on a host of topics, such as finding a carers support group, helping make contact with others in the same situation, or helping to access information on carers breaks.

They're also able to advise on financial help (such as grants, benefits and discounts) and rights in employment. They also signpost to a host of other relevant services.

To access support from Reading and West Berkshire Carers Hub complete the [Reading and West Berkshire Carers Hub Referral Form](#) or ring 0118 324 7333

GP – will often refer to village agents who will call on you and tell you about the services.

[Village Agents](#) can provide support and information and be contacted through the Volunteer Centre (1 Bolton Place, Newbury RG14 1AJ Phone: 01635 581 001).

www.villageagentswb.org.uk

Adult Social Care can signpost to available services and make referrals (01635 50 30 50)

Access to information is problematic where people have no access to the internet or a mobile phone and some GPs are unable to support carers by signposting to a relevant contact or service.

There's a lot of good stuff out there but you need to communicate this.

Welcome to the **West Berkshire Directory**
Your one-stop shop for help and support in West Berkshire

Adults
Find information on the wide range of services available to support you to remain independent. This includes support in your local communities, including home care, care homes, leisure activities and voluntary organisations. [Click here](#) for information to support adults.

Families
In this section you will find information, advice and support available to families and professionals in West Berkshire. To access the information either use the search box at the top of the page or click on the various categories. If you need help then please use the contact details shown on the next page.

SEND Local Offer
This is the SEND Local Offer - advice and support for young people, families and professionals supporting families with Special Educational Needs and/or Disabilities in West Berkshire. To access the information either use the search box at the top of the page or click on the various categories. If you need help then please [contact us](#) for additional support.

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Overview on Transforming Care for People with Learning Difficulties, Mental Health Issues and Autism

Sarita Rakhra (Lead Commissioning Manager – Transforming Care, Carers/Voluntary Sector/Mental Health – Berkshire West Clinical Commissioning Group)

Transforming Care has grown from the Winterbourne View. It has five work streams. Finance and Activity, Children and Young People, Autism, Workforce Development and Housing and Accommodation.

Where people are in long stay hospitals Care and Treatment Review visits are carried out to check if a person is safe and their treatment is appropriate. Where they are transferred from long stay provision after 5 years their funding allocation of £180k per patient goes with them.

In West Berkshire 7 beds have been closed and reinvested into an intensive support team set up with funding from NHS England. However, there is a need for the right infrastructure as some people need intensive wrap around services.

33 people have been seen and provided with support to go into their own homes and 31 still remain so. Five people have been funded through grants from Central Government of £1.2m to buy their own home.

This programme ends Nationally in March 2019 when the target is for a 50% closure of beds, but West Berks is committed to continuing with the service.

The emphasis is now on preventing people going into long stay provision and remaining in the community and training for those involved in support.



Berkshire West

Clinical Commissioning Group



Although West Berks is emphasising prevention of long stay/residential care there are some people with complex disabilities for whom 24-hour care in a specialist home is appropriate. Residential placements are costly and with the move away from these, local authorities are reducing provision so there is less of it and it becomes more costly. Placements now are becoming more expensive and this is further reducing a decline in available placements.

Carers express concern about the future for their cared-for and have the stress of keeping themselves healthy. Sadly, they hope that they will outlive their cared-for.

My 18-year-old non-verbal son has been in John Radcliffe Hospital. He requires a carer to stay with him all the time. There was no provision for a carer to stay so I had to sleep on a chair and they left me to do everything as if I was a member of staff. He is at the College and leaves at 19 but his assessment has been delayed and I don't know what will happen What then? If someone can no longer care, who then takes over

Carers also reported difficulties when transitioning between children's services and adult social care

There is a black hole at transition as people move from children's services to adult services

GPs across West Berkshire are signed up to the Direct and Enhanced service to provide health checks for 70% of people with learning disabilities by 2020. The aim being to detect any underlying issues early and for which they receive an additional payment.

I am concerned this is pump priming money and will then be a cliff edge

Why target of only 70% for health checks"

Sarita says" I'm a commissioner and am surprised to hear people don't know about the services, so I'd like to hear more".

What would you like to see to improve your wellbeing?

Matt Pearce (Head of Public Health and Wellbeing, consultant in Public Health

People were clear that they wanted access to services and activities and to be treated equally in respect of their physical, social and mental wellbeing. They wanted to be able to be happy, saying that loneliness is a big barrier to their health.

I want to be the best person I can

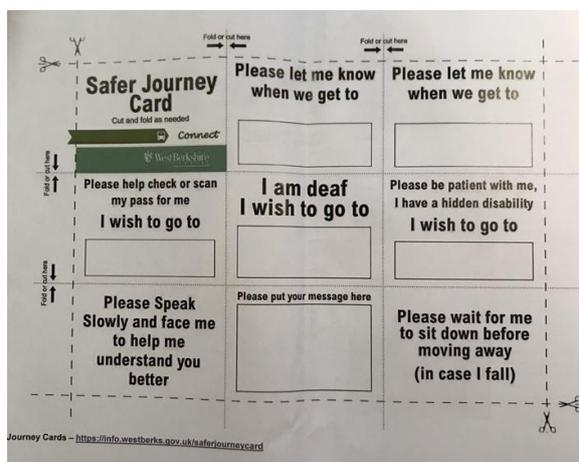
When I feel I'm understood. I have an invisible condition – one that isn't immediately shown and there needs to be customer training in equality

For me wellbeing is accessibility, transport, healthcare etc.

Keeping fit and healthy. Healthy eating

What makes me happy is when I do something nice for other people

There are a number of things that West Berks Council is trying to do to improve services for people with learning disabilities. Regarding transport for example, there is a safe journey card which can be shown discretely to a bus driver, e.g. 'please wait for me to sit down before you move away', although drivers should do that anyway! Or it could say where you want to get off.



However, there is a severe lack of getting information to the right people at the time they want/need it.

Information from Volunteer Centre West Berks

Garry Poulson, Director

Community transport is very good in this area.

There are 10 volunteer car schemes in West Berks, information about which can be best found through an internet search for 'voluntary car schemes'. Schemes are in Lambourn, Kintbury, Thatcham, Hungerford, Downland (Compton), Newbury, Chapel Row/Bucklebury, Bradfield, Theale.

Pangbourne/Streatley/Goring. If there is no access to the internet ring 01635 49004.

There is also a Handybus that runs between Newbury and Thatcham and this takes group bookings. Contact Trevor on 01635 37111.

To book the car scheme or Handybus it is necessary to contact with information about disabilities and what is required.

In Newbury there is a shop mobility service. For £3 a day a scooter or wheelchair can be hired from the Northbrook Street multistorey car park (and you get to park for free).



Technology and Innovation

Technology is developing fast and technological innovation is helping people with disabilities to be more independent. Computers and internet technologies are helping people to access information and have social contact with others. However, it must not be assumed that everyone has access to a computer or wishes to learn how to use one.

Not everyone has smart phones and internet, so include everyone. A one-stop-shop of information. A lot of the services are there but people don't know how to access them



There is a need for occupational therapists to be 'technologically savvy' so that people can be helped to use technology aids. Voluntary technology advice is also suggested.

Call systems, Alexa and the like, can be programmed to respond to voice commands, for example to call a named person or the emergency services in a fall.

People with disabilities have lots of ideas about how technology could be used to help maintain positive health and wellbeing. E.g. if a person is unable to lift a kettle, a hot water machine that dispenses one cup at a time can make making a cuppa possible.

The need for adequate lighting for people with sight impairments is often missed and back lighting heating dials would be a simple way of enabling access as would lighting in meter cupboards. Or perhaps electricity and gas meters and dials could 'speak' the readings.

Other technological support spoken about include:

A crisis phone app

A sensor mat something to let someone know if partner has got out of bed, e.g. risk of fall.

Using technology reminders

Age UK has a telephone shopping service when the internet cannot be used but I would like it directly with the supermarket as online shoppers do

Communications device for child to communicate. They're £10-20k.

I have a non-verbal child. Could use eye gaze, look at pix and it speaks. Or tap and say a phrase. Speech and language therapists say, 'try this', but £400 to just try it.

Physical education helps my children, can't afford clubs, activities, no time to walk in the woods. I need low cost activities.

WBC will fund telecare

Red Cross loan out equipment.

I asked, (Mencap), for a ramp but couldn't help.

Hospital appointment – if big delays problem with ADHD. Give device to keep you up to date with when likely to be seen

Some restaurant beeps when food ready

Something to keep children occupied while having to wait.

An app for parking, so you know where there are disabled parking facilities.

Then, not just parking, but where there are seats, where disabled toilets are, where shop mobility scooters are.

Packaging with a sell by date, but if can't read them

Nottingham Rehab Services (NRS), nationwide; but locality based. So, if person needs

equipment visiting Manchester, still must pay for it there too – no co-ordination by this NRS service. If visit, difficult to get equipment in vehicle but they have depots all over. Was in Hull last year and cost £1400 to hire all the equipment that needed

Philip been trying to get a phone with big numbers. Vodafone said they don't do that. But their head office is up the road they've just joined the H&WBB, so could ask them there

What if want to speak to someone. Why not ring WBC and they will tell you who you need to speak to? That should go for all services. Too often directed to a website.

Helping YP (young people) with disabilities to have more of a social life.

Link Eye Gazer with the internet so they could Skype, access the internet etc. So you can have some independence

Can't book a wheelchair space at theatres online, though can for cinemas. Corn Exchange have to talk them.

Disabled tickets in theatres the more expensive.

London theatres – maximum you pay is £35 and you get a free carers ticket. Ensure they know if you don't need a wheelchair or you'll just be given a space. You get set up for that on the system and then don't need to prove things.

Also, for gigs, your essential companion goes free.

Andrew Sharp – should talk to Corn Exchange and Watermill also.

I am a dental inspector for CQC. If you have problems with dentist, contact them first. Also have Healthwatch West Berkshire. They talk to us. But if you're really desperate don't hesitate to contact us, e.g. whistleblowing.

If you need advocate with dentists, SEAP provide statutory advocacy.

THANKS

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West Berkshire Independent
Living Network

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Special thanks to Karen Swaffield, Healthwatch West Berkshire for compiling this
report.

Going forward

Healthwatch West Berkshire may host future events focusing on specific issues. It would be good to hear from you more about any health and/or wellbeing issues you may experience.

Healthwatch West Berkshire

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4-8 The Broadway
Northbrook Street
Newbury
RG14 1BA

T: 01635 886 210

E: contact@healthwatchwestberks.org.uk

www.facebook.com/HealthwatchWestBerkshire

twitter.com/HealthWWBerks

APPENDICES

Appendix 1

Attendees

73 people attended the workshop of which 34 were service providers (including the voluntary sector). Representatives came from:

Service Providers	Public Health	WB Transport Service
Voluntary	H&WBB members	Open for Hope
BCT	Webcas	CQC (Care Quality
(BetterCommunities	WB Commissioner	Commission)
Together)	Volunteer Centre	Thatcham Council –Mayor
seAp	WB Adult Social Care	WBILN
Newbury College	West Berks Mencap	(West Berks Independent
Berkshire West CCG	DWP	Living Network)
AllTogether	Swings and smiles	

Appendix 2

What is good and what challenges of services for people with a disability are there in West Berkshire Health and Social Care?



What's Good?

Health

- Health. Good support, from surgery and ongoing
- Social care and district nurses when needed
- All therapists available Castle School
- Pain clinic is starting to treat people holistically
- Good relationships with local GPs, for clients with LD. But not so good when get into specialist services and consultants
- Support from different therapist at Castle School is excellent
- I am exceedingly thankful for the NHS. In all probability I would have died by now without the many ways they have helped me. This is a burning issue because there is so much negative talk about it

- Empathy of practitioners and staff generally
- Highly trained professionals in adult social services
- Duty social worker always available
- Annual reviews and health checks – good communication and support and chance to set goals and get more support
- Swindon outpatients very good
- West Berks community Hospital very good
- Red Cross Ambulance Service very good
- GP atmosphere very good (Thatcham Medical Centre)
- Thatcham dentist very good
- Sport in Mind
- Wiltshire Farm Foods
- Park run
- Brilliant NHS
- Healthcare good – I feel very supported and receive good care
- District nurse and Adult Social Care brilliant when my husband died in 2013
- GP referral to fitness for health
- Stroke Club
- Steady Steps keeps me moving

Carers / Support

- Peer support and access to town
- centre
- Once under crisis, the support is good
- Goodwill. People making a difference in voluntary groups. E.g. Cameo, people
- General acceptance in the local community of people with disabilities
- Volunteer Bureau
- Community Furniture Project

Access

- Built environment is good in Newbury, pedestrianisation, but not so good in the villages, isolated
- Built environment pretty good, flat and accessible with trip hazards removed
- Kennet Centre has good changing facilities in toilets
- Vue ok with spaces but can't book online

Transport

- Volunteer drivers
 - Reading / Newbury buses can take wheelchairs
-

Social

- 3 Frogs club for young people with autism but want more places to go
 - Young learning-disabled people Social clubs
 - Diamond dining centre at Greenham Business Park, very good
 - MENCAP Gateway Club
 - Phoenix Centre sessions
 - New Horizons Club for people with disabilities and good trips
 - Aquadrome special session, disabled swimming
 - Open for Hope every Tuesday in Thatcham Memorial Hall
 - Eight Bells for Mental Health mates
-

Education

- Mix abilities
 - Excellent support from Winchcombe school
 - Recovery in Mind
-

Services / Facilities

- WBC Disability Scrutiny Board is unique in that anyone disabled can be a board member and this is supported by the WB CEO
- Services, groups, not always relevant to our needs
- Kennet good changing facilities, with a hoist
- Active, thriving voluntary sector
- Assisted bin collection
- Good social workers / occupational therapists
- When accessed, charities and services encountered are positive
- Most of Berkshire is a good place to live. Lots of open space. Healthwatch good and we have a Health and Wellbeing Board
- Good services, eg Volunteer Centre, but now everyone is aware of them

Other

- This event is good
- Healthwatch events
- I want to register I'm here on the system so can be sent more information about events

What's Not Good/ Challenges?



Health

- CAMHS waiting list. Been told to wait 2 years
- My children are on the CAMHS waiting list and I have been told to expect a wait of approximately two years. I am having a nightmare and will continue to do so until my kids receive some sort of diagnosis. This is NOT acceptable. We as a family are struggling. Medication cannot be prescribed without a diagnosis through CAMHS
- Lack of resources so timely intervention at Low level doesn't come and increases to big problems needing more input
- Waiting times for mental health in young people poor
- Is there an OT unit for people under 60 but none for over 60s? I can't access a bath and need a wet room. (Answer) OTs work for WBC as well as health, and if need for equipment they can come out and assess
- OT Service
- RBH changing facilities, difficult for LD and wheelchair users
- Support needed for carers of adults with disabilities in hospital, they are treated as staff
- Waiting list – lack of resources in Adult Social Care, mental health, NO timely intervention
- GP specialist service poor
- Communication especially with social care. Moved to Thatcham, health good but not heard from social care, e.g. for help and advice. Want to be recognised and heard and in the system
- When I moved here in 1987, I got a welcome pack from the Council but this time nothing. I've now lived here for 12 weeks and received no social care support.
- Understanding NHS language: acronyms, terminology, definitions

- Beyond GP and broader health services specialists are less understanding
- GP appointments in three weeks
- No communication between GP surgeries and buses eg Handybus for timely appointments
- GP surgeries only open a few days a week
- No communication between providers
- Repetitive requests for Information
- Waiting times for appointments too long
- Lack of respite for carers: support for mental and physical health needs – better carer support
- Child – adult transition ill prepared for
- No support from GP to manage meds reviews (long term condition) – advised to make appointment three months in advance to see own GP
- The Local Offer sets out provision which is available for children and young people with Special Educational Needs and Disabilities (SEND), aged 0 to 25, including education, health and social care services but I can't access it. I get a carers allowance of £50 a week and for overnight care it costs £900. I want some sleep.
- No after care after seeing NHS professionals, I called an ambulance, they treated me, then I was left alone
- People with disabilities avoid making GP appointments because of problems getting there
- One size does not always fit all adult respite facility for wheelchair users once they are adult and have complex medical needs
- Challenge to see a psychiatrist at Hillview House community hospital. I got diagnosed and was told to see a psychiatrist on a regular basis and that my GP would follow-up, but GP knew nothing and said he would investigate it but didn't. I am now lost back in the system. I have suffered from mental health issues since 16 and now at 31 am a carer for a child with disabilities and still I can't get help
- Adult Social Services, children's services, GPs, mental health all lack resource

Carers / Support

- Lack of respite options for adults. Funding has been cut for short stay respite
- Lot of groups helping people but challenge as information not being passed down

- Everyone on this table said lack of respite for carers or mental health support for them
- Personal Independence Payments for carers with health issues are poor. No income or support for medications and dentist
- I need carer training – how to lift safely, First Aid – updated regularly
- I lack knowledge about what to do as a carer
- We need support for parents with children that have poor mental health
- I don't know what is available – no support to sort out mobility scooters and wheelchairs, GP has no information
- I don't get any respite as I can't buy it in, can't afford it. The direct payment rate is £10 an hour but Mencap charge £18 per hour. I want a two-week holiday, which is what I'd get if I was an employee

Access

- W Berks, trying to get better and sensitive to people with autism, but more needed in shops etc.
- Took my relative to RBH. I can't manage a large wheelchair but had to transfer to a large wheelchair at the hospital. Large chair won't go into the toilets for the disabled so had to transfer to smaller one just for the toilet. Made a complaint. Letter back saying thanks for bringing to our attention. then nothing.
- No hoists at GP surgeries so I can't be examined
- I need assistance for putting questions to the Council
- Some GPs appear to have no knowledge of their patients. Do not know their medical history. Do not offer support regarding a child with special needs or help with regards to mental health.
- A specialist will recommend talking to a GP regarding services (nappy pickups) but GP's do not know what services are available or how these can be requested / put in place
- People with hearing aids often have problems with indistinct recorded messages
- Lack of accessible toilets
- Wheelchair access in shopping areas
- Thatcham Football Club refuse to provide a covered area for wheelchair users
- Time constraints on equipment hire, eg if going to family for the weekend need to pay for a day's hire
- Understanding NHS language and abbreviations. E.g. CCG

- Communication aids are necessary for children and should be more accessible. Our 9-year-old child cannot talk. We do not have the money to pay for different apps (£300 - £400) to “try” and buy communication aids that can cost £1000’s

Transport

- There is a bus service to the rural areas. But only 3 buses a day at not the most convenient of times / within the school day
- I am registered blind and pavement parking makes walking unsafe – Council and police response poor
- In supermarkets and shops, it’s hard to find things because all the signs are written rather than any images, for people who can’t read
- I have to travel to Swindon for hospital appointments, couldn’t consultant hold clinics at WBCH?
- Barrier to getting Blue Badge – I receive a care package but no badge
- Main challenge, transport funding cuts, creating isolation
- Lack of accessible parking in many car parks
- Drivers often not aware of disabilities, e.g. don’t put ramp down
- Drivers make excuses not to take people with disabilities
- Buses to college no good I need to use ‘mum’s taxi’
- Can’t use public transport unless book 24 hours in advance
- Bus drivers don’t park close enough to the pavement
- No drop curbs and some pavements rough especially on A4 between Church Hall and ½ mile East
- Incident: bus driver not giving people time to sit down
- Drop curbs not lined up
- Handy Bus difficult to access
- Bus drivers don’t give people a chance to sit down (Jet Black 1). As a result, passengers have fallen over
- Bus drivers drive past even when a disability is visible
- No late-night buses generally and assistance service problematic
- Lack of public transport in West Berkshire, ie Compton has limited service. Does not help with employment
- Loss of companion bus passes for carers
- Road crossing between College and Tesco’s
- Care home, hospital transport, changing rules. Fewer groups eligible for hospital transport (need PIP, DLA, blue badge?)
- I have trouble getting on and off with my trolley walker

- My husband was dying cancer. Had to get to RBH. Not nice conversation to book in. Dr said could have transport. Person on the desk said needed to fit box. 'Isn't dying enough?'
- I tried to get dad on wheelchair taxi but said couldn't take that wheelchair. Said had been on course, needed to be hard back, and attachment points. Means everyone will have to change their wheelchair.
- In Mortimer there is no transport on Sundays and Bank Holidays, they have been removed
- There are two sides to the issue re bus drivers. It is true that some drivers are rude and inconsiderate, however (a) so are passengers and (b) the employer puts constraints on the driver which often puts makes for difficult situations for him. Eg I was a bus driver in Bristol for two years and was allowed 28 seconds for a stop. Taking on a woman with a pram and toddler takes over the allocated time.
- There are overgrown hedges around bus stops
- Lack of wheelchair taxis
- Cannot use disability bus pass until after 09.30 – this is a disadvantage for hospital appointment
- No transport to WB Calcot offices
- Booking a train – passenger assist – ok but not accessible at a times. Eg Thatcham station unmanned on Saturday after 12 noon.
- Additional dropped kerbs often do not marry up
- Cars blocking pavements
- Public transport from Cold Ash v poor
- Hospital transport – I was recently told it is NOT available to Personal Independence Payment / Disability Living Allowance recipients and Blue Badge holders in the future
- Buses have a seat where people with disabilities should have priority. However, they are more often occupied by people, mostly women, and most of them use the seat for their shopping and don't move although they can see you need the seat
- Disabled parking spaces are often taken over by builders skips and equipment or mobile X-Ray units
- Trains – help 24 hours for those in a wheelchair
- Trains must be booked 24 hours in advance for wheelchair users if a ramps needed
- Wheelchair users – booking a taxi is a nightmare – availability, cost, refusal to take – West Berks are investigating incident where a taxi driver refused to take my dad in a wheelchair
- Trains – access for people with disabilities, ie not have to go to the next station to have help to get off the train with the right help
- Bus and taxi drivers need training in the requirements and show of respect to people with disabilities
- Large wheelchairs don't fit on buses
- Langley Hall Drive is often blocked by waste operatives' replacements of bins

- Taxi drivers are reluctant to take wheelchair users and it is difficult to get one. Many lifts are too small to get a wheelchair as well as a carer in
- Not enough disabled parking at RBH and you must enter the car park to find out disabled spaces are full – you then must pay to get out
- Thatcham football club - not disabled friendly - no parking and no covered area for wheelchair users. Toilet has a slight step too

Social

- Being aware what's out there
- Need for age appropriate activities for people with high needs
- I'm recently bereaved and loneliness
- Difficult meeting new people and getting to know them
- Age appropriate activities needed for those with complicated needs
- No drop-in centre for vulnerable and lonely people
- Isolation in rural communities

Education

- Alleged 'bullying' behaviour towards people with a learning disability from other students
- Newbury College: more activities with animals, more computers that work, more sports activities, eg football, longer lunchbreak

Financial

- People should be assessed on what they can't do not what they can do for PIP, because people have occasional good days and fluctuating difficulties
- DWP fit you into a category in order to tick a box. You are known by your diagnosis
- PIP waiting times for assessments and appeals cause real difficulties
- Personal assessment
- Disability reduction on Council Tax is hard to get
- The threshold for earnings is too low
- Cancellation of home to school transport for anyone with SEND
- Sovereign Housing not always helpful
- Expenses difficult that come with living with chronic and serious illness

Technology

- WBC rely too much on people having access to email for information. Not everyone has or can use a computer
- Internet access for people on benefits – may not have / often do not want to learn (as they fear looking silly).

- The council expect that everyone has access to or own a computer for information
 - Carers Rights day needs webinar access, so I can attend
 - Breakdowns in communications for GP urgent referral to optician cause delay
-

Services / Facilities

- Assisted bin collection, will go to back door. But [another group said] people emailed about it and then had a large form to fill in and it takes 12 weeks to get in place
- Voluntary sector not well supported financially so people with a learning disability are losing out
- The geographical spread of the area makes it difficult to provide services to individual families
- Thatcham MEP - so difficult to get an appointment as a carer. If the carer becomes ill things can fall apart
- There is no home help for occasional need. I am told to go to hospital, but I can be looked after at home when needed
- Bins – family of five – larger bins but the same as other
- West Berks complaints procedure is awful – you get no results.
- Children’s wheelchair clinic – a long wait to be seen; a long wait for repairs; a reluctance to give wheelchairs at the level needed resulting in people being restricted and isolated
- Bins are needed if an adult is incontinent
- Need for changing facilities for older children who are incontinent in public places
- Information is not available re voluntary service
- Making sure there’s information about where to get support. E.g. cancer charity could give lifts but only found out about it ad hoc with 3 Frogs

Other

- Need more comprehensive ombudsman over and above SEAP (adult social care)
 - Raise awareness of how local councillors can help
-

Appendix 3

What does wellbeing mean to you?

- Wellbeing is being happy, having boyfriends, a quiet time, good food, listening to music, going to college and help from learning support assistants. Being with animals, sport and football
- Healthwise it is healthy eating, more exercise, going outside and being active and being active inside (sports)
- Challenges to wellbeing are too much sugary stuff, not seeing family every day and not wanting to go for walks.
- Pain management
- Being able to get out and about and meet people
- Being mobile
- Accessing what I need when I need it
- Being able to access sports/exercise venues
- Kerbs, bus companies, more parking
- Not being dizzy, able to breathe
- Being supported by those around us, professional and personal
- See same GP each time
- Feeling safe and happy in your own home
- To be able to live life as you want
- To feel comfortable
- To have help when you need it
- Not to feel or be threatened by others
- Independence
- Helpful neighbours / community support
- Links to others and wanting to be part of a wider community

Appendix 4

What would you like to see to improve your wellbeing?

- More resources for CTPLD (Community team for People with a Learning Disability) - only two staff left!
- I don't know about the different groups that are available
- Better training for frontline staff – empathy
- Funding support to access groups, cost is a barrier
- Not feeling lonely or isolated
- More information about what is available
- Prompt access to treatment when you have a problem
- Not having to pay for physiotherapy
- Help with motivation to keep fit if you have a mental health issue
- More cycle/pedestrian paths where there are no cars
- Information in hard copy as well as on line
- To be able to carry on working
- To be able to manage my disability in everyday life
- Suitable time slots for activities, eg an autism hour for shopping
- Treating mental health and physical disabilities in a holistic manner
- Waste collection assistance for moving full bins over uneven ground. I called, emailed, filled in form but nothing for three months
- More accessible clubs/activities
- Supermarket phone for shopping where cannot access the internet

Appendix 5

How might innovation and technology help me in the future?

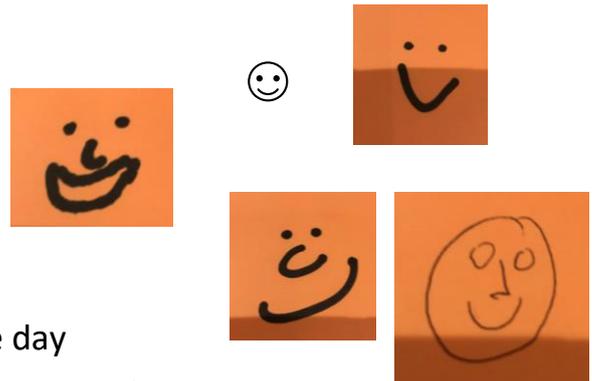
- Improved customer digital systems eg can't book wheelchair space online
- Access to volunteers to show people how to use Google/iPad etc. in my home
- Training on the use of mobility scooters
- A lot of technology available but need help in choosing which is the most appropriate for the person. Difficult to keep up with advancements. Need a technology advisor
- Linking Eye Gazer with the internet to enable Skype and email and communicate with friends
- More human voice technology
- Trains with ramps to not have to book.
- Car club vehicle that can take a wheelchair
- Automated vehicles

- Bring back the Welcome Pack when move to the area, on line with dial in for more information
- Supposed to be one dial in number, someone answer the actual phone
- Skype GP appointments
- Find my Phone so I know where my child/partner is
- GP app on phone
- Disabled persons app: parking locations and availability of disabled spaces, public transport appropriate stops, toilet facilities/with hoist, shopping area, etc
- Email facility for my GP
- An exercise program with specific exercises for me – a lightweight box.
- Tablet talking reminder, text, call
- Emergency network of volunteers for support in a crisis
- Shopping app
- App to give information if appointment is on time/running late
- Communication device so that my daughter can communicate with me that doesn't cost £20 - £30k
- Alexa link to call emergency services
- Pads for older people to engage/entertain to reduce isolation
- Heating dials back lit as sight impaired people can't see to adjust
- Electricity and Gas meters too small and often located in difficult situations
- More companies to send audio disks rather than letters
- Larger fonts on packaging
- Bigger number mobile phones at affordable price – Vodafone a local company that could sort
- Scales that read out measurements
- Where pavements/kerbs have knobby bits are not obvious (most) could use lights or colours.
- Coloured bicycle lanes as difficult to see what is pedestrian and what cycle
- Supermarket phone for shopping where cannot access the internet
- Picker gadget/revolving shelves where cannot reach shopping shelves
- Signage with pictures as well as words
- Smart houses tailored to individual needs

Appendix 6

What people thought about the day?

1. Very interesting 😊
2. Excellent day 😊
3. I was very happy what came out of the day
4. Very helpful, food great, opportunity to offer good and bad
5. It was really good and interesting. I'm going to feedback to the It's My Life group
6. Good day. Good to be listened to. Let's hope these things are worked out.
7. Really good. Proves that 'conversations' and networking equal a great sharing of information which is needed. Great, into sharing.
8. Good time keeping.
9. Excellent participation by ALL
10. Great lunch
11. Good networking
12. but quite long!



Rate this service provider by circling the appropriate number

Poor 1 2 3 4 5 Outstanding

Summary of your experience (a few key words)

Really good to hear the ideas and promises west berk's council + west berk's CCG have but feel they don't have a realistic understanding of how difficult services are

Please explain here

Tell us more about your experience
(We would like to hear what was good as well as what could be improved)

EXPLAIN TO AUDIENCE WHY THERE IS A HEARING LOOP. THEN MAKE SURE ANYONE WHO SPEAKS HAS A MICROPHONE OR THAT THE QUESTION OR STATEMENT IS REPEATED. OTHERWISE VERY WORTHWHILE DAY!