



Staying healthy with a learning disability: accessing Annual Health Checks



May 2017

What was the project about?

The Annual Health Check scheme is for adults and young people aged 14 or above with learning disabilities, who need more health support and who may otherwise have health conditions that go undetected.

Healthwatch Bucks commissioned Talkback to engage with people with a learning disability to understand their views on the Annual Health Checks.

Talkback is a user led organisation for people with a learning disability and autism. It achieves its aims through supporting people to express a real voice in choice and decision making and in creating safe and positive learning environments. Talkback is about choice, opportunity and respect for all people with a learning disability.

This project focussed on those people living independently, with family or with minimum support rather than in supported living accommodation. The project looked at four areas:

- Awareness - what do people know about the Annual Health Check
- Communication - how are people told about the Annual Health Check
- Barriers - why don't people attend the Annual Health Check
- Experience, outcome and evaluations - what people thought about the Annual Health Check

Why did we do the project?

In Buckinghamshire, there are an estimated 5870 adults with learning disabilities, aged 18-64 years. Whilst life expectancy is increasing for people with mild learning disabilities, the mortality rates among people with moderate to severe learning disabilities are three times higher than in the general population (see Appendix A for more details).

We know that in Buckinghamshire adults with learning disabilities, particularly those living independently, are not accessing their Annual Health Checks. The figures for 2015-16 for Chiltern Clinical Commissioning Group (CCG) are 39% and for Aylesbury Vale CCG are 42%. This is below the National Average (44%) and there is an additional challenge to achieve the 75% national target by 2020.

We also know that accessing the Annual Health Check provides many benefits for people with learning disabilities. It often uncovers treatable health conditions as well as serious illnesses, such as cancer, which could be treated if found at an early stage. The Annual Health Check is also a chance for the person to get used to going to their GP practice, which reduces their fear of going at other times.

What did we do?

Talkback talked to a total of 45 individuals with a learning disability between January and March 2017. Talkback met them in locations they were familiar with, such as day activity provisions. For example, Social Link in High Wycombe and Sees the Day in Aylesbury. They also did 1:1 consultations, home visits and telephone interviews. This included individuals from ethnic minority backgrounds. Visits took place in both north and south Buckinghamshire.

To ensure people were able to contribute to this consultation honestly and freely, Talkback engaged with people using the following creative approaches: Paper rolls, photos and pictures, questionnaires, body maps and personal statements.

For further samples of feedback see Appendix B.



What did we discover?

Awareness



We found that:

- Most people didn't know what an Annual Health Check was and there was confusion around the name. Respondents said that it should be called something easier to remember. In particular people did not understand the word "annual" - out of the 9 people who knew they had attended one, one person understood the word annual.
- Most people weren't sure if they had received an Annual Health Check - out of 45 people 9 people knew that they had attended one. Those that used a private GP had not had one as far as they were aware. Annual health checks are supported by the NHS not private routes, so this may explain the difference. It is recommended that everyone is registered with an NHS GP.
- People confused the Annual Health Check with other medical checks. Those over the age of 40 confused it with the NHS Health Check. Others were confused by other checks that they had (medication reviews; diabetes; specialist appointments). One man had visited the doctor about a spot on his back and thought that this was a health check.
- People did not understand the purpose of an Annual Health Check - more than one person said that they did not need to have one as they were fit and well.

Communication of the Health Check



We found that:

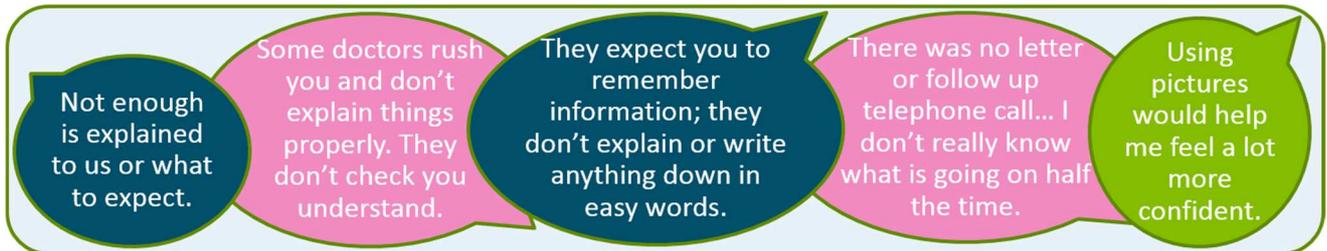
- Communications about Annual Health Checks were not consistent. One person had asked for one. People in the Chesham area appeared to have slightly higher awareness of the Health Check - one man said he was telephoned by his surgery and then was sent a letter, which he thought was excellent.
- Many people relied on support workers or relatives (some of whom were elderly) to handle any correspondence - and some even had to turn to neighbours. And many relatives did not share the information with the addressee.
- There was no single way identified to communicate the Annual Health Check properly. Many people disagreed on whether it was good to be sent a letter or not. Most people that lived independently said that they thought it was good to send a text in easy words; that way they would remember it and could make the words bigger so it was easier to read. Some people said that they preferred a phone call and then a letter sent afterwards so as they didn't forget the information.
- Everyone told us they would like all communication to be in easy read with pictures. Some thought that this would encourage their families to let them read the letter, as if it was easier to understand families might be more encouraged to share the information.
- For those people that did receive a letter, they said that it wasn't in easy read so was difficult to understand. This caused a real problem for those people that live independently as not being able to understand a letter makes them stressed and more anxious. "I can't read letters when they arrive, I have to wait until my floating support comes and they help me to understand it."

Barriers

People spoke freely about the barriers around both attending an Annual Health Check and going to the GP surgery.

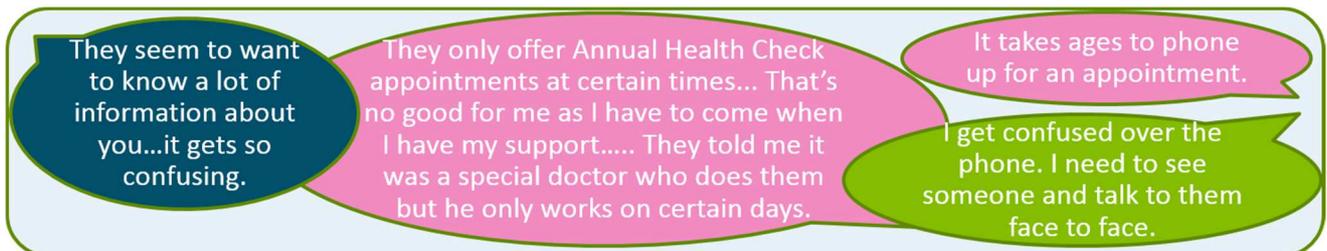
There were some main themes that emerged:

Communication (general)



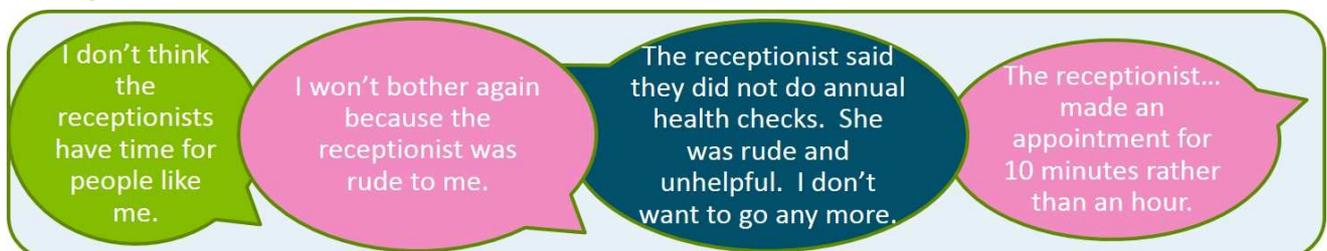
Communication is a key barrier for people with a learning disability in accessing Annual Health Checks as well as other health appointments. This impacts significantly on the ability of those with learning difficulties to manage their health. Everybody we spoke to said communication needs to be improved to make GP services more accessible.

Difficulty in making an appointment



Many people said that a huge barrier was being able to make an appointment. People said that it put them off going to the doctor as it was so difficult especially if you needed an urgent appointment. People explained that they got confused about which buttons to press on automated systems. Some people told us that because of the barriers around making an appointment via telephone, they can't make an appointment at all until their support is available as they don't like going out. This could mean waiting nearly a week until they see their support worker who can either telephone the doctor's surgery for them or go along to make an appointment leading to delays in treatment.

Reception staff



Many people said that they thought the reception staff didn't understand their needs. They felt that reception staff could be quite brusque and sometimes seemed not to know about Annual Health Checks. This put some people off attending an Annual Health Check.

Waiting times



Waiting times are a big issue for lots of people, especially those people with autism who said that they start to get very anxious and stressed which can bring on other symptoms. One man said that if the appointment is running late, he needs to get out and walk around or do something to occupy himself as he gets so stressed. He worries if he goes outside in case he misses his appointment which creates more anxiety.

Support



Most people said that having support to attend a health check was really important. This was especially so for those people that live independently as understanding any health communication and managing a health need can be very difficult. It also meant that an appointment could be delayed until support was available which could result in a delay in necessary treatment. Some people did want to demonstrate that they did not need support so as to appear independent - it was clear on questioning that they did not understand all the information they had received from the GP.

Lack of understanding regarding general health



Many people think that if they are well, there is no need to go to visit the GP. People said that they didn't see the point in having an Annual Health Check if they were well. However, on speaking to people about day-to-day illnesses and specific conditions like diabetes and asthma, it was clear that people didn't understand how this affected their health and quite what it meant. One lady told us that following her Health Check she was told her cholesterol was high. She had no understanding what this meant. She lives independently and nobody gave her any easy read information to help her understand how she should manage it. She said "I felt scared; I had never heard that word before. There is nobody to help me. I didn't know how to find out about it". Nearly everybody we spoke

to said they would listen to what their parents told them as to whether they needed to go to an Annual Health Check.

Fear



Fear was a huge barrier for people. One lady who lives with her father explained that she had never heard of any type of health checks. She is 50 years old and didn't know anything about having regular checks such as a mammogram etc. When talking about these things she became very anxious and worried. She raised this at home with her father who told her she did not need to worry and didn't need any checks as there was nothing wrong with her.

Mental Health



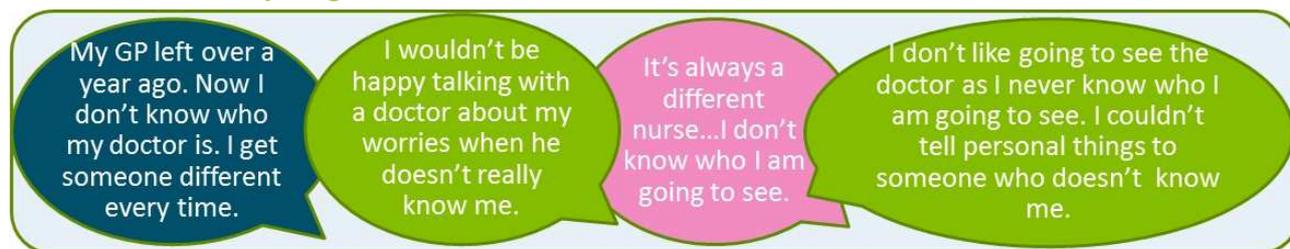
Some people with learning disabilities also had a mental health condition, which made the process of accessing the Annual Health Check even more complex for them. Being unable to book an appointment and being asked to call back was a particular problem.

Environment



Some people struggled with the waiting room environment - it could become quite noisy and the waiting rooms could feel crowded with chairs close together.

Lack of continuity/regular staff



Many people with learning difficulties find it important to build trusted relationships. It is particularly important to have someone who understands their needs properly - and they felt that someone who did not know them or a locum would struggle to do this. One lady who lives with minimum support said that she 'couldn't stand her doctor'. "The doctor talks to me like a child and she broke my trust and confidentiality by telling my Mum things that she wasn't meant to. She said it just slipped out by mistake. I don't want to see her again." (She is 22 years old).

Demographic insights

These barriers appeared to be most challenging for those people living independently who had little or no support in managing issues such as fear and communications. Booking appointment times was a particular problem for this group as they were often restricted as to when their support was available and had trouble getting an appointment to coincide with this. People with minimal support expressed that they experience real problems with making appointments and seeing a doctor at a time when they can go with their support. Whereas, people who live with families are better supported to attend appointments and the biggest barrier appears to be "parental/family control" and the lack of shared communication.

Experience



For people who live independently or with minimal support, the experience tended to be a positive one. Their experience very much reflected on whether the member of staff was kind to them and explained things effectively. For people who live with family, evidence suggests that they have a better understanding of whether it was a positive or negative experience but this is influenced by the thoughts and views of their supporter.

- **Pre-questionnaire** - Everyone said that they had not received a questionnaire prior to the appointment. “I never received one of those.” “If I did get one of those, my Mum didn’t show me.” This is currently an optional tool sometimes given out prior to the appointment but often used during the health check.
- **Waiting times and cancelled appointments** - Most people did not have to wait very long for their appointments, but some found it difficult to handle when they did “I had to wait 45 minutes for my appointment... I was about to walk out”. Cancellations were also rare, but when they happened caused considerable consternation. One man was left a voicemail message, but because his family checked it for him when they visited, did not get it on time and travelled to the surgery to find his appointment had been cancelled “This upset me and made me really stressed”.
- **Interaction** - People were generally positive about how they had been treated during the Health Check but could have received more support around understanding. One man who lives independently said “He seemed to ask just bits and bobs of questions. He spoke to me like a normal person though...some don’t do that.”. Another lady who lives independently said “The doctor spoke clearly but didn’t use any pictures which would have helped me.”
- **Process** - There were considerable variations in reported length and content of the Health Check. Not everyone was asked to do a urine sample and a blood test - and some were asked to arrange one themselves which they found challenging. To raise awareness of the Annual Health Check, the Mencap document “About having a Health Check” was referred to. A couple of people told us that their Health Check wasn’t like it is described in the booklet. One man said “Well, it wasn’t like you’ve just explained...mine didn’t last that long and they didn’t check all those things.”
- **Health Passports and Health Action Plan** - These are used to help people with learning disabilities and medical staff to keep track of their healthcare. Only one person we spoke to said that the doctor wrote in their Health Passport and gave them a Health Action Plan. Everybody we spoke to said the doctor didn’t ask to see a Health Passport.
- **Ending the check** - Most people we spoke to told us that they weren’t sure what happened at the end of the Annual Health Check. Some people recalled being given a piece of “printed” paper but couldn’t recollect what it said. For those living independently or with minimum support, feedback suggested that due to a lack of support people struggled to process and understand the information “I don’t remember being given anything, or if they did they gave it to my support. “The writing is small, I can’t read it”.
- **Follow up** - A few people from all the groups told us that the doctor had organised further tests. “They found out I was diabetic...I am on a special diet now.” “I was told to drink more water. I have to come back for a blood test.” Only one person reported that the GP asked about self-examination and demonstrated how to

undertake a breast check. This resulted in a lump being detected leading to further tests. Only a few people told us that they had to have ‘follow up’ treatment.

Recommendations

It is clear that there is still a lot of confusion about the Annual Health Checks starting with the name - and that there are still considerable barriers to accessing it. These recommendations are focussed on enabling those with learning disabilities, who often do need support from families, carers and support workers, to navigate this process as independently as possible.

- Change the name of the Annual Health Check to something more memorable, unique and meaningful
- Ensure consistency with the name to help raise awareness
- Raise awareness of and explain the need for the Annual Health Check more widely. Information should be targeted both at those with learning disabilities and their relatives and support workers and as part of this. Families should be encouraged to discuss health issues with relatives with learning disabilities and to support them in managing their own health rather than doing it for them
- For each patient with a learning disability identify a preferred method of communication and ensure this is used consistently across services
- Identify a special number to ring for appointments for people with learning disabilities so that they do not have to deal with automated booking systems
- Ensure staff are aware of Annual Health Checks and all other services available within the surgery
- Where possible carry out all tests including NHS Health Check during or at the same time as the Annual Health Check
- Ensure reasonable adjustments are available for people with learning disabilities (see Appendix D)
- Provide information in easy read format wherever possible and in particular on the Annual Health Check; for the Health Action Plan; and for the pre- Annual Health Check questionnaire where the latter is used
- Promote and encourage use of the Health Passport and the Health Action Plan with surgeries, families, carers and individuals
- Ensure that all staff receive learning disability awareness and communication training including active listening; checking of understanding, avoidance of medical jargon and taking time
- Work with people with a learning disability to help create a best practice guidelines tool and use to assess each surgery to raise standards and promote consistency
- Use experts by experience to evaluate/monitor quality and delivery of Annual Health Checks

- Produce a simple Easy Read evaluation tool for people to complete following the Annual Health Check
- Identify ‘flagship’ surgeries across the county and share learnings across all surgeries as to promote good practice and raise consistency
- Ensure that waiting times are managed more effectively for those likely to experience anxiety such as people with a mental health condition or autism

What are we doing to ensure there are delivered?

We will pass these recommendations to the Clinical Commissioning Group and work with them to understand how they will be taken forward by them or with individual surgeries as appropriate.

Report drafted by Talkback for Healthwatch Bucks

Appendix A: Background Information

In Buckinghamshire there are an estimated 5870 adults with learning disabilities, aged 18-64 years, of those:

4,590 have moderate learning disabilities (MLD)

1,120 adults are estimated to have severe learning disabilities (SLD)

160 people have profound and multiple learning disabilities (PMLD)

Whilst life expectancy is increasing with people with mild learning disabilities approaching that of the general population, the mortality rates among people with moderate to severe learning disabilities are three times higher than in the general population (Tyrrer 2009).

The types of health needs that are greater within the learning disability population include:

Cancer; in particular, gastro-intestinal cancers

Coronary heart disease; the second highest death rate in people with a learning disability

Dental issues; more likely to have gum disease, tooth decay

Diabetes

Epilepsy; 33% of people with learning disability have epilepsy compared to 1% of the general population

Gastro-intestinal problems; constipation, Gastro oesophageal reflux disease (GORD)

Obesity; more noticeable in those with mild learning disabilities

Respiratory disease; this is the main cause of death in people with learning disabilities

Sensory impairments; sight and hearing problems are common

Swallowing and feeding problems

People with a Learning Disability are less likely to receive regular health checks and access routine screening. Additionally, people with learning disabilities are likely to find it more difficult than others to describe their symptoms, thus it is more difficult for healthcare workers to identify health needs among people with learning disabilities which leaves some problems unrecognised. This “diagnostic overshadowing” may lead to some health care professionals not investigating early enough as they rationalise new symptoms as part of the learning disability rather than explain new symptoms particularly with mental health issues (Mason 2004).

Appendix C: Case studies

CASE STUDY 1

One young man who lives in a shared lives scheme said he had heard about the Annual Health Checks. He was told that his surgery was carrying them out so he tried to make an appointment but has not been successful.

When he telephoned the surgery, he spoke to the receptionist and asked if he could make an appointment. The receptionist told him that the surgery didn't do them which made him confused and unsure what to do or say.

He asked a friend if he could help him. The friend agreed and spoke to the receptionist and explained that they had heard that the surgery was offering Annual Health Checks. The receptionist insisted that they weren't doing them and that she didn't know what they were talking about. "She was rude and unhelpful".

Because of this experience, the young man no longer wishes to attend an Annual Health Check. He said "I don't want to go any more, it has put me off".

CASE STUDY 2

Lorelle* lives with her Mum. She said her Annual Health Check went very well.

"Well, actually, the first time we went, the receptionist had messed up and not made the appointment long enough so we had to make another one and go home. Mum wasn't very pleased as she had paid for a taxi. The next time we went, it was very different; we didn't have to wait very long at all. I saw a special doctor who visits the surgery to do the Annual Health Checks. She was very good....she understood me. A lot of people just speak to Mum but she spoke to me too, explaining everything. She was marvellous! She made a note of everything and asked me lots of questions and did lots of tests. She asked to see my Health Passport and wrote down my blood pressure. I have to go back for my blood test as the nurse wasn't there but I did a urine test. I would go again...it was good. I was there for an hour.

I panic when I see a letter from the doctor or hospital, I think there must be something wrong or that I have done something wrong and I get scared. I try to ignore it, so I put it down somewhere and try to forget all about it. It would help if I could understand the letter, that would help my stress levels. It's very hard for people like me, living independently with lots of things I can't cope with or don't understand.

CASE STUDY 3

Gary* lives independently with minimum support. A support worker visits him once a week for 3 hours most Thursdays. He said he had a real problem trying to make his Annual Health Check appointment. He had to wait for his support worker to go with him to make the appointment and then there was a further problem trying to get a Thursday appointment at a time that was convenient for everyone.

The appointment didn't go very well. He had to wait over 30 minutes in a busy waiting room. Since his doctor left 18 months ago, he no longer has a regular doctor so didn't know who he would see. He explained how he started to get anxious and worried before going in for the check "the longer I sat there, the more I started to panic about things. It isn't good for my mental health." He chose to go into the appointment alone as his support worker is a female and so didn't think it was appropriate for her to join him. The doctor asked a few questions and did his blood pressure. On leaving he was given a "print out" for a blood test. The doctor explained that the nurse wasn't available in the afternoons so he would either have to return on another day or go to the hospital for the blood test. The appointment lasted for twenty minutes.

Gary decided it would be best to go straight to the hospital with his support worker rather than try to rearrange another appointment at the surgery.

CASE STUDY 4

One man said he lives with his family and they encourage him to be "one of the boys" and so he spends a lot of time telling everyone that he is "building, plastering, painting", "working in London" with his dad and "getting on with things" with "no sleep" or rest. He said he knows when other people are in pain but as a "bloke" he wouldn't admit to any personal medical problems.

He is a very assertive young man and he sees himself as being able to do many things independently but the reality is that he does need support and can put himself in vulnerable positions because of his "can do" personality. When it comes to taking care of himself, he feels that eating and drinking (in abundance) is how he can sort himself out.

On speaking to him about going to the doctors, he insists he is capable of going alone; that he feels confident to go without support. However, it is clear that he would need extra support to have things explained and easy language used. He is very much a "yes" man and so can appear more capable than he is.

Appendix D: Reasonable adjustments

- Arrangements to minimise waiting times
- Provision of quiet or safe waiting areas where possible
- Identification of a named doctor (or nurse)
- Provision of easy read information
- Automatic provision of longer appointment times to give additional time to enable extra explanation to take place, for example around medication
- Flexible appointment times for appointments (a time when the supporter/carer is free to take the person)
- Clear explanations of any medical words or jargon

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Address: Healthwatch Bucks

6 Centre Parade,
Place Farm Way,
Monks Risborough,
Buckinghamshire
HP27 9JS

Phone number: 0845 260 6216

Email: info@healthwatchbucks.co.uk

Website URL: www.healthwatchbucks.co.uk

Twitter: @HW_Bucks

Facebook: HealthWatchBucks

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