

# Learning Disability Annual Health Check Engagement

A report into the experiences of people with learning disabilities accessing annual health checks







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# **Healthwatch County Durham**

Helps you and your family get the best out of health and social care services in County Durham. We are independent and powerful, we make health and social care providers answerable to you, the people who use their services.

## We listen, we advise and we speak up

We listen to patients of health services and users of social care services, along with their family members or carers, to find out what they think of the services they receive.

We advise people how to get the best health and social care for themselves and their family.

We speak up by making sure the consumer views are heard by those who provide health and social care.









We advise We speak up



## **Executive summary**

As part of the 2016/17 work plan, Healthwatch County Durham chose to investigate the uptake of health checks by people with learning disabilities. Improving the health of people with learning disabilities was a clinical priority area for both North Durham and Durham, Dales, Easington and Sedgefield Clinical Commissioning Groups. Increasing the uptake of annual health checks was one of the measures identified to help achieve this.

NHS England has stated that it is committed to ensuring that people with learning disabilities receive the right care in the right settings, with the right support and this is one of their national priorities. They want to understand and reduce health inequalities amongst this group of society.

According to NHS England in 2013/14 the proportion of eligible adults with a learning disability having a health check in County Durham is 51.8% which is lower than the regional average or 56.6% and higher than the England average of 44.2%. In 2013/14 there were 2654 (18+yrs) people recorded on practice registers with a learning disability.

Healthwatch County Durham were keen to understand if there were any barriers stopping people accessing health checks or if there was any good practice they could identify and share which would increase the numbers of eligible people accessing annual checks. Therefore it was agreed by the Healthwatch Board that this would be included in the workplan for 2016/17.

#### Research tells us:

- people with a learning disability have lower life expectancy than the general population and are more likely to have undiagnosed long term conditions and musculoskeletal problems (Disability Rights Commission. Equal Treatment: Closing the Gap; 2006)
- regular health checks for people with learning disabilities often uncovers treatable conditions. Most of these are simple to treat and make the person feel better, while sometimes serious illnesses such as cancer are found at an early stage when they can be treated.
- annual health checks enables the person with a learning disability go to their GP practice and have aspects of their health checked. It also is an



opportunity for them to talk about anything that is worrying them in relation to their health and wellbeing.

To fulfil the brief of the project we undertook a number of different activities, including:

- utilising some existing events and groups to gather the views of people with learning disabilities first hand
- sending out an on line survey to a wide range of organisations who support people with learning disabilities asking for service users to tell us their experiences
- speaking to eight providers of care homes for people with learning disabilities about their perspective of how the service works
- contacting GP surgeries to ask about their experience of providing annual health checks

In total we received 100 completed surveys from the events and on line surveys.

The information we gathered identified that:

- 54% of the people with a learning disability who completed a survey had received their annual health check, which compares to 52% in the NHS England 2013/14 survey
- all of the care home providers confirmed their service users had received their annual health check
- various ways were utilised to contact patients by GP surgeries to offer a health check and some examples of good practice which help to encourage uptake.

In conclusion, we have made some recommendations for the CCG's to consider:

- All eligible patients should be contacted to offer a health check in an appropriate and user friendly manner. Any letters sent should be in an easy read format.
- GP surgeries should be encouraged to share best practice to maximise the uptake of health checks
- The use of peer groups to promote health check uptake should be encouraged
- Where necessary GP surgeries should consider using alternative venues to offer health checks which may be less intimidating for people with learning disabilities who are reluctant to go to surgeries.



## Background to this work

The learning disability health check was originally introduced in 2008. The service was introduced in primary care and GPs were paid for this as a directed enhanced service (DES). It has been subsequently extended each year. Since 2010, the learning disabilities observatory has produced annual reports on the progress in implementing learning disability health checks.

The annual health check enables the person with learning disabilities go to their GP practice and have aspects of their health checked. It also is an opportunity for them to talk about anything that is worrying them in relation to their health and wellbeing.

During the health check, the GP or practice nurse will carry out the following for the patient:

- a general physical examination, including checking their weight, heart rate, blood pressure and taking blood and urine samples
- assessing the patient's behaviour, including asking questions about their lifestyle, and mental health
- a check for epilepsy
- a check on any prescribed medicines the patient is currently taking
- a check on whether any chronic illnesses, such as asthma or diabetes, are being well managed
- a review of any arrangements with other health professionals, such as physiotherapists or speech therapists

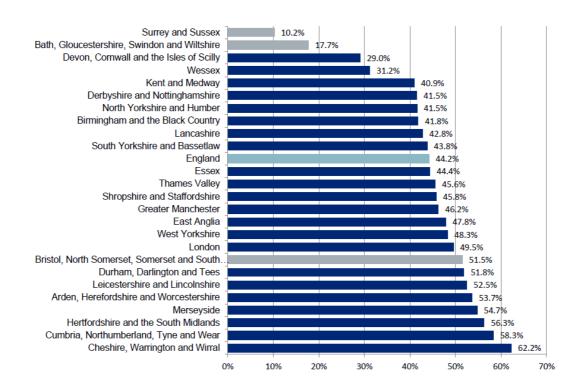
If the person's learning disability has a specific cause, the GP or practice nurse will often do extra tests for particular health risks. For people with down's syndrome, for example, they may do a test to see whether their thyroid is working properly. (NHS Choices)

NHS England has stated that it is committed to ensuring that people with learning disabilities receive the right care in the right settings, with the right support and this is one of their national priorities. They want to understand and reduce health inequalities amongst this group of society.

According to the Public Health England learning disability profiles for 2013/14, 51.8% of eligible adults with a learning disability received an annual health check in County Durham.



The graph below, produced by NHS England, shows the percentage of eligible people in 2013/14, by geographical areas, receiving an annual heath check.



## Why this work was necessary

People with learning disabilities are a diverse and vulnerable population with differing needs, often experiencing health inequalities. People with a learning disability have lower life expectancy than the general population and are more likely to have undiagnosed long term conditions and musculoskeletal problems (Disability Rights Commission. Equal Treatment: Closing the Gap; 2006)

Research shows that regular health checks often uncovers treatable conditions. Most of these are simple to treat and make the person feel better, while sometimes serious illnesses such as cancer are found at an early stage when they can be treated. We wanted to identify if there was anything that could be done to increase the uptake in County Durham.



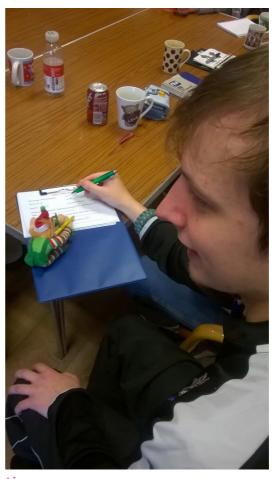
#### What did we want to find out?

Healthwatch County Durham wanted to discover if there were any opportunities to increase the uptake of health checks by investigating whether barriers existed for learning disabled people in County Durham which prevented or discouraged them from accessing an annual health check at their GP surgery. It was also seen as an opportunity to identify any particular good practice which could be shared across the county to increase uptake.

#### Who we listened to

We utilised some existing events and groups to gather the views of people with learning disabilities first hand.





Having fun at one of the events completing surveys



Our engagement events were launched on 24<sup>th</sup> October 2016 at the "Fulfilling Lives" event at New College, Durham where we spoke with attendees. 12 surveys were completed at the event. Following this, we met with a mixed group of people with learning disabilities ageing from 23-57 years at a support network called 'Options' on the 21<sup>st</sup> November 2016. This group meet regularly at Newton Aycliffe Leisure Centre. The 14 members of the group were able to share their views together.

We created an on line survey and the link to the survey was emailed out to a number of organisations such as Durham Voice, Investing in Children and the Children's Disability Team. A full list of organisations is on page 16 of this report.

To gather the views of some stakeholders we also spoke to eight organisations who provide support for learning disability service users in residential settings checking the uptake of health checks of 34 individuals who live in registered care homes.



Service users talking about their positive experience of health checks



## How we listened

We compiled a brief survey to find out if people with learning disabilities were accessing their health checks and if not why was this. The survey was carried out:

- face-to-face at engagement events and at a focus group
- as an online survey, through survey monkey

The majority of the responses received were from our on line survey.

As part of the survey we asked for the first part of their postcode so we could capture what areas had been covered and whether there were any significant geographical differences in the uptake of checks.

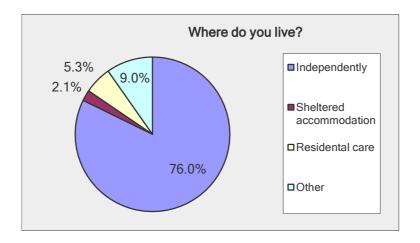
Survey attached at Appendix 1

## What we heard

We received 100 completed surveys which was a mixture of on line and through our engagement activities and:

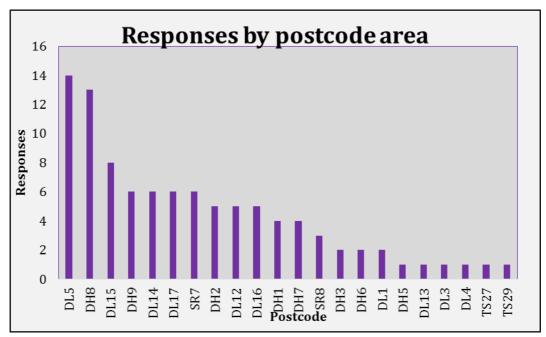
- 81% of service users who completed our survey had a learning disability.
- 98% were over the age of 18, these ages varied from 16 up to 78 years of age.
- the mix between male and female was a 50/50 split.

We asked where the service users lived, this was distinguished between independently/living with parents, sheltered accommodation, residential care or other.



From the nine that mentioned 'other' six lived in supported living accommodation, two in foster care and one did not respond.

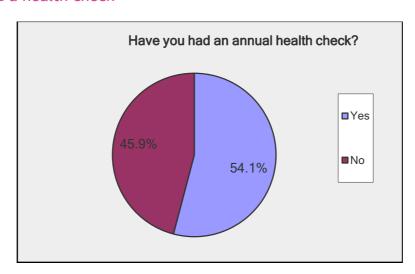




Above shows the postcode areas of where services users lived.

We asked if service users had an annual health check and if not why was this. Just under half had not received a health check. The common themes for not having a health check was because they did not know about them and that they had not been offered one.

Graph showing the number of service users with a learning disability who have had a health check





As well as the survey questions we also captured some comments from people with learning disabilities about the reasons they were not accessing health checks, although this only reflected the views of people living in the DDES area of the county.

One service user stated they only go to see the GP when they needed to, as do not like injections. Another stated that they were too anxious and scared and finally, one said that they wouldn't like a GP to touch them.



The last question in our survey was to ask if individuals would like some more details about health checks, 22 people requested this and provided their contact details. Healthwatch followed up all of these requests for further support or information.

We contacted a number of GP practices to ask what their experience was on the uptake of service users accessing health checks and also to see if they had any examples of good practice.

Three practices responded to our information requests. The responses included the following:

• all patients on the learning disability register are sent a letter/telephoned to invite them for a 30 minute annual health check which is normally done mid-September when the practice can also off flu vaccines.



- home visits are offered to learning disability patients if required to facilitate patient comfort of review in familiar surroundings.
- the practice offers flexible appointments/home visits if required.
- an example of good practice was a GP surgery who sent out a hand written birthday card with a reminder that the health check was due and
- booking three consecutive appointments for each health check to give plenty of time for the patient to be comfortable and ask questions.

#### Conclusions

It is apparent that there are some barriers to accessing health checks, from the comments received through the survey it was identified a large proportion of people with a learning disability are still not aware that they are entitled to an annual health check. In total 14 respondents told us they did not know about health checks and seven said they had not been offered a health check which is 21% of all respondents. There is a need for health care professionals to use appropriate communication techniques and methods to ensure they maximise the opportunity for patients to access this valuable service. For example, using an easy ready format in their publicity, sending it out as a reminder in a friendly format or offering checks in other venues

#### Recommendations

Following a review of our findings we would recommend the following actions:

- All eligible patients should be contacted to offer a health check in an appropriate and user friendly manner. Any letters sent should be in an easy read format.
- GP surgeries should be encouraged to share best practice to maximise the uptake of health checks.
- The use of peer groups to promote health check uptake should be encouraged
- Where necessary GP surgeries should consider using alternative venues to offer health checks which may be less intimidating for people with learning disabilities who are reluctant to go to surgeries.
- HWCD should monitor the data produced by NHS England to identify whether the uptake in County Durham is improving.



# Thank you

Healthwatch County Durham would like to thank those who have contributed to this piece of work. This could not have happened without service users/family members and carers giving us their comments.

Investing in Children
Durham County Carers Support
SENDIASS
DISC

14 Area Action Partnerships

**Durham Voice** 

East Durham College

Children's Disability team

Adult Services, Durham County Council

**Options Group** 

Peoples Parliament

Durham Dales, Easington and Sedgefield Clinical Commissioning Group (DDES CCG)

North Durham Clinical Commissioning Group (ND CCG)

GP Practices in the DDES area

Oswald House, Newton Aycliffe

Kaydar, Shotley Bridge

Accept Care Ltd



# Appendix 1

# Uptake on Health Checks

Do you have a Learning disability?	Yes 🗌	No 🗆	
Are you over 18?	Yes 🗌	No Age	
Male  Female	First part	of postcode	
Do you live Independently $\square$ Sheltered accommodation $\square$ Residential Care $\square$			
Other			
Have you had an Annual Health Check? Yes \( \square\) No \( \square\) Why is this?			
	••••••		
Would you like to be given more details on Health Checks? No $\Box$			
If yes, name and contact details			

