

**Annual Health Checks
for people with
learning disabilities**

Carers views

July 2022

Introduction

Healthwatch Sandwell (HWS) are the independent voice of the public in health and social care services in Sandwell. HWS carry out projects each year that are based on the priorities of the public, service providers and service commissioners. The purpose of the projects is to gather information to help inform and influence change in health and social care delivery in Sandwell.

Background

Access to high quality General Practitioner (GP) services is a fundamental right for all citizens in England, which is underpinned by the core values of the NHS to provide a comprehensive health service available to all. We expect it to be free at the point of delivery, available to everyone based on need and that patients will have positive experiences and be treated with dignity and respect. We expect effective, high-quality support to manage existing conditions and help us live healthy lives and people with learning disabilities and or autism should expect no less and receive the same service as everyone else. People with a learning disability generally have poorer outcomes in life, experience inequalities in access to healthcare and have significantly lower life expectancy (Care Quality Commission, CQC, 2016¹ & ²). National research, such as the Confidential Inquiry into the deaths of people with learning disabilities (CIPOLD) report³, reviewed the deaths of 247 people with learning disabilities and identified that 42% were classed as premature. The review attributes the deaths to delays or problems with diagnosis or treatment, coupled with problems identifying needs and providing appropriate care in response to changing needs.

The quality and effectiveness of health and social care given to people with learning disabilities and or autism has been shown to be deficient in several ways. Despite numerous previous investigations and reports, nationally, many professionals are either not aware of, or do not include in their usual practice, approaches that adapt services to meet the needs of people with learning disabilities and or autism. The CIPOLD study has shown the continuing need to identify people with learning disabilities in healthcare settings, and to record, implement and audit the provision of 'reasonable adjustments' to avoid their serious disadvantage.

Annual Health Checks

Evidence suggests that providing health checks to people with learning disabilities in primary care is effective in identifying previously unrecognised health needs, including those associated with life-threatening illnesses.

¹ https://www.cqc.org.uk/sites/default/files/20160505%20CQC_EOLC_LearningDisabilities_FINAL_2.pdf

² <https://www.cqc.org.uk/guidance-providers/gps/gp-mythbuster-53-care-people-learning-disability-gp-practices>

³ <http://www.bristol.ac.uk/cipold/reports/>

NHS GPs in England can be paid to undertake annual health checks for people registered with them who have learning disabilities and meet the eligibility criteria. They must be aged 14 and over and on the practice learning disability health checks register. People with autism without a learning disability are not included

The scheme also requires practices to undertake relevant training and to use a health check protocol agreed with their local commissioning organisations.

Purpose of Report

To seek the views of parents/carers of people with learning disability about access to GP appointments and annual health checks.

Objectives

- To listen to the experiences of carers of People with a Learning disability and or Autism about annual health checks for people with learning disabilities
- To listen to the to the experiences of carers of People with a Learning disability and or Autism about accessing GP appointments
- To share the feedback with key stakeholders
- To help shape equitable health care service for people with a learning disability and or autism - making necessary reasonable adjustments on an individual basis person centered way.

Methodology

We used a mixture of ways to collect feedback from carers in Sandwell. A survey to reach a wide cohort and a focus group and one to one conversations. The survey was disseminated to carers via request and through the support of voluntary sector organisations. We carried out one focus group and 3 interviews, to gain a deeper understanding.

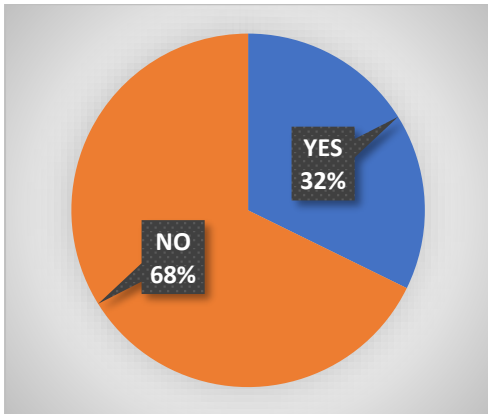
Findings

Although there were some positives experiences regarding the Annual Health check and accessing GP appointments, overall carers experience and views were disappointing. Some carers were unaware of the right to an annual health check for people with learning disabilities and some found it challenging to get face to face appointments with GP - often the barrier being with front facing staff.

31 Surveys were returned:

The findings have been grouped using the question headings from the survey. Any names used have been changed for anonymity.

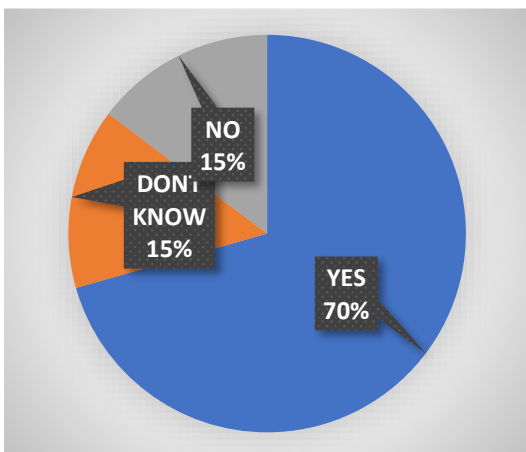
Are you offered a face-to-face GP appointment for the person you are supporting?



“I am told that I have to book a face-to-face appointment first and then the Dr. will decide if Harry needs a face-to-face appointment”

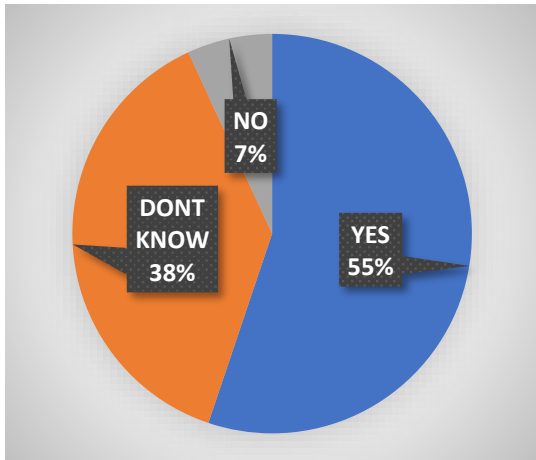
“I have been told that I cannot book an appointment for my son as he is over 18 and he has to give consent”

Is the person you support on the learning disability register at the GP practice?



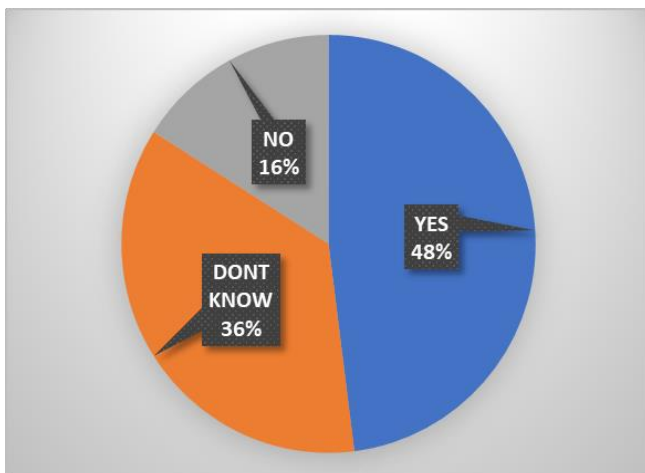
“I didn't know about a learning disability register. I have not been living here very long and it is difficult to get help for my daughter who is in a wheelchair - she needs help with everything - it is very hard looking after her”

Are you registered as a carer at the GP Practice?



“The Dr. I usually see if my son is ill knows that I am a carer but I don’t know if I am registered as a carer so unsure if I see another Dr they will know”

Does the person you support receive an annual health check?



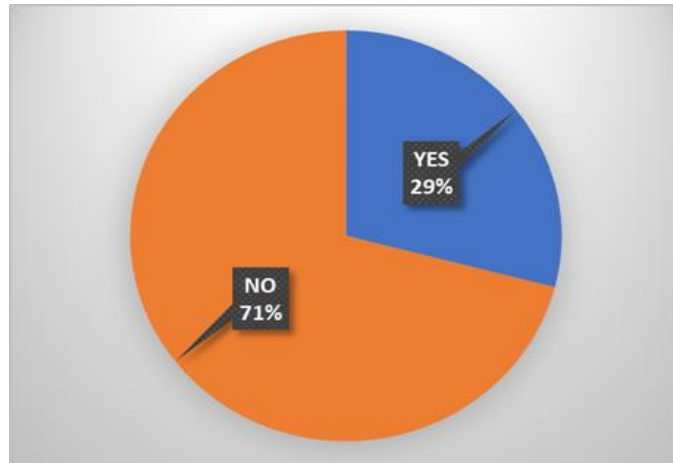
When I had a phone appointment with the Dr. when Sarah was sick, they asked me about Sarah’s weight and diet. Does that mean she had an annual health check?”

“I called the surgery to ask about an annual health check but they didn’t know what this was.”

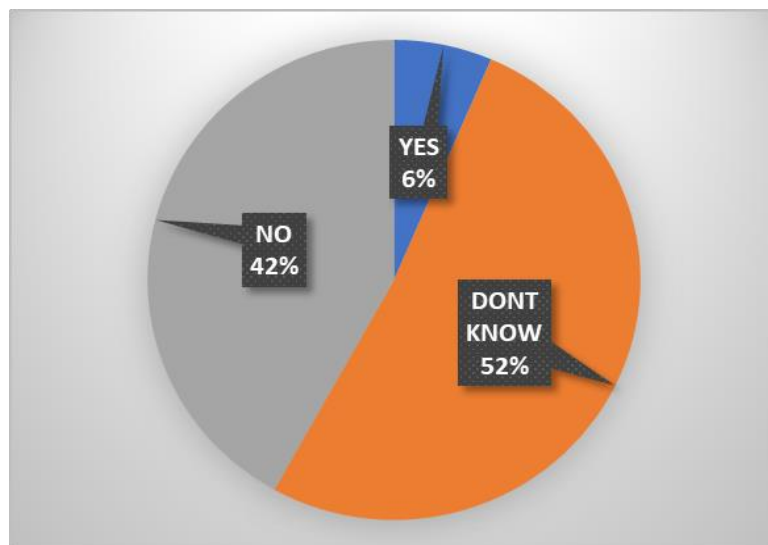
“I tried to book my son in for an annual health check but was told he would have to book himself as he was an adult. My son would not be able to do this himself so I was told he must write a letter to the practice manager saying that I could help him. My son cannot write though”

“My son does have an annual health check, but he cannot be weighted at the surgery as he is in a wheelchair. I must take him to another place. The day center helps me with this”

If the person you support does receive an annual health, check do you get a reminder to make an appointment from your GP Practice?



Does the person you support have a Health Action Plan?



“The day center have set up a little folder for my daughter. There is information about appointments and medication. There is a section about diet and healthy eating and a weight chart. They also help with other appointments and going to the dentist. I did not know if this is a health action plan but it is very good and gives me peace of mind that my daughter is be cared for well”

Findings from Focus Group

A focus group was made up of 5 parents of people with learning disabilities and or autism. Three parents had dependants with complex needs, one of which was a recent school leaver. Two parents had dependants with learning disabilities and autism, one of which had two dependants with learning disabilities and two dependents with autism.

“ My GP is very accommodating with appointments. I do have to wait ages on the phone but have no problem getting a face-to-face appointment. I think this might be as by daughter is palliative care”

“ Both of my sons had been poorly recently, and I needed to book an appointment where I could take both of my sons together as they appeared to have the same issues. I was told that I had to have separate appointments - one would be face to face and the other on the telephone. The appointments were within an hour of each other - this does not make sense”

“My daughter has just left school; the support at school was brilliant. Now I feel like I have no one. I have had to sort out a day service placement for her - they have been great, and I don't think I would have coped without their help. They have helped me get on to the learning disability register as I was not aware of this. They have also explained about the annual health check so I now have the confidence to talk to my Dr about this. I have a health action plan for my daughter that has been put together by the centre - just waiting for my Dr to do the annual health check so we can add that to the health action plan”

“When I had the invitation to join this group, I did not know what the annual health check was about, so I called my surgery to find out more. The receptionist told me that they do not do this. Explained that I had been informed that all people over the age of 14 with a learning disability should have an annual health check if they are on the learning disability register. The receptionist said they would find out a call me back. That was last week, and I have heard nothing since.”

“My daughter has complex needs. She is totally dependent on us for caring for all her needs. She has lots of medical appointments as she has quite a few things wrong. Our Dr is supportive. I have no problems getting an appointment and they always ask me if I am ok and can they help me in any way. My daughter has an annual health check. The surgery calls me up when this is due and have already made an appointment for us to attend. At the appointment they ask lots of questions including things about benefits and equipment we need for home to help us care for our daughter. They also check that medication is ok and have knowledge about all the other consultants that are involved in my daughter’s care. The only thing they cannot do is weight my daughter as she uses a wheelchair and is unable to stand up. They do arrange an appointment for me at the place where I can have this done.

When I hear other parents talk about how difficult the find accessing their Dr I feel very lucky that I have this support. All Drs should be offering the same standards of care”

“I have two dependants with autism - they do not have learning disabilities but are quite complex and it impacts quite a lot on everyday life, including health and wellbeing. However, they are not entitled to an annual health check and as far as I know not on a register at GP regarding their autism. They have capacity but are unable to navigate through the GP access system. There is an inequality here that needs to be addressed”

Conclusion

There has been some positive feedback from carers where pockets of good practice have been identified. However, in the main there are inconsistencies from practice to practice to do with both accessing GP appointments and the annual health check. There is a definitive inequality and who is served best depends on which GP service people are registered with.

There is also a question to be answered about people with autism, without a learning disability - is access suitable and should there be a register for people with autism that would enable consistency in ensuring that they are supported to maintain physical and mental health?

Next Steps

- Collect feedback from a selection of GP services in Sandwell to establish what services are provided people with learning disabilities.
- To determine what support is in place from GP services for people with autism.
- To share findings with stakeholders.

autism
west midlands



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**Transforming Care
Partnership** 

For people with learning disabilities and/or autism in the Black Country