

**Conversations
about my GP
appointment**



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, 2016). National research, such as the Confidential Inquiry into the deaths of people with learning disabilities (CIPOLD) report, 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 a number of 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.¹

Objectives

- To listen to the experiences of People with a Learning disability and or Autism of accessing GP appointments
- 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

¹ Mencap Look and Listen report

Methodology





This project engaged with people through a series of focus groups and one to one discussions.

The approach was taken to approach venue's people regularly attend to attempt to speak to as diverse range of people as possible within the time frame. Several venues were identified who had people who were open to speak about their experiences.

We made use of participatory methods in order to allow a range of people to take part in the group without having to be confident speaking within a group.

Findings

Participants were asked to give ratings to services using dots and emojis to indicate what they thought of the appointment and the Dr

			
7 participants	4 participants	2 participants	1 participants

A person said they felt shy because other people were in the waiting room and that there was no safe space for them to use

The Dr gave me two different tablets to take every day - I don't know what they are for, and they do not make me feel better.

I did not know what was wrong with me as the Dr did not tell me - I worry what is the matter with me

The waiting room was very scary to me and had a smell that was weird. I didn't like it so I kicked off. I was asked to leave so I did not see the Dr in the end.

I have to talk with different Drs, they do not know who I am, and they don't understand what I say

I am a bit frightened of the masks, I can only see eyes and no lips so I ran away from the Dr and was not seen

I like the Dr he is funny and makes me laugh but I cant see them any more, my mom has to talk to them on the phone

Participants spoke about not being listened to properly by the Dr It was felt by some that they were not believed comments included 'they think I am telling lies, and no-one is bothered' and that people were not 'believing that you are ill'.

Roberts Story

I am 22 years old; I have learning disabilities and autism . I live with my mom who helps me with things sometimes. I work full time and get paid money.

I needed a repeat prescription for a skin condition that flares up on occasions. Mom tried to order a repeat prescription but was advised due to the time lapse from my last prescription, I would need to have an appointment with my Dr I did try to make an appointment on the telephone, but I have to work so calling from 8am onwards was a difficult for me and caused me to be anxious. I really needed an appointment but was worried about my work.

I find reading quite hard, and I do need time to make sense of what writing says and also what people say to me. I can use the computer but there is too much writing for me to read on NHS app and also on the Drs web site so I cannot use this.

My mom had to help me and was able to link an account for me to her on line account so was able to book me an appointment, but this was not for four weeks. I was happy that I had an appointment, but not very pleased that I could not do this myself. I worry that if I need to go to see the Dr when my mom isn't here, I won't be able to sort it out

My appointment was on the telephone when I was at work. I was worried that the Dr would not understand what I was on about and they could not see what the problem was. I was also worried that I might not understand some of the things that the Dr was saying, sometimes I need someone to explain with gestures as well as their voice. I had to ask my mom to help me, and she had to take time from work to be with me.

My Dr did not call at the appointment time - it was an hour later. I told the Dr that this was not right as I had to wait about and couldn't do my work. The Dr told my mom that the appointment time had a two hour window, my mom said that she did not know about this as it did not say on the web site when she was booking my appointment.

The Dr said I could have some more cream he also said that I should have booked a face-to-face appointment because of my autism. Mom said that there was no where to say about this on the on-line booking system. My mom also talked to the person on the desk at the Dr about this but they told her that I had to have a telephone appointment

My skin problem had got worse as I had to wait a long time for my appointment. There were cuts that bleed sometimes and my skin was very itchy and sore - this was in private area. The cream could not be used until the cuts were healed.

If I could have seen the Dr sooner my skin would not be like this now. I would like to make an appointment to see my Dr to be easier and for me so I can sort out on my own. I am a man and have a job earning real money but feel a bit stupid as I can't do this without my mom.

Next Steps

- To gather more feedback from people with Learning disabilities and or autism about GP experiences
- To engage with Parents/carers of people with Learning disabilities and or autism about GP experiences
- To develop an experts by experience review team who will engage with GP surgery Practice Managers to find out about what service people with Learning disability and or autism are receiving.

autism
west midlands



healthwatch

**Transforming Care
Partnership** 

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