

Intro to Healthwatch Calderdale report ‘Improving services for adults with autism in Calderdale’, for the Adult Health and Social Care Scrutiny Panel on 14/11/19, delivered by Jo Budgen.

At Healthwatch Calderdale we have had regular contact from adults who are having difficulties getting an autism assessment or a second opinion, plus people who have an autism diagnosis but cannot get the support they need to lead a fulfilling life.

We have used the voices and experiences of the people who contact us as the basis of our two reports, the first one ‘Adults experiences of autism services’ (May/Oct 2017), and now the second, ‘Improving services for adults with autism’ (Nov 2019).

In the report we are bringing to scrutiny today we acknowledge that progress has been made, and the attached progress report from Calderdale CCG and South West Yorkshire Foundation Trust (SWYFT) gives a more detailed summary of progress against the recommendations that we made in the 2017 report.

Yes, a diagnostic pathway has been commissioned, waiting times have been reduced, and the autism hub is now in its second year, but there is still more progress to be made:

- There is still no treatment pathway for adults with autism in Calderdale;
- GP practices are still not autism friendly;
- Staff still needing training in autism awareness and reasonable adjustments;
- People with autism are still being turned away from sources of mental health support;
- And there is still no general advocacy support for adults with autism.

So where are we now...

In our new report we outline some issues that we are particularly concerned about:

- Although a diagnostic pathway has been commissioned, the current referral and triage process is dependent on the input of GPs, with no opportunities for people to speak for themselves.
- The number of adults receiving a diagnosis of autism in Calderdale is exceptionally low, with only 6 diagnoses made by the commissioned service in the last 2½ years. (This was previously raised as an ongoing concern at an Adult Scrutiny Panel in March 2017).
- For adults that do get a diagnosis of autism, the only post diagnostic support on offer is up to 2 support sessions, to discuss the implications of the diagnosis and their concerns.
- Post diagnosis, any health and social care needs people that might have can only be managed by referral to existing community services, and these do not have expertise to supporting people with autism
- It is extremely difficult to get a referral to a diagnostic service other than the one which has been commissioned, or to get a second opinion
- The commissioned diagnostic service does not always accept valid diagnoses of autism made by other services, both NHS and private

Also the feedback we have had from SWYFT raises a few questions...

Why is the diagnosis rate in Calderdale so low?

SWYFT suggest that this was initially because there was no specialist triage in place, and that it was also due to the poor quality of clinical referrals, to quote:

'The SWYPFT Service is not thought to be different from other NHS Services using a similar pathway.'

'It is of concern that the referrals put forward in Calderdale are not for people who have Autism.'

As the diagnosis rate in Calderdale is so much lower than that reported in most areas in England, including neighbouring and statistically similar areas, surely the reason for Calderdale being a statistical outlier should be explored and understood?

Are adult autism diagnoses being rationed in Calderdale?

Calderdale CCG have commissioned an adult autism diagnostic pathway for 30 cases a year, and SWYFT suggests an approximate diagnostic rate of 20% from referrals that go to a full diagnostic assessment.

This would suggest that SWYFT expect to diagnose 6 adults with autism per year.

Surely the diagnosis rate should depend on the individuals being assessed?

If people are not being diagnosed with autism, what are they being diagnosed with, and what support do they go on to receive?

What feedback is available about this?

Another key issue...Data:

There is a limited amount of local data about the number of adults with autism and no LD in Calderdale. The Statutory Guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy (2015) states that LAs and NHS bodies should jointly: *Consider and include the number of people with autism in their area as part of the JSNA, including factors such as the age profile and range of support needs of people living with autism so as to predict how need and numbers will change over time.*

And to finish, we are pleased to see that a new All Age Autism Strategy is in development. We hope it will address these issues, and also lead to increased opportunities for people with autism to be involved in the development of services in Calderdale.

I would now like to draw the panels attention to our recommendations which are summarised on page 17 of the Healthwatch report. We would like you to consider them once you have heard from our three experts by experience.

Now I will hand over to our experts by experience...