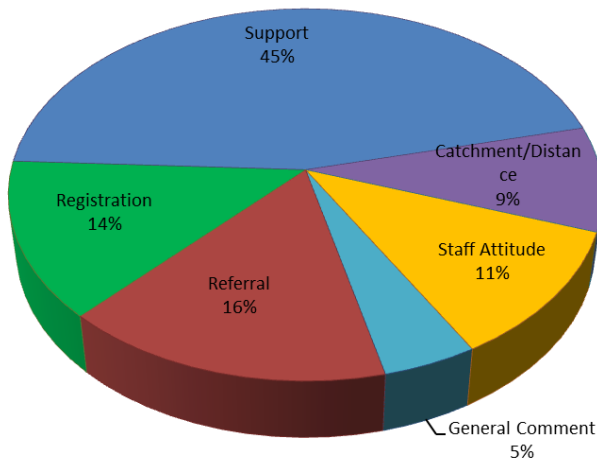


## Healthwatch Cornwall - a report on feedback in relation to Autism 2014.

Healthwatch Cornwall (HC) has received more than 62 patient feedback stories that relate specifically to Autism and Asperger's so far in 2014. This accounts for 4% of all feedback that HC has received. This feedback has been collected through outreach events across the county as well as a targeted outreach event held in partnership with Spectrum. 92% of the feedback is negative with almost 45% concerning the lack of support patients and family have received - see charts on the left:

**Top Trends**



The majority of the feedback relates to the diagnosis process (Primary care) and the support once a diagnosis made (Community and Social Care). The chart below shows the top trends for Primary care which shows that support and referral are the top two trends for this care stage. A number of feedback comments are listed below to give better understanding on what people are telling Healthwatch Cornwall:

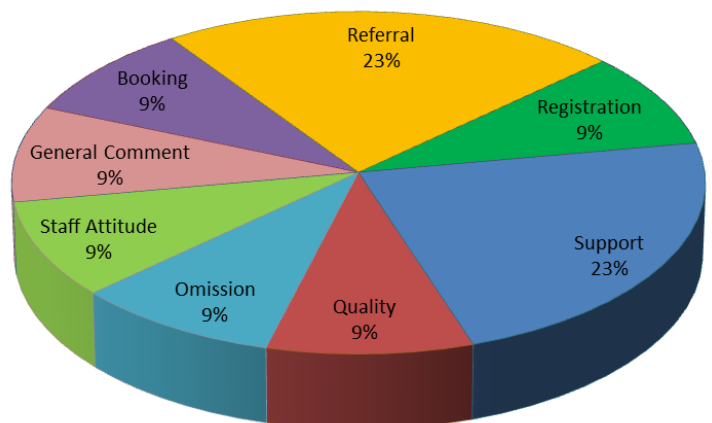
*“Scared and confused by doctors because they talk too fast. Assumptions made about ability to understand. GPs and front line services need additional training in ASD and learning disabilities.”*

*“Early intervention in psychosis - getting more referrals but not psychosis related - is usually Asperger's/ Autism. Not our area. Pick up later through follow up and not being sorted. As staff we need info on where to refer people, what services etc.?”*

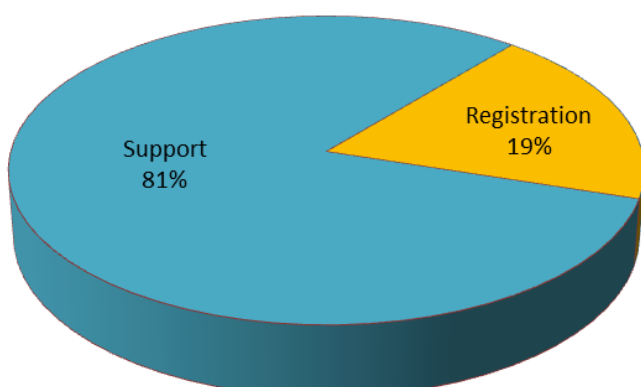
*“People with autism have to ring the dentist to make an appointment. This is too challenging for them. There should be a system where cards are sent out with a time and date on every 6 months.”*

As mentioned above one of the most commented on areas was community and social support. Unlike the Primary care there is only one stand out theme 'support', which mainly received negative feedback. Some of the feedback is shown below:

**Primary Care Top Trends**



**Community Services Top Trends**



*“Son is autistic, 14 years old. Early years support worker Jayne Collins. JC has been brilliant has supported whole family; attended TAC's been great for the whole family.”*

*“Client needs community support for day to day living and to enable him to have purposeful life and fulfil his potential. This proved to be problematic as there was no service that could provide the support needed for this gentleman and it was finally recognised by a Senior Social Worker that a bespoke service was needed. However, when I finally had to disengage with the client, Adult Social Care was still reluctant to provide this due to the costs involved. This man is still at risk of taking his life.”*

*“My son with Asperger's has an IQ of 84 which is too high for a lot of support that would benefit him and eventually enable him to live without or very little support, but no, due to this he falls into the abyss between Mental Health and LD. Where do you go? Who decides who to help? I say that if the time and money was put into care and support now for people with similar conditions, they would need less support later in life. My son is very able to learn but there is nothing out there and no support for him, so he will in time be ripped off by someone, or maybe someone will hurt him, or worse case the other way round.”*

*“A family she has worked with has a child (11) with ADHD, going to Liskeard School, has 1 - 1 there, and is on Ritalin, but when he returns home he is violent, no support. Younger sibling (9) missing out, mum has to spend all her time caring for older child.”  
Family need extra support / child could do with special school / boarding school. (special needs school N. Cornwall)*

**Summary:**

Support received from the initial contact with a GP through to follow on support after diagnosis has been recorded as missing or non-existent for a large percentage of people that HC has spoken to. Lack of training around Autism and Asperger's for Primary care staff (GP and Dentists) is a common comment. Minimal support for family's and people with ASD in the community is another well commented on theme with no support for families (respite) once somebody has received a diagnosis. People have used the word stranded and alone to describe how they feel.

