

Wells-next-the-Sea SEND Event Feedback

Healthwatch Norfolk works to capture the patient's voice in regards to health and social care experiences. Helping people to share and tell their stories about accessing health and social care services gives us a deeper understanding of the emerging trends and issues. Lately, we've been hearing more complex and wide-ranging stories from patients and service users in Norfolk. We attended a SEND event in Wells-next-the-Sea on the 22nd of November and heard the following stories.

"I have an 18 year old daughter who has never been formally diagnosed and a 17 year old daughter who was just diagnosed this year. It took 10 years for us to get her diagnosed. Due to the long wait for help, my daughters have had a build up of issues that have gone untreated. They've dealt with self-harm, eating disorders, claustrophobia and agoraphobia. My youngest daughter was admitted to hospital several times due to an eating disorder and has finally been diagnosed with autism spectrum disorder and now we are getting help with the eating disorder and self-harm. Once we got the diagnosis, we had an appointment with Dr Summers who is a clinical psychologist. Once we saw her everything clicked into place and we've been given all the help we need for my daughter and all the issues she's been struggling with. I just wish we'd got to this point sooner."

"We couldn't wait for years and years to get my son diagnosed, so we paid and went privately. It happened really fast and now we are waiting for his finalised report. The GP has referred us to occupational health, sleep clinic and mental health services. We've been told it will be at least 18 months before we see any of them. We had some communication to say that we'd been triaged and then referred to Ormiston, but they 'can't say when you will be seen.' It feels like we got the diagnosis and then were just sent off with nothing and no support. Apparently, we are also on the waiting list for the community paediatrician and that could take 4 years!"

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"My son is adopted and he has additional needs. We knew he needed an ASD assessment and were told we'd be on the waiting list for at least 3 years. We could not wait 3 years for help, we just couldn't. We were lucky enough to be able to pay to get a private diagnosis. Once we went down the private route the diagnosis happened quickly. After the diagnosis we were given an appointment with a Community Paediatrician. It was not a pleasant appointment, she seemed put out by the fact that we'd gone down the private route for diagnosis. Before the appointment I had researched the medicines used for treatment so I went to the appointment prepared with questions. Those were not well received and I felt shut down. We were given very little information about the 4 medicines my son was prescribed. They gave us a list of websites and just sent us off. The medications have also been hard to find. The last few times I've had to go to at least 4 different chemists to get all the medications. I am very thankful for Adoption Services, they've been giving us the most support and have been so helpful."

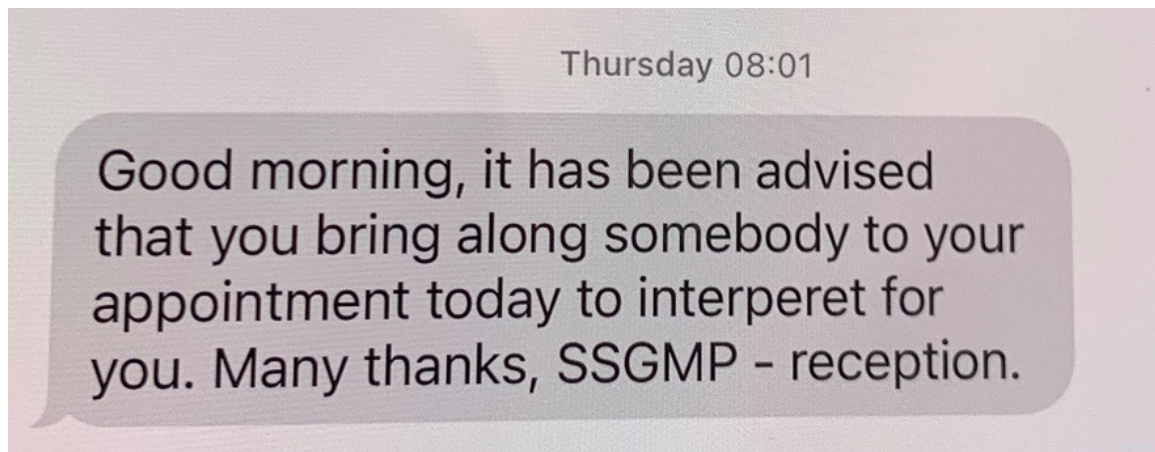
"I've contacted Just One Norfolk quite a lot and find that it can be hard to get through to the person you need to talk to. I know exactly who I need to speak to, but it's never easy to get through to that person. It can be quite frustrating. I've lost my NHS dentist, the dentist has left and now I'm without one. I know it's hopeless trying to get a new one."

"My son has additional needs and is signed up at the special needs dentist in King's Lynn. It's been over two years since his last routine check up. I keep calling to ask for an appointment for him and they either don't answer or they say they will call me back and don't. I can't just take him to a regular dentist, he has to see a special one."

"I have three children. My eldest was diagnosed 18 years ago and from start to finish the process took less than 6 months and he got excellent support. About 5 years ago my middle child received a diagnosis that took about 18 months to complete. Now my youngest is going through the process and we've been told it will be a 4+ years wait. Even after diagnosis there's not really much help offered. My middle child gets a phone call with the paediatrician once a year and that's it."

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"I am a patient at St Stephens Gate practice and I communicate using BSL and the surgery is aware of this. If I book an appointment in advance, then usually they get an interpreter for me. I attended an appointment last week that had been scheduled 2 weeks prior. I contacted the practice a few days before to make sure they had an interpreter scheduled for me. They reassured me that they would have one at my appointment. The morning of the day of my appointment I received the following text from my practice:



I then had to quickly try and find someone who could come along and interpret for me at very short notice. The doctor asked me if I could lip read and I said yes, but that does not help me to communicate with the doctor, it's only works one way and I'm left unable to communicate or ask them questions."

We would like to thank the SEND event attendees for taking the time to share their stories with us. We will be sharing this report with the organisers of the event and with the services mentioned here.