

Patient Experience

A personal account of the Leeds Autism Diagnostic Service, written by a former service user.



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After being referred for adult autism assessment by my GP, I was sent various leaflets containing useful information in the post and advised to read the LADS website. I organised an appointment time convenient to myself and the service. I found appointment process quite flexible, as it allowed me to work around my other commitments.

It was at the appointment I met with an autism nurse, where I was supported in filling in a registration form and questionnaire. During the appointment, the nurse asked me further questions about various aspects of my life. The interview seemed to me to be semi-structured, in a very positive way. I didn't feel I was simply responding to a set list of questions: it felt like a genuine conversation.

The nurse responded empathically to my answers and attentively to all I said and whilst the purpose of the conversation was of course to help her determine whether to refer me for the next stage, the tone of the meeting felt utterly non-judgemental: no aspect of my life felt too 'strange' to talk about in this safe and confidential environment.

This appointment was emotional but a very positive experience. It was the first time I had truly felt able to talk, at length, about how much I struggle with seemingly simple things that to others just seem to come naturally. The questions asked of me were not just tick boxes: they allowed space for me to write quite freely about my experiences.

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Following the initial meeting with an autism nurse, I received some further information from LADS in the post, plus a questionnaire for others who knew me (particularly in childhood) to complete. After these were returned to LADS, and two months after my initial meeting with the autism nurse, I attended a formal diagnostic meeting with a panel of LADS staff including the autism nurse and the Centre's Clinical Lead psychiatrist.

Those present were sensitive to my great nervousness on the occasion and were very supportive. This diagnostic / observation meeting involved various tasks and prompts, as well as a more extensive conversation. At times during that afternoon, I was surprised and puzzled by some of the observational tasks involved, but the staff conveyed that the important thing was to just be myself and again, the atmosphere felt very safe.

After the meeting was over, I was asked to wait in the reception area of the Centre while the panel had a further discussion. I was quite emotional by that point, as I waited to be called back in to hear the outcome. A very helpful volunteer at the centre saw that I was quite upset, and got me a cup of tea while we had a quiet chat. I was then called back into the assessment room (it's actually a pleasant office, looking out towards a garden – it's not some ominously clinical room). I was then told the outcome – that I am autistic. A formal letter followed in the post, and I also attended a follow up meeting with an autism nurse, which was again very helpful.

Since being diagnosed, I felt strongly about empowering people in similar circumstances and have supported the service in raising the awareness of autism in the area. The staff of LADS – the nurses, the psychiatrists, the receptionists and the volunteers – have been wonderfully supportive to me at every stage; so much so that I was moved to dedicate my book to the NHS itself. If you would like to know more about the book please contact the service for further details.

A personal account of the Leeds Autism Diagnostic Service, written by a former service user who is an active member of the Service User Reference Group