

SUPPORTING PEOPLE WITH AUTISM TO LIVE THEIR LIVES

Understanding my health and wellbeing

Accessing a diagnosis

Victoria

Background before support

Victoria, a secondary school IT teacher in her late twenties, has been unemployed for over a year.

Victoria had initially studied history at university. A friend (who was studying psychology) asked her if she had considered whether she might have High Functioning Autism as it appeared that Victoria was struggling with the social and interactive demands of her course. After discussing it at length, Victoria met with the Disability Advice Officer at the Students Union who told her that plenty of support was available for students on the autism spectrum but that she would need a formal diagnosis to access the full range of support. There was an NHS diagnostic clinic in the city, however, upon investigation the waiting list for appointments was currently standing at over 12 months. Victoria decided against proceeding with a referral because she felt “It can’t be that important if it takes a year for them to see you” and chose to carry on without support. She struggled immensely though and failed her end-of-year exams.

Luckily she was able to gain a place on an alternative course for the following year, one in IT. This course Victoria found “much easier” because the students rarely chatted to each other in large groups and, like her, enjoyed computer gaming. The majority of the other students were male and she was much more comfortable in this environment having spent her school years “hanging out with the boys,” finding them much more direct and straightforward than girls with their “boring interests and emotional games.” She successfully completed her degree after three years and went on to complete her PGCE (teaching qualification) after another year.

Victoria had no difficulty finding a job at a girl’s private school; IT qualified women teachers were scarce then. She liked being a teacher and her lessons were well-planned, clearly structured and predictable. She could avoid any involvement in staff room gossip. Her Head Teacher appreciated Victoria’s skills and style, which she thought were conducive to achieving positive results for the school, however a sudden serious illness meant the Head had to leave at short notice, taking early-retirement on health grounds.

The new Head Teacher arrived with fresh ideas and he wanted to restructure the school’s curriculum. Victoria felt pressurised by this unfamiliar approach and disagreed with the changes being implemented, feeling increasingly embittered that her views were disregarded and confused by the new system. Within a short space of time she lost all motivation and soon found herself making excuses to avoid going in to work.

Victoria was asked by her employer to attend an Occupational Health Assessment which found that she was suffering from stress and anxiety. After a prolonged period of sick-leave, Victoria was informed her that her services were no longer required - key IT skills would be taught as units within other subjects, negating the need for an IT specific teacher.

The skills, competences and knowledge to make a positive change

Occupational Health Nurse

The Occupational Health Nurse told Victoria he had a daughter with High Functioning Autism, diagnosed in childhood, and immediately recognised Victoria’s difficulties. He pointed out that a diagnosis could open the way to her understanding herself better and access to a range of support. He also explained that it would help in discussions with her employer to seek adjustments in the workplace. He thought it could explain why she managed well until there was a change of the way she was expected to work at the school. He went on to say that, from his experience, his daughter was doing ok but found changes in routine really difficult because of her autism. He gave her an information leaflet on autism from a national autism charity and contact details for a local support group for adults on the autism spectrum. He encouraged her to see her GP about a referral for an assessment.

Job Centre Officer

Having been out of work for over a year, Victoria was becoming depressed, turning down work that involved a lot of customer contact and one-off teaching cover in places she had never been. At this point a new officer at the Job Centre who had just undergone introductory autism training asked Victoria if she had an autism diagnosis. She said she didn't but it had been asked before - what difference would it make? The Job Centre officer advised that if she did, she would be able to get more help in obtaining a job, including support through 'Access to Work' arranged by the DWP. This benefit could also help to keep her in work once she found a job. She decided to go to her GP and see if they agreed that an assessment would be the right course of action.

GP

The GP had received the guidance from the Royal College of General Practitioners and had attended additional training on autism with a particular focus on undiagnosed adults. When Victoria came into the surgery she was clearly very flustered. Her GP allowed her time to express her difficulties in entering the crowded waiting area and how she particularly found the crying infant difficult to manage. (In future she could await her appointment in her car). Victoria went on to describe her difficulties at work and in general. The GP made some suggestions to her about writing her difficulties down, something that might help in a referral for an assessment of autism. They went on to discuss the impact of her mood and anxiety on her daily life - Victoria felt that this was getting worse, to the point that she was afraid of leaving her house or her car, and she was really worried that she would not come back from this. She explained that her father had experienced depression and anxiety and was worried she may go down the same path. Although she found large social situations difficult she still wanted to have friends and be amongst people and didn't want to be isolated.

The GP prescribed some mild anti-depressants in order to bring her anxiety back to manageable levels in the immediate term. He also agreed to refer Victoria to the Autism Diagnostic Clinic. He further recommended she see him at least three-monthly until things in her life became more settled in order to closely monitor her physical and mental health.

Peer Support Group

Victoria attended the support group suggested by the Occupational Health Nurse and immediately felt at home. The staff had long experience of working with adults with autism and spoke in a very clear and direct manner. The structure of meetings was consistent each time and the attendees always knew in advance what the theme or activity would be.

The group provided Victoria with a no-pressure social network that accepted people for who they are, including their anxieties, which was new to Victoria. They held discussions about autism and how it impacts them all in different ways but that there were similar traits or experiences that people could face.

Victoria started to recognise more about herself and how many aspects of her life could be explained by autism: her preference for food with a very dry texture; her need for silence and solitude when working at her computer; her unusual tolerance of cold or her strict need for routine. It also could explain why she avoided informal social occasions or mistook her online contacts for real friends. She recognised how social communication had been exhausting for her but she had learnt over the years to 'fake it' by simply copying people around her.

Outcome achieved for Victoria

16 months after referral, Victoria attended the diagnostic clinic where it was confirmed that she has Autism Spectrum Disorder. She is now employed through an agency as an IT teacher/trainer.

Supporting outcomes

- Positive engagement from Occupational Health Nurse, Job-Centre Advisor and GP allowed Victoria confidence to progress to Diagnostic Clinic.
- Stress, anxiety and depression symptoms were closely monitored by her GP. These were initially controlled with short-term medication and have since become stable.
- Peer Support Group validated Victoria's experiences and allowed her to feel comfortable in her own skin rather than permanently defensive.
- Post-diagnosis Victoria has engaged with an autism-specialist employment support organisation, funded by DWP Access to Work, to help her find and maintain work.
- She is now registered with a teaching agency. With the above support she was able to discuss her individual needs with her employer who have responded by offering her only longer-term assignments and rather than short-term cover.
- Victoria is now confident discussing her challenges in the workplace (e.g., struggling to understand or participate in staff room culture without appearing rude).