Neurodiversity: Functioning labels help no-one

Nicola Sherlock,[1] a Dental Nurse Team Leader for Special Care within the Community Dental Service, is keen to dispel the myths about functioning labels for neurodiverse patients.

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Dental treatments can be complex for neurodiverse patients for lots of different reasons depending on what they find challenging. This article provides a snapshot of autism; it addresses the question 'are functioning labels useful?' and considers how best to establish effective communication and meet the needs of the dental patient.

According to an article in *Harvard Health*:

'Neurodiversity describes the idea that people experience and interact with the world around them in many different ways; there is no one "right" way of thinking, learning, and behaving, and differences are not viewed as deficits.

'The word neurodiversity refers to the diversity of all people, but it is often used in the context of autism spectrum disorder (ASD), as well as other neurological or developmental conditions such as ADHD or learning disabilities.'[1]

High functioning autism is a term originating from researchers in the late 1980s, based on IQ assessment of autistic individuals rather than functioning assessment.[2,3]

According to an article published in *Autism* in 2020:

'[It is] often used for individuals diagnosed with ASD who have an intelligence quotient (IQ) estimate of 70 or above… While not a formal category in current diagnostic manuals,[4,5] the term is still widely used within clinical practice and research and sometimes used interchangeably with Asperger's syndrome. Over time, "high functioning" has become a term synonymous with expectations of relative strengths in language, higher IQ, milder symptom profiles, and better long-term outcomes, despite a significant amount of

Author information

[1]Nicola Sherlock is a special care dental nurse and team leader in the secondary care setting, and Executive Secretary for the Society of British Dental Nurses (SBDN).

Nicola is mum to three children, one of whom is autistic.

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research countering these assumptions.'[6]

An individual may have previously been diagnosed with the outdated term Asperger's syndrome if they were deemed as 'high functioning'.

However, whilst the term Asperger's is no longer used in diagnosis, high-functioning labels (and therefore low-functioning labels by contrast) seem to persist, for this context, in the language of our medical history taking. These labels have crept into societal everyday use; high functioning implies 'never needing support' and does not take into account the fluctuating functioning that many autistic people experience. It should be recognised that these are not medical diagnostic labels.

Autism + Environment = Outcome.[7]

Assuming we are using these labels to determine what sort of support one of our autistic patients or colleagues may need, what do these words tell us? Nothing about whether the patient is verbal or non-verbal, has a learning disability, has auditory processing difficulties, or any of the other range of co-occurring conditions or difficulties associated with autism. Only approximately four in ten autistic people have a learning disability so we must use our investigative training to ascertain how the spectrum presents itself in each individual.

After speaking to some of our patients, a large proportion of the autistic community finds the terms 'high functioning' or 'low functioning' offensive and inaccurate. To be deemed high functioning is seen as dehumanising and creates a divide. It is commonly said that high functioning is used to deny support and low functioning is used to deny agency within communities.

Those denied the level of support they require are then left to develop unhealthy habits in order to navigate their lives and essentially hide their autism from peers, colleagues and society. This is referred to as 'masking' and frequently results in mental ill-health such as burnout, shutdowns, meltdowns, social anxiety and depression.

As the saying goes, if you've met one autistic person, you've only met one autistic person; just as allistic (non-autistic) people are all different, so too are all autistic people.

Some autistic people are good at communicating verbally, whereas others prefer to do so via text or email, sign language or Makaton. All have things that they enjoy and are good at and all have tasks or environments which they find difficult.

Some autistic people may have been labelled as 'selective mute' but for many they are not able to 'select' when they are unable to speak, but rather find themselves physically unable to do so due to their anxiety in certain situations or environments. For this reason, the term 'situational mutism' is preferred by many in neurodiverse communities.[8]

Non-verbal patients are often still able to understand what is being said to them and in some cases are able to find and use their voice with the right care and when their needs are being met.

Autistic Spectrum Disorder (ASD) also sits uneasily with the community, the preference being ASC – the 'C' standing for 'Condition' rather than Disorder. This language is more fitting with the view that autism is a neurological difference, not a disorder. Rachel Winder, a popular social media influencer who was diagnosed with autism, dyslexia and ADHD in her forties, describes it as follows:

'I always explain autism as being like a person at the checkout with a trolley full of items. Someone who is of the predominant neurotype – so is without autism or other diagnosis – may have just a basket of items. You're both putting the things through at the same speed, but the autistic person will finish later. Not because they are slower. It's just more to process.'[9]

Hints and tips for members of the dental team when working with autistic patients

The terms we use to describe others should be relevant and current, as should our perceptions and attitude.

We must acknowledge the distress that functioning labels may cause, and consciously work to remove them from our vocabulary in favour of terms that affirm an autistic person's humanity and value. All people deserve to be treated with respect and humanity, regardless of their differences.

Identifying specific strengths, needs and support required are a better way to understand how to support a person. Have an open discussion with the patient or their parent/carers. Ask the following questions:

- Do they have speech, sight or hearing difficulties?
- Do they usually consent for treatment themselves?
- Do they become anxious or agitated in unfamiliar surroundings?
- Are they better to have the first appointment of the session to avoid waiting?

All information gathered can help us to tailor our environments and make reasonable adjustments, which in turn may reduce the patient's anxieties and make them feel listened to. Of course, this approach will help if you are working with colleagues who are autistic as well.

Conclusion

It may be that some patients' needs are still too complex to be accommodated in the primary care setting given the complexities within the field and the need to build empathy, understanding and create a rapport, which all takes time and an ability to share these skills. In this case, a referral to the appropriate service should be made. This is by no means saying that patients with neurodiverse differences cannot be seen in the primary care setting, but rather to raise awareness of the specialist service provision and provide some hints and tips for colleagues working in the primary care setting.

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