It's only words: a critical 'insider' perspective on the power of diagnosis in the construction of autistic social identity

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Editorial comment

Gillian is a woman with Asperger syndrome and this paper presents her views on autism and how autism may be portrayed in diagnostic reports and the literature generally. Being told you will have problems can become self-fulfilling and being given positive messages about the strengths of autism, can imply that success was down to autism and not the efforts of the individual. It is in some senses a shocking read in that the impact of what and how professionals (with good intentions) write about autism can have unexpected consequences. How often do we ask autistic people to give feedback on the content of what is written about them?

Gillian's key concern is not that she has the diagnosis but with the socio-political power of the diagnosis, and in the pervasiveness of its use as an 'explanation' at the level of specific, observable behaviour – "an account for everything that I am and everything that I do". She argues convincingly that this is clearly not the case and that such perceptions can work against autistic children and adults alike.

Introduction

I'm writing this in a week when autism, and specifically concerns about the under-diagnosis of autistic women, has featured prominently in the media. Newspaper articles presenting first-person accounts of women's late diagnosis and the Twitter hash-tag "#shecantbeautistic" have sought to expose and bring to public concern questions about how autism may manifest in women, and why it may be so under-diagnosed. Such concerns are also apparent in recent academic research (see, for example Bargiela et al (2016). The question of how to better recognize and diagnose autism in women is a hot topic, and an appropriate diagnostic framework is now the Holy Grail.

I should be glad about this.

I am an autistic woman. I have a psychological report that confirmed this several years ago when I was in my late teens. According to my diagnostic report:

- I am "an average-built, smartly dressed young woman"
- I "lack social skills and have poor conversational skills that hinder my ability to form relationships"
- I "try hard to be tactful' but am 'blunt and do not consider other people's views"
- I have a history of "temper tantrums"
- I "prefer routine and like things to be the same"

This, along with other, more sensitive, contents of my report means that I have an impairment in reciprocal social interaction, communication and a tendency to stereotyped behaviour, along with:

- psychiatric co-morbidity and
- sensory sensitivity

I don't like these words. I hate them, but I need them. The thing is though, that right now I also hate how much I need them.

I have Asperger syndrome.

I've spent years trying to find out more about this so that I could explain myself. I've worked so hard. I've studied. I've spoken. I've written and I've taught. But I'm tired of having to justify myself. I'm tired of fighting to explain that autistic women are different – different from other women, different from autistic men. I'm tired of trying to set myself apart by explanations that are unique to autism. I'm tired of it because it gives the words in my diagnosis, along with social understandings of autism, a power in my life that I'm sick of – all in the name of making me 'other'.

I'm tired of it because I believe strongly that this power comes not from the autism itself, but from a society that cannot tolerate difference, and that especially cannot tolerate unnamed difference. If you can't find the words to articulate your difference – and the hurt, the brokenness and the vulnerability that it causes, then those things can't exist – you are told that you are 'normal' or that, 'we all feel that'. Well I'm fed up of this power – the power of a diagnostic label to account for, and to own, my inability to conform.

The route to diagnosis

I worked hard to obtain my diagnosis – it was a process of piecing myself together and searching every corner of myself by reference to what is known, discussed and written about autism – a painstaking exercise in measuring myself and ascertaining what fitted and what did not. And I do need it. The world makes sure that I need it but its power has turned it into a walled garden that has shut me off from so much of life, because I've been so afraid that stepping outside of autism as a pervasive explanation of my differences would invalidate the 'specialness' of those differences and erase them. My fundamental need to name my distress has led me to cling to a diagnosis that cannot stand to be challenged.

So I want to challenge it. Not the diagnosis itself as a description of (part of) my identity, but the power of this diagnosis as an explanation of everything I am.

Two of the most common arguments that I've come across as to why people seek a diagnosis of Asperger syndrome, and that I claimed for myself, are a need to understand and explain who one is, and a need to access services and support to meet one's needs, so I'm going to attempt to articulate my frustrations with the power of my diagnosis by referring to both of these arguments.

Explaining who I am

This is certainly one of the most common reasons that many adults give for seeking diagnosis. It's one I've clung to. But it's tricky, and now I'm beginning to doubt its usefulness. The reason for this is because of how all-consuming this explanation (and one's reliance upon it) can become. I've been so passionate about this idea. I am an autistic woman. I am not a woman with autism. Autism is a pervasive developmental difference and it affects every part of me. I don't dispute this, but this is not where I suggest the problem lies. I argue that the problem lies not in the pervasiveness of autism in me as an individual, but in the pervasiveness of its use as an 'explanation' at the level of specific, observable behaviour – an account for everything that I am and everything that I do.

I need this explanation because the world is unkind and does not tolerate difference. Anything that strays too far from 'normal' gets stamped on, unless it can account for itself and make itself legitimate – legitimate in terms that are acceptable to the social world. And so, my diagnosis takes on a social life of its own. It's either a gremlin on my shoulder or a gold star on my chest, but it's a social entity – inside of me, but also around me.

Failure and autism

What I mean by this, is that the use of my autism as a pervasive explanation of who I am and what I do robs me of agency, of ownership, and ultimately of the chance to learn and grow. In the case of pain, or of failure, we feel a need to name these – to account for them and to attribute them. Therefore, in moments of worry about (potential) failure, my story becomes:

> *"Autistics can't do that. My autism makes that impossible for me."*

This story is a way of accessing accommodations (whether this be the avoidance of social disapproval, or some practical adaptation) but it does nothing to change the world. It just allows me to exist within it, albeit with the tainted label of 'autism'. So the raw, unmediated pain of personal failure may be avoided, but it is also not owned. And this is important because we can learn from pain and from failure, but only if we own them. What we need is to strive for a world where it is safe to own our failures and to consider what they teach us, without the fear that they will crush us. So the story should be:

> *"I (who am autistic) failed to do this – there is a possible explanation that might lie within the scope of what we already know about autism. It's not the end of the world, and it doesn't make ME a failure. I am more than this particular action."*

But the 'I' has to be in there, as the grammatical subject, because if I don't own it, I can't examine it. If I think it's attributable to my autism, then I excuse myself (and the world may excuse me as one who is 'tainted' and therefore not to be held to the same account) but I also resist change, because to contemplate change is to suggest that my autism, such a fundamental part of me, is a shameful thing that needs to be fixed, which is to contribute to my own tainting. So the autism becomes a stone wall – strong, safe and immovable to hide behind. It protects me, but it also obscures my view.

This is why I think that if you want to help those autistic people who are in pain, from failing according to society's expectations, you can't just do this by finding out more about autism in order to give words to our failure to conform, so that we are 'off the hook' (though still 'different', 'other', 'broken'). You need to – **we** need to work to make the world a more comfortable, more loving place for **everyone** to fail according to the harshness of society's expectations and demands, and to learn from those failures and hurts (because, apart from anything, one of the best ways to make me comfortable with failure is to enable me to see others very obviously failing and recovering. Imitation is one of my learned skills – let me use it!). Otherwise we can't grow – and we in turn cannot shape society.

Success and autism

Likewise in the case of successes – here, autism as a pervasive explanation of the individual leads to lists of things that autism is particularly good at – the special talents of autistic people. It leads to blogs about, "five ways in which my autism helped me get my PhD". And this aims to challenge the stigmas that we face when we are associated with autism. We're just as good as everyone else, and in some ways we might even be better. It helps to show the world that we are capable, and that we can do anything that typical people can do. But for me, this too is unsatisfactory because it belittles the power of our agency in the struggle to succeed, and consequently, it robs us of agency in our successes. It was the autism that led to the success not the individual.

If I succeed at something that "autistic people are good at" (attention to detail, memory, single-mindedness, "thinking outside the box") then the autism takes the credit. Alternatively, sometimes I might succeed at things that don't typically fall within the scope of that which is thought to be 'autistic'. I can put myself through social situations that hurt and terrify me, and I can stay there and be charming, and competent and confident. I succeed in academic subjects that autistic people are not supposed to be good at – however, if we use autism as a pervasive explanation, then all of these 'non autistic' successes simply make me less autistic.

> *"She can't be so very autistic because she can manage."*

Actually, I manage because I am strong and determined, and I will not give in. The autism does not get to own that – I (who happens to be autistic) own it. It's my success because of my autism or in spite of it, or, more likely both. But it's mine. I (who happens to be autistic) own it.

Accessing services

Another argument for seeking diagnosis is that it acts as a gateway to access services and support. This sounds promising. However, in my experience it's also problematic, and I think these problems lie in the very perception of specialness that I have been so desperate to try to prove for autism. In setting autism apart as something special and different, we let the world outside of specialist services get away with the argument that we are too difficult, too complex to access their services. We give them an excuse to stop trying.

There was one particular time when I tried to access psychological support a few years after my diagnosis. I was desperate and terrified. I went through the onion skin layers of gate-keeping – via my GP and at least one phone interview with the hospital, and then an assessment appointment where for about two hours I told an old, male clinical psychologist as much as I dared about every aspect of my life (though not too much, because you can't give away too much of yourself to a stranger, even if they say they're going to help you, because it makes you vulnerable – you have to 'save face'), while he ticked off his check list, and framing everything according to what I know of autism as it relates to me, because autism is the word that legitimizes my weirdness. Without it, I'm nothing. I tried so hard to find the words because I really needed help. I was so scared. I didn't think I could manage on my own.

I got a letter after about six weeks telling me that the service was unable to accommodate 'specific needs such as Asperger syndrome'. No help. No hope of help. Alone. That hurt – it hurt like hell. But I managed. I'm still here. I'm angry and a bit more battle-scarred. But I'm still here. I managed because I can be vulnerable **and** strong.

I'm not saying here that autism is not special. It is special and unique, and certainly knowing more about it is some part of driving social change and making the world a better place – for autistics and non autistics. However, as this knowledge of autism relates to me, and how I tell my own story, it's special in the same way that I'm a special snowflake – but so are you. What I am saying is that I think one of the reasons why so many of us might feel that we need specialised services is not necessarily just because of our uniqueness per se, but rather because services require labels and categories in order to place us and to pigeonhole our words. I offer the quote:

> *"If speaking for someone else seems to be a mysterious process … that may be because speaking to someone does not seem mysterious enough."* (Cavell, cited Geertz, 1993, page 13)

And I offer this because it has always felt to me, in trying to access support, that I have to prove why speaking to me is 'mysterious' – otherwise the assumption is that I'm typical – 'normal'. The person I'm talking to doesn't hear my words, but hears their own internalised version of my words, which are actually really their own words, and we end up speaking different languages. I'm fed up of this though. I'm not 'normal'. I don't want to be 'normal'. I want others to be able to understand that speaking to me is 'mysterious'. And I want to be able to acknowledge that for me, speaking to others who are not me is 'mysterious' too without this being pathologized as my own personal lack of 'Theory of Mind.' This seems to be a much more egalitarian approach to understanding and validating human suffering than simply arguing blindly for my own status as a special snowflake.

Concluding thoughts: so where does that leave me?

This leaves me scared. Questioning internalised power is terrifying. Women who feel that they might be autistic and that this may provide an account for their troubled, painful, frightening life experiences are desperately seeking official diagnosis. Yet here am I, in the privileged position of the diagnosed, safely tucked away in the confines of the 'walled garden', questioning my position. However, I don't question my autism. I question why this part of my identity has to be diagnosable. I question why I feel so much need to find the words to account for myself. I question why 'not normal' is so terribly frightening, and so apparently difficult to accommodate.

Mostly though:

- It leaves me accepting that, for now at least, the diagnosis of my autistic identity is necessary. I need the diagnosis, and all that it does, until the world becomes a kinder place
- It leaves me thinking that one of the ways to make the world a kinder place is to challenge its inability to accept any kind of difference, and that we who care about autism ignore this truth at our peril
- It leaves me aware of the power of diagnosis in my life and with a need to further question this power – to "feel the fear and do it anyway". One of the features of power is that it doesn't have to account for itself, and I want to change that

Really, I guess it leaves me committed to drawing my own map with the full range of materials that I can find – making it up as I go along – telling my own story – singing my own song, and eager to find out what the view is like outside of the 'walled garden'.

References

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