

The strength of autistic expertise and its implications for autism knowledge production: A response to Damian Milton

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**The strength of autistic expertise and its implications for autism knowledge
production: A response to Damian Milton.**

By Richard Woods & Dr Mitzi Waltz.

Nottingham.

United Kingdom.

08th August 2018.

Dr. Larry Arnold.

Autreach Press.

Coventry.

United Kingdom.

Dear Larry Arnold.

Milton (2017)ⁱ describes different types of expertise to be found amongst autism stakeholders and notes that there can be an exchange of expertise between stakeholders.

Traditionally the autistic perspective has been neglected in autism knowledge production leading to distrust from autistic persons towards researchers, and contributing to a negative feedback cycle of increasing tensions between stakeholder groups. This article revisits these claims in light of the growing case for seeking autistic expertise, including how ignoring this could fuel stakeholder distrust and rivalry entrenching the prevailing biases within each stakeholder group (Milton, 2017). Additionally, autistic academics are increasingly producing scholarship at masters, doctoral and professional level (Woods et al 2018); reinforcing biases could silence this important source of autistic voice. We provide suggestions on emancipatory knowledge production methods to start a debate on how best to remedy this source of stakeholder conflict. Before, this article explores the strength of autistic expertise including recent research developments.

The autistic theory of monotropism can be viewed as the strongest autism theory. It explains both the cognitive and sensory differences experienced by autistic persons (Chown, 2017; Murray, Lesser & Lawson, 2005). Monotropism, views autistic experiences as based around interest creating “attention tunnels” where the amount of processing resource or attention each person can utilise at any moment is a limited resource. How each person experiences attention varies forming a continuum, with polytropism at one extreme and monotropism at the other. Monotropism is a single,

hyper focused attention tunnel compared to polytropism when an individual has multiple simultaneous slightly aroused or primed interests, with a low level processing flow constantly connecting them. During a monotropic state, perception is hyper focused on a narrow range of subjects which may be broad or deep in themselves, while outside stimuli are occluded from perception. Sudden interruptions to monotropic states can be highly distressing and disorientating, proportional to the intensity of monotropic state and the severity of its ending. Such occurrences explain demand avoidance behaviour in Pathological Demand Avoidance. It is argued that the characteristic spiky skills profile is caused by which interests arouse a monotropic state, while other skills remain side felt experience (Milton, 2017). Monotropism (Murray, Lesser & Lawson, 2005) clearly offers much to elucidate traits associated with autism as compared to the main cognitive theories, conversely at present it is not widely recognised (Chown, 2017; Milton, 2017). As many research articles do not rely on autism theory (Chown, 2017), there is also little prevent further exploration of monotropism.

Increasingly evidence supports placing autistic perspectives centrally within autism studies, as with regards to specifically supporting autistic critiques of pathologising discourses and treatment. For instance a recent study reported that almost half of autistic individuals who received the intervention Applied Behavioural Analysis often experienced Posttraumatic Stress Disorder, with autistic ABA recipients 86% more

likely to experience PTSD criteria than others with autism (Kupferstein, 2018). Milton's double empathy problem (2017) interrogates locating social communication issues experienced by autistic persons as caused solely by autistic Theory of Mind deficits. Crucially, wider research lends credence to autistic views on the harmful nature of pathologising treatments and the benefit for autistic persons of being in control of therapeutic directions (Milton, 2017). Inevitably, as more progressive literature arises, autistic academics and their allies will increasingly lobby for emancipatory autism knowledge production.

In light of research practices and policies that increasingly place patient, service user and pupil voice central in other fields (for example see Shippee et al 2015), we agree that it is unsustainable to ignore the case for autistic parity with other stakeholders in autism knowledge production. Further, with each passing year there is increasing momentum for research to be autistic-led on both epistemic and ethical grounds. A debate is urgently required regarding how parity would look in practice, the evidence threshold needed to trigger this paradigm shift, and how "autistic-led" should be defined. We propose two methods that could be adopted by the autism research community that may help to solve these stakeholder tensions. Firstly, there needs to be a debate where autistic scholarship compliments or succeeds traditional key literature: for instance a case can be made for monotropism being accepted as a key autism theory

(Chown, 2017; Milton, 2017; Murray, Lesser & Lawson, 2005), and this should give rise to further empirical research. We also recommend wider adoption of inclusive practice, criticality, new lines of inquiry and epistemological integrity. These traits intersect on many different levels in critical autism studies (Woods et al, 2018). If adopted, either of these proposals should acknowledge autistic perspectives, while decrease inter and intra stakeholder mistrust conflict. Failure to recognise the strength of autistic perspectives, on the other hand holds back progress and increases the risk of poor quality research.

Yours sincerely.

Mr Richard Woods.

Dr Mitzi Waltz.

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ⁱ A version of the article is available in the book, for the full reference:
Milton, D. (2014) Autistic expertise: A critical reflection on the production of
knowledge in autism studies. *Autism*, 18: 794-802.