In learning about autism in education, have you ever found yourself listening to a panel with no one that is autistic? What about seeing education policies and practices implemented without input from disabled (including autistic) students? And then there is the odd opinion piece, although well-intentioned, leaves out views from the autistic community on how best to take action in support of autistic children. That piece published last year is mine and I decided to reach out to an autistic academic to deepen my understanding.

In this interview with Dr Damian Milton, you will see how my questions and previous opinion piece were assumptive. No doubt, I have gained a better understanding learned from this simple conversation with Damian. Please read on as I am certain you will benefit from it too.

MK: Could you tell us more about what autism is and your take on identity-first language?

DM: For me, autism is not one ‘thing’ but an umbrella term used to describe development. At its core I would say autism refers to ways of being in the world, ways of processing information and the resultant impact this has upon interactions. These ways of being are often mischaracterized in stereotypical ways however. For a deeper understanding, I have written extensively in my attempt to answer what exactly autism is.

My own preference is for ‘identity-first’ language, as I see it as somewhat dehumanising to be expected to state that I am a ‘person-first’. Being a person should be taken for granted. Some people will say that by placing the ‘autistic’ before the person this is somehow defining everything about them. I see this as no more the case than saying I am a sociologist, or a teacher. The danger is when autism is seen as something separate to a person’s development rather than a description of it, something that can be removed or remediated in some way without impacting on the person as a whole.
When working with individuals it’s best to use that person’s preference. When writing about a formal diagnosis, at present, someone should use Autism Spectrum Disorder (ASD). When talking in generalities, it’s best to go with the preferences of the majority of the autistic community, which would be ‘identity-first’ language. Such language use needs to be supported by practice ethos too.

MK: Do you feel that disabled students tend to be left behind in educational reform? If so, what can we do to make sure their voices are heard?

DM: Unfortunately, yes. All too often reforms and policies do not sufficiently take into account the needs of disabled students. I would suggest that involving disabled people of varying age in designing educational reforms and policies would potentially have a large impact. All too often only children and younger people are consulted in a tokenistic fashion.

MK: From your experience, how has this rapidly-changing world been affecting autistic students who are often known to have considerable preference for predictable routines?

DM: A rapidly changing world can have an impact on the psychological well-being of anyone. There are many sociological theories which attest to this. Rather than a preference for routine, I would say autistic people need to have a sense of stability in their perceptions of the world around them, but this can be hard to accomplish. A sense of personal autonomy and control is essential to well-being. If autistic people are part of bringing about a change, working with trusted others, in an area of interest, and so on, sometimes autistic people can cope with change remarkably well.

Autistic people will thrive when they are fully part of a process and following their interests. No doubt for some innovations one will find autistic people involved. One will also find autistic people being left behind by technological changes, especially without support.
MK: Are there any other future educational challenges that autistic students in particular would face?

DM: The school environment. Given the sensory sensitivities of autistic people, schools are often designed without such needs in mind. Often overcrowded, noisy and unpredictable – schools can easily become overwhelming. In which case, this is not the best context for learning.

MK: In your previous work, you questioned the purpose of "interventions" conducted on autistic students. What educational interventions should we be aiming for and what is the future of education that you would like to see for autistic children?

DM: By implementing truly person-centred, humble and reflective support. We should not be aiming to remediate autism, but working with autistic ways of being in an inclusive future of education – which means building collaborative communities of practice where autistic children feel they belong.

MK: How do you think the Autism Awareness Month can have a higher impact in the general population?

DM: If such campaigns had more significant input from autistic people themselves!