

'Autopia'

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Luke Beardon:
'Autopia'; a vision for autistic acceptance and belonging

Based on Luke's presentation of 'Autopia' (a vision for autistic acceptance and belonging in a future dimension) this chapter introduces the author's statement: 'My hypothesis is that there is a pervasive and invidious pattern of thought, behaviour, and belief that is at the heart of a societal 'norm' that is, in effect, destroying autistic lives'; identifies various components of autistic existence that appear to be common (current) experiences; and elaborates on some areas of practice that could change in order to reduce harm to autistic children and adults, and redress the (im) balance that appears to be the status quo.

From the mini poem - 'conform to the norm...or be deemed in the wrong...' onwards the chapter firmly roots itself in direct contrast to the medical model of disability and identifies that the myriad problems faced by autistic people are not as an outcome of being autistic per se, but often (usually) through lack of knowledge, understanding, acceptance, willingness to listen, and change.

Concepts such as 'inclusion' are critiqued in favour of Luke's preferred goal - the autistic quality of life. Education, autistic sociality, and employment are just some of the areas that the chapter will discuss, along with Luke's 'three golden rules' that he promotes as a way of working towards autistic well-being for the future.

Note on terms: by 'we' I refer to society in general; I refer to me, Luke Beardon (and views are my own, based on decades of experience and engaging with the autistic population); Autopia refers to an 'autistic utopia' – a vision for the future that we should, in my view, be striving towards, and is achievable; PNT stands for Predominant Neurotype, my preferred term for the non-autistic population.¹

Ok – so to be absolutely clear, when I refer to autistic populations for the purposes of this chapter, I am simply doing that – in other words, I am *not* referring to autistic individuals who have additional intellectual disabilities. I am also very well aware of the negative impact that being autistic within current society can bring; please note – language is important – I am not suggesting that being autistic is negative per se, nor that being autistic means that there is invariably a negative impact. I am absolutely of the belief that it is the combination of being autistic within a society that has a misplaced, problematic, and inherently negative view of autism that causes myriad problems for the individual (and wider family). *It is not being autistic that is the problem.* The first of my golden rules that I have written about elsewhere (Beardon, 2017:11) is worth reiterating:

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Autism + Environment = Outcome

This is a simple yet effective way of explaining why the environment has such a huge part to play in the concept of Autopia. Autism in and of itself does not automatically 'lead' to any particular outcome; it is the *combination of the person and their environment* that will dictate outcomes throughout life. If we can't change a person being autistic (which we can't) and if we want to change outcomes for the autistic population, we then by definition must change the environment. Environment literally covers everything that influences the autistic person – so if we understand that the problems faced by autistic people currently are as a result of environmental factors (which, in the main, means 'people') then it is clear that we have an awful long way to go to reach a fair society that doesn't disadvantage the autistic population.

This may sound a little harsh – but I do believe that society in general has an unconscious bias against autistic people; not invariably, but commonly, autistic children and adults are seen as very much second-class citizens. I genuinely think that this is analogous to institutionalised racism – and is widespread across all corners of Western society. The fact that it is an unconscious bias is perhaps the most troubling – as it denotes just how deep rooted the problem is; why would anyone be addressing a problem that isn't even in conscious thought? As Milton (2016) notably points out, social oppression of autistic people can be to the extent of such ableism as to deem individuals lesser than human. And yet the issues are hiding in plain sight; they don't need much searching for. Scratching beneath the veneer uncovers horrors that (I hope) most of society would be horrified to be a part of. The tragedy model of autism (Chown and Beardon, 2017) whereby the very existence of a human can be seen as problematic along with the lower life expectancy of autistics (Bishop-Fitzpatrick and Kind, 2017) and higher incidents of suicide (Cassidy and Rogers, 2017) speaks volumes. I believe that at some point in the future we will look back at these times and wonder what on earth we were thinking; much like the utter, indefatigable, and just contempt we now have for our past whereby homosexuality was deemed a psychiatric condition and individuals were persecuted for their sexuality, so we will wonder why, in order to 'be autistic' one to be clinically assessed as 'lesser'. Current autism criteria and most definitions are rife with deficit-based language – one is referred to as impaired, disordered and so on – in other words an imperfect model of what is seen as the 'norm' This is hateful, unjust, and inaccurate. Being different is not the equivalent of being less; hence the mini poem cited in the introduction that, while terribly written to the point of literary criminality, does sum up how autism seems to be viewed in current society. Any 'difference' identified in the autistic child's development, cognition, sensory world, communication style, and sociality is immediately branded as an impairment, or deficit – as opposed to a different way of being.

I can only briefly identify some of what I understand to be the key areas for change before Autopia becomes more than just a premise. What is clear from the outset, though, is that there needs to be a paradigm shift in thinking as to what autism actually means to those who are autistic. It is astonishing that so little is afforded to 'the autistic voice' when there are so many autistic people who have so much rich experience to share. The very foundations upon which autism is currently understood seem to me to be flawed. The fact that autism is defined within medical manuals - one within a manual for psychiatric conditions, the other within a manual for diseases - speaks volumes. Surely it is safe to say that autism is not a psychiatric condition or a disease, and yet here we are. Until this outdated medical model of autism ceases to be taught as if it were current thinking, we are doing the autistic population a huge disservice. Even the terms that we are encouraged to

use tell autistic people that they are 'disordered' - and rarely do professionals take a step back and reflect on just what impact that referring to humans in this way will actually have. So much of the autism narrative is about dehumanising autistic people, no wonder so many end up on the wrong side of mental well-being.

The Autopia vision aims to reframe autism within the disability framework. Autism is (currently) firmly placed as a disability; this is useful as it helps protect individuals from discrimination and gives some level of guidance within the environment as to how autistic individuals might be better supported. However, it also means that one is required to get a 'medical diagnosis' before being 'allowed' to be autistic. I acknowledge that there are some areas in which self-identification is demed as just as valid as a medical diagnosis – for example some autistic-led research will accept co-researchers who self-identify; these examples could be seen as windows into a future Autopia.

- Autopia recognises that what might be considered disability in one context might be considered an ability in another

Autopia recognises that autistic individuals are likely to have a so-called 'spiky profile'; in other words, they are more likely to have areas of skill and areas of weakness that are more profound than their predominant neurotype (PNT) peers. This is a clue as to how society can adapt to meet the needs of autistic individuals; giving credence to the spiky profile and thus changing education and employment could dramatically alter the life outcomes for the autistic person. 'Allowing' a secondary school pupil to utilise her academic autodidactic strengths so she reaches her potential, or providing autism-friendly job descriptions based on specialism rather than generic skills could make all the difference to the autistic human. Matching (adapting) the environment to the person (not the other way around) may go a long way to decreasing the uneven playing field that so often autistic people find themselves on.

- Autopia recognises that disability is a fluid concept that requires challenging

Disability is a term that has either no neat definition or, at least, a variety of neat definitions that not everyone can agree upon. As a result, it is unclear to many whether autism should be considered as a disability. Autopia recognises that, irrespective of definition, autism can be disabling (in the extreme) or poorly understood; Autopia promotes the concept that if autism is misunderstood then the risk of bad practice (which, in some cases, can lead to irreparable harm to the autistic person) will increase.

- Autopia understands autism (currently) as a *disadvantage* rather than an inherent 'problem'

Rather than framing autism automatically as a disability (with all its medical model deficit-based connotations) I think we are far better off understanding autism as a high-risk disadvantage. And this is no hyperbole. Autistic children and adults can be at a huge disadvantage simply by existing in the PNT world if there are no adaptations to the environment. This can, and must, change. Not only is it unethical to ignore the need for environmental change for autistic people, in many cases it is unlawful. It is clear that autistic people are often at a substantial disadvantage in environments that, with change, could level the playing field and remove that disadvantage. The question remains as to why so many institutions seem reluctant to make those changes.

Autopia understands the harm that can be done from the outset, when autistic people disclose to others that they are autistic. Even this seemingly simply declaration can cause damage; some extraordinary responses to the phrase 'I'm autistic' that are real-life examples in recent months that I am aware of include (with additional comment in parentheses):

- But you don't look autistic (what does 'looking autistic' even mean? It's a nonsensical idea that one can 'see' autism)
- But you're nothing like my friend's son (so what? Why would I, an adult woman, be anything like your friend's five year old boy?)
- But you're a woman (...thanks for noticing...but what has gender got to do with it? Just because society needs to catch up on the notion that autistic women exist doesn't mean that they haven't been around for decades)
- But you're an adult (yes, autistic children invariably become autistic adults)
- But you seem so caring (such a damaging thing to say – autistic people can be just as caring, if not more, than the PNT)
- But you can read and write (it is astonishing that anyone might assume that being autistic means that one lacks specific capabilities)
- But you can talk to me (since when has being able to talk led to people thinking one is not autistic?)
- But you're lovely (this one really demonstrates how negative some people view autism; the fact that there is ever an assumption that being autistic precludes one from being a lovely person shows just how far we need to go before a good understanding is reached)
- But you've got loads of friends (being autistic does not mean that one doesn't like people – contrary to popular belief)
- But you've got a good job (yes, autistic people can work! And many will ake for excellent employees so long as the right environment is created)
- But you're married (autistic people can make for fabulous spouses)
- But you're rubbish at maths/music/IT/etc. (this indicates just how 'one dimensional' much of society is when it comes to understanding autism)
- But you've got kids (er – not to get too gritty but yes, being autistic does not preclude one from engaging in activity that subsequently leads to human creation)

The three Autopian 'golden nuggets':

Golden rule: autism + environment = outcome

**Golden concept: PNT-based concepts need to be translated
before they are applied to the autistic**

**Golden notion: the amount of energy put into effecting change
needs to warrant the intended outcome**

I have already covered the 'golden rule'. The 'golden concept' in our Autopian future will be embedded as a standard mantra that all those involved with the interaction between self and autistic understand and follow. What it means is that any engagement with an autistic person needs some level of attention and possible translation to make it suitable; that the PNT approach – while useful and suitable for the PNT – may increase risk of detriment if applied without due consideration to the autistic person. So, everything from education

(including how we assess knowledge) through to employment (including how we recruit) through to communication, socialising, relationships – everything in life, in fact – should be understood within an autism context. Otherwise we are at risk of discrimination and disadvantage.

The ‘golden notion’ identifies that while many autistic people can learn to adapt to conform to PNT expectations, the amount of energy it takes is simply not worth it. And yet, this is still the apparent ‘go to’ option in many areas (if not all) for the current day autistic. It seems almost invariable that the immediate response to an autistic child behaving in a normally autistic manner is to try and change the behaviour to make it more in line with the PNT. It seems almost invariable that the immediate response to an autistic adult behaving in a normally autistic manner is to try and change the behaviour to make it more in line with the PNT. Why can’t autistic children and adults be allowed to be themselves if it isn’t causing a genuine problem? Why isn’t the autistic way of being accepted (even embraced) on a par with the PNT way of being? Of course, critiques will come up with examples of instances which would appear to make this argument a dangerous one, such as self-injury (to give just one example) and claim that I am suggesting that we should all simply ‘let’ people suffer. This is a nonsense; not all autistic people will self-injure and self-injury is not an exclusively autistic way of being – any person within humankind who has elevated levels of anxiety that lead to self-injury clearly needs support of one kind or another. What I am referring to are the plethora of variations of being an autistic person that are so often seen as ‘lesser’ and demands are made to conform – often at great expense to the autistic person – for seemingly extraordinarily little reward. Along with Milton’s ‘idealisation of normalcy’ (2017) concept and the damage it can lead to Autopia embraces autistic normality and does not impose the need for conformity.

An Autopian educational system understands that how autistic pupils learn might significantly differ from their PNT peers. Therefore, Autopia embraces difference and includes the following in light of autism acceptance and well-being: fully supported learning opportunities outside of traditional school, including home schooling, flexi-schooling, and schooling in alternative venues (e.g. Yurts); better support for autistic adults to train as teachers to allow for more access of autistic students to autistic teachers; block learning opportunities readily available – i.e. subjects taught in blocks (e.g. for a day, a week, or a term at a time) for learners who find learning multiple subjects simultaneously disadvantageous; opportunities to complete ‘homework’ in environments that are not at home; eradication of assessments that disadvantage autistic students and an increase in the range of ways that knowledge is assessed; educational hours made flexible to suit a wide range of needs; the offer of laptops for those who struggle with writing; autodidactic learning opportunities made available; breaktimes are created to allow for relaxation, not necessarily socialising; recognition that some subjects simply will not engage an autistic learner and could be substituted for others that are far more appropriate for longer term interests; assessments should be governed by readiness rather than age; the notion of age-related peers is questioned for validity.

Autopia also questions whether the concept of inclusion requires a revamp. Rather than a focus on inclusion (whatever that might mean) Autopia firmly situates autistic well-being, need, acceptance, and understanding at the forefront of all educational values and beyond; these values are embedded over the breadth and depth of the autistic life. Inclusivity is likely to mean something quite different from one person to the next; indeed, it may well mean something vastly different to one person depending on which environment s/he is in.

Therefore, inclusion is based entirely on individual circumstance and wishes, rather than something that is more likely to be imposed on the population as a whole.

Autistic sociality is absolutely recognised as likely to differ qualitatively and quantitatively in comparison to PNT peers. The notion that the more friends one has is an indication of happiness or well-being is rejected; there is absolute acceptance that solitary activity might be beneficial (or necessary) for a person's well-being; that while social skills might differ to the PNT does not mean that the autistic person is impaired – it means that there is a valid set of autistic social skills that should be respected; and that the PNT conclude that, in the main, they are, in fact, severely impaired in autistic social skills! Autopia also notes that social chit chat is rarely the (autistic) norm, and it is perfectly acceptable to withdraw from engaging in such activity that might be harmful to the autistic person.

Employment presents its own challenges to many autistic people and Autopia strives to redress this balance. From application to retirement party and everything in between Autopia encourages a different way of engaging with autistic employees in several ways. The way in which people are recruited in Autopia looks vastly different to current processes. Job descriptions ask for specific skill sets rather than an entire range of largely unnecessary skills. Applications forms are just one method of how one might apply for a job; there are other options available, such as presenting one's CV via a video clip. Employers recognise that only having one way of recruitment is likely to disadvantage autistic employees so endeavour to be more creative and flexible in their approach. Interviews become a thing of the past for those who are at a distinct disadvantage in those kinds of situations. Employers are no longer made to train up in skills areas that they do not need to possess – jobs are allocated on a skills level, rather than having to force an employee into working in areas that do not come naturally to them. Open plan offices are an option, not a rule. Meetings focus on the agenda, not the social life of the PNT, start on time, keep to time, and finish on time. Autistic specialist advocates are the norm and are available via central funding to support autistic employees with their employer to identify area of potential from the outset and consult on how to avoid them.

So – how might this vision be realised? The development of a genuine relationship between the PNT and autistic populations whereby the former is willing to be led by the latter in matters relating to autism would be a start. From research through to well-being concepts we need to establish a far better understanding – not of 'autism' per se (though I would certainly support that!) – but, more importantly, the autistic lived experience. And the best way to do that? Listen to autistics.

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