

Transforming autistic children and young people's school experiences through difficult conversations between educators

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Why difficult conversations between educators are needed to transform autistic children and young people's school experiences and educational outcomes.

Jo Billington

Abstract:

The majority of identified autistic children in the English state school system are educated in mainstream settings. However, many autistic children and young people in such settings have difficult school experiences and impoverished educational outcomes. Historically, the debate around how to improve outcomes for this group of pupils has centred on identifying ways in which autistic learners can better adapt to the school environment rather than considering the ways in which teachers, educators, and policymakers might adapt their assumptions, beliefs, and practices. In this chapter, I review some of the key literature and employ a combination of relevant theory and my own empirical research with autistic young people to make the case for why difficult conversations between staff in schools are necessary to urgently address the stigma and prejudice which surrounds neurodivergent pupils.

Introduction

In accordance with national and international legislation intended to promote the social and educational inclusion of children with disabilities (Children and Families Act, 2014; United Nations, 2006), 72% of identified autistic children in the English state school system are educated in mainstream settings (Department for Education, 2022b). However, despite the inclusive ideology that forms the basis of special educational needs provision in England, many autistic children and young people have difficult school experiences and impoverished educational outcomes.

Of the autistic children in mainstream schools, around three-quarters do not meet the criteria for an Education Health and Care Plan (Department for Education, 2022b) and have been determined by their local authorities¹ as capable of accessing a mainstream education without the specialist multidisciplinary support provided by such plans. Therefore, one might expect the attainment data for this particular group of children would be more or less in line with national averages. However, the attainment gap between autistic and non-autistic pupils is long-standing and well documented (Keen et al., 2016). At the time of writing, the 2022 key stage 2 (year 6 SATs) and 4 (year 11 GCSEs) attainment data has not yet been published and figures during the height of the Covid-19 pandemic are not necessarily reliable due to the disruption caused by lockdowns and exam adjustments. However, the last set of reliable pre-pandemic figures showed that 32.5% of autistic children achieved the equivalent of five A* - C grades at GCSE in 2018/2019 compared with 63.9% of the general school population in the same period (Department for Education, 2020). An even wider attainment gap existed at the end of Key Stage 2 (year 6) with 25% of autistic children reaching expected levels in reading, writing and maths compared with 70% of the general school population in the same academic year (Department for Education, 2019).

The causes of this disparity have not been clearly identified and while previous research evidence has highlighted several potential factors including an uneven academic profile in autistic learners (Griswold et al., 2002; Jones et al., 2009), time spent away from the classroom undoubtedly plays a part. Recent research has shown that in primary school, children regarded as having the highest level of need spend the equivalent of more than a day a week separated from their teacher, their peers, and the curriculum engaged in various out-of-class activities and interventions (Webster, 2022). Autistic children are also more likely to display behaviour described as 'disruptive' resulting in significantly higher formal exclusion rates than children with no special educational needs (Brede et al., 2017), and are

¹ Local Authorities (LAs) are organisations responsible for governmental administration of public services at a geographically localised level. They have a legal duty to ensure that children and young people identified as having Special Educational Needs and Disabilities (SEND) have access to suitable education provision.

an over-represented group in Pupil Referral Units² (Department for Education, 2022a). Moreover, charities such as the National Autistic Society have been concerned for some years about the rise in unofficial exclusions. Such unlawful exclusions include being sent home to 'cool off' when showing signs of distress or overwhelm and being excluded from school trips and extracurricular activities. The extent of these exclusions is difficult to pinpoint because they are not recorded in official statistics, but in a recent survey of 3,470 parents and carers of autistic children, more than one in five respondents reported that their child had been informally excluded at least twice in the last year (National Autistic Society, 2021).

Furthermore, there is an increased awareness of the growing number of autistic children who find school so stressful that they are unable to attend regularly or at all, resulting in burnout or protective self-exclusion (Dalrymple, 2022; Totsika et al., 2020). Research suggests that central to the issue of attendance difficulties is the fact that autistic children and young people are considerably more likely to experience bullying, peer victimisation and social isolation than their non-autistic peers (Humphrey & Hebron, 2015; Maïano et al., 2016), all of which undoubtedly play a significant role in the disproportionate rates of mental distress in the autistic child population (Strang et al., 2012; White et al., 2009).

Arguably key to addressing this crisis is the level of understanding and acceptance there is of autistic pupils in mainstream schools. The level of support that is available to autistic children in English mainstream schools is highly variable and largely teacher-dependent, leading some families to describe the process of securing the right support for their child as a lottery. Given the central role of the individual teacher in the success or otherwise of an autistic child's school experience, it is troubling to know that some teachers

² Pupil Referral Units are alternative educational institutions designed for children and young people who are unable to attend mainstream or specialist schools due to illness, exclusion, or having needs that cannot be otherwise met.

have ambivalent views towards including children with disabilities in mainstream classrooms (see De Boer et al., 2011 for a review), and others do not necessarily feel confident about their ability to provide the right support to autistic pupils, citing insufficient funding, resources and autism-specific training (Humphrey & Symes, 2013; Ravet, 2018; Roberts & Simpson, 2016). I argue that this development of understanding and acceptance can be reached through engagement in what might be considered difficult conversations, which I discuss in the next section.

Why difficult conversations are needed

There has been considerable debate among researchers, teachers, parents, policymakers and others about how best to improve the experiences and outcomes for autistic children and young people in mainstream settings (e.g. Dillon *et al.*, 2014; McKinlay *et al.*, 2022; Walsh & Hall, 2012; Warnock & Norwich, 2010). However, this conversation has not fully included autistic people and has often failed to honour and value autistic ways of being (Milton & Bracher, 2013). Instead, the conversation has largely been confined to non-autistic people (adults, mainly) and has tended to focus on the changes autistic children need to make in order to fit into the education system rather than identifying how changes in the structures, practices and cultures in our schools might actively disadvantage neurodivergent pupils (Milton, 2014). This one-sided perspective poses a difficulty for all involved as it emphasises that the current ways of working are not inclusive and require a shift not only in practical terms but also in relation to traditional attitudes and principles that underpin current practice. Attitudinal shifts of this kind are always challenging as they destabilise the status quo and prompt everyone to examine their own assumptions (Ahmed, 2018; Bhabha, 2002). However, not engaging in these difficult conversations carries ethical risks that our schools will remain ill-equipped to support autistic pupils – a risk that, in my view, must be addressed and mitigated.

While we unquestionably still have a long way to go, our education system has progressed in recent decades in terms of recognising and celebrating ethnic, cultural, sexual, religious, and gender diversity. However, it is arguable that neurodiversity is still a largely under-recognised and poorly understood concept in English schools. Rather than an identity worthy of respect and appreciation, autism (and other neurodivergent conditions such as ADHD and dyslexia) is still viewed by many as an economic burden or a problem to be solved (e.g. Buescher et al., 2014; Rogge & Janssen, 2019) and this can have a catastrophic impact on the health and wellbeing of autistic children and their families. It is my belief that these social and attitudinal factors are at the heart of the challenges faced by autistic children and young people in mainstream schools, and indeed for autistic people of all ages across society. One way to address the stigma around neurodiversity could be to engage in critical conversations, some of which may be difficult and uncomfortable due to the fact that they require us to examine our values and beliefs in novel ways. For example, it is possible that we may have never considered the privilege and power that comes with being of a dominant neurotype. Furthermore, we may have never examined our attitudes towards neurodivergent pupils and how these attitudes might shape our interactions with them, our assessment of their strengths and difficulties and, in turn, the support we offer to them.

I am frequently asked by school staff and families how conversations about autism can be had in the classroom but prior to any conversation with pupils, arguably the most important place for these conversations is the staffroom. Conversations that explore the idea that our education system may be inadvertently causing harm to autistic children are challenging but necessary. As I aim to explain in this chapter, this is a subject that needs to be discussed, however difficult it may be for us as educators to critically engage with the unintended consequences of educational and societal neuronormativity. It is necessary that we 'sit in the uncomfortable' (Ahmed, 2018; Stone et al., 2011) if we are to identify and break down potentially oppressive practices within our education system. It is my intention in this

chapter to set out why I believe this to be the case and offer some ideas for reflection. I will do this by outlining two aspects of research evidence: (1) a short review of relevant theory (2) my own empirical research with autistic young people. To become agents of urgently needed social change we must harness the transformative power of difficult conversations and lean into the discomfort of this liminal space because, as I will discuss later, the lives of autistic people may, quite literally, depend on it.

Pause for reflection

- What are your attitudes towards the inclusion of autistic children and young people in mainstream schools?
- What experiences contributed to the formation of your attitudes?
- What are the barriers to the successful inclusion of autistic learners in your particular educational setting, if any?

Moving from the medical model to the neurodiversity model of autism

Historically, autism has been understood predominantly through a medical lens, one that makes a binary distinction between ‘normal’ and ‘abnormal’ development. In the clinical literature, autism is classed as a “neurodevelopmental disorder” (American Psychiatric Association, 2013, p. 31) and autistic ways of being which differ significantly from non-autistic norms are pathologised as deficits and impairments with the implication that autistic behaviours are defective and in need of treatment or correction. This has fed into what Stone and Priestley (1996) refer to as the “personal tragedy model” (p. 701) where a diagnosis of autism for a child may be seen as a blight on the person and their family. This view has also undoubtedly contributed to the interventionist culture of autism support in

English education. Indeed, the statutory guidance set out in the SEND Code of Practice maintains that the process of identifying if a child has special educational needs is determined by their need for support which is “additional to or different from that made generally for other children or young people of the same age” (Department for Education and Department of Health, 2015, p. 16) - an assessment which is largely determined by how far a child may have deviated from a perceived ‘normal’ developmental trajectory determined by their chronological age.

In the case of autistic children, the deviation from the norm, be it determined behaviourally or otherwise, carries with it the supposition that the autistic child is in some way broken and needs to be fixed; the end goal being not that the child is encouraged to be their authentic autistic selves and supported to lead a full and flourishing life on their own terms, but that they behave and function as closely as possible to a norm set by their non-autistic peers of roughly similar age. Given the paucity of critical autism education in teacher training and the interventionist nature of governmental guidance (Department of Health and Social Care and Department for Education, 2021), it is easy to see how these views are shared by many who work in mainstream schools to the extent where they are rarely questioned. I propose that these views are examined critically in order to expand the understanding of educators’ own attitudes toward teaching autistic pupils and the impact those attitudes have on this group of pupils. This is because, despite being unintended, the consequences of this approach can and do cause harm and they need to be considered carefully – a theme I will expand on as this chapter continues.

Due to how entrenched the medical model of autism is in our society, an autistic-led resistance to its principles has been steadily growing since the early 1990s. A member of the autistic rights movement, Australian sociologist Judy Singer, proposed the term ‘neurodiversity’ in 1998 to describe the “emerging social movements for civil rights for people with various devalued, medically labelled neurological conditions” (Milton et al., 2020, p. 3).

The term has been interpreted in different ways over the intervening years and, being still very much in its infancy as a concept, is the subject of some debate (den Houting, 2019; Walker, 2021). However, it is essentially rooted in the idea that a 'normal' brain is a social construction and neurological difference is as natural a form of human diversity as, say, differences in ethnicity and sexuality (Singer, 2017).

In this way, the concept of neurodiversity is at the heart of a social justice movement which challenges the deficit model of autism by resisting the pathologisation of autistic ways of being and recognising the strengths of autistic people while not seeking to dismiss or trivialise their experiences of disablement (den Houting, 2019). The concept of neurodiversity also provides a framework for considering the social and political considerations central to this chapter. It provides an alternative to deficit-based medical-model thinking by exposing the stigma and hostility autistic people face as a minority group in a society largely designed by and for people who are not autistic. Thus, the emphasis on criticality, social change and collective resistance central to the neurodiversity movement is closely aligned with the theoretical foundations of difficult conversations as set out in the introduction of this book by scholars such as Giroux (2022) who underlines the importance of critical thinking and challenging the status quo in the quest to build a more equitable society.

Pause for reflection

- Do you identify as 'neurotypical' (i.e. majority neurotype) or 'neurodivergent' (i.e. minority neurotype), or is it something you've not thought about before?
- How might your neurotype affect your expectations of others?
- How might the values and attitudes of those with the majority neurotype adversely affect those of minority neurotypes?
- How might the power relations between adults and children of different neurotypes play out in a school setting?

The double-empathy problem: how people of different neurotypes can misunderstand one another

In accordance with the medical model of autism, the social and communication challenges autistic children experience in school are usually attributed to their neurology. Indeed, the deficit model of autism which underpins clinical assessment dictates that “persistent deficits in social communication and social interaction” (American Psychiatric Association, 2013, p. 31) are diagnostic criteria. As mentioned previously, this has led to a model of autism support, particularly in childhood, in which the child is subject to a range of formal and informal interventions with the aim of reducing the ‘autistic behaviours’ in favour of ‘non-autistic behaviours’. However, the idea that autistic interaction is defective and in need of modification has been challenged by autistic people for many years (e.g. Baggs, 2007; Sinclair, 1993/2012).

This challenge has been theorised by autistic sociologist, Dr Damian Milton as the ‘double empathy problem’ (Milton, 2012). His theory posits that instead of autistic interaction

being 'wrong' and non-autistic interaction being 'right', they are both simply different. Each has its own integrity but the distinct differences between them can lead to mutual misunderstanding. Milton goes on to explain this as "a 'double problem' because both people experience it, and so it is not a singular problem located in any one person" (Milton, 2012, p. 884). However, due to the power imbalances between autistic (minority group) and non-autistic people (majority group), any difficulties or misunderstandings are generally attributed to the autistic person. This leads to the widely accepted belief that it is autistic people who need to adjust their behaviour to more closely match the conventions and expectations of non-autistic people who, in turn, are not usually required to make adjustments because how they behave is not subject to the same scrutiny.

There are serious and sometimes catastrophic consequences to the widely held belief that autistic people need to adapt to the linguistic and behavioural conventions of non-autistic people. The pressure to behave less autistically and adapt to neurotypical norms can lead autistic people to try to camouflage their natural ways of being. Not only is this effortful to the point of exhaustion but it can also lead to feelings of worthlessness and a lack of belonging, both of which have been strongly associated with suicidal behaviours (Cassidy et al., 2020). When we also take into account the fact that suicide is a leading cause of early death in autistic adults (Hirvikoski et al., 2016), the urgency of the need to have conversations about this subject is clear.

Thus, the double empathy problem offers an alternative way of thinking since it proposes the solution to the misunderstandings between autistic and non-autistic people is not one that rests entirely with autistic people but is one that is shared. It implies that instead of autistic people needing intervention in order to behave more typically, non-autistic people need to learn how to interpret, understand and appreciate autistic ways of being. However, given the stigma associated with autism, this learning process arguably needs to begin with non-autistic people examining how their internalised beliefs and assumptions

might impact on their engagement with autistic people. This is where difficult conversations aimed at sensitively exploring one's own preconceptions can play a crucial role in overcoming the double empathy problem. In engaging in conversations of this nature, we lay the foundations for a deeper understanding of ways of being which may be very different to (but no less valuable than) one's own (Buber, 2002; Freire, 1970).

Autistic young adults' reflections on the double empathy problem in mainstream primary schools: a qualitative study

But, how does the double empathy problem play out in schools, and what is its impact on autistic children and young people? To answer this question, I will now refer to a focus group study (The University of Reading Research Ethics Committee, approval code 2017-196-FK) I conducted with 6 autistic young adults (4 female, 2 male) aged between 19 and 25 years in which they were asked to reflect on their experiences of mainstream primary school (Billington, et al., forthcoming). The group discussion was recorded, transcribed verbatim and then analysed in order to identify themes across the participants' contributions. Three themes were constructed from the data which I will briefly describe below and illustrate with participant quotes. Pseudonyms are used throughout.

Theme 1: The undesirability of difference

Although most of the participants did not know they were autistic until well into their adolescence, they all knew they were different from a very early age. They described their experience of being different in negative terms which they attributed to interactions with peers, teachers and occasionally parents. They also reported that their earliest memories of primary school were of a place where they did not belong and were not necessarily welcome:

I was just so different from everyone else that not even the teachers really knew how to address me, and I just felt really...like I wasn't meant to be there at all. (Sophie)

In addition to feeling on the outside of the everyday business of school, the participants reported that when they interacted with teachers and peers, their natural approaches to communicating, learning and socialising were often misunderstood. They spoke of unwittingly making social mistakes which in some cases were perceived as wilfully defiant. In these instances, it could lead to criticism or sanctions from teachers:

[I was] always being told off for things which I didn't understand were wrong.

(Georgia)

Recent research suggests that having a formal diagnosis of autism earlier in life may be helpful in developing a more positive self-concept (Gould & Ashton-Smith, 2011), but for some participants this wasn't the case and the sense of being 'other' that came with their diagnosis was distressing:

I really didn't like [having an autism diagnosis] because I always thought that was what made me different and I was trying...I remember sitting there thinking trying to work out ways to get un-diagnosed and not liking it, basically. Basically, trying to work out how to be normal and get rid of it. (Daniel)

As demonstrated by the participants' expressions, feeling different or continually being treated differently by crucial community members can have a profoundly lasting impact on one's sense of belonging. Turner (2012) posits that spaces where these differences can be explored, can help the group to develop a greater sense 'of the other'. These spaces are not aimed at merely creating a consensus about a set of behaviours (Bohm, 2000) but at empowering the engaged to learn through the liminality of these spaces where one is allowed to 'not know' and to arrive at realisations about own assumptions or prejudices (Cherry, 2021).

Pause for reflection

- How did you feel when reading the quotes from the autistic young people above?
- Can you recall any instances from your life that made you feel different or 'othered'? How would you have liked to enable people to better understand your experience?
- How might you begin to have conversations with colleagues about the themes raised in this section?

Theme 2: The various guises of bullying

Daniel's description of not feeling 'normal' cited above was one that was expressed by others in the group who described examples of how being different made them targets for bullying. Most of the participants could recall numerous instances of obvious bullying by peers such as name-calling or physical assaults, but much of the bullying reported was less overt. These more subtle forms of bullying typically involved some form of social exclusion:

...being picked later for sports teams or just not having people to sit with at lunch...or kind of having difficulties like finding the right things to talk about that people would be interested in... or not being invited to birthday parties. (Holly)

The participants also reported bullying not just from their peers but also from their teachers. However, they perceived the teachers' bullying to be different from their peers. Whilst peers engaged in physical and verbal assaults, their teachers' bullying tended to centre on the implication that if they were 'less autistic', life would be easier for them:

[I] remember a teacher...basically saying...the way that you'll get bullied less if you act like a normal person...and the reason he said that was that I liked to just sit read a book erm, and not go play football. (Daniel)

When I asked the group what might have motivated this behaviour from their teachers, they responded that it was possible that their teachers were acting in their best interests, as exemplified by Georgia:

[She] told me that she was doing it for my own good. I was very clear I didn't want friends, and she thought that made me, like, selfish, like 'one day you're going to regret you didn't make friends when you were younger'. (Georgia)

However, even though the participants acknowledged there was a possibility that this treatment from their teachers came from a place of concern, this did nothing to minimise the invalidation and shame they experienced. In some cases, it led to fear and anxiety so overwhelming that they would regularly struggle to attend school:

The main person that put me off [attending school] in primary school was my year 5 teacher who used to bully me quite a lot... I don't know why she had such a problem with me but...she just seemed to have this real dislike for me and I don't know why. (Jack)

While the participants' accounts above illustrate the extent to which the bullying related to their difference was prevalent in their school experiences, I would like to draw your attention to the issue of teachers' assumptions about normalcy. If, as educators of neurodivergent children, we only accept the non-autistic definitions of normalcy, how can we be open to the needs and realities of those who are different? Engaging in conversations about what we consider 'normal' and what we consider 'different' can be challenging since these concepts are often based on deeply entrenched ideas. As such, we might be required to 'sit in the uncomfortable' of what these conversations might unravel (Ferner & Chetty,

2019). With this risk of the discomfort in mind, please consider the following points for reflection:

Pause for reflection

- Is it ethical to avoid potentially difficult conversations about normalcy in educational settings?
- How can educators provide support to autistic children that is identity-supporting rather than identity-invalidating?

Theme 3: The emotional labour of 'being good'

Given the level of hostility towards their differences, it is unsurprising that the participants reported feeling under significant pressure to behave in more neurotypical ways and engage in more neurotypical activities, despite the discomfort and distress that caused:

I was always very nervous about trying to fit in potentially so like, making sure I didn't go do anything that would be not normal. (Daniel)

All participants reported feeling overwhelmed by the emotional labour involved in either blending in or coping with the fallout of non-conformity. Invariably, the effort expended in attempting to cope with others' attitudes towards their differences led some participants to suppress their emotional response while in school and release some of the tension in the safety of their homes:

In school, I would bottle it up. And try and be good to kids and good to teachers. And that's probably why me and my mum never got on because I probably just exploded on her really. Like, just let rip because then I knew that I wasn't going to get bullied from people that way. I could just be angry at her. (Sophie)

This idea of 'trying to be good' was central to the participants' experience of primary school. They worked hard to have a good school experience, but, as expressed by Katie below, many felt that their efforts to fit in were not reciprocated by school staff and peers:

I liked school, but school didn't like me. (Katie)

The data also suggest that the costs of the challenges experienced during primary school were borne by the participants, and these costs were not just felt at the time. The impact has been long-lasting and is still something many of the participants feel they are paying for in adulthood:

*Now I'm angry, I'm unforgiving, I'm cold, and I never used to be like that...y'know?
(Sophie)*

These themes clearly show the double-empathy problem in practice. The participants all felt undesirably different from an early age because of the way in which they were perceived by the people around them. Whenever misunderstandings occurred, they were seen as solely responsible and were either sanctioned or shunned. They were subject to bullying by peers and invalidation by their teachers. In response, they felt the pressure to conform in ways that were effortful and distressing. The results of this study suggest that the participants' primary school experience was characterised by routine invalidations and hostilities which had long-lasting implications for their self-esteem and self-concept. It is important to note that all the participants in this study completed their compulsory schooling and went on to enrol in post-16 education, with most studying for a university degree. As such, they represent the minority of autistic young people who continued their education to tertiary level. A key question to contemplate though is, at what cost?

Freire (1970) argues that education should offer opportunities to challenge hierarchies, privileges, and traditional identities, and it is important to recognise the position of power and authority educators occupy within the circumstances illustrated in this chapter.

This position of power, albeit traditionally embedded in accountability and performativity measures (Ball, 2013), carries the danger of life-long negative impacts on pupil identity when it is not reviewed critically. I propose that difficult conversations are considered as a way of opening an inclusive dialogue where the double empathy problem can be addressed, where children and young people's experiences are brought to the forefront to inform educational practice, and where the learning community can engage in the 'liminal space' to learn with and from each other's difference (Turner, 2012).

Pause for reflection

- How can we develop a learning environment in which autistic learners do not feel under pressure to conform to neuronormative expectations?
- How can we as educators critically reflect on the unintended consequences of the authority we might exert over children of different neurotypes to our own?

Conclusion

Consequently, in the words of disability rights activist Elly Chapple, we need to "flip the narrative" (Chapple, 2019) around how autistic children are supported in our schools. The idea that autistic children are a group in need of highly specialist (and costly) approaches has steadily gained ground in recent years, but in an education system with ever-decreasing access to resources, and a group of children with ever-deteriorating outcomes, the focus on funding and training is potentially misleading and distracts from what I see as the bigger issues of equity and social justice. Instead of locating the challenges experienced by autistic pupils solely within the children themselves, as educators we need to carefully consider our own roles in those challenges. Instead of the conversation continuing to centre on concerns

about resources and interventions designed to increase greater conformity, we need to pause to consider what are undoubtedly more pressing questions.

In the work that I have done with teachers and families over the last ten years, I have become increasingly aware that mainstream school can be completely intolerable for many autistic children. For those who are not traumatised to the point of crisis or permanently excluded, school is all too often a place where autistic children need to dig deep, don their masks and try their best to cope. As previously highlighted, not only can this pattern of behaviour lead to catastrophic consequences including self-harm and suicide, coping is a long way from flourishing and living a rewarding and enjoyable life. Simply trying to just get through each day cannot be our aspiration for this group of young people. But the idea that school and the attitudes of the people in it could be at the heart of the challenges an autistic child is experiencing is not one that is readily or openly discussed. We need to acknowledge that harm may still be caused despite the very best of intentions and this is where our difficult conversations need to begin. For those of us who identify as part of the majority neurotype, this may challenge the way we see the world and how we define our role as educators. Engaging in these difficult conversations with ourselves and our colleagues may involve threats to our identities with the acceptance that the dominantly neurotypical culture of our education system might be part of the problem. Care needs to be taken so that we can navigate this complex process of transformation, but before we can look at specific support for individual pupils, we first need to acknowledge that maintaining the status quo in our education system is no longer an ethical option.

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