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A good life: towards greater dignity for people with learning disability

Ben Newmark and Tom Rees



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Introduction

The Special Educational Needs and Disabilities (SEND) Review is an important opportunity for a national conversation about how our education system works for society's most vulnerable children.

In this paper, Ben Newmark and Tom Rees argue that although the current plans for reform take us a step in the right direction, we should be more ambitious as a society for inclusion – to have a more dignified and affirmative way of considering disability.

This paper makes the case for a greater understanding of the damage caused by the medicalised model of disability and the limitations of a meritocratic society which creates both winners and losers. It argues that for reform to be successful, as well as addressing the issue of resource allocation, it should help us to better understand people with disabilities as complete humans and promote a broader and more ambitious vision of what a good life is, and can be.



About the authors

Ben Newmark is a secondary Vice Principal and history teacher. He has worked in education for nearly twenty years. His eldest daughter Bessie has Williams Syndrome. She is kind, enthusiastic, charming and popular with her friends, family and teachers. Next year she begins Year 1 at a wonderfully inclusive mainstream primary school.

Tom Rees is Executive Director of Programmes at Ambition Institute and has worked in education for twenty-five years. Tom was a primary headteacher and

then Education Director in a school trust over a ten year period, which included running a Special Unit for children with Learning Disabilities. His eldest son, Freddie, loves swimming and dancing. He also has Down's syndrome and autism. Tom was the founding chair of a charity which supports children and families affected by Down's syndrome.



Executive Summary

The government's recently published 'Green Paper' (DfE 2022) gives a welcome and honest appraisal of the many challenges that exist within the Special Educational Needs and Disabilities (SEND) system. Potential reform in this area offers an important and overdue opportunity to tackle the important question of how the education system works for society's most vulnerable children.

The Green Paper is a step in the right direction, identifying problems within a complex SEND system that must offer better support, better outcomes and better value for public money.

But we should go further, and this paper explores two additional challenges.

Firstly, the current SEND system rests on an outdated medical and deficit model, where to receive additional support in schools and throughout life, people with disability and their families have to demonstrate failure, regularly and repeatedly.

Secondly, this problem of deficit framing is located within the wider societal issue of the meritocracy, life's 'sorting principle' which has narrowed what we perceive a 'good life' to be and what is valued within education and across society.

This status quo is unnecessarily disrespectful and undignified for people with learning disability.

It is unrealistic to think that SEND reform alone can fix what are much wider societal problems, but we do think that reform, along with the influence of schools and Trusts, can play an important role in helping to move us forward. Within this paper, we propose two principles to help us make progress towards more people living with greater recognition and dignity:

1. **People with learning disability are complete humans.** They are not broken and do not need fixing. We can treat them with greater dignity, avoiding deficit language that suggests they are special cases or somehow worth less.

2. **We need a broader and more ambitious vision of what a good life is.** Human flourishing and dignity for all, requires us to have a wide set of success measures. Placing greater value on things such as contribution, difference, common values, and the process of learning and work itself, can provide a healthy balance to meritocratic values of academic credentials, occupational status and wealth.

The Green Paper consults on the creation of national standards for SEND provision across the country which could be helpful in addressing important areas of reform such as improved use of evidence and wider access to expert practitioners. The current proposal for national standards for SEND could also be expanded to address the challenges of deficit framing that exist within the education system. For example:

National standards for SEND to address the challenges of dignity and deficit framing within the SEND system.

- **Affirmative language:** the use of affirmative, respectful and dignified language and narratives, which avoid the unintended consequences of deficit framing that exist within the current SEND system.
- **Dignity of process:** an expectation that a process of accessing additional support should treat people with dignity and respect, rather than requiring them to demonstrate repeated failure.
- **A broad view of success:** the importance of recognising a broad range of success measures when working with children who have learning disabilities, rather than assuming that success looks the same for every child.
- **Need vs. identity:** a clear understanding of the difference between specific learning difficulties that can be overcome, as opposed to the variation in rates of learning that are part of who someone is.

SEND Reform

In March the government published a Green Paper which set out proposals for further consultation on reforms to the system for Special Educational Needs and Disabilities (SEND). We welcome this.

It's important we surface a debate around how we educate our most vulnerable learners and the Green Paper is a step forward.

The Green Paper makes some sensible and pragmatic suggestions about how the system can be more effective and efficient.

It is honest in capturing the problems children with SEND and their families experience, and confronts the dire outcomes that exist within the system despite the efforts of schools and trusts.

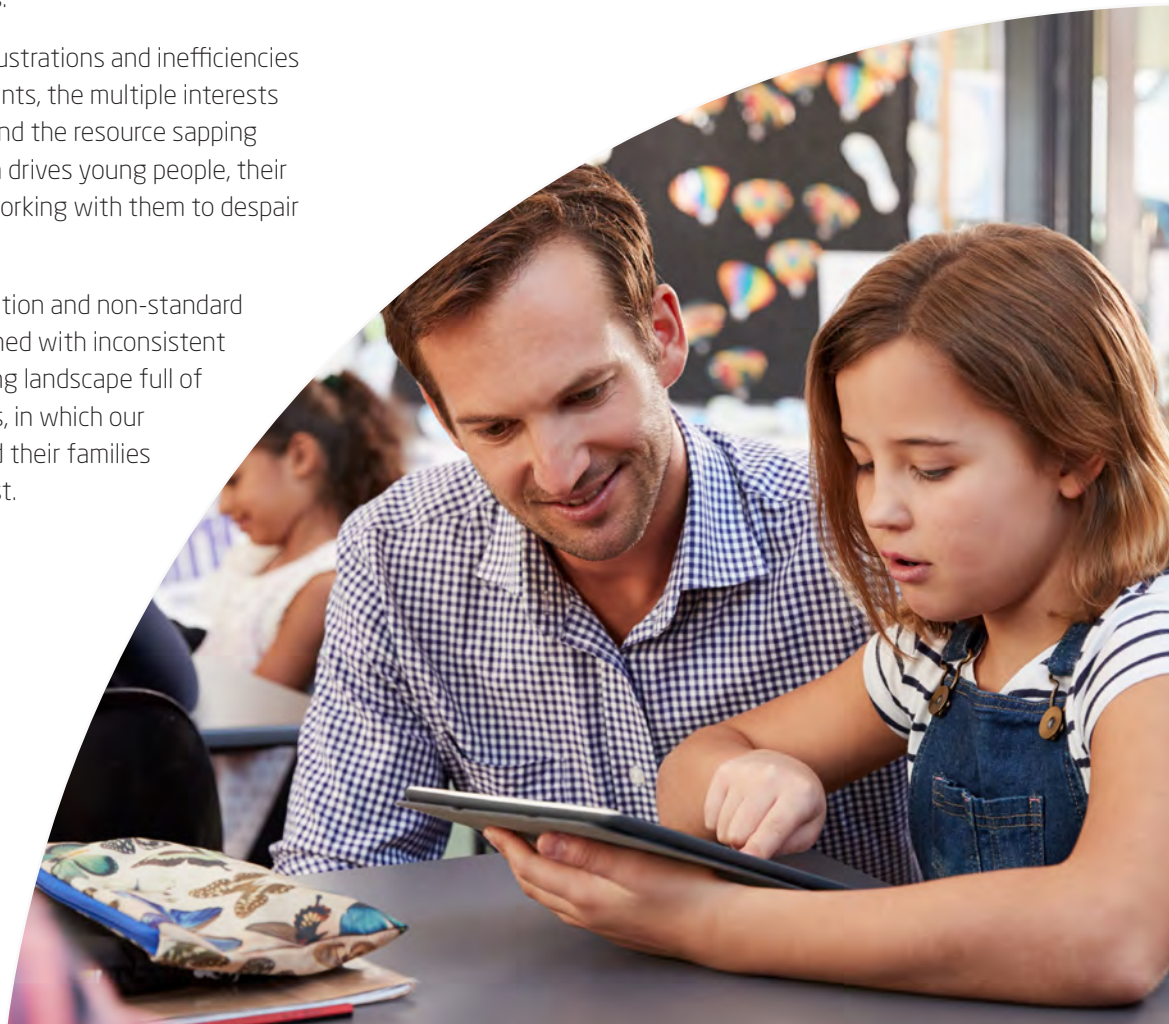
It accurately captures the frustrations and inefficiencies – the delays, the disagreements, the multiple interests working across each other and the resource sapping bureaucracy – that too often drives young people, their families and professionals working with them to despair and disillusionment.

It reflects how regional variation and non-standard ways of doing things combined with inconsistent provision creates a mystifying landscape full of cul-de-sacs and wrong turns, in which our most vulnerable children and their families are often bewildered and lost.

It appreciates how hard it is to regain purpose and momentum once things have begun to go wrong stating that: "carers and providers alike do not know what is reasonable to expect from their local systems."

This sort of honesty is welcome.

A lack of clarity around exactly who is responsible for what, is a source of many of the disagreements and frustrations between families and professionals. Those of us who contribute to EHCPs in school know just how difficult it can be to agree exactly who should provide a service, by when and who should be held to account – and how this creates unpleasant tension that can unhelpfully damage important relationships that work best when they are free of conflict.



Many of the proposed solutions are sensible too – particularly consistent national standards for how special educational needs are identified and met, standardised approaches to EHCPs across the country and greater clarity around what can be expected. The current EHCP system is a source of enormous inefficiency and the current postcode lottery where children with complex needs get varying levels of support depending on where they live is clearly unsatisfactory.

Overall, the Green Paper frames these different problems through three challenges:

1. Outcomes for children with SEND are poor.
2. Navigating the SEND system is not a positive experience for children, young people and their families.
3. Despite unprecedented investment, the system is not delivering value for money.

We recognise these challenges and are supportive of any reform that will help to improve the efficiency, effectiveness and user experience of the SEND system.

But we think there is a fourth and more fundamentally important challenge the Green Paper does not recognise. Special Educational Needs and Disability is still framed within a deficit narrative – it conceptualises learning

disability and special educational needs – and by association, the people with them – as something wrong that should be fixed.

We think there is an alternative lens through which to consider SEND reform – one in which we see all people as complete in their humanity as opposed to having something missing or broken. This lens would allow us to see ability and disability not as binaries, but as a continuum through which all of us move at different points in our lives.

As Leora Cruddas, chief executive of the Confederation of School Trusts says:

‘It is important for us to move on from a deficit narrative built around the medical model of disability to a more inclusive and socially affirmative narrative of human flourishing.’

The challenge, the problem to be solved, is the education system’s (and indeed, wider society’s) approach to disability, not children and young people with disabilities themselves.



Deficit narratives

When we compare outcomes of children with special educational needs to those without, we risk implying that success always looks the same. This can imply that disability or greater need is something to be educated out of someone – even a defect.

We see this in the application processes for support such as Education Health Care Plans (EHCP), Disability Living Allowance (DLA) and respite care where to access additional support, parents and professionals must gather evidence which demonstrates that a child is so behind their peers they can't possibly catch or keep up without additional resource. For children requiring most support, the process of receiving an Educational Health Care Plan (EHCP) requires evidence that at each stage of a lengthy process, the different interventions that were planned and provided had failed.

The intent is not malicious – a way of identifying children who need support is necessary – but the process is unpleasant and lacks dignity.

To access help, a child needs to be seen to fail at things other children succeed at. Professionals and parents who navigate this process both know this. Ben says that

'We were warned about it - told from the outset the process we'd need to get Bessie help would be unpleasant but like many other families - were advised not to let our love get in the way of confronting objective reality - as if all our positivity and joy was a childish fantasy that now needed to be shoved aside.'

We were advised by professionals to show her in the worst possible light - to hold our daughter up for judgement to strangers and provide evidence of her failure ourselves.'

No family should be subjected to this indignity.



It creates the sense that the world sees your child as worse than other children, and this can create adversarial relationships between families and the education system. Tom says that:

'The Ups 'n' Downs parents WhatsApp group is often full of joy, support and inspiration. But it is also a place of anger, sadness and frustration as parents support each other through difficult processes such as school applications, EHCP assessment and Disability Living Allowance applications. As specialist services have become more stretched and access to support more sought after, these processes have become even more bruising.'

'I believe the education system is full of good people who care about the inclusion agenda and act professionally and with compassion on an individual basis. Yet collectively, the way we act as a system often lacks respect and dignity towards children with disability and their families which leads to unhelpful conflict.'

As Barney Angliss writes in the researchedED Guide to SEND, "it often seems the only way for young people with SEND – or their parents and carers to get help... is to characterise themselves as 'impaired', somehow less."

This deficit framing of learning difficulty and disability is widely established within the SEND system and underpins the foundations within the Green Paper.

The Key Facts section of the paper notes that – for example – the average attainment 8 score for KS4 students with SEND is much lower than for those without any identified needs and uses this as an example of evidence things are not working.

Most children who find learning significantly harder end up with lower grades than those who don't.

Of course they do and we should not be scared to say so. This doesn't mean there is something wrong with these children. Equally, this is not an excuse to give up on them – every child is entitled to the expertise which enables them to learn well, to be challenged and to achieve ambitious things.

Deficit narratives around disability are embedded in our system, partly as a result of outdated medicalised models of disability. We think there can be a better way for society to identify those who need more help and to offer support without such humility and indignity. To do this, we think it is important to consider the wider forces at play and the concept of the meritocracy, a dominant organising principle of society.



The Meritocracy

The term 'meritocracy' is the ideal of success, status or power being distributed on merit (talent, accomplishment and hard work) rather than through other means such as social class or on a hereditary basis. It's the ideal of people getting further in life not because they were born into it, but because they earned their success.

We hear the language of meritocracy in everyday language such as:

You can make it if you try.

You make your own luck.

Work hard at school and you will get good grades, go on to university, get a good job and lead a happy and successful life.

Or more negative variants such as:

If you don't work hard and get good grades, you will end up stacking shelves at Tesco's.

You'll waste your life doing that.

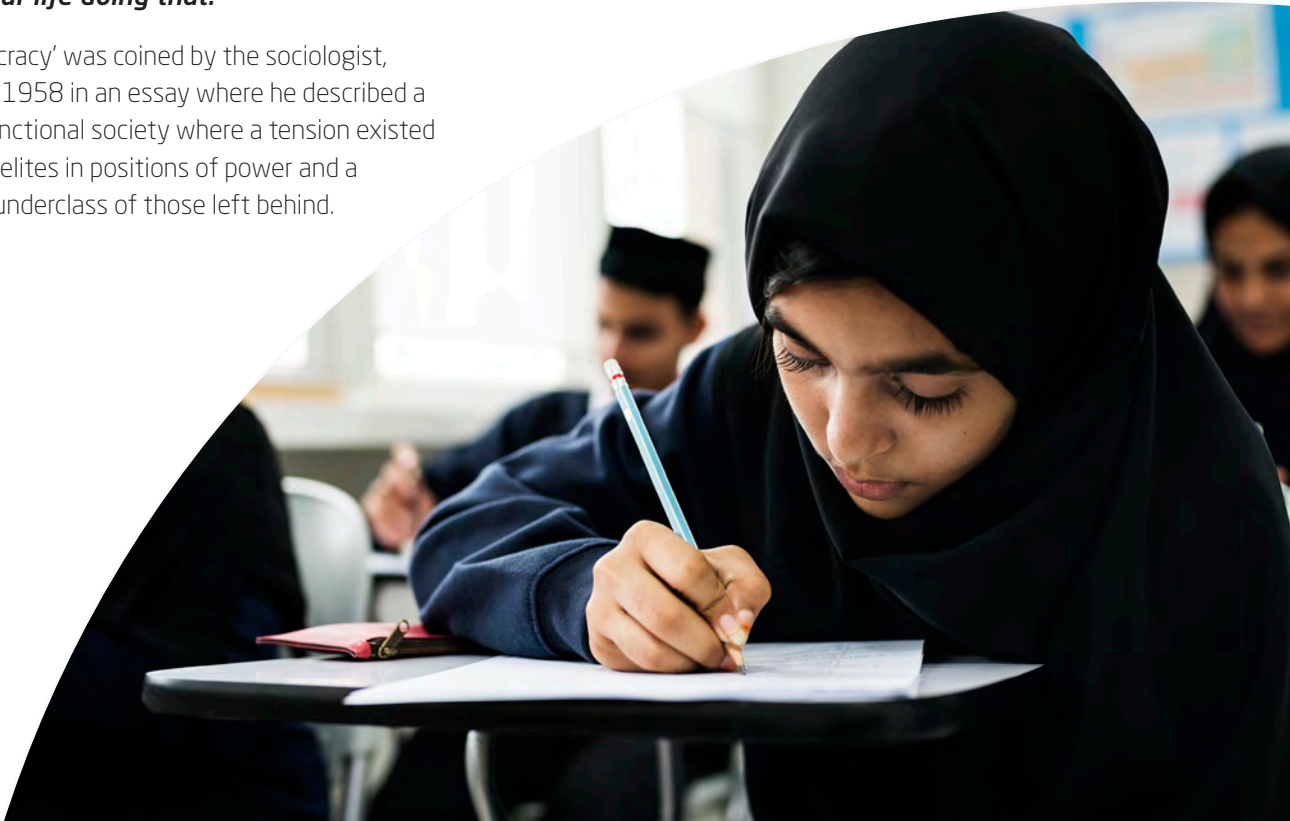
The term 'meritocracy' was coined by the sociologist, Michael Young in 1958 in an essay where he described a future and dysfunctional society where a tension existed between high IQ elites in positions of power and a disenfranchised underclass of those left behind.

In Michael Sandel's 2020 book: The Tyranny of Merit, he argues that these narratives of meritocracy have become increasingly common in western society. It's the American dream: the belief anyone, regardless of where they were born or what class they were born into, can attain their own version of success in a society in which upward mobility is possible for everyone (Sandel 2020)

But listen more closely to the meritocratic rhetoric: 'everyone can rise', 'you can make it if you try', 'what you earn, depends on what you learn'. Compelling no doubt, but is it true?

Sandel argues that during this same period of increased faith in meritocracy, social mobility has actually declined and highlights four failings:

1. It doesn't deliver the social mobility it promises
2. It creates losers as well as winners
3. It creates the hubris of the successful
4. It leads us to a narrow vision of what a good life is



1. The meritocracy doesn't deliver the social mobility it promises

Sandel points out, in countries where the narratives of social mobility are strongest, there is in fact less equity and social mobility than in others.

In England, from the perspective of narrowing educational gaps between children from high- and lower-income families, our school system has so far failed to tackle educational inequality. Children from low-income families start school four months developmentally behind those from more affluent backgrounds. Despite over a decade of pupil premium funding and a national focus on 'disadvantage', the gap doubles by the end of primary school, and doubles again by the end of secondary school to nearly 20 months (EPI 2019).

The attainment gap is not a problem found only in schools assessed by Ofsted as performing poorly – in fact, it's just as large in schools rated 'Outstanding' as it is in schools rated 'Inadequate'.

2. The meritocracy creates losers as well as winners

It's easy to talk about the ideal of jumping up a social class or rags to riches tales of people who 'make it' against the odds. But the reality is that these stories are against the odds and not typical.

They also often fail to acknowledge the uncomfortable truth that for someone to become a winner, it must happen at someone else's expense.

Meritocratic success is finite and there are a limited number of places at desired universities or top jobs.

There can only be winners if there are losers too. If someone 'makes it', someone else has not.

In a zero-sum game, being a winner requires someone else to be a loser and we're often not honest enough about this displacement.

This is true also in a school setting. For every celebration we hear of someone 'moving up a set' or 'making the team' there is someone else who travelled down.



3. The meritocracy creates the hubris of the successful

The meritocracy leads us to believe that if we achieve well, it's because we deserve our success - that we earned it through our own hard work and talent.

This leads to the hubris of the successful, the belief our success comes through hard work or talent, rather than because the odds were stacked in our favour, or we were in the right place at the right time.

But if we believe that those who are successful deserve it and got there through hard work, we must also hold the same belief for people who are less successful – that their failure is deserved and linked to their lack of hard work. People who experience success might not say this out loud – they might not even consciously think it but one cannot believe that success is deserved without also believing that failure is deserved too.

In a school environment, this is damaging for those who don't achieve, not just for children with learning disability but for the 30 percent or so of the school population who leave primary school without an expected standard in reading or mathematics, the third of children who leave secondary school without qualifications that enable them choice. A life with reduced status, choice and opportunity, and an implicit meritocratic belief from society that this is deserved.

4. The meritocracy reinforces a narrow set of ideals about what a good life is

Sandel argues that we've become more fixated as a society on a particular type of success, one that is recognised through credentialism: qualifications, exams, and particular professions.

This credentialism has become an almost singular focus of our education system which leads, in turn, to a narrow conception of what a good and worthy life is. The section in the Green Paper of describing the gap in academic outcomes between the overall population and children with special educational needs and disabilities is an example of this. This effect is magnified by the sorts of people who teach in and lead schools who almost by definition are those that have succeeded at education. This can make it harder for them to see and recognise other forms of success.

This leads us to a central challenge for our school system and society: for children who don't leave school with academic credentials, where is their dignity located?¹

If we are to take this opportunity as society to think again about the place for those with special educational needs and disability, we must be able to make fuller and more inclusive articulation of what a good life is, and what it could be.

1 A phrase attributed to Michael Merrick, primary headteacher

So far in this paper, we have highlighted two challenges.

Firstly, the current SEND system rests on an outdated medical and deficit model, where to receive additional support in schools and throughout life, people with disability and their families have to demonstrate failure, regularly and repeatedly.

Secondly, this problem of deficit framing is located within the wider societal issue of the meritocracy, life's 'sorting principle' which has narrowed what we perceive a 'good life' to be and what is valued by schools and across society.

This status quo is unnecessarily disrespectful, undignified and discriminatory for people with learning disability.

It is unrealistic to think that SEND reform in England's schools can fix what are wider societal problems, but we do think that reform, along with the influence of schools and Trusts, can play a key role in helping to move us forward. Within the second half of this paper, we explore two principles that could help us make progress towards more people living with greater recognition and dignity:

- 1. People with learning disability are complete humans.** They are not broken and do not need fixing. We can treat them with greater dignity, avoiding deficit language that suggests they are special cases or somehow worth less.
- 2. We need a broader and more ambitious vision of what a good life is.** Human flourishing and dignity for all, requires us to have a wide set of success measures. Placing greater value on things such as contribution, difference, common values, and the process of learning and work itself, can provide a healthy balance to meritocratic values of academic credentials, occupational status and wealth.



Complete humans

'We all have the same twenty-four hours' is a common saying which badgers us towards greater productivity. The idea is that we should take pride in our achievements and not look for excuses if we aren't as successful as someone else because we all have the same amount of time.

While this is of course technically true, in practice it is meaningless because not everyone starts from the same point. Some of us have more advantages and privileges than others do. Such sentiments also tend to be reductive and unimaginative because the sorts of achievements deemed worthy of celebrating are usually those that speak only to meritocracy. Running an Etsy side hustle that brings in thousands a year is good. Caring for an elderly relative less so. Achieving high scores in an exam is a cause for celebration. Being a caring and loyal friend is rarely recognised with instrumental reward.

Purely meritocratic measures of success impoverish most of us.

By measuring everyone with the same ruler and only with this ruler we construct some people as failures and narrow the range of things for which humans can achieve honour and dignity.

This is of concern to us.

Ben's daughter, Bessie, has Williams Syndrome and is unlikely to ever become a famous millionaire businesswoman, singer, or nurse. Tom's son, Freddie, has

Down's syndrome, Autism and due to early childhood epilepsy is mainly non-verbal at 16 – it is unrealistic for him to become a doctor, a teacher or to hold a position of public office.

Ben says that:

'Bessie is a typical five-year-old in many ways.

She learns phonics and numeracy at school and spends much of her time playing babies and cats with her sister, Rose.

There are differences too.

Her learning disability means she is already behind most of her peers at reading and counting.

This gap will almost certainly widen but this does not mean there is anything wrong with her.

Williams Syndrome is part of what makes her the person she is. It is part of her personal charisma.

It is why on the first day of school when far more academically able children struggled, she placed herself on the threshold smiling and beckoning them in.

Her learning disability is part of why her twenty-four-hours - and those of her family - are so full and rich. It is an inherent and immutable part of what makes her, her.'

There are no better versions of Bessie and Freddie without their learning disabilities living in parallel universes.

They will always have them. Nothing has gone wrong. They are not unwell. They are fine as they are and only as imperfect as every other human.

We know Bessie and Freddie are not typical of all children with SEND.

Many children identified as having SEND have medical conditions which rely on the medicalised model and a system of diagnosis and allocation of resources, treatment, or care in order to keep them safe and in some cases alive. There are many children identified with disabilities who are perfectly capable of achieving typical measures of success.

These contradictions are at the heart of the challenge between the damage of the medicalised model, but also the necessity of it in ensuring that we do not lower our expectations for children with particular conditions.

We understand this well because we have high expectations too.

We want our children to do as many of the other things in life that others do – if possible, to read, to add up, take-away and multiply. Ultimately to understand more about the world they live in and to make their own contribution to it.

We also want and expect our children to get extra help. We do not want the adults in their lives to say things like ‘bless their heart’ while allowing them to spend all day playing in the sandpit because this is what they say makes them happy. While this may appease them it would be an affront to their human dignity.

We want them to be known, identified, and properly supported. We want them to be challenged – to have teaching which is expert, rigorous and evidence-informed.

The beginning of resolving this apparent contradiction – between helping with need but also affirming them as individuals – is understanding that what means that an individual may struggle more than others is not a fault to be educated out of them.



The Green Paper is not framed in this way.

Instead, it implies that if we intervene early, we can stop children developing SEND or make their SEND less severe, and by doing so better equip them to compete in the meritocratic battle of life.

This of course is true in some cases. For example, young children who are slower to acquire speech and language, are often classified as having SEND as a mechanism to access more specialist support and are then typically declassified as having SEND once they reach a particular level of proficiency. We could argue that in this case, a label of SEND is unnecessary – what a child needs in this situation is the right expert input, not a label of SEND. A counter to this would be that within the system we have with limited expertise and resources, a label helps as a way of accessing that support.

Even if this paradigm is useful for some children, it is exclusive to others and it means framing those who find learning hardest as problems.

There are lots of people who find learning hard, who don't achieve things that are deemed valuable by mainstream society and who are unlikely to win many existing competitions.

By making the value of humans contingent on their ability to excel in such a narrow sense, we strip away their dignity.

This is what deficit framing does.

It is the reason a father of an eleven-year-old with autism once told Ben in a meeting “I just want him to be normal” before breaking down into tears of defeat and shame at what he'd just said.

It is why any ambition to reduce the level of SEND among England's children by teaching it out of them is misguided – it legitimises the sense there is something wrong with you if you can't learn as quickly as others.

And this isn't just about children with SEND.

In assuming failing to learn quickly and meritocratically achieve is a defect, it confines all but those who are the highest and fastest fliers to failure. We think we can do better and that all children and their families are entitled to a more ambitious and fuller articulation of what a good life is.



A broader conception of a good life

It is comforting to believe that meritocratic talent is distributed evenly and is something in everyone just waiting to be unlocked, and the reason not everyone is able to rise to life's top table is because we are doing education wrong.

This sort of thinking is well-intentioned. It moves the blame for bad outcomes away from those who struggle and places it on a failure of our education system. If it were true, we could solve these problems by working on radical pedagogies that would unleash this, in order to give everyone the same chance in life as each other. But it isn't true.

While as humans we are of inherent equal value this does not mean the most meritocratically advantageous capabilities are distributed equally. To pretend otherwise is a fiction we tell to make ourselves feel better about society's inability to properly include all its members because it fails to recognise human value as inherent.

Our squeamishness about confronting this is unhelpful.

We hear our society's defensiveness about facing up to who our children really are when parents like us are told they have 'delays' in learning, as if struggles at communication or reading are just speedbumps on a road to the same place everyone else is going.

Tom says:

'Adele (Tom's wife) and I sat through at least 5 years of nursery and primary school parents' evenings being told that 'Freddie's not mark-making'. It became a joke between us: if one of us couldn't get to the parents' evening, the other would say 'guess what they said?'

'He's still not mark-making?'

Freddie doesn't write. I don't think he'll ever write - he doesn't need to.

So why does he need to mark-make? And why did we as parents need to spend 5 years having written reports that told us he wasn't doing it very well?'

This is an example of the school system placing everyone on the same path – where difference is seen as a delay and ultimately failure. To state that not everyone can achieve the same things is not to fall into the trap of determinism – we are all capable of learning well through the expert help of teachers, but meritocracy cannot be the only thing we value.

A first step towards more genuine inclusion could be to widen the things we value and view as success. This means celebrating more everyday success – things that matter to families and communities. It could also include placing a higher value on the process of work and learning for the sake of contribution; learning new and challenging things well, not just because of the salary or exam result. Only a few can earn the highest salaries or reach a particular academic standard, but everyone can enjoy the dignity that comes from making a contribution through good work and committing to the struggle of learning something well.

A broader conception of good life also means moving on from a celebrations of disability achievement that – despite being well-meaning – reinforce meritocratic ideals. This can be seen in the attention given to Special Olympic success and stories about those with learning disabilities achieving mainstream qualifications. While such stories are inspirational, without examples of other sorts of success they make things harder for those with

the most profound disabilities because they expose them to fundamentally inappropriate measures. To be fully inclusive we should celebrate more everyday milestones too – a young man learning to tell his family what he'd like to eat for breakfast or a teenager learning to tie her own laces.

At this point, it is important to say that despite our criticism of the meritocracy, its credentialism and narrow conceptualisation of 'a good life', we are not making an argument against a focus on high academic achievement in schools, exams, or performance tables.

On the contrary, we believe that these things have value and are important tools in advancing education, just as having an Olympic Games does not devalue the achievements of those of us who don't exercise at international athletic standards.

High academic achievement and strong exam results are legitimate aims and to suggest that we shouldn't value them, because not all children can excel at them, would be a mistake. It would damage the life chances of millions of young people capable of better academic outcomes and meritocratic success than they might realise.

We should celebrate ten grade 9s at GCSE as impressive. Just as we should celebrate Usain Bolt's 100m world record.

The problem is not that there is anything wrong with celebrating achievement, it is just we've got a bit lost and come to see meritocratic performance

indicators – like exam results – as virtues in themselves rather than being potential contributors to a good life for those capable of achieving them. A narrow vision of what learning is for and what a good life is, puts it out of reach for children like Bessie and Freddie and impoverishes the endeavour for everyone.

How then might we educate children of all abilities in ways that allow them recognition and honour for their work regardless of whether it results in academic or normative success? How can we show children that they don't need to be a celebrity, achieve top academic results or move out of their communities for a high-powered job to be valued within their communities and to make a contribution to the world?



Ways forward

So far in this paper, we have identified challenges within the existing SEND system which create a deficit paradigm in which people with learning disability exist. We have located this within a wider societal challenge, arguing this is a symptom of the meritocracy which values a narrow set of things including academic credentials, wealth and occupational status. We have suggested two principles that could act as helpful counter narratives: first, that we should see people with learning disability as complete humans, and second, that through valuing a broader range of things, we can create a wider and more accessible vision of a 'good life'.

The meritocracy is an established principle of free society and brings many benefits. Even if we wanted to, it is unlikely to be something that we could change overnight so this is not a call for revolution or to suggest that we should re-engineer society from first principles. Rather, it is a suggestion of how we could live more compassionately, with greater human flourishing within the realistic constraints of the society that we have.

As Sam Freedman writes:

'...the raft of books about the limits of merit is an important correction to the arrogance of contemporary entitlement and an opportunity to reassert the importance of luck, or grace, in our political thinking. The more we are able to accept our achievements are largely out of our control, the easier it becomes to understand that our failures, and those of others, are too. And that in turn should increase our humility and the respect with which we treat our fellow citizens. Ultimately, as the writer David Roberts put it: "Building a more compassionate society means reminding ourselves of luck, and of the gratitude and obligations it entails."'

(Freedman, 2021)



Can the Green Paper help us make progress?

The Green Paper proposes several things which we described earlier as a step in the right direction, including a commitment to establishing new national SEND standards.

If developed and implemented well, national standards could help establish much higher and consistent expectations for children with SEND in different areas. One such area could be a much greater level of due diligence and consistency for the process of identification of SEND, including the mechanism for how children are placed on a school's SEND register. A label of SEND in and of itself, does little to identify any specific need and, worryingly, can often lead to children spending less time with a qualified teacher and accessing expert support. History also tells us that well-meaning reform to encourage inclusion can often have unintended consequences. The 2016 GCSE cohort which left Year 11 with 39% of children being identified as having SEND at some point is one such example.

National standards could also help us move beyond a focus on 'additional and different' provision and towards more expert and rigorous, specific teaching for children with SEND. Children who learn slowest do not learn in fundamentally different ways yet the existing definition of SEND in the current Code of Practice describes provision which is 'different from or additional to that normally available to pupils of the same age' (DfE, 2015). Standards and policy reform which stops incentivising schools from evidencing 'additional and different' and instead encourages more widespread expert practice, informed by high quality and relevant research could be an important paradigm shift. This is something that's been said well by SENDCo Nicole Dempsey, who says of her school Dixons Trinity Academy: ***"The quality of input, high expectations and staff accountability that we apply to our highest attaining learners is the right of all pupils."*** (Dempsey, 2020).

Consistency, higher expectations of expertise, evidence and decision making are all important aims for SEND reform, but there is also an opportunity to use national standards to address the challenges of dignity and deficit framing within the SEND system.

For example:

National standards for SEND to address the challenges of dignity and deficit framing within the SEND system.

- ***Affirmative language:*** the use of affirmative and respectful language and narratives, which avoid the unintended consequences of deficit framing that exist within the current SEND system.
- ***Dignity of process:*** an expectation that a process of accessing additional support should treat people with dignity and respect, rather than requiring them to demonstrate repeated failure.
- ***A broad view of success:*** the importance of recognising a broad range of success measures when working with children who have learning disabilities, rather than assuming that success looks the same for every child.
- ***Need vs. identity:*** a clear understanding of the difference between specific learning difficulties that can be overcome, as opposed to the variation in rates of learning that are part of who someone is.

A call to leaders for action

In 2003 Paul Farmer, a doctor working in the developing world was quoted on how he kept going in the face of seemingly endless frustration in Tracey Kidder's "Mountains Beyond Mountains":

He said: "We want to be on the winning team, but at the risk of turning our backs on the losers, no, it's not worth it. So you fight the long defeat."

What Farmer meant was that his motivation was the personal moral price he'd pay if he abandoned those whose circumstances meant almost inevitable tragedy.

Fighting the long defeat has gone on too long in the world of SEND and learning disability.

There are many who know the challenges that we have discussed in this paper well and who have committed their lives to making progress towards more genuine

inclusion. But the conversation is often confined to a limited and relatively small proportion of those with the power and influence to make progress. It is an issue which is often left in the 'too difficult' pile.

We are grateful to the Confederation of School Trusts for their leadership here. Through their signalling of the importance of this issue and by inviting us to write this paper, we hope to make a small contribution to generating debate and widening the conversation.

Thank you for reading this far. As someone reading this paper, it is likely that you are in a position of responsibility or power where your decisions, policies and language can have an influence on children, young people and professionals.



A duty of care

Although we have focused specifically in this paper on inclusion, and the opportunity to address this through planned reforms to the SEND system, there is a potentially bigger prize at stake.

In her keynote address at the CST conference 2022, Leora Cruddas talked of Peter Hennessey's recent book 'A Duty of Care'. In this, he argues that in the post-war period, it was a consensus around the need to take greater care of those who needed society to help them the most, which was at the heart of the Beveridge report in 1942 and then the great pillars of the Welfare State: Education for all, a National Health Service, and the establishment of the social care system.

Leora said the following:

"Professor Hennessey goes on to say that this concept of a duty of care should again define us as we learn how to live in a post-pandemic world with such political, economic, and social uncertainty.

I wish for this to be the basis of a new social contract with government and more widely with our parliamentary democracy. Hennessey says: "The great question of UK politics ... is whether we can find the pessimism-breaking policies, the people, the purpose, the language, and the optimism to shift [our current] system and replace it with something much closer to who we are and, above all, who we can be."

There are many societal challenges that require attention, yet our resources are finite. We emerge from a global pandemic into an unsettled world of conflict and polarisation where continued growth and prosperity look uncertain and our relationship with the planet requires urgent rethinking.

Building consensus on what to focus on is hard and there will be difficult decisions to make.

Getting this right will mean remembering why we bother with the notion of growth and progress at all. If this isn't to advance human flourishing, what is the point of any of it?

A renewed duty of care will need to incorporate many of today's pressing issues, but it is both essential and urgent for it to reconsider how we look at special educational needs and disability in our schools and across society. We cannot allow this opportunity for reform to pass us by without making significant progress.


And on this final thought, we would like to end with more of Leora's words from her conference speech that have motivated us to write this paper and we hope will encourage others to take action too.

"We do not need to wait for a political settlement - it is within our gift to find the people, the purpose, the language, and the optimism to shift our mental models, to see education as the building of who we can be.

"So, let us reflect on the great issues of our day. Let us lead with an understanding of our educational history and with the sharp intellect that seeks to cut deep into inequalities and social injustices in the fabric of our society. Let us lead with kindness, compassion, and a duty of care.

"Colleagues, I say to you today: we can do this."

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