



Right To Review *Project Report*

Parent responses to the SEND
Review and participation in the public
consultation process

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Summary

The UK Government Green Paper 'Right Support, Right Place, Right Time', known as the SEND Review, was published in March 2022 followed by its Improvement Plan in March 2023.

The Right to Review Project at Sheffield Hallam University interviewed twenty one parents of young people with SEND during the March-July consultation period to document their responses to the SEND Review and the reasons they did or didn't take part in the public consultation process. Parents in this project had extensive knowledge of the SEND system and had spent significant amounts of time and energy engaging in the SEND Review, yet a strong sense of their voice in the recently published SEND Improvement Plan is missing.

- Parents were empowered by each other. Many took part in the consultation despite finding it difficult, onerous, and emotionally draining, to advocate for and support other families. A recurring theme was that parents wanted young people in the future to have a better experience of education than their own families. They felt a sense of responsibility and ownership to contribute to the consultation despite personal reservations that their views would result in change.
- Parents were disempowered by the Review. They felt it did not represent their experiences of the SEND system nor give them trust or confidence that the proposed reforms will improve their families' lives, despite this being an explicit aim of the Green Paper.
- The Review undervalued young people and was not for, or about, their lives. Parents noted the absence of proposals relating to improving inclusive practice, and the density of proposals centred around funding and cost-saving.
- The Review was inaccessible to parents, despite government Consultation Principles that consultations should be 'clear and concise' and 'take account of the groups being consulted' (Cabinet Office, 2018). Parents told us that the document was too long, the language was too opaque, the proposals were too vague, and that both themselves and their children were positioned as problems. They had strong feelings about the lack of opportunities for young people themselves to participate in the consultation.

Summary Recommendations

1. The SEND Review as a public consultation exercise was inadequate and inaccessible. Co-production with young people and families must underpin any future reforms, including future consultations. This means actively designing co-production with a diverse range of people in mind, including those that communicate using modes other than speech and facilitating their participation in consultation processes.
2. Young people are entitled to have an agentive voice in policies about their lives and their futures. Disabled People's Organisations (for example, [ALLFIE](#)) and young people directly advocating for themselves (for example, [Spectrum Gaming](#)) must be front and centre of the development of consultation processes and the contribution to their content.
3. Those constructing consultation documents must consider the implications of the language choices they make and the disempowering effect these choices can have upon those that it speaks of (see Pluquailec & O'Connor, forthcoming).
4. While these recommendations are particularly pertinent in consultations for young people with SEND, it is evident that they are significant to consultations across a broad range of policy domains.
5. The pendulum must swing away from parent-blaming and towards Local Authority transparency, accountability, and compliance. Parents were clear that they did not see current failings in these areas being improved by the proposals in the Review.
6. The ever-increasing numbers of tribunals will not be quelled by imposing further barriers to redress in the system. Parents were clear that the reasons for pursuing tribunals were a lack of compliance with the law in Local Authorities. Evidence elsewhere is inline with these parent reports (Ministry of Justice, 2022, Ombudsman for Local Government, 2022; IPSEA, 2022).



The Project

The Right to Review project was a snapshot of a significant moment in the policy landscape of children and young people with Special Educational Needs and Disabilities (SEND) following the long-delayed publication of the government's SEND Review (Department for Education, 2019). 2014 saw the biggest SEND reforms in over two decades (SEND Code of Practice, 2014) responding to the Lamb Inquiry's (2009) identification of a culture of low expectations and a failure to deliver what children and families needed for a full and successful education.

Well over a decade on from Lamb, and a further eight since the Code of Practice (CoP), lack of ambition continues, and Local Authorities are routinely found not to be implementing key areas such as co-production with families or joined-up working between health, education, and social care (UK Parliament, 2021; Ofsted, 2021; House of Commons Education Committee, 2019; National Network for Parent Carer Forums, 2019).

Poor family experiences of the SEND system are evidenced by a year-on-year increase in SEND tribunals since 2014, with the most recent data showing 96% of cases being found in favour of the appellant (Ministry of Justice, 2021). The SEND Review was a watershed moment for policymakers, practitioners, and families to restore faith in the system of enacting aspiration for disabled children, or a further entrenching of existing problems (Lamb, 2021).

Early analyses since the publication of the Green Paper were critical of both where in the system the reforms are targeted (oral evidence at House of Commons Education Committee, 2022), and the significant over-hauling such proposals would require of the current legal framework (IPSEA, 2022).

This project asked the following questions:

1. What are parents' responses to the SEND Review?
2. What are the reasons for parents' non/participation in the SEND Review public consultation?

Methods

Between May and June 2022, six focus groups and two individual interviews were held with parents and carers of young people with SEND. The majority were facilitated online across the geographical spread of England alongside support from Sheffield Parent Carer Forum and specific sessions for ACCT Sheffield and Sheffield Downs Syndrome Support Group. In total, we spoke to 21 parents. 9 parents returned to take part in a collaborative workshop to write a collective submission for the Green Paper consultation, the visual outputs of which can be viewed [here](#).

Our approach in this report

Whilst we report on parents' responses to the SEND Review we are mindful that we do not perpetuate the harmful positioning of parental knowledge and feelings that many families in the SEND system have experienced. Representing parent responses as a key source of expertise and acknowledging the significant amounts of emotional labour parent advocacy requires in both research participation and policy consultation, is a difficult task. So whilst we report on parents' 'feelings', we recognise that these feelings must be valuable and valued sources of knowledge, as one parent articulated:

"I think that there is a lot of professional privilege given to teachers, social workers, paediatricians, and anybody that wears a badge, but a parent has just feelings. Just feelings. And it's a very subtle use of language to minimise the truth of what's going on."



Findings

1. The SEND Review proposals did not restore parents' trust and confidence in the SEND system

Two key related themes that ran throughout parent responses were empowerment and more notably disempowerment. Parents showed us how the Review empowered professionals and local authorities while disempowering them and their children.

Many parents gave examples of times when they had felt disempowered in the SEND system, for example, by medical professionals, or by the professionals involved in Education Health and Care Plan (EHCP) processes. Many of these examples centred on involvement, or lack of, in decision making processes. While a minority had felt appropriately involved, most parents gave examples of where their voices felt silenced. While some described schools as being an example of where positive relationships had been established, a common example of where parents felt ignored was by those perceived as experts, who they were told not to question.

"The way I would sum up dealing with the system, it's like screaming into a void and trying to scoop the sound up with your hands all at the same time. It didn't seem to matter what I did, what I spent, what I do. You can't make it work for you"

Rather than see the consultation acknowledge these experiences, and seek to further develop positive collaboration, all parents who were familiar with the Review saw it as attempting to further shift decision making away from families. An example parents drew on was the proposal of a list of educational settings presented as families being given a choice (chapter 2, p.27). Parents felt that in reality, this would empower local authorities to influence this list and thus actually serve to limit parental choice. Parents talked about how the review perpetuated disempowerment and damaged their confidence in the system.

"It is soul destroying, and you feel you're very inferior. You feel inferior to be honest. Our children aren't worth it."

"It's about power. It's always about power. And we haven't got much power, and we want to try and make sure that our children have some power."

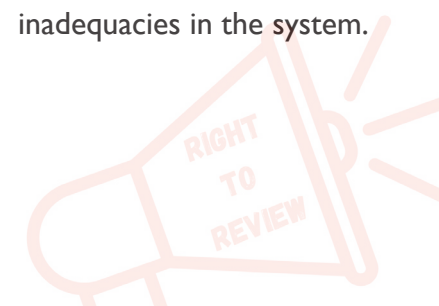
Parents reported only feeling empowered by each other. The majority of positive experiences were of mutual support from other parents (either individuals or parent groups/parent-founded organisations), with only a small minority coming from interactions with professionals.

"Lots of things I do are about making a difference for other people because that will then help us and that then means our bad experiences have counted for something."

The focus groups highlighted that parents' knowledge of the Review was very varied with little information being shared with them through official channels. Parents told us this perpetuated the disempowerment they had experienced elsewhere in the system when professionals were sometimes the only ones privy to important information and seemingly withheld or hidden from the view of parents. Many found out about the Review via social media, from other parents, parent groups, or support organisations. There was surprise from some that they had not found out from their child's school.

While most of the parents were aware of the Review, the majority had to independently search for details about its proposals, how it might affect their children, and how they could participate in the consultation. Given the government's own guidelines state the importance of ensuring target groups are aware of consultations and able to access them (Cabinet Office, 2018), parental reports suggest that the process did not achieve this. This failure to include, for many, resulted in a feeling of exclusion and as a result made the consultation a disempowering experience.

Parents told us that the way funding reforms were framed perpetuated a system that felt hostile to them and their children, a system where they had often experienced being blamed for both their child's difficulties and the system itself's failings. The Review emphasised ensuring fair distribution of funding (chapter 4, p.56), but to the parents, the implication was that existing inequalities of funding were the result of some families having more than their fair share. Furthermore, parent blaming (both implicit and explicit) was viewed as a deliberate act to draw attention away from inadequacies in the system.



“it felt like parents were a problem, and it was their perceptions that needed to be addressed rather than the provision”

“So to me you’re still cherry picking what you want to hear...I really would like to make a response and I would back up my response with data to counteract bringing it down to parental emotions...they’ve always blamed parents. To deflect from the fact that they’re failing our children.”

“I was going to try and start reading it again in a more systematic way, so that I can give proper feedback but it felt very anti-parent, I would say, and quite patronising – everything was directed at schools and what schools needed to do, and there was nothing on what local authorities and health providers and most importantly the DfE needed to do.”

During the focus groups, the parents shared situations that caused them to feel devalued. One parent quoted p.10 of the Review document, which said ‘Too many parents and carers do not feel confident’ (regarding mainstream provision) as an example of this. They explained that by writing in terms of parents’ feelings the Review implied it was the parents’ view of the process that was at fault, rather than seeing this as evidence of a real problem - inadequate provision and lack of inclusion.

“‘Too many parents and carers do not feel confident’ and so it’s about our feelings and our confidence and not about the extensive evidence that we have that things are really fundamentally quite a mess. And it’s a way of, I think, devaluing and downgrading those contributions. And it talked about, from what I remember, it just talked about children and young people with SEND very much as objects, almost. So it felt like parents were a problem, and it was their perceptions that needed to be addressed rather than the provision and the quality or range of settings, and the woeful lack of inclusion in mainstream schools, in any kind of meaningful sense at all”

2. The Review devalued young people by being neither about nor for them.

From the perspective of many of the parents who took part in the focus groups, despite mentioning young people, the Review was not about or for them nor the quality of their education. Instead, it was felt to be about minimising the challenges that young people present and focused on the system and the changes that would benefit it. This was frequently expressed through a view that the Review was predominantly about funding rather than their children’s futures. Parents’ felt the Review suggested that the cost of support needed to be justified by longer term return and they feared some young people might not be considered worth supporting.

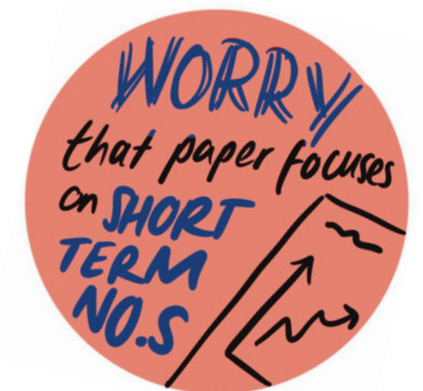
“at the very root is a child not being supported while the government’s agenda is economics, politics, conformity, and whether or not this child is worth supporting, because is this child going to give back to us at the end of the day?”

Parents’ comments demonstrated how they had interpreted the financial framing of the Review and its proposals,

“one thing that I noticed, there is a statement somewhere about ‘the financial cost is unsustainable’. And that automatically sets off a red light of okay, they’re trying to save money”

Parents not only felt that the Review was prioritising money over young people, but there was also a sense for some that young people themselves were deemed unimportant.

“The children are not important to them, it’s about the economics...”



Many parents felt their children were viewed as burdens, not just in terms of financial costs, but in terms of the challenges they presented for inclusion. Parents' experiences of inclusion were varied, with some reporting a significant lack of inclusion for their children, and others sharing very positive experiences of successful inclusion,

"I'm happy, but she's in a mainstream school with one-to-one, and she is doing really well, so I can't speak for like a specialist school or anything, but the input that she's getting is pretty good I feel but then I've got nothing to compare it to".

A number of parents told us that within the Review young people with SEND were thought of as separate from other young people. This sense of separation from other young people was not just around need, parents reported seeing a disconnect between the SEND system and the broader education system.

"the fact that it's published in the same week as an Education Review [the Schools' White Paper] but it doesn't even speak to it, as if they are not part of the education system."

Many parents also felt that the Review should have been more accessible for young people themselves to contribute. Criterion 5 of the Code of Practice on Consultation (UK Government, 2008, p11) says, 'Keeping the burden of consultation to a minimum is essential if consultations are to be effective and if consultees' buy-in to the process is to be obtained.' The Review did not appear to be aimed at the young people for whom its suggested changes would most impact:

"I think there is a huge lack of consideration of the fact that young people might want to complete this."



"Like why can't my daughter be engaged in this, she is highly articulate, why can't they engage with her and say it's your rights, your responsibilities and you are a citizen of this country and it's all about you. Why can't the school engage, you know, – of course it affects me as a parent but it affects her a million times more... Just a bit more of an active ... It needs to be a longer process, it needs to be more accessible, and it needs to not start off with a massive document that tells us that we're the problem, basically."

3. The proposed reforms compounded parents' sense of voicelessness in the SEND system

While the SEND Review was intended to be an opportunity for stakeholders to contribute by sharing their views and experiences, there was doubt and distrust among the parents regarding the motivations behind this and the real role this was perceived to play in the Review process.

"I think that it's not addressing what I see as the main issues at all; as in literally not mentioning them, and the things that it's trying to do I think risk making things considerably worse in many respects. But I think that one of the things that is difficult to unpick is exactly where the red flags are, because lots of it is very vague, and the bits that are specific are really bad! So it's a bit like what is going to emerge from the bits that are vague, because they are consulting on something that you can't really give a response to because they're so vague. So it feels like there's a secret hidden agenda that has arisen because of who they have consulted with. I feel like they haven't consulted in a proper and meaningful way with disabled people's organisations, with disabled children and young people, except to add a glossy shine to things at the eleventh hour"

"I feel that we're going backwards again, we're going in a circle. We just keep going round and round. New idea. Try again. Try again. And very much that feel... looking at mediation for Educational Health Care Plans whereas parents are already saying it's difficult, it's really difficult, we have to go to tribunal and now it's like 'Well let's put something else in before we go to tribunal' and it just feels like they're already starting with a problem ... it feels like they have their solutions, but those solutions that they're offering aren't the ones that a lot of parents are looking for. So they are already putting something out which I don't think will work, and they're consulting. But I don't think what they're looking for is people to come along with brand new ideas. They want people to agree, and that is why I think it might not work."

This finding is important because disempowerment is not just frustrating for families, it has left them without an effective voice. Some parents had prior experiences of

giving feedback that they felt had made no difference which made it harder to believe anything would change by being involved in this consultation.

"I am sort of feeling no hope with this, and just despair. It just feels like they've got this massive agenda and I guess I just think that everything that came out of the education select committee inquiry has been ignored. And that was really powerful, massively powerful... So yeah, the whole thing is horrendous. That is my summary."

"I will fill in the consultation but I very much doubt it will make any difference, because they won't be asking the right questions and they won't be hearing what they need to hear because they don't listen. They don't know, yeah, they don't understand, they won't hear it, but I will fill it in anyway."

Although our questions to parents and carers were about responding to the Review itself, what became apparent is that there is often so much work, time, and distress involved in trying to ensure that young people's needs are met that this became an inevitable and significant part of almost every conversation.

"Parents go through a lot of stress fighting it out with the school, then they go through the stress of fighting out with the council, and then you have to go through the EHCP, the waiting, and then you get a document which partly has got misinformation..."

"It is not just a one-off fight, it's every step along the way."

For some, this ongoing fight to have their children's needs met presented a barrier to having the time and emotional energy to respond to the consultation,

"Who can take part? What do they have to sacrifice to take part?"

"I have completed it... it took me four days."

"What I do also feel really strongly about is I think that there are a lot of parents right now who are literally zapped of any energy and don't have the strength to read this"

4. Parents found the consultation inaccessible

Although Criterion 4 of the Code of Practice on Consultation (UK Government, 2008, p10) says, 'Consultation exercises should be designed to be accessible to, and clearly targeted at, those people the exercise is intended to reach', parents repeatedly told us that the consultation itself was inaccessible to them.

"I remember kind of making a pledge with myself quite early on, thinking if it needs input from me for it to happen I will do it, I won't have them missing out because of some inactivity from me, but what it's taken me has naively shocked me to my core. I am an optimistic person – I have become cynical and I have become jaded through this process."

"you had to have two documents open, you had to have the response document and you had to have the SEND document. Why you couldn't have had one that you read it and then typed in your answer I do not know, because that made it even more complicated. I often found... the bits that I wanted to respond to weren't the questions."

For others, there was a strong pull to respond despite, or sometimes because, of this inaccessibility.

"I had time to do it. And I feel if I don't put something in then I've not contributed. And I can't moan about SEND if I've not had a go at trying to change. I fully understand why faced with that document an awful lot of people either haven't got the time, the skill, the ability to do it. It is huge."

"It is really important and I do want to engage with it, because I think particularly that thing about the list of schools is just so horrific from my perspective that we have to engage in it, but I wish there were other ways to engage and there were ways to engage more directly and I wish I felt that my views would actually contribute to change... it does feel like I could spend lots of time reading a document that is really hard to read and really inaccessible that feels like They are not even going to take any of that forward. It's kind of time and access and all these kinds of things as well."



The final words of these findings go to a parent who took part in our collaborative writing workshop where parents came together to construct a collective response to the SEND Review consultation. This parent summarised much of what we had heard in this project about accountability, transparency, and honesty, and the group found her words to be poignant in articulating their feelings about their participation in the public consultation.

“...about accountability and transparency and honesty, and it’s just like – it’s like you are trying to make a cake and they are putting in eggs that are out of date and milk that is out of date and worrying about what candles to put on the top. Do you want a sparkly candle or a regular one? Forget about the candles, we need the eggs to be safe first. Do you know what I mean? It’s like all of these steps are being missed out.”

Recommendations

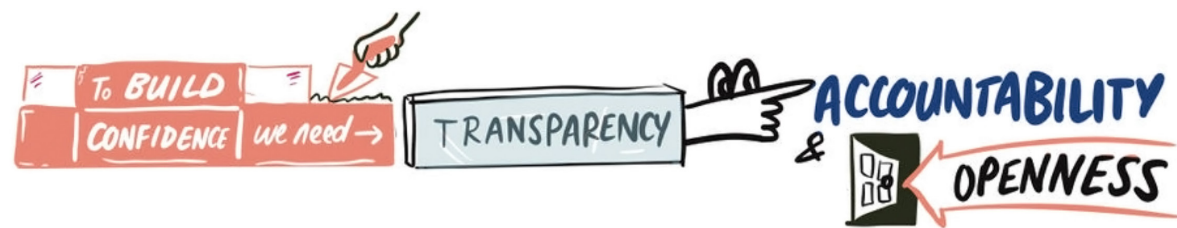
Future consultation processes

1. The SEND Review as a public consultation was inadequate and inaccessible. Co-production with young people and families must underpin any future reforms, including future consultations. This means actively designing co-production with a diverse range of people in mind, including those that communicate using modes other than speech and facilitating their participation in consultation processes.
2. Young people are entitled to have an agentive voice in policies about their lives and their futures. Disabled People’s Organisations (for example, [ALLFIE](#)) and young people directly advocating for themselves (for example, [Spectrum Gaming](#)) must be front and centre of the development of consultation processes and the contribution to their content.
3. Those constructing consultation documents must consider the implications of the language choices they make and the disempowering effect these choices can have upon those that it speaks of (see Pluquailec & O’Connor, forthcoming).
4. While these recommendations are particularly pertinent in consultations for young people with SEND, it is evident that they are significant to consultations across a broad range of policy domains.



Future SEND reforms

1. The pendulum must swing away from parent-blaming and towards Local Authority transparency, accountability, and compliance. Parents were clear that they did not see current failings in these areas being improved by the proposals in the Review.
2. The ever-increasing numbers of tribunals will not be quelled by imposing further barriers to redress in the system. Parents were clear that the reasons for pursuing tribunals were a lack of compliance with the law in Local Authorities. Evidence elsewhere is inline with these parent reports (Ministry of Justice, 2022, Ombudsman for Local Government, 2022; IPSEA, 2022).



Since the publication of the Green Paper, the country has had two new Prime Ministers, a new cabinet, and more than one new minister with responsibility for SEND. With the SEND system's long-documented failings and tribunal backlogs now spanning over an entire academic year, the government must address the parental concerns raised in this project and elsewhere in the community if it is to protect educational futures.



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