

Parental Experiences of the United Kingdom Special Educational Needs and Disabilities (SEND) Review Consultation

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ORIGINAL ARTICLE

Parental experiences of the UK special educational needs and disabilities (SEND) review consultation

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Abstract

This qualitative study explores the experiences of parents of disabled young people in the UK regarding their participation (or non-participation) in the 2022 Special Educational Needs and Disability (SEND) Review public consultation. The consultation followed the UK Government's Green Paper on reforms to the SEND system. The study conducted interviews and focus groups with 21 parents to capture their responses to the SEND Review and understand the challenges they encountered during the consultation process. Findings revealed that parents considered the consultation to be both inadequate and inaccessible, alongside a broader finding relating to parents' compounded experiences of voicelessness in the SEND system. This study calls for future SEND reforms, and their associated consultations, to be more transparent, inclusive and genuinely collaborative with both parents and young people.

KEYWORDS

disability, disabled children, education policy, parental experiences, public consultation, SEND, SEND reforms

Key points

- The SEND Review consultation reinforced mistrust among parents, who felt their concerns were undervalued and the system remained focused on managing budgets rather than addressing fundamental issues in their children's lives.
- Young people with SEND were largely excluded from the consultation due to poor accessibility and a lack of targeted engagement methods, despite being central stakeholders.
- Parents faced significant barriers to participation, including inaccessible documents and a lack of direct engagement opportunities.
- The proposed reforms were viewed as vague and disconnected from the real needs of families, leading to doubts about their potential to bring meaningful change.

INTRODUCTION

This article reports on a qualitative research project called Right to Review which took place in 2022. The Right to Review project explored parents of disabled young people's experiences of participating (or not) in

the UK Government public consultation about reforms to the special educational needs and disabilities (SEND) system. The 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 was a snapshot

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of a significant moment in the policy landscape of children and young people with SEND following the long-delayed publication of the Government's SEND Review (DfE, 2019). The project interviewed 21 parents of young people with SEND during the initial consultation period to document their responses to the SEND Review and the reasons they did or did not take part in the public consultation process.

CONTEXT

The 2009 Lamb Inquiry (Lamb, 2009), which reported a failure to deliver what children and families needed for a meaningful and successful education, resulted in the biggest SEND reforms in over two decades, culminating in the 2014 SEND Code of Practice, as part of the Children and Families Act 2014. Nearly a decade on came the SEND Review (DfE, 2022c). The Review was necessary as a response to the weight of evidence showing that many of Lamb's findings remained entrenched in the system, with local authorities routinely being found lacking in both co-production with families and joined-up working between health, education and social care (Commons Education Committee, 2019; NNPCF, 2019; Ofsted, 2021; UK Parliament, 2021). Compounding this need for further reform was data evidencing poor family experiences, with the number of SEND tribunal cases increasing year on year since 2014, and those cases consistently being found in favour of the appellant, some 98% as of 2023 (Ministry of Justice, 2023). As such, the SEND Review was a significant moment for policymakers to re-enact aspirations for disabled young people or further entrench existing problems (Lamb, 2021). Initial sector responses to the Review proposals for reform were frequently critical. IPSEA (2022) identified that the implementation of certain proposals in their fullest sense would require a significant legislative overhaul, something that was not a stated aim of the reforms. Evidence given to the Commons Education Committee (2022) by Michael King, Local Government and Social Care Ombudsman, on the issue, criticised where in the system the attention of reforms were targeted. In both cases, the proposed reforms were viewed as creating new sets of problems while simultaneously failing to resolve current problems.

To date, most literature in the arena of parental experiences of the SEND system has focused specifically on a central facet of the 2014 reforms: the Education, Health, and Care Plan (EHCP) process. In a systematic review of users' experience of the EHCP process, Ahad et al. (2022) explored several angles of parental experience. Involvement of parents in the EHCP was a statutory requirement of its introduction (DfE, 2014), with Ahad et al. (2022) reporting findings of a largely negative persuasion in the literature. These findings included parents reporting that

staff in the process lacked knowledge (Adams et al., 2017; Cullen et al., 2017; Palikara et al., 2019), that they were not listened to or had a lack of involvement (Adams et al., 2018; Bentley, 2017; Cochrane, 2016; Commons Education Committee, 2019; Cullen & Lindsay, 2019; National Autistic Society, 2016), that they had to keep repeating the same information to different professionals (Franklin et al., 2018; Holland & Pell, 2017) and that communication issues resulted in concerns about the quality of EHCPs (Skipp & Hopwood, 2016).

More broadly, literature regarding parent-professional working, often termed 'co-production', paints a picture of parental dissatisfaction and mistrust in the functioning of the SEND system, which was in part recognised by the SEND Review's aim to 'restore families' trust and confidence in an inclusive education system' (DfE, 2022c, p. 5). Boddison and Soan (2022, p. 91) described co-production in the system as an 'illusion', with Hellawell (2017, p. 411) raising concerns about parents being positioned problematically as 'compliant partners'. The work of McCarthy et al. (2022) found there were significant barriers for parents accessing support for their children from the outset. Solvason and Winwood (2024) identified that parental knowledge was often overlooked in multi-agency working, while Fleming (2021) found that parents reported not having an effective voice in decision-making about their child. This literature supports the need to take parents' responses to the SEND Review seriously. As such the project asked: (1) What are parents' responses to the SEND Review?

This is the first study addressing the parental experience of SEND consultations and as such is an important reference point for future research in the area, given the increasing use of public consultations in Government policymaking (Baxter, 2010; Morison, 2016, 2017) and the number of policy domains a family with a disabled child may well encounter. For example, during the same period as the SEND Review consultation exercise, the UK Government also had live consultations for the timeline for EHCPs (DfE, 2022b), the revision of school behaviour and exclusion guidance (DfE, 2022a) and the Ofsted and CQC (2022) new approach to SEND inspections, all of which are of direct relevance to the lives of these young people and their parents. Together these drivers make clear that exploring parental experience of public consultations can offer meaningful insights to inform their future design and implementation. As Morison (2017, pp. 657–658) cautions:

consultation on policy development can re-invigorate democratic engagement, but it can also often silence views through a sort of participatory disempowerment whereby the existence of an official consultation exercise closes off further, alternative or subaltern voices that are silenced by the existence of an official depiction of 'the public'.

In recognition of consultations' ability to both empower and disempower, and to explore 'the public' depicted by the SEND Review, this project asked: (2) What are the reasons for parents' (non-)participation in the SEND Review public consultation?

METHODS

Research design

The project was underpinned by a critical interpretivist paradigm (Denzin, 2001), combining a commitment to understanding the subjective, lived experiences of parents and carers with a critical focus on the structural power dynamics that shape and often marginalise their knowledge. By using flexible, inclusive methods and recognising the emotional labour involved in parental advocacy, the project treats parents' feelings and narratives as valuable sources of knowledge, challenging dominant assumptions that privilege professional expertise over parental insight within the SEND system.

While we report on parents' responses to the SEND Review, we are mindful not to 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 while 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.

Participants

The project received ethical approval from Sheffield Hallam University. Participants were recruited through social media advertising and local parent groups. We initially planned for both in-person and online focus groups at a variety of times of day, days of the week, and locations. The rationale was to increase access for parents who already committed large amounts of time and energy to attending appointments, and who would be combining that with both childcare and working commitments. However, due to an influx of 'scam' or fake participants, we cancelled all in-person data collection and arranged additional online focus groups. The data collection and collective consultation response workshop resulted in the transcription of 116 pages of rich and valuable data.

We chose not to collect demographic information from participants, informed by the project's critical interpretivist methodological framework, which prioritises the nuanced lived experiences of parents and carers over reductive categorical distinctions. Given the sample size of a project of this nature, demographic data risked the reduction of experience to tokenistic representations, particularly for participant backgrounds historically underrepresented and misrepresented in research. Likewise, we chose not to gather information about their children's impairments or diagnostic categories in order not to detract from the core focus: understanding parents' responses to the SEND Review and the reasons behind their participation or non-participation in the public consultation.

Data collection

In May and June 2022, six online focus groups and two individual interviews were held with 21 parents and carers of young people with SEND (see Table 1 for the schedule). In keeping with good inclusive practice principles

TABLE 1 Focus group/interview schedule.

Topic	Example focus questions/prompts
Understanding participants' feelings/perceptions about the SEND Review, regardless of how familiar they are with it	<ul style="list-style-type: none">Where/how did you hear about the SEND Review? <p><i>Prompts: news, social media, other parents, etc.</i></p> <ul style="list-style-type: none">Have you read any of it? Why/why not?How important does the Review feel for you/your family?Do you have any strong feelings or views about it? <p><i>Optimistic, pessimistic?</i></p> <ul style="list-style-type: none">Can you explain what makes you feel that? <p><i>Any specific part? Something you heard?</i></p> <ul style="list-style-type: none">Is there anything in the Review that gives you hope or makes you unhappy about the future of the SEND system?For those who've read parts/all of it: Did any of the language stand out to you?
Exploring experiences, motivations, barriers related to taking part in consultation	<ul style="list-style-type: none">Are you planning to take part in the consultation? Why/why not?Have you taken part in a Government consultation before? <p><i>What was that experience like? Did it encourage/discourage future participation?</i></p> <ul style="list-style-type: none">If not planning/unsure: What are your reasons?

(Cascio & Racine, 2019), and the project's philosophical underpinnings, the option of an interview was offered to accommodate participants' differing communication needs and also their availability. Nine parents returned to participate in a collaborative workshop to write a collective submission for the public consultation.

Data analysis

Data analysis was carried out using Atlas.ti software which enabled the storing of transcripts and facilitated close and careful coding. Rigour in the analysis was supported through a collaborative approach to coding, with two researchers ensuring consistency and reliability through inter-coder validation, engaging in iterative discussions to refine codes and ensure consistency, with the third overseeing the development of coherent themes. The thematic analysis followed Clarke and Braun's (2016) six-phase framework, offering a structured yet flexible approach. Recognising the risk of reducing parental accounts to 'feelings', particular care was taken to centre their narratives as legitimate and deeply informed, countering the tendency to minimise affective knowledge. In doing so, the analysis aimed not only for accuracy, but for justice to participants' lived expertise.

Interestingly, even though the focus group (and individual interview) schedules were designed to align with the project aims of insight into experiences of the SEND Review consultation, the most frequent codes in the data spoke to parents' broader experiences of navigating the SEND system. With 121 and 96 occurrences respectively, 'work in getting children's needs met' and 'power imbalance with professionals' dominated initial coding of the data. Additionally, we were struck by the frequency with which participants referred to a nebulous or ambiguous 'they'. Participants were not always referring to the same 'they' or 'them' but this recurring term often seemed to refer to, or reinforce, a separation between the 'we' of the participants as parents and carers of young people with SEND, and those with a role in the SEND system or its associated policy. This indicates how tightly interwoven parental experiences of the consultation and their potential experiences of future reforms are with their historical and present negative experiences. While recognising the bigger picture that may be implied within the dataset, the data analysis progressed thematically to focus on the particular project research questions. Following Clarke and Braun's (2016) principles of thematic analysis in the process of coding and development of themes, the research team drew together data on the following four interrelated findings, each of which will be discussed in turn in the next section:

1. The SEND Review perpetuated parental mistrust.
2. The SEND Review was disconnected from young people.

3. The inaccessible path to participation.
4. Reforms that deepened parental voicelessness.

FINDINGS AND DISCUSSION

The SEND review perpetuated parental mistrust

The stated aim of the SEND Review to 'restore families' trust and confidence in an inclusive education system' (DfE, 2022c, p. 5) was not achieved in the eyes of participants in our study, as the following comments show:

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.

'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 ... 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.

We will do a tick box exercise, paper exercise, gets filed, and it's never actually implemented, never actually amounts to anything in a practical sense.

It is perhaps not surprising, given the aforementioned literature on parental experiences of the SEND system and the often-missed deadlines for Government initiatives relating to SEND, that participants spoke of an expectation that their responses would be devalued and that they would be left waiting for meaningful action. Government Consultation Principles (Cabinet Office, 2018) state that responses to consultations should be published within 12 weeks. The Government response in the form of the SEND Improvement Plan was published in March 2023, eight months after the close of the consultation. One participant commented:

It just feels like actually this is a response to the recent report that the Local Government

Association did which talks about parents being too demanding, these middle-class sharp-elbowed parents that want the golden ticket. It feels like it's a response to that and not actually a response to the [Education] Select Committee inquiry at all.

Here, reference to an Education Select Committee report is cited by this participant as having well-evidenced the failings and need for reform in the current system (Commons Education Committee, 2019). Parents in this study often cited both reports and research evidence to support their views, demonstrating how well-informed they needed to be to feel heard by professionals within the system. This is in line with literature that shows how parents of children with SEND are often so entrenched in having to advocate for their families' needs that they become expert in ways that are often overlooked or undermined by other stakeholders in their children's lives (Hodge & Runswick-Cole, 2018).

The SEND review was disconnected from young people

Despite being the central figures in any proposed SEND Reforms, only 162 responses from young people were received in the SEND Review consultation (Sinclair & Zaidi, 2023). This represents less than 3% of the total number of responses, and 0.01% of the 1.6 million young people with SEND in England (DfE, 2024). Fewer than 100 under-18-year-olds responded (Sinclair & Zaidi, 2023).

A repeated concern expressed by participants in this study was about where the focus of both the Review document itself, and the proposed reforms within it, lay. For many, the central concern of the Review appeared to be finances rather than children like their own:

I think that it's wrong that the Government and local authorities are saying that supporting SEND depletes our budget, because what message is that sending the community that those children are living in and those families are living in? A negative one, yeah?

This led parents to report that the Review was disconnected from young people, their lives, and their concerns for the future:

I think there is a huge lack of consideration of the fact that young people might want to complete this ... They've made a big thing about people's point of view, and yet what they presented them with was a 90-page document or something incredibly simple. And nothing in between. No opportunity to *really*

respond, apart from to respond through the 90-page document. There isn't any other way if you're a young person, apart from having to go on to that document and find the right page to put it in, which is ridiculous. So I think that in terms of content for young people, it's really, really poor.

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? Of course, it affects me as a parent but it affects her a million times more ... 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.

It is notable that in the brief UK Government Consultation Principles (Cabinet Office, 2018), one of the 11 principles relates to the targeting and tailoring of consultations to 'the needs and preferences of particular groups'. Only three groups are named; one is 'younger people' and another is 'people with disabilities' (Cabinet Office, 2018). Both the quantitative lack of responses reported by Sinclair and Zaidi (2023) and our qualitative findings suggest that, despite specific principles aimed at improving and broadening the range of voices contributing to consultations, the SEND Review failed to account for arguably its most central stakeholders. Here, Morison's (2017) caution about participatory disempowerment can be heard in the misrecognition of 'the public' that the Review was originally intended to serve.

The inaccessible path to participation

The SEND Review received nearly 6000 responses, of which 53.4% were from parents/carers (Sinclair & Zaidi, 2023), meaning parents were the single greatest contributors to the consultation process. Our findings related to parent participation in the consultation paint a picture of the significant amount of time and energy parents had to give to contribute, alongside the challenges they faced in doing so:

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 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 ... 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.

I think the fact that they didn't even publish an accessible version, for me it's just such an example of how they are just not actually that interested.

Parents in this study had actively taken part in other consultations with the often-cited aim of making sure that families in the future had better experiences than their own. Our participants had a number of suggestions of ways in which the consultation exercise could have been more accessible to a broader range of contributions:

I think some more active participation – why are they not holding focus groups? Why are they not having public discussions? Why are they not engaging with us directly? Why are they not working directly with the groups who are trying to represent us beyond the ones that are kind of funded by them? So a more proper consultation period, rather than saying please type some things online, actually talk to parent groups, come to schools, get schools to talk to us, do you know what I mean? It could have been a much longer, better, active consultation period rather than please tell us online when we have already told you that your problem is that you're not confident in the system.

The experiences of confusion and inaccessibility recounted by parents in this study are reflected in the broader literature on the barriers to consultation participation: 'Consultation information is often missing, incomplete, or presented in inconsistent and often confusing ways' (Baxter, 2010, p. 266). As mentioned in the above quotations from participants, on initial publication there were no accessible or alternative formats of the consultation document. What was evident in participant responses was that consultation exercises beyond the online submission were unknown to parents. The Department for Education attended over 60 events with parents and/or young people (DfE, 2023), yet none of the participants in this project had attended one of them, or knew of them. This suggests that there were flaws in the implementation of the broader consultation exercise which failed to reach a significant set of stakeholders.

Reforms that deepened parental voicelessness

Parents stated that the SEND Review had worsened their experiences of voicelessness in the very systems meant to support their families. As well as the aforementioned inaccessibility of participation, they told us this was often because the proposed reforms lacked enough detail to be meaningful:

I think it's not addressing what I see as the main issues at all; literally not mentioning them, and the things that it's trying to do risk making things considerably worse. 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 what is going to emerge from the bits that are 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, meaningful way with disabled people's organisations, or with disabled children and young people, except to add a glossy shine to things at the eleventh hour.

One parent expressed exasperation, shared by many participants, that the reforms were targeted at the wrong parts of the system, a sentiment that had been echoed in other parts of the sector (Commons Education Committee, 2022; IPSEA, 2022):

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 ... it feels like they have their solutions, but those solutions 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. I don't think what they're looking for is people to come along with brand new ideas. They want people to agree.

Participants often made reference to the fact that their greatest source of support and information in SEND-related issues was other parents of disabled children. Many spoke of their deep-rooted commitment to this broad community of parents as a central reason why they persisted in contributing to the consultation. One participant pointed out:

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.

Participants recognised that there were long-standing issues with taking parents' views seriously in the SEND system, as evidenced in the earlier section on context. Rather than the SEND Review providing a watershed moment in turning the tide in co-production, parents in this project made it clear that the Review instead perpetuated and compounded their sense of their families' voices remaining unheard.

RECOMMENDATIONS AND CONCLUSION

The findings of this project have resulted in the following recommendations in relation to both future consultation processes and future SEND reforms.

Future consultation processes

As evidenced by both the depth and breadth of parental views in this project, the SEND Review as a public consultation exercise was both inadequate and inaccessible. To avoid facing similar challenges in future consultation processes with parents and young people, engagement must be an underpinning feature of both the consultation design and its implementation. As noted, the Department for Education failed to publish the original Green Paper in accessible formats until public pressure resulted in the eventual release of British Sign Language, large-print and easy-read versions more than six weeks later. The original deadline for consultation responses was consequently extended by only three weeks (Booth, 2022). For parents in this project, such omissions compounded their mistrust in the process and disbelief that their children's voices were considered valuable contributors to policies so central to their everyday lives and futures. An essential remedy for such failures in design and implementation is mechanisms that enable young people to have agentive voices in policies that directly affect them. Disabled people's organisations (such as Spectrum Gaming and the Alliance for Inclusive Education (ALLFIE)) are centred on representing young disabled people's concerns. Such organisations should be front and centre of both consultation design and implementation.

Our findings also demonstrate how those authoring and constructing consultation documents must better consider the effect that language choices have upon consultees' ability and willingness to participate and give feedback on reform proposals. As many parents emphasised, those language choices can be explicitly and implicitly disempowering for the communities that the policy reforms should seek to serve. Elsewhere we have extended the exploration of the SEND Review through a critical discourse analysis available in the *Journal of Disability Studies in Society* (Pluquailec &

O'Connor, 2023). Taken together these analyses make a compelling case for policymakers to more closely interrogate the discursive power of the language decisions they make in any and all public consultation exercises. While these recommendations are made in the context of a consultation about young people with SEND, it is clearly evident that much of their underpinning sentiment is applicable across a broad range of policy domains relating to minoritised parts of the population.

Future SEND reforms

Any foray into parental experiences of SEND, no matter how specifically or narrowly focused, must be prepared to acknowledge and situate the findings within the broader context of parenting a disabled child within the current UK SEND system. The findings of this project were closely intertwined with broader literature regarding negative, often traumatic experiences in relation to being a parent advocate for a disabled child. It was evident that parents in this project did not see the current failings of the SEND system being redressed by the proposed reforms. Parents participating in the project who had experienced the tribunal system were clear in their assessment of the problem – that their need to pursue an appeal was a consequence of local authority non-compliance with the law. This is reflected in both the tribunal data itself (Ministry of Justice, 2023) and in broader analysis (IPSEA, 2022; Ombudsman for Local Government, 2023).

Since the publication of the Green Paper and its subsequent Improvement Plan, the country has had a change in Government. Prior to that change in July 2024, there was political upheaval including two new prime ministers and a quick turnover of ministers with responsibility for SEND. With the SEND system's long-documented failings and tribunal backlogs now spanning over an entire academic year (Ministry of Justice, 2023), the current UK 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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CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest.

DATA AVAILABILITY STATEMENT

Research data are not shared.

ETHICS STATEMENT

This project received ethical approval from the Sheffield Hallam University Research Ethics Committee (UREC reference: ER42365232). All participants were provided with full written project information prior to their participation and gave informed consent.

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