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A thematic analysis of the family experience of British mainstream school SEND inclusion: can their voices inform best practice?

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Key words: SEND, disability, human rights, education, family life, diversity and inclusion.

Inclusion of special educational needs and disabilities (SEND) in the UK mainstream school provision has been identified as a human right in the United Nations Convention for the Rights of Persons with Disabilities (UNCRPD). The UK Children and Families Act of 2014 stipulates that children in mainstream school provision must have access to appropriate SEND support, and it protects the families right to be included in these decisions. The present study investigates the parent perspective of mainstream school SEND inclusion, highlighting the impact on family life. Thematic analysis was used to identify themes from the data, derived from answers to open-ended questions presented in a questionnaire format. Master themes recorded were: the family experience of (1) discrimination, (2) lack of diversity and inclusion awareness from others, (3) advocacy, (4) well-being and mental-health decline (including economic decline) and (5) damage to the family relationships. This study unearthed that adherence to the SEND legislation has been sorely misunderstood by some schools. Future research could investigate the relation between the level of inclusion training that staff have received, with staff attitudes towards inclusion and the well-being of families experiencing SEND inclusion to inform teacher training.

Introduction

The UK Children and Families Act 2014 (section 19) stipulates that children in mainstream school provision must have access to appropriate SEND support. This legislation protects the rights of parents and children to participate in decision-making regarding their SEND support. Section 19 sets out the principles underpinning the legislation and the SEND Code of Practice (2015) with a focus on inclusive practice and removing barriers to learning.

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The legislation initiated a response from the Initial Teacher Training expert advisory group (Bennett, 2016) that would stipulate the focus on SEND within standards and training for qualified teacher status and the new national professional qualification for headship would ensure that inclusive education was understood. However, the 2019 audit of the Department of Education, ordered by the House of Commons, found that although some pupils with SEND are receiving high-quality support, significant concerns were identified that indicate that many pupils are not being supported effectively, and that pupils with SEND who do not have education and healthcare plans are particularly exposed. The following research has unearthed and evidenced the impact of unlawful SEND practice (since the 2014 legislation) within schools on families in the UK.

Research conducted post 2014 UK send legislation

Research of the pupil view of SEND mainstream school inclusion has been the predominant focus in the UK since 2014. Following evidence from the Department for Education (2018) SEND report, Dimitrellou and Male (2020) raise the concern that maintaining pupils with SEND within mainstream schools is one of the greatest challenges for schools in the UK. They analysed the experiences of secondary-aged pupils with SEND in mainstream schools, focusing on pupils with social emotional mental health difficulties and moderate learning difficulties as a way of understanding their needs and thus, facilitating their inclusion. The findings showed that these pupils felt particularly dissatisfied with their relations with teachers and peers. The report provided a platform for the voices of SEND students to be better understood and thereby better included. Equally, Goodall and MacKenzie (2019) investigated the UK mainstream school SEND inclusion experience from the perspective of two autistic girls using the same method. The two children evidenced that they were not experiencing effective inclusion and described that their experiences of fear, isolation and anxiety were heightened by inexperienced SEND-uneducated teachers who would routinely ask that they 'choose a partner' for classroom activities. In addition, Dolton,

Adams, and O'Reilly (2020) investigated the mainstream school experience of 104 primary school students in the UK with SEHM via thematic analysis of data derived from qualitative semi-structured interviews. Similarly, they found that additional SEND support was not always provided, which had a negative impact on pupils. However, the meaning of 'inclusion' was the dominant SEND theme investigated by Goodall (2018) in which 12 autistic high school pupils drew upon experience from multiple educational placements. Thematic analysis of qualitative data derived from semi-structured interviews revealed that for these children inclusion meant being respected, accepted and valued by teachers and peers. It meant being content and safe and having relationships with others as part of the school community (Goodall, 2018). The pupils reported that for them, inclusion was not happening in mainstream school due to the lack of support and understanding they received from teachers in multiple settings, along their school experience.

There are several limitations to the literature of inclusion so far. First, scholars in the UK have mainly relied on semi-structured interviews to collect data. However, this may not be a fully inclusive research method when working with neurodivergent children and their families. For instance, participants may suffer anxiety due to trauma associated with the research topic. Additionally, as this method relies on verbal interaction, it assumes that the participants in research can withstand an interview. This in turn would exclude the experience of non-verbal individuals from research. Second, research in this area is limited with regard to the parents' perspective and is a pivotal aspect of understanding the needs of families (Armstrong, Armstrong and Barton, 2016; Roberts and Simpson, 2016). Third, research is replete with work that re-proposes the dominant medicalised and institutionalised view on disability, which is seen as a problematic and non-functional condition of the individual that should be 'cured' in order to restore the 'normal' or 'typical' biological human functioning. Inevitably, this will affect the way parents raise their SEND children, the hopes they hold for their children's future which will exhaust the family resources and impact on their mental health, social and economic well-being.

Corcoran, Claiborne and Whitburn (2019) looked at the paradox of an inclusive education system that must adjust to accommodate people with impairments and not vice versa (Gordon, 2013) with the British neoliberal cultural and education system that supports economic principles such as competition and free market agendas (Goodley, 2014). Dunn (2019) addressed the outcomes of this paradox. She highlighted internalised ableism, deindividuation, stigmatisation and stereotyping and problems that are posed by benign ableism. The UK education system of high standards of achievement and behaviour that is measured and tested across national averages of age-

appropriate development and attainment norms are in conflict with the ideals of inclusion of all learners. At present the minefield of the merging of competitive normative models of success, mixed with inclusion for non-visible disabilities or Special Educational needs (SEN), reins the mainstream school system, leaving practitioners on the ground in schools to try to make sense of competing ideologies in arriving at a way of working which impacts positively on all learners (Lauchlan and Greig, 2015).

The present study gains insight of the impact that UK SEND mainstream school inclusion has on the family unit from the parent's perspective. It specifically addresses the effects of school staff opinion of SEND and the communication of positive and negative views on the family's personal, social, emotional and economic well-being, to assess how these experiences can enhance good practices in school. The present research is justifiably important to further facilitate the efforts to understand the experiences of persons and improve their lives as the parent's experience of their child's SEND is pivotal to outcomes for the family unit. Hence, it is hoped that the critical approach to inclusivity of this study will support the views of critical disability scholars (Davis, 2005; Goodley, 2016) and help to back a paradigm shift where normative perceptions of achievement are disentangled from the realities of human ontological variants or neurodiversity (Bertilsson Rosqvist, Chown and Stenning, 2020). Normative perceptions of achievement are described by Davis (2005) as the human paradigm, where able-bodied standards take president (Goodley, 2016). The primacy of able-bodied standards is particularly relevant to the present study as it affects how people talk about and perceive disability in the school system.

The aim of the study is to understand how the dominant views of disability through school affect the families experience of inclusivity from parents' perspective and to understand the impact on the family unit to provide a foundation for better practice. The specific objectives of the study are:

- to investigate the SEND mainstream experiences of inclusion of families who have children with non-visible disabilities through the perspective of the parent;
- to investigate the impact of SEND mainstream inclusion on family's personal, social, emotional and economic well-being;
- to assess how these experiences can enhance good practices in school.

Epistemology

The epistemological approach undertaken in this study is critical realism (Bhaskar, 1975). The critical realist lens argues that visible and non-visible ontological variants of human phenotypes exist, irrespective of discursive relations. The analysis is framed by the pre-supposition that

ableism and the human paradigm (Davis, 2005) determine standards of achievement and behaviour appropriate, in this case for a mainstream school setting. The ontological approach in this study that views people in terms of the notion of ‘ubuntu’ (‘I am because you are’) (Bhaskar, 2020, pp. 113), acknowledges and values all human lives, irrespective of differences (Goodley, 2014).

Methodology

Participants

This study utilised a small number of participants who respect the underpinnings of qualitative research in working with ‘depth rather than breadth’ (Robson, 2011) and with guidelines for conducting a Thematic Analysis (Braun and Clarke, 2006) for a small-size project. Seven participants were sourced from online UK SEND support groups through Facebook and the Neurodiversity Seminar group at Manchester Metropolitan University. With consent from the moderators, a research advert was posted to the groups (Table 1).

Participants were over 18, they were parent/carers of their school aged children, aged 3–17 years, with non-visible disabilities and who have participated in the British mainstream education system after 2014 took part to the study. Four children in this study were autistic, four of them were officially diagnosed although one was awaiting a diagnosis. One parent chose not to disclose their children’s diagnosis, one had a diagnosis of SEND due to trauma and another was diagnosed with a developmental language condition. One participant had two children with a different disability; therefore, they completed the questionnaire twice.

The researcher

I relate to the participants as I am mother to a child with a non-visible disability and work with children with disabilities in mainstream schools. We engaged in a long battle for inclusiveness and to have our son’s uniqueness recognised and embraced in school.

Table 1: Participants’ profile

Name of parent (pseudonyms)	Number of children	Disability
Billie	1	Autism
Charlie	1	Autism
Francis	1	Autism
Jamie	2	One child with Developmental Language Condition and one undisclosed disability
Andie	1	Autism
Max	1	Awaiting Autism diagnosis
Nicky	1	Special educational need from trauma

Data collection method

The chosen data collection instrument for this small-scale project consisted of primary data from responses to an open-ended questionnaire (Weller et al., 2018). The data were collected by email in response to the research advert. During the Covid-19 pandemic, time allocation to research participation was limited for most participants because they were actively involved in balancing home-schooling children and other workloads. Therefore, in respect of parent’s affordable time limitations, a questionnaire format was selected so that participants could contribute remotely from home, whenever suitable to them or complete the questionnaire in self-selected time slots. So that the questionnaire was made inclusive and accessible and as a means of gathering authentic knowledge about subjective realities (Grover, 2004). Further adjustments were planned to accommodate the participants, they were informed that they could either type, handwrite or dictate and record their responses to the questions. In addition, it was felt that the questionnaire format was more inclusive to those suffering anxiety from the effects of school related trauma, who may be impacted by the perceived gaze of the researcher that would be present in an interview. The questionnaire was provided digitally via email which gave the greatest opportunity for the parent to be honest and give credible information. The aim of the questionnaire was to enable participants who have children with non-visible disabilities to think and write about their experiences. The questions were designed in recognition of their communication with the school staff in order to unearth the experiences that had emerged from those conversations. A detailed consent form and information pack was also sent out by email to each potential participant who responded by email and agreed to participate. Following the receipt of the information pack, each participant had the option to ask questions by return email prior to answering the questionnaire. The participants’ well-being was considered throughout, they were informed of the option to withdraw at any time prior to the research deadline, and signposting to appropriate help-lines and groups to mitigate the risk of mental health triggers was sent.

Disadvantages associated with the questionnaire format included limited/reduced ability to build rapport with the participant that could have enabled further detailed explanations. Furthermore, difficulties with asking probing questions to gain further insight and limitations on depth of written answers to questions due to apparent constraints of the format of this measure. It is possible that an interview format could have generated more rich accounts, and the research will consider this limitation and provide further developments to the methodology in future. However, the interview format was considered inappropriate in this case as it would have been difficult for participants, who were all parent carers, to make time available, and this could have led to distress. Added to

this, the questionnaire format was more sensitive to non-verbal participants' needs.

Data analysis method

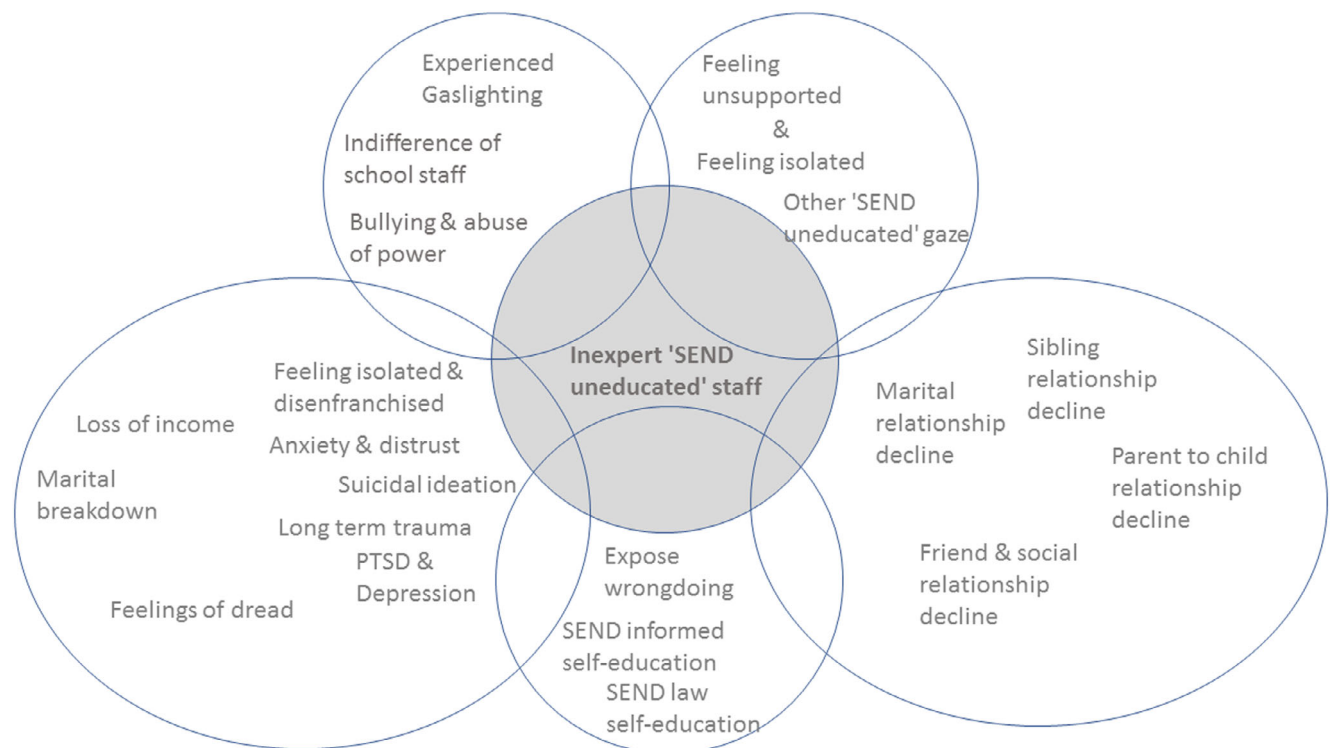
The data were analysed using Thematic Analysis (Braun and Clarke, 2006) to create and analyse relationships between the categories. Thematic Analysis allows for a rich exploration of experiences and can identify patterns which could enlighten on the phenomenon under study. Master themes that occurred across the individuals' accounts were identified to highlight patterns of the insider perspective. Braun and Clarke's (2006) six-step process for identifying, analysing and reporting qualitative data in thematic analysis was used to determine the overarching themes that emerged from the data.

Step 1: Becoming familiar with the data required reading through the written questionnaire responses several times before highlighting salient parts of the data and adding notes in the comments function of Microsoft Word or on a separate document for the handwritten responses. Step 2: Generating initial codes helped with reducing the volume of data into manageable portions and categories. Step 3: the Identification of themes emerged as the initial coded data was reviewed, and the themes were inputted into a Venn diagram to see where themes overlapped (Figure 1). Step 4: Themes were reviewed to seek for possible interconnections of themes. Step 5: Themes were defined and given labels that reflect the content of the themes, which defined the response to the research question.

Ethical considerations

The code of conduct employed in this study was adherence to practices that would ensure integrity, accountability, independence/impartiality, respect and professional commitment (WHO, 2017). The integrity of the interactions with participants was paramount to the data collection. It was acknowledged that many of the participants would be sharing traumatic experiences and potentially experiencing post-traumatic stress (Ehlers and Clark, 2000). Thus, honesty and truth were important tools that were used to negate participant anxiety and possible distrust of the research process. Therefore, there were no covert or discreet elements to the study and the participants were informed of the research aims and intentions. The language used within the questions was selected to be sensitive. Added to this, participation was voluntary; informed consent sought; anonymity was ensured by using pseudonyms and confidentiality was upheld by holding data in locked folders on the Manchester Metropolitan University (MMU) OneDrive where data and consent were filed separately. Protection from harm was mitigated by the provision of appropriate mental health helplines and online resources. Equally, accountability was an important part of this study as there was a sense of responsibility to the participants to complete a noteworthy report that would collate, elevate and give a platform for their voices. Impartiality was essential for the ethics of this study and so the MMU ethics approval committee and dissertation tutor were incorporated as an asset in the process of ensuring ethical protocol adherence and that open-ended non-bias questions were proposed to the participants. Analysis of the data was

Figure 1: Venn diagram of themes and subthemes emerging from the analysis of questionnaires



presented verbatim, and interpretations of the data were recorded in the Discussion. Respect for the participants has been the driving force in the completion of this study as the questionnaire responses were rich in important and traumatic family experiences that needed to be presented.

Analysis and discussion

In response to the research aim, to investigate the SEND mainstream experiences of inclusion of families who have children with non-visible disabilities through the perspective of the parent, five master themes (Figure 2), with subthemes, became apparent from the analysis of the data. These were the following: experienced discrimination, (lack off) diversity and inclusion awareness, advocacy, well-being and mental-health decline and damage to family relationships. These will be discussed in the analysis together with subthemes.

Theme 1: Experienced Discrimination, suggested that there has been unlawful discrimination of SEND students in schools and in communication with the families.

Participants reported receiving discrimination in many forms. One parent experienced discrimination through gaslighting, which refers to the act of manipulating a person that is aimed at making victims seem or feel irrational, creating a surreal interpersonal environment (Sweet, 2019):

They (the professionals) denied our reality... gaslighting. So, they saw me anxious with them and jumped

to conclusions that I caused my son's anxiety... They did not look at our life how it was. They only concentrated on what helped them to judge me.
(Nicky, 166 & 174)

Participants also reported discrimination through the indifference of school staff:

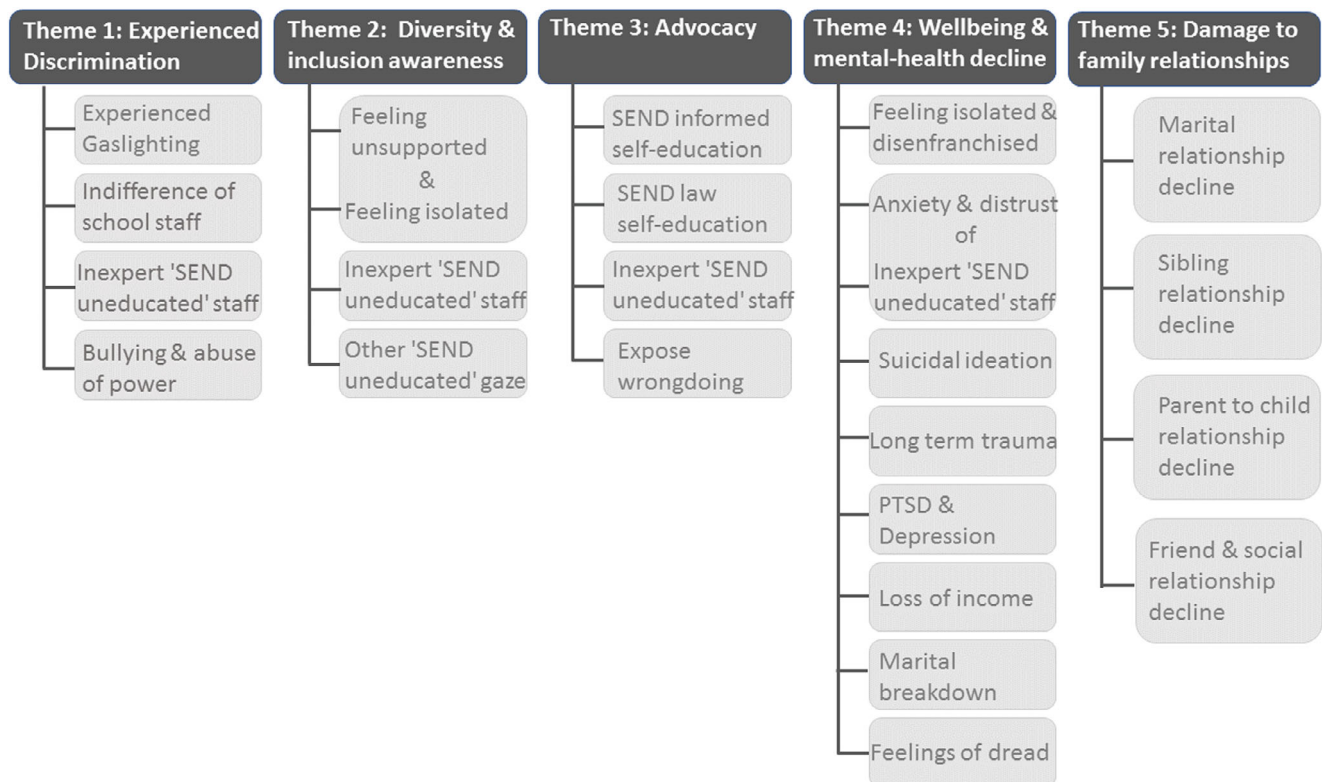
Regarding the school not listening: Total indifference to our reported suffering. Making assumptions on shallow observations. Judging me and parent blaming.
(Nicky, 273)

Also, through the direct discrimination and bullying. The abuse of power (Smith and Sharp, 1994) from the perceived social dominance (Gabarino and Delara, 2002) of school staff was reported:

..the governor said: "It feels like you are beating us with a stick to deliver this EHCP provision. It's not fair on the school to take all their funding."
(Max, 39–40)

I sat down to speak, and he (the teacher) tossed the weighted blanket over the desk to me and said "what's this? We don't need this in school it's distracting the other kids in class – they all want a turn on the wiggle cushion."
(Max, 7–9)

Figure 2: Themes and subthemes emerging from the analysis of questionnaires



Headteacher- "(I) wont bend over backwards for one pupil" This is the same for all SEN children it seems. (Francis, 53)

We knew that teachers thought our child was strange or a problem. E.g. at one parents' evening I commented to a teacher that I was concerned my son didn't seem to have many friends. I mentioned a child my son had said he liked and queried whether I should invite that the child on a play date. The teacher said, "ah well, pseudonym: Tom is a very popular child." The clear implication was that not only was my child not popular but that he was second class in some way. This made me feel uncomfortable around other teachers and parents. (Andie, 154)

Participants reported teachers' comments that evidence discrimination as teachers referred to the child with SEND as being disruptive to the other children, often complaining to the parent about the difficulty that their child proposed to the school:

Oh yes, many times! - "It's unfair on the other children if we treat James differently", "The other children tolerate James, "We've had complaints from other parents that Sam disrupts their child", "If we allow James to have/do that, then we will need to do it for the others". Discrimination at its finest! (Charlie, 80)

(Yes.) To us, this feels like a way of saying that our child is less important than other children and/or is unwelcome in the school. (Andie, 139)

Many times I was told by the Senco that he was 'tolerated' by his friends and peers. Despite asking her to refrain from using that term, she continued to. (Charlie, 22)

He was just expected to be like the others, if things were too much he would be sent to sit outside the head's office or in isolation (Charlie, 21)

Regarding the parent experience of allegations made from a school to a nine years old child with SEND: We were mortified - both for our son who had been discriminated against, unsupported and bullied, but also for his and our reputation with such slander. (Max, 50)

The pupil's dissatisfaction with their relations with teachers and peers is mirrored by the experiences of the participants in the present study (Dimitrellou and Male, 2020). In addition, it drew attention to section 11 of the

UNCRPD (2016) which states that teachers should receive SEND education and training. The accounts above demonstrate that teachers should receive education training to provide them with the values and competencies to 'accommodate inclusive environments' (Goodall and Mackenzie, 2018). Self-determination theory (Deci and Ryan, 2012) underscores the importance of the influential motivational frameworks such as being related to others and well-being in school through feeling competent and autonomous. Positive social-emotional school experiences are an important educational goal. The value that is often placed heavily on academic achievement skews the perception of teachers to view children with additional needs as disruptive.

Theme 2: Diversity and inclusion awareness, refers to the lack of awareness and acceptance on diversity and inclusion, that participants have experienced from school staff and other parents.

Participants implied feeling unsupported and isolated by the limited awareness of others including inexperienced 'SEND uneducated' staff:

I will never forget the shameful feeling and all the negative gossiping from parents and children. (Max, 107)

If attitudes don't change nothing will and these children will continue to be failed. (Francis, 121)

Our experience was that even after diagnosis, teachers did not consistently follow our son's SEN plan. (Andie, 124)

Regarding communication between schools and families, participants expressed the need for training for all school staff on diversity and inclusion with a clear focus on better communication with families. Staff training on the use of non-discriminatory, non-judgmental language was highlighted so that families could communicate with the school about their child with SEND, without fear, anxiety and dread. Seven participants stated their preference for once weekly communication by email and one parent would prefer contact by phone. Nicky stated that post-traumatic stress disorder (PTSD) made it difficult for her to respond to emails in a timely fashion which highlights the importance of flexibility when addressing the communication needs of parents. In agreement with this study, Dimitrellou and Male (2020) highlighted the necessity for staff training in SEND pupil engagement and disability inclusion training when they reported the pupil's dissatisfaction with their relations with teachers and peers. The necessity for teachers to respect others, and to value people, encouraging acceptance of individual differences was suggested as a way forward.

Theme 3: Advocacy, refers to the self-informed parent who knows their child best, speaking-up and speaking-out to educate others about the SEND their child experiences through disability.

Sub themes were unearthed through statements that described the journey of the parent's self-education on their child's SEND:

I have very good insight into what happened to me, to us and I keep educating myself to improve my and the children's trauma.

(Nicky, 182)

So, we knew with the right support, he could do this and that kept us fighting.

(Charlie, 52)

In addition, participants reported having learned about SEND law, seeking advice and employing independent legal advice. This expresses a kind of self-education to inform their advocacy:

As a result of all of this, I contacted a barrister and took advice about what we could do. She recommended removing him from the school and trying to get an EHCP. We paid our barrister a fixed fee of £17,000 plus VAT to act for us in the EHCP process. We re-mortgaged our home to pay for this.

(Andie, 92)

Some participants found their efforts were in vain and the theme returns to the actions of inexperienced 'SEND uneducated' staff:

Our life was hell and no matter how I tried to explain to them, turned everywhere and fought for all services to support him, it was too late.

(Max, 15)

Honestly, we feel that the school don't really care about us or our son or understand him. We have spent the last year trying to explain his needs and how the school can help by making reasonable adjustments, and they haven't been able to put in place pretty much any of what we have asked for

(Billie, 59)

Added to this, some participants utilised the present study as a platform to advocate for their rights publicly, speaking directly to the researcher:

Parents views not taken into account. Parents have to fight every day for their child to have an education that is able to engage them. This is a basic right.

(Francis, 125)

One participant who had experienced marital breakdown after their child with SEND needs had been physically restrained on multiple occasions and put into isolation by school staff called for accountability, stating:

I just feel that a very bright light needs to be shone on the failings that are happening every day to our SEN children and their families.

(Charlie, 136)

The aim of advocacy is to reduce stigmatisation by educating others. The findings of Dolton *et al.* (2020) revealed the detrimental impact that poor child–adult relationships can have on the children, as they expressed feelings of anxiety, frustration, feelings of injustice and extreme anger. The present study mirrored these findings in the effects on the family mental health and well-being, from the parent perspective. Feelings of anxiety and trauma were clearly depicted, and frustration and anger were implied through advocacy. Advocacy from the parent can inform the staff who work with the child, so that inflicted trauma, from inexperienced 'SEND uneducated' staff, to the child with SEND and their family, can be negated. Advocacy and resistance to the oppression of normative ideals mirror the Posthumanist (Braidotti, 2019) view that disability breaks the concept of what it means to be a 'normal' human. Advocacy for acceptance on diversity and inclusion takes control under neuronormative schemas that have ruled the perceived norms of behaviour and achievement to enable flexible and multiple identities (Braidotti, 2019) and helps parents to define themselves as active authors of their world (Giroux and McLaren, 1986).

Theme 4: Well-being and mental-health decline, reports implied feelings of isolation and the families becoming disenfranchised which was similar to the investigation by Goodall and MacKenzie (2019) of Autistic pupils, who experienced fear, isolation and anxiety of not being wanted at school. This theme responds to the research aims, to investigate the impact of SEND mainstream inclusion on family's personal, social, emotional and economic well-being.

Interpretation of the parent reports indicated that they experienced feelings of anxiety and distrust of inexperienced 'SEND uneducated' staff and professionals:

I get anxious, upset when I am mistreated, or my children are. I know I was doing the right thing for my child, but I had to feel bad about it.

(Nicky, 376)

We were heartbroken that the school could treat him like this.

(Max, 28)

Some families reported coping with the horrors of their child's suicidal ideation and dangerous behaviour as a direct response from their school experience:

Regarding Junior school experience: Around this time, he climbed out of an upstairs window during an argument, which was terrifying.
(Andie, 36)

His mental health began to deteriorate in 2017, he was in year 5 and refusing to attend school. On one occasion the Head and Senco physically dragged him by legs and arms out of my car and into the school, he was screaming and at that point I knew I had to take control. I kept him off and contacted CAHMS, which was pointless, he was really low and saying he wanted to die, as a parent this is the worse you'll ever want to hear.
(Charlie, 23)

I strongly believe that pseudonym: James wouldn't be here if he had continued at that school, in that environment and with those attitudes towards him. They thought they knew all there was to know about SEN. By pulling him out when we did, we saved him.
(Charlie, 56)

Long-term trauma was also reported:

Regarding communication with school staff: (I feel) worried, shocked, angry, upset, horrified. I still feel all these emotions five years on. I'll never get over the way my dear son was discriminated and treated.
(Max, 57)

On top of my child's suffering his siblings and I got traumatized because of the lack of school support my son bottled his feelings up bringing them home. . . we all suffered secondary trauma
(Nicky, 6)

Also, depression:

I am broken and keep going like a robot, constantly pushing for the right support.
(Nicky, 471)

Some families struggled with a loss of income and difficulties juggling work hours with school non-attendance:

Regarding school exclusion and school refusal: (it) can be really stressful, especially when trying to juggle work and other family commitments.
(Max, 124)

Regarding the financial impact: I gave up work to home educate my son whilst a specialist placement

was found. I felt like I had no option – this was not a choice I should have been forced into.
(Max, 130)

There were also reports of feelings of worry and dread and the devastating effects on well-being:

In primary years there was always a lingering feeling of dread when standing at the school gate. Wondering what might have gone wrong today, what negative message was I going to get from staff/parents at the end of the day.
(Max, 98)

Regarding school non-attendance: In 2016 we were devastated. I didn't sleep or function well. I was even more worried for my wellbeing as I was pregnant at the time.
(Max, 127)

Participants experience higher levels of stigma induced stress, related to daily discrimination than parents of non-disabled individuals (Song, Mailick, and Greenberg, 2018) that traumatises the family unit.

Theme 5: Damage to family relationships, reports the breakdown of relationships in the home and with friends.

The process of getting the right support in place was forced upon us abruptly. . . I worked from home where I could, it took a toll on our marriage as I was the main person that dealt with professionals, assessments, whilst still running the day-to-day things. . . I had very little support until I broke.
(Charlie, 149)

My other son couldn't understand why he (his brother with SEND) didn't need to be in school, why they had treated him unfairly, why we were upset a lot
(Charlie, 148)

He came to see himself as naughty and green (doing well) as something he couldn't attain. I was often frustrated with him and couldn't understand why he didn't just behave. This damaged our relationship, I feel.
(Andie, 29)

And friends started to back away from me because the whole process was consuming me. I had very little support until I broke.
(Charlie, 152)

Interestingly, participants in the present study appear to support the findings of Goodall's (2018) research from the pupil perspective, that mainstream inclusion is not appropriate for all young people. Goodall's (2018)

findings actually opposed the right to inclusive education set out by Article 24 of the UNCRPD. The participants in the present study reported celebrating the relief once their child was accepted into a specialist school. Two participants wrote positively about their relief after moving from mainstream school to specialist provision. However, it is important to note that there is no ideal or 'utopian' school of full inclusion (Lauchlan and Greig, 2015) in the UK, available to the families in this study. Also, the social structure, social action and their articulation (Frauley and Pearce, 2007) need to be addressed because the parent and pupil preferences for specialist school would be affected by the ableist popular views. It becomes clear in this construct that families in the UK cannot access their rights to full inclusion in the British mainstream schools. For this reason, some basic routes forwards are now discussed.

Findings: Broad theme and way forward

The present study unearths a potentially lethal risk factor of the 'SEND uneducated' school staff and the discriminatory gaze of others. Reports of family PTSD and depression, long-term trauma, anxiety and suicidal ideation were evident in the data. Programmes designed to teach students about different types of disability may help to build acceptance and understanding of human differences (Godeau et al., 2010). Teacher training on SEND inclusion and human rights needs to be a priority. An investigation into why some school culture is successfully inclusive and why others are fiercely discriminatory and damaging is imperative.

Regardless of the British ratification of the UNCRPD (2016) to include the provision of special and specialist schools, as segregated alternatives to the mainstream school system and the continuing debate over what the ideal mainstream school inclusive provision should look like, it is apparent from the data supplied from this study, that for some families, mainstream school inclusion is 'cruel' and 'painful' with devastating effects on the family unit and therefore must be the focus of an overhaul and improvement of the system.

In response to the research aims, to assess how these experiences can enhance good practices in school, it is suggested that, along with inclusivity training delivered to all school staff, the visibility and accountability of individual schools and education settings will need to be made visible to the Local Authorities by including the opinion of those in receipt of the services in the reports of each school and education setting. The present research evidence that not all schools are successfully inclusive. In agreement with Lamb (2019), the Department of Education (DfE) should consider how an enhanced SEND Information Report, designed to function more as a direct analogue to the Local Offer, could strengthen accountability with parents. Along with greater delegation of funding, the accountability of

schools and settings could be improved by holding them individually more accountable for ensuring adequate provision and outcomes (Lamb, 2019). A survey of Parent Carer forums demonstrated that 57% were not confident that schools provide good SEND support that enabled children to achieve good outcomes and only 2% were reported as feeling very confident (Contact et al., 2017). The present study evidences the cruel and unusual suffering that families endured although schools and education settings are not individually held accountable for SEND inclusivity. Nick Whittaker (SEND Specialist Adviser for Ofsted) stated that 'No school can be rated "outstanding" if it's not inclusive' (Education Inspection: Whittaker, 2018). Thus, a transparent SEND Information Report of each school should include the parent and child experience of the school SEND service to be delivered alongside the Ofsted inspections that are available online for parent review.

Limitations and future research

One limitation of the study was the potential selection bias (Thomas, 2009) due to the restricted number of people in the relatively small participant pool. This was likely due to the current climate, amid the Covid-19 pandemic, where parents are juggling the responsibilities of working, parenting and home-schooling their children whenever they are sent home, due to Covid illness at school. In addition, parents of disabled children with SEND may find it difficult to allocate time for contributing to research. Ideally, in future research an optional semi-structured phone interview following the questionnaire would allow the researcher to probe those who want to participate further, for more detailed answers. In addition, this would have prevented misinterpretation of a question. For example: one participant interpreted a question regarding the emotional experience of dropping-off a child at the school gate to be asking about the convenience of school transport.

A second limitation was that only families who had experienced school trauma participated potentially as a means of self-advocacy and so there was limited data regarding positive SEND inclusion experiences that would have added more detail to the study and helped to inform on what can be done by successfully inclusive schools that could be transferred as knowledge to schools that are not successfully inclusive.

A further limitation was that the questionnaire was designed by the researcher and did not include participant input on the design of the questions to be asked. An element that most participants took advantage of was the question at the end of the questionnaire asking, 'Is there anything else you would like to tell us'. In this section, participants were empowered to direct their own narrative and so it is reasonable to suggest that involving participants in the questionnaire design would be effective in sourcing data rich in experience and as a mode of

including participants as active authors of their world (Giroux and McLaren, 1986).

Reflection

Through the research process, I became invested in the necessity to advocate for the needs of the families of children with SEND in UK schools. Through the research process, participants shared their experiences evidencing that not all schools in the UK are successfully inclusive. It became clear that much suffering has been experienced by families even after the Children and Families Act (2014) was mandated. I expected to find that all participants would be in support of the UNRCPD (2016) for the rights to a fully inclusive mainstream education, but my assumption was incorrect as many felt overjoyed with the provision of specialist school that segregated or specialised in disability. I considered the belief from disability studies that parents can be disabling to their child (Goodley, 2014) when they propagate ideals of classical human norms by submitting to or celebrating segregated education. I feel it is necessary to take caution here as the present research unearths much parent shaming and blame that contributed to the stigmatisation of the family and thus, deterioration of the family's well-being. In the process of this research, I became interested in disability studies and through further research. I would like to better understand how the theory interacts with the constructs of UK infrastructure to see how practical steps can be made. The methodology that was used was effective, however, one parent questioned my authenticity and so on reflection I would like to have demonstrated my validity by recording a video explanation of the research that could have accompanied the research advert. In addition, the use of sensitive language within the questionnaire was brought into question when two participants stated that some of the terminology was somewhat offensive. Through the process, I have learned that 'school refusal' is a leading statement that can be perceived to incorporate an intention from the child to 'refuse school' which is offensive to the experience of a family, who's child cannot, for reasons of disability and/or anxiety, attend school.

Conflicts of interest

All authors declare that they have no conflicts of interest.

Ethics

Ethical approval for the study was granted by the Ethics Committee at Manchester Metropolitan University, application number: 34427. The research was conducted in a manner consistent with the British Psychological Society's ethical guidelines.

Data availability statement

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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