



Special Educational Needs: Understanding Drivers of Complaints and Disagreements in the English System

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OPEN ACCESS

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Specialty section:

This article was submitted to
Special Educational Needs,
a section of the journal
Frontiers in Education

Received: 11 March 2019

Accepted: 11 July 2019

Published: 07 August 2019

Citation:

Cullen MA and Lindsay G (2019)
Special Educational Needs:
Understanding Drivers of Complaints
and Disagreements in the English
System. *Front. Educ.* 4:77.
doi: 10.3389/feduc.2019.00077

This paper explores why some special educational needs (SEN) disagreements become very distressing for parents and how such disagreements can be prevented or resolved. It is a qualitative study of the experiences of 78 parents (70 mothers, eight fathers) who participated in a national study of experiences of England's SEN disagreement resolution system, 2015–17. The study took place in the context of the biggest reform of the English SEN legal landscape since the seminal Warnock Report in 1978: the Children and Families Act 2014. This legislation extended aspects of individual statutory rights for parents and for the child/young person with SEN and increased expectations of their meaningful involvement in the assessment of needs and planning of provision to meet those needs. It also had a much greater focus on partnership working as a way to prevent disagreements and made statutory the requirement to offer mediation to support early resolution of disagreements. Data were analyzed inductively using the Framework approach and then interpreted in the light of stress theory and the “drama triangle.” The main findings are that disagreements are initially driven by a belief that the child's SEN are not being met; and that complaints and disagreements are subsequently driven by experiences of delays and role dissonance during the process of seeking to have the child's needs met. The parental experience of distress can be understood in the light of classic stress theory. The emotional intensity and metaphors of battle can be understood as part of a “drama script.” Prevention and early resolution are aided by professionals and practitioners showing empathy, having the knowledge, skills, and understanding to do their job properly, taking responsibility to redress wrongs, by greater investment in the SEN system (staff, staff training, range of appropriate educational provision), and by parents offering peer support. This paper is unique in two ways: in covering parents' experiences across the English SEN disagreement resolution system and in interpreting our findings using psychological frameworks to understand what drives the intensity of such disagreements—and therefore of the way through them to resolution and improved prevention.

Keywords: special educational needs, complaints, disagreements, Tribunals, parental experiences

INTRODUCTION

The Warnock Report (Warnock, 1978) declared that it was “pre-eminently about the quality of special education” but stated that this required more than a legislative framework:

“The framework provides *the setting within which people work together in the interests of children*, and the quality of education depends essentially upon their skill and insight, backed by adequate resources – not solely educational resources – efficiently deployed.” (Warnock Report, 2.85; emphasis added)

Forty years on, this article addresses what flaws in “the quality of special education” drive a numerous minority of parents (Cullen et al., 2017) to complain about processes or disagree with decisions. It covers those who made formal complaints about the provision or treatment of their child with special needs, sought mediation, and/or lodged an appeal against a decision about their child made by the local authority (LA) officer responsible for SEN in their area.

We focus on three themes in particular from the Warnock Report: the foundation principles of a human right to education (paragraph 1.7), accurate assessment of needs¹ (2.73; chapter 4), and professionals working in partnership with parents (1.5; chapter 9).

The Report, published by the UK government, was ahead of its time in its emphasis on individual statutory rights for children with SEN for which LAs were accountable, and in its advocating that education professionals and administrators work much more in partnership with parents of children with SEN. The United Nations Convention on the Rights of the Child (UNCRC), including Article 28 on the right to education, was not ratified in the United Kingdom until 1992. The Report was also a child of its time, building on previous UK government circulars and guidance. Its recommendations, implemented through the Education Act 1981 (England), built on existing systems to create a new administrative system at LA level to process the paperwork and decision-making involved in statutory assessment and annual reviews of needs and provision. Thus, the Act created a new “exosystem” (Bronfenbrenner, 1979, p. 25), a decision-making structure that excluded parents (although they had a statutory right to be asked to provide “parental advice”). When Warnock’s emphasis on partnership with parents (mesosystem interconnections) was missing in practice, a site of tension was created between parents and LA personnel making decisions on individual cases. Conflict was perhaps inevitable.

Children and young people (CYP) with SEN are, by definition, exceptional. Consequently, it is not surprising that differences of view about the nature and degree of their SEN may lead to disputes, which are different from other disputes in education, such as choice of mainstream school for typically developing young people. Lake and Billingsley (2000) identified eight categories of factors that, from parents’ perspectives, increase conflicts with schools, regarding special education, namely

different views about the child or child’s needs, knowledge, service delivery, reciprocal power, constraints, valuation (e.g., that their child was being devalued), communication, and trust.

Due to increasing parental concern, in 1994 the Special Educational Needs Tribunal was set up to hear appeals from parents in England against LA decisions about their child with SEN. Such appeals increased substantially from 1,170 in its first year (1994/95) to 3,772 in 2002/03: Special Educational Needs and Disability Tribunal (SENDIST), 2004). The SENDIST was then replaced as part of a broader restructuring of a number of public service tribunals and became the First Tier Tribunal (Special Educational Needs & Disability) (hereafter the Tribunal). The UK government, concerned by the continuing high number of appeals, sought to develop means to enable disagreements to be resolved earlier, including voluntary mediation (see Lindsay et al., accepted), which formed part of the Children and Families Act 2014.

Focus of This Study

This article uses augmented analysis of in-depth qualitative data from 78 parents who participated in a national study of experiences of England’s SEN disagreement resolution system, 2015–17, to address two new research questions. That study (Cullen et al., 2017) was part of a broader commission by the Department for Education (DfE) to provide independent information to support Ministerial commitments to conduct a review of disagreement resolution arrangements relating to SEN. It included the pilot extension of Tribunal powers to enable recommendations to be made in relation to the health and social care aspects of an EHC plan, in addition to orders in relation to the education sections of a plan. The research took place between April 2015 and March 2017. In April 2017, the results of the research informed a Ministerial report to the United Kingdom (UK) Parliament (Department for Education and Ministry of Justice, 2017).

The study took place in the context of the biggest reform of the English SEN legal landscape since Warnock: the Children and Families Act 2014. This legislation extended aspects of individual statutory rights for parents and for the child/young person with SEN and increased expectations of their meaningful involvement in the assessment of needs and planning of provision to meet those needs. It also had a much greater focus on partnership working as a way to prevent disagreements and made statutory the requirement to offer mediation to support early resolution of disagreements. The government hoped that the use of independent mediation between the LA and the family would help to resolve disagreements and reduce Tribunal appeals. The Act did not amend or reform the multiple complaints processes relevant to children/young people with SEN and disabilities.

Using both the policy agenda (parents’ rights, partnership with parents), and the theoretical frameworks of the bioecology of human development (Bronfenbrenner, 1979; Bronfenbrenner and Morris, 1998, 2006), stress theory (Lazarus, 1966; Lazarus and Folkman, 1984), and the “drama triangle” (Karpman, 1968) to interpret our data, the paper seeks to understand why a minority of SEN disagreements become difficult to resolve and are experienced by parents as intensely emotional and stressful.

¹Building on the Department of Education and Science (DES) Circular (2/75), “The discovery of children requiring special education and the assessment of their needs” (Warnock report, 2.73).

Theoretical Frameworks Used to Interpret Our Data

A number of theoretical frameworks shaped our thinking at the point of mapping and interpreting our thematic analysis. They did not drive the data collection or the thematic analysis, only the interpretation of our findings.

The SEN System as Part of the Human Bioecological Environment

Forty years on, the tension remains between two aspects of SEN law: the individual rights of parents and young people and the corporate duties of LAs. From an education perspective, Bronfenbrenner's theory of the ecology (later bioecology) of human development (Bronfenbrenner, 1979; Bronfenbrenner and Morris, 2006) is helpful in pinpointing that this site of tension lies in the exosystem: a place where decisions are made that affect the developing person but which do not include the developing person. This site has not changed in these 40 years. What has developed over that time in successive SEN Codes of Practice (Department for Education, 1994, 2015; Department for Education and Skills, 2001) is stronger guidance on working "in partnership" with parents and, by the 2015 version, "involving" parents and young people in expressing their views about needs, provision to meet needs and in that decision-making process. Those involved in the education, health, and care (EHC) needs assessment and plan development processes (which replaced earlier statements of SEN) are expected to have "high quality engagement" throughout that process. In this article, we focus on the roles² of parents and LA SEN team personnel.

The role expectations of the LA SEN team personnel (officer responsible, other officers, case workers; administrative staff) have been set out in ever more clarity over the successive Codes of Practice. These include following the statutory timetable for the assessment of needs and writing of an EHC plan (Department for Education, 2015, 9.44) and a strong emphasis on working closely with the child or young person, and the child's parents (Department for Education, 2015, Chapter 1 "Principles"). The three underpinning principles are germane to this study. These are that LA staff must "have regard to the views, wishes and feelings of the child or young person, and the child's parents," enable them to participate in decisions affecting them, and give support and make provision "to help [the children] achieve the best possible educational and other outcomes, preparing them effectively for adulthood" (Department for Education, 2015, 1.1).

Particularly relevant for this study is the paragraph defining what parents "participating in decision making" means during the statutory EHC needs assessment process:

"Local authorities, early years providers and schools should enable parents to share their knowledge about their child and *give them confidence that their views and contributions are valued and will be acted upon*. At times, parents, teachers and others may have differing expectations of how a child's needs are best met. Sometimes these discussions can be challenging but it is in the child's best interests for a *positive dialogue between parents, teachers and others to be maintained, to work through points of*

difference and establish what action is to be taken". (Department for Education, 2015, 1.7; emphasis added).

The 2015 Code of Practice chapter on resolving disagreements includes four principles: making decisions about SEN provision jointly with parents and CYP; open communication about the decision-making process; providing information; and support to take part in the decision-making process; and telling parents and young people about the routes for resolving SEN disagreements (Department for Education, 2015, paragraph 11.1).

The emphasis on joint decision-making and on open communication can be viewed as encouraging the enrichment of two aspects of the bioecology of families with a CYP with SEN: (i) at the "microsystem" level, that is, creating more of what Bronfenbrenner (1979) defined as "settings" where face to face communications take place; and (ii) at the mesosystem level which is made up of all the interconnections between the micro- and the exo-systems.

Stress Theory

The parents we interviewed talked about the stress involved in challenging a LA decision affecting their child and/or complaining about the way in which their child's special needs were addressed. In seeking to interpret and understand what parents said about stress/distress, we drew on stress theory (Lazarus, 1966; Lazarus and Folkman, 1984): that prolonged and multiple forms of stress build up and may tip individuals into physical and or mental ill-health. This shaped our presentation of these findings.

Role Dissonance: The Drama Triangle

When the "pattern of activities, roles, and interpersonal relations" (Bronfenbrenner, 1979, p. 22) goes awry, as described by parents involved in this study, one way of understanding this is offered by the Karpman's "drama triangle" (1968, 2007). This is a heuristic device that can be used to conceptualize the roles and role reversals that happen in dysfunctional personal interactions. Like core concepts from Freud's psychoanalysis theories, Karpman's insights around the drama triangle have seeped beyond the discipline from which they derive (transactional analysis) into the much broader fields of psychology and counseling. We draw on this in the discussion to help make sense of our findings.

Previous Research

Previous research has reported that some parents find SEN disagreements stressful and both emotionally and, in the case of Tribunal appeals, financially costly (e.g., Duncan, 2003; Runswick-Cole, 2007; Kids First, 2013). One gap we seek to fill is that previous studies have focused on only a part of the parental experience of SEN disagreement; for example, on informal disagreements (Wright et al., 2012), or on mediation (Tennant et al., 2008); or on Tribunal appeals (Runswick-Cole, 2007). In addition, previous work on parental experiences of SEN disagreements has comprised relatively small scale qualitative studies or larger-scale surveys with limited contextual detail.

The second gap identified in our review of the literature on parents' experiences of SEN disagreements is a focus on understanding *why* a minority of such disagreements are

²Using the Bronfenbrenner (1979, p84) definition of "role".

experienced as extremely stressful. Duncan (2003) in a small-scale study (10 families; two LAs) identified two, “particular leitmotifs that seemed to aggravate the parents as much as the substantive issues [...] helpful and unhelpful people; personal cost” (p. 344–345). Other studies have tended to describe that the experiences are stressful, rather than illuminating why this is the case.

Purpose of the Study

This paper addresses two research questions: (i) Why do some SEN disagreements become so distressing for parents? (ii) How can such disagreements be prevented or resolved? These questions were identified after analysis of our data to address the research questions of the national study, reported in Cullen et al. (2017).

METHODS

We used a qualitative research design and analytical approach because the depth and contextual richness of such data enables the development of new understanding. The data analyzed were collected through semi-structured interviews with parents who had experience of using at least one disagreement resolution process since September 1, 2014, when the Children and Families Act, 2014 (England) came into force.

Participants

Seventy-four interviews were held with a total of 78 parents (in four cases, with male-female couples). In total, 70 were mothers and eight were fathers. Age ranged from 20s to 60s with the largest group in their 40s (a majority-53- were in their 40s or 50s). Sixteen different ethnicities were self-described, including Black British, British Asian, British Indian, British Pakistani, Chinese, Greek, Irish, Mixed, White American, with a majority (49) stating, “White British.” Seven different types of relationship status to the other parent of the child discussed were used: the majority (49) were married; other states were “adoptive single mother” (2) divorced (6), partner (3), separated (5), single (4), and widower (1). Of the 66 asked about employment status, 36 were in full-time (18) or part-time (18) employment and 30 were not in paid employment. Of the 65 asked about highest educational qualification, the range was from Level 2 (e.g., O-levels, GCSEs) to Level 8 (doctorate degree). The majority (42) had either a degree (21) or a post-graduate degree or qualification (21). This was therefore a diverse group of mainly mothers, with a skew toward those with above average educational qualifications.

PROCEDURES

(i) Participant Recruitment Process

Parents were recruited by multiple routes. Our starting point was that 17 LAs had agreed to be case study LAs for the DfE-commissioned research³ (Cullen et al., 2017). These LAs were given leaflets for parents/young people who had appealed to the

Tribunal. The leaflet explained about the research and asked permission for the LA to forward their contact details to the research team after the appeal’s conclusion. The leaflet stated that contact details would only be used by the researchers to send an invitation to participate in the research, along with a detailed information sheet and consent form. This opt-out route was designed after discussion with representatives from the 17 case study LAs and the DfE. All other routes were opt-in routes based on an invitation leaflet and information sheet for parents/young people with experience of at least one disagreement resolution route since September 1, 2014.

These leaflets were distributed to relevant parents/young people in the 17 case study LAs through mediation services, parent-carer forums, and local SEN information, advice and support services.

Recruitment went wider than these 17 LAs partly through word-of-mouth (participating parents telling others about the research) but mainly through posts on social media by the DfE and by individual participating parents containing a link to our webpage with the invitation leaflet, information sheet and consent form. In total, parents from a quarter of all English LAs took part (39 of 152). The diversity of routes by which parents came to the study was designed to enable us to access parents with experience, across the sample, of as many different disagreement resolution routes as possible.

No incentives or compensation was offered to participants. Each was sent a thank you e-mail or card and was offered the opportunity to be thanked by name in the Acknowledgments section of the published report. Most chose this option. The study was granted full ethical approval by the University of Warwick’s Humanities and Social Sciences Research Ethics Committee (Ref: 111/14-15; 24.7.2015).

Contact details were received for 96 potential interviews, through LAs or most commonly directly from parents. Of these, 74 took place and 22 did not (77% success rate). Two of the 22 did not meet our selection criteria (experience of disagreement resolution since September 1, 2014). One withdrew because of illness. In the remaining cases, the parent did not respond to our initial or follow-up e-mails/texts. Interviews were held over a period of 10 months, starting mid-March 2016 and finishing in late January 2017.

(ii) Data Collection

Participants were offered the choice of face-to-face or telephone interviews. Almost all chose the latter. A minority (5) were face-to-face with venue agreed to suit the convenience of the parents.

The interviews varied in length from about 50 min to about 6 h (that one was split over three conversations). Most took between 90 and 120 min. The variation in length was driven by the number of disagreement resolution routes used by the parent, the number of children discussed and how much detail, including of the backstory, was shared. We wanted the parents to feel listened to, whilst we covered the topics on the interview schedule. Therefore, those who wished to share a lot of detail were not hurried on or “closed down.” In these interviews, disagreement resolution pathways were discussed involving 81 children/young people, of whom 64 were male and 17 female.

³These were also the LAs involved in the pilot of the extended powers of the SEN Tribunal.

Interview Schedule

In addition to basic demographic information about the interviewee and about the child or children whose case/s were the focus of the interview, the main sub-sections of the interview schedule focused on: open questions about parents' experiences of the EHC needs assessment and planning process; knowledge, use and views about the local information, advice and support service, mediation service, disagreement resolution service, complaints routes, and the appeals route, including the Tribunal pilot. The interview concluded with an open question asking for anything else the parent wanted to convey.

As a result of listening to parents in the first few interviews, a question was added asking for the parent's perspective of their child's strengths, following on from the one asking about their perspective of their child's needs. We quickly learned that the interview worked best if we gave parents the choice of beginning with their experience of the EHC assessment and planning process or with the disagreement resolution route uppermost in their mind.

All the interviews were digitally recorded, with permission. Due to limited financial resources, a minority (15) were transcribed in full. These were the first 10 interviews undertaken (to provide full texts from which to begin developing the analysis framework), plus five of the more multi-faceted cases, involving several different disagreement resolution routes. For the rest, very full notes were taken during the conversation, always using the interviewees' vocabulary, including many verbatim phrases. These were augmented afterwards by listening again to complex sections to clarify or fill out the notes with transcription. These complex sections, where it was not possible to note down quickly enough with adequate detail and accuracy what the interviewee was saying, were marked on the notes taken during the interview, cross-referenced to the time indicated on the digital recording. This enabled efficient use of partial transcription of the majority of the interviews.

Analysis

The overall approach to data analysis was inductive and followed the five stages of the "Framework approach" described by Ritchie and Spencer (1994): familiarization; creating a thematic framework; coding the text ("indexing") to identify which sections relate to which part of the framework; summarizing these data in Excel worksheets built to reflect the framework ("charting"); and finally seeking to make sense of these data through mapping of concepts and interpretation of meaning ("mapping and interpretation"). This method was used because it was designed for applied policy research and we have used it successfully many times before.

The main coding categories were derived from the topics structured in to the semi-structured interview schedule: EHC assessment and planning; Information and Advice Service; Disagreement Resolution Service; Mediation; Appeals; Pilot appeals; and Complaints, plus a Summary sheet collating information about the parent (e.g., gender, age, ethnicity, relationship to the child); the child (e.g., gender, age, SEN from parent's point of view, strengths from parent's point of view); and the disagreement route/s followed (e.g., domain of

disagreement (e.g., refusal to assess), external support if used (e.g., legal, support group), outcome. Each sheet contained a row per child/young person's case discussed and multiple columns headed by the sub-topics relating to each theme. The sub-themes within each main category were initially the relevant sub-topics included on the interview schedule. Additional sub-themes were added, derived directly from the data. For example, sub-topics such as "impact on health" and "impact on family" were added to the "Costs" sub-theme relating to the main categories, "Appeals" and "Pilot appeals."

Most of the interviews were conducted by Cullen with the remainder by Thomas; Cullen and Thomas met to debrief after each interview or day of interviewing. Cullen and Thomas conducted the initial analysis, making it easy to collaborate and to agree on the original framework and on additions as these emerged from the data. Any issues were resolved by discussion and going back to the notes, transcript, or voice file for clarification. Cullen added analysis relating to the two new research questions (for example, topics such as "unmet need" and "delays in process" were added to the Summary sheet and additional main coding categories were added, derived from engagement with the data: Backstory to disagreement (summary narrative); and Driving the disagreement (parent's "thoughts," "feelings," "behavior"; and "thoughts," "feelings," "behavior" (as reported by parent) of all others involved, such as school staff, LA staff, medical staff. The "Backstory" theme was sub-themed *within* each case, because the context and detail provided varied so much from case to case. Cullen and Lindsay developed the "mapping and interpretation" of these data presented for the first time in this paper.

RESULTS

Reasons Why Some SEN Disagreements Become So Distressing for Parents

In this section, we summarize six main themes that emerged from our data as to why some SEN disagreements became so distressing for parents.

Our participants experienced all the normal stresses of everyday adult life, with its routine contingencies, temporary inconveniences, and routine irritants, as well as major life events, such as family bereavements. In addition, some experienced specific additional everyday stressors, such as long-term health conditions. This was the background stress to which all the other stressors (themes 1–5) added.

1. These Children had Significant SEN

The children and young people were described by their parents as having complex needs. We did not collect independent evidence of this but, in every case, the parents' account of the severity and/or complexity of their child's needs were reported to have been corroborated by professionals through the statutory assessment process. In cases where a refusal to assess need was the decision that caused the dispute, the parent's views about the child's level of needs were not corroborated until after assessment had been agreed at mediation or ordered by the Tribunal appeal panel judges.

None of the children discussed by our participating parents as the subject of the disputes with the LA had needs that meant borderline decisions had to be made; their assessed needs were significant. For example, in 19 cases where the LA had initially refused to assess the child's need, but then agreed to do so after mediation or a Tribunal order, all the children proved to have complex needs. Examples included: a young child about to enter a school-based nursery who was profoundly deaf, had cochlear implants, speech, language, and communication needs, and global developmental delay; an 11 year old with attention deficit hyperactivity disorder (ADHD), dyspraxia, mental/emotional issues, abdominal migraines, and working at the expected level for a 6 year old. In our data, there were also six cases where the LA assessed needs and then refused to issue an EHC plan, a decision later overturned either through mediation or by Tribunal order. Again, these were not borderline cases: for example, the reported assessed needs of these children, in summarized form, included: a 16 year old with chromosome deletion, dyspraxia, and anxiety and depression; and a 9 year old with autism, severe ADHD, sensory processing disorder, generalized anxiety disorder (GAD), dyspraxia and sleep difficulties.

In all other cases in our data, the disagreement was over the content of an EHC plan or over the decision to cease a statement of SEN at a point of transition. The largest sub-group of parents we interviewed were those who disagreed with elements of the content of the EHC plan. Their disagreement was about a perceived failure to describe needs accurately, and/or to record a plan and placement that would meet their child's needs. In all these cases, the child's needs had been previously assessed as being at a level requiring the LA to ensure additional provision was in place to meet significant SEN.

Thus, in all the cases discussed by parents in our research, the CYP were described as having significant SEN. This can be thought of as the "baseline additional stressor" theme in parental accounts: "the real life issues of your child," as one father (Interview 2) put it. In five interviews, the parent/s discussed having more than one child with significant SEN. Having more than one child with SEN increased the stress such parents felt at this "additional baseline" level.

2. Concern Over Unmet Needs

The first driver for the parents to engage with the statutory assessment process was a strong belief that their child's educational needs required support over and above that available in the current educational setting (or in the setting the child was about to move to). This is the situation the system of statutory assessment was designed to deal with. For our participants, the system did not deliver this; at least, not at first. When they received a decision such as a refusal to assess or a refusal to issue an EHC plan, it was this belief that drove these parents to challenge school practices and LA decisions. They believed they had to seek a different outcome to ensure that their child's special needs would be met, and their strengths flourish. At stake, was their child's well-being and life chances: for example, "We're talking about [our son's life]" (Father, Interview 67); "[Our son] is our responsibility. There is nothing I would not do for him. [He] did not ask to be born with SEN" (Mother, Interview 108).

For example, one mother explained that her decision to go to mediation and to appeal had been triggered by the "harrowing time" she and her son both experienced:

"[...] sending my kid into that school every single day, knowing that he was getting kept in for break because they weren't supporting him through his work and he was getting told off. He was self-harming, everything." (Mother, Interview 32).

She reported that her son, in Year 6 at time of interview, had been diagnosed with Tourette's syndrome, high-functioning autism, sensory processing dysfunction and fine motor coordination difficulties. She described two "wasted" years of schooling for her son as he first of all waited for the LA to agree to assess his needs, which was done after conceding to her Tribunal appeal, and then found that his school ignored the EHC plan, unilaterally removing the 25 hours of support assigned to him, "because they wanted him independent for high school," and accusing him of "using his Tourette's as an excuse." After a meeting with the head teacher, she removed her son from the school and placed him elsewhere, explaining:

"I said to them, 'If you can't accept a medical diagnosis as a valid reason [for behavior], there's no point my son being around you. You've done enough. He's suffered enough.'" (Mother Interview 32).

The mother in interview 32 was not alone in taking exception to the behavior of some school staff toward her child with SEN. This was also true for a substantial subgroup of our participants. For example, one mother (Interview 81) described her son's difficulties in secondary school having started after a new person took on the role of special educational needs coordinator (SENCO). Reportedly, this SENCO told this mother that her son was, "too clever to have SEND" and removed the support provided in accordance with his statement of SEN. When the parents met with the headteacher to seek a solution to the bullying their son was experiencing daily, the headteacher reportedly told this mother, "I can't help it if [your son] is irritating." As a result of these cumulative issues, these parents chose to take their son out of schooling, enrolling him in an online alternative.

Neither was the mother in Interview 81 alone in removing her son from schooling. Our participants also included a subgroup of participants who had done the same for similar reasons: issues around unmet needs in school having gone on for years, getting worse over time. This removing or rescuing of a child from a school perceived as inimical to their well-being was one response. Other parents who spoke to us described responding to similar situations by fighting back. For example, in Interview 30, one mother described writing a five-page letter of formal complaint about her son's headteacher to the Chair of Governors and copying it to "absolutely everybody I was aware of in the whole system." It contained:

"[...] five pages of documented complaints about failures; failure to do any of the transitions, failure to make any allowance for

his autism, failure to manage anxiety in a school environment.” (Interview 30).

The complaint was upheld, as were two further complaints to the same Chair of Governors. In this parent’s view, the Chair, “knew that they were on very, very dodgy ground because what they had done was not legal; they had made no allowances for his disability at all.” (Mother, Interview 30). This mother described herself as “absolutely ferocious” in “using [the school’s] own processes” to ensure that her son’s needs were met as far as possible while he waited for his EHC plan, stating that she wrote e-mails to the school, “every single day for months.”

In order to get their children’s needs met, three of the five participants who had more than one child with SEN found themselves in the position of having to appeal against LA decisions for two or three of their children in parallel. For example, the mother in Interview 23 had twins aged 17, each with complex needs (one with high functioning autism, ADHD, anxiety, and literacy difficulties; the other with autism, dyspraxia, visual processing disorder, epilepsy, learning difficulties, sleep disorder, and post-traumatic stress disorder). Unhappy with the content of both EHC plans, the parents appealed separately for each twin. For one twin, the LA conceded shortly before the Tribunal hearing; the parents won their appeal for the second twin. Having multiple children with unmet needs increased the stress experienced by these parents.

3. Engaging With the Statutory Processes

There were three aspects of having to engage with statutory processes that added stress to the lives of the parents who spoke to us. One was the demands of the various processes, a second was delays experienced during these processes and the third was behavior by staff involved in these processes which was perceived by these parents as unpleasant and unprofessional.

(a) Demands of the processes

The demands of the various statutory processes varied, according to our participants. The least stressful processes (in terms of the demands of the processes themselves, not the issues involved) were making a formal complaint and contacting a mediation service. With few exceptions, these were reported as being easy to do. The most stressful processes, in terms of what was required of parents, were contributing views to the statutory assessment process, commenting on draft EHC plans, and preparing evidence to substantiate an appeal to the Tribunal. In relation to the first two of these, time, effort, and emotion were invested which was felt to be worthwhile when the views solicited were taken into account in subsequent decisions made by the LA SEN personnel involved. When this did not happen, that investment was deemed a stressful waste. For example, one mother (Interview 108) who had already experienced administrative incompetence (her son’s first EHC plan was issued with the wrong name, date of birth, school and syndromes) also found that his amended plan ignored his parents’ views, despite these having been requested via a specific form:

“What is the point of completing all that information about your child? [...] You lay yourself bare and spend time and effort filling in the forms. [...] If we’re asked for our views in the future, we won’t give them. We’re not going to play anymore.” (Mother, Interview 108).

In relation to the appeals process, the demands of lodging an appeal were low but the demands associated with putting together the evidence required to win the appeal were reported as high. For example, one mother said:

“I’m somebody who I would say is extremely well-educated and I’ve found this process extremely, extremely challenging. I think there are children out there who have parents from poor social class, poorly educated, they haven’t got a chance in hell. Children are being let down.” (Mother, Interview 25).

Parents who had experience of the Tribunal process reported costs in terms of large amounts of time, energy, stress, and direct financial costs varying from zero (those eligible for legal aid or who chose to represent themselves and not to pay for independent professional reports) to those who spent many thousands of pounds. The process itself could also be prolonged. For example, one mother of a 12 year old with complex needs appealed to the Tribunal and found herself involved in a case that went on for over a year and took four hearings with Tribunal panels to reach a conclusion. Although she won the appeal, achieving “99% of the amendments I wanted in the Plan,” she was left feeling, “angry that it’s taken so much time away from me being with my son to help my son deal with what he is coping with.” She added:

“I find it appalling that that a [LA] would put a parent through all this, much less a single parent who already can’t work because her son has such high level needs [...]”. (Mother, Interview 26).

(b) Delays

Delays during the processes engaged in whilst seeking to get their child’s needs met exacerbated parents’ distress. Very often, parents in our research reported multiple experiences of delay. The experiences described in Interview 50 illustrate this. This mother’s son was aged 19 at time of interview and had had a statement of SEN since he was 12 years old. The LA approached the mother to suggest the statement be transferred to an EHC plan in view of the 2014 legislation. She described the following 2 years as, “a nightmare,” one strand of which were the repeated delays experienced. These included a wait of 9 months between submitting her views as part of the EHC assessment process and any professionals’ reports being received; a wait of 3 months in agreeing a draft plan as meeting after meeting was canceled by the LA’s SEN staff; a wait of 4 months in receiving a final EHC plan. The process, which is meant to take a maximum of 20 weeks (Department for Education, 2015, p. 154), took 64 weeks. She even faced delays in responses at all three stages of her formal complaint against the LA (which was upheld by the Local Government Ombudsman).

Meanwhile, her son was attending college with no support, consequently failed key exams, and so lost his college place. This case is one illustrative story from our data demonstrating that delays during the statutory processes added to distress, not only because of frustration with the system, but because of the negative consequences for the child or young person with SEN. As illustrated in this case, delays in a key process also often triggered formal complaints.

(c) Dissonances between role expectations and reality

There were two main ways in which parents in our research reported a sense of dissonance between their expectations of staff in professional and practitioner roles and the reality they sometimes experienced. One was realizing that not all staff were competent in the roles they held; the other was that staff could behave in ways perceived by these parents as unexpectedly unpleasant and unprofessional.

Examples of administrative incompetence were frequent in our data, including EHC plans being sent out with the wrong name; decision letters being sent to the wrong parents; draft EHC plans being lost by SEN officers; documents for Tribunal appeals being sent in by the LA with pages missing. None of these were unique examples and all caused delays and irritation or distress.

Examples describing what parents perceived as professional incompetence were also common in our data. These included LA SEN case workers and officers who were described as not knowing their legal duties, or not knowing how to put into practice the principles set out in the legislation and Code of Practice regarding the role of parents and young people in decision-making. For example, Interview 71 was with the mother of a 10 year old boy described as having ADHD and severe dyslexia, as well as other assessed needs. She reported that, despite the partnership and involvement principles underpinning the Children and Families Act and the Code of Practice, her, “views seemed to count for absolutely nothing” during the assessment process; that her “views were dismissed [by the principal SEN officer]” during the mediation meeting; that “none of my amendments were included [in the final EHC plan] with no explanation given as to why this was so”; that the LA SEN team “did not consult with any of the schools I’d asked [to be named in the plan].” Her appeal was upheld by the Tribunal but her experience had led her to believe that, “the views and wishes of parents are [...] not being used as an underpinning principle.” She reported that the effect was, “emotionally and psychologically exceptionally distressing,” saying that she had “felt so alone.” (Interview 71).

A number of parents reported LA staff behaving in unpleasant and unprofessional ways toward them. One mother reported (Interview 57) being in a mediation meeting (the purpose of which is early resolution of disagreements) where the head of the LA’s SEN team said, “This file is closed and that’s it” as she emphatically closed her physical file of the child’s paperwork held by the LA. Shocked that one person could have that power to close down discussion and negotiation, she and her husband immediately lodged an appeal to the Tribunal, which they won. They viewed this incident as illustrative of a “corrupt” and “shocking” culture of ignoring parents within their LA. Others

spoke of LA SEN staff displaying bullying behavior. What one described as “bully boy tactics” (Mother, Interview 9) seemed to be associated with the period after an appeal had been lodged and before the Tribunal hearing. For example, one father described behavior by the LA SEN team during that period as being, “outrageous” and bullying:

“The Council’s behavior was outrageous. They took the law in to their own hands. They thought they can bully us as parents but unfortunately for them they picked on the wrong people.” (Father, Interview 67).

(d) Parents acting out of role

A minority of parents talked about their own behavior as being out of line with what was expected of parents of a child with SEN. This was always reported as a response to behavior by LA staff that was perceived by these parents as deliberately or thoughtlessly unhelpful. For example, several parents described using repeated Freedom of Information Requests to annoy the LA SEN staff who they perceived had caused them unnecessary stress and trouble. Others repeatedly lodged formal complaints or used as many routes of complaint in parallel as possible. One mother who reported having adopted this tactic explained that she later realized that, “I’m better off trying to cut a deal with them,” rather than complaining. She experienced her upheld complaint as a “hollow victory,” saying, “Being right x years later [...] won’t change what’s happened. That’s what my complaining has taught me.” (Mother, Interview 6).

Another approach was to involve the media. For example, one father went to the local TV news channel as well as to ITV to publicize his daughter’s case. He reported that “feedback from a number of charities was that you have to shout and swear and make a stink” (Father, interview 103). Another mother, outraged by the amount of time her son was missing his education because of the disagreement process, wrote letters to the Head of the SEN team and to the Director of Children’s Services “fining” them (*in loco parentis*) for failing in their responsibility to make provision to meet his SEN. She found that simply threatening to go to the media with this story was an effective weapon.

Some simply got very angry, shouting at the SEN caseworkers and/or officers whom they felt were treating them badly. For example, one father (Interview 77) of a 5 year old non-verbal child with autism “on the severe side” described losing his temper when a case worker said, “I understand exactly what you are going through”—after months of interaction with multiple staff whom his wife had experienced as “very rude, racist and ignorant,” a “refusal to assess” decision, and three inadequate draft EHC plans in which, “none of our expressed wishes had been taken on board.” At that point, he reported shouting at her and demanding a final plan be issued so that he could appeal to the Tribunal. Afterwards, he felt ashamed at having raised his voice, and so chose to communicate by e-mail only from that point on. He also escalated things by gaining legal help through a parent support organization, making a formal complaint to the LA’s Cabinet Member for Education, and putting in Freedom of

Information requests relating to therapist reports that had not been passed on to them.

Others expressed their sense of being “picked on” by their LA and stated their determination to fight back with all the resources at their disposal, partly on behalf of those who were not able to do so. For example, one couple reported that their attitude toward their LA was combative: they involved a lawyer, their local MP, and made Freedom of Information requests because they had come to believe that the LA would, “push you off until you make a serious fuss.” They knew they had the education and financial resources to fight back (“If you had to pick on someone, you wouldn’t pick on us!”) but they did this in part because they believed that, “the system is stacked against those who can’t fight back” (Father, Interview 93).

4. The Number of Processes Over Time

Almost all the parents, without prompting, provided the “backstory” to the issue that had caused a disagreement to arise around assessing and/or meeting their child’s needs. The power of this backstory in driving parents to seek a resolution to the disagreement was clear in the interviews but the nature of that driving power only became apparent during analysis. It was the number of times, over time, that they had had to get involved with practitioners and professionals in order to ensure that their child’s SEN were recognized and met. To illustrate this, we pick out one example from each end of the age range of children discussed in our data. Even the two parents interviewed about children aged 3 had had to engage with multiple processes. For example, one mother (Interview 5) of a 3 year old had requested an assessment of her son’s needs supported by “two and a half years’ worth of clinic letters, hearing tests, health visitor reports, pediatrician reports [...] reams and reams of paperwork,” been refused, had sought help from the local Information, Advice and Support service, and had requested and attended mediation (which she experienced as “confrontational,” “like a courtroom,” as a “battle”).

She had previously had a “big battle” with the local health authority, including having made a formal complaint. This mother expressed what it felt like to have “another big battle going on,” when she was already “juggling” the usual stresses of life, plus having a child with a disability.

For those participating parents whose children were in the post-19 age group⁴, the number of processes and the number of years of “fighting” and “battling” for their child was concomitantly greater. The new issue they had in common was to get their LA to agree their child could continue their education. For example, one mother of a son aged 22 (Interview 76), who had had his statement transferred to an EHC plan aged 21 was distressed to find that this was withdrawn after an annual review (without this possibility having been addressed at the annual review). The LA’s SEN panel, according to his mother, had withdrawn his educational provision, “because they felt he would be better served by social care funded provision.” Following a formal complaint and a mediation meeting, his

education provision was partially restored but not before he had lost a year of education because of the withdrawal of provision. This mother mentioned having had voluntary, independent support for 10 years from a family advocate, at “meetings and in complaints against social services.” After 10 years when such support was necessary, she reported that she and her husband were “exhausted” and therefore did not want to take the LA to Tribunal over the remaining outstanding issues related to his EHC plan.

This sense of being too “exhausted” or “worn out” by all the “battles” over time was something mentioned in many other interviews too. For example, the mother of the twins mentioned earlier who had had to appeal to the Tribunal in both cases (one was conceded by the LA; one was won by the parents) said:

“After the appeal, we wanted to complain about the broken rules over deadlines [i.e. about delays in the process] but we were too worn out. And it wouldn’t have made any difference anyway.” (Mother, Interview 23).

5. Fear for the Future

The number of times, over time, that parents had to “do battle” on behalf of their child was a fourth level of stress that also created a fifth layer: fear for the future; a dread that at every annual review the LA was given a new opportunity to take away hard won support from their child. For example, comments such as this one were frequent: “It concerns me that every year we will have to go through the same thing—the battle starts again.” (Mother, Interview 109). Even one couple who had been through six different disagreement resolution routes and two formal complaints whilst seeking agreement that their choice was the right school placement for their son (who was visually impaired, and affected by three other conditions) reported no sense of security about the future of that “placement: We feel it could all be pulled away. [...] There is no security around it.” (Mother, Interview 88).

6. The Cumulative Consequences on Family Life

All the parents we spoke to had experienced the stress associated with having a child with significant SEN (theme 1) and believing that at least some of these needs were unmet (theme 2). They all experienced, but varied in the extent to which they were affected by, the demands of engaging with statutory processes and the extent to which they experienced delays and role dissonances (theme 3), in the number of processes with which they were involved over time (theme 4) and the extent to which they feared for the future (theme 5). Consequently, they also varied in the extent to which the process of seeking resolution to their SEN disagreement had a negative impact on their lives.

For example, in one case, the delays caused by professional incompetence of an EHC plan writer led to negative impacts on both the child and the mother. This mother, who had been very positive about the “child-centered” approach to gathering the information on which her son’s draft EHC plan was based, was then disappointed with the draft plan: “The Plan was very poorly written [...] not measurable, reasonable or achievable. [...] We went through nine drafts to get to the Final” (Mother, Interview

⁴The Children and Families Act 2014 extended statutory SEN processes and provision beyond age 19 up to age 25.

37). During that prolonged drafting stage, her son's headteacher threatened him with exclusion and so the LA moved the child to a special unit for the seven remaining months of that school year. The following school year, he was transitioned back into mainstream school 1 day at a time but was permanently excluded by the November (with the headteacher arguing that the school could not meet his needs). As a result, the mother was forced to give up her own university course to look after him during the 9 months he remained out of education. At time of interview, he was accessing 3 days a week in school. In addition, she reported her son's distress at losing his friendship group at his original school and then at the special unit, only to be excluded on return to his original school.

To give an example arising from a formal complaints process, one mother described herself as still, "deeply stressed" months after the case had been settled:

"I feel deep resentment to the system. I feel complete injustice. We tried so hard through all the right channels to settle. Even now, 9 months since the case was effectively settled, I feel deeply stressed when I see an e-mail from the LA." (Mother, Interview 102).

Over half our interviewees (47) had experienced an appeal to the Tribunal and every one of these interviewees spoke about the negative impact on their health and/or on the family. (This was in addition to direct financial costs incurred.) The balance between the impact on health and on the family varied. For example, one mother reported the main impact on her health as being anxiety-based loss of sleep which was, "draining and frustrating," but the broader impact on the family was much greater as she had given up full-time work to look after her son and the loss of earnings had then caused financial strain and family divisions. Another reported that her husband had suffered depression and, "had had a breakdown over it" (Mother, Interview 19), in part due to their decision to home educate their son (in response to lack of agreement with the LA). She described them both as feeling stressed and fighting more because of this.

Others described the negative impact of stress and anxiety on parental health (including time off work, use of anti-depressants) yet pulling together as a family. Still others spoke of the opportunity costs of the time, energy, and money invested in an appeal: for example, "I spent a lot of time on the appeal instead of having couple time or time as a family. You can't cost that (Mother, Interview 40); or, "Otherwise I would have used the money [over £15,000 spent on the appeal] to go on holiday, pay for my other son's driving lessons, and pay to move house" (Mother, Interview 74). The negative impact on the child at the center of the disagreement, as well as on siblings, was also raised by many of our interviewees, in particular, their declining mental health (anxiety, depression).

In our sample, there was a minority who reported serious negative impact of the cumulative stresses, including the stresses involved in an appeal to the Tribunal. These included cases of getting into debt, becoming homeless, feeling suicidal. In each case, the respective interviewee attributed this to the financial and other costs of seeking to resolve the disagreements over how the LA should meet their child's SEN. The most serious

case was a father who reported that his wife, who had a pre-existing mental health condition, had killed herself the day after a residential placement was refused for their 11-year old, non-verbal, incontinent daughter, who required "constant care and supervision" (Father, Interview 103). He did not blame the suicide on the LA but believed the LA's decision had been a contributory factor. After an adjournment of the appeal hearing, the LA conceded the appeal.

Overall, the cumulative effect of the stresses involved in resolving disagreements over how their child's SEN were met led to an increase in what we earlier termed the "background" stress of everyday life: health concerns, money worries, relationship difficulties et cetera. The words of one mother sum up the views of our participants: "No-one should have to go through this to get proper education for their child" (Mother, Interview 84).

How Can Such Distressing Disagreements be Prevented or Resolved More Quickly?

In this section we present five clear themes that emerged from our data relating to perceptions of how best to prevent, or more quickly resolve, disagreements about a child's SEN and/or the provision to meet these needs.

1. Show Some Understanding

The first theme arose either directly or by implication in almost every interview. Our participants indicated that some acknowledgment from the staff they encountered of the lived reality of having a child (or children) with significant SEN either did or would have reduced the stress of engaging in school-based and statutory processes. For example, as a mother of two boys with different significant special needs put it,

"These are families and these are children: vulnerable children. They should have a little more compassion; a bit more of a humanitarian outlook approach toward these families who already go through so much stress every day. [...] The child has got to be the focus in this." (Mother, Interview 64).

2. Do the Job Properly and Listen to Parents

The second theme also arose in every interview, again either directly or by implication. If staff they encountered in public services (such as school, LA, health settings) did or had behaved in accordance with role expectations, the participating parents reported that this had or would have made it easier to resolve issues. In a school-based example, one mother contrasted her ability to work with her son's SENCO and headteacher during Year 2, with the refusal of the new headteacher and SENCO to entertain the possibility of making any reasonable adjustments for her son's ASD in Year 3, while they waited for his EHC plan to be issued and a special school to be named:

"How I used to work with the previous head and SENCO is we would work together, 'Could we do this?' and they might say, 'Well, that's not possible but we could do that.' So we would kind of ideate it together. I sat there and I said [to the new headteacher], 'Could we do this? Could we do that? [...] In the end, I went, 'Could we move him to another Year 3 class where the teacher isn't changing all the time.' [The head] just looked at me. All she

ever said was, ‘Do you understand we cannot have your child at this school?’” (Mother, Interview 30).

3. Take Responsibility to Sort It When Things Go Wrong

A strong theme in our data was parents’ desire for those in authority at school and LA levels to be accountable: to take responsibility when things went wrong and to act to sort things out. Several parents expressed a desire for the education complaints system to be revised and strengthened, having had frustrating and negative experiences of these processes. For example, one mother said in relation to a formal complaint at school level: “There was nobody who actually addressed the issues that we were raising as parents.” (Mother, Interview 8).

A desire for greater accountability was also expressed in relation to the LA SEN team. For example, one parent said: “As a SEN parent, it’s normal experience to be let down! [...] No-one is held accountable!” (Mother, Interview 17). The minority who had experienced mediation agreements not being implemented or even Tribunal decisions not being put into practice were particularly vocal about the need for greater accountability, querying, for example, “Who is holding the LA to account for *not* meeting the needs set out [in my son’s] statement?” (Mother, Interview 66).

To give a positive example, in separate interviews, two mothers from the same LA described how a new head of the LA’s SEN team stepped in to right wrongs that she had noticed in their respective children’s cases. These were children whose needs were not recognized in their respective schools. The parents (not known to each other) made parental requests for assessment. When the LA SEN caseworker then requested documentation of what the respective schools had already done to meet the children’s needs, none was forthcoming. At the LA SEN panel, the new head of service picked up on this, and intervened directly, visiting these parents at home and meeting with the headteacher and SENCOs at the two schools. This action was viewed very positively by the parents. For example, one said:

“Somebody very high up [i.e. the SEND manager] had sat on the panel and heard a story about [our son] and wanted to know how we got so far with no paperwork [from the school]. [...] She goes beyond and past a mile to help and she’d only just joined. We called her our guardian angel. Such a lovely caring person.” (Mother, Interview 13).

4. Invest in the LA SEN System

In spite of the psychological distress and cost, both financial and otherwise, caused by the disagreements with decision-makers involved in their child’s education, one theme in our data was that some parents contextualized their individual experiences within an overall SEN system that was, in their view, under-resourced. This included financially under-resourced: for example, “I know that they do care but ultimately they’ve got strapped resources and a lot of children to attend to,” (Father, Interview 2). It also included under-resourced in terms of the number, quality and training of its staff: for example, one mother who also worked for a LA as a SEN information, advice and support worker noted that

she had received more training for that role than the case workers in the EHC assessment and planning team:

“It’s down to who is managing [a SEN team], what their knowledge base is and whether or not that is cascaded to the team. There is no standard. I think that is what is missing. I think there should be a set continuing professional development [input] before you are let loose [in that role].” (Mother, Interview 78).

This sub-group were magnanimous in acknowledging the pressures on LAs and how that affected individuals trying to work within a pressurized environment. Parents asked for investment in more staff and for staff to be well-trained in SEN law and in the skills of working in partnership with parents, and with empathy and understanding of children with complex needs. There was acknowledgment that the Children and Families Act 2014 set out a positive framework but an awareness that, in their experiences, the implementation in practice did not live up to the underpinning principles. As one father put it:

“The new SEN framework depends on culture change and that has not happened. [...] Training is not enough; there needs to be follow-through to implementation in practice.” (Father, Interview 59).

5. Offer Peer Support to Other Parents

Having come through all the stresses and strains of their own disagreement resolution experiences, a minority of mothers and fathers used this to provide support to other parents going through similar issues. For example, one father (who had appealed five times in relation to his own children) set up a not-for-profit business supporting other parents to prepare Tribunal cases and attended Tribunal with them. One mother who had had to give up her job in order to give support to her son later became a parent champion for an online charity supporting families with children with SEN. Another mother became an ambassador explaining: “I don’t want to stop the fight because there are lots of other parents out there [...] who can’t necessarily write the letters.” She had become an autism ambassador in order to help other parents: “You have to pay back. So many people helped me when I needed it that I now need to go back and help other people” (Mother, Interview 30).

Others volunteered their help in more informal ways. For example, one mother reported that she had, “joined some forums and realized that I’m not alone. There are lots of us.” (Interview 71).

DISCUSSION

Our findings need to be viewed in context. Parents involved in a formal disagreement or complaints process related to their child’s SEN are, at any time, a minority of the population of parents with a child with SEN. For example, in an English study of EHC plans issued in 2015, of over 13,600 parents and young people, two-thirds were satisfied with the process and three-quarters agreed the EHC plan led to the child or young person receiving appropriate SEN support (Adams et al., 2017, p. 11).

Nevertheless, those in disagreement are an important minority. They flag up when the, “quality of special education” and the “skill and insight, backed by adequate resources[...] efficiently deployed” of the “people working together in the interests of children” (Warnock Report, 2.85) fall short.

Understanding Why

Findings in relation to our first research question, *Why do some SEN disagreements become so distressing for parents?*, can be understood in three inter-connected ways. First, our findings show that, from these parents’ perspective, there is one main driver of disagreements (belief that the child’s SEN are unmet) and one main driver of complaints (delays and role dissonances experienced while seeking to ensure the child’s needs are met). This is a new insight.

Secondly, using Lazarus’s four-part model of stress (Lazarus, 1966, 1993; Lazarus and Folkman, 1984) as a lens, we can see that the initial driver of the disagreement (“agent of stress”) from the parents’ point of view is the belief that their child’s needs are not being met and hence their child’s strengths cannot thrive. This is viewed as a serious threat (“appraisal of stress”) to the immediate and long-term interests of their child, setting up the situation as a main source of distress. Engaging with statutory processes can be viewed as the “coping mechanism.” The demands, delays, and role dissonances experienced during these process lead to the “stress reaction.” The delays and role dissonances then, in turn, act as further “agents of stress,” appraised as further threats to the child’s well-being. Having recourse to formal complaints processes and making use of other options, such as Freedom of Information requests, can thus be viewed as different “coping mechanisms.” As the length of time and the number of processes engaged in increased, and fear for the future grew, the cumulative “stress reaction” became more serious. Some of the decisions made as a result of the stressful situation in which parents found themselves, such as taking a child out of school, giving up paid employment, in turn became new “agents of stress,” appraised as threatening to the well-being of the whole family. Parents’ “coping mechanisms” were tested by this, with many reporting that the “stress reaction” had reached very negative heights, including mental and physical illnesses. Understanding this pattern is also a new insight into SEN disagreements and complaints.

Thirdly, one way of understanding the powerfulness of the emotions (the “stress reaction”) felt by parents when confronted by professionals and case workers who did not behave in accordance with reasonable expectations of their role is to draw on learning that has its roots in transactional analysis of everyday behaviors. Specifically, the insight that the drama of conflict and emotional intensity is created by unexpected role switches around the “drama triangle” of Rescuer, Persecutor, Victim (Karpman, 2007). This is a useful heuristic device when interpreting our findings about role dissonance. When parents and education professionals act as expected of their roles, they have a mutual responsibility to work together to support the special needs of the vulnerable child. Once this has gone awry and the parent believes the school-based professionals are not playing their part of supporting the child’s needs, the parent turns

to the LA professionals. The expectation is that the LA SEN team will work in partnership with the parent to ensure that the child’s needs are met. When this in turn goes awry (a refusal to assess, for example, or by experiencing delays or unexpected behavior), some parents react to this role dissonance as a perceived attack (i.e., the expected ally in the SEN team is suddenly perceived as acting against their child’s interests). In response, they take on the dramatic role of “rescuer” of their child who becomes “the victim” in the drama, leaving only the role of “persecutor” for the LA personnel.

The use of the word “drama” in transactional analysis, and here, is not derogatory or dismissive; it is a signal that the adults have switched out of consciously taking responsibility for their actions into unconscious “roles” with set “scripts.” In what we could call the “drama of unmet SEN,” the script becomes filled with metaphors of battle. These metaphors pepper our data, as they did in other studies of parental disagreements relating to SEN in England (e.g., Duncan, 2003; Kids First, 2013), in America (e.g., Mueller and Buckley, 2014), and in Scotland (e.g., Weedon and Riddell, 2009). In some cases, as our data also illustrates, parents may at times take on the “persecutor” role with the LA staff as the “victim.” The “drama” continues until it is interrupted. This can happen when one of the “players” consciously steps out of “role” (as the mother in Interview 6 did when she realized that “cut[ting] a deal,” i.e., working cooperatively together, was a better option for her child than continuing her “battle”). It can also happen when the case is taken to an independent mediator or to an independent panel at a Tribunal. That the “drama” is unnecessary is illustrated by the actions of the LA officer who intervened directly to address the unmet needs of the child of the mother in Interview 13. In doing so, she acted professionally in the expected mode of partnership with parents and prevented a disagreement arising.

Aspects of our findings can be found in previous research on parental experiences of SEN disagreement resolution. For example, the negative impact of delay Local Government Social Care Ombudsman (2017) or of role dissonance (Valeo, 2003; O’Connor, 2008; Yates and Hulusi, 2018); the pressure associated with demands of the processes (Penfold et al., 2009); a model of costs that includes opportunity costs, emotional costs, productivity costs as well as direct costs (Levine, 2001). Our work extends all of these studies. Previous categorizations of parents as “awkward customers” (Duncan, 2003, p), “their child’s champion” (Weedon and Riddell, 2009, p 77) or as “high profile” or “bull-dog” parents (Rehm et al., 2013, p. 1381) may also be illuminated by our insights from the “drama triangle.”

Our work makes three significant contributions to understanding parental perspectives of the dynamics of SEN disagreements. By allowing parents to include the backstory, and by asking about their experiences of every available form of SEN disagreement resolution in the English system, it has, firstly, provided the most complete picture to date of the parental, “journey through the SEN ‘system’ [and their] perceived struggles to attain special educational provision for their child” (Tennant et al., 2008). By framing our study in the light of Bronfenbrenner’s theory of human ecology, and using the lenses of stress theory and the “drama triangle” to interpret our data,

we have, secondly, identified the drivers of disagreements and complaints; and, thirdly, increased understanding of why some of these become so distressing for parents.

Prevention or Earlier Resolution

Findings in relation to our second research question, *How can such disagreements be prevented or resolved?*, are important as they demonstrate a way forward that could address each of the stress levels we identified as experienced by the parents. The normal stresses of everyday life are ameliorated by others showing ordinary kindness and understanding. When a family is also dealing with one or more children with significant SEN, this level of human empathy becomes even more important. If all school and LA SEN staff treated parents with this everyday courtesy and understanding, that is a cost-free way in which some of the stress would lift. Similarly, ensuring that all such staff were properly trained, and willing and able to do their jobs in the spirit of partnership with parents that has underpinned legislation and SEN Codes of Practice since the Warnock Report, the demands of engaging with the statutory processes would become much more manageable for parents. Without unnecessary delays and experiences of role dissonance, the focus would remain on addressing the needs of the child, and the drivers of complaints and the “drama” of the ‘persecuting’ authority, the “rescuing” parent, and the “victim” child would be unnecessary. In this way, the negative impacts on the parents, child and family would disappear or be greatly reduced and there would be no need to fear for the future.

As early as 1998, Evans identified that the qualitative factors associated with LAs with lower levels of appeals were to do with high quality relationships with parents and other stakeholders. (Evans, 1998) In relation to preventing complaints, the Local Government Social Care Ombudsman (2017) also recommended that LA SEN staff, “work closely with families throughout the EHC process” (p. 21) and also ensure staff received proper training in the law. In a small scale study interviewing 10 school district level directors in one USA state, Mueller and Piantoni (2013) also concluded that good practice in preventing and resolving SEN disagreements was largely about the quality of relationship the professionals created with the parents, including seeking to put themselves in the parents’ shoes.

Our finding that parents wanted schools and LAs to be more accountable is given weight by facts, such as that, in England, in the first 2 years of local area SEN inspections, 31 of 68 areas (46%) had to provide a written statement of action (Ofsted, 2018, p. 12). Similarly, the Local Government Social Care Ombudsman (2017) stated that, “Councils and all other bodies providing local public services should be accountable to the people who use them” (p. 22). The context was that, after over 100 investigations of complaints related to EHC plans, 79% were upheld compared to an average “uphold rate” of 53% of all their investigations.

Finally, our finding that a sub-sample of the parents went on to support other parents following resolution of their own cases may be a sign that there is some altruistic awareness of the inequity inbuilt in the system (described by Gross, 1996). It indicates that “parent power” can be “generous in spirit rather than narrowly focused on particular interest groups” (Gross, p. 8).

Limitations

A strength of this study is its scale. To our knowledge, this is the largest study on the topic to date in terms of number of in-depth interviews with parents. There have been questionnaire surveys of larger number of parents expressing views about SEN disputes (e.g., Kids First, 2013, received 400 responses to a survey), but these inevitably lack the richness and contextual detail of in-depth interviews.

One limitation is that here we deliberately focused on parents’ perspectives only. The theoretical lenses we chose to help to make sense of these perspectives reflect the microsystemic and mesosystemic foci of these data. Perspectives expressed by local authority representatives, not included here, would require a wider lens to incorporate the more macrosystemic aspects affecting disagreements and disagreement resolution that they raised, such as budgetary constraints—and differing views—on the national and local allocation of resource to children and young people identified as having significant special educational needs.

Another limitation is that we do not know how representative our parent participants are of all those in England who have completed at least one SEN disagreement resolution process since September 2014. In fact, it is not possible to assess this as no demographic data is published on parents of children with SEN who make complaints, attend mediation, or appeal to the Tribunal.

More than three-quarters of the children/young people discussed by the parents were male. This is reasonably representative of the gender balance in the population of children with a statement of SEN or EHC plan in England (males 4.2%: females 1.6%, Department for Education, 2018, p. 7).

The interview schedule included questions at the end about the interviewee’s age (in decades), self-described ethnicity, relationship status to the other parent of the child discussed; highest educational qualification; employment status; and job, if employed. Due to the semi-structured nature of the interview, and their placement at the end, these questions were asked in the majority, but not in all, cases. Our data therefore does not describe the interviewees as a whole; rather, the majority of that group. Nevertheless, a strength is that our participants were diverse. They were drawn from 39 English LAs (a quarter of the total); they were diverse in age, ethnicity, relationship status, employment status, and educational qualifications. A limitation is that there was a gender skew: more than eight times as many mothers were interviewed as fathers. Mueller and Buckley’s study (2014) of the views of fathers of children with disabilities is a welcome redressing of the domination of mothers’ viewpoints in SEN research.

Our study was qualitative and designed to generate new understanding of a sample of parental experiences of SEN disagreements in England. It should not be assumed that these can be generalized to all such parents in England, nor to other national contexts. However, it is robust enough to serve as a useful starting point for further larger-scale and potentially multi-national research that could test out the findings.

Implications

Forty years on from the Warnock Report (1978), our findings indicate the continuing need to focus on the “quality of special education” and on ensuring that those “people [who] work together in the interests of children” with SEN have the “skill and insight” and “adequate resources” to do so effectively. The LA retains the responsibility to make adequate provision for the SEN of all the CYP in the area. It has to do so in a much changed context, affected by delegation of resources, of support services, the “freeing” of schools from LA control, and a post-2008 period of austerity. Yet, as our findings show, the underpinning principles of the Warnock Report remain relevant: the human right to education, accurate assessment of needs, and professionals working in partnership with parents. When these are in place in practice, our data indicate that SEN disagreements will be prevented or more easily resolved.

DATA AVAILABILITY

The datasets for this manuscript can not be made available because this possibility was not included in the original contract with England’s Department for Education nor in the consent forms with participants.

ETHICS STATEMENT

This study was carried out in accordance with the recommendations of the UK Concordat to Support Research

Integrity, The University of Warwick’s Humanities and Social Sciences Research Ethics Committee with written informed consent from all subjects. All subjects gave written informed consent in accordance with the Declaration of Helsinki. The protocol was approved by the The University of Warwick’s Humanities and Social Sciences Research Ethics Committee.

AUTHOR CONTRIBUTIONS

MC led the research on which this paper is based and led the writing of the paper itself. GL was co-investigator and co-wrote the paper.

FUNDING

The research on which this article is based was funded through a contract with England’s Department for Education, awarded in open competition (Contract Reference Number: EOR/SBU/2014/025).

ACKNOWLEDGMENTS

The authors would like to thank all the participating parents; the professionals who helped us reach parents; our former colleague, Ruth Thomas, who contributed to data collection and initial analysis; and the three reviewers.

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Conflict of Interest Statement: The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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