

For
every
child, a great



'TOO LITTLE, TOO LATE'

**The views of parents/carers on their child's
experiences of the Special Educational
Needs (SEN) process in mainstream schools**

November 2019



For every child

all adults
should do what
is best for you



This report of parents/carers' views was commissioned by the Northern Ireland Commissioner for Children and Young People (NICCY) as part of its Children's Rights Based Review of Special Educational Needs Provision in Mainstream Schools. It is one of a suite of reports that explores the issues preventing children and young people from fully realising their rights to an effective education in the context of SEN provision in mainstream schools.

The full suite of 'Too Little, Too Late' reports are available on NICCY's website at www.niccy.org/senreviewreports. This includes the main report, summary report and an Easy Read version. The main report sets out the views of various stakeholders including Principals/Special Educational Needs Coordinators (SENCOs), Educational Psychologists, representatives from the Voluntary Community Sector, and parents/carers as presented in this report. It also includes an analysis of operational data on SEN provision, and sets out a range of recommendations for improving SEN provision in mainstream schools that are grounded in the evidence collected.

TABLE OF CONTENTS

Executive Summary.....	3
Chapter 1: Legislative and Policy Context.....	6
Chapter 2: Methodology.....	20
Chapter 3: Results.....	26
Chapter 4: Discussion.....	133
Chapter 5: Conclusion and Recommendations.....	148
References.....	155

EXECUTIVE SUMMARY

- The research set out to obtain the views of parents/carers about their and their children's experience of accessing or attempting to access services and support for a SEN or suspected SEN in mainstream schools in Northern Ireland.
- The research was funded by NICCY and carried out by a team from Stranmillis University College, Belfast between March and September 2019.
- The research proposal received full ethical permission from the Research Ethics Committee of Stranmillis University College, Belfast in April 2019.
- The research adopted a mixed methodological approach involving an overview of the current legislative and policy context in Northern Ireland, followed by a detailed online survey (n=608), ten focus group interviews held in eight locations across Northern Ireland (n=55) and a further six individual interviews with parents/carers.
- Survey results highlight that in terms of 'Availability' (one of the key Children's Rights Benchmarks), the SEN system is currently severely lacking: only 1 in 8 respondents felt that there were adequate facilities and services in place to meet the needs of all children and young people with SEN, while in terms of 'Accessibility', only 1 in 6 respondents felt that all children with SEN have equal access to services without discrimination of any kind. Less than 1 in 5 believed that the SEN process is child-centred ('Acceptability'), while a similar proportion felt that the education environment is adaptable in order to meet the needs of children with SEN ('Adaptability'). Only 1 in 7 felt that children and young people with SEN receive a quality service which meets their needs ('Quality/Impact'), and the same proportion of parents felt that the views of children with SEN are sought and taken into account in their education and development of policy and services ('Participation'). Only 1 in 10 agreed that there is timely and appropriate cooperation and integration of services to ensure a holistic approach is taken to meet the needs of children with SEN ('Cooperation').

- These summary results were expanded upon in the focus group and individual interviews where the majority of parents and carers spoke of their growing sense of frustration as they were forced to ‘fight’ to access services in the first instance, often having to wait for lengthy periods and/or resort to phoning on multiple occasions to speak to professionals. Schools were having to prioritise at times very limited numbers of referrals, meaning that many children with less ‘visible’ needs were more likely to be overlooked. Even when they were able to access services, parents/carers spoke of delays, inadequate communication with them and between service providers, inaccuracies in statements, staff with limited knowledge and understanding of SEN, and a failure to provide statutory special educational provision.
- Parents/carers spoke of the negative impact that the current overstretched SEN system was having on their children, whose learning needs were too often not being met. This also had an impact on children’s behaviour and mental health.
- Parents/carers also spoke of their own growing frustration, anxiety, confusion and alienation from a system which many found unnecessarily complex and protracted, and where guidance and support, although promised, was often inadequate or absent. This had an impact on their mental health, relationships, home life and ability to work.
- Six key recommendations are made. These recommendations and the underpinning findings, alongside the evidence collected from other stakeholders and analysis of operational data, have informed a further set of recommendations contained within the main report ‘Too Little, Too Late: A Rights Based Review of Special Educational Needs Provision in Mainstream Schools’¹.
 - To provide more funding to relevant government departments, the EA and schools to provide more staff, better resources and more adequate training.

¹ This report is available on [NICCY's website](#) along with a summary report and an Easy Read version.

- To revise the statutory assessment model to introduce a new independent assessment body so that there is no longer a conflict of interest for the EA which is currently legally responsible *both* for drawing up the statement *and* paying for its provisions.
- To place the child firmly at the heart of the SEN system where all decisions would be taken in their best interests and having taken into account their own views and perspectives.
- To provide a free, accessible, face-to-face service across each EA region where parents/carers could raise issues and voice their concerns, and where trained EA officers could provide individual advice at all stages, from Stage 1 to Stage 5 of the current *Code of Practice*.
- To provide more comprehensive pre- and in-service SEN training for teachers and other professionals, including SENCOs.
- To conduct further research into the experiences of parents/carers of very young children (aged 0-3), those who are currently educated in special schools, and those who are home schooled. The voice of these parents/carers also needs to be heard.

CHAPTER ONE: LEGISLATIVE AND POLICY CONTEXT

International Context: UNCRC and Salamanca Statement

The current policy context in Northern Ireland in relation to SEN and inclusion needs to be set in the wider context of two significant international agreements to which the United Kingdom government is a signatory.

First, the UN Convention on the Rights of the Child [UNCRC] (UNICEF, 1989) highlights the civil, political, economic, social and cultural rights of all children across the world. The UNCRC expresses the right of all children, including those with a disability, to the highest possible standards of education (and health) provision within an inclusive education system. Many of the UNCRC Articles have direct relevance to SEN. For instance, Article 2 of the UNCRC states that no child must be discriminated against in relation to a number of factors, including disability, and, crucially, Article 3 states that all public bodies should act at all times in the best interests of children:

“In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration.” (UNICEF, 1989, Article 3)

Article 12 states that a child capable of forming his or her own views must be given the right to express those views freely in all matters concerning them, with the weight given in accordance with the age and maturity of the child. Article 13 confirms the right of children to express those views in a range of formats or media (not always written or oral). Article 23 expresses a strong espousal of social inclusion. It states that a child with a disability has the right to “enjoy a full and decent life” and in conditions which “ensure dignity, promote self-reliance and facilitate the child’s active participation in the community”. The Article continues by stressing the “right of the disabled child to special care” and insists

that any assistance extended “shall be provided free of charge, whenever possible” and “shall be designed to ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child's achieving the fullest possible social integration and individual development.” (UNICEF, 1989, Article 23). Article 24 expresses the right of the child to the “highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health”, and makes a commitment that all States Parties shall strive to ensure that “no child is deprived of his or her right of access to such health care services.” In relation to education specifically, Article 28 outlines the fundamental right of the child to education and affirms the importance of actions including school discipline being administered “in a manner consistent with the child’s human dignity”, while Article 29 states that the education of the child “shall be directed to the development of the child’s personality, talents and mental and physical abilities to their fullest potential”. General Comment 1 on the Aims of Education (UN, 2001) stresses that education must promote the core value of the UNCRC: “the human dignity innate in every child and his or her equal and inalienable rights”. It further notes that education must be “child-centred, child-friendly and empowering” and adds:

“The goal is to empower the child by developing his or her skills, learning and other capacities, human dignity, self-esteem and self-confidence. “Education” in this context goes far beyond formal schooling to embrace the broad range of life experiences and learning processes which enable children, individually and collectively, to develop their personalities, talents and abilities and to live a full and satisfying life within society.” (UN, 2001)

Just over two years after the UNCRC came into force in the UK on 15th January 1992, representatives of 92 governments and 25 international organisations attended the *World Conference on Special Needs Education*, held in Salamanca, Spain, in June 1994, organised by the Government of Spain in co-operation with UNESCO. The resulting

Salamanca Statement urges the international community to endorse the approach of inclusive schooling. Signatories agreed that “those with special educational needs must have access to regular [=mainstream] schools which should accommodate them within a child-centred pedagogy capable of meeting these needs” and adds that “regular” schools with an inclusive orientation are “the most effective means of combating discriminatory attitudes, creating welcoming communities, building an inclusive society and achieving education for all”. Signatories to the Statement also called upon all governments to “give the highest policy and budgetary priority to improve their education systems to enable them to include all children regardless of individual differences or difficulties” (UNESCO, 1994), thus setting out the importance of making adequate funding available to support an inclusive education system.

The Definition of Special Educational Needs

The most significant piece of legislation in Northern Ireland in terms of the definition of special educational needs (SEN) remains The Education (Northern Ireland) Order 1996 which states that “a child has ‘special educational needs’ if he (sic) has a learning difficulty which calls for special educational provision to be made for him” (Article 3). The Order further states that a child has a ‘learning difficulty’ if:

- (a) he has a significantly greater difficulty in learning than the majority of children of his age
- (b) he has a disability which either prevents or hinders him from making use of educational facilities of a kind generally provided for children of his age in ordinary schools, or
- (c) he has not attained the lower limit of compulsory school age and is, or would be if special educational provision were not made for him, likely to fall within sub-paragraph (a) or (b) when he is of compulsory school age. (Article 3)

‘Special educational provision’ is further defined in the Education (Northern Ireland) Order 1996 in relation to a child who has attained the age of two years as “educational provision

which is additional to, or otherwise different from, the educational provision made generally for children of his age in ordinary schools.” (Article 3)

A brief history of SEN policy in the UK

The development of government policy in the UK dates back to the 1970s. The *Report of the Committee of Enquiry into the Education of Handicapped Children and Young People* (HMSO, 1978), also widely known as the Warnock Report after its chair Professor (later Baroness) Mary Warnock, has been referred to as a ground-breaking step towards the creation of an education system that can reach out to all children and served as a catalyst for major international developments. Over the past 40 years the impact and legacy of the Warnock Report on the education of children with special education needs (SEN) has been contested (e.g. Wedell, 1990; Warnock, 2005; Lunt, 2007; Ainscow, 2018; Norwich, 2018) but it is beyond contention that many of the key elements of the current SEN system have their origins in this seminar report (which led to legislation across the UK), including the very term ‘special educational needs’, the concept of ‘integration’ (later to develop into ‘inclusion’), the notion of parents as ‘equal partners’ and the model of the ‘statement’ offering statutory support for children with the most complex and/or severe educational needs. In the report Warnock (1978) stresses the importance of removing obstacles and barriers facing children with SEN and to finding resolutions to these issues:

The purpose of education for all children is the same; the goals are the same. But the help that individual children need in progressing towards them will be different. Whereas for some the road they have to travel towards the goals is smooth and easy, for others it is fraught with obstacles. (1.4)

A rigid system of 11 categories of handicap predated the changes in legislation driven by the Warnock Report labelling blind, deaf, epileptic or physically disabled/aphasic children as seriously disabled, and if adequate provision was viable children with other disabilities might attend ordinary schools (1944 Education Act; Handicapped Pupils and School Health Service Regulations 1945). The Warnock Report represented a policy shift from a medical to a social model of disability, and set out two long-term goals of education that

were applicable to all children and which aimed to remove any systematic barriers or obstacles facing children with SEN: first, to develop a child's knowledge, experience and imaginative understanding, leading to greater awareness of moral values and capacity for enjoyment; and second, to prepare the child to become an active participant and contributor to society, living as independently as possible.

Through its influence, the Warnock Report asserted the principle that education is a "human good, to which all human beings are entitled" (§1.7), advocated parents as "equal partners" in the education of their children, and developed the "statement" which helped safeguard appropriate educational provision by local authorities for those children with more severe or complex learning difficulties. Significantly, and in a rarely cited section, the Warnock report also included recognition that integration "is not a cheap alternative to provision in separate special schools, and there is no short cut" and indeed the report stresses that the dispersal of services currently concentrated in just a few (i.e. special) schools "will be considerably more expensive" (§7.56). In summary, the report emphasises that successfully 'integration' (inclusion) in 'ordinary' (mainstream) schools depends on careful planning, training and (importantly) financial resourcing from the very start. Writing forty years after its publication and just months before her death, Warnock (2018) referred to her Report and the ensuing 1981 Education Act as representing the "last gasp of welfarism" (p.3), following in the earlier tradition of the 1942 Beveridge Report (which led to the creation of the welfare state) and the 1944 'Butler' Education Act (which led to free secondary education for all). It was a source of profound regret for Warnock (2018) that her plans were never given the necessary public funding required to implement them fully under Margaret Thatcher's Conservative government of the 1980s.

The Current SEN Context in Northern Ireland

The current SEN system (in terms of the identification, assessment and statementing of children with SEN) was first introduced in Northern Ireland in January 1986, and

corresponded closely to legislation in England and Wales. This was later updated by the the Education (Northern Ireland) Order 1996 (DENI, 1996), which set out the statutory definition of SEN (see above), provided the main statutory framework for the current SEN system, and, on a more practical level, also stipulated that the Education and Library Boards (now EA), schools and other relevant bodies must 'have regard to' the *Code of Practice on the Identification and Assessment of Special Education Needs* (more commonly referred to simply as the *Code of Practice*) which became operative from 1st September 1998.

The Code of Practice on the Identification and Assessment of Special Educational Needs

The *Code of Practice* sets out five key principles which highlight that the needs of all pupils with learning difficulties must be addressed, giving them the greatest possible access to the Northern Ireland curriculum, where possible, within a mainstream setting, taking into account the knowledge, views and experience of parents. Given their relevance to this research, the Principles of the Code (DE, 1989, p.2) are reproduced in full below:

1.6 The fundamental principles of the Code are that:

- the needs of all pupils who may experience learning difficulties during their school careers must be addressed; the Code recognises that there is a continuum of needs and a continuum of provision which may be made in a variety of forms;
- children with special educational needs require the greatest possible access to a broad and balanced education, including the Northern Ireland Curriculum;
- the needs of most pupils will be met in mainstream schools, and without a statutory assessment or a statement. Children with special educational needs, including those with statements, should, wherever appropriate and taking into account the wishes of their parents, be educated alongside their peers in mainstream schools;

- even before a child reaches compulsory school age, he or she may have special educational needs requiring the intervention of the Boards as well as the health services;
- the knowledge, views and experience of parents are vital. Effective assessment and provision will best be secured where there is partnership between parents and schools, Boards and other agencies.

The *Code of Practice* also establishes a series of essential practices and procedures to be followed by the Boards (now EA) and schools which prioritise early identification, partnership with parents, efficiency of assessment, clarity and thoroughness of written statements, involvement of the child, and close cooperation between relevant agencies. The relevant section (DE, 1998, p.2-3) is once again included in full below:

1.7 The essential practices and procedures which the Code embodies are that:

- children with special educational needs should be identified as early as possible and assessed as quickly as is consistent with thoroughness;
- provision for children with special educational needs should be made by the most appropriate agency. In most cases this will be the child's mainstream school, working in partnership with the parents, and no statutory assessment will be necessary;
- Boards should complete assessments and statements as quickly as thorough consideration of the issues allows;
- Boards must produce clear and thorough statements, setting out the child's educational and non-educational needs, the objectives to be secured, the provision to be made and the arrangements for monitoring and review; they must ensure the annual review of the special educational provision made for the child and the monitoring and revision of educational targets;
- the ascertainable wishes of the child should be considered, in the light of his or her age and understanding;

- there must be close co-operation between all the agencies concerned and a multi-disciplinary approach to the resolution of issues.

The *Code of Practice* also sets out in detail the Five Stage Approach to the identification of children with learning difficulties, the assessment of their SEN and the making of necessary provision (including statutory provision) to meet those needs. As well as detailing the Five Stage Approach (including arrangements for carrying out a statutory assessment), the *Code of Practice* sets out the duties of the class teacher, SENCO and Boards of Governors, and provides guidance on Individual Education Plans and Annual Reviews.

The Special Educational Needs and Disability Order (SENDO) 2005

The Special Educational Needs and Disability Order (SENDO) came into effect in Northern Ireland on 1 September 2005 and strengthened the right of children with a statement to be educated in an ‘ordinary’ (mainstream) school “unless that is incompatible with (a) the wishes of his parent, or (b) the provision of efficient education for other children” (Article 3)

The SENDO also includes a section (21A) entitled *Advice and information for parents* which states that “A board shall arrange for the parent of any child in its area with special educational needs to be provided with advice and information about matters relating to those needs” and adds that the board (now EA) shall take all appropriate steps to make their SEN services known to the parents of children in its area (as well as school principals).

Another major feature of SENDO is the requirement placed on Education and Library Boards (ELBs - now EA) to provide a means of avoiding or resolving disputes between ELBs or schools and parents of children in its area (which led to the establishment of the cross-Board independent Dispute Avoidance and Resolutions Service – DARS), and further required the ELBs to comply with the outcome of any (SENDIST) Tribunal within the stipulated timeframe. The SENDO also set out the grounds on which an appeal could

be made to the Tribunal to include an appeal against the statement's description of the child's SEN, the statement's specified special educational provision, or, if no school was specified at all in the statement.

A duty is also placed on a school under Article 9 of the SENDO to inform parents if special educational provision is being made for their child because it is considered that he/she has special educational needs.

SENDO also placed new disability discrimination duties on ELBs and schools not to treat pupils with a disability less favourably and without justification for a reason that relates to their disability, to make "reasonable adjustments" so that pupils with a disability are not disadvantaged in any way, and to plan proactively (as well as responding reactively) to increase accessibility to premises and the curriculum to pupils with a disability.

In light of the significant changes introduced by the SENDO, a *Supplement to the Code of Practice on the Identification and Assessment of Special Educational Needs* was published operative from 1 September 2005, which includes detailed information and guidance to schools and ELBs as well as a series of 11 case studies in the Appendices to illustrate good practice in relation to the 'efficient education' caveat and also the notion of 'reasonable steps' to be taken by schools to accommodate/include pupils with special educational needs and/or disabilities (DE, 2005a)

In 2005 the Department of Education in Northern Ireland (DE, 2005b) also issued guidance to schools to help them categorise the special educational needs of the children for recording purposes. The guidance identified seven main areas of SEN: cognitive and learning; social, emotional and behavioural; communication and interaction; sensory; physical; medical conditions/syndromes; and other. In January 2019, new guidance was issued to schools to replace the 2005 categorisation model (DE, 2019). Entitled *Recording SEN and Medical Categories*, this guidance followed a full review of SEN categories undertaken in 2017/18 and comprises a new list including a comprehensive list

of medical categories. Importantly the guidance advises that “Pupils with a medical diagnosis/es who do not have an associated special educational need (SEN) should be recorded on a school’s Medical Register only.” (DE, 2019, p.2).

The Review of the SEN System in Northern Ireland

A prolonged period of review began in August 2009, with the DE consultation on *The Way Forward for Special Educational Needs and Inclusion* (DENI, 2009). After several years of discussion and significant revisions to the original 2009 proposals, new legislation was finally passed by the Northern Ireland Assembly in 2016. The Special Educational Needs and Disability Act (Northern Ireland) 2016 means that the Education Authority (which replaced the five education and library boards on 1 April 2015) must publish a plan of its arrangements for special educational provision at least annually, boards of governors must appoint a *Learning Support Coordinator* (a new role replacing the SENCO) with responsibility for coordinating provision, and each child with SEN must have a Personal Learning Plan (replacing the previous Individual Education Plan). In addition, a duty is now placed on the EA to have regard to the views of the child when making decisions about their SEN, and a duty is placed on Health and Social Care bodies to provide services identified by them as likely to be of benefit in addressing the child’s SEN. In essence, the new Act provides the legislative changes necessary to support a new SEN framework. The passing of the new legislation was followed by a public consultation on new draft SEN regulations (February–May 2016) but thereafter progress has been halted by the collapse of the Northern Ireland Executive in January 2017, so that at the time of writing, ten years after the publication of the original SEN Review consultation, the SEN regulations have not yet been passed, and the 1998 *Code of Practice* remains in use.

Figures from the Department of Education Northern Ireland (DE, 2019) show that for the 2018-19 academic year there were 78,917 pupils with SEN in Northern Ireland, representing 23% of the school population. A total of 18,425 pupils have been issued a statement of special educational needs, equivalent to 5.3% of the total school population.

The overall number of children with SEN in Northern Ireland has risen by 48% since 2004/05, and over the same period the number of children with statements has risen by 60%. Enrolment in special schools has also risen in recent years: for instance, from 2008 to 2018 the number of pupils enrolled in special schools in Northern Ireland rose by 30% from 4598 to 5958 pupils (DE, 2018).

A significant report on *Special Educational Needs* for the Northern Ireland Assembly by the Comptroller and Auditor General (NI Audit Office, 2017) has also drawn public attention to the growth in expenditure on SEN. In 2015-16 this expenditure was over £250m of which £217m was Education Authority (EA) expenditure and the remainder DE spend, primarily in relation to transport costs and SEN funding to Voluntary Grammar and Grant Maintained Integrated Schools. £55m was spent on classroom assistant costs in 2015-16. The Audit Office report concluded that “neither the Department nor the EA can currently demonstrate value for money in terms of economy, efficiency or effectiveness in the provision of support to children with SEN in mainstream schools” (NIAO, 2017, §13). A report published by the National Audit Office in September 2019 on *Support for Pupils with Special Educational Needs and Disabilities in England* has also highlighted a rise in the number of pupils with the greatest needs (those with EHC Plans) but noted that funding by the Department for Education has not kept pace with this rise in need, so that Local Authorities are increasingly overspending their budgets for supporting pupils with high needs. It further notes that the Department failed to fully assess the likely financial consequences of the 2014 reforms and that “The system for supporting pupils with SEND is not, on current trends, financially sustainable” (National Audit Office, 2019, p.11).

Recently the Chief Executive of Northern Ireland’s single Education Authority warned that the local education system is facing a £350m funding gap by 2019-20 (BBC, 2017). Shortly after this warning was given, the EA refused to approve budget plans submitted by a total of 632 schools since they were unable to show they could stay within their budgets (BBC, 2018a). By way of illustration of the severe budgetary pressures experienced by

schools, at a recent presentation to the Northern Ireland Affairs Committee at Westminster as part of their inquiry into education funding in Northern Ireland, one primary principal admitted that parents were now donating toilet paper, tissues and soap to his school (BBC 2018b), and there was anecdotal evidence given that SEN funding for classroom assistants was often cut first by school managers in their attempt to balance the books.

In its final Report (House of Commons, 2019, §127) the Northern Ireland Affairs Committee concluded “It is clear that the system does not currently have the resources it needs to meet demand for SEND support” and recommended that future budget allocations to DE reflect the growing numbers of children with SEND in the school system. Faced with the current political stalemate, the Northern Ireland Affairs Committee (House of Commons, 2019, §131) also concluded that, in order to unblock the system, the Secretary of State should lay before parliament (in Westminster) the necessary regulations to give full effect to the SEND Act.

Parental Experiences of the SEN system

Despite strong endorsement of the model of parental partnership within the SEN system emanating from the Warnock Report (1978) and reflected in the *Code of Practice* (DE, 1998), there has been a paucity of research into their experiences and even fewer published first person accounts (see Harrison *et al.*, 2007; Moore, 2007).

The most significant study to date in Northern Ireland, carried out in 2005 by O'Connor, McConkey and Hartop, was commissioned by the Department of Education to inform their review of the assessment and statementing procedures. All parents of children who had a statement at that time were contacted by letter. Questionnaires were completed by 1054 parents, representing 14.6 per cent of all parents of children who had a statement. A further 96 telephone interviews were carried out with parents. The comprehensive study found that 82 per cent of the parents felt that the reports gave an accurate description of

their child's needs; 80 per cent felt that the statement represented a fair and accurate assessment as to how their child's needs would be met; and 74 per cent felt that having a statement had benefitted their child. However, three core suggestions for improvement were made by parents which focused on reducing the time taken to complete the assessments and issue the final statement; improving communication between parents and professionals involved in the process; and enhancing the clarity of information provided to parents throughout the process to ensure unambiguous terminology and information on parental rights. Several further subthemes were identified in relation to earlier intervention, the importance of enforcing the statutory recommendations of the statement, reducing the bureaucratic nature of the process, improving professional attitudes and knowledge of professionals, and the need for more support for and awareness of the needs of parents and family circumstances throughout the process. The study notes that the present assessment procedures "have not been developed either from the parents' perspective or with the needs of parents and children uppermost. Rather the system has been designed by professionals to suit professionals" (p.266), and concludes by outlining the challenge of marrying a national system of statutory assessment to one that can meet the needs of individual children and their families, something which O'Connor *et al.* refer to as an "elusive goal" (2005, p.268).

This research by O'Connor *et al* (2005) followed the findings of an earlier report by the Audit Commission (2002) which noted that the statementing process is often stressful for parents and offers little extra reassurance to them. Other studies also indicate instances in which parental involvement was lacking, resulting in frustration with statutory processes and a lack of ability to influence outcomes (Keenan *et al.*, 2010). By contrast, a stronger relationship between parents and educators can encourage empowerment and fairness in decision making, leading to agreed boundaries of responsibility and improved special educational need provision (Horby *et al.*, 1997). Other studies have similarly reported parental frustration at the limitations of the statutory assessment procedures, and their lack of ability to influence decisions and feel like truly valued partners in the process of

providing support to their children (Lindsay and Dockrell, 2004; Kay *et al.*, 2006; Keenan *et al.*, 2010; Bajwa-Patel and Devecchi, 2014)

Furthermore, Rose *et al.* (2017) report how some parents seeking early years assessments in Ireland opted to pay educational psychologists and other professional service providers for private assessments in order to guarantee resources for their children when faced with long waiting lists.

CHAPTER TWO: METHODOLOGY

In order to meet the project goals and objectives and to ensure the feasibility, robustness and efficiency of the research, a mixed-methodological research design was proposed. Mixed methods research rests on the core assumption “that the combination of qualitative and quantitative approaches provides a more complete understanding of a research problem than either approach alone” (Creswell, 2014, p.4). The design of the study had three main research methods which are discussed below:

Online Survey

The survey comprised of a total of 60 main questions (many with supplementary questions) in a range of formats including tick boxes, Likert rating scales, multiple choice questions, and a number of open ended questions. Questions focused on the goals and objectives of the study and included information such as: background details (e.g. parent or carer); age and gender of child; diagnosed or suspected SEN; school phase and management type; EA region; experiences of the SEN process in general; barriers to accessing support; experiences of engagement with school, EA, DE, health professionals; and actions recommended to improve the SEN process. There was also a question which asked parents/carers to identify the most positive aspect of the SEN system for them.

Every effort was made to ensure that the questions were clearly expressed and without using complicated language, so that as many parents as possible were able to access and complete the survey, including those with learning difficulties and those with English as an Additional Language.

Drafts of the survey were piloted with a small sample of parents to allow for feedback and review of the order and clarity of questions. A link to the online survey was then sent to all mainstream nursery, primary and post-primary schools in Northern Ireland for distribution to parents/carers. Principals were strongly encouraged to forward the email and hyperlink

to the anonymous online survey to all parents/carers of registered pupils - rather than just those already on the SEN register as it was important that the voices of parents of children with a “suspected SEN” were also included. Both NICCY and Stranmillis University College also promoted the survey through a range of social media platforms (e.g. Facebook, Twitter).

The online survey was designed using *Smartsurvey* and was accessible to users on multiple devices including tablet, PC and smartphone. The survey was open for a period of 4 weeks from 3rd to 31st May 2019. A total of 681 responses were submitted, but following screening and in line with the project specification, 73 responses were removed as the children either attended special schools or were aged 0-3 and not yet in mainstream nursery education. This left a total of 608 valid responses which were subsequently exported to SPSS for analysis.

Focus Groups

The final section of the online survey invited parents/carers to provide contact details and the names of their home/nearest town if they were willing to participate in follow-up focus group interviews. Based on this information, a total of 10 focus group interviews were organised across Northern Ireland: 3 in Belfast and 7 more in different towns across each of the EA regions. Parents/carers were invited by email and/or phone. A total of 55 parents/carers participated in the focus groups: mean group size was 5.5 with numbers ranging from 2 to 12 participants. Interviews were held at various times of the day: morning, afternoon and evening to facilitate the various commitments of parents/carers.

A pilot focus group involving a group of 4 parents was held first in Belfast and allowed the research team to refine the practical activities and question structure. As a result, some questions were amended and further clarification provided as some parents were unclear as to the respective roles of the EA, health professionals and, in particular, DE. It was also

agreed that the semi-structured approach should be consistent across all 10 focus groups, and that parents should be encouraged to remain focused on the questions throughout.

An innovative activity-based approach was adopted with the parents/carers in which parents/carers were invited at the outset to say 3 or 4 sentences (only) to introduce their child and to explain which of 10 cue cards (featuring key aspects of the SEN process) was most significant to them in their experience. This helped to settle participants and gave everyone a summary of each parent's context at the outset. These 10 key terms were: School; Education Authority; Health Professionals; Identification; Appropriateness of Support; Communication; Timeframe; User-friendliness; Impact on the Child; Impact on parents/carers/families.

Parents were then asked a series of questions related to the key aims and objectives of the study: experiences of SEN process in general; barriers to accessing support; experiences of parents/ carers in engaging with school; experiences of parents/carers in engaging with EA; experiences of parents/carers in engaging with DE; experiences of parents/carers in engaging with health professionals; and actions recommended to make SEN process easier for parents/carers.

In the final part of the focus group interviews post-it notes were distributed and participants were invited to give feedback on the 10 key aspects of the SEN process (see above), reflecting what had 'worked well' and providing 'recommendations/suggestions' for the future. Parents/ carers were invited to write and attach as many post-it notes as they wished onto large sheets of paper, and on returning to their seats, were each invited to summarise their one most significant recommendation for improvement in 2 or 3 sentences. Following the completion of the focus groups, the post-it notes from each interview were collated on master sheets.

All focus groups were audio-recorded and transcribed.

Individual Interviews

A series of 6 further individual interviews were carried out with parents/carers, allowing them to tell their individual stories and experiences in much more detail than the survey or group interview would permit. Participants were recruited from the focus groups or through personal contact. Selection for participation in this section of the study was based on involving a representative range of parents and carers (in the end interviews were carried out with 5 parents and 1 carer), with children in a range of phases of education, and including a range of special educational needs and experiences, positive and negative. These in-depth interviews led to the creation of a set of 6 detailed case studies which have also been included in the results section below. Names have been changed to protect the identity of the parents/carers and children.

Data Analysis

The online survey results were exported from Smart survey and analysed using SPSS (version 25). Open ended questions were also analysed by theme, coded and represented in tables/figures. As well as basic frequencies a number of cross-tabulations were also run on the data to explore any potential correlation between parental experience and other variables such as EA region, level of highest parental educational qualification etc.

Following the transcription of the focus groups interviews, the data was coded according to concepts identified and a thorough thematic analysis was conducted on the text-based data (transcripts) using two Computer Assisted Qualitative Data Analysis tools: NVivo12 and Leximancer.

The data gathered using the post-it notes from the parents/carers was also collated, digitalised and analysed by theme.

Finally, each of the case study interviews was edited to ensure consistency of presentation, and a short contextual paragraph was provided to introduce each one. The themes were once again analysed (reflecting themes which had already emerged from the focus groups).

Ethical Considerations

In line with BERA (2018) *Ethical Guidelines for Educational Research*, Stranmillis University College's *Code of Ethics* (2018), and key principles outlined in Brooks *et al.* (2014) all participants were informed in advance of the purpose of the study, were voluntary participants, and were assured of anonymity and confidentiality. Participants were made aware of their right to withdraw at any stage of the study. Every effort was made to explain to participants the focus and purpose of the research and the role and requirements of the participants. This was done in person at the start of each focus group or individual interview with the aid of an information sheet which was distributed to each participant. Parents/carers were also given a consent form with a number of statements which they were invited to read, tick and sign. An opportunity was given for all participants to ask any questions before the interview began. The online survey also included explanatory information about the nature and purpose of the study and participants had to tick a box giving their consent before they could access the questions.

All information was held and processed in accordance with the General Data Protection Regulations (2018). Data collected was used for the sole purposes of the research study (and subsequent research articles and/or presentations) and was held securely. All personal information was encoded or made anonymous as far as is possible, and as early as possible after collection/transcription. The names of any teachers/SENCOs, pupils, schools, parents or principals or any other individuals (e.g. EA or health professionals) have not been included in this report.

Data and files generated in the course of the study were stored securely on a secure, cloud-based server. Any hard copies of consent forms or focus group practical activities were held in locked Stranmillis University College filing systems.

The potential for physical/psychological distress to the participants (parents/carers) was low. If a participant did become distressed for any reason during the focus group/individual interview s/he could leave the room. Any distressed adult participant was signposted to relevant support if necessary. It was noticeable to the research team that, at the end of the interview, the focus group participants often chatted on in the room or outside, swapping contact details and sharing further experiences.

CHAPTER THREE: RESULTS

SECTION ONE: SURVEY RESULTS

The online survey was completed by 591 parents and 17 carers, giving a total of 608 valid responses (Q2). Of the 17 carers in the sample, 11 identified as kinship foster carers (i.e. a relative or person known to the child), 5 as non-kinship foster carers, and 1 as a respite carer (Q3).

Respondents were asked in Q4 to indicate the level of their highest educational qualification. The results indicate that 54 per cent (n=329) of parents/carers were educated to degree level (undergraduate/postgraduate), 15 per cent (n=93) to Higher National Certificate/Diploma level, 12.5 per cent (n=76) to A-level or equivalent, 11.8 per cent (n=72) to O-level/GCSE or equivalent. There were 15 parents/carers (2.5%) who had no qualifications. See Figure 1 below.

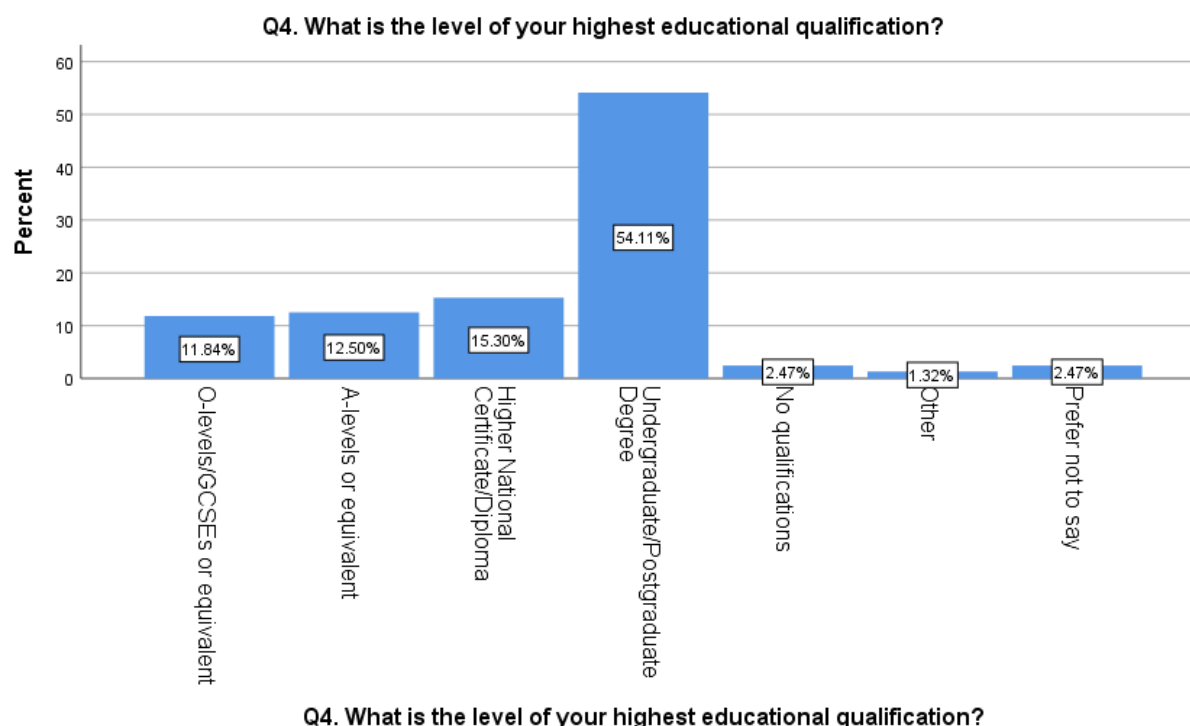


Figure 1

These responses were then recoded using SPSS into secondary level qualifications (26.0%, n=148) and tertiary (=HNC/HND or degree level) qualifications (74.0%, n=422).

Q5 asked respondents to identify the Education Authority region (corresponding to the previous Education and Library Boards areas) in which their child's school was situated. As Figure 2 illustrates, there was a spread across the 5 EA regions with the highest percentage of schools in the South Eastern region (33%, n=201) and the lowest in the Western region (11%, n=65). There were 13 parents/carers (2.1%) who didn't know which EA region their child's school was situated in.

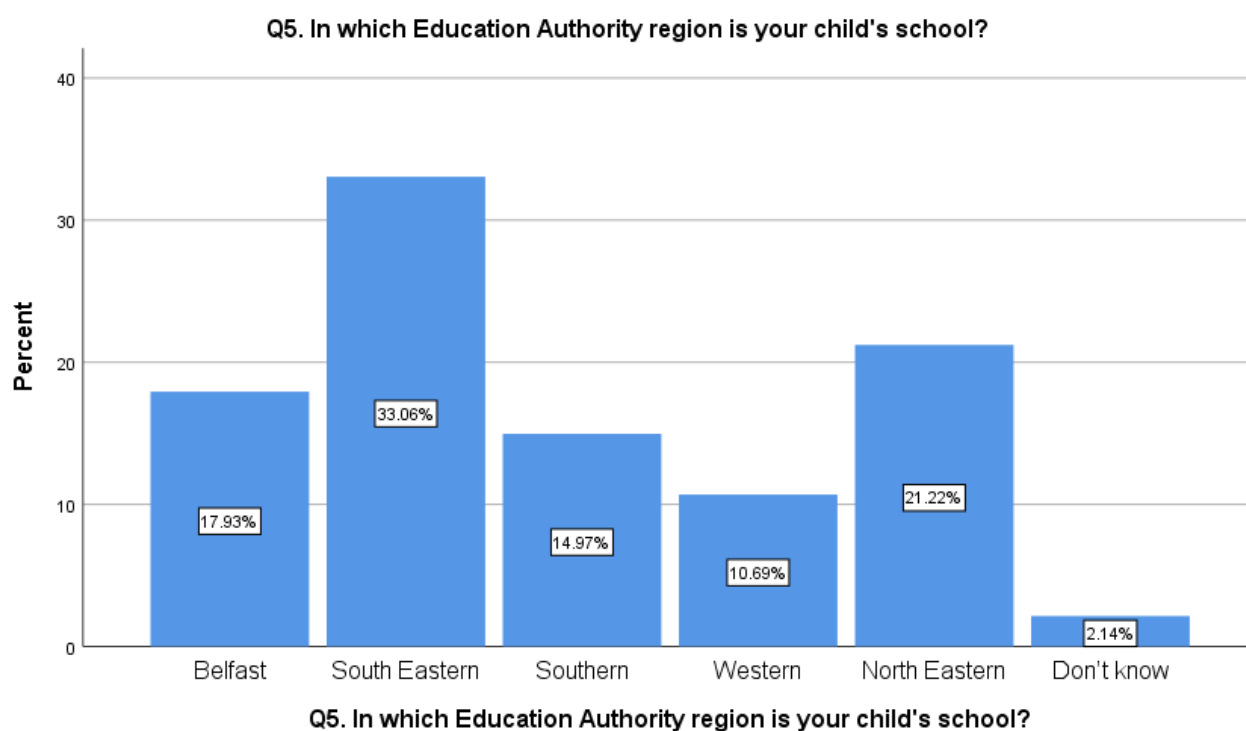


Figure 2

Q6 asked respondents to indicate where their child received their education. 94% (n=571) of parents/carers responded that their child received their education in a mainstream class, while the remaining 6% (n=37) received their education in a learning support centre attached to a mainstream school. As indicated in the methodology, any responses from parents/carers indicating that their child attended a special school or pre-school playgroup or was 0-2 years old were eliminated from the sample, as were the responses of 11 parents whose children were home-schooled.

Q7 identified the school phase of the sample. Almost two-thirds (63%, n=381) of the parents/carers responded that their child attended a primary school, while 31 per cent (n=189) were at post-primary school and the remaining 6 per cent (n=38) were at nursery school. See Figure 3 below:

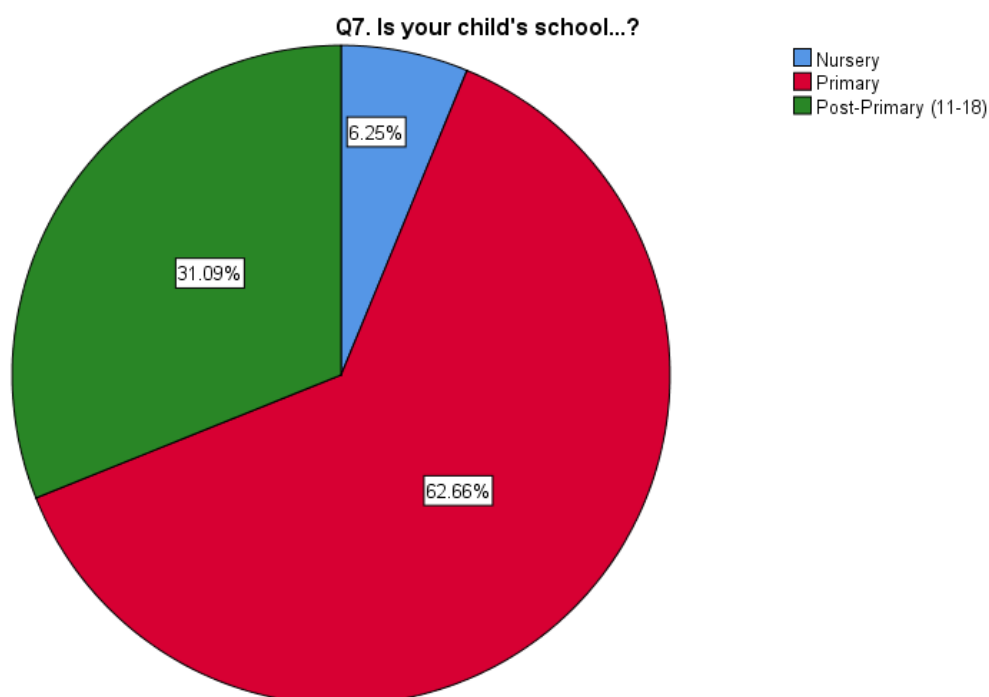


Figure 3

Q8 explored the school management types represented in the sample. The most common school management type was the controlled sector (40%, n=243), followed by the Catholic maintained sector (25%, n=152), Integrated sector (15%, n=89), and Voluntary Grammar sector (8%, n=51). There were also 17 responses (3%) from the Irish Medium sector – see Figure 4 below.

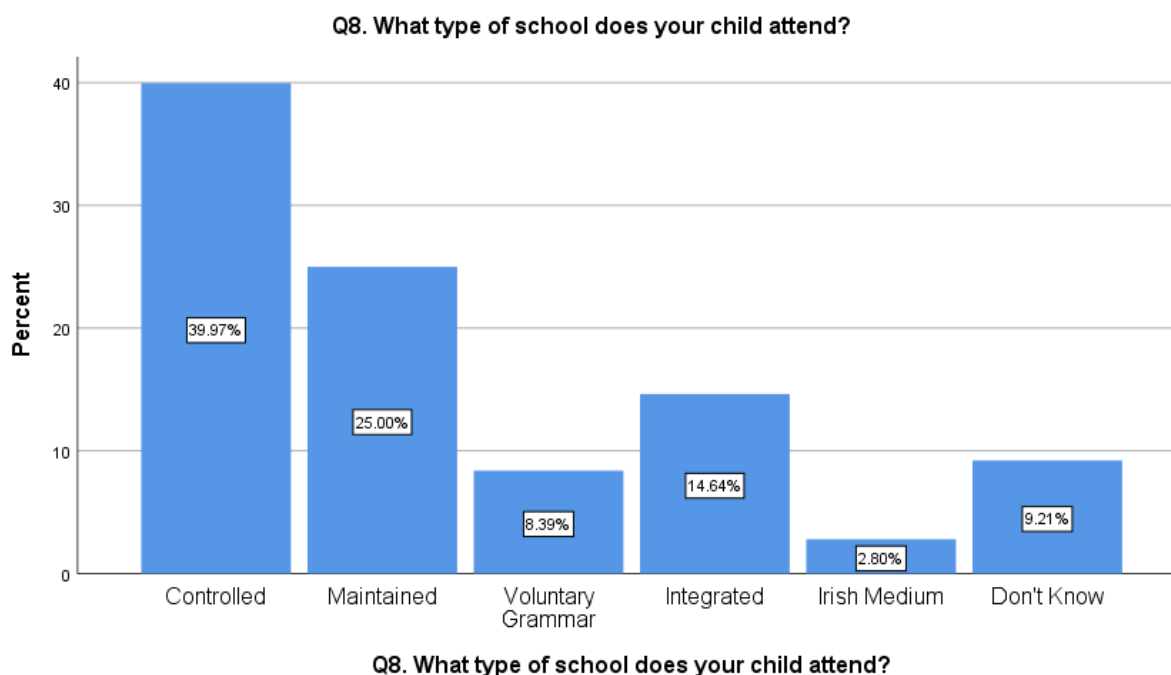


Figure 4

In Q9 respondents were asked to indicate their child's school year. The results (see Figure 5 below), in line with Q7 above, show that the majority of pupils were at primary school (9-10% from each year group from P2 to P7) and that of the minority of pupils in secondary/post-primary education, there were much higher numbers at Key Stage 3 (Years 8-10) than in Key Stages 4 (Year 11-12) or Key Stage 5 (Year 13-14).

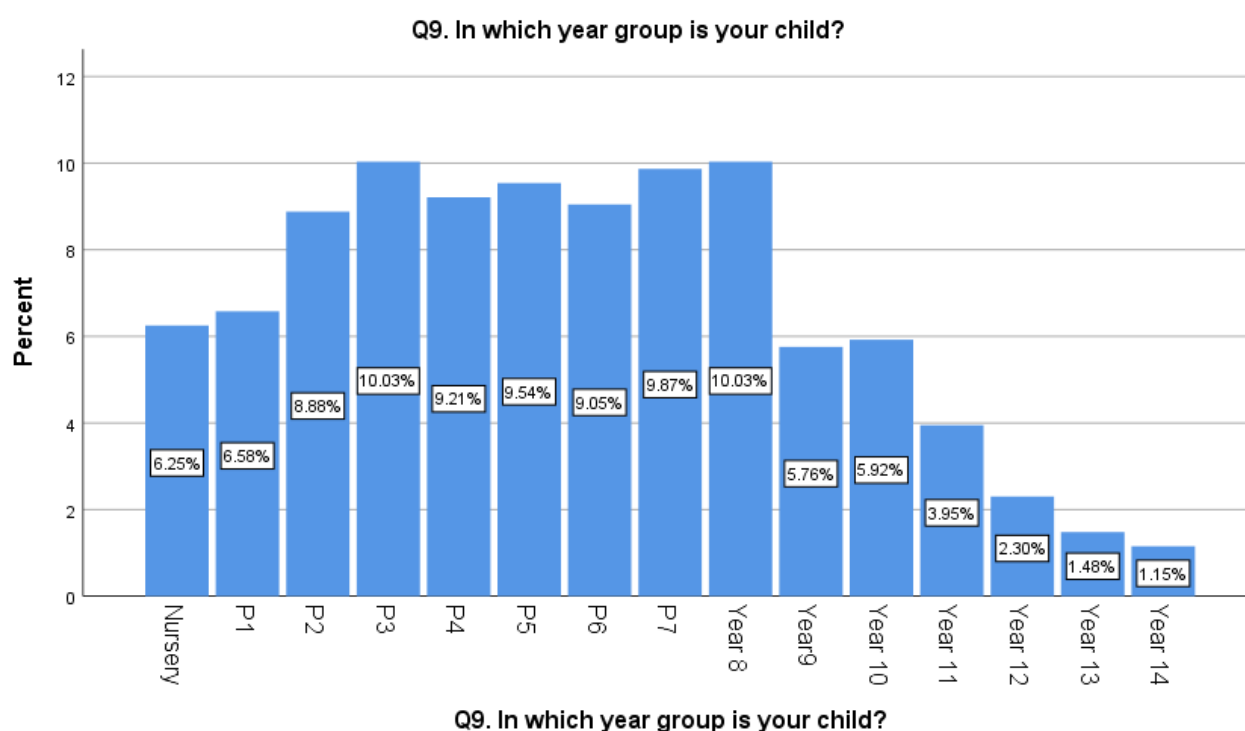


Figure 5

The following question (Q10) asked parents to indicate the gender of their child. More than two thirds of the children were male (70.6%, n=429), 28.9% (n=176) were female, while 2 parents (0.3%) preferred not to say, and 1 parent (0.2%) indicated "other" ("born girl but with gender issues").

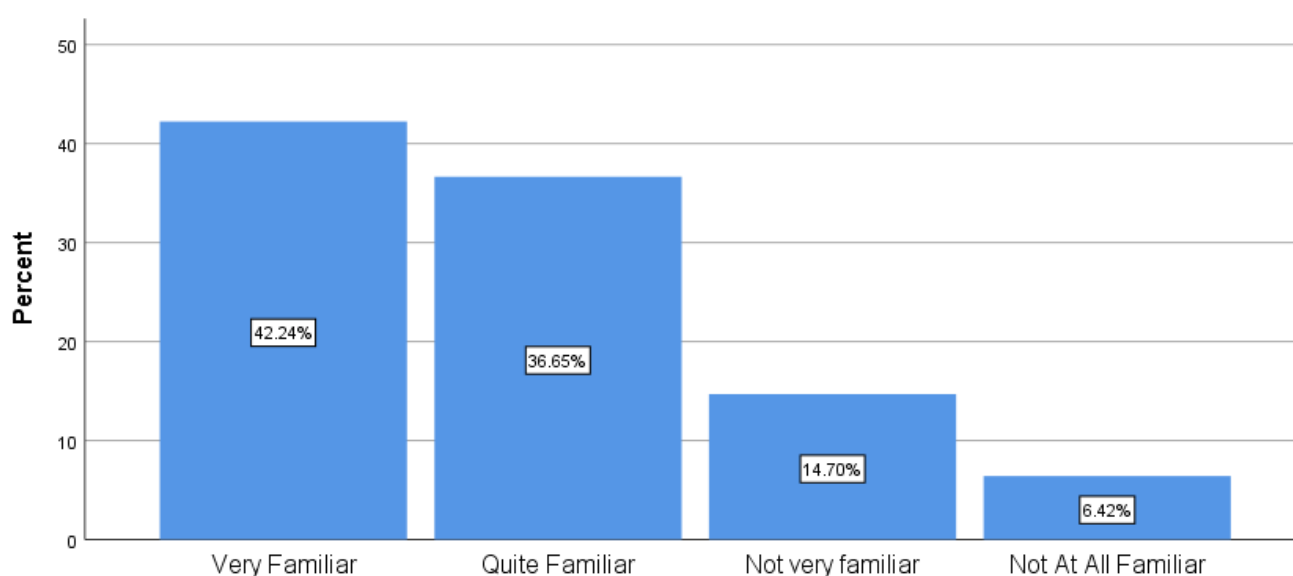
Q11 asked parents/carers whether their child was already on the SEN register. More than three-quarters of parents/carers (79.4%, n=483) responded 'Yes' while the remainder (20.6%, n=125) responded 'No'. When analysed further by school type, there was very little difference between the percentage of primary school children (79.3%, n=302) and post-primary children (82%, n=155) on the SEN register in this study sample. Within the

nursery sector, perhaps unsurprisingly, there was a lower percentage of children already on the SEN register (68%, n=26).

Parental knowledge of the SEN system was considered in Q12 which asked parents/carers to indicate their level of familiarity with the 5 stages of the SEN process as set out in the Code of Practice. Over three-quarters of parents were either 'very familiar' (42.2%, n=204) or 'quite familiar' (36.6%, n=177) with the 5 stages, leaving over a fifth of parents either 'not very familiar' (14.7%, n=71) or 'not at all familiar' (6.4%, n=31) with them. See Figure 7 below.

When Q12 is analysed further by recoded level of highest educational qualification of parents/carers, the results show that parents/carers who are educated to tertiary level are more likely to be familiar with the stages of the SEN Code of Practice than parents educated to secondary level only. 83.5 per cent (n=282) of parents educated to tertiary level were either 'quite familiar' or 'very familiar' with the SEN Code of Practice compared to just 69.5 per cent (n=80) of parents educated to secondary level. This result was found to be statistically significant (χ^2 12.226, df=3, p=0.007).

Q12. Based on your experience, how familiar are you with the 5 stages of the SEN process as set out in the Code of Practice below?



Q12. Based on your experience, how familiar are you with the 5 stages of the SEN process as set out in the Code of Practice below?

Figure 7

When asked what stage of the Code of Practice their child was currently at, the results show just over half of the children (51.2%, n=250) were at Stage 5 (statement) with a further 7.7% (n=37) currently at Stage 4 (the statutory assessment stage). Just under one-in-five of the children (18.2%, n=88) were at Stage 3 (in school but receiving external support), with 9.9 per cent (n=48) at Stage 2 and 4.1% (n=20) at Stage 1. A total of 40 parents/carers (8.3%) did not know what stage of the Code of Practice their child was currently at: see Figure 6 below. There were no significant differences by gender.

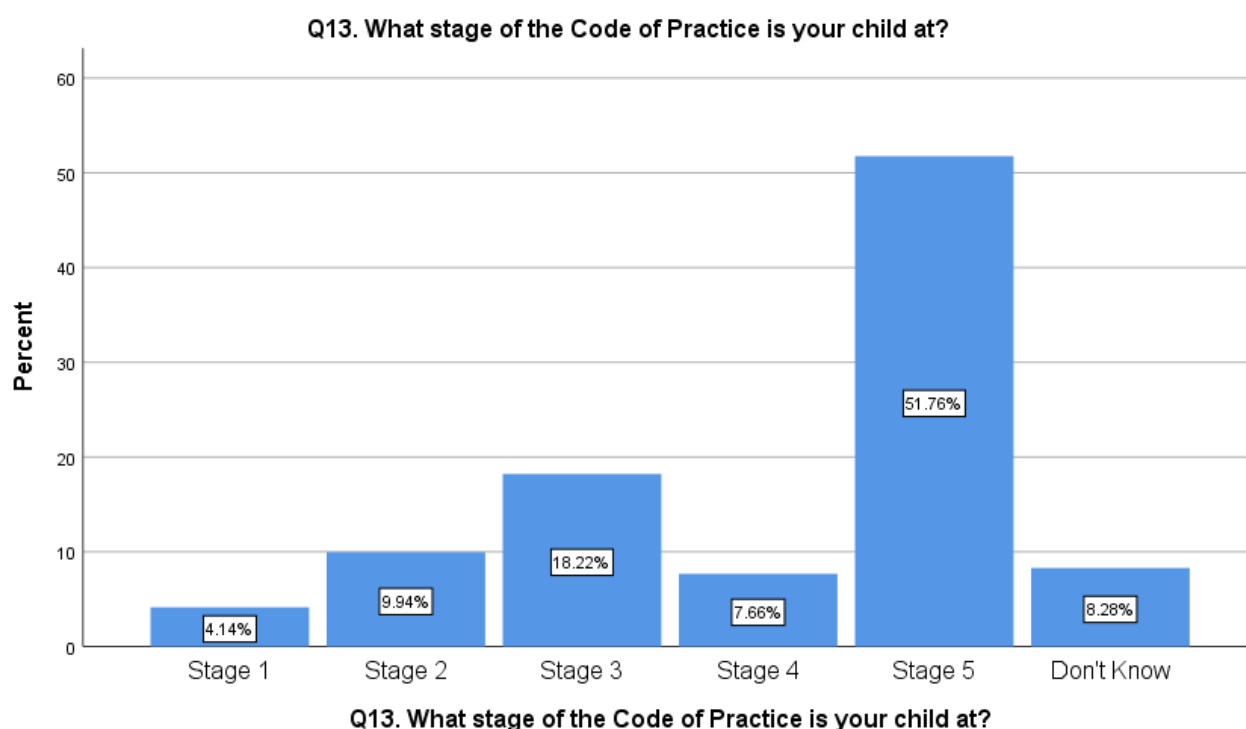


Figure 6

For the purposes of cross-tabulations, this variable was recoded and showed that of those parents/carers who knew which stage of the Code of Practice their child with SEN was at, 56.4 per cent (n=250) were at Stage 5 (with a statement) and the remaining 43.6 per cent (n=193) were at Stages 1-4 (on the SEN register but without a statement of special educational needs).

Q14 was an open-ended question which asked parents/carers to identify their child's main special educational need. The responses were then coded using the Department of Education categories, as published in the Department of Education's *Guidance for Schools: Recording Children with Special Educational Needs – SEN Categories* (DE, 2005b) and recommended for use in schools in Northern Ireland until January 2019. The results are presented below in Figure 8 and show that the most common category was 'Communication and Interaction' which included almost half of the children in this sample (49.3%, n=238). This category includes children with Speech and Language Difficulties, Autism and Asperger's Syndrome. Of these 238 children, 218 (163 boys and 53 girls) were identified as having either autism or Asperger's Syndrome. This represents 45 per cent of the children in the sample whose special educational needs had already been identified. One in five of the children (20.5%, n=99) were categorized under 'Cognitive and Learning' (e.g. Dyslexia, Dyscalculia, Dyspraxia, MILD, MLD etc.), and a further 14.9% (n=72) in 'Social, Emotional and Behavioural' (SEBD, ADD/ADHD). There were small numbers of children in each of the other categories as follows: Medical Conditions (5.8%, n=28), Sensory (3.5%, n=17) and Physical (1.9%, n=9).

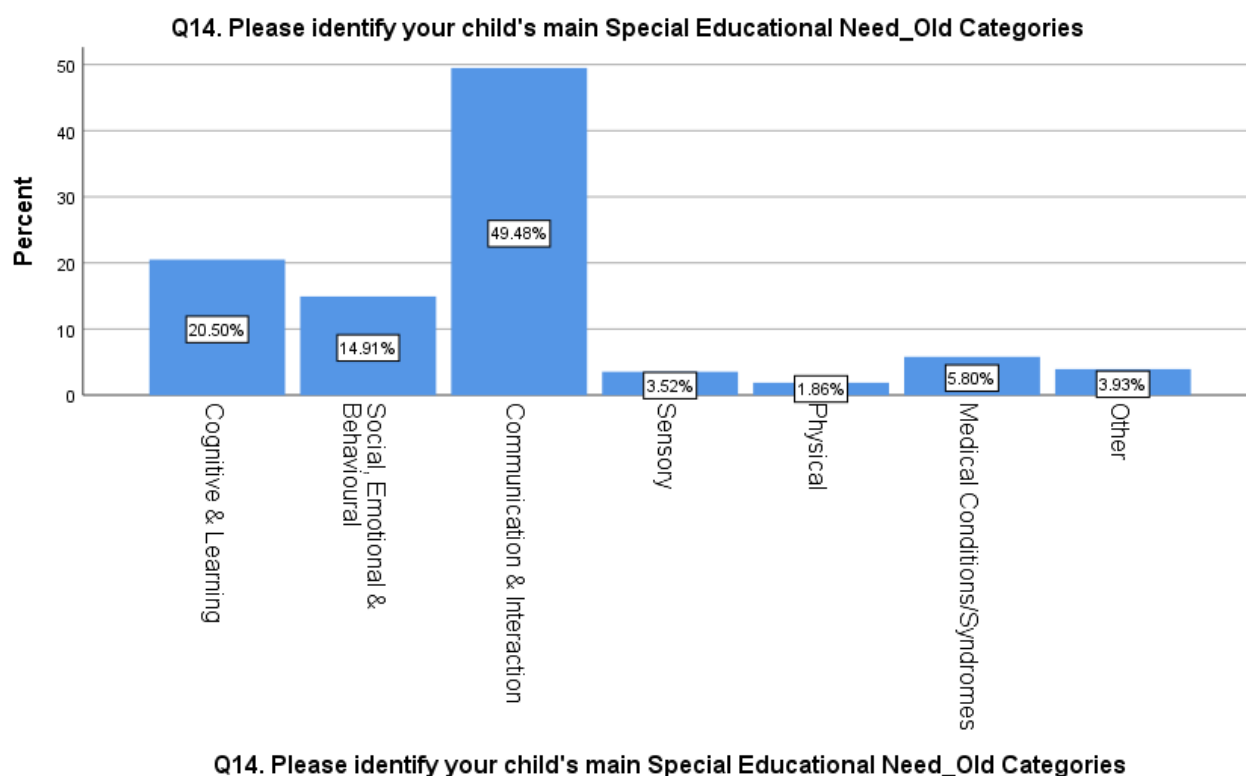


Figure 8

For children whose needs have not yet been formally diagnosed/identified, Q15 asked parents/carers to identify what they *believed* to be their child's main special educational need. This was again an open-ended question, but once again the most common need mentioned by this group of 117 parents/carers is autism (41%, n=48), followed by 'Cognition and Learning' (23.9%, n=28) and 'Other Medical Needs' (17.1%, n=20). There were smaller numbers of needs which were later coded as 'Social, Behavioural, Emotional and Well-Being' (6.8%, n=8), 'Speech, Language and Communication Needs' (3.4%, n=4), Sensory Needs (3.4%, n=4), and Physical Needs (1.7%, n=2).

Q16 asked parents/carers whether their child currently receives special educational needs support. The majority of parents/carers said 'yes' (59.7%, n=363), while 36.7 per cent (n=223) said 'no', and 3.6 per cent (n=22) didn't know.

Q17 explored the nature of educational support provided to the children. The results are presented in tabular form below and show a wide range of support provided from different sources. Within this sample, the most common forms of support were (in order) literacy support, numeracy support, behaviour support and autism support.

Table 1

		One-to-one (n)	Group (n)	School (n)	Education Authority (n)	Not Applicable (n)
1	Literacy support	119	68	130	45	113
2	Numeracy support	93	55	117	20	143
3	Behaviour support	78	22	85	38	194
4	Autism support	56	25	71	48	201
5	Educational psychology	35	1	49	103	198
6	Specific Learning Difficulty support	59	17	77	26	217
7	Sensory support	56	19	76	18	221
8	Counselling	26	4	31	6	301
9	Full-time classroom assistant	93	15	37	24	228
10	Part-time classroom assistant	73	13	34	33	238

When the results of Q17.9-10 were cross-tabulated against the recoded Q13 (Stage 1-4; Stage 5 of the Code of Practice), it revealed that 99 per cent of those who had a *full-time one-to-one* classroom assistant and 85 per cent of those who had a *full-time group* classroom assistant had a statement of special educational needs (at Stage 5 of the Code of Practice). In terms of part-time classroom assistants, the figures are broadly similar: 97 per cent of those who had a *part-time one-to-one* classroom assistant and 67 per cent of those who had a *part-time group* classroom assistant had a statement of special educational needs (at Stage 5 of the Code of Practice).

Q18 asked respondents to detail the health support currently provided to their child and to identify the provider. The results are presented in Table 2 below.

Table 2

		One-to-one (n)	Group (n)	Health & Social Services (n)	Private (n)	Other (n)	Not Applicable (n)
1	Speech and Language Therapy	44	8	60	15	6	259
2	Physiotherapy	18	3	25	6	5	314
3	Occupational Therapy	30	7	63	15	8	253
4	Medical/Physical Support	28	0	92	16	8	236

Q19 asked parents/carers to indicate whether specialist equipment was provided by their child. 19.8 per cent (n=72) responded 'Yes'. When asked to provide more information, the responses included the provision of a wheelchair, ipad, writing slope, magnifying prism, visual schedules, chill out tent, PECS cards, hearing aids, overlays, laptop, FM audio system and sensory toys.

Q20 comprised five different questions where respondents were asked to indicate their agreement with a range of statements in relation to the provision of support for their child.

Q20.1 invited parents/carers to respond to the statement 'My child's special educational needs are being adequately met'. The responses are set out below in Figure 9 and highlight that just over a third of parents/carers 'agreed' (29.8%, n=108) or 'strongly agreed' (8.3%, n=30) with the statement and so felt that their child's needs were being adequately met. Almost half of the parents/carers by contrast either 'disagreed' (20.7%, n=75) or 'strongly disagreed' (24.8%, n=90) with the statement. There was no statistically significant variation between EA regions in this sample.

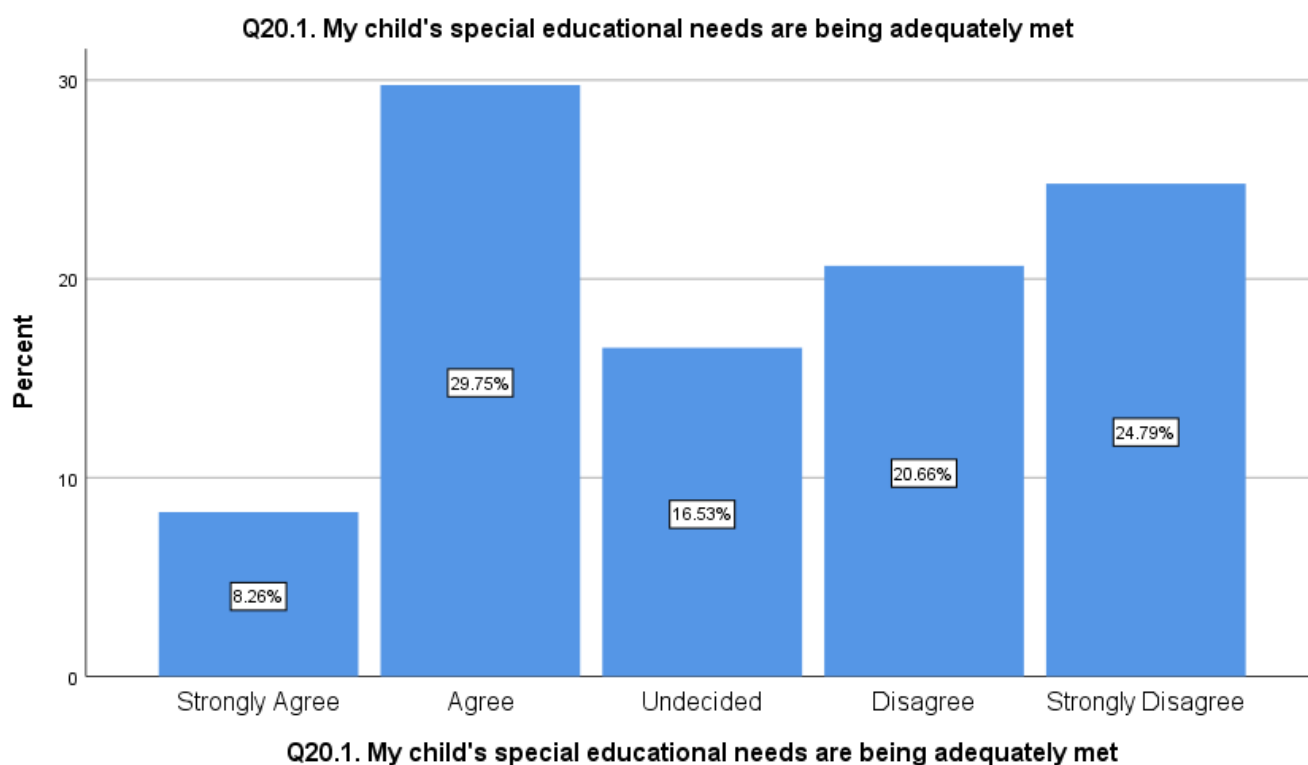


Figure 9

Q20.2 asked parents/carers to respond to the statement 'Additional support for my child has been provided without unnecessary delay. Here, almost two-thirds of the respondents either 'disagreed' (24.5%, n=89) or 'strongly disagreed' (42.1%, n=153) with the statement. Just 21 parents (5.8%) 'strongly agreed' with the statement. The results are presented below in Figure 10. When analysed by EA region, there were no statistically significant differences.

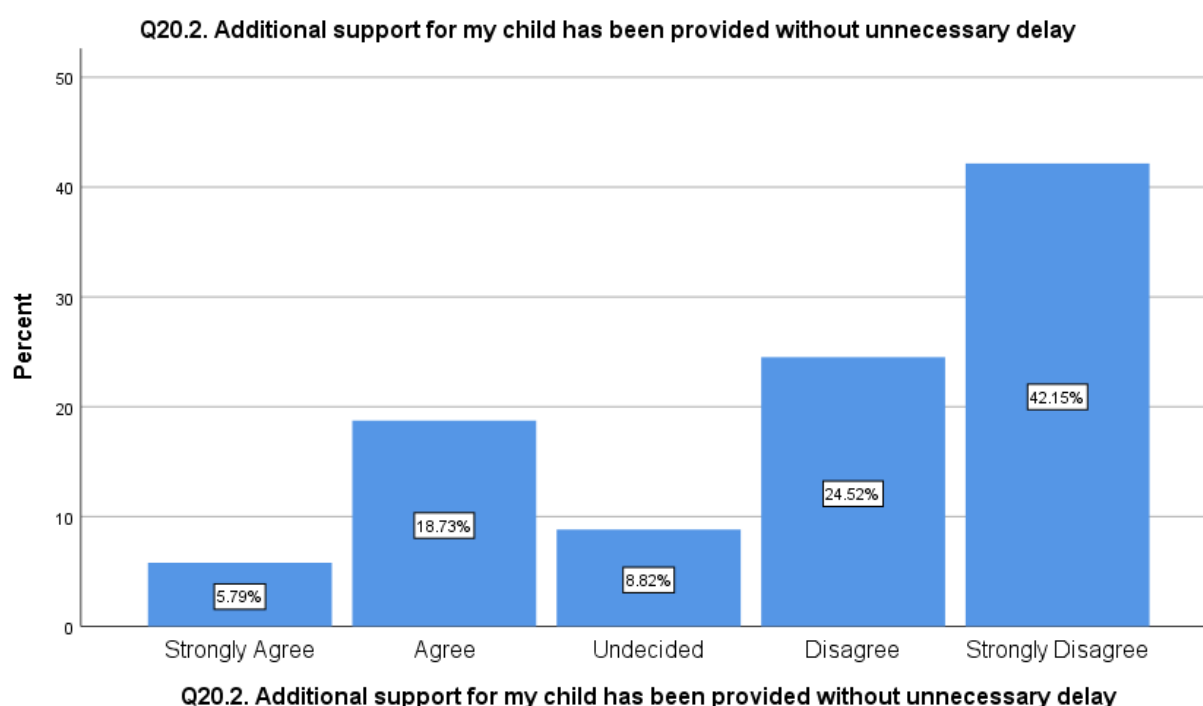


Figure 10

In Q20.3 parents/carers responded to the statement 'I am confident about expressing my views about my child's needs'. The results indicate high levels of parental confidence with more than three-quarters of parents 'agreeing' (35.8%, n=130) or 'strongly disagreeing' (43.5%, n=158) with the statement. The results are presented in Figure 11 below:

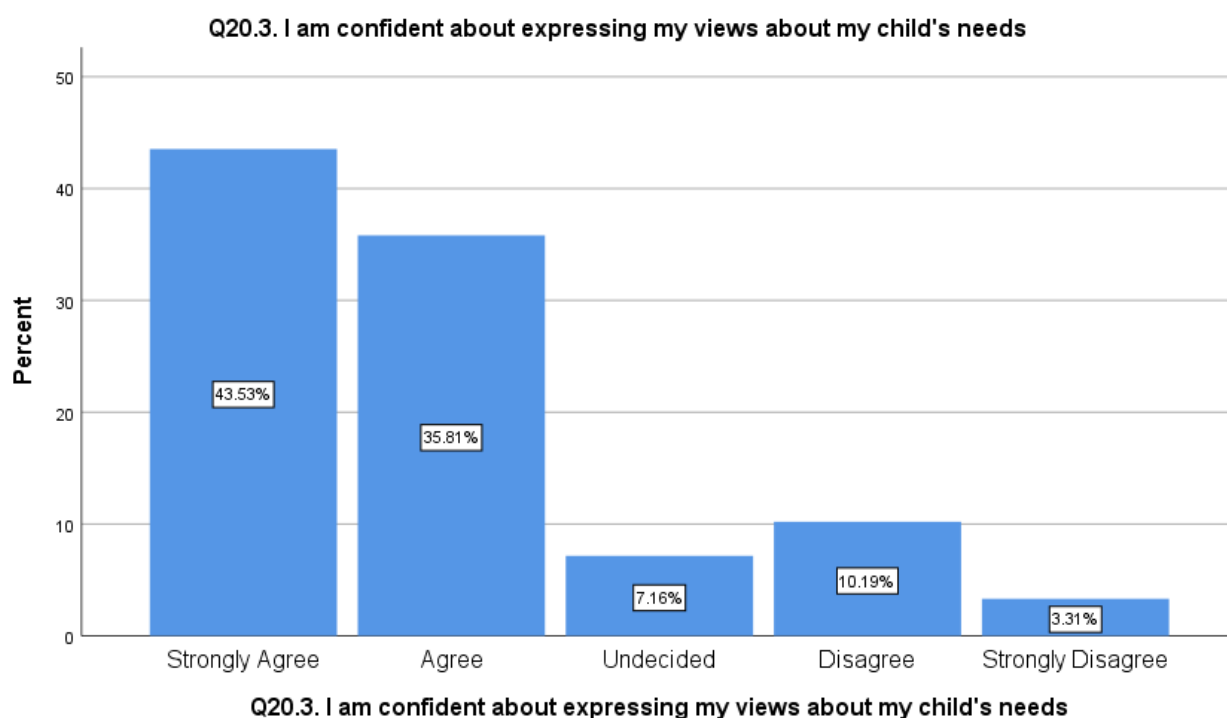


Figure 11

The following two sub-questions addressed statements concerning the extent to which parental and children's views had been taken into account.

Q20.4 invited parents/carers to respond to the statement 'My views about my child's special educational needs have been taken into account'. Just under half of respondents 'agreed' (35.5%, n=129) or 'strongly agreed' (14.9%, n=54) with the statement. Almost one in three parents/carers however 'disagreed' (17.9%, n=65) or 'strongly disagreed' (12.7%, n=46) with the statement. These findings are illustrated in Figure 12.

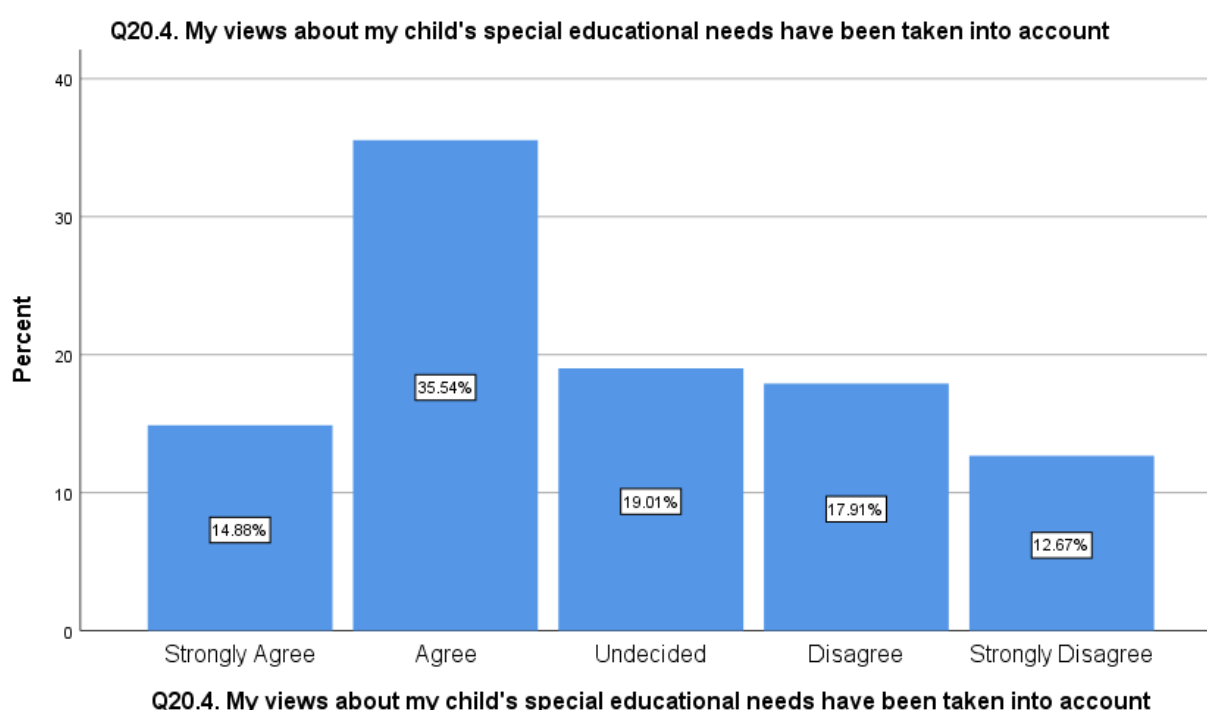


Figure 12

In Q20.5 parents/carers responded to the statement “My child’s views have been taken into account’. Here again more parents ‘disagreed’ (25.1%, n=91) or ‘disagreed strongly’ (15.2%, n=55) with the statement than ‘agreed’ (24.0%, n=87) or ‘agreed strongly’ (8.3%, n=30). Therefore only around one in three parents were in agreement that their child’s views had been taken into account. See Figure 13.

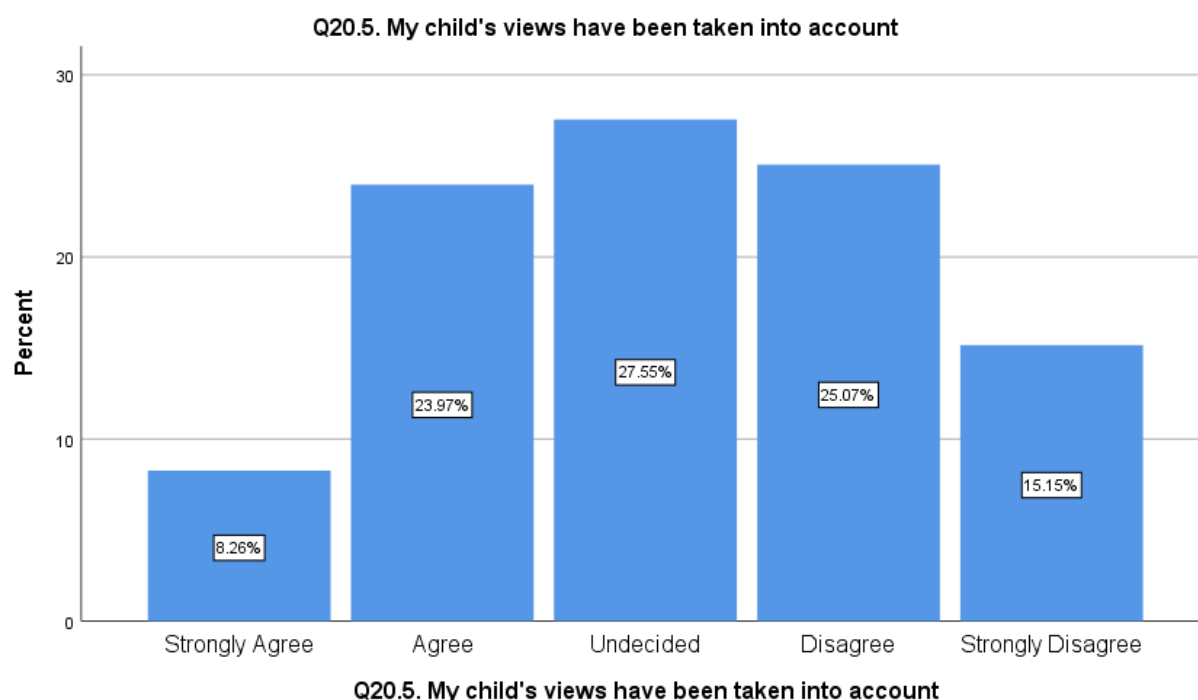


Figure 13

Q21 asked respondents to indicate who first raised the difficulty regarding their child. In the majority of cases, it was the parent/carer themselves who raised the issue (59.2%, n=215), followed by their child’s primary school (17.6%, n=64), nursery school (11.8%, n=43) and Health & Social Services (7.4%, n=27).

Q22 asked how old their child was when their special educational needs first became apparent. The range was from 1-14 years old, while the mean age was 5.24 years. The modal age was 3-4 years old. The range of ages are presented in Figure 14 below:

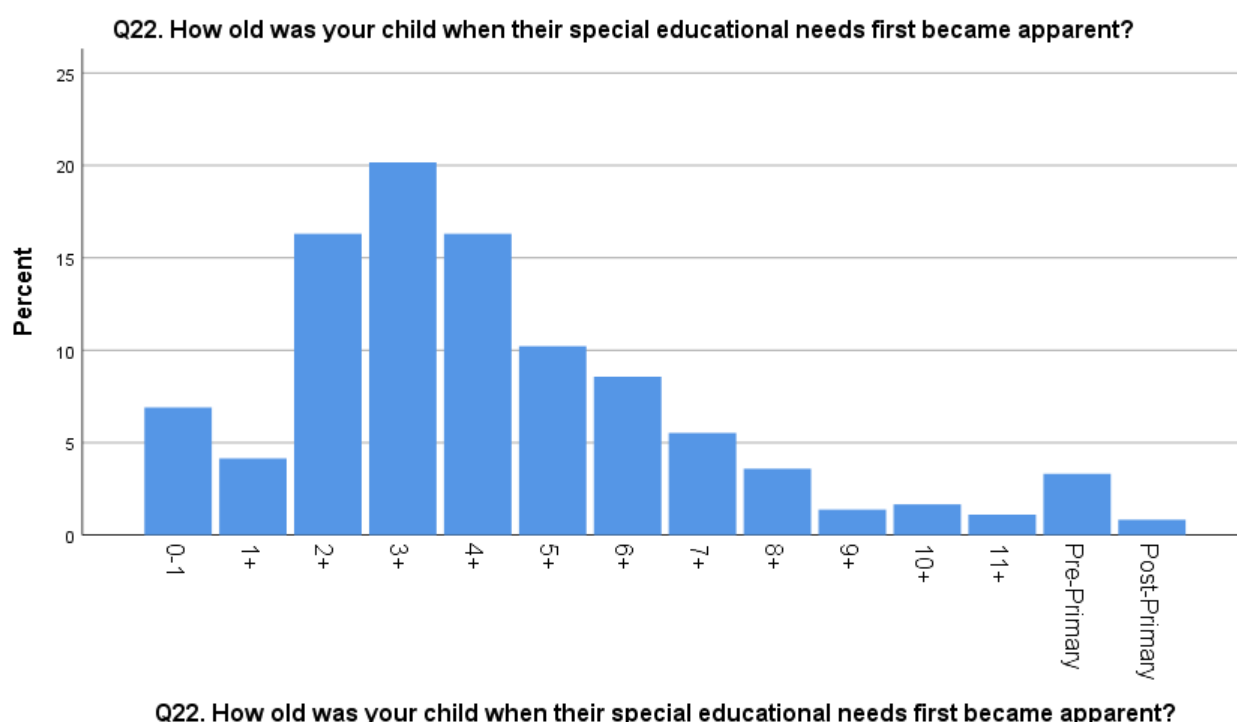


Figure 14

Individual Education Plans

Responses to Q23 revealed that 91.2 per cent (n=331) of the children with SEN had an Individual Education Plan (IEP). 4.4 per cent (n=16) of the parents/carers said that their child did not have an IEP while a further 4.4 per cent (n=16) didn't know. The following three questions were supplementary questions in relation to IEPs.

Q24 asked parents to indicate the extent to which they had been involved in the development of their child's IEP. The results were very mixed: 38.1 per cent (n=126) of parents/carers said they were 'quite involved' and a further 16.6 per cent (n=55) 'very involved' in the development of their child's IEP. By contrast 31.7 per cent (n=105) of parents/carers said they were 'not very involved' and a further 13.6 per cent (n=45) were 'not at all involved'. This is illustrated in Figure 15.

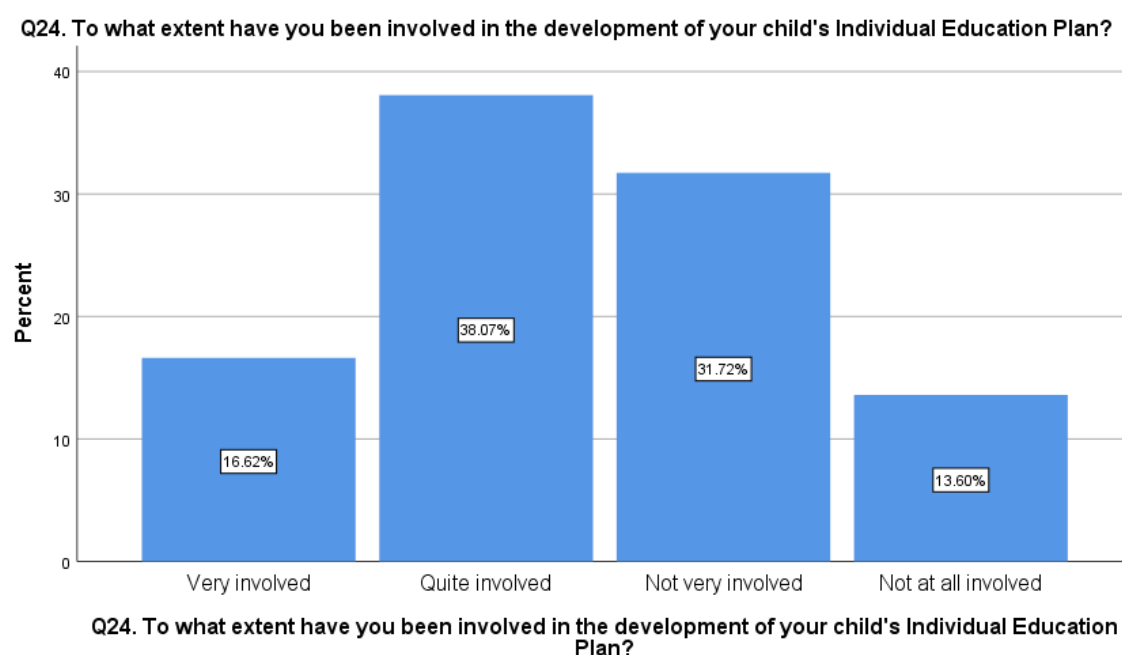


Figure 15

Parents/carers were then asked to what extent they were familiar with the targets set out in their child's IEP. Results were positive: more than three-quarters of respondents were either 'very familiar' (38.7%, n=128) or 'quite familiar' (40.5%, n=134) with the IEP targets. See Figure 16 below:

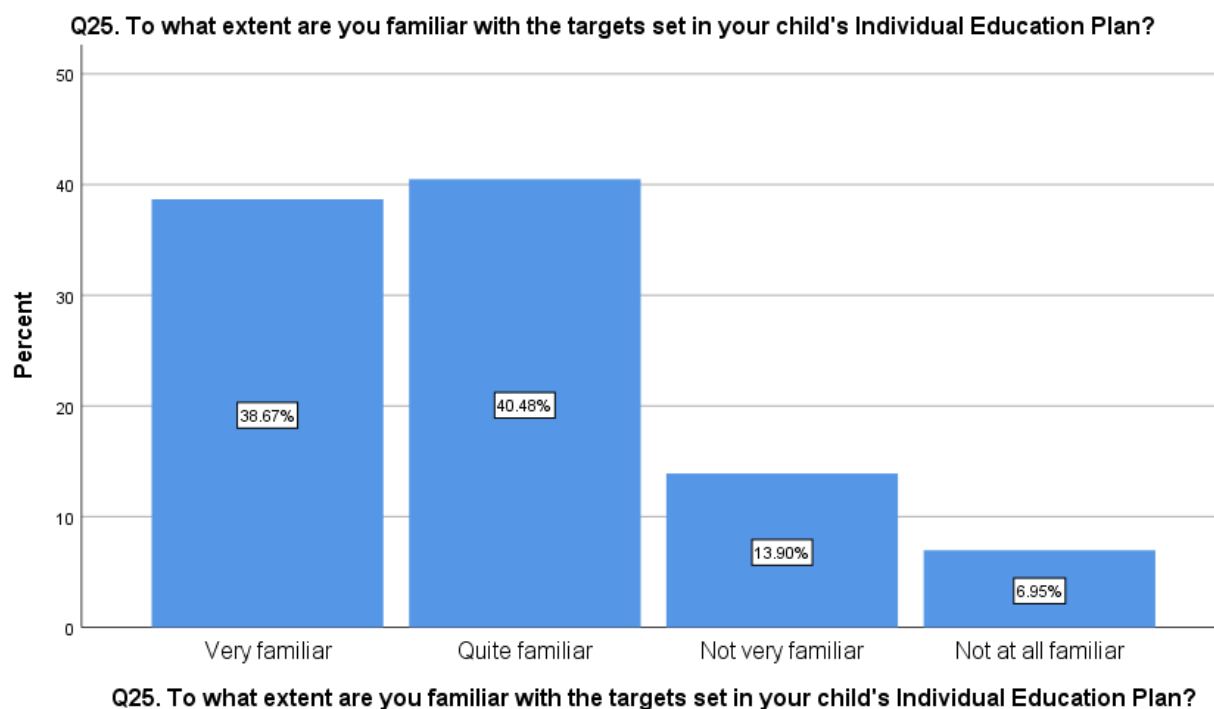


Figure 16

The results were less positive in relation to Q26 which asked parents/carers to what extent they felt that having an IEP has helped to meet their child's SEN. A majority of respondents were nonetheless positive with 38.7 per cent (n=128) saying that the IEP 'has helped a little' and 21.5 per cent (n=71) saying the IEP 'has helped a lot'. See Figure 17 below:

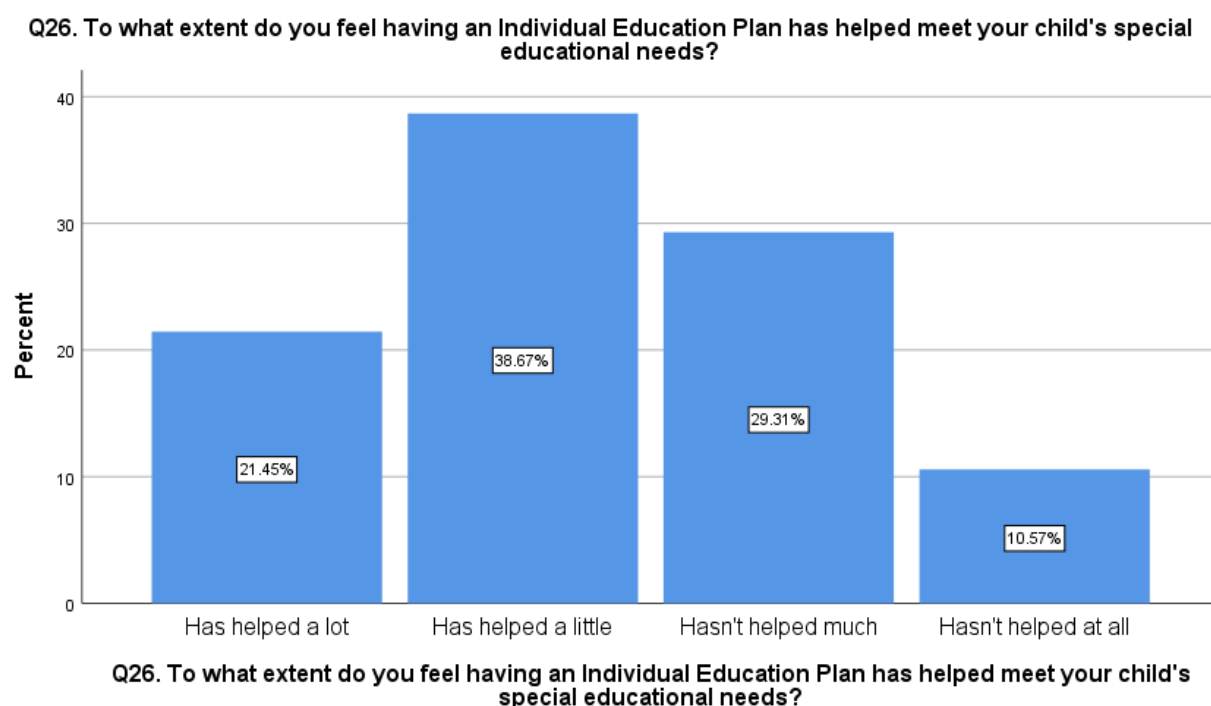


Figure 17

The statementing process

As the first in a series of questions on the statementing process, Q27 asked parents/carers whether their child has had an assessment carried out by an educational psychologist. 93.1 per cent (n=308) of those who responded said 'yes' (the remainder said 'no') and there were two follow-up questions for these parents/carers who said 'yes'.

The first of these follow-up questions, Q28, showed that for 91.9 per cent (n=283) of respondents, the educational psychology assessment was carried out by the Education Authority but that in 8.1 per cent of cases (n=25) parents/carers paid for the assessment privately.

When these 25 parents were subsequently asked in an open ended question (Q29) why they had opted for a private educational psychology assessment, the most common reason given was that they were unable to access assessment in any other way (36%, n=9), followed by equal numbers (28%, n=7) who opted for private assessments because of the shorter waiting times or because they were concerned about the impact arising from a misdiagnosis or no diagnosis at all. The results are presented in Figure 18 below, and some illustrative comments are also given:

- “The EA refused to assess”
- “I paid privately initially as his primary school would do nothing to help”
- “The primary school did not consider our son's difficulties to be "bad enough" to warrant an assessment. We could see, however, that he was a bright boy who was struggling to understand why he was having difficulties. We were concerned that he was losing confidence before changing to secondary school. The school were concerned about "labelling him". We hoped that a confirmation of "dyslexia" would help him and his teachers to understand his strengths and difficulties much better.”
- “After my experience with my older son who also has autism. Education Authority were totally inadequate. My son was misdiagnosed and support was inadequate. He suffered a lot due to their total incompetence and so I learned a lot about the system and the disability, thus my daughter has benefited from my experience and knowledge and has had better educational experience as I bypassed the normal educational psychology routes.”

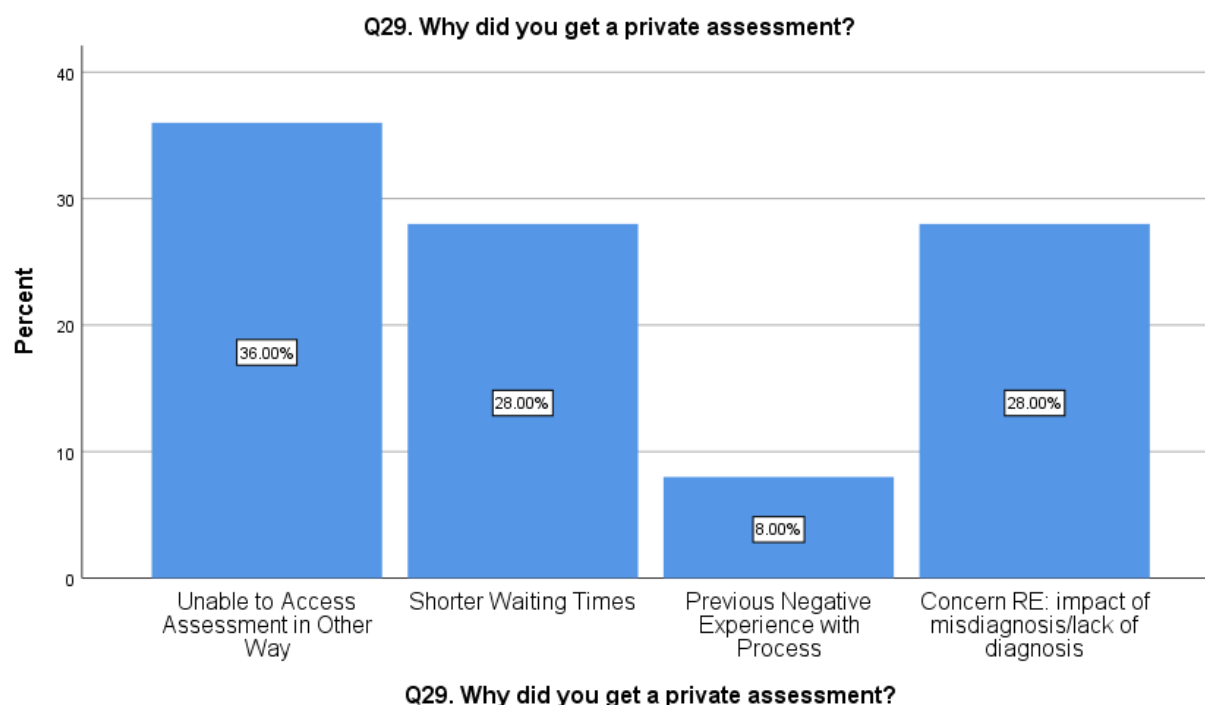


Figure 18

Q30 and Q31 were follow-up questions for the parents/carers who had responded 'no' to Q27 indicating that their child (on the SEN register) had not (yet) had an assessment carried out by an educational psychologist. Q30 asked these 23 parents/carers if they felt that their child did require a statutory assessment of educational needs to be carried out, and almost three quarters of them (73.9%, n=17) said 'yes', while 5 others said 'no', and the remaining one parent said that they didn't know. When asked in Q31 why the statutory assessment hadn't taken place, a majority of the parents/carers (59.1%, n=13) said that it was because their child had not been prioritised for referral, while 4 others (18.2%) said that their child had been referred but was still waiting on an assessment. Two other parents indicated that they were unsure how to request an assessment.

Q32 asked parents/carers if they had ever considered having a private assessment of educational needs carried out by an educational psychologist or other professional. Almost half of those who responded (45.8%, n=140) said 'yes' while the remainder said 'no' (54.2%, n=166).

Q33 asked parents/carers whether the private assessment of educational need they had carried out by an educational psychologist or other professional was accepted by the Education Authority. Of the 92 parents/carers who knew, 79.3 per cent (n=73) said that

the private assessment had not been accepted by the EA, while 6.2 per cent (n=19) said that it had been accepted.

Q34 followed up with those parents/carers who had answered Q27 to say that they had gone through the statementing process. Here respondents were asked how old their child was when they were first assessed. More than two-thirds (69.0%, n=223) said that their child was of primary school age, while 27.2 per cent (n=88) reported that their child was younger than 4 years old. Just 2.8 per cent (n=9) of the children were first assessed at secondary/post-primary school. See Figure 19 below.

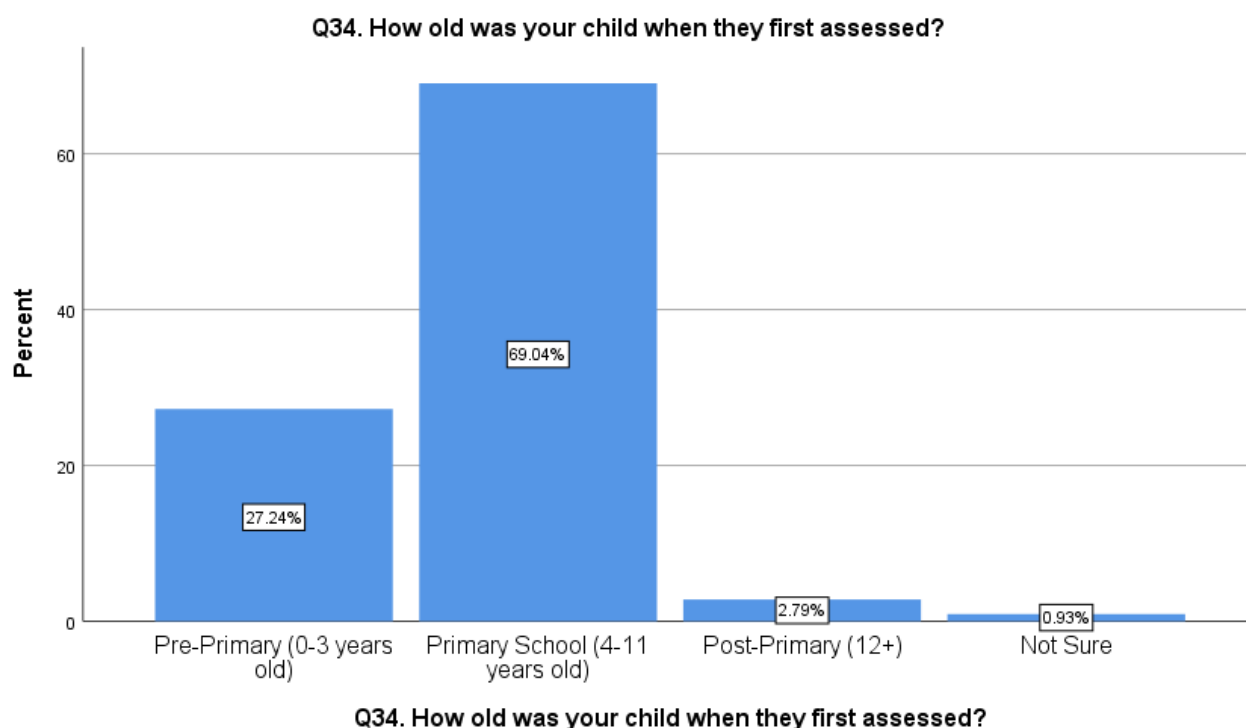


Figure 19

Q35 asked parents/carers to say what year their child's assessment took place. The assessments took place between 2002/03 and the present day, but with most of the assessments taking place between 2016 and 2018. See Figure 20 below:

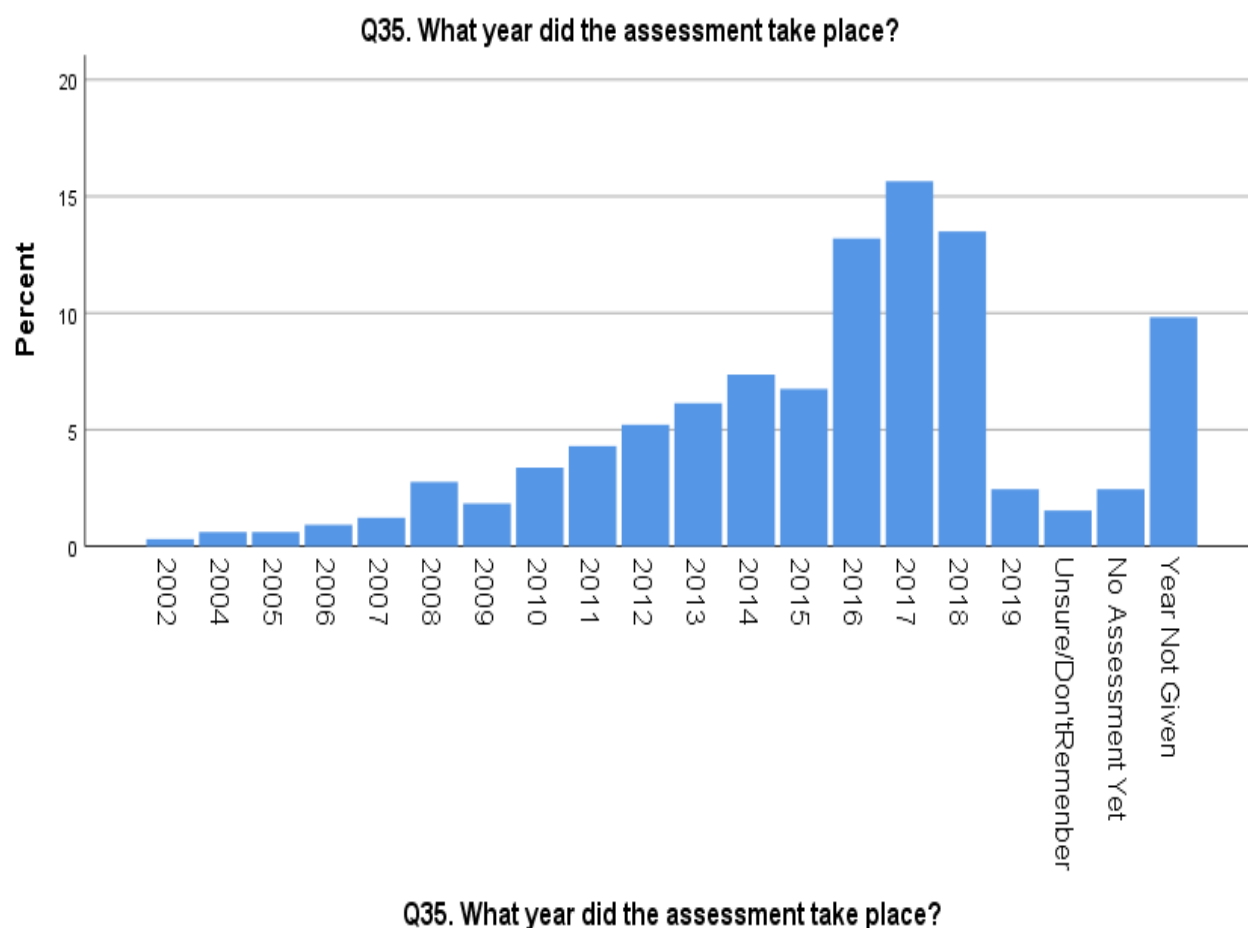


Figure 20

Q36 asked how long parents/carers had been concerned about their child's needs prior to assessment. The results are displayed in Figure 21 and highlight how the majority of parents/carers had been concerned about their child's needs for up to 2 years or more. 2.8 per cent (n=9) of parents/carers had been concerned for more than six years prior to the statutory assessment being carried out.

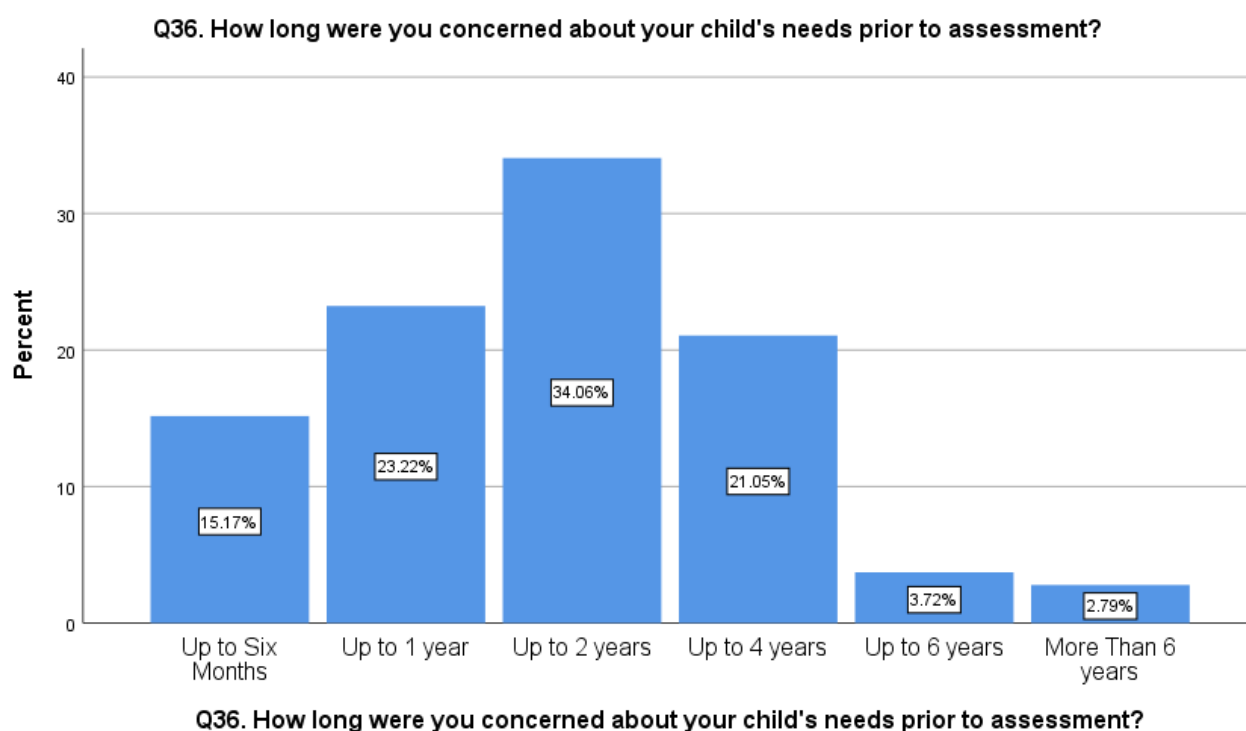


Figure 21

When asked who made the referral for their child's statutory assessment, 34 per cent (n=112) reported that they had made the referral themselves, while 42.6 per cent (n=140) said that their child's school had made the referral. Of the other answers, the most common was a referral from a doctor or other health service professional (15.5%, n=51). The results are displayed below in Figure 22:

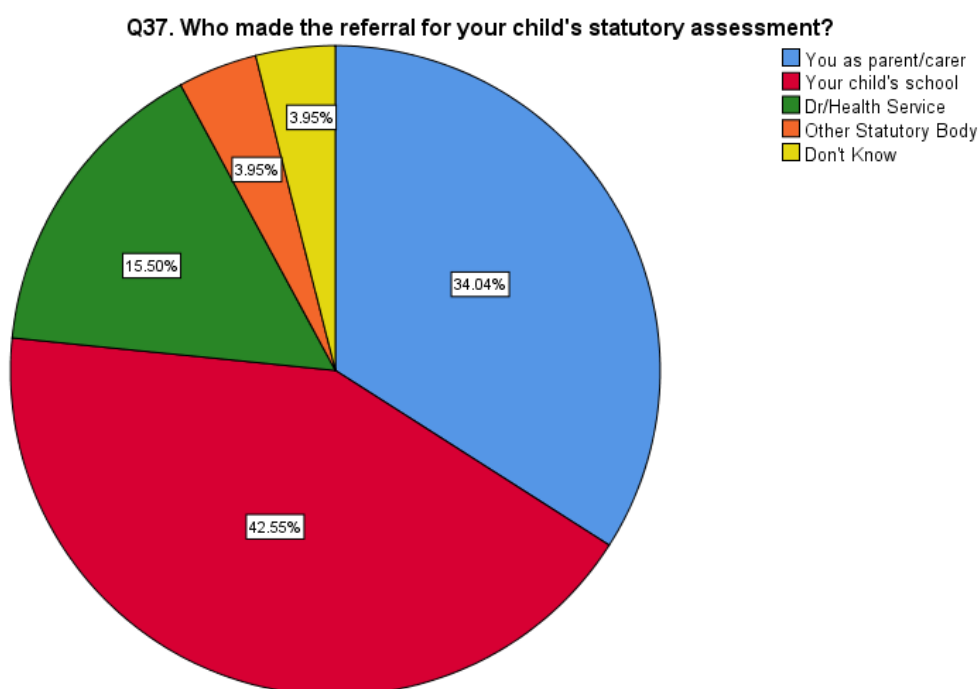


Figure 22

Q38 focused on the procedures followed during the statutory assessment process. The results are displayed in Table 3 and the key features described below.

Table 3

Base=331		Yes % (n)	No % (n)	Don't know % (n)
38.1	The EA notified me within 6 weeks of the referral as to whether a statutory assessment was needed	43.8 (145)	25.4 (84)	30.8 (102)
38.2	The EA notified me of a named EA officer to support me through the process	33.2 (110)	48.6 (161)	18.1 (60)
38.3	The EA officer kept me informed	20.5 (68)	64.7 (214)	14.8 (49)
38.4	I was informed of my right to be present at any interview, test, medical or other assessment involving my child	34.7 (115)	48.9 (162)	16.3 (54)
38.5	I was made aware of my right to provide a written or oral report about my child's needs	62.8 (208)	24.8 (82)	12.4 (41)
38.6	The EA provided me with guidance to help complete this report	18.1 (60)	62.5 (207)	19.3 (64)
38.7	I provided a written or oral report	73.4 (243)	16.1 (55)	10.0 (33)
38.8	I received copies of written reports completed about my child	78.5 (260)	13.9 (46)	7.6 (25)
38.9	The EA sought the views of my child on their SEN and the way in which their needs might be met	25.4 (84)	48.6 (161)	26.0 (86)

Responses to Q38 highlight in particular that many parents did not feel supported by the EA through the statutory assessment process: only a third (33.2%, n=110) had been notified of a named EA officer to support them, only a fifth (20.5%, n=68) had been kept informed by the EA officer, and only a third (34.7%, n=115) had been informed of their right to be present at any interview, test, medical or other assessment involving their child. While a majority of parents (62.8%, n=208) had been informed of their right to provide a written or oral report, less than a fifth (18.1%, n=60) had received any guidance to help them complete the report.

In response to Q38.7 almost three quarters (73.4%, n=243) of parents/carers indicated that they had provided a written or oral report. When this question was analysed further by recoded level of parental educational qualification, it was found that those parents/carers educated to tertiary level were significantly more likely to have completed a written or oral

report than parents/carers educated only to secondary school level: 77.7 per cent (n=181) of parents/carers educated to tertiary level completed a report compared to 58.8% (n=47) of parents/carers educated only to secondary school level (χ^2 11.039, df=2, p=0.004). 78.5 per cent (n=260) of parents/carers reported that they had received copies of the written reports completed about their child, but only a quarter (25.4%, n=84) said that the Education Authority had sought to establish the views of their child on their special educational needs and the way in which they might be met.

Q39 asked parents/carers to rate their level of satisfaction with the statutory assessment process for their child. Of the 331 respondents to this question, a majority were either 'dissatisfied' (27.8%, n=92) or 'very dissatisfied' (24.5%, n=81). The most common response was 'satisfied' (39.3%, n=130) while just 8.5 per cent (n=28) indicated that they were 'very satisfied' with the process. The results are displayed below in Figure 22:

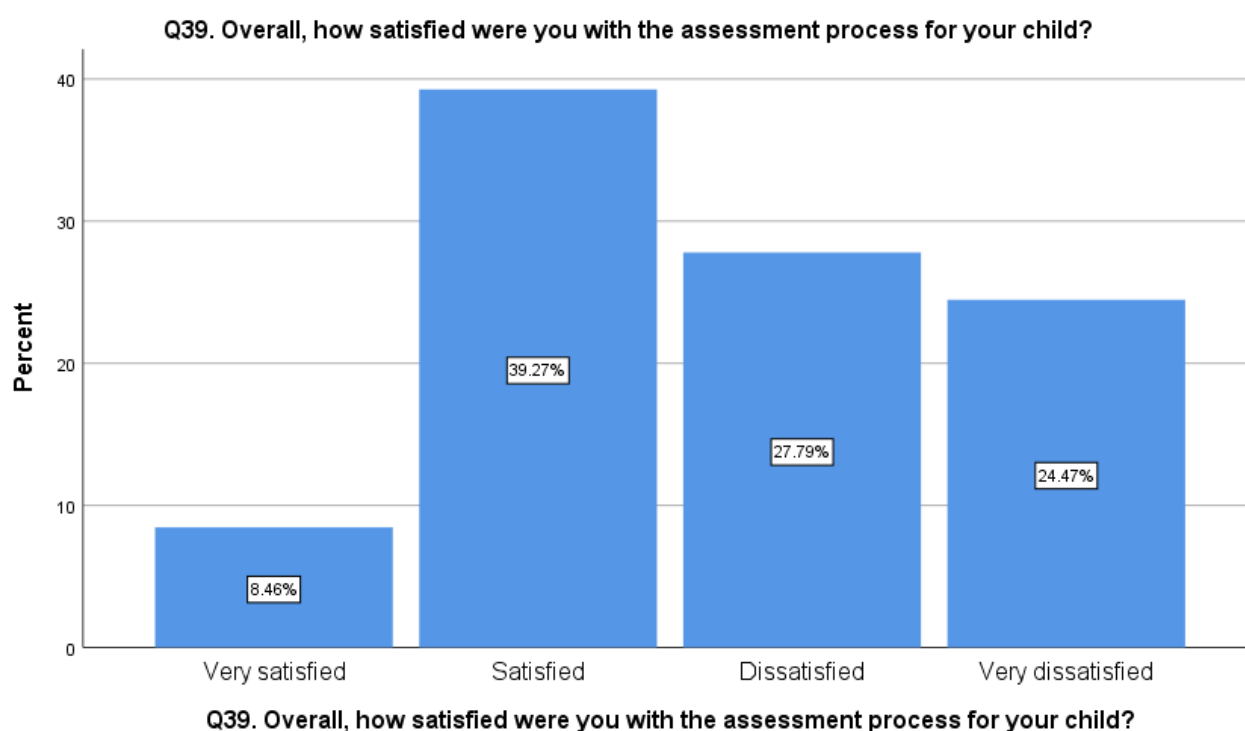


Figure 23

Q40 asked parents/carers who had gone through the statutory assessment process whether their child now had a statement of special educational needs. Almost three-quarters of the respondents (72.2%, n=239) said that their child had a statement, with the remainder (27.8%, n=92) saying no.

Q41 asked whether parents/carers felt that once issued, the statement gave an accurate description of their child's needs. Almost half (49%, n=117) agreed, while 40.6 per cent (n=97) said 'partly'. The remaining 10.5 per cent (n=25) said that the statement did not give an accurate description of their child's needs.

The following questions Q42.1-Q42.6 asked parents/carers for further information about the statementing process – see Table 4 below.

Table 4

Base=239		Yes % (n)	No % (n)	Don't know % (n)
42.1	Was the statement issued within 18 weeks of the request for an assessment?	27.2 (65)	46.9 (112)	25.9 (62)
42.2	Was the wording of the statement easily understood?	58.2 (139)	38.9 (93)	2.9 (7)
42.3	Was the proposed statement specific to your child's needs?	62.3 (149)	29.7 (71)	7.9 (19)
42.4	Did you request a change in the proposed statement?	43.1 (103)	51.9 (124)	5.0 (12)
42.5	Was the final statement issued within 8 weeks of the proposed statement?	38.1 (91)	29.7 (71)	32.2 (77)
42.6	Did you agree with the recommended school?	82.4 (197)	11.3 (27)	6.3 (15)

Responses to Q42 highlight delays in the statementing process: only a quarter of respondents (27.2%, n=65) reported that their (draft) statement was issued within the required 18 weeks, and in response to Q42.5 only 38.1 per cent (n=91) said that the final statement was issued within 8 weeks of the proposed statement. Most parents/carers (58.2%, n=139) found the wording of the statement easy to understand (though this means that almost two in five parents did not). No differences were found here by highest level of parental education. Most (62.3%, n=149) felt that the proposed statement was specific to their child's needs. Almost one in three parents/carers however (29.7%, n=71) did not feel that the proposed statement was specific to their child's needs. Over two-fifths (43.1%, n=103) requested a change in the proposed statement. More positively however, over four-fifths (82.4%, n=197) of the parents/carers agreed with the recommended school.

Q43 asked those parents/carers who had experienced the statementing process to rate their level of satisfaction. Results were almost evenly spread between those who were 'satisfied' (43.1%, n=103) or 'very satisfied' (7.1%, n=17), and those who said they were either 'dissatisfied' (29.3%, n=70) or 'very dissatisfied' (20.5%, n=49). These results are presented in Figure 23 below:

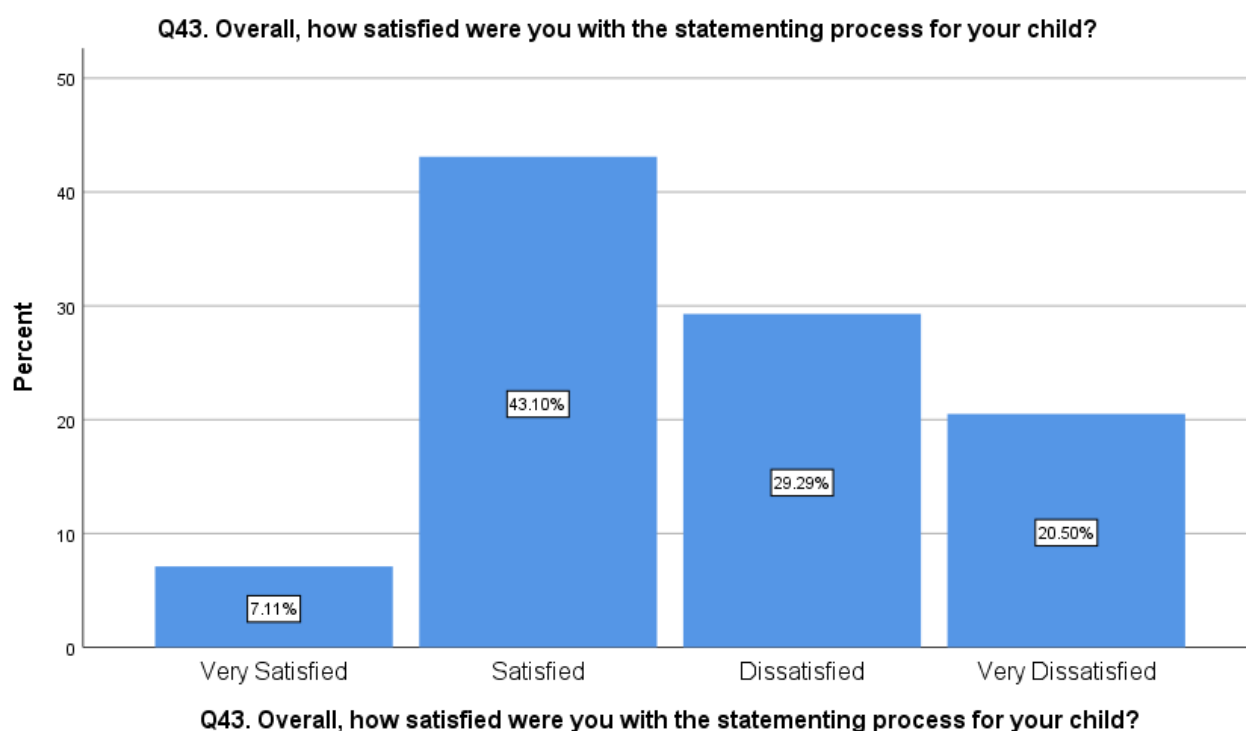


Figure 24

When these results are further analysed, levels of satisfaction were highest in the Western region of the EA (71% either 'very satisfied' or 'satisfied'), followed by the Belfast region (53.9%), Southern region (48.4%), South Eastern region (46.4%) and North Eastern region (44.3%). These differences were not however statistically significant.

When Q43 was analysed by recoded parental levels of highest educational qualification, the results show higher levels of satisfaction and much lower levels of dissatisfaction with the statementing process among parents/carers educated only to secondary level when compared to parents educated to degree level. These results are statistically significant (χ^2 7.824, df=3, p= 0.05). See Table 5 below:

Table 5

		Very Satisfied	Satisfied	Dissatisfied	Very Dissatisfied	Total
Secondary level qualification	Count	2	26	20	5	53
	%	3.8%	49.1%	37.7%	9.4%	100.0%
Tertiary level qualification	Count	14	72	45	42	173
	%	8.1%	41.6%	26.0%	24.3%	100.0%
TOTAL	Count	16	98	65	47	226
	%	7.1%	43.4%	28.8%	20.8%	100.0%

Disputes Avoidance and Resolution Service (DARS).

The next series of questions related to the Special Education Disputes Avoidance and Resolution Service (DARS). When asked in Q44 if they had been made aware of DARS, 54 per cent (n=129) of parents/carers said 'yes' while the remainder (46%, n=110) said that they hadn't.

Q45 asked whether, if parents/carers disagreed with their child's statement, they had contacted DARS. Of the 70 parents/carers who responded to this question, 42.9 per cent (n=30) said that they had contacted DARS, while the remainder (57.1%, n=40) had not.

Of the 30 parents/carers who had contacted DARS, half of them (50%, n=15) responded in Q46 to indicate that they felt the issue had been resolved satisfactorily, while the remainder (50%, n=15) felt that the issue had not been resolved satisfactorily.

When asked in Q47 to rate their overall level of satisfaction with the DARS process, the majority of the 30 respondents indicated that they were 'satisfied' (53.3%, n=16) or 'very satisfied' (6.7%, n=2). See Figure 25:

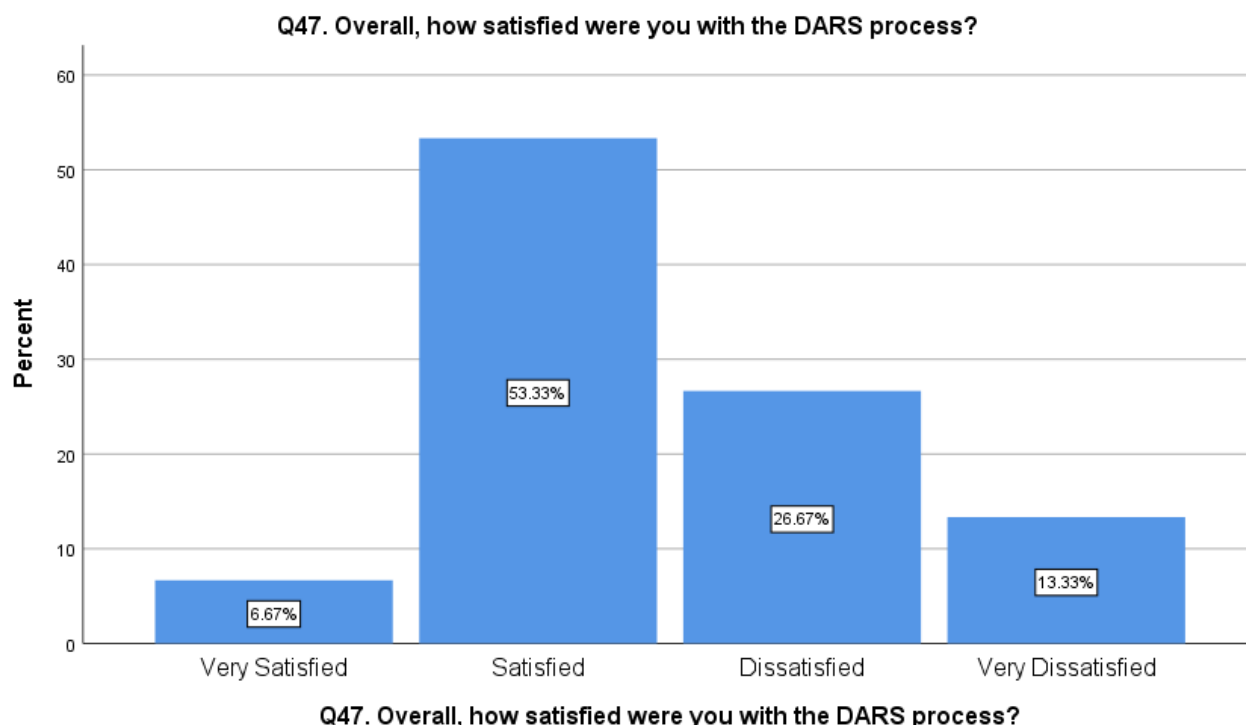


Figure 25

Special Educational Needs and Disability Tribunal (SENDIST).

Q48 asked whether, if parents/carers disagreed with their child's statement, they had contacted SENDIST. Of the 113 parents/carers who responded to this question, 43.4 per cent (n=49) said that they had contacted SENDIST, while the remainder (56.6%, n=64) had not.

Of those parents/carers who had contacted SENDIST, more than half of them (58.3%, n=28) responded in Q49 to indicate that they felt the issue had been resolved satisfactorily, while 20.8 per cent (n=10) felt that the issue had not been resolved satisfactorily. The remaining 10 parents/carers (20.8%) wrote "n/a".

When asked in Q50 to rate their overall level of satisfaction with the SENDIST process, almost three quarters of the 48 respondents indicated that they were 'satisfied' (72.9%, n=35) while 12.5 per cent (n=6) said that they were 'dissatisfied'.

Annual Review

Q51 and Q52 focused on the Annual Review process (a requirement for children with a statement). Of the 239 parents/carers who responded to Q51, a large majority (84.9%, n=203) indicated that they had been invited by their child's school to attend annual review meetings to see if their child's statement needed to be changed in any way. By contrast 7.1 per cent of parents/carers (n=17) said that they had not been invited to an annual review.

When asked in Q52 to rate their level of satisfaction with the Annual Review process overall, the majority of parents/carers indicated that they were either 'satisfied' (36.0%, n=86) or 'very satisfied' (27.6%, n=66). Less than a quarter were either 'dissatisfied' (14.2%, n=34) or 'very dissatisfied' (9.2%, n=22). See Figure 26 below.

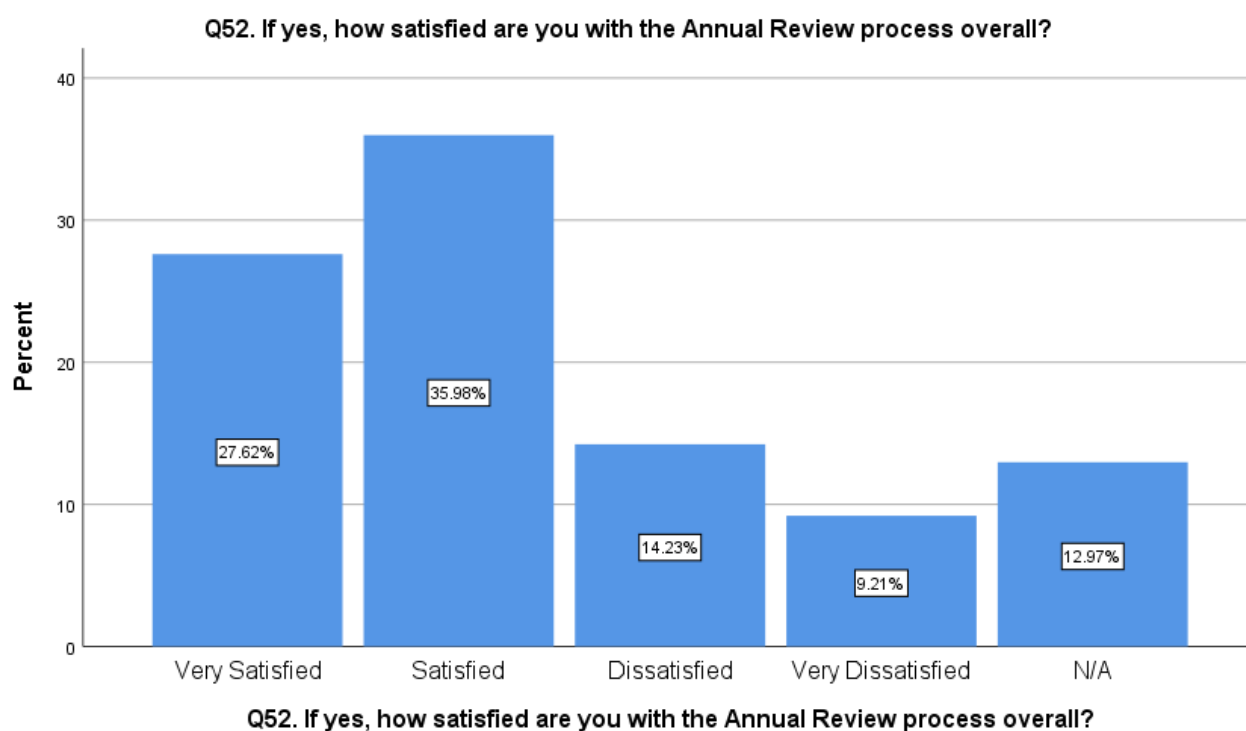


Figure 26

Experiences of the SEN process

The final section of the survey (Q53-Q60) focused on parents' and carers' overall experiences of the SEN process.

The first question in this section (Q53) asked parents/carers to rate how supportive key individuals within the school context had been. The results are displayed in the Table below.

Table 6

		Very supportive	Quite supportive	Not very supportive	Not at all supportive
1	Class Teacher	46.9% (277)	26.9% (159)	16.6% (98)	9.5% (56)
2	Classroom Assistant	59.4% (241)	25.6% (104)	7.6% (31)	7.4% (30)
3	SENCO	36.3% (205)	29.6% (167)	18.1% (102)	16.1% (91)
4	School Principal	36.5% (197)	28.3% (153)	19.3% (104)	15.9% (86)
5	Board of Governors	14.8% (38)	12.1% (31)	14.8% (38)	58.4% (150)
6	Form Tutor (Post-Primary)	36.6% (67)	30.1% (55)	13.1% (24)	20.2% (37)
7	Year Head (Post-Primary)	35.3% (65)	27.7% (51)	13.6% (25)	23.4% (43)

The results above indicate high estimations of the support provided by the classroom assistant in particular where 85 per cent of parents/carers who responded to this question found the classroom assistant either 'very supportive' (59.4%, n=241) or 'supportive' (25.6%, n=104).

The other results were more mixed: for instance, over a quarter (26.1%, n=154) of respondents found the class teacher to be either 'not very supportive' or 'not at all supportive', while over a third found the SENCO (34.2%, n=193) or the school principal (35.2%, n=190) to be either 'not very supportive' or 'not at all supportive'.

The second question in this section (Q54) asked parents/carers to rate how supportive key individuals within the Education Authority had been. The results are displayed in the Table below.

Table 7

		Very supportive	Quite supportive	Not very supportive	Not at all supportive
1	Educational Psychology Service	22.6% (106)	26.8% (126)	25.1% (118)	25.5% (120)
2	Autism Advisory Service	16.9% (56)	30.4% (101)	23.8% (79)	28.9% (96)
3	Behaviour Support Service	15.4% (35)	20.2% (46)	24.6% (56)	39.9% (91)
4	Specific Learning Difficulties Service	14.5% (29)	14.0% (28)	18.0% (36)	53.5% (107)
5	Sensory Service (hearing/Visual Support)	16.4% (23)	19.3% (27)	16.4% (23)	47.9% (67)
6	Other EA Service	10.8% (20)	13.0% (24)	20.5% (38)	55.7% (103)

The results in Q54 show high levels of dissatisfaction with the level of support provided by all Education Authority Services. The most positive ratings were given to the Educational Psychology Service where just under half of the respondents felt that the Service was either 'very supportive' (22.6%, n=106) or 'quite supportive' (26.8%, n=126), and the Autism Advisory Service where 16.9 per cent (n=56) felt that the Service was 'very supportive' and 30.4 per cent (n=101) felt it was 'quite supportive'. By contrast, more than two thirds of respondents felt that the Specific Learning Difficulties Service was either 'not very supportive' (18%, n=36) or 'not at all supportive' (53.5%, n=107). The comments

made by parents/carers often highlighted a certain level of confusion as in many cases they related to services not provided by the Education Authority e.g. Speech and Language Therapy, Occupational Therapy, CAMHS. Where the comments did relate to the EA, they were almost always negative as the following examples illustrate:

- “I have had to fight tooth and nail for extra help for my son who is 10 years 5 months and has reading ability of 6 years 1 month. My child has been failed massively by the EA!!”
- “Every input from EA services - Ed Psych and in particular Family Works has been a battle.”
- “I have found the EA to be unhelpful, dishonest and condescending/rude in much of their communication with me.”
- “Mr X [name removed] EA is outstanding officer. He explains everything so clearly on phone. Is our caseworker.”

Q55 focused on the levels of support provided by Health and Social Care Professionals, and the results are presented in the Table below:

Table 8

		Very supportive	Quite supportive	Not very supportive	Not at all supportive
1	Occupational Health	30.2% (96)	30.2% (96)	20.1% (64)	19.5% (62)
2	Physiotherapy	36.7% (66)	28.9% (52)	16.1% (29)	18.3% (33)
3	Speech and Language Therapy	42.9% (118)	32.0% (88)	11.6% (32)	13.5% (37)
4	Social Services	15.0% (19)	18.9% (24)	22.0% (28)	44.1% (56)
5	Other Service	42.4% (73)	21.5% (37)	12.2% (21)	23.8% (41)

The results above indicate high levels of parental satisfaction with all of the Services provided by Health Professionals. For instance, almost three quarters of parents/carers

felt that Speech and Language Therapists had been either 'very supportive' (42.9%, n=118) or 'supportive' (32.0%, n=88), almost two thirds felt that Physiotherapists had been either 'very supportive' (36.7%, n=66) or 'supportive' (28.9%, n=52), and over half felt that Occupational Health professionals had been either 'very supportive' (30.2%, n=96) or 'supportive' (30.2%, n=96). By contrast a majority of respondents to Q55.4 felt that Social Services had either been 'not very supportive' (22%, n=28) or 'not at all supportive' (44.1%, n=56). Other services (most commonly CAMHS and medical professionals) were also seen as supportive.

Q56 was a three-part question which asked parents/carers whether, in providing support to their child, they felt that the three bodies work well together in the best interests of their child. The results are displayed in the Table below, and show that in each instance, at least two-thirds of parents/carers felt that the collaboration was either 'not very effective' or 'not effective at all'. The lowest scores were given to the level of collaboration between the Education Authority and Health and Social Services where more than four out of five respondents felt that the collaboration was ineffective: 34.8 per cent (n=142) felt it was 'not very effective' and 47.1 per cent (n=192) felt it was 'not effective at all'.

Table 9

		Very effective	Quite effective	Not very effective	Not at all effective
1	School / Education Authority	9.0% (51)	26.0% (147)	35.7% (202)	29.3% (166)
2	School / Health & Social Services	9.4% (39)	21.9% (91)	32.0% (133)	36.8% (153)
3	Education Authority / Health & Social Services	4.2% (17)	14.0% (57)	34.8% (142)	47.1% (192)

Q57 was an open-ended question which asked parents/carers first whether they had experienced any barriers to accessing support for their child, and if so, to provide details. More than three quarters of respondents (77.8%, n=473) responded that they had experienced barriers to accessing support for their child. When the open-ended answers were analysed a number of main themes emerged which are presented by order of frequency in the table below:

Table 10

Barrier to accessing support	Percentage	Number
School is unsupportive	17.3%	78
Child not considered a priority need	16.8%	76
No support available/cannot access support	14.8%	67
Getting a formal diagnosis/assessment/statement or changes to same	14.2%	64
Having to fight or battle or push to get any support	13.5%	61
Lack of understanding/training about SEN	11.9%	54
EA is unsupportive or incompetent	11.9%	50
Lack of necessary funding/resources to provide support	10.8%	49
The recommended support is not provided (delay/incorrect provision)	9.7%	44
Lack of effective collaboration between bodies in SEN process	8.6%	39
Poor communication from statutory bodies in SEN process	8.2%	37
Support provided is inadequate, lacks continuity or has been removed	8.0%	36
Process is over-complicated	6.0%	27
Other	5.3%	24

Some illustrative comments from parents are presented below:

- “Lack of knowledge from SENCO and teachers about special needs and lack of knowledge/willingness to help. All onus on child to improve. No help given. Punished if not doing what he's supposed to.”
- “I have been fighting for more hours for my child for a year. She has been discriminated against because the EA are trying to save money. I am currently appealing my daughter's amended statement. It has been a fight from the very start of P1 with the EA. I have had to come out of work to support my daughter. It's been an awful process altogether.”
- “They just seem to brush me off”
- “Can't get an Ed Psy referral for child, even though his paed asked for one. School say there are too many children on the list and mine isn't a priority given the limited time allocated”
- “Waiting lists, poor communication between teams, stretch in staff leaves less support for child, passes from pillar to post and only for fighting parents would have been swept under the rug”

Q58 asked parents/carers to rate their agreement with a series of 7 statements reflecting the Children's Rights Benchmarks: Availability, Accessibility, Acceptability, Adaptability, Quality/Impact, Participation and Co-operation. The statements and parental ratings are presented in the Table below:

Table 11

	Strongly Agree	Agree	Undecided	Disagree	Strongly disagree
Q58.1 Availability: adequate facilities and services are in place to meet the needs of all children and young people with SEN	3.8% (23)	9.2% (56)	14.6% (89)	26.6% (162)	45.7% (278)
Q58.2 Accessibility: all children with SEN have equal access to services without discrimination of any kind	6.7% (41)	10.7% (65)	13.5% (82)	25.0% (152)	44.1% (268)
Q58.3 Acceptability: the SEN process is child-centred	4.6% (28)	14.1% (86)	19.2% (117)	22.0% (134)	40.0% (243)
Q58.4 Adaptability: the education environment is adaptable in order to meet the needs of children with SEN	4.8% (29)	16.1% (98)	20.2% (123)	21.9% (133)	37.0% (225)
Q58.5 Quality/Impact: children and young people with a SEN receive a quality service which meets their needs	3.9% (24)	10.5% (64)	20.2% (123)	24.0% (146)	41.3% (251)
Q58.6 Participation: the views of children with a SEN are sought and taken into account in their education and development of policy and services	3.0% (18)	10.7% (65)	25.5% (155)	24.2% (147)	36.7% (223)
Q58.7 Co-operation: there is timely and appropriate co-operation and integration of services to ensure a holistic approach is taken to meet the needs of children with SEN	3.1% (19)	7.6% (46)	19.9% (121)	23.2% (141)	46.2% (281)

The results for each of the 7 statements show high levels of parental disagreement across all Children's Rights Benchmark statements. In fact, less than one in five parents/carers 'agreed' or 'strongly agreed' with any of the statements. The highest level of disagreement was in relation to Q58.1 "Availability: adequate facilities and services are in place to meet the needs of all children and young people with SEN" where only 13% of respondents 'agreed' (9.2%, n=56) or 'strongly agreed' (3.8%, n=23) with the statement, and almost three quarters either 'disagreed' (26.6%, n=162) or 'strongly disagreed' (45.7%, n=278).

Q59 was another open-ended question and asked parents/carers to outline what they would say has been the most positive aspect of the SEN process. There was a wide range of answers but closer analysis revealed a number of key emerging themes which are presented in the Table below. The most common response was that there was nothing positive to report (27.1%, n=163), followed by recognition of support from school staff (22%, n=132) and acknowledgement of the formal diagnosis or recognition of the child's special educational needs (13.8%, n=83).

Table 12

Most positive aspect of the SEN process	Percentage	Number
Nothing positive	27.1%	163
Support from school staff	22.0%	132
Formal diagnosis/recognition of child's SEN	13.8%	83
Additional supports put in place e.g. classroom assistants	11.1%	67
Early intervention/ quick process	4.2%	25
Support from health professionals e.g. SLT, OT	3.7%	22
Being listened to, heard, treated with professionalism	3.0%	18
Using knowledge to highlight need/support from other parents	2.8%	17
Support from external agencies	1.8%	11
Support from Educational Psychologist	1.8%	11
Support from Education Authority (e.g. Autism Advisory Service)	1.2%	7
Support from RISE NI	1.0%	6

Some illustrative comments from parents/carers are presented below:

- "Nothing. Haven't had a positive experience whatsoever. Have to jump through hoops and fight to get your child support and help they need. The system is a total disgrace."
- "My child's school are extremely supportive and have done their best to help our daughter to access the curriculum and to develop skills to deal with Social and emotional difficulties. Very human and caring."
- "Once the statement was in place support was offered year on year"
- "Finally getting the answers to my child's needs"
- "I have had a good experience. Nursery, primary and post primary school have been excellent with fantastic classroom assistants throughout. I'm not sure everyone has been so lucky."
- "Finally getting the label 'dyslexia' meant that we could educate our son on how to enhance his strengths and manage his difficulties and we were able to help him to communicate these to teachers which resulted in agreement to a test for a reader and scribe which was granted and was exactly what he needed."
- "Honestly it's been awful. We have been through hell with it all"

The final survey question (Q60) provided an open-ended opportunity for parents/carers to make any suggestions they felt would improve the SEN system. Once again there was a wide range of responses, which were then coded, leading to the emergence of the following key messages:

Table 13

Suggestions for improvement	Percentage	Number
Provide more adequate funding and resources (including more assessments)	30.9%	128
Improve timescales/shorten process/reduce waiting lists	21.5%	89
Create a more child-centred system/education culture	18.8%	78
More training for staff about SEN/increased awareness of SEN	16.4%	68
Listen more to parents	15.7%	65
Improve guidance for parents/make the process easier to navigate	14.5%	60
More effective communication with parents	14.0%	58
More joined-up working/more effective collaboration	13.3%	55
Recognition needs hidden/considered as less critical	8.7%	36
Recognise external/private assessments/opinions	6.3%	26
Earlier intervention	5.6%	23
More adherence to legislation or recommended supports	4.6%	19

Some illustrative examples of parental comments are provided below:

- “The whole system needs a complete overhaul and a child centred approach needs to be adopted. Parents views need to be given greater significance. More placements need to be made available for kids with additional needs. More money invested. Mandatory autism training rolled out in every school nationwide.”
- “More parent/child friendly, more focused on supporting the child than how much it will cost, a quicker process, parents should not have to resort to court in order to obtain the right support for their children.”
- “Rip it up and start again. Make it child centred.”
- “Honestly it’s shambolic - the EA was absolutely appalling and this box isn’t big enough to type in all that needs fixed with it”
- “Simple more help/people/resources/money!”
- “Make it less adversarial between the EA and the parents.”
- “Shorter waiting lists. More staff in schools. Better training for teachers.”
- “Listen to the parents, they are the ones that knows the child best, they see and deal with the daily struggles”
- “Disgrace that schools can only refer one child at a time. Better links with health trusts, EA and schools”
- “Where to start?? Primarily the service needs to be properly funded. The rationing to only the most severe and visible problems is a terrible abandonment of other children with real and serious needs. The second thing is to trust parents to be experts in their children and real partners in their children’s education. And finally centre the process and resources around the children not the school.”
- “The process must be less time bound and more flexible and adaptable in order to best meet children’s individual needs. There must be much more transparency throughout the

process in order to ensure greater effectiveness. Money must not be the primary factor and must not prevent children from accessing the support that they need.”

- “Schools should have no restriction on numbers of children be put forward for assessment, if school tests and teachers see a child struggle they should be allowed to have an assessment carried out where a parent supports concern”
- “Needs to be faster and stop children with behaviour issues jumping the queue. Kids are struggling daily but because they have no behaviour they are overlooked and pushed back down the list.”
- “More funding!!!!!!”

Significant differences in responses from parents of statemented (stage 5) and non-statemented (stages 1-4) children

In order to establish whether parents' responses were dependent on whether their child had a statement (CoP Stage 5) or not (CoP Stages 1-4), a series of chi-square tests were performed. Those question responses that did have a significant relationship ($p < 0.05$) are presented here, though it is important to remember that the non-significance or independence of the relationships with the other question responses not presented here is nonetheless an important finding.

There was a significant association between parents' reported familiarity with the SEN Code of Practice (Q12) and whether or not their child had a statement $\chi^2 (3) = 30.444$, $p < .001$. This seems to represent the fact, demonstrated in the clustered bar chart below, that parents of children with statements were far more likely to be 'very familiar' with the SEN Code of Practice.

Based on your experience, how familiar are you with the 5 stages of the SEN process as set out in the Code of Practice below?

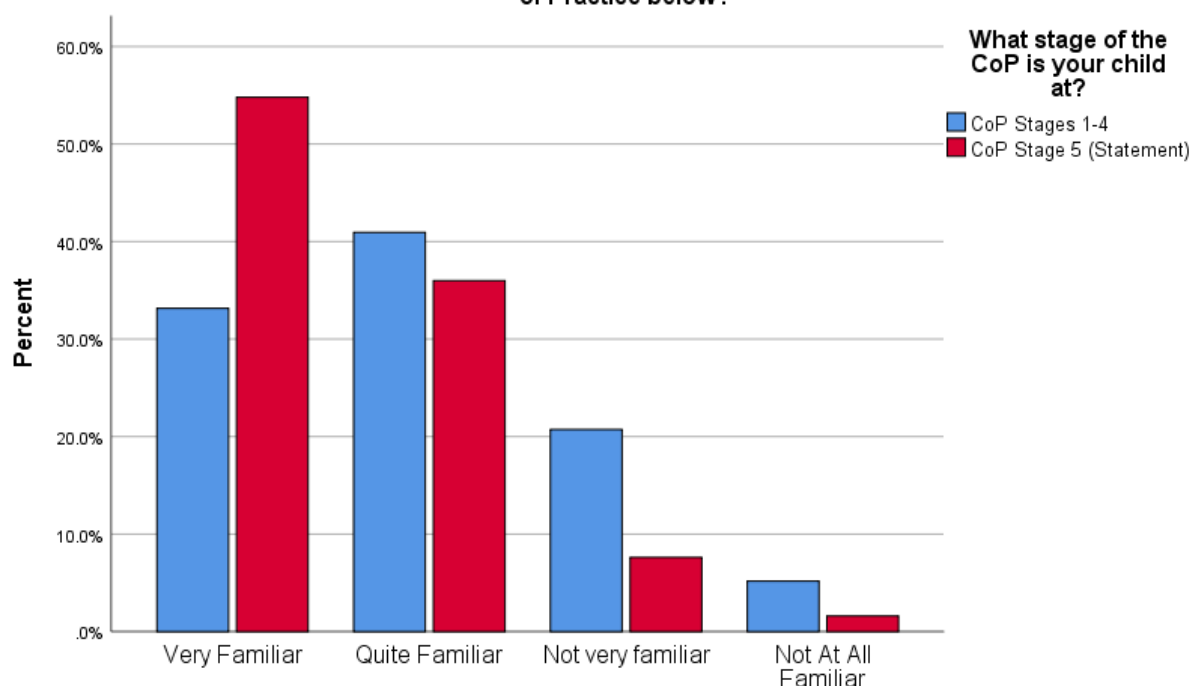


Figure 27

Chi-Square Tests			
	Value	df	Asymptotic Significance (2-sided)
Pearson Chi-Square	30.444 ^a	3	.000
Likelihood Ratio	30.788	3	.000
Linear-by-Linear Association	29.522	1	.000
N of Valid Cases	443		

a. 0 cells (0.0%) have expected count less than 5. The minimum expected count is 6.10.

There may be a significant association between parents' reported confidence expressing their views about their child's needs (Q20.3) and whether or not their child had a statement $\chi^2 (3) = 11.157, p < .025$. The certainty of the statistic is compromised by the fact that two expected frequencies were less than 5. If there is a significant association, it would represent the fact, demonstrated in the clustered bar chart below, that parents of children with statements were more likely to 'strongly agree' that they were confident expressing their views.

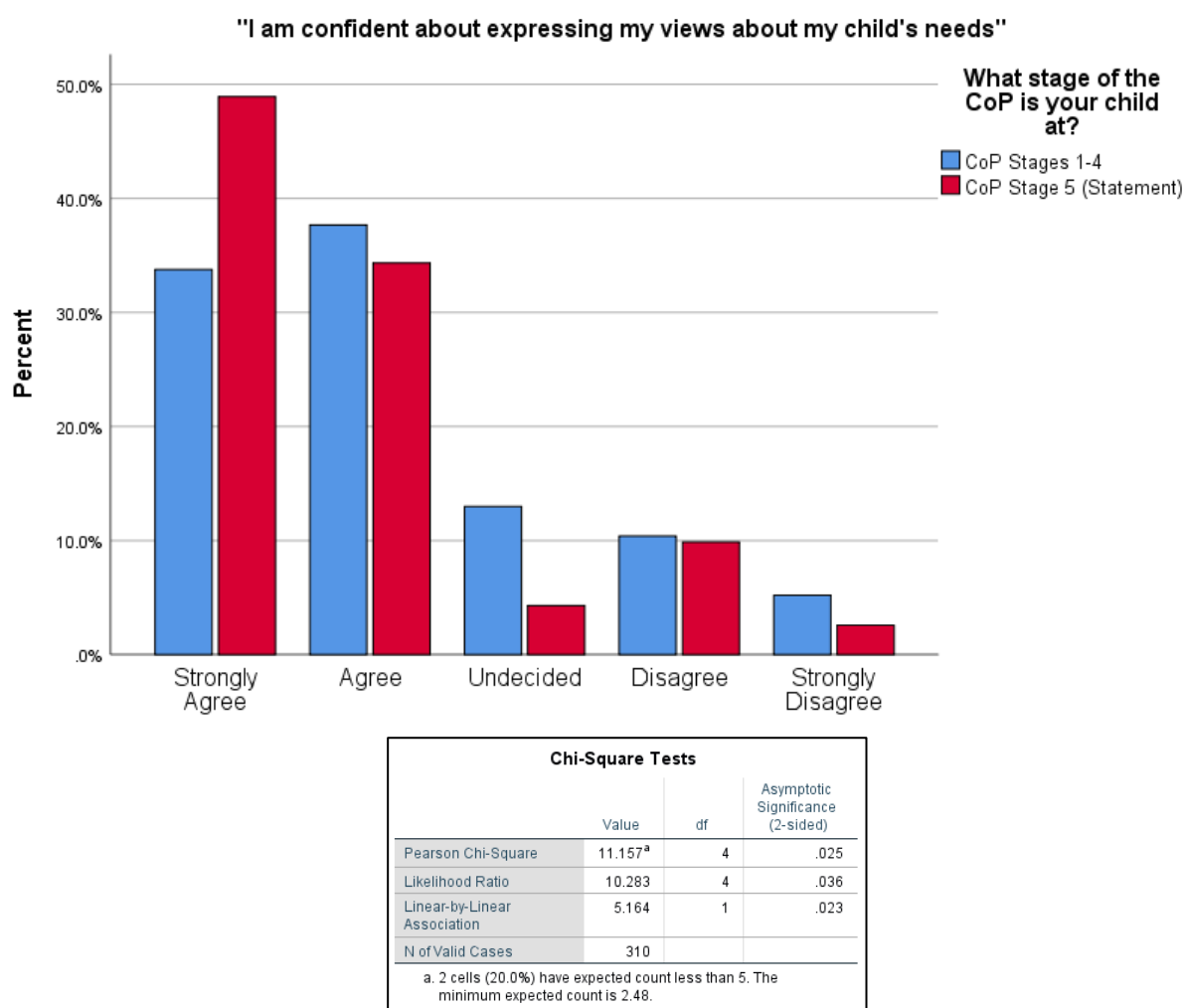
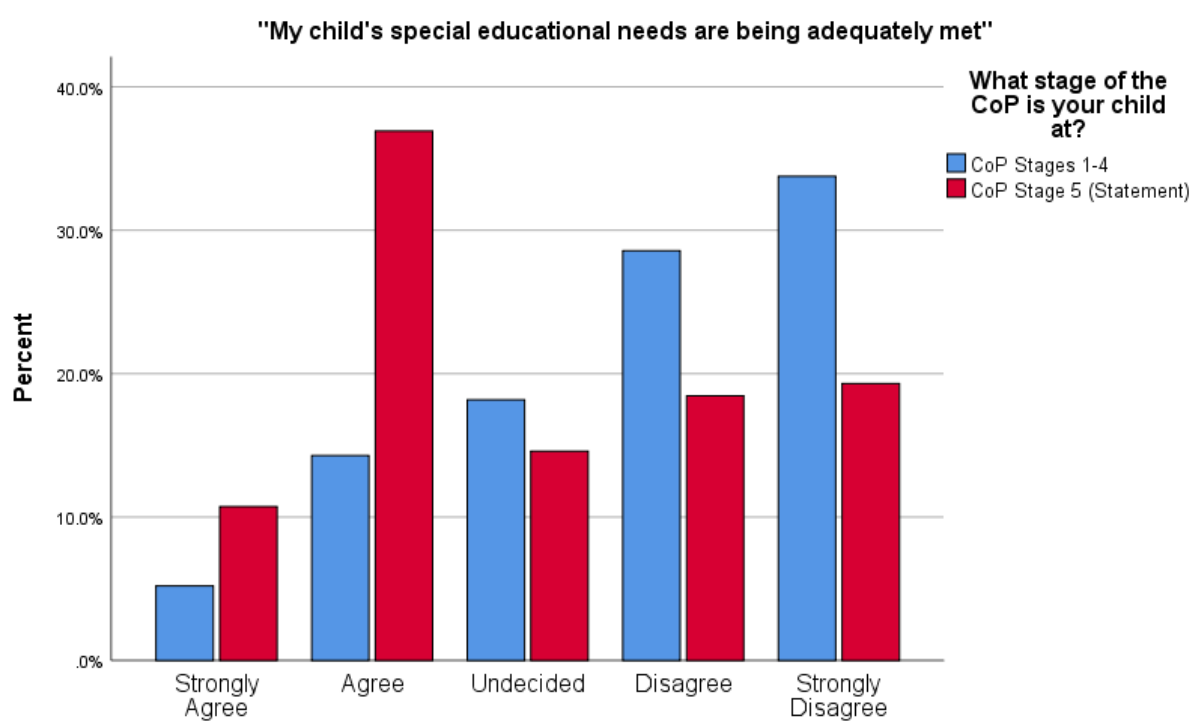


Figure 28

There was a significant association between parents' agreement that their child's special educational needs were being adequately met (Q20.1) and whether or not their child had a statement $\chi^2 (3) = 19.947, p < .001$. This seems to represent the fact, demonstrated in the clustered bar chart below, that a large proportion of parents of children with statements 'agreed' that their child's special educational needs were being adequately met, while parents of children without statements increasingly disagreed.

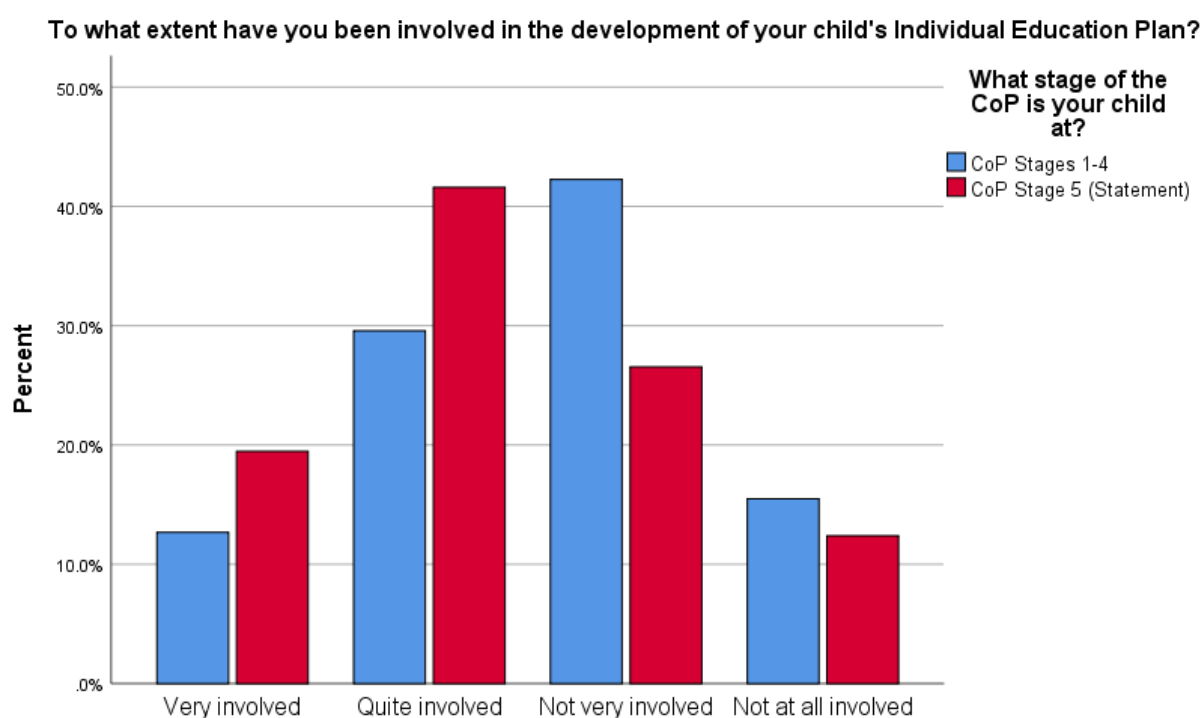


Chi-Square Tests			
	Value	df	Asymptotic Significance (2-sided)
Pearson Chi-Square	19.947 ^a	4	.001
Likelihood Ratio	21.253	4	.000
Linear-by-Linear Association	17.091	1	.000
N of Valid Cases	310		

a. 0 cells (0.0%) have expected count less than 5. The minimum expected count is 7.20.

Figure 29

There was a significant association between parents' reported involvement in the development of their child's Individual Education Plan (Q24) and whether or not their child had a statement $\chi^2 (3) = 8.205, p < .042$. This seems to represent the fact, demonstrated in the clustered bar chart below, that parents of children with statements were likely to be 'quite involved' as opposed to the majority of other parents, who were 'not very involved'.



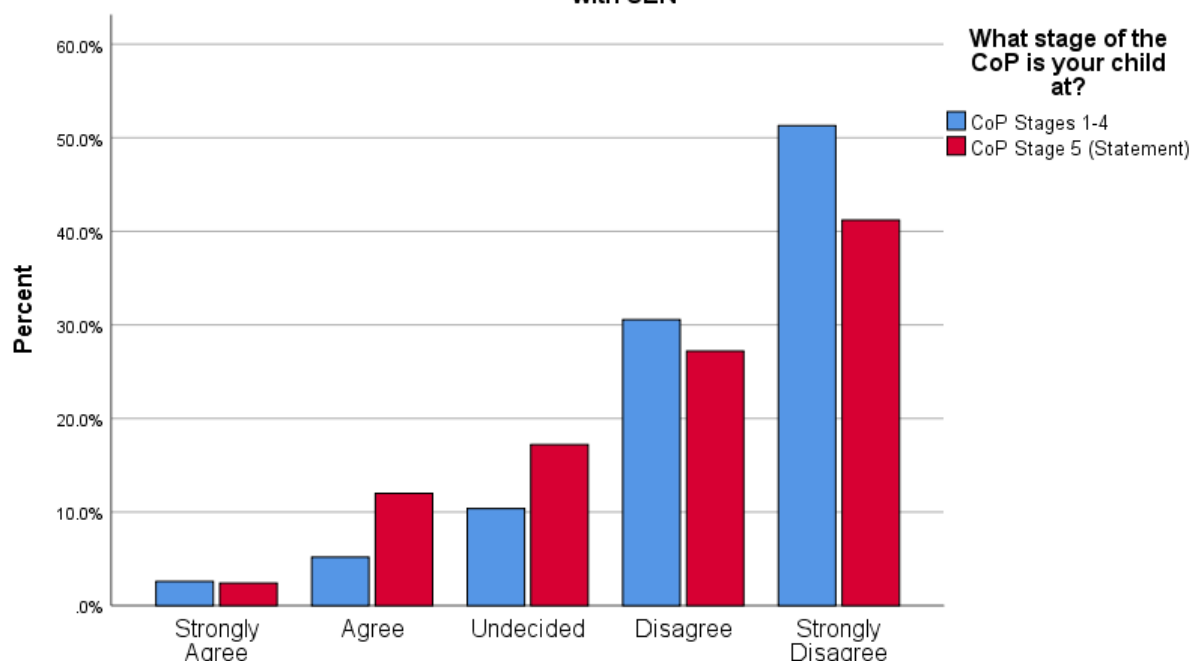
Chi-Square Tests			
	Value	df	Asymptotic Significance (2-sided)
Pearson Chi-Square	8.205 ^a	3	.042
Likelihood Ratio	8.104	3	.044
Linear-by-Linear Association	5.178	1	.023
N of Valid Cases	297		

a. 0 cells (0.0%) have expected count less than 5. The minimum expected count is 9.32.

Figure 30

There may be a significant association between parents' agreement that adequate facilities and services were in place to meet to the needs of all children and young people with SEN (Children's Right Benchmark) (Q58.1) and whether or not their child had a statement $\chi^2 (4) = 12.070, p < .017$. The certainty of the statistic is compromised by the fact that one expected frequency was less than 5. If there is a significant association, it would represent the fact, demonstrated in the clustered bar chart below, that parents of children with statements were more likely to 'agree' than other parents, a greater proportion of whom 'disagreed' or 'strongly disagreed'.

Availability: adequate facilities and services are in place to meet the needs of all children and young people with SEN



Chi-Square Tests			
	Value	df	Asymptotic Significance (2-sided)
Pearson Chi-Square	12.070 ^a	4	.017
Likelihood Ratio	12.513	4	.014
Linear-by-Linear Association	8.292	1	.004
N of Valid Cases	443		

a. 1 cells (10.0%) have expected count less than 5. The minimum expected count is 4.79.

Figure 31

There was a significant association between parents' agreement that the education environment was adaptable in order to meet the needs of children with SEN (Children's Right Benchmark) (Q58.4) and whether or not their child had a statement $\chi^2 (4) = 15.293$, $p < .004$. This seems to represent the fact, demonstrated in the clustered bar chart below, that parents of children with statements were more likely to 'agree' than other parents, a greater proportion of whom 'disagreed' or 'strongly disagreed'.

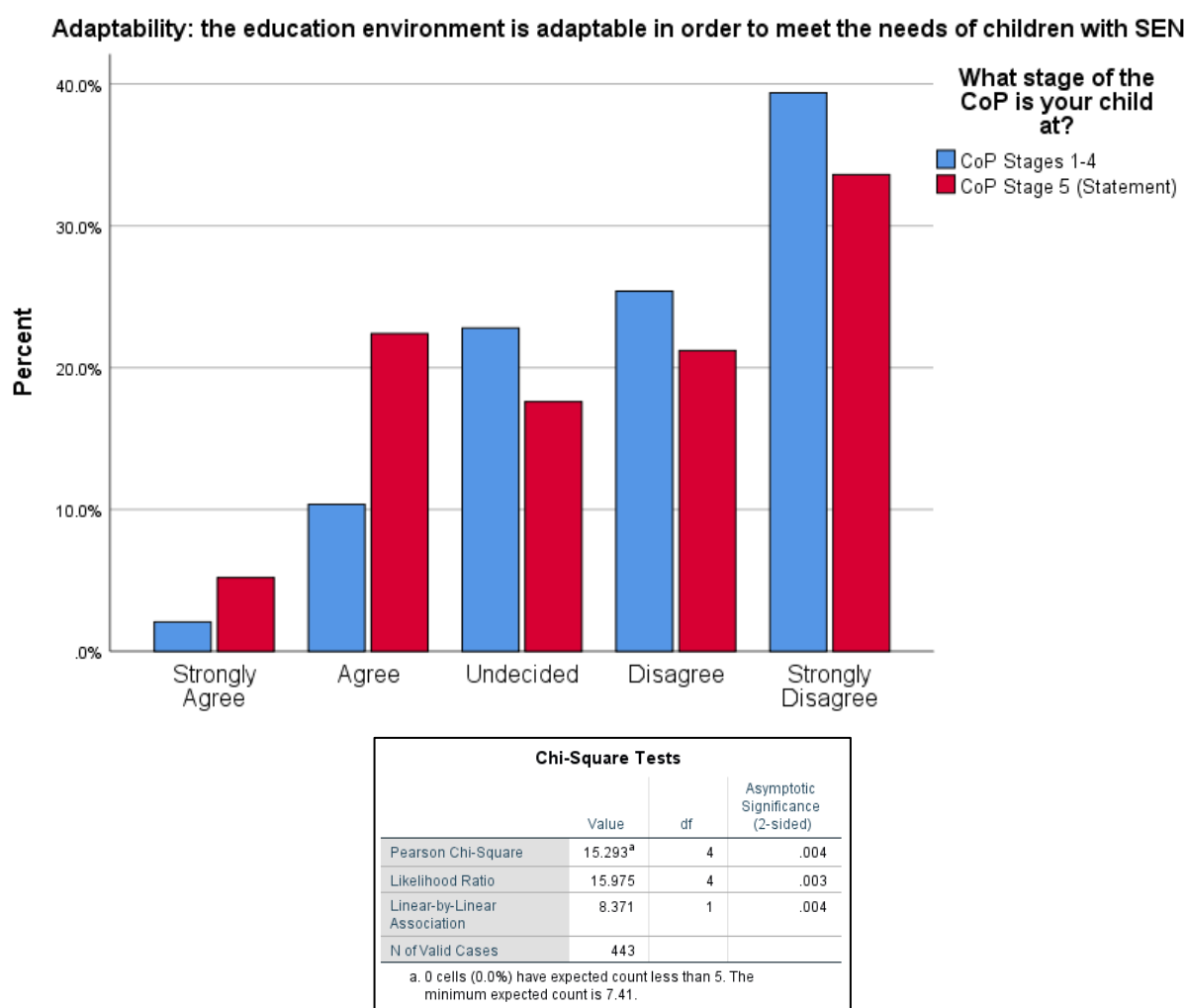


Figure 32

There may be a significant association between parents' agreement that children and young people with a SEN receive a quality service which meets their needs (Children's Right Benchmark) (Q58.5) and whether or not their child had a statement $\chi^2 (4) = 22.113$, $p < .000$. The certainty of the statistic is compromised by the fact that one expected frequency was less than 5. If there is a significant association, it would represent the fact, demonstrated in the clustered bar chart below, that parents of children with statements were more likely to 'agree' than other parents, a greater proportion of whom 'disagreed' or 'strongly disagreed'.

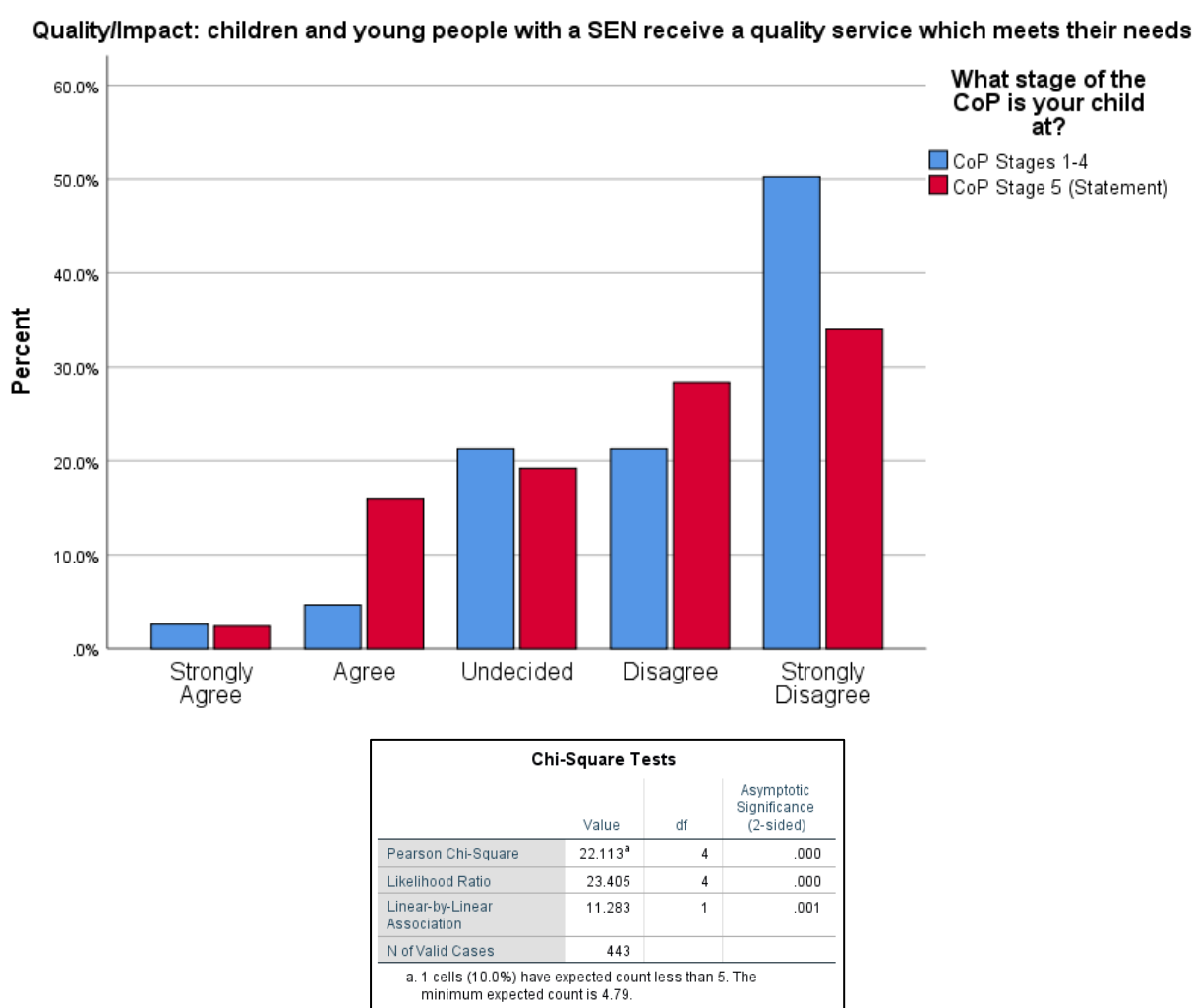


Figure 33

SECTION 2: FOCUS GROUP RESULTS

Theme 1: Communication

Effective communication with parents/carers

One of the most significant themes to arise from the focus groups was the importance of effective communication at all levels. One in seven comments related to the positive impact of effective communication with parents/carers. The most positive parents/carers described having an open relationship with the school; where principal, teachers, classroom assistants and school secretaries were informed about their child's needs, frequent contact was made and their voice was heard:

"Any time I rang they've rung me back within an hour and they've any amount of time to talk about him. It's just been amazing."

Many parents/carers felt that the process of defining their child's need and accessing the most appropriate provision was complex:

"I'm a parent. I don't know anything about the education system, you know."

Positive experiences of this process were linked to informed staff, principals and SENCOs/LSCs who advised them, were proactive and helped them to navigate the pathways to support. These schools were keen to provide for children with SEN and medical needs in the mainstream classroom and make adjustments prior to diagnosis. This was key as parents/carers were aware of the timeframe involved in following educational procedure and were concerned about the impact of a delay in the provision of services. Parents/carers were also very appreciative of the sacrifice of resources that schools were making, given the current constraints upon school budgets. Where this was not possible, informed and compassionate practice built trust and reassured parents:

"P1 was great. Even though he was in mainstream without any classroom support, his teacher had a handle on things, you know, she had a bit of authority and she came and listened and the school were really supportive, I went in on day one and just cried, just cried to her, I couldn't help it, she's just one of those teachers you see and you know she's gonna love him, she's gonna really support him."

Ineffective communication with parents/carers

The majority of parents/carers however did not have a positive experience, with participants in all focus groups describing the process as a 'battle' or a 'fight'. Without guidance, they expressed feelings of worry, confusion and isolation:

"It was horrendous, absolutely horrendous: no support, no information, no communication and I was left feeling just shell shocked, you know...I can't tell you how many people are affected."

"It's just a mess. I'm currently in the situation where I don't know...I don't know the next step or where to start."

Parents felt 'naïve' and that, without appropriate communication, they were being placed in an impossible situation:

"It's a whole new language so, if the EA had a glossary to hold all the new terminology for a parent...'Who they were going to see?', a lovely wee flowchart to say, 'This is what happens' and 'What happens if ...?' that would be very, very helpful."

This was deemed to be particularly important for parents/carers who struggled with literacy:

"I think they forget that as parents we're lost in all this paperwork. And they're sending you guff that you don't even understand. And you're sitting reading it and it's brought me to tears a few times just looking at it going, "What do I actually do?"

As in all communication, the notion of 'being heard' was central to focus group discussions. The difficulty in 'being heard' for many parents/carers was in finding someone to talk to, either because their pathway was blocked at the reception desk or because staff, at all levels of the process, did not return calls or respond to emails. Parents/carers were keen to point out that reasonable communication was both a 'common courtesy' and a 'legal' responsibility:

"I was hung up on seven times in the space of a half an hour: 42 times to get through! It's come to the point where I was recording phone calls."

Once contact was made, some parents felt that they were 'lied to' or that information was withheld. Others felt that their voice and the voice of their children was not attended to or respected:

“Being ignored or laughed at by people who you think are experts or professionals is probably the most difficult thing.”

A number of parents felt that their experience of their child outside of school and their understanding of the challenges their child faced were disregarded, the result being wasted time in identifying need and accessing appropriate support.

Discrepancy between cases of medical and learning difficulties

The parents of the nine children with a medical diagnosis had the most positive experiences of the early stages of the process. Once diagnosis was confirmed, support agencies became involved and services were put in place. Open communication and advice from health professionals reassured parents that appropriate provision would be set in place and they were given clear advice on their role in the process. Where a difficulty was ‘visible’ and paperwork existed, schools were quicker to recognise the SEN and begin the process of accessing support:

“It made such a big difference with (name) and (her) development both personally and academically. Without the support of the school she wouldn’t have achieved what she’s achieved today, and I can say that without question.” (Parent of child with Down’s Syndrome)

Despite a positive experience of mainstream provision, this parent expressed concerns that communication had broken down relating to post-18 provision, since no-one appeared to have experience of this situation. Another parent of a child with the same diagnosis had great difficulty communicating with EA regarding their child’s provision, post-nursery. Despite their own struggles, these parents expressed ‘guilt’ that the parents whose children had ‘invisible’ difficulties had to ‘fight’ to be heard.

Parents of children with a diagnosis or awaiting diagnosis of dyslexia (n=13) stood out in four of the focus groups. They described the difficulties in drawing the school’s attention to the challenges their child was facing, resorting to paying for a private diagnosis, even if the EA would not recognise it. They felt that it was only when paperwork was available, that the school began to listen and investigate the child’s needs, leading to a referral. One parent, with three children with or awaiting a diagnosis of dyslexia, felt the expense of having her first child assessed was justified as the school was then prepared to discuss the needs of her other children. Parents also commented that where children were

achieving reasonably well in school, dyslexia was not recognised. Parents understood that budget and staffing restrictions meant priority was given to children with the most extreme learning challenges but nevertheless the impact upon their child's academic performance, and more importantly mental health and home life, also needed to be addressed. A similar issue was raised by parents of children with high functioning ASD. Attention was drawn to the changes in the recording of SEN (following the new *Recording SEN and Medical Categories Guidance for Schools* issued by DE in January 2019) and the potential that children whose academic performance falls within the average range will not qualify for SEN registration and additional support, despite diagnosed difficulty.

Lack of communication between professionals

A significant area of concern across all focus groups irrespective of the particular SEN of the children was the lack of 'joined up thinking' between services and the consequences in terms of clarity of communication and speed of access to diagnosis and support. For children with medical conditions and diagnoses, there were often poor links between health professionals and educational professionals:

"There is no continuity between all the services, between the school and the Autism Advisory and the EA. Nobody seems to know what the other's doing. You are constantly repeating yourself, you're constantly having to keep notes because you need to pass on the information. They won't pass on the information."

While in the special school sector external professionals can support the child within the school setting, parents/carers of children in mainstream schools commented that the lack of joined up thinking between health and education made this impossible, even in situations where schools were trying to accommodate. Better liaison between health professionals and educational psychology was also advocated to avoid parents/carers getting involved in disputes over what constituted a need for SEN provision:

"So, it's the parent's fight and I think the health professionals, education should be able to work it out."

One parent commented of EA, "If they could talk to the trust, that would just be magical".

It was also felt that proactive schools were either being hindered or not being heard by the EA.

Theme 2: Parents/carers accessing support

Given the difficulty parents/carers expressed in contacting services and accessing support, it is unsurprising that the most discussed theme, across all focus groups, was parents' need to access support by themselves. Two support groups for parents/carers, one in Newry and one in Armagh, were mentioned and two parents discussed the value of support from other parents/carers of children with SEN. While some parents/carers had been able to use personal contacts in health and education to advise and direct them, or used work contacts to bypass systems, the majority of parents had felt the need to navigate the process alone, with no prior knowledge of these systems and without points of contact. They described how they had to coordinate communication between schools, services and external agencies, often 'getting lost in the paperwork':

"While we're trying to get our child the help they need at school, we're also trying to get them help through the trust. And see the amount of, I have a file this thick about my daughter and she's five."

As has been stated, parents/carers initially lacked the vocabulary and overview of services available. Some described the range of training courses they had undertaken to improve their knowledge and understanding of their child's difficulty, to enhance their ability to engage with experts and professionals. However, difficulties still remained in gaining the support and advice of the school principal or SENCO, while some parents/carers referred to SENCOs, new to the job, who did not understand the process themselves. Often this lack of awareness of procedure resulted in duplication of effort, errors and wasted time:

"I tried to instigate support for (name) and that was me, the mummy instigating support for (him), not his SENCO, not his principal, not his teacher – me. When I tried to get Autism Intervention Service involved ... I was told the line in his statement was not specific enough and I said, 'Are you serious?', and I'm still fighting for that six months in; I'm still trying to get that line because of a wording issue."

The importance of understanding the specific wording used in educational psychology reports and educational statements, plus the consequence of being uninformed, was reiterated across focus groups. At one focus group, a parent explained that she re-wrote and resubmitted their child's statement which was very challenging, given her mathematical rather than literacy background. The challenge of the task was also heightened by

opposition. Parents/carers noted that the ‘fight’ involved ‘stalking’ or ‘torturing’ services with phone calls, emails, written correspondence or by resorting to sit-ins in government reception areas. For another this involved contacting the Health Minister and the Education Minister which resulted in her child getting the placement needed.

Although many parents had been successful in overcoming obstacles to assessment and support, they objected to having to go to such lengths to do so:

“When you’re talking about us becoming bolshy, it’s what you’re driven to because it’s like, unless you say the magic word “complaint” or something like this you feel that you will inevitably just be fobbed off. So, you have to then take on this persona of being a really irate, ‘I’m going to take you to court’ type of person, which is not who I am.”

For a number of parents, legal proceedings had been necessary; some were still ongoing. They noted how stressful and ‘surreal’ it was to be placed in this position. For others, efforts were not successful with some resorting to private assessment and home tutoring. During two of the focus groups, a parent became aware, for the first time, of what could be achieved through parental intervention and expressed notable concern:

“I feel like such a bad parent. I haven’t really had any input from the Education Authority apart from the Educational Psychologist review that he [her child] had in play group and I feel so bad now because he’s in third year and he had nothing in primary school. He’s never been statemented. He had an IEP, but I didn’t even really understand what was going on... I didn’t know what to do so I feel totally let down.”

The groups supported these individuals, reaffirming that a ‘battle’ should be unnecessary.

“We should be working together surely. Everybody’s should be working in the child’s interests.”

Theme 3: The Impact

At the outset of each focus group, parents were asked to arrange cue cards to illustrate the process of ensuring appropriate educational provision for their child/children, as they had experienced it. While a range of influences were identified, the impact upon the child at the centre of the process was by far the most frequently chosen (n=20; 36%). See

Figure 27 below for more details:

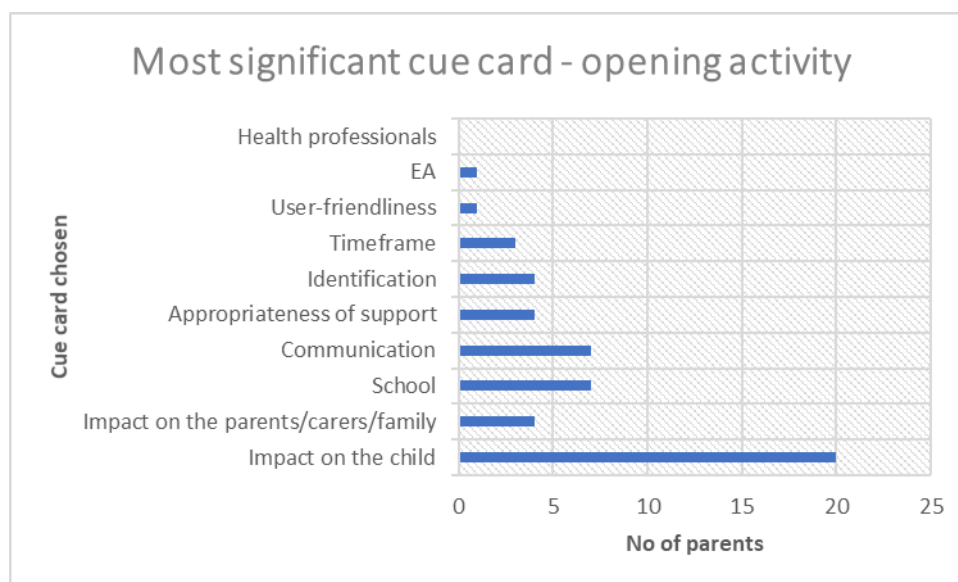


Figure 34

Impact on the child

Parents believed that academic progress was being hindered by the current SEN system, the reasons varying with the child's specific needs. For those with medical difficulties, time taken out of schools for medical appointments meant missed and disconnected learning, resulting in lower attainment levels. Where children were awaiting diagnosis, some schools did not recognise or attempt to meet the child's needs. In more proactive schools, lack of a clear definition of SEN meant that schools could not develop more specific strategies or gain access to additional resources to meet children's need. In a few cases, children received incorrect diagnoses or placements:

"‘I’m doing P3 work mummy’, this is the way it went on. He was leaving P5 about to do 11+ work and doing P3 work and this went on. And then the Education Authority, eventually they did say, ‘Oh, he has been wrongly placed.’"

Parents of children with dyslexia felt that their child's SEN was secondary to other SEN and that provision could not be as specific as required because of lack of teacher expertise and large class sizes. There was also concern for children with ASD. Parents felt that a

focus on ensuring their child's behaviour was appropriate meant insufficient effort was being made to help them achieve their academic potential:

"He does have a learning difficulty because of everything, the way he is and the way he thinks, he is not able to perform as well at school as another child. So, that's not going to help because... it's going to be not particularly on a special needs register. They'll say, well, he's smart enough, you know."

Secondly, a lack of appropriate diagnosis and the provision of a 'tailored environment' was impacting children's behaviours. At times, classroom assistant time was being misused, resulting in poor attention or emotional outbursts and 'meltdowns':

"[The classroom assistant] wasn't with my child half the time and he was missing out on lessons because he couldn't cope with smells."

While lack of appropriate provision was highlighted, the stress on supportive teachers and schools was also noted to be a result of the process being too complex and taking too long. For others the situation had become more extreme:

"He's 8. So, he's in the process of being expelled. The paperwork is in the post. Even with the statement, that's what's happening."

Thirdly, the impact on children's social development was noted. For those with behavioural issues, children were becoming 'utterly socially isolated'. This was a particular issue for children with ADHD or ASD. In five of the ten focus groups, children had been or were still being bullied.

The final and greatest cause for concern expressed by parents/carers was the impact on children's mental health. This was discussed in all of the focus groups. In two of the groups, parents discussed how children have had suicidal thoughts and in seven focus groups, Child and Adolescent Mental Health Services (CAMHS) had been involved. All focus groups discussed their children's high levels of anxiety. This presented in a range of ways. In school, children were feeling sick, crying, running to the toilet, soiling themselves, having 'meltdowns' and refusing to complete work or engage in school activities. Parents were aware that this increased teacher workload impacted other children in the classroom and, consequently, further isolated their children from the teacher and their peers. Some children were school refusing. These behaviours were replicated at home:

“We were still sitting at home with a child who stripped himself naked every morning and paced the floor, wetting himself and being sick and crying because he had to go to school and they’re telling me, you know, you’re not getting another assessment.”

However, the behaviours described were accompanied by self-harming, conversations about suicide and plans to harm other children. It was the utmost priority for parents that their child’s needs should be understood so that they could develop strong emotional and mental health:

“I am most concerned with strengthening them, encouraging them and protecting them from a negative impact that either the diagnosis has or not having a diagnosis has.”

Impact on the family

Although only four parents initially mentioned the impact of the process on parents, carers and family, the impact on the family was a strong theme in the ensuing discussions. As parents focused on overcoming ineffective communication between and from professionals, and sought to drive the process themselves, a number of costs became apparent. The first of these concerned finances and time. The need to avoid delays in accessing medical and educational support for their children meant that some parents sourced and were funding these services themselves; including Occupational Therapy, Speech, Language and Communication therapy, Behavioural analysis, Specialist Health Treatments, Academic tutoring and Educational Psychology assessments. In addition, many parents/carers had taken part-time hours or left work completely to meet the needs of their children. This was necessary to home- or flexi-school their children. Six parents had more than one child with autism, including various co-occurring difficulties, and five parents had multiple children with diverse diagnoses. Some of these parents had reduced their working hours or left work completely because of having to attend various medical and educational appointments with their child in a working week and also to ensure that they had the energy and time for their children, with and without SEN. This was not always feasible. The challenges for single parents in ‘juggling’ the demands of the process were also identified. Some parents expressed concern that, as a result of the new DE guidance to schools on categorising children with SEN, their child would no longer be seen as having SEN and would no longer qualify for Disability Living Allowance, adding to their financial burden.

These constraints of time and finances were noted to have had a negative impact on relationships within the family. In addition to losing out on time and academic support from their parents, siblings were also under pressure to support their brothers/sisters with SEN:

“I think support of siblings is a huge area that we’re going to see the backlash from because so much parental focus and services is placed on the child in focus that the other children are missed.”

In one extreme case, a child had to monitor his brother for self-harming:

“He was always cutting at the back of his legs where you couldn’t see it and then you would have seen the blood running down his legs into his socks... He relies heavily on his twin brother which was putting stress on his brother and the teacher.”

Another issue raised was the lack of trust in parents/carers from professionals and professional organisations. Accounts of parents being accused of being over-protective, of causing or exacerbating the educational or behavioural difficulty or, more seriously, unjustifiably reported for child abuse or Munchausen’s Syndrome by proxy, resulted in parents being removed from the home. This left a remaining parent to manage the family alone. It is unsurprising that a number of relationships had ended in separation or divorce and that arguments between partners had resulted in further isolation within the family unit. Some parents further explained that either they or their spouse/partner were autistic and that this added complexity to their struggles.

Parental mental health

It is unsurprising that fatigue, sleep deprivation and stresses on physical health have impacted the mental health of parents and carers. The majority of parents/carers noted being emotionally overwhelmed:

“I cried in front of those people and I actually went to the bottom of the hill and I sat in the car with my head on the steering wheel and I cried for 40 minutes and I’m not a crier, I’m definitely not a crier.”

However, many parents expressed mental exhaustion; at being over stretched and at

breaking point:

“I personally am highly anxious and I’m highly vigilant and my brain is on overdrive, I’m like with 6 tabs open and I’ve no clue where the music’s coming from most of the time.”

For two of the parents, efforts to achieve recognition of need and support for their child resulted in a breakdown or self-hospitalisation.

Theme 4: Access Arrangements and the Child’s Experience

There was clearly a diversity of approach and experience evident. The single most positive factor, resulting in a satisfactory or positive process and appropriate access to services, was an early diagnosis for the child. This was most commonly linked to medical situations (e.g. where there was a physical disability). While a minority group, these parents demonstrated the value of an early diagnosis as their views of the school experience were the opposite of those without an early diagnosis. There were a small number of examples where complex needs were not immediately apparent in the diagnosis of a child’s condition, or, where the diagnosis was incorrect and later rectified, resulting in children’s experiences being negatively impacted.

By contrast, the majority of the groups and parents represented children with late or no diagnosis, among whom were a significant number of families who had been involved with the procedure for many years (up to five years or more). Many of these children were still without appropriate access to services. These were mainly families of children with conditions such as Asperger’s Syndrome, Autism or ADHD or specific social, emotional and associated learning needs, but some were parents of children who had other learning related difficulties and/or co-occurring difficulties e.g. children with dyslexia, dyspraxia and other anxiety or behaviour related difficulties.

A significant number of parents in these groups strongly voiced their opinions in relation to the need for more professional staff to carry out assessments/ diagnostic tests and,

interestingly, many were already bridging the gap with the support of either private services (where they could afford to do so) or charitable or private organisations to help them to present their case for access to services with an independent diagnosis / assessment. Many of the responses reflected parental experiences of engagement with the Education Authority and other agencies involved in the process. Often parents were aware of where the responsibility lay for resource requirements, access related issues and/or associated delays, but often parents also criticised school staff, who were inevitably associated with the process, albeit often outside their control. Some parents felt schools were not doing enough:

“My son has absolutely no support and up until Christmas didn’t even have an IEP in place despite having his autism diagnosis and they [the school] are fully aware of that but because he is smart it’s you know he can keep up”

“Not actually understanding what you need [reference to teachers and SENCOs]...sensory overload. He had a 45-minute meltdown with pokers banging doors”

Parents/carers also referred to the poor access to services, and long waiting lists, which resulted in some paying for private assessments:

“Because our son is not the classic autism, [he] is social.... so that immediately for our colleagues here, ... immediately puts you out of the autism diagnosis. We had report after report of problems, things just wouldn’t work, strategies wouldn’t work so we had the resource and we went private [for a diagnosis].”

“We paid for a private Educational Psychologist [assessment] because he wasn’t seen through the school. We had to pay for a private OT driving an hour there and back. There was only one OT that would do private for children because the community OT just kept sending us on parent training courses knowing we’d actually see him. We were referred to paediatrics when he was in P2 and we had an assessment where we came into the room and the doctor laughed at him when he came into room... laughed at him writing his name... laughed at him

drawing himself...mocked the child throughout the interview. That was our experience.... So actually, really...we are [now] really anxious about going back into the system because we haven't had a good experience so not good...and anyone that has been good we've paid £85 per hour and driven an hour and back to see them".

For some parents, there was a lack of support from the class teacher:

"Timeframe... everything sort of went against us. [He] didn't get the statement until this year, you know, it was just that we applied for it again after the failure and [the child] didn't get it again... It's just frustrating that the teacher you're supposed to be depending on can't guide you through anything, you're having to find out everything yourself and second guess her."

In other cases, the lack of available support resulted in parents having little option but to move their child to another school:

"We as parents got a really hard time, there was no support whatsoever, it was all about you need to try harder, you need to be stricter, you need to be firmer until eventually the grammar school fell apart and we had to move her..."

For other parents, the only solution was flexi-schooling:

"My experience of accessing services.... so I am a primary school teacher... so it was quite hard seeing my children struggle and not get the support....that I know the school I had worked [had given]...My husband and I took [the child] to be assessed privately before she went into P5 [having raised it with school in P1] and that's the only reason that she actually got assessed by the educational psychologist for the board in P5 but by that point she was two marks above in her reading [due to parental support at home] so she missed out on support. She was the lowest quintile for her maths but they have no support for maths, so she's basically gone through all her primary school not getting any additional support. Last year, I decided to take [children] out of the school and I flexi-school them... I only wish I had done that earlier."

Theme 5: Primary / Post Primary School Differences

Respondents discussed their views of school experiences and of working with the Education Authority, the Department of Education, and Health as well as other agencies or support services. Many parents had children who were in nursery or primary education while others had gone through those years and also discussed their current experience of post-primary education. Differences in primary and post-primary were discussed and focus group responses demonstrated that a disparity exists.

Parents of post-primary children often spoke of the need for support and access to services, particularly where their child had not received appropriate support during their primary schooling. The larger size of most post-primary schools and the extended role of many SENCOs also emerged as a factor in accessing school-based services for the child. This was not universally the case however and it would seem, from the majority of respondents, that the level of support depended on the school's awareness and understanding of particular special educational needs. For instance, it was found that some needs (e.g. medical needs or severe ASD) were better understood and supported than other needs (e.g. ASD, ADHD, SEBD, dyslexia, dyspraxia).

The parental accounts highlight that, where a child's needs are understood within post-primary schools, there is more likelihood that the school response will be supportive. Once again, the medically diagnosed needs were better understood and better supported in most schools (as in primary schools), and where there was an early diagnosis in place, access to services was, in most instances, a positive experience.

Prevalent special educational needs, particularly those without statements (e.g. ASD, ADHD) were once again more often dealt with either within the school resource, which may be greater than in primary settings, yet, without appropriate access to services or referral agencies. The responses were themselves diverse in relation to why this was the case. It would appear that the lack of awareness and understanding of the particular need

or condition was the main cause. In primary schools, by contrast, the delay in accessing an initial referral and the decision-making process over resources seemed to be major problems. Even where there was a statement in place, because it had arrived late, or the parents had had to fight for the outcome, there remained difficulties for the majority of parents/carers in accessing services.

Theme 6: Working with Multi-disciplinary teams

It is clear from the focus group interviews that the SEN process works best when there is a joined up approach to the initial assessment, the diagnosis, the implementation of support needs and the ongoing monitoring procedure in support of the child's and family's needs. In the majority of cases, where parents reported a positive, supportive, transparent experience, it was very apparent that the condition was medical and the procedure for support had followed a robust, early diagnosis of needs. For the majority of parents/carers in the focus groups, however, this was not the case. Those receiving early diagnosis had received medical interventions from an early stage in the process and, for most, from an early age, whereas most of those with more complex (often emotional, behavioural or learning-related) needs were without diagnosis for some time, if indeed the diagnosis came at all. A concerning number of respondents remained in the process without diagnosis and reported that the needs of their child remained unmet across primary and post-primary schools.

For the participants who had received a diagnosis for their child, albeit late, it was also concerning to hear that there remained many challenges in terms of accessing multi-disciplinary support and/or failings in terms of the level of communication across, and, between teams of professionals: school, the Education Authority, DE and, in a small number of instances, the Health and Social Care Trusts.

Many difficulties reported stemmed from poor verbal communication and/or a lack of contact and transparency in the procedures and written communications. There were

many reports of instances where a child's assessment report was incorrect or misrepresented.

Parents/carers spoke of many different challenges including: inadequate and/or unprofessional levels of communication with the Education Authority; reports with errors or incorrect names [for the child]; changes to the wording after the final report was agreed with the family; a lack of transparency or clarity in the process; being passed to and from between different professionals; a sense that pieces of paper were "flying everywhere"; delayed timeframes with knock-on effects on the child and family; inadequate reviews of the quality of their child's Individual Education Plan (IEP); a lack of opportunity for the voice of their child to be heard; poor transition planning between schools and colleges; and being passed from one agency to another.

Theme 7: Barriers and Obstacles

Fundamentally, the groups all agreed that the paperwork and stages involved in the process were exacerbated where there was a late and/or inaccurate diagnosis of the child's needs, or no diagnosis at all. Complaints focused on paperwork difficulties, the lack of support for initial assessments at school level, the unsatisfactory handling of the procedure and associated enquiries, and the lack of transparency throughout the process. Difficulties were linked to accessing support e.g. access to occupational therapists, access to behavioural support teams, access to specialist aids and resources. Alarming, this also pertained in a minority of cases where the diagnosis and statement were in place, but where the child had still not received their statutory support. Whilst not exclusively the case across all groups, it would appear that girls often fall into this category:

"My daughter is 14 and she was diagnosed at the end of first year with ASD and she was diagnosed this year with ADHD... Girls get lost sometimes in the system because no one knows what to do with them, so we've had to take some very 'out of the box' types of therapy that other people sometimes look at me and go 'you are doing what?' but it keeps her in school

and she is highly intelligent. She has just 70% attendance at a grammar school and she is still hitting over 90s in her subjects...”

Children with dyslexia appeared to be particularly vulnerable in terms of the family’s ability to access either an assessment (referral) and/or diagnosis of need. The obstacles presented among this group of parents/carers included having the child assessed, the ‘test score’ itself and the overall resource available to support the need at school level. The role of the SENCO was predominantly highlighted as a problem in terms of accessing assessments and in many cases in terms of access to services. Even where families accessed help externally, financing their own assessments, there was little change in terms of access:

“My husband and I took her to be assessed private the summer before she went into P5... but... by that point she was two marks above in her reading (due to parental support) so she missed out on support.... However, she was the lowest quintile for Maths but they (the SENCO) have (offer) no support for Maths, so she’s basically gone through all her primary school not getting any additional support.”

In some cases parents/carers spoke of very small, yet significant obstacles caused by a lack of awareness or understanding among school staff (including SENCOs) which made it difficult for their child’s needs to be met in school. For instance, where a child simply required information about mealtime routines at school, or required access to facilities or needed school staff to be more aware of their child’s difficulties with social communication and interaction:

“Really, really simple things that aren’t always thought of.... when they start a new school, secondary school, especially when they are supposed to be independent...simple things like someone showing them where a toilet is, you know, on the way past the dinner hall... the door from the right... they don’t have one to one, they [no longer] have anyone asking, ‘have you eaten, do you need to go to the toilet?’”

“I think it’s probably the case [at lunchtime] where [the child] is just sort of wandering around and you know, perhaps that is a good thing in that he’s sort of in [at] the deep end just having to make the best of the situation but he doesn’t have [the] social skills that the other kids have and I think it would be nice if there could be something, perhaps just the word that I’m looking for there is... ‘choice’, just something else other than break time football or yard time which relies on social interaction”

Recommendations from Focus Groups

A number of key recommendations were made by the parents/carers in the focus groups, when asked how they could improve the SEN system.

Recommendation 1: Listen to the voice of the parent and child

In their discussion of communication from and between professionals, parents emphasised the importance of being listened to. While parents accepted the expertise of professionals from education and health, they raised concerns that understanding and diagnosis of the child’s needs and their recommendation of services and resources should not be based purely on clinical observation but should be viewed more ‘holistically’ in light of the wider history of the child’s responses, and, crucially, should be informed by valued, trusted parents:

“Give parents a voice in the process, a meaningful voice, we know our children best as mummies, they know them in other professional realms, but parents need a voice.”

The importance of building a valued and trusting relationship between parents/carers and professionals was seen as essential to an effective assessment of their child and to parents’ confidence in the process:

“Maybe them getting to see you as a person and know you, maybe having that chance to meet with a parent because I feel when I phone into the Education Authority, the health professionals were quicker and more helpful.... they are not telling lies, they are telling the truth...but it’s as if the Education Authority don’t even want to read your information or know,

it's like oh, it mightn't even get looked at you know..."

It was interesting that parents/carers who had the most positive experiences felt that their views had contributed to assessments. They also emphasised the need for the child's opinion to be listened to. At a fundamental level, this was seen to be the responsibility of the teacher:

"He [child] has said to us that she [class teacher] puts words in his mouth. So, she basically will tell him why he feels the way he feels instead of asking him why he feels the way he feels. That's how he describes it."

However, the right of the child to be heard by all concerned was also noted:

"I think our children have a voice and should be listened to as to what they need from the education system and from their parents and from their teachers and I think that's something that could be introduced as well as a children's advocacy to hear their voices."

"Start listening more to the child as they tell us what school is like for them. And we need to stop punishing and give more support".

Recommendation 2: Compulsory training for school professionals

The need for more training for all professionals was discussed. Parents/carers described experiences where a lack of understanding of divergent processes in health and education and a lack of training in specific medical needs and SEN had slowed down or over-complicated the process leading to inappropriate or delayed diagnoses or provision:

"The whole thing is a minefield...if the school was a good school with the right expertise or the right access to expertise and the right advocacy within that school for the parents, that would solve a lot of the problems..."

Newly qualified teachers and more recently appointed principals were viewed as more informed and empathetic, however, parents/carers suggested that more experienced teachers and principals had not had the training required to recognise specific SEN and meet the needs of children in the classroom. Parents/carers who were themselves primary or post-primary teachers explained the complexity of the task teachers face as they try to meet the needs of an increasingly diverse classroom, with insufficient training and

resourcing. One parent described more recent training from EA as ‘wishy-washy’ and explained that, even if training was free, lack of funding for supply cover was impacting teachers’ ability to attend during school hours.

Many parents/carers also queried the qualifications of current SENCOs/LSCs:

“I think for the SENCO, there’s more training required. Because I think if they come into the job as a SENCO, with no training... it’s like the blind leading the blind. Because when we ask them a question, they don’t know the answer.”

Recommendation 3: Improved Services from the Education Authority

There was much discussion of the need for better communication with the EA in particular and greater transparency at all stages of the SEN system for parents/carers, many of whom felt isolated, confused and desperate to access support for their child. As a result, many spoke of their experience to date as a “fight” or a “battle”, an experience they found unsettling and stressful, but essential if they were to access appropriate support:

“It shouldn’t be a parent’s fight... at that stage...I had enough worries without a fight.’

Parents/carers recommended that there should be a specially trained EA advisor for them to contact who could talk them through the process, answer questions and provide guidance and reassurance.

In terms of EA services, parents/carers spoke too of the need for earlier intervention, of more realistic timescales to meet children’s needs and for equal treatment of children with ‘visible’ and ‘invisible’ difficulties e.g. children with medical difficulties were perceived to receive support more readily than children with, for instance, dyslexia.

There were also some parents/carers who felt that services were unequally distributed across Northern Ireland. As one parent explained, the EA must ensure that provision is

“fair and reasonable through the North of Ireland”, while another complained that provision was disproportionately centred on Belfast meaning that for the EA “life past Sandyknowes doesn’t happen!”

Parents/carers felt that staff in the EA required additional training too as decisions were being made by individuals without an in-depth understanding of specific SEN. Concerns were also raised that final statements were being drafted by untrained clerical workers who were unaware that certain phrasing was placing undue restrictions on the services which children could access after a long fight for provision:

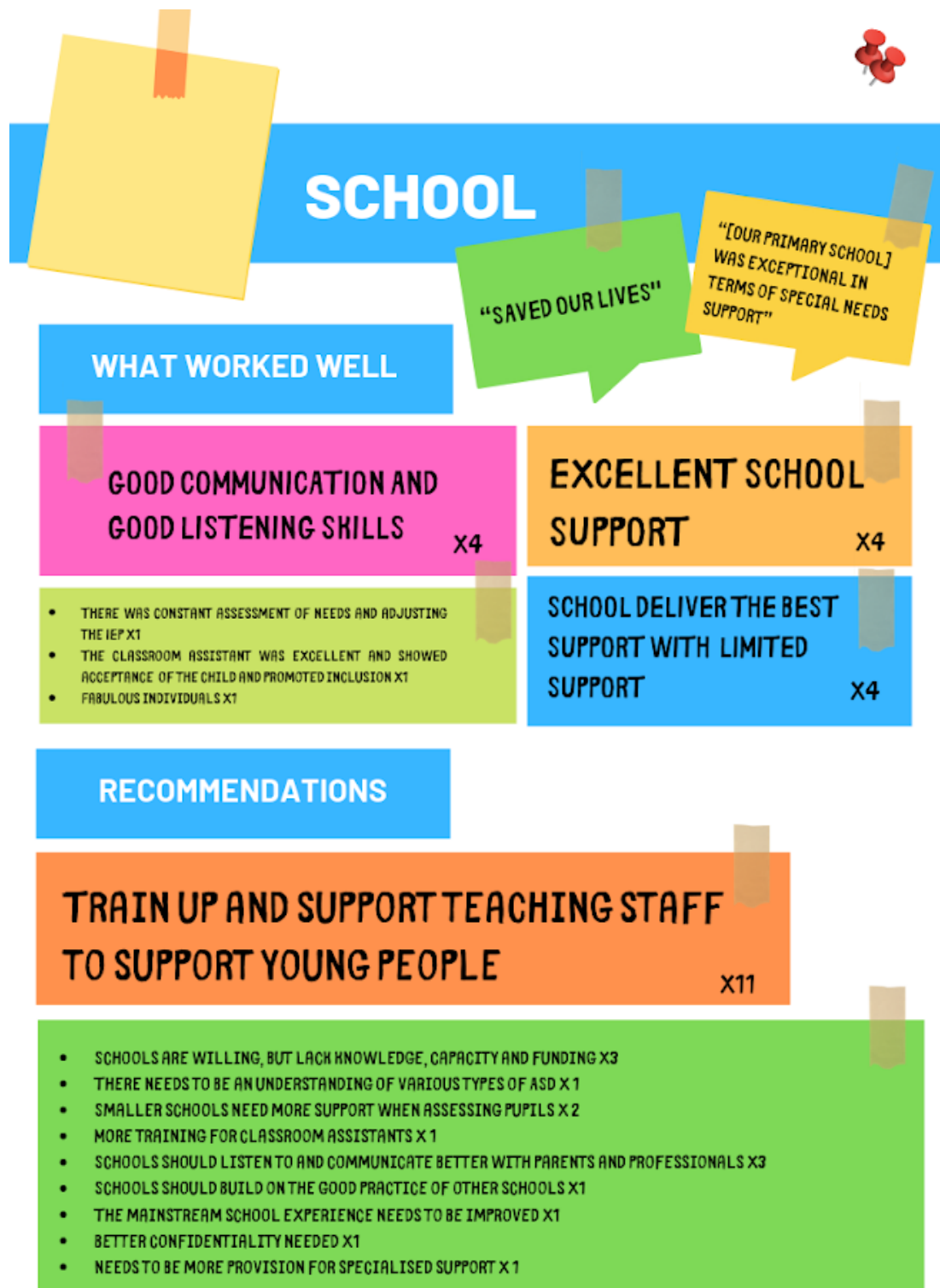
“There needs to be the support ... and everybody needs to sit down in one meeting and get their heads right and get help for that child in its life....”

In short, parents felt that the EA needed to become less focused on bureaucracy and more child-centred in its approach:

“The Education Authority would [become] more aware of the child’s needs rather than a child [being viewed] on a piece of paper....”

Focus Group Post-it Activity

The following pages provide a digitalised summary of the post-it activity that concluded each of the ten focus groups, including a note on the frequency with which comments were made. Parents/carers were asked to take as many post-it notes as they wished to express their feedback on what had worked well and to provide suggestions for improvement on each of the ten themes identified at the very start of the focus groups using the cue cards. These ten key terms were: (1) School (2) Education Authority (3) Health Professionals (4) Identification (5) Appropriateness of Support (6) Communication (7) Timeframe (8) User-friendliness (9) Impact on the Child (10) Impact on Parents/Families/Carers. While the key themes overlap with those of the online survey and focus group interviews, notable examples are included in the Discussion chapter below.



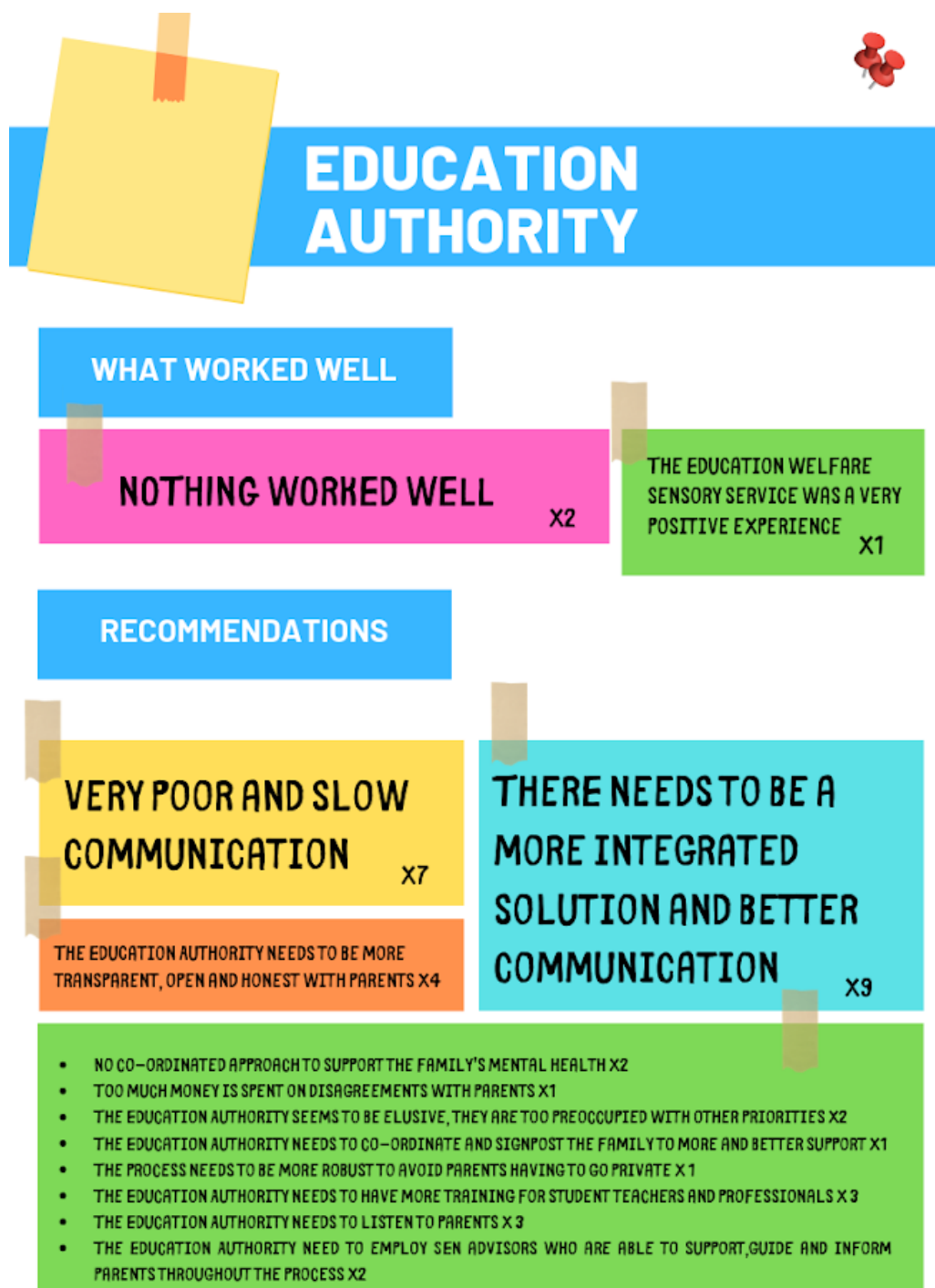
SCHOOL

RECOMMENDATIONS

- NEEDS TO BE MORE SUPPORT FOR CHILDREN WITH INVISIBLE DISABILITIES X1
- SCHOOLS NEED TO AVOID SUSPENDING PUPILS AND PROVIDE BETTER SUPPORT X1
- THERE NEEDS TO BE CONSISTENCY ON THE STAFF WHO LOOK AFTER YOUR CHILD X1
- SCHOOLS NEED TO PROVIDE MORE INFORMATION ABOUT THE ASSESSMENT AND ABOUT THE IEP TO PARENTS X3
- ALL CHILDREN WHO HAVE A NEED MUST BE ASSESSED, NOT JUST THE WORST ONES X 1
- THE SCHOOL SHOULD NOT ASK PARENTS TO SUPPLY VITAL EQUIPMENT NEEDED BY THEIR CHILD X1

**“STOP HIDING BEHIND
OUTDATED EDUCATION
POLICIES AND ADDRESS
THE NEEDS OF OUR CHILD”**

**“[SCHOOLS NEED
STAFF] WHO GO
THE EXTRA MILE”**





EDUCATION AUTHORITY

RECOMMENDATIONS (Contd)

- MORE GUIDANCE ON THE BEST SCHOOL FOR THE CHILD X1
- THERE NEEDS TO BE MORE INVESTMENT IN SUPPORT FOR DYSLLEXIC CHILDREN X1
- PERHAPS EMPLOY STUDENTS FROM THE UNIVERSITIES WHO ARE STUDYING DEGREES RELATED TO SEN X1
- THE EDUCATION AUTHORITY NEEDS TO ALLOW PARENTS TO REVIEW LETTERS AND LEAFLETS BEFORE PUBLICATION X1
- THE EDUCATION AUTHORITY NEEDS MORE STAFF, MORE FUNDING X3
- THE EDUCATION AUTHORITY NEEDS TO BE MORE PRO-ACTIVE FOR FUTURE YEARS X1

- NOT PERSON OR CHILD-CENTRED X1
- MORE CONSISTENT SUPPORT ACROSS ALL EDUCATION LEVELS X1
- IMPROVED FOCUS ON DIFFICULT CASES X1
- FAILURE TO FOLLOW THEIR OWN GUIDELINES X2

"IT SHOULDN'T FEEL LIKE
A FIGHT JUST TO MEET MY
CHILD'S NEEDS"

"NEED TO REDUCE
THE BUREAUCRACY
AND FOCUS ON THE
CHILD'S NEEDS"

"EA IS NOT FIT
FOR PURPOSE"

"STOP THE EXCUSES,
HELP PARENTS NOW"

HEALTH PROFESSIONALS

WHAT WORKED WELL

THERE WAS A GREAT UNDERSTANDING OF NEEDS AND IMPACTS

X1

ALTERNATIVE THERAPY SUCH AS MINDFULNESS WAS HELPFUL

X1

HELP FROM CHARITABLE ORGANISATIONS SUCH AS FORWARD STEPS AND BARNARDOS

X2

POSITIVE EXPERIENCE AT RISE NI (EDUCATION AUTHORITY)

X1

GP LISTENED CAREFULLY AND TOOK ACTION

X1

GOOD EXPERIENCE WORKING FROM NON-MEDICAL ORGANISATIONS, EG. CAMHS AND EOTAS

X1

RECOMMENDATIONS

BETTER INTEGRATED REPORTING STRUCTURE

X8

- NEEDS TO HAVE MORE GUIDANCE AFTER A DIAGNOSIS IS GIVEN (X1)
- WAITING LISTS NEED TO BE REDUCED (X1)
- BETTER COMMUNICATION NEEDED (X2)
- MORE ROBUST REFERRAL SYSTEM NEEDED WITHOUT THE NEED FOR A PRIVATE ASSESSMENT X1
- A CLEARED AND DEFINED AND SYSTEMATIC INTERFACE X1
- IMPROVED CONSISTENCY AMONGST HEALTH PROFESSIONALS X2
- IMPROVED MENTAL HEALTH SERVICES X1



IDENTIFICATION

WHAT WORKED WELL

**IDENTIFICATION OF NEEDS AND
IMPLEMENTATION OF IEP**

x1

**ATTACHMENT NAMED
ON THE STATEMENT
WAS HELPFUL**

x1

RECOMMENDATIONS

**EARLY INTERVENTION FOR CHILDREN
WHO ARE NOT REACHING DEVELOPMENT
GOALS**

x6

**CLEARER CRITERIA
FOR IDENTIFYING
DYSLEXIA**

x1

**ALL TEACHERS SHOULD BE
ADEQUATELY TRAINED**

x2

TO BE ABLE TO ACCESS ALL SERVICES

x1



APPROPRIATENESS OF SUPPORT

WHAT WORKED WELL

OUR PARENTS ARE AN
EXCELLENT SOURCE
OF SUPPORT

GREAT SUPPORT FROM
MIDDLETON AUTISM
CENTRE

THE SUPPORT FROM CHILDREN'S LAW CENTRE WAS GREAT

RECOMMENDATIONS

MORE SUPPORT AND INFORMATION
SHOULD BE AVAILABLE TO PARENTS X3

"I OFTEN FEEL
ALONE WITH
THE SYSTEM"

THE SUPPORT NEEDS TO BE IMPLEMENTED QUICKER X1

PARENTS NEED TO BE DIRECTED TO SOURCES OF SUPPORT X1

COMMUNICATION

WHAT WORKED WELL

THERE IS EXCELLENT AND POSITIVE
COMMUNICATION WITHIN THE
HEALTH CARE TEAM

X1

COMMUNICATION
WITH THE CLASSROOM
IS INVALUABLE WHEN
ISSUES ARISE

X1

RECOMMENDATIONS

CO-ORDINATION AND COMMUNICATION
NEEDS TO BE IMPROVED BETWEEN
PARENTS AND SERVICES

X12

- COMMUNICATION NEEDS TO BE EASY TO FIND, DIGITAL AND TIMELY X2
- DATA PROTECTION NEEDS TO BE CLOSELY MONITORED X1
- THE EDUCATION AUTHORITY NEEDS TO BE MORE HONEST AND TRANSPARENT X2
- THE MENTAL HEALTH OF ALL CHILDREN NEEDS TO BE ADDRESSED IN THE EARLY STAGES X1
- PROFESSIONALS NEED TO LISTEN TO PARENTAL CHOICE AND RIGHTS X1
- CORRESPONDENCE FROM THE EDUCATION AUTHORITY NEEDS TO BE SIMPLIFIED X1
- THERE NEEDS TO BE MORE COMMUNICATION TRAINING FOR EVERYONE IN THE PROCESS X1
- COMMUNICATION NEEDS IMPROVED BETWEEN SCHOOL AND HOME X1
- THERE NEEDS TO BE CONTINUITY IN THE PROCESS X1
- IT WOULD BE HELPFUL TO HAVE AN ADVOCATE TO GUIDE YOU THROUGH THE PROCESS X1

"COMMUNICATION
NEEDS IMPROVED, IT IS
VERY POOR FROM EVERY
ASPECT



TIMEFRAME

WHAT WORKED WELL

RECOMMENDATIONS

**PROCESS NEEDS TO MOVE FASTER FROM
INITIAL CONCERNS TO DIAGNOSIS**

X12

POOR COMMUNICATION

X1

**NEEDS MORE STAFFING
TO COPE WITH WORKLOAD**

X2

NEEDS SIMPLIFIED

X1

MORE EARLIER INTERVENTIONS

X1



USER FRIENDLINESS

WHAT WORKED WELL

SENAC HAVE BEEN INVALUABLE AS A SOURCE
OF SUPPORT AND GUIDANCE

X1

RECOMMENDATIONS

THE SYSTEM NEEDS TO BE MORE USUAL
FRIENDLY AND LESS DIFFICULT TO NAVIGATE

X6

CHILDREN NEED TO BE LISTENED TO
THROUGH EVERY STAGE OF THE JOURNEY

X1

THERE NEEDS TO BE CLEARER
GUIDELINES AND EXPECTATIONS

X1

THERE NEEDS TO BE MORE TRANSPARENCY
WITHIN THE PROCESS

X1



IMPACT ON THE CHILD

WHAT WORKED WELL

**CLASSROOM ASSISTANTS
WERE KIND AND HELPFUL**
X3

**TEACHERS WHO TALK AND LISTEN
TO THE CHILD ARE WORTH THEIR
WEIGHT IN GOLD**
X2

**PRINCIPALS ARE LOOKING
OUT FOR THE PUPILS**
X1

RECOMMENDATIONS

**MORE MENTAL
HEALTH SUPPORT**
X3

**MAKE SURE THE CHILD HAS
THE CORRECT SUPPORT AND
TREAT THEM AS INDIVIDUALS**
X2

- MORE POSITIVE REPORTING (X2)
- TEACHERS NEED TO UNDERSTAND THE CONDITION (X1)
- MORE PUBLIC AWARENESS OF THE IMPACT ON THE CHILD (X2)

- THE CHILD NEEDS TO BE A CENTRE OF EVERY DECISION (X1)
- A MORE HOLISTIC APPROACH IS NEEDED (X1)
- MY CHILD IS A PERSON — NOT A NUMBER (X1)



IMPACT ON PARENTS/FAMILIES/CARERS

WHAT WORKED WELL

RECOMMENDATIONS

**CHILDREN NOT GETTING
PROPER SUPPORT**

x5

**FRUSTRATIONS
TAKEN OUT IN
THE HOME**

x2

LACK OF TRUST

x1

AFFECTS RELATIONSHIPS

x1

ANGER

x1

TRAUMATISING

x1

**PARENTS NOT
BEING LISTENED
TO**

x2

SECTION THREE: CASE STUDIES

CASE STUDY 1 – Cathy's story

Cathy's 14-year-old son, Tim, is an intellectually capable child who has successfully transferred to a grammar school post AQE, however from before he started formal schooling there were parental concerns regarding Social Emotional and Behavioural difficulties (SEBD). Matters were further complicated by a younger sibling being diagnosed with a rare illness. The family felt the behaviours initially may have been influenced by this situation. As Tim progressed through his primary school years, things became increasingly difficult with little credible support from the school. Following her son's transfer to post-primary education Cathy felt things began to improve with the school being increasingly supportive, willing to listen to her as a parent as well as implementing a number of strategies to support Tim. Finally, at the age of 12, Tim was diagnosed as suffering from Auditory Processing Disorder alongside ADHD, which it was felt contributed very much to his SEBD. Despite the support of the grammar school the situation deteriorated to the point that he became a school refuser. Cathy is currently in the process of moving Tim to a non-selective secondary school outside her local area in order to access the support of a particular EA Link service which, although perfect for his needs, would not be made available to Tim if he remained in his current school.

"My son's difficulties were evident from an early age and prior to starting formal schooling there appeared to be Social, Emotional and Behavioural difficulties. My younger child had a complicated medical condition which had a major impact on our family. After discussing concerns with my health visitor, we agreed that a wait and see approach would be best. Tim enjoyed a relatively successful P.1 year. By P.2 the difficulties were becoming extreme and this was largely the case throughout primary school except for two teachers, P.3 and P.5, who had carried out personal research and drew upon their previous

experiences. Unlike many, these teachers had a proactive approach to Tim's difficulties and their specific strategies succeeded. The school SENCO meticulously attended to all the paper work, however, I would say it was a mechanistic approach. The majority of teachers in the primary school had a reactive approach to his behaviours and the principal told me "my staff don't have time for this." I felt that unlike literacy and numeracy difficulties, Tim was not identified as having a special need. The school believed his behaviour and actions were a choice he was making, which made it very difficult to pursue statementing. He was told that the primary school had never had a more badly-behaved child, a conversation he still recalls. After the primary school's approach appeared to be fruitless, a private assessment identified Tim's Auditory Processing Difficulties. It was transformational to be believed by another professional and begin to decipher reasons for this behaviour. In his final term of P.7 Tim mentioned the need for a fresh start which is very sad for a child of that age.

Following completion of AQE and successful entry into grammar school, from the outset, the school could not have been more positive. As a parent it was reassuring to be supported in trying to ascertain more fully reasons for his unwanted behaviours. The SENCO in grammar school ensured that Tim had access to a counsellor and, for support, connected us with another family who had gone through similar circumstances. By the second year of grammar school Tim was also diagnosed with ADHD. I recall someone at the time commenting that he should have met the system sooner.

With regard to the process I feel strongly that the ethos and the approach of a school makes a huge difference. While the primary school was quite traditional in its outlook, conversely, the grammar school staff accepted that pupils could exhibit a wide variety of spectra. The pastoral care of the grammar school alongside working closely with us as a family eventually led to my Tim's diagnosis. My experiences of accessing help for my son have therefore been both positive and negative.

The process itself was also far from straightforward. Tim was on Stage 2 of the special needs register from P2 to P7. On numerous occasions I asked for him to be removed from the SEN register if his needs were being met, or to keep moving him through the process. I was informed he had no need to progress further and that the school were using educational psychologist appointments for children with literacy and numeracy difficulties. This resulted in a delay to statementing. From the first year of grammar school Tim was much happier. He recognised that the school were supporting him and that he was receiving help. From the time of formal EA involvement, I was greatly relieved, as other professionals were having an input. Most staff in the EA were helpful and supportive. The educational psychologist who assessed Tim as an intelligent child with complex and significant difficulties, actually listened to him which made a very valuable contribution. The grammar school also listened and provided him with one to one classroom assistant support, covering the funding for this themselves. Unfortunately, Tim continued to exhibit difficulties regarding SEBD and despite the support of the school his inability to concentrate was detrimental to his academic work. His anxiety also increased around specific classes and particularly regarding assessment. The school were extremely supportive and enabled him to complete exams at home. Despite all of this Tim is currently a school refuser.

Although we received immense support from the grammar school and aspects of the EA, I have nonetheless found a lack of communication, coherence and clarity between the various EA regions and services. Through self-research I became aware of a specific service tailored for children like Tim, which can offer much needed support in terms of school anxiety and reintegration into a school setting. Although an EA organised service, it is only available in some regions and not for children attending grammar schools. Despite the need and the fact that this service has achieved 'outstanding' from ETI, it appears to be limited in availability. This prompted our decision to transfer Tim to a local secondary school in order to access this service. As his school move has resulted in a

move of EA region this has in turn, created a prolonged delay in Tim's accessing the required help in what should have been a smooth transition.

Evidence of further disconnection within the system was apparent by the fact that I was the main conduit of communication between the health and educational professionals regarding Tim's progress. Even though Tim eventually received his statement, I spent many nights in tears of frustration, searching the internet for services offering support for the difficulties he exhibited.

I would wholeheartedly recommend that schools listen to parents. Schools should also ensure staff training regarding identification and treatment of children with SEBD. The youngest children exhibiting SEBD would benefit from nurture rooms with qualified staff. Increased assistance should also be given to schools regarding children exhibiting SEBD without having to endure the protracted process of the statementing route.

As a parent of a child going through the statementing process, I welcome the current major review of the reduction of the statementing stages, however, I have at no time been informed by EA that this is taking place.

In my communication with the EA, my place of work was very supportive, and I often wondered how other parents with less flexibility in their working day would be able to access EA services out of hours. I would also recommend that EA look at accelerating the statementing process as a whole with identification and testing sooner rather than waiting for a child to underachieve through numerous IEPs which can also have detrimental effects on an already struggling child's self-esteem.

Regarding health recommendations, it might be valuable for specialist nurses to be placed in each EA region as a point of contact for schools and could assist with frontline support strategies as well as enabling schools and parents to make medical referrals.

Around the area of family support, I would recommend support for siblings of children exhibiting SEBD. From a family context this would have been very beneficial for my younger children. The EWO mentioned referring us to a Family Help Service. To date I have had no contact from this service. Tim remained at home from Easter to the end of the school year and I am hoping with the help of the specialised service, he will be enabled to reintegrate successfully into his new secondary school."

CASE STUDY 2 – Helen's story

Helen's daughter Katie was born profoundly deaf and from a young age had cochlear implants. From the time of Katie's diagnosis, Helen and her husband engaged fully with the National Deaf Children's Society (NDCS) and described the support of this charity as a vital part of their journey. Helen was determined to have everything in place to ensure her daughter accessed all of the help regarding school and education that was available to her. Helen and her family had a very positive experience with the charity advising and informing them at every stage and well in advance of everything Katie required. This, together with the support of the teacher of the deaf, effective liaison and regular communication with the staff at Katie's school resulted in a very positive experience for them all. Training sessions were provided for the school staff with audio equipment in place before it was required. There was very clear liaison between the health and education services as well as all the personnel involved. This resulted in Katie enjoying a very profitable, successful and valuable time throughout her years in primary school. True to form, as Helen's daughter approaches Year 7, the charity is assisting the family in preparations for the transition to secondary school.

"My daughter, Katie, was diagnosed as profoundly deaf from birth, which was very overwhelming and daunting for me as a new mum, however, throughout her journey, we have had a very positive experience. We attended their parenting course alongside various weekends and from quite early on the NDCS provided excellent information regarding the SEN process. Their support enabled me to approach all of the professionals involved in Katie's statementing, for example, the paediatrician, teacher of the deaf and speech therapist. We were able to obtain reports for all of these people from the implant centre and, due to this, Katie progressed smoothly through the statementing process. We had Katie's official assessment carried out in her pre-school year which meant we were ahead of the game. From the outset I felt it was important to have her statement correct to

ensure that all of Katie's needs were being supported. When Katie's statement first came, I asked for it to be reviewed with specific hours as these had not been initially quantified. When she progressed to Key Stage 2, I asked for her statement to be updated with increased hours of one to one support and these were granted. Now we are heading to transition and I am currently preparing for this. Katie will have another psychologist's report in this her last year of primary school and this will help to pave the way for a smooth transition and effective support throughout her secondary school years.

Having everything in place before a deaf child starts school is very important and we found joining support networks very early on was vital. The NDCS are passionate about supporting deaf children and at the forefront of their campaign is removing barriers for deaf children. I know that every child with a need does not have a support group as dedicated as this and again children can have a range of needs that cross the barriers of different charities, but I don't think we would be at this point right now if it wasn't for NDCS. The charity has a family support officer that will visit the child's home and give unlimited support and advice. They are available to assist with completing all forms, which in itself can be a daunting process. All of this could easily affect the mental health of the parents of a child with special needs, especially with what can be a long, slow and draining experience. NDCS made all the difference. They held our hands, and although slow and long, reminded us that it was well worth it for Katie; their support system kept us going. The NDCS also informed us recently that there were changes coming within the SEN process, moving from a five to a three stage process. With their help we are currently making preparations for Katie's transition to post-primary school.

The teacher of the deaf and Katie's primary school worked very well together and were very supportive. Her one to one support was fantastic providing realistic assistance without being intrusive. The teacher of the deaf liaised with the one to one support and the class teacher, accessing copies of the teacher's planners in advance which assisted in supporting Katie's class work during her withdrawal sessions. The class teachers were

specifically trained regarding Katie's needs before each new academic year and the teacher of the deaf ensured all of the audio equipment required for her cochlear implants was installed in each classroom well in advance of the new school year.

The primary school were very supportive from the outset and put systems in place to allow Katie to settle in quickly. From her one to one support I had a report of each day. This was also useful for me to reinforce her learning at home. There was always open communication between home and school and if I ever had queries, I knew I was able to approach the school at any time. School also worked closely with the teacher of the deaf and myself in providing evidence to strengthen my request for extended one to one support when Katie entered Key Stage 1. This helped greatly with the care of her portable hearing equipment at the end of each school day.

It is very evident that Katie is happy and confident in school. It has been very positive to see her in a mainstream school, being accepted, accessing the curriculum like any other child and blossoming in that environment. Yes, there have been little ups and downs in her confidence and blips along the way which have driven self-esteem and resilience, however I would say the whole experience in school has been very positive.

As parents it is important to get out there and access the information to help make the right decisions. I really cannot emphasise that enough. Although I would say with hindsight not to panic unnecessarily over timescales, it is more important to have the correct and best statement in place for a child's needs. The best source of support networks has been through the charity and talking to other parents: getting that peer to peer support has been vital. We as a family were also determined from the start to have a positive experience, which I think helped immensely.

I would strongly recommend that the various parts of the system, from home, school, health, EA and charities work together fully and successfully to meet the needs of each

child. Regarding health, we had a very good consultant who pointed us in the right direction at the right time. Training of professionals is very important. I don't think the educational psychologist we had was particularly aware of the needs of a deaf child and that could be difficult, so training regarding specific special needs, I feel, is very important. Educating these professionals who are the key decision makers in a child's journey can then in turn signpost parents to access the most appropriate services. This helps parents to build up an accurate picture of their child's needs which assists in the accumulation of vital evidence to ensure a smooth statementing process. In our area we had an excellent multi-disciplinary team who worked well and communicated effectively together. The funds were available to get the right support. We had Speech and Language support alongside the teacher of the deaf coming to our home and this all began when Katie was only three months old. Looking back, it was all so vital, and it really did shape our journey.

Now as a volunteer for NDCS, I want to support others and have sadly met parents who have not had the positive experiences we have had. Their joined-up systems did not work as successfully. Maybe there was a change of personnel within the various systems and this importantly highlighted a lack of continuity. These parents really felt they had to fight at every turn for their child's needs to be met. This is not acceptable. When the wheels fail to turn at the right time it can be an extremely difficult journey. I am very thankful that our experience was a very positive one and with the correct processes in place this can be the same for every child."

CASE STUDY 3 – Moira's story

Moira's son Kane was born with Down's Syndrome. Despite the shock of this diagnosis Moira and her husband wanted the best possible outcome for their son and almost immediately became involved in the Down's Syndrome support network. They were keen to engage with other parents whose children were Kane's age and had similar difficulties. They gained a lot of helpful information and support from Northern Ireland and throughout the world. This information was very valuable with regard to accessing health services for their son. Following encouragement and recommendations they sent Kane to a mainstream nursery school where he had a very positive experience. Despite the positives, due to Kane being largely non-verbal, they realised the best placement for their son after nursery school would be a special school. Although asked by the EA for their decision, they entered into a very difficult two year period where they were informed by the special school, that Kane did not in fact have a place in the school of their choice and in fact no special school. They were also informed by the EA that they had declined such a place, which had not been the case. The nursery school readily agreed to have Kane for a second year to provide support, continuity and to afford the family extra time to find a place for Kane in their school of choice. Their second year was not without its trials. They have been informed by the EA that a place will be available. The school, however, has not confirmed this. They are hoping that the new school year will see Kane attending, albeit a year later than anticipated, the special school of their choice.

“When my son Kane was born with Down's Syndrome, I immediately wanted the best for him, and joined a Down's Syndrome support group soon after he was born. This enabled me to meet other parents and children of a similar age to Kane while obtaining sound advice and information. I also joined special needs mums and toddlers' groups and accessed the Children's Law Centre. The charity signposted me to all of this. Hence,

when we attended our first Child Development appointment, we were well informed and able to request various referrals to the different departments in advance. Although there were positives, the overall health system lacked coherence and continuity. Our OT appointments came regularly, however Speech Therapy was quite erratic. During my son's first year at nursery school the new Speech Therapy programme previously proposed did not happen which resulted in Kane receiving very minimal Speech Therapy input. Being non-verbal, Speech Therapy is vital for his development. Following this I accessed private Occupational Therapy and Speech Therapy appointments. These worked very well together and provided Kane with excellent support, from which he made valuable progress.

Our experience of nursery school was incredibly positive. We made the decision to send Kane to a local mainstream nursery school which was outstanding in every way. I knew Kane would thrive in this wonderful environment and he did. The school were so inclusive, and the principal was meticulous in accessing support for Kane. Kane's classroom assistant was excellent, and I knew she really cared about my child, attending Makaton training and other events outside of school hours. Each day in Kane's home school diary I received details regarding his time in school. This was very valuable as Kane has developmental delay and it meant I could reinforce his learning at home. At all times the school provided excellent communication with home. They were so efficient at carrying out various roles which meant if any issues arose, they were dealt with sensitively, promptly and successfully. The fact that Kane was so happy at school and the environment so supportive, really helped us survive what was to follow.

The next part of our journey was not so positive. Dealing with the EA can best be described as a total disaster. When considering Kane's options for the following year, we realised that his specific needs would be better catered for long term within a special school. Kane's annual review took place in the January of his first year at nursery and at this point we informed EA of our plans to send Kane to a special school. We were told that

would not be a problem, Kane's statement would be amended accordingly, and we would be contacted in a few weeks. After waiting and receiving no communication from EA, I made contact with them. Each time I rang I was told it would be another few weeks. My calls were never returned, and I was often told the EA official dealing with Kane's file was unavailable. On one day in particular I rang 42 times before my call was answered. On another occasion the person taking my call hung up 7 times in the space of 30 minutes. As the nursery year progressed, we were becoming increasingly anxious regarding Kane's future. In the end I gave up ringing the EA and contacted the special school directly. The VP of the school, surprised that I had not been informed by EA, told me that my son did not have a place for September.

It was at this point that the principal of the nursery school, wishing to minimise the impact of all of this on my son, and with the support of the Board of Governors, agreed to take Kane for a second year. With hindsight this second year was very positive for Kane, adding to his successful development. The school again were outstanding.

Knowing how slow and difficult the process had been to date, before the end of Kane's first year in nursery, in desperation I contacted my MLA. The MLA was very supportive and arranged a meeting with senior EA staff. It was during this meeting where Kane's folder was opened and, written in large letters across the file, I read 'PARENTS DECLINED OFFER OF SCHOOL'. The Senior EA official knew by our reaction that neither my husband nor I had been informed of any of this and I assured them at no time were we ever offered a place in a special school verbally or written. How could it, therefore, say on my son's folder that we had declined the aforementioned place? The senior EA official assured us that this would be investigated, and that Kane would have a place in the special school of our choice.

Following this, I experienced a very difficult time with EA staff. On one occasion there was an incorrect name on my son's form, and on another occasion during a telephone

conversation, the staff member discussed another child's details with me, assuming I was the parent, despite my protests to the contrary. This staff member was then the one who attended my son's annual review in his second year of nursery school. Both the nursery principal and I were very surprised that this was the case.

Currently Kane is hoping to enter the special school of our choice. The EA have again told me this will happen. Following this I contacted the school to be told again that they did not have a place for Kane as the EA had failed to send the required paper work. A few hours after this conversation, I received a call from a senior EA official and was assured that my son had a place in this school for the new school year. I am currently waiting for confirmation from the school that this is the case.

It has certainly been a long and exhausting fight not to mention an emotional rollercoaster to get my son finally into special school. It did not need to be like this. A lot of our difficulties came down to a lack of courtesy, coherence and effective communication within and between services. Although my situation may be slightly more extreme, I am aware of many other parents who have also had difficult experiences when dealing with the Education Authority. At no time is it made clear to parents who they should contact within the EA and there is minimal information on their website. Parents should be able to access help for their children from the relevant people. I have been extremely shocked at how poorly managed and ineffective the EA performance has been regarding my son's case.

As a teacher I would also say that EA should provide more training within schools for professionals to enable the most effective support for children and their varying needs. Every child deserves the opportunity to reach their potential and teachers are frustrated by the lack of training which, if provided, would help them better support, on a daily basis, the children under their care.

A more efficient service with trained staff and clear lines of communication between services would ensure a smooth transition throughout their educational journey for all children regardless of their needs.”

CASE STUDY 4 – Paula’s story

Paula is a teacher and is a kinship carer to Karl (P6). Karl has Attachment Disorder and behavioural issues. External agencies have been into school to provide support and this has been positive for all concerned but Paula believes there is insufficient support generally. She is caught between health professionals, school and social workers. Early intervention has been difficult and finding the right school for Karl at post-primary is going to be challenging. Paula believes a more joined up approach is needed for Looked After Children (LAC) like Karl.

“When Karl went into primary school he had lots of social issues and the principal wanted to put interventions in place. So, the RISE² team came in and worked with him. They were good but it didn’t target him quickly enough. He still was having a lot of behavioural issues and ended up getting suspended in P3 which has had a really detrimental effect on him and he’s now petrified of getting suspended again. There was a classroom assistant put in place but there weren’t enough strategies taught to him and enough things to help him to overcome the specific issues that he was having. There wasn’t a lot of support given to the teacher in how to deal with him either, like how he could calm down. However once RISE came in they were brilliant. They worked really, really well with him but it’s half an hour a week. This is a child who is having major behavioural difficulties in school and he has Attachment Disorder. There was a lack of knowledge of what Attachment Disorder was: the school don’t really recognise what it was or how to deal with it.

He is a difficult child to deal with because he has had an awful lot go on in his life and I don’t know if there is enough understanding in school about how to deal with LAC children.

² RISE NI is a regional early intervention service which supports children in pre-school educational and mainstream primary school settings by working closely with parents and education staff to help children develop the foundation skills for learning i.e. speech, language, communication, sensory-motor, visual perception, social, emotional and behaviour skills.
<http://www.southerntrust.hscni.net/services/1839.htm>

It has taken me 2 years to get to know him and know how to deal with him and every time he meets a new teacher he doesn't trust them so we're back to square one.

Karl had quite a negative view of school in that he sees it that he just gets told off all the time, you know, and he gets very frustrated and when he can't do the work he'll just throw the head up and he has no resilience. I guess when people react to that and don't teach him how to keep going, then he kind of becomes just, "I can't do this, I don't know how to do that" and now he's in P6 he's very aware that he is low ability. He is now more self-aware. His behaviours are cyclical. He fears being sent to the Principal's office but panics and acts out.

There's an awful lot of me finding out what different services are available and then suggesting them to school but the challenge is if school can't or don't take it on board where do you go from there? So this is where we come unstuck because we've offered them free training. We've offered them different sensory things, we've offered people to come in but if school won't do it, and whenever you phone the EA and you talk to the EA about it they're like "Oh, they should do this or they should...we'll talk to them" but there's no follow-up, there's no decisive action on anything. There's not really one person in charge and because I'm a carer, and he's got a social worker, schools sort of go between us and play this whole, "Oh well, we'll talk to the social worker about that" and then "Oh, well, we'll just clue you in and talk to you about that."

At Karl's annual review I wasn't happy he was sat facing the wall on his own at the back of the classroom. Now this is a child who has attachment disorder, so I mean, anxiety is already very high. Even whenever the social worker complained about him facing a wall, they brought him back into group work and then they put him back there again because he wasn't doing what they wanted. So he was to face a wall, you know, so I got to a point where I wanted to remove him because I felt this was damaging his self-esteem, damaging

everything really and labelling him. And he would say “I’m bad. I can’t make good choices. This is who I am”.

And all his paperwork is meant to be in the Belfast Board because he’s a LAC child. We phoned the Belfast Board and they say, “No, his paperwork is South Eastern because he’s at a South Eastern school”, so I phoned the South Eastern division and they say “Oh, well we don’t know where it’s meant to go” and then, “Oh I can’t talk to you. I used to be able to talk to you, but now I realise that you’re a foster carer, I can’t talk to you. I need word from the social worker” and I said, “But we’ve had these conversations for two years now” and she went, “I know, but I didn’t realise, so I need the social worker to phone”, so the social worker has to phone and say that it’s okay for me to talk to them. There’s no straight path, there’s no straight answers and people at EA.....trying to get a reply from anybody at EA... it took them three weeks to call me back.

I think that EA need to go out and see what is actually happening with special needs. One thing on paper but another thing on what is actually being done for the children. To see what strategies they could make sure that those children are being looked after, especially I mean with LAC children: they have so many other things going on. There may be learning difficulties that need sorted out, but there’s all those other things and the EA need to look at what is going on to support these children, different companies or different outside agencies that can come in and support them. Are the teachers needing help with them? Can we give them resources they need to follow up? I think there should be involvement from foster carers and from school and from EA making sure that they’re working as more of a team. I feel like the EA are very much “Oh, the school are doing this and so we’re kind of in the background” whereas I think they need to be more involved in following up and making sure that those children are making progress and that they’re being looked after properly.

You have to explain who you are and what your situation is. And it's very difficult, especially if, you know, when I phone up, I'm not just a normal parent so I have to explain why my name is different from his name, and then the person has to go and check if I can speak to you and who you are. You know, if you had one person that you rang all the time and also if that person then came to the school and was involved in what is happening with these children. You know, LAC children need so much more, and the board give money to schools for LAC children so they should be involved in how that's spent. I don't see it getting spent on that child. It just gets swallowed up into school budgets. And whenever I asked school "How did you spend that money for my child?" there's very little responses. A lot of waffle really is what came back. And not specific things that could help him, you know. And I think if the EA are going to give schools money, they should be following up what's being done with their money."

CASE STUDY 5 – Esther's story

Esther moved to Northern Ireland from London in 2017. Her son, James, was born in 2013 and was a special care baby. As part of his illness there was a chance of developmental delay. Making the move to Northern Ireland meant that, although the referral process had begun in London, a new application for support had to be made when the family relocated. Esther explains how she sought private help for assessment of her son and how through this he benefitted from the strategies and interventions introduced. She faced challenges in the formal setting of school in getting support for her son.

“At his 2 year development check there were lots of issues and as he started pre-school these issues became exacerbated. We were kind of caught between two systems then because we moved here in August 2017 and had sought help for diagnosis in England in January 2017, so it was a kind of moving timeline for getting him assessed, trying to get continuity of care, in terms of meeting professionals.

The first people I probably came into contact with was the EA and that was the time when I was submitting my son's P1 school application and, as time progressed, the school nurse started really saying there's a lot of issues and that's when we went to Child Development to get a referral to the Child Mental Health Centre in London. We moved to Northern Ireland in August and we missed an appointment at the Child Development Centre because my son was really sick in A&E. I started looking then at schools because it became more apparent to me he had a special need: there were problems with his behaviour and social emotional regulation.

I spoke to EA to explain I've put this form in but I've found this school that I think would be more suitable and I would like to take him, and the EA refused point blank to look at this as an exceptional circumstance. They said, “You know, does he have a diagnosis? He

doesn't have a diagnosis, you know." I'm in-between this move and they were extremely unhelpful. I asked them "Could you please send me the Department of Education's policy or your policy on this movement, because this is an exceptional circumstance?" The lady who I spoke to was incredible unhelpful and just shut everything down completely so then I spoke to the school that had said they were going to accept my son and I said "Look, there's going to be issues here and they said that was fine so in the interim period I went to see a private educational psychologist in Belfast in a place called Sensations. They did an assessment for us and that went to school before he started in September.

So then my son started P1 in September and it was horrendous. He could not cope at all in school. The first day he came out covered in blood. He had had a major melt down at school and it was very, very distressing and I just thought to myself "I cannot and I don't know how to take him back to school the next day". So I met with the Head again and with the SENCO. They looked in detail into the report that the educational psychologist had sent, the private one, and they had started to put into place recommended practice, but with the teacher it wasn't a good experience, but I think she was just shocked at his behaviour. I think she, she couldn't control him. I think she was as distressed as my child was. The school then started Stage 1, 2 and 3 referral in terms of getting special educational support. Because of his waits with the Health Trust I decided to get a private diagnosis for him and so we went to Sensations and he actually started a programme called Fledglings in January 2018.

When he started back in September, he ran out of school twice at five years old and he made it out of the school grounds and onto a pitch about half a mile away. When he is stressed, his flight response kicks in.

The school weren't pushing him because of his significant difficulties. They said to me, "You know, you need to do a parental referral because EA give much more weight to parental requests for special educational needs". I was astounded really that that was the

case, so I put in the parental referral because there's a defined timescale, whereas I think with the school processing things, there are not. So I came into more and more contact with the EA and have found it opaque, not transparent with no defined processes.

I feel that they have just frustrated the process as much as possible they've taken any opportunity to delay and waste as much time as possible. With EA and sitting with the educational psychologist I was asking, "Can you signpost me to a road map that takes me through this process?" They were talking about what the school were doing and it was all very vague. I just kind of felt like all the power sat there and none of the information was coming here to allow putting all the subsequent documentation together. There's no kind of clear framework that says, "This is what this looks like".

The way the process is now is not fit for purpose; it is not meeting the needs of children; it's not meeting the needs of parents; and it's not meeting the needs of the school. I know that they are in the process of changing the staging system. Also, they lose sight of what it just feels like, such a battle with them and such a fight.

So the things I can be positive about are the private support that I got was fantastic. And the Autism Intervention Service at the Trust: I've been to a couple of really good talks with them - professional and very pragmatic, so that was good again. The only hiccups there was the length of time.

The challenge has been trying to cut through the maze of accessing help for him in an educational setting and that was, that's a challenge in itself and then learning about his condition and putting interventions in at home and understanding him and the way that his pathways work in his brain. I just didn't realise that it would be so difficult to get the support that he needed when we moved here, so it left me feeling quite anxious because he was distressed and is distressed. It was just a horrible situation to see your child in distress and not being able to fix it for them. I'm quite a pragmatic person who likes to solve problems.

The most negative impact on me personally is that I've had to give up my career and become a carer for my son. I thought that we, that I would move here and I would settle the children in school and kind of have a nice six months of settling in and then I would go back to work but I have not been able to go back to work.

Rarely during this whole process did I feel that anyone cared or treated me as a service user. I just always felt like I was annoying people and bothering people. I just think that some of those attitudes need to be addressed, I think parents need to be treated with compassion, empathy, support, because not only are you having this big battle educationally to get your child support, but you know you're going through stuff as a parent with your child on a day-to-day basis and that is extremely challenging and at no point does anybody reassure you. It's kind of picking on the weakest in society, not doing what you're supposed to do and if you're not in a position to have a strong advocate, you will just basically be pushed aside."

CASE STUDY 6 – Sharon’s story

Sharon first had concerns about Levi when he was a toddler. Although as parents they pursued different medical avenues, they did not get a specific diagnosis as he presented as ‘normal’ and in fact as Mum said ‘too well’ to warrant being sent further ‘up the chain’ for referral. Levi had been seen by paediatricians and neurologists but nothing concrete was established. When Levi started nursery school it was obvious from his behaviour that something was amiss. Sharon is a child-minder so is experienced with young children and their expected development patterns. Sharon realised she had to pursue this herself. After trying various routes, GP, EA etc., and after almost 2 years Levi was given a statement and provided with school support. The school staff, including the SENCO were very supportive and empathetic regarding Levi and his needs. Sharon expresses how the journey was long and stressful, and that, had she not kept up the contact with the various authorities, Levi would be in a very different place today. She recommends a more ‘joined up approach’ and keeping parents informed of what is happening in a more timely manner.

Levi had been at home up until he began nursery school so had experience of mixing with the children in his mother’s care. During his nursery year the staff of the school asked educational psychology to “keep an eye” on him if they were in observing another child. Nothing ever came of this. Things really got worse when Levi went to P1. An Educational Psychologist was asked to observe him again but the outcome was “it is just behaviour”. However Sharon realised he definitely faced challenges with literacy and writing, and there was an issue with him getting what he wanted down on paper which was causing him frustration. He seemed to be able to keep up with the class in relation to phonics. His writing skills were poor but it wasn’t a motor skills problem. “Towards the end of P1 we got an appointment with CAMHS which was very positive in terms of what strategies we were

told were to be put in place so we left feeling relieved and feeling we were getting somewhere.”

However at the second appointment Sharon and her husband were told “No, we have decided we are just going to wait and see.” Levi’s parents were shocked as they had placed their hope in moving forward with support for Levi, believing someone was finally listening to them. “I felt the man at CAMHS was patronising then at this point stating that he had spoken to an OT and this was the decision.”

By this stage Levi was having some unusual movements and a problem with his right leg. Sharon explained that “The man at CAMHS had seen the videos of Levi and agreed initially that OT should be involved, a wait and see approach...I felt we were getting nowhere at the appointment”. Levi’s parents were then told that Levi’s case was to be closed and no further action taken. However the school staff felt so strongly that this was not the correct course of action that they wrote to the staff of CAMHS. “We heard nothing more from them”, Sharon explained. In the meantime Sharon went to her GP and the primary school staff had Levi referred and he was seen by an OT. The RISE team also became involved and they agreed to provide behaviour strategies and OT for Levi. It took almost a full year for any of this to be put in place.

Meanwhile Sharon had noticed that Levi’s movements had become more pronounced and it was suggested that this was why he found difficulty in holding a pencil. He was diagnosed with a tick disorder and began taking medication. However during the summer holidays he started having seizures so it became apparent he had epilepsy too. In November he was seen again by the educational psychologist and an Asperger’s diagnosis was the outcome.

Sharon explained that “School had been very good”. However getting a report from Educational Psychology was more difficult. “Having been seen in November, I was still chasing it in February. I phoned the Educational Psychologist and found her

unapproachable. She wouldn't answer my questions on the phone and when the report came in, I could see why. There were discrepancies, a few things that were factually wrong and contradicted Levi's Asperger's diagnosis – rather it said he presented as a child who had epilepsy.”

Sharon stated that they didn't know where that left them: did he have Asperger's or not? She contacted the paediatrician that had seen Levi originally and explained the situation. The paediatrician asked to see the report which Sharon facilitated.

“So we had to contact DARS”. Sharon stated DARS were very helpful, and were able to facilitate changes to get the facts right. Sharon asked DARS “Can an educational psychologist go against a group of professionals?” They said that should not happen. A decision was received in June and a statement was provided for Levi in August, however Sharon had to go to a tribunal to have the number of support hours increased which took until January.

Sharon explains, “I think if I hadn't been the parent to keep pushing, Levi would not have had any help whatsoever. Levi's school have been proactive in trying to help us and him. He sometimes said ‘I hate school, I am going to run away.’ He was obviously stressed which could have brought on a seizure.”

In relation to the impact on Levi, Sharon stated that there was a delay from referral to Levi actually being seen by professionals such as Occupational Therapy. Indeed almost a year had passed. Levi took a dislike to anything that was school colours such as the uniform colours, as Sharon recounted, “He was worse on a Sunday night and especially after holidays. The school put in place a strategy whereby Levi would go to the SENCO as soon as he went in and that worked really well – it was familiar. The school and SENCO have been fantastic, the biggest difficulty is, Levi is so impulsive and his behaviour is so erratic. Peer relationships are not important to him and he seems to relate better to adults.

I have had a lot of contact with school. I am in nearly every day. The support now provided has made a big difference to Levi academically”.

“From this whole experience I think the authorities need to listen to the parents more, by that I mean the EA. I wasn’t being unrealistic in my requests but everything took a very long time! I actually had to go through their policies and work things out myself. The school, teacher and SENCO were supportive however they struggled with getting feedback from outside services, so they couldn’t go any further. The whole process was delay, delay and long. As far as EA are concerned, I don’t know where to start. I don’t even know what the process is meant to be. They forget they are dealing with people with children with special needs. One day there was a voice message left by someone from EA and they called Levi the wrong name. We had to fight very hard to get the support for Levi. Early intervention is the key and listening to the parents. The different agencies need to work together and talk to each other.”

DISCUSSION

The research undertaken sought to explore the views of parents/carers on their child's experience of the SEN process in mainstream schools in Northern Ireland. The study employed a mixed methodological approach comprising an online survey (n=608: 591 parents and 17 carers), followed by a series of 10 semi-structured focus group interviews in 8 venues across Northern Ireland (n=55) and finally 6 in-depth interviews (n=6: 5 parents and 1 carer).

The following discussion draws on the results of all 3 data collection methods. It aims to address the overall findings in relation to the experiences of parents/carers with the SEN process, and then more particularly in terms of their engagement with schools, the Education Authority, and Health & Social Services professionals.

Parental Experiences of the SEN process

Positive Experiences

There was a minority of parents/carers who expressed positive comments both in the survey and in the group and individual interviews. These most often related to individual school staff (e.g. class teacher, classroom assistants, SENCO, principal):

"[Principal] is a genius, her SENCO, [Name], they were just phenomenal, they were absolutely phenomenal and all that sort of individual... all that social...including the children having like a special bench for if you're feeling lonely or isolated, the child went to it and the other children would see that and come over. And the classroom assistants were out on the playground watching this and encouraging it, you know, it was just.... Anyway, we had a brilliant primary school experience." (Focus Group)

"The classroom assistant was excellent and showed acceptance of the child and promoted inclusion" (Post-it note, Focus Group)

“My child's school are extremely supportive and have done their best to help our daughter to access the curriculum and to develop skills to deal with Social and emotional difficulties. Very human and caring.” (Survey response)

Other positive comments related to individual health professionals or members of staff at the EA (e.g. educational psychologists: “Once we eventually got to Ed Psych, she was very thorough and professional” – survey response). A small number of parents/carers also spoke very highly of the support they had received from voluntary sector organisations who provided much needed support and advice as parents strived to navigate the SEN system (see Case Study 2). Parents/carers whose children had received a diagnosis were often relieved that the lengthy assessment process was over and were glad to have some support finally provided (Survey Q59). Many parents/carers were positive about medical interventions and support from health professionals, especially when that support was provided following an early diagnosis (at birth or in infancy). This was in contrast to what was perceived by many parents/carers to be a “fight” or “battle” to secure an assessment from the EA if the child was already a pupil at a mainstream school (often competing against the needs of many other children for an assessment) and had a learning difficulty which was less ‘visible’ (e.g. dyslexia) or was not accompanied by challenging behaviours. This difference was often quite stark in the focus groups where parents from the same town/area sitting next to each other had children with contrasting needs and correspondingly very different experiences of accessing support.

Negative Experiences

However, it must be noted that, while there were a number of very positive accounts of individuals who had provided outstanding support, the majority of survey responses and experiences described in the interviews were negative. For instance, when asked in an open-ended survey question to identify the most positive aspect of the SEN process, the

most common response (by over a quarter of respondents) was that there was nothing positive about it at all:

“Nothing. Haven’t had a positive experience whatsoever. Have to jump through hoops and fight to get your child support and help they need. The system is a total disgrace.” (Survey Q59)

“Nothing at all, complete shambles.” (Survey Q59)

Many of the survey questions elicited mixed responses (at best) from parents and often overwhelmingly negative responses. For instance, evidence gathered from the survey suggests that parents/carers of children with SEN (already diagnosed) were more likely to feel that their child’s SEN were not being adequately met (44%), than to feel that they were (38%). Almost two-thirds of respondents felt that there had been unnecessary delay in providing the support to meet their child’s needs. In relation to the statutory assessment process in particular, a majority of the respondents were not kept informed by an EA officer and were not provided with guidance to help them complete the parental report. The results also highlight that, perhaps as a result of this lack of guidance, less well educated parents were much less likely to have completed a written or oral report as part of the assessment process. A majority of parents/carers were also dissatisfied with the assessment process overall, with less than half feeling that the resulting statement gave an accurate description of their child’s needs, and just over a quarter reporting that the statement was issued within the statutory time frame. When asked to assess the entire statementing process, only half of parents/carers were ‘satisfied’ or ‘very satisfied’ with their experience.

While there were isolated comments in the focus groups suggesting a variation in provision between EA regions (e.g. a perception that for the EA “Life past Sandyknowes doesn’t happen!”) this was not borne out in the online survey where cross-tabulations

found minor variations but no statistically significant differences on any parental satisfaction scores between EA regions. This suggests that for this sample there is no significant difference in parental experiences of accessing SEN support across the five EA regions. All seemed dissatisfied in roughly equal measure in response to most questions.

Parents/carers were asked to identify any barriers or obstacles they had faced in accessing support for their child, and here the most common general comments related to a lack of support (especially in school), and delay or difficulty in accessing support or an assessment as a result of delays, waiting lists or because their child's needs were not considered a priority compared to other children also seeking support:

"School say there are too many children on the list and mine isn't a priority given the limited time allocated". (Survey Response)

Parents in the focus groups often spoke with anger and frustration of being told that their school had access to a limited number of referrals for assessment each year and that their child's needs were simply not severe enough to be chosen when compared with other children in the school:

"...the difficulty with the small primary school is that you don't get, [pause] the SENCO is the headmistress and she kept saying that they only have enough funding for one person in the year to get assessed so you really have to be the worst in the school before you get assessed, so anybody who is just a little bit under, you don't get it." (Focus Group)

Participants in the focus groups and individual interviews felt that communication could be very effective, especially with well-informed and sensitive teachers, principals and SENCOs, but more commonly was wholly inadequate, leading to parental confusion and anxiety. Parents here expressed strong feelings that they were unsupported in the process, and that the complex terminology and amount of paperwork involved in the

process was daunting and at times overwhelming. This was particularly the case for those with literacy difficulties.

However, most comments related to an inability on the part of parents/carers to access information, and the consequent inadequacy or lack of communication between services (e.g. EA/Health) as well as between the service providers and parents/carers. This was further reflected in a total of 12 post-it comments which referred to the need for better coordination and communication between parents and services.

The particular issues faced by carers are outlined by one kinship carer in Case Study 4 where Paula recounts how school and EA staff often bypassed her (as a carer) in communications, preferring to deal directly with social workers, and failed to understand the particular needs of Looked after Children with SEN. This correlates with the survey findings where, of the 11 carers with children with diagnosed SEN, 9 felt that their child's needs were not being adequately met (Q20.1), and all 11 felt that there had been unnecessary delay in the provision of additional support for their child (Q.20.2). Only 4 of the 11 parents felt that their views about their child's SEN had been taken into account (Q.20.4).

Some parents/carers also spoke of phoning the EA multiple times before getting through (e.g. "I rang 42 times before my call was answered" - see Case Study 3), being hung up on, feeling like they were "annoying people and bothering people" (Case Study 5), being lied to, using the wrong child's name in communications, being sent "guff that you don't even understand" (Focus Group), or having to go directly to the EA offices to demand to see someone since no other form of communication had yielded any results:

"My experience was good with the Education Authority, but I think it was good because I fought and I fought from the minute I found out to the minute I got him statemented and the fight, it was

every day, like if they didn't contact me I arrived at their desk. If the health professional didn't send in the speech report, I arrived at her desk. Like I literally hounded her". (Focus Group)

Many parents spoke of the fact that they had had to develop an aggressive approach simply to be heard, something which they were prepared to do for the sake of their child's education, but which, they were keen to stress, did not come naturally to them.

"I think as parents what happens is we often become very bolshy and we're the difficult parents but it's because we do fight for our kids. It would be very easy to go, do you know what, I couldn't be bothered anymore, that would be much easier for the schools and much easier for the Education Authority if we did do that but instead then we become the difficult bolshy parents because we're constantly fighting with them." (Focus Group)

Respondents to the survey felt strongly that in terms of 'Availability' (one of the key Children's Rights Benchmarks), the SEN system is currently severely lacking: only 1 in 8 respondents felt that there were adequate facilities and services in place to meet the needs of all children and young people with SEN, while in terms of 'Accessibility', only 1 in 6 respondents felt that all children with SEN have equal access to services without discrimination of any kind. Less than 1 in 5 believed that the SEN process is child-centred ('Acceptability'), while a similar proportion felt that the education environment is adaptable in order to meet the needs of children with SEN ('Adaptability'). Only 1 in 7 felt that children and young people with SEN receive a quality service which meets their needs ('Quality/Impact'), and the same proportion of parents felt that the views of children with SEN are sought and taken into account in their education and development of policy and services ('Participation'). Only 1 in 10 agreed that there is timely and appropriate cooperation and integration of services to ensure a holistic approach is taken to meet the needs of children with SEN ('Cooperation').

In terms of pupil voice, this study revealed a lack of effort being made to engage meaningfully with children with SEN about their learning needs. In the survey, over 40 per cent of respondents felt that their child's views had not been taken into account during the whole SEN process (only 32% felt that they had been taken into account). When asked about the statementing process in particular, only 25 per cent of parents said that the EA had sought the views of their child on their SEN and the way in which their needs might be met. Furthermore, when asked about 'Participation', only 14 per cent of parents/carers agreed that "the views of children with SEN are sought and taken into account in their education and development of policies and services." This was echoed in comments made in the focus group interviews where several parents/carers recommended that professionals should "start listening more to the child as they tell us what school is like for them".

When asked to make suggestions to improve the SEN system in general, the most common survey responses focused on the provision of more adequate funding and resources, including more assessments, shorter timescales and waiting lists, and better training for staff. Many of the comments also advocated a more child-centred, less bureaucratic process ("Rip it up and start again. Make it child-centred" – Survey response). Many other comments encouraged a greater level of trust in and collaboration with parents. The recommendations from the group interviews also focused on improved services, especially from the EA, as well as better training for all professionals (including teachers) and enhanced communication at all levels.

The impact of the SEN process on children and families was a central theme of the interviews in particular. In terms of the children, there were often emotional and occasionally harrowing accounts given in the interviews of children who, as a result of delays in accessing support, became increasingly anxious, engaging in challenging and/or self-harming behaviours, or became school-refusers:

“we’re at the point where my son actually [long pause] is so mentally unwell that he’s out of school completely [gets emotional], he wants to kill himself [cries].” (Focus Group)

Some parents recounted that they had to leave their jobs to look after their child, or home educate or flexi-school them. Others described the impact on their lives as parents/carers and in particular on their mental health and relationships, as they sought to do the best for their child:

“I completely fell apart, I had managed this whole thing all by myself, everything was on my shoulders just like the other mummies around this table, family was breaking down, things were chaotic, things were terrible at home, there was me, there was dad, there was this crazy child who we loved and were trying to do the best for...” (Focus Group)

Parents recounted that they became increasingly anxious, stressed, tired and at times completely overwhelmed, with additional strain placed on their relationships with their partners:

“My husband took a breakdown you know, like he was at the top of his game in his job, our marriage is like under pressure, you know.” (Focus Group)

Additional cross tabulations (see pages 67-73) did however reveal more positive responses to some questions by parents/carers of children with statements (Stage 5 of the Code of Practice) when compared to parents/carers of children without statements (at Stages 1-4 of the Code of Practice). For instance, parents/carers of children with statements were more likely to be familiar with the 5 stages of the SEN process as set out in the Code of Practice; were more likely to agree that their child’s special educational needs were being adequately met; were more likely to have been involved in the development of their child’s Individual Education Plan; and were more likely to agree that the educational environment was adaptable in order to meet the needs of children with SEN.

The following sections draw together the data relevant to parental engagement with schools, the Education Authority and Health & Social Services.

Experiences of Engagement with Schools

Respondents to the online survey had children with a very wide range of needs in a variety of school types (e.g. controlled, maintained, integrated etc.) receiving many forms of special educational provision from many sources across each of the five EA regions.

When survey respondents were asked to rate how supportive key school personnel were, the responses were mixed: the most favourable responses were attributed to classroom assistants (85% found them 'supportive' or 'very supportive'). Results were less positive for class teachers, SENCOs and principals. In each case parental satisfaction scores were highest for staff in nursery schools compared to primary and post-primary schools.

While there were a number of glowing tributes to individual members of school staff (e.g. class teachers, classroom assistants, principals, SENCOs with expertise, understanding and sensitivity who were prepared to go 'above and beyond' - see Case Study 1) and an acknowledgement that schools were facing severe budgetary pressures, there were also many reports of unsympathetic school staff, teachers who lacked knowledge, skills and experience, and a lack of willingness to provide any support. While there were comments made to that effect in the online survey, more qualitative detail was provided in the focus groups and in the individual interviews. Several parents/carers spoke here of a particular lack of understanding among more experienced teachers, principals and SENCOs, whose Initial Teacher Education had not adequately prepared them for the nature and extent of SEN in the modern classroom ("I think for the SENCO, there's more training required...it's like the blind leading the blind"), and some of the stories recounted were disturbing:

“...they used every one of his triggers against him right down to the very last day when he was in that building where he was told at the age of 6 he was only fit to clean the floor of the headmistress’s office.” (Focus Group)

Interviewer: Can we go back to the grammar school? What would have helped there?

Parent: A wee bit of humanity would have been nice. It was horrific, it was absolutely horrific.

Interviewer: Did you feel that the teachers understood or sought to understand?

Parent: No. Didn’t understand, didn’t want to understand, didn’t particularly care about understanding, they very much saw her as a difficult child, she doesn’t fit into this school, we don’t like the way things are going here and we don’t like the way you, as parents, are responding to this, um, so and it got to the point where we very much felt if we don’t move her they’re just going to throw her out.

By contrast parents felt that more recently qualified school personnel were more likely to have the knowledge and skills to provide appropriate support to their child. In the focus group post-it note activity, the most frequently occurring comments under the heading “School” related to schools’ lack of knowledge, capacity and funding (x3), the need for better communication with parents and other services (x3), and more guidance about the SEN process and IEPs (x3).

Experiences of Engagement with the Education Authority

There were several survey questions which focused on the role of the EA. While there was a small number of positive comments made in relation to EA personnel in Q59 (which asked respondents to identify the most positive aspect of the SEN process), the responses to Q54 (which asked parents to rate their level of satisfaction with a range of EA services) were generally negative. For instance, only 49 per cent of respondents felt that the Educational Psychology service had been ‘supportive’ or ‘very supportive’, and 47 per cent felt that the Autism Advisory Service had been ‘supportive’ or ‘very supportive’.

In the open-ended questions, there were also many comments in response to Q57 (where parents/carers were asked to identify particular barriers to accessing support for their child) which made reference to the EA. Some of these referred to the inaccessibility of support, a perception that the EA were more focused on money than on children's needs, the inadequate levels of communication, guidance and support through the statementing process, the long waiting lists, and a sense that they as parents/carers had to 'fight' to be heard.

In the focus groups, there were long discussions about the EA, and many stories detailing poor communication (see above), inadequate resources, and even some instances where parents/carers felt that EA staff didn't care about their child at all:

"They don't need more resource, they don't need more staff, they need properly trained staff who realise that they're there for more than their mortgage payment and I think if we threatened a few mortgage payments of the EA staff they'd soon step up...They couldn't care less about the children." (Focus Group)

Much of the parental frustration concerning the EA focused on the difficulty in accessing assessments, often by an educational psychologist. Parents were told by schools that they had been allocated a limited number of assessments per year and that decisions had to be taken to prioritise needs. Often parents of children with less 'visible' difficulties (e.g. dyslexia) were not prioritised for referral, leading to increased frustration. Parents/carers felt that this selection process within schools was not based on individual needs but on a crude allocation of resource depending on school size.

In the post-it activity at the end of the focus groups, there were many more post-it notes written about the EA than about any of the other 9 topics. Only one of these post-it notes was positive (in relation to the EA Sensory Service). The most commonly occurring

comments were criticisms of poor or slow communication from the EA (x7), and the need for a more integrated solution with better communication (x9). There were also several comments related to the need for more staff training (x3), the need to listen more to parents (x3), and more staff and funding (x3).

The inaccessibility of EA testing or assessment led many parents to consider paying for private assessments, even though most realised that the EA would not recognise them. Almost half of parents/carers of children with SEN indicated in the survey that they had considered paying for a private assessment for their child. As one parent explained, “We were having such a hard time and everything was a waiting list that we looked into it.” The other comments reveal a range of parental views on private assessments: some had paid for a private assessment in desperation only to discover that the EA would not recognise it; others did not opt for the private assessment *because* they were aware that the EA would not recognise it; others were unable to afford a private assessment; others were not aware until now that private assessments were an option; and several commented that they would have no hesitation in paying for a private assessment if they would be accepted by the EA and so would enable their child to access support more quickly.

In relation to the statementing process, Q38 of the survey revealed that only a third of parents/carers had been notified by the EA of a named officer to support them through the process, and only a fifth reported that the EA officer kept them informed. Only 18 per cent of parents/carers had received support from the EA to help complete their written or oral report, and only a quarter reported that the EA had sought the views of their child on their SEN and the way in which their needs might be met.

When asked about their experience of the Special Education Disputes Avoidance and Resolution Service (DARS) which is provided through the EA, 15 of the 30 respondents who had used the service reported that the issue had been resolved satisfactorily.

While there were several positive comments (among hundreds) in both the survey and the focus groups in relation to specific EA staff members, the overwhelming sentiment expressed by the parents/carers in this study is one of frustration, disengagement, poor communication, inaccessibility and lack of resource within an over-stretched service:

“Every input from EA services...has been a battle” (Survey Response)

“The Education Authority needs to be more transparent, open and honest with parents” (Post-it Note, Focus Groups)

Experiences of Engagement with Health and Social Services

The experiences of parents/carers in engaging with Health and Social Services professionals was considered in Q55 of the online survey where responses suggest that a majority of parents found Occupational Health (60%), Physiotherapy (66%) and Speech and Language Therapy (75%) to be ‘supportive’ or ‘very supportive’. Other services (most commonly CAMHS and medical professionals) were also found to be ‘supportive’ or ‘very supportive’ by 64 per cent of parents. By contrast only a third (34%) of respondents found Social Services to be ‘supportive’ or ‘very supportive’.

In terms of cooperation between services, a large majority of parents/carers found however that collaboration was ineffective between their child’s school and Health & Social Services, and between the EA and Health & Social Services:

“It’s not even that there’s poor communication, there is no communication, I am the one doing the communicating. I am the one going to school and telling them what CAMHS are saying or I am the one going to CAMHS and telling them what school are saying and if I didn’t do that, there would be no communication whatsoever.” (Focus Group)

When asked to identify the most positive aspect of the SEN process, 22 parents/carers referred to support from Health professionals:

“The speech therapists we saw were fantastic. They helped with many aspects of behaviour, not only speech.” (Survey Q59)

The qualitative data from the focus groups and individual interviews was more mixed but also generally positive in relation to engagement with health professionals, especially by the parents of children who had received an early medical diagnosis. Case Study 2 tells the story of Helen and her daughter Katie, born profoundly deaf, who had received support from a voluntary sector organisation (the National Deaf Children’s Society) as well as a paediatrician, teacher of the deaf and speech and language therapist. Katie recounts that she had a “very good consultant who pointed us in the right direction at the right time” and speech and language support from when Katie was just three months old. All of this meant that Helen felt that they had “progressed smoothly through the statementing process” with the support of an “excellent multi-disciplinary team who worked well and communicated effectively together”. This positive experience is also confirmed by several post-it comments in the final activity (e.g. “GP listened carefully and took action”) and by comments made during in the focus groups by parents/carers who found the support from health professionals to be of a high standard:

“...when he was referred to paediatrics from school the paediatrician was fantastic, from day one she told us that she had suspicions from the first meeting. She helped a lot when it came to the statementing process, she was very keen to help me, she was very approachable.”
(Focus Group)

Conversely, Case Study 3 (Moir’s Story) is less positive and found speech and language support to be “erratic” and inadequate to meet her son’s needs, with the result that Moira resorted to paying for private Occupational Therapy and Speech and Language support.

With this privately accessed support her son, Kane, made “valuable progress.” The experience of Sharon (Case Study 6) was also less positive as she felt that the support from CAMHS was unsatisfactory and the attitude of the staff “patronising”. Several parents in the focus groups did speak much more positively about the level of support they had received from CAMHS (once they were able to access it) but one parent in the Southern region described how children with ASD were automatically excluded from CAMHS support, even if they displayed dangerously suicidal behaviours.

CONCLUSION and RECOMMENDATIONS

This original piece of research is set in a legislative and policy context which is steeped, first, in commitments to children's rights: from the recommendations of the Warnock Report (1978) to subsequent legislation in Northern Ireland such as the Education (Northern Ireland) Order 1996, the Special Educational Needs and Disability Order (SENDO) 2005, and the most recent Special Educational Needs and Disability (Northern Ireland) Act 2016, alongside international commitments made by the UK as signatories of the *United Nations Convention on the Rights of the Child* (1989) and the *Salamanca Statement* (1994). The 1998 *Code of Practice on the Identification and Assessment of Special Educational Needs* and its 2005 *Supplement* (written to incorporate the SENDO and Disability Discrimination legislation) further expound the importance of placing the child at the very centre of the educational process, and of listening to and respecting their views.

Second, there is a consistent commitment in the legislative and policy context to meaningful engagement with parents, beginning with Warnock's original proposition from over forty years ago that parents should be viewed as "equal partners":

"We have insisted throughout this report that the successful education of children with special educational needs is dependent upon the full involvement of their parents: indeed, unless the parents are seen as equal partners in the educational process the purpose of our report will be frustrated". (HMSO, 1978, p.150)

This commitment is reflected in the *Code of Practice* which acknowledges the vital role played by parents in a child's educational progress and the effectiveness of any school-based action (§2.21) and further notes:

“Children’s progress will be diminished if their parents are not seen as partners in the educational process with unique knowledge and information to impart. Professional help can seldom be wholly effective unless it builds upon parental involvement and provides reassurance that account is taken of what parents say and that their views and anxieties are treated as intrinsically important.” (§2.21)

This commitment to partnership with parents is reinforced by The Special Educational Needs and Disability Order (SENDO) which strengthens the right of children with a statement to be educated in an ‘ordinary’ (mainstream) school “unless that is incompatible with (a) the wishes of his parent, or (b) the provision of efficient education for other children” (Article 3), and further places a duty on ELBs (now the EA) to provide parents with advice and information about matters relating to their child’s SEN and its SEN services.

Third, there is a commitment to provide adequate funding to ensure that children’s special educational needs are appropriately met and within statutory timeframes. This commitment was first voiced in the Warnock Report itself which, over forty years ago, had insisted that the inclusion of children with SEN in mainstream schools “is not a cheap alternative to provision in separate special schools, and there is no short cut” (HMSO, 1978, §7.56). Writing in 2018, Warnock herself saw her seminal report as “the last gasp of welfarism”, in its recommendation of an increased level of public spending (just as the great welfare Bills of the late 1940s had done). Moreover, Article 4 of the UNCRC (UNICEF, 1989) commits governments to “undertake such measures to the maximum extent of their available resources...” in order to implement the Convention. Crucially, the UN Committee’s General Comment No.5 on the implementation of the UNCRC outlines a duty on governments to make budgetary decisions “with the best interests of children as a primary consideration”, even if circumstances are challenging:

“Whatever their economic circumstances, States are required to undertake all possible measures towards the realization of the rights of the child, paying special attention to the most disadvantaged groups.” (UN, 2001)

While there are undoubtedly glimmers of hope threaded through this report and accounts of highly committed, knowledgeable and skilled professionals in all sectors, the overall findings of this report have clearly demonstrated a stark dissonance between, on the one hand, the rhetoric of child-focused, parent-respecting, inclusive legislative and policy commitments to high-quality, well-resourced SEN provision, and, on the other hand, the prosaic daily reality of inaccessibility and inadequacy of provision within a SEN system which is severely under-resourced so that decisions are too often made based on cost rather than need. For instance, survey responses highlight that only 18 per cent of parents/carers feel that the SEN process is child-centred, 14 per cent felt that their child’s views are taken into account, and just 13 per cent agreed that adequate facilities and services are in place to meet the needs of children with SEN.

Qualitative responses in the survey, and stories recounted by parents/carers in the interviews shed further light on the reality of an SEN system in crisis, beset primarily by inadequate government funding (as the 2019 Northern Ireland Affairs Committee Inquiry into education spending confirmed) which has led to insufficient staffing at all levels (e.g. schools, EA, Health Trusts) and resulting delays in accessing assessments and support for children with SEN in mainstream schools.

The details are disturbing: lengthy waiting lists, restricted referrals by schools, inadequate knowledge and understanding of SEN by some professionals, reduced availability of resources including classroom assistant hours, poor communication with parents and also between services themselves, and, ultimately, too many children with SEN in mainstream classrooms whose needs are currently not being adequately met or not being met at all.

The impact of this system in crisis is described in detail by parents/carers who must ‘fight’ to be heard, and ‘battle’ to make the case for their child’s needs to be assessed over many others. These are parents who spoke passionately of their commitment to continue to fight for the support which they feel their child needs. This study has found that in the current SEN system, parents/carers only rarely see themselves as “equal partners” and too often struggle to be heard at all.

Unless immediate action is taken to remedy the crisis in the SEN system, there is little doubt that parental frustration will continue to grow with accompanying feelings of anxiety, stress, confusion and alienation, and, even more significantly, children will move further and further from where they belong at the very centre of the process. Consequently, six core recommendations from this research are outlined below. These recommendations and the underpinning findings, alongside the evidence collected from other stakeholders and analysis of operational data, have informed a further set of recommendations contained within the main report ‘Too Little, Too Late: A Rights Based Review of Special Educational Needs Provision in Mainstream Schools’³.

Recommendation 1

The most constant theme emerging from this research is the significant under-funding of the SEN system in Northern Ireland. In response, there is an urgent need for government to increase the respective department budgets to allow *all* children with SEN or suspected SEN to be assessed in a timely manner and for early intervention to become a practical reality rather than a policy-level aspiration. In particular, it is clear that the EA budget is wholly inadequate to meet the needs of the growing numbers of children with SEN, and this should be redressed as a matter of urgency. Finally, there is a need for additional funding for schools so that they too can enhance their SEN provision and fund

³ This report is available on [NICCY's website](#) along with a summary report and an Easy Read version.

professional development for their staff. Only with appropriate funding in place will the other recommendations be achievable.

Recommendation 2

There is a fundamental flaw in the current SEN system, which Warnock herself came to recognise, in that the *statement* (one of the main proposals of her committee's 1978 report) is currently drawn up by the same local education authority which is legally obliged to pay for its provisions. Writing 40 years later, Warnock referred to the statement as the "most baleful element in our report" (2008, p.5) and it has undoubtedly led to conflict between what a child really needs to access the curriculum and what the EA is actually able to afford. It has also led to numerous disputes and tribunals as parents have appealed decisions made by ELBs/EA and argued for an increased level or different form of support. The result of this fundamental systemic flaw has been additional and unnecessary delay, bureaucracy and expense, when resources could and should have been directed towards supporting the children's learning needs in classrooms. There is accordingly a need to re-design the SEN system so that decisions around SEN provision (and especially the statutory assessment procedure leading to a statement) are taken by an independent body, separate from the EA and thus freed from budgetary constraints and conflicts of interest which increasingly obfuscate and too often override the child-centred principles of the SEN system. As one parent noted in the survey when asked how the SEN system in Northern Ireland could be improved: "Rip it up and start again. Make it child-centred."

Recommendation 3

This research has confirmed that the child should be placed at the very heart of the SEN system, so that everything planned and implemented is truly in the best interests of the child, and where the voice of the child (where possible) is heard and respected. These

commitments are already enshrined in legislation and policy on a regional, national and international level, but this study has highlighted how too often parents/carers report that budgetary or resource implications are prioritised above the needs and best interests of the child. Only when Recommendations 1 and 2 are adopted will Recommendation 3 become a reality so that education and the SEN system in particular can finally become truly “child-centred, child-friendly and empowering” (UN, 2001, General Comment 1). As one parent put it (on a post-it note): “The child needs to be at the centre of every decision”.

Recommendation 4

This study has sought to listen to parents and carers, feted as “equal partners” in numerous policy documents, but too often alienated or ignored, leading to feelings of confusion, anxiety and frustration with (at times) serious consequences for their own working life, mental health and relationships at home. Only when there is adequate funding in place within a reformed statementing process and with the child’s needs at the heart of the SEN system will parents’ views be truly welcomed. The current experience of too many parents/carers is negative (and it is especially negative in some regards for those whose children do not have statements), where parents/carers reported that they must adopt a combative, adversarial stance to fight for their child’s needs to be assessed and/or met. This is the very antithesis of equal partnership. Moving forward, parents’ and carers’ unrivalled experience, detailed knowledge and profound understanding of their child must be actively sought and valued at all stages of the Code of Practice (and not just at the statutory assessment stage). While there are already commitments in legislation and policy to provide appropriate guidance and support to parents/carers throughout the SEN process, this is demonstrably not happening in reality in all cases. Rather than parents/carers having to resort to voluntary sector support, the EA should provide a free, accessible, face-to-face service across each EA region for parents/carers where they could raise issues and voice concerns, and where trained EA officers could provide individual advice at all stages, from Stage 1 to Stage 5 of the current *Code of Practice*

Recommendation 5

There is a need for more comprehensive training for all professionals working within the SEN system. In particular, parents/carers identified a lack of knowledge and understanding of special educational needs and of the SEN system among staff at the EA but also among some teachers, SENCOs and principals, especially those whose Initial Teacher Education had been completed at a time when there was little or no SEN content in the programmes. There is also a need however for high-quality, accessible and up-to-date professional development opportunities for in-service teachers. This should be provided free of charge by the EA or subsidised through the HEIs, with adequate substitute cover provided to schools.

Recommendation 6

There were 73 parents/carers of children currently in special education, aged 0-3, or who are home schooled, whose responses had to be removed from the survey database as they fell outside the project specification. While the number of children with special educational needs in the mainstream system is much higher, the experiences of the parents/carers of very young children (0-3), those who are educated in special schools, or those who are home schooled, are undoubtedly worthy of attention, but have often attracted comparatively little research. The voice of these parents/carers also needs to be heard and so there is an urgent need for further research with these groups of parents/carers in Northern Ireland.

REFERENCES

- Ainscow, M. (2018) 'The Warnock Report: a catalyst for global change?' *Support for Learning*, Available online at: <https://onlinelibrary.wiley.com/page/journal/14679604/homepage/warnockvirtualissue> (accessed 12 August 2019)
- Audit Commission (2002) *Statutory assessment and statements of SEN: in need of review?* London: Audit Commission.
- Bajwa-Patel, M., and C. Devecchi. 2014. "'Nowhere That Fits': The Dilemmas of School Choice for Parents of Children with Statements of Special Educational Needs (SEN) in England." *Support for Learning* 29 (2): 117–135.
- BBC (2017) 'NI schools in the red: Education system faces £350m funds gap'. Available online at: <https://www.bbc.co.uk/news/uk-northern-ireland-42317279> (accessed 12 August 2019)
- BBC (2018a) 'Budget plans refused for 632 NI schools'. Available online at: <https://www.bbc.co.uk/news/uk-northern-ireland-42798691> (accessed 12 August 2019)
- BBC (2018b) 'Maghaberry primary school principal says parents donating toilet roll'. Available online at: <https://www.bbc.co.uk/news/uk-northern-ireland-46047134> (accessed 12 August 2019)
- British Educational Research Association (2018) *Ethical Guidelines for Educational Research* (4th edition). London, BERA.
- Brooks, R., te Riele, K., Maguire, M. (2014) *Ethics and Education Research*. London, Sage/BERA.
- Bruce, E. And Schultz, C. (2002) 'Non-finite loss and challenges to communication between parents and professionals', *British Journal of Special Education*, 29(1), 9-13.
- Creswell, J.W. (2014) *Research Design* (4th edition). London, Sage.
- Department of Education Northern Ireland (1996) *Code of Practice on the Identification and Assessment of Special Needs*. Available online at: <https://www.education-ni.gov.uk/articles/special-educational-needs-code-practice> (accessed 12 August 2019)
- Department of Education Northern Ireland (2005a) *Supplement to the Code of Practice on the Identification and Assessment of Special Needs*. Available online at:

<https://www.education-ni.gov.uk/publications/code-practice-identification-and-assessment-special-educational-needs> (accessed 5 September 2019)

Department of Education Northern Ireland (2005b) *Guidance for Schools: Recording Children with Special Educational Needs – SEN Categories*. Bangor: Department of Education.

Department of Education Northern Ireland (2009) *The Way Forward for Special Educational Needs and Inclusion*. Available online at: <https://www.education-ni.gov.uk/publications/every-school-good-school-way-forward-special-educational-needs-consultation-document> (accessed 12 August 2019)

Department of Education Northern Ireland (2018) *Annual Enrolments at Grant-aided Schools in Northern Ireland*. Available online at: <https://www.education-ni.gov.uk/sites/default/files/publications/education/annual-enrolments-at-grant-aided-schools-in-northern-ireland-201819.pdf> (accessed 12 August 2019)

Department of Education Northern Ireland (2019) *Statistics and Research*. Available online at: <https://www.education-ni.gov.uk/publications/education-data-infographics-201819> (accessed 5 March 2020)

Education (Northern Ireland) Order 1996. Available at <https://www.legislation.gov.uk/nisi/1996/274/contents> (accessed 5 September 2019)

Harrison, J., Henderson, M. and Leonard, R. (2007) *Different Dads: Fathers' Stories of Parenting Disabled Children*. London: Jessica Kingsley Publishing.

HMSO (1978) *Report of the Committee of Enquiry into the Education of Handicapped Children and Young People (The Warnock Report)*. (London, HMSO).

House of Commons (2019) *Education Funding in Northern Ireland – Report of the Northern Ireland Affairs Committee*. Available online at: <https://publications.parliament.uk/pa/cm201719/cmselect/cmniaf/1497/1497.pdf> (accessed 12 August 2019).

Kay, E., M. Tisdall, and S. Riddell. 2006. "Policies on Special Needs Education: Competing Strategies and Discourses." *European Journal of Special Needs Education* 21 (1): 363–379.

Keenan, M., K. Dillenburger, A. Doherty, T. Byrne, and S. Gallagher (2010) 'The Experiences of Parents During Diagnosis and Forward Planning for Children with Autism Spectrum Disorder', *Journal of Applied Research in Intellectual Disabilities*, 23(4), pp. 390–397.

Lindsay, G. and Dockrell, J. (2004) 'Whose job is it? Parents' concerns about the needs of their children with language problems'. *Journal of Special Education*, 37(4), 225–236.

Lunt, I. (2007) 'The challenge of meeting additional educational needs with or without statements of special educational need' in R. Cigman (Ed.) *Included or Excluded? The challenge of the mainstream for some SEN children*. (London, Routledge).

Moore, C. (2007) 'Speaking as a Parent: thoughts about educational inclusion for autistic children', in R. Cigman (Ed.) *Included or Excluded? The challenge of the mainstream for some SEN children*. London: Routledge.

National Audit Office (2019) *Support for Pupils with Special Educational Needs and Disabilities in England*. Available online at: <https://www.nao.org.uk/report/support-for-pupils-with-special-educational-needs-and-disabilities> (accessed 12 September 2019)

Northern Ireland Audit Office (2017) *Special Educational Needs*. Available online at: <https://www.niauditoffice.gov.uk/sites/niao/files/mediafiles/Special%20Educational%20Needs.pdf> (accessed 12 August 2019).

Norwich, B. (2018) 'Impact of the Warnock Report on English policy and practice: a personal view' *Support for Learning*, Available online at: <https://onlinelibrary.wiley.com/page/journal/14679604/homepage/warnockvirtualissue> (accessed 12 August 2019).

O'Connor, U., Hartop, B., & McConkey, R. (2005) 'Parental views on the statutory assessment and educational planning for children with special educational needs'. *European Journal of Special Needs Education*, 20 (3), 251–269.

Rose, R., Shevlin, M., Twomey, M. and Zhao, Y. (2017) 'Gaining access to support for children with special educational needs in the early years in Ireland: Parental perspectives', *International Journal of Early Years Education*, 25(4), pp. 379-392.

Special Educational Needs and Disability (NI) Order 2005, Available at: <http://www.legislation.gov.uk/nisi/2005/1117/contents> (Accessed: 5th September 2019).

UNESCO (1994). *The Salamanca Statement and Framework for Action on Special Needs Education*. Adopted by the World Conference on Special Needs Education: Access and Quality. Salamanca: Spain.

UNICEF. (1989). The UN Convention on the Rights of the Child. Available at: <https://www.unicef.org.uk/what-we-do/un-convention-child-rights/> (Accessed 5 September 2019).

United Nations (2001) General Comment No.1: The Aims of Education (article 29). Available at: [https://www.ohchr.org/EN/Issues/Education/Training/Compilation/Pages/a\)GeneralCommentNo1TheAimsofEducation\(article29\)\(2001\).aspx](https://www.ohchr.org/EN/Issues/Education/Training/Compilation/Pages/a)GeneralCommentNo1TheAimsofEducation(article29)(2001).aspx) (Accessed 5 September 2019)

Warnock, M. (2018) *SEN: The past and the future. Support for Learning*, Available online at: <https://onlinelibrary.wiley.com/page/journal/14679604/homepage/warnockvirtualissue> (accessed 12 August 2019).

Wedell, K. (1990) 'Children with special educational needs: past, present, future' in P. Evans and V. Varma (Eds.) *Special Education: Past, Present, Future* (Basingstoke, Falmer Press).

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