



## **“Not thriving... Just about coping”**

**Liverpool’s response to the health and  
social care needs of children and young  
people (0 - 25) with Special Educational  
Needs and Disabilities (SEND)**

**March 2020**

**(Updated September 2020)**

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# Introduction

This report was researched and compiled prior to the Covid-19 crisis and was submitted to Liverpool’s SEND Partnership Board in draft form in the week before the country went into lockdown in March 2020. The report and recommendations clearly need to be considered in this light; however the issues raised within the report have not ceased to exist. In many ways they have become even more pressing.

Healthwatch Liverpool has added this introduction to highlight some immediate points of concern in the first six months of the pandemic, and we have also added an additional recommendation (Recommendation 18) which underlines the need to continue support for children and young people with SEND, and their families and carers, within the new landscape. In all other respects, the report remains as it was in March.

The SEND Partnership Board’s initial response to this report confirmed that its findings would help to inform the SEND Joint Strategic Needs Assessment (JSNA), the SEND Co-Production Charter and the SEND Joint Commissioning Strategy. Healthwatch Liverpool welcomes this commitment and looks forward to continued partnership with the Board in the future.

Over the past six months, the main concerns that have been raised with Healthwatch Liverpool in relation to SEND support for children/young people and their parents/carers have related to:

- a. **The Coronavirus Act 2020** and fears about its potential impact on 3 areas of SEND policy/practice in particular.
  - i. **SEND duties under the Children and Families Act.** Section 16 of the Coronavirus Act gives powers to the Secretary of State to vary/dis-apply/modify some statutory provisions. For instance, Section 43 of the Children and Families Act (the duty on schools to admit a child where they are named in an Education Health and Care Plan (EHCP)), or Section 42 (the duty to secure special educational provision and health care provision in accordance with an EHCP)

could change from an ‘absolute’ duty to ‘reasonable endeavours’ by the LA or CCG.

- ii. **Adult Care and Support.** The Act suspends almost all provisions of the Social Care Act 2014 and, in particular, the need to meet eligible needs for disabled people (Section 18) and their carers (Section 20). It also dis-applies most of the transition provisions for young people moving from Children’s/Paediatric services into Adult services. Instead of ‘duties’, Local Authorities now have ‘powers’ to do these things, and a duty to avoid a breach of a person’s rights under the European Convention on Human Rights (N.B. this Convention falls within the remit of the Council of Europe, not the European Union, so should still apply (in theory) after Brexit). The threshold for breach of rights to care and support is already high, so disabled young adults may be left without care and support when they are additionally vulnerable.
- iii. **Mental Health Act.** Now allows people to be detained on the authority of one doctor instead of two. This potentially puts vulnerable people (including those with SEND) at additional risk.
- b. **School closures / re-opening and SEND provision.** National discussions have focused on the need to maintain safe access to education for all children/young people and it is crucial that those with SEND are not left behind by this conversation or by national or local strategic priorities. In order to ensure equity for all children and young people, access to education must be supported by needs-led health and social care support.
- c. **Additional stress factors on parents/carers during lockdown.** Healthwatch Liverpool’s online survey about the impact of Covid-19 on access to local health and care services received responses from a number of parents/carers of children/young people with SEND. The difficulties they had experienced included delays to assessments and the completion of EHCPs; reduction of external support and care for their children; the impact of lockdown restrictions and sudden changes in routine for children with SEND; and the additional impact on the mental health of family carers.

*Claire Stevens, Information and Project Officer (Engagement), Healthwatch Liverpool, September 2020*





# Executive Summary

It has been five years since the Children and Families Act 2014 introduced significant changes to the delivery of education, health and social care services to children and young people (aged 0-25) with special educational needs and disabilities (SEND).

During this time, parents, carers, children and young people needing assessment and additional support in Liverpool have reported frustration at the pace of change, including strategic responses and service re-design, and have expressed concerns about the impact that this has had on their wellbeing - above and beyond the day-to-day challenges which they face.

During this period, Liverpool, in common with the rest of the country, has experienced increasing demand on education, health and care services in a climate of austerity and reduced resources.

A joint Care Quality Commission/Ofsted inspection of Liverpool's SEND provision in January 2019, whilst highlighting examples of good practice, identified “significant weaknesses”, noting a number of areas of concern and setting out specific areas for improvement.

Liverpool City Council, NHS Liverpool CCG (Clinical Commissioning Group) and key partners have responded positively to the issues highlighted, acknowledging that change has been slow and producing a SEND Written Statement of Action (WSOA). This Statement outlines how the city intends to address concerns relating to, for example, multi-agency working, Education, Health and Care Plan (EHCP) assessment, Autism Spectrum Disorder (ASD) and Attention Deficit Hyperactivity Disorder (ADHD) pathways.

It therefore felt timely for Healthwatch Liverpool to offer an independent opportunity for children and young people, parents and carers, and SEND professionals to provide comments and feedback on how change is progressing, to help to inform ongoing strategic development and implementation, and to contribute to positive progress in the spirit of co-production.

It is also in line with the Healthwatch role, as set out in the SEND Code of Practice (DfE, DoH, Jan 2015), in terms of:

- i. Provision of information and advice about education, health and care, which should be included as part of the Local Offer
- ii. Engagement of children, young people, parents and carers in the SEND commissioning process
- iii. Local accountability through membership of the Health and Wellbeing Board
- iv. Local Independent NHS Complaints Advocacy

Over 9 months we received input from 208 individuals, including:

- + 75 parents and carers
- + 72 children and young people
- + 61 SEND practitioners<sup>1</sup>

The aim of our engagement with children, parents, carers and professional stakeholders was to capture, and learn from, their experiences of Liverpool’s SEND provision and to make a series of recommendations, based on their expert insights. We aimed to look at the whole process, from identification and assessment of need, through to the production of EHCPs (where required), individually tailored support, and transition to adulthood and adult services. We were particularly mindful of the fact that the Children and Families Act 2014 emphasises working collaboratively with children and young people with SEND, and their parents or carers – and states that EHCPs and other appropriate support should be co-designed with them and take account of their views, wishes and aspirations.

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1 Including Special Educational Needs Co-ordinators (SENCOs), teachers, health and social care commissioners, voluntary sector practitioners and health service professionals.

# Methodology

This report is the culmination of a Healthwatch Liverpool project which ran between May and December 2019.

Initial contact was made with a range of key stakeholders within Liverpool City Council, NHS Liverpool CCG and the voluntary sector, to gather baseline information and seek expert perspectives on Liverpool’s SEND successes and challenges. This took place alongside a literature review.

A call was also put out via parent and carer networks and social media for children, young people, parents and carers who would be prepared to participate by completing surveys or taking part in semi-structured interviews /focus groups.

Three surveys were designed, based on initial conversations with stakeholders, and circulated to:

1. Parents and Carers
2. Children and Young People
3. SEND practitioners

It should be noted that Healthwatch’s statutory remit under the Health and Social Care Act 2012 covers health and social care services but does not extend to education. However, given that all three areas are intrinsically interlinked and covered by EHCPs and SEND policy, it is impossible not to consider all three elements of provision to some extent. They all contribute to the overall wellbeing of children and young people and, by extension, their families and carers – and thus to the city’s wider public health outcomes, as set out in the Children’s Transformation Programme Board’s document ‘A Plan for the Delivery of a New Model of Integrated Community Child & Family Services Across Liverpool, 2018 – 2021’.

The surveys were available online at the Healthwatch Liverpool website between October and December 2019 and were also circulated to the SEND Partnership, LivPaC (Liverpool Parents and Carers Forum), ADDvanced Solutions, SENDIASS (Special Educational Needs and Disabilities Information Advice and Support Service), Liverpool Parenting Strategy Working Group, ADHD Foundation and YPAS (Young Persons’ Advisory Service) with requests to circulate to their networks. Hard copies were also available and were sent out on request, as well as being handed out at all relevant meetings. We also undertook to provide the surveys in a range of alternative formats and languages, if requested.

In-depth, semi-structured interviews were conducted with the parents or carers whose family experiences appear in this report as case studies. To encourage participation from Black, Asian, Minority Ethnic and Refugee (BAMER) families, a focus group was held at Mary Seacole House and a further focus group was held with parents attending an ‘English as an Additional Language’ group.

Healthwatch Liverpool also commissioned the Liverpool Safeguarding Children’s Partnership (LSCP) Young Advisors to conduct 6 peer-led focus groups with young people, based on our survey questions.

During the period in which this report was being researched and compiled, Healthwatch Liverpool also attended SEND Partnership Board meetings and training events and was able to observe collaborative working and co-production in progress.

# Recommendations

1. **Increase the size of the SEND Case Work Team** and ensure that parents/carers and, where appropriate, children/young people know who their Case Worker is, what their role entails, and how to contact them. This will a) further reduce caseloads; b) reduce waiting times; c) improve communication with parents/carers; and d) provide a single point of contact for signposting and co-ordination of information. It is encouraging to note that additional staff are already being recruited.
2. **Renew the emphasis on early intervention.** Early awareness of the signs or indicators of SEND can be as helpful to those not meeting the EHCP ‘threshold’ as to those that do. This entails professionals listening to parents/carers and valuing their expert insights about their own children’s strengths, needs and aspirations. Early support is crucial to reduce crises, costs and mental distress for the whole family; and increased training and support for nurseries and early years professionals to assist parents/carers with initiating EHC assessments as early as possible is essential.
3. **Increase the representation of parents/carers and children/young people at all stages of the commissioning cycle** – including additional places on the SEND Partnership Board – to improve co-production and further amplify the voices and expert experience of these groups. This should include the introduction of formal and informal mechanisms for children/young people to feed into strategic decision making and governance. Again, more value needs to be given to the expertise of parents/carers and to diversity of inclusion.
4. **Work to develop ‘whole life’ pathways** – from early years through the transition between stages of education, to the transition to adult services. This should include ‘easy access’ to adult services for young people/adults with late diagnoses. A clear majority of parents/carers who responded to the Healthwatch Liverpool survey said the EHCP doesn’t contain enough information about transition to adulthood. It is encouraging that the NHS Mental Health Implementation Plan 2019/20 – 2023/24 addresses this to some extent in respect of psychological support but this should also apply to neurodevelopmental and other additional needs.
5. **Refresh and redesign the SEND Local Offer website** – and include Healthwatch Liverpool (HWL) as part of the Local Offer; particularly in relation to its roles in information provision (e.g. maintaining the Live Well Directory<sup>2</sup>) and independent NHS Complaints Advocacy. Parents/carers and professionals still feel the need for clearer access to information, advice and advocacy on e.g.



diagnosis, treatment, peer support, professional support, training (e.g. on social skills, dealing with violence from children/young people, independent living, employment opportunities and Access to Work), culturally appropriate support, etc. The Liverpool Local Offer app, co-produced with children and young people, provides a useful model for how parents and carers could be further involved in designing a Local Offer website which responds to their needs more efficiently, and which shows evidence of wide consultation with equalities groups and with parents/carers/children/young people living with under-represented SEND support needs as well as those with more common diagnoses/conditions. Any redesign should take account of a range of access needs (e.g. pictures may help some groups but may be problematic for others without a description) and ways of presenting information which is navigable by people with a range of additional needs, including sensory impairments.

6. **Improve the consistency and quality of EHCPs** – to include specific/quantifiable support which can be easily monitored and evaluated. This will enable parents/carers to have a better understanding of what support is in place and who is responsible for delivering it; and will also enable all stakeholders to monitor the support delivered, and its associated outputs/outcomes, more effectively.
7. **Ensure that EHCPs are meaningful to children/young people.** Children and young people who attended focus groups facilitated by LSYP Young Advisors on our behalf requested a one-page document, explaining the EHCP aims and actions. They suggested that this should be provided in addition to a detailed explanation, before and during their appointments, about what the meeting is about, what will happen at it, how the meeting and subsequent support plans have been designed to help them, and how they can provide feedback about whether or not EHCP actions or support plans are working well for them.
8. **Increase investment in voluntary and community sector support** for parents/carers and children/young people. This could also include increased commissioning of voluntary sector organisations, such as Parent and Carer organisations and statutory services provided by voluntary sector organisations (e.g. LivPaC and SENDIASS) and those with a focus on equality and diversity (e.g. Mary Seacole House) to increase their already excellent delivery of information, advice and support. Increased capacity in the voluntary and community sector should reduce pressure on statutory services whilst providing reassurance to families through peer-led support and ‘lived experience’ expertise.
9. **Increase investment in BAME voluntary sector and language support** to ensure equality of access for Black, Asian, Minority Ethnic and Refugee families; and those whose primary language is not English (including BSL). Ensure BAME parent/carer representation on the SEND Partnership Board, and increased diversity in the Board membership and the SEND workforce, which should increase cultural sensitivity and reduce unconscious bias.

- 10. Increase the focus on mental health support** for the whole family unit, including via peer support. One of the most striking features of the feedback from Healthwatch Liverpool’s SEND work has been the levels of stress, anxiety, depression and fear that families live with, in addition to the everyday pressures of living with SEND. This still requires de-stigmatisation and easy access to support.
- 11. Improve access to information about personal health budgets** - what they are, how to access and manage them, the advantages and drawbacks, and where to find further advice and information.
- 12. Improve information about choice of educational setting** - including mainstream provision, specialist provision and home education as options for parents/carers. Listen to parents/carers and children/young peoples’ concerns, aspirations and preferences and provide clear information on the advantages and drawbacks of the available options. Encourage use of existing facilities (e.g. libraries/schools out of hours) by home educators and peer support groups, and encourage collaboration and partnership between mainstream and specialist schools, to share resources, expertise and best practice, to the benefit of all.
- 13. Improve communication** between professionals and parents/carers, and between professionals. Co-production and multi-agency working should always focus on the child/young person’s best interests and this requires more opportunities for contact between all stakeholders, on a level playing field and with mutual respect. Named case workers should play a key role as facilitators but there is also a need to continue developing ‘Local Offer Live’ events, and opportunities to work collaboratively through co-production working groups, lead jointly by parents/carers and professionals. There should also be emphasis on two-way communication between strategic leads and professionals working in the field, to ensure that strategy is informed by the reality ‘on the ground’.
- 14. Increase access to training opportunities.** This includes SEND awareness training for professionals across education, health and social care and, particularly those teaching (and training to teach) in mainstream settings. Co-production might also include parents/carers and children/young people delivering training to professionals and/or developing joint training sessions with professionals. Training for parents/carers, children/young people and siblings should continue to be offered at flexible times and locations. Some parents/carers would find shorter courses (6-week rather than 12-week) easier to commit to. Some parents/carers requested support around violence from their children/young people as they become older. Again, there are opportunities to commission training from voluntary sector partners.

- 15. Increase access to short breaks, respite, Local Authority-provided social activities for families.** This would help to alleviate stress for all family members. However, at present, families report that they do not meet thresholds, or that services do not cater to their needs, so they feel excluded. The geographical spread of services also prevents access by those without their own transport.
- 16. Improve alignment of Neurodevelopmental and CAMHS support.** Some concerns remain that children/young people can miss out on accessing additional support once they have a diagnosis for another specific Pathway. It is encouraging that the NHS Mental Health Implementation Plan 2019/20 - 2023/24 addresses this to some extent.
- 17. Ensure wider diversity of representation.** Other recommendations focus on greater involvement of parents/carers and children/young people – including those from BAMER groups – at strategic level, in the workforce and across advisory groups. This also applies to e.g. low- incidence disabilities. It is important to ensure equally good provision and choice for children/young people with less common additional needs as for those who are relatively well provided for. The views of those with rarer conditions are not always gathered or represented effectively in surveys or other mechanisms for participation and co-production, including in this report, and action needs to be taken to address this.
- 18. Maintain existing levels of support services across education, health and social care,** and work towards strategic improvements notwithstanding the implications of The Coronavirus Act 2020 or any subsequent legislation which may reduce pre-Covid-19 statutory duties towards children and young people with SEND.

# Report Findings

## Context

A child or young person (0-25) is said to have SEND if they have a learning difficulty or disability which requires special educational provision to be made for them in order to support them to progress. Local service provision is governed by Part 3 of the Children and Families Act 2014 and the SEND Code of Practice 2015, although other legislation, such as the Equality Act 2010, is also relevant.

The introduction of the Children and Families Act and SEND Code of Practice placed greater emphasis on the inclusion of children, young people, parents and carers in planning and decision-making, as well as on supporting aspirations and improving outcomes. This should be facilitated by strengthening joint planning and commissioning of services and the publication of a Local Offer, listing information about local SEND support.

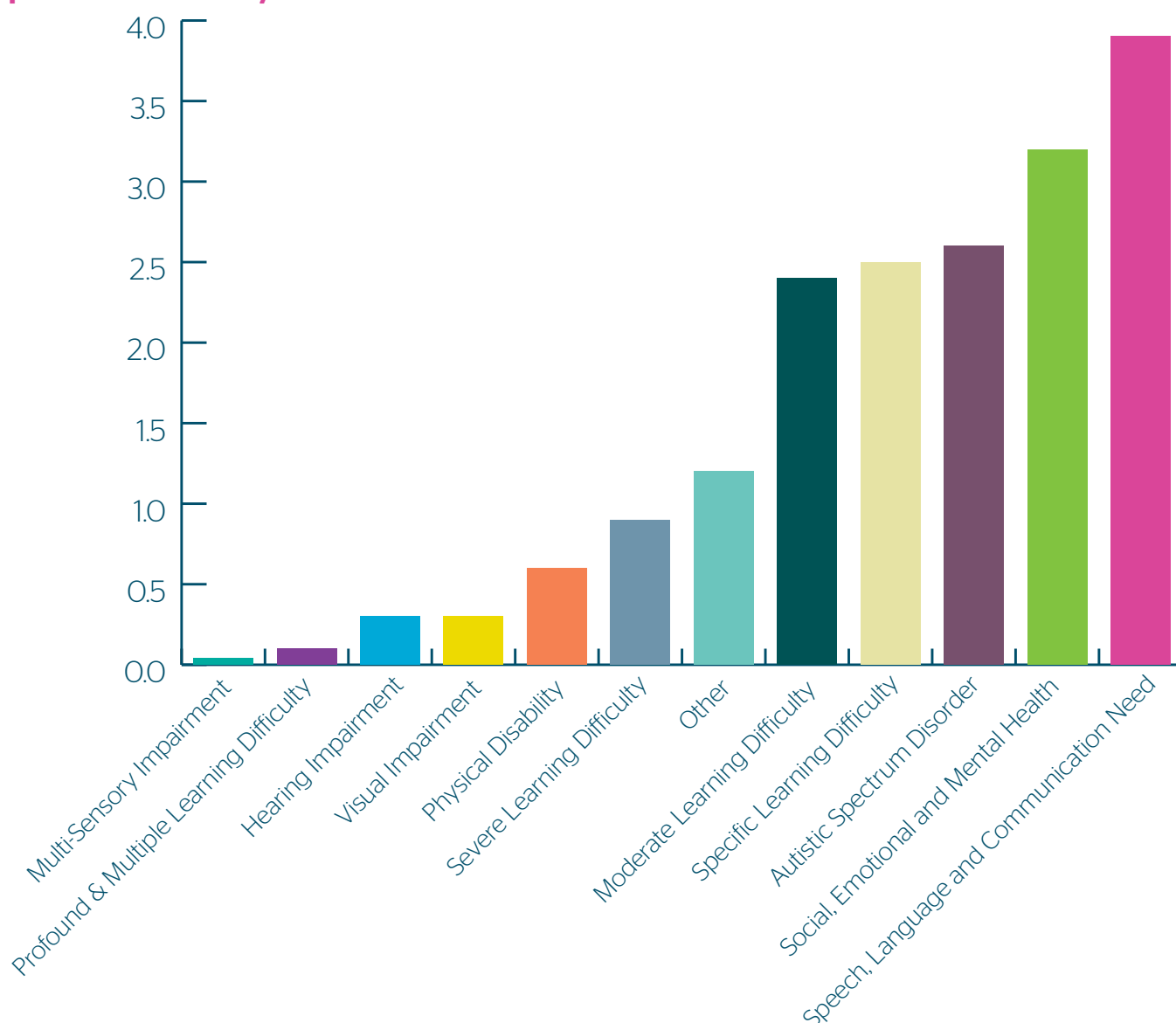
In England, the number of pupils with SEND increased for a third consecutive year (as of Jan 2019), representing 14.9% of the total pupil population. This reflects increases both in the number of pupils with an Education, Health and Care Plan (EHCP) and with SEND support.

271,200 pupils (3%) of England’s pupil population have an EHCP and a further 1,047,200 pupils (12%) receive SEND support.

In Liverpool, Department for Education (DfE) data for 2019 lists a total of 74,405 pupils in 180 schools (including primary, secondary, state-funded, independent and special schools), of whom 11,847 (16%, 4% higher than in England as a whole) receive SEND support, and 2,163 (3%, in line with national figures) have an EHCP or Statement. These pupils have a wide range of support needs but the most prevalent relate to those pupils with:

- + Speech, Language and Communication Needs (SLCN); 2,916 pupils (3.9% of Liverpool’s total pupil population)
- + Social, Emotional and Mental Health needs (SEMH); 2,414 pupils (3.2%)
- + Autism Spectrum Disorder (ASD); 1,967 pupils (2.6%)

## SEND Support Needs in Liverpool Schools, by Primary Need, as a % of the pupil population - January 2019



Source: Department for Education, Special Educational Needs in England: January 2019

Following an Ofsted/CQC inspection in January 2019, and the subsequent Joint Outcome Letter, Liverpool’s senior leaders produced a Written Statement of Action (WSOA) which sets out how the city will tackle the areas of significant weakness identified. The WSoA was accepted as ‘fit for purpose’ by Ofsted in August 2019 and the SEND Partnership is now working to implement and deliver the statement.

### 1) Strategic Progress

Over the past 12 months, key commissioning and service provider partners have made significant strides in responding to joint Ofsted/Care Quality Commission (CQC) criticisms. This has resulted in a revised and refreshed SEND Partnership Board working well towards improving governance, monitoring and review of support to children and young people in Liverpool, whatever their support needs - and whether or not they have an EHCP in place.

The establishment of the SEND Partnership Improvement Steering Group, the EHCP Quality Assurance Group and the new SEND Joint Commissioning Board (all in partnership with parents and carers),



together with the production of the Written Statement of Action (WSOA) – and the SEND Joint Strategic Needs Assessment (JSNA), have been the necessary steps in starting to rebuild trust, share best practice, improve outcomes, and establish a shared vision for SEND provision in the city.

Evidence presented at SEND Partnership Board meetings shows that progress has also been made towards increasing staff numbers in the SEN Assessment Team, with plans that further staff will be recruited in the coming months. This has already resulted in caseloads being reduced from 450 to 350, with a target caseload of 143 cases per caseworker, in line with equivalent Core Cities<sup>3</sup>.

Further progress has been evidenced by factors including completion of the Strengths and Difficulties Questionnaire (SDQ) exceeding the ‘in year’ target; reduction in Autism Spectrum Disorder (ASD) waiting times exceeding the interim target; and the completion of the Transition Pathway for 18-25 year olds with ADHD from paediatric to adult services being completed, with the backlog of cases being cleared to meet the target date.

There has also been marked improvement in the timeliness of receipt of EHCP Advices. The most recent figures at the time of writing show that Educational Psychology advices have been at 100% for 4 consecutive months, Health advices return rates were at 96% and Social Care advices at approximately 80%. All the above is very much welcomed. However, there is still much to be done.

Although EHCP timeliness has improved overall, the target is still not being met, and the SEND Partnership Board’s Performance Risk Register and Written Statement of Action Plan show slow progress overall – in some cases being almost 12 months behind schedule.

A recent SEND Partnership Development session identified that the board would consider itself to be working successfully if:

1. Children and families feel their needs are being met by receiving the right support at the right time.
2. The decision-making processes are demonstrably transparent, and inclusive of parents/carers and children/young people.
3. There is a shared understanding of strategic priorities, policy, procedure, commissioning responsibilities and service provision/the Local Offer.
4. All stakeholders – including parents/carers and children/young people – have a shared vision, expectations and ambitions.
5. The collective view is agreed and communicated effectively/clearly understood by all stakeholders.
6. All stakeholders have a clear understanding of what processes, services are available.
7. Communication is clear and accessible to all.
8. Joint use is made of people, resources, evidence/data to deliver agreed timelines and quality assurance.

<sup>3</sup> A group of UK regional cities including Belfast, Birmingham, Bristol, Cardiff, Glasgow, Leeds, Liverpool, Manchester, Newcastle, Nottingham and Sheffield.

The challenge is to translate these aims into reality, which can be evidenced by families reporting improved outcomes. In order to move towards this, SEND Partnership Board members agreed (in January 2020) that their immediate priority themes (in addition to existing Action Plans) should be:

- + Engagement
- + Communication
- + Co-production
- + Early help/early intervention
- + Consistent/clearly mapped SEND ‘journey’ for all children/young people and their families/carers
- + Improved use of shared data/intelligence

During the period in which Healthwatch Liverpool was working toward this report (May 2019 – March 2020) there were three events hosted jointly by LivPaC and Liverpool City Council, which not only demonstrated genuine partnership working between parents/carers and the local authority but also involved an impressive range of organisations which offer SEND support.

The first of these was the ‘Local Offer Live - SEND Information Day’ at St George’s Hall on 19th June 2019. This was followed by the ‘Children with SEND – Developing our approach to participation, engagement and co-production’ event at LACE Conference Centre on 7th October 2019 and the ‘SEND Co-Production Charter’ event on 24th February 2020.

In addition to these locally-focused events, the ADHD Foundation hosted a ‘National Neurodiversity and Mental Health Conference’ on 4th October at the ACC Conference Centre, aimed at Clinicians, Teachers, Counsellors, Social Workers, Nurses, SENCOs, Psychologists and Occupational Health practitioners. The following day (5th Oct), the ADHD Foundation also hosted the ‘National Parents and Carers Special Educational Needs and Mental Health Conference’ at the same venue. The conference attracted approximately 500 parents and carers - a number of whom were local residents - and covered a broad range of SEN-specific practical advice and expert opinion on subjects including Autism, ADHD, Mental Health, Dyslexia, Dyspraxia and Dyscalculia.

These events were complemented by ongoing work to improve:

- a. Mental health support for children and young people, including the ‘Children and Young People’s Mental Health Local Transformation Plan Workshops’ held in November.
- b. Support to parents, through the work of the Liverpool Parenting Strategy Group and the ‘Liverpool Parenting Survey’ circulated in September.

Healthwatch Liverpool was invited to join the Liverpool SEND Partnership Board as an independent observer and attended a Board development session and training on the SEND Code of Practice on 2nd September 2019 and a further Board Development session on 15th January 2020.

All of these events, and other initiatives, such as the Multi-agency Training Needs Analysis circulated in February 2020, demonstrate the commitment of local leaders to improving the Local Offer, increasing opportunities to access information, advice and support and co-produce strategic approaches with parents, carers, children and young people.

As noted above, the challenge now is to maintain these partnerships and approaches, do more to ensure that children and young people are kept at the centre of everyone’s agenda, and produce (and

maintain) evidence that structural changes are leading to improved outcomes for children, young people, their parents and carers, and the professionals who support them on a daily basis.

The parents/carers, children/young people and SEND practitioners who responded to the Healthwatch Liverpool survey expressed a range of experiences and opinions, which this report aims to include representative samples of, and which have informed the thematic sections below.

Some respondents, particularly professionals, expressed doubts or caution about strategic approaches:

*“We all want the best for our children, but the constant ‘reviews’ of the service are not effecting change. As a Head Teacher, I want to see something happening now.” SEND Practitioner*

*“The SEND reforms introduced in 2014 are ambitious and laudable. However, to introduce such comprehensive reform without the resource to support implementation, and even worse during a time of huge cuts in public expenditure, is disingenuous at best!” SEND Practitioner*

*“I feel sad that many aspects of the reforms have simply not been addressed.” SEND Practitioner*

*“Strategy should be bottom up not top down. Often, we are told what we have to do with little consultation, or this is simply established as a paper exercise. Decisions are made when there is little knowledge of what services offer, why they exist and what their role is... Decisions are made on where we should go without any real understanding on where we are or if it is even possible.” SEND Practitioner*

However, despite obvious and often deeply held frustrations, many of which have built up historically, there was also ample recognition that all stakeholders have the best interests of the city’s children and young people at heart.

*“Just to say that I am continuously inspired by staff involved with SEND practice. Their passion and enthusiasm to make a difference for this cohort of CYP and their families is overwhelming.” SEND Practitioner*

An important point is that the improvements and focus for change predominantly looks at EHCP processes, yet another, equally important, focus should be on mainstream SEND support, and support for all children and young people’s individual needs and aspirations. It is generally acknowledged that SEND provision is over-stretched and under-resourced and consequently there is often a push for EHCPs in order to access the support needed, when this should not always be necessary. Greater improvements to mainstream SEND provision still need to be addressed.

*“The themes and focus of strategy prioritise EHCP resulting in minimal attention to SEND support. This creates escalation and misunderstanding around SEN support. The Code of Practice details the statutory requirements for SEN support also.” SEND Practitioner*

## 2) Healthwatch Liverpool Survey Data: Key Themes

In addition to analysing the quantitative data submitted in the surveys (see Appendices for data tables), we also undertook a thematic analysis of the qualitative data included in the completed surveys, one-to-one interviews and focus groups. Comments and feedback largely fell within the following 13 thematic areas and, since Healthwatch Liverpool’s remit is to amplify the voices of service users and ensure they are heard by policy-makers and service commissioners, we have included a large number of representative quotes.

Inevitably, there is considerable overlap between themes (e.g. lack of clear communication may lead to delays in the assessment process, which then increase stress and anxiety for parents/families and reduce effective co-production of EHCPs) however, there was enough feedback (or, in some cases, lack of feedback) about the following themes to warrant listing them separately. To the best of our knowledge, all comments were accurate at the time of submission, but circumstances may, of course, have changed subsequently.

Our own commentary is based on the information that was submitted to and/or shared with us and does not necessarily reflect the wider views of all families or professionals. We have, however, attempted to reflect the available information as fairly and constructively as possible. This section is based on input from parents/carers and professionals; feedback from children/young people is discussed later.

### 1. Delays to assessment of need, implementation and review of EHCPs and other support plans

A recurring theme from parents/carers and professionals was that issues of concern are often picked up too late. This is not necessarily because parents/carers haven’t sought help or advice, but because they feel they have either not been taken seriously or because the system has simply not been quick enough to respond to requests for assessment or support. This underlines the need for SEND awareness across the board, from parents to professionals, including generalist professionals working in health, care and education as well as specialists.

The importance of Early Years support and early interventions cannot be underestimated. Delays to appropriate support being offered can further delay children’s development, reduce their future prospects and increase the pressure on parents and families, leading to increased mental health support needs and reduced outcomes for children and families.

Whilst timely assessments are absolutely central, it is equally important that diagnoses should be accurate, as misdiagnosis can lead to the wrong medication being prescribed or the wrong therapy or support offered, again decreasing the potential for the best possible outcomes and the ability of children and young people to meet their full potential/aspirations. Similarly, resources could be allocated more efficiently with a timely planning meeting preventing costs associated with delays and errors later.

*“Trying to get an agreement to assess from (the Local Authority) is like trying to get blood out of a stone; the more you provide the more they want.” Parent/Carer*

*“Awaiting draft to be finalised; into the 35th week so 15 weeks overdue.” Parent/Carer*

This applies to reviews of EHCPs or other support plans as well as to initial assessments. Typical responses from parents and carers included:

*“We have been waiting a year for a first appointment. Someone is making mistakes with the referral.” Parent/Carer*

*“EHCP completely out of date, still awaiting review from 18 months ago that contains essential changes to be completed.” Parent/Carer*

*“[EHCP] has not been properly reviewed since 2015 and is vague and out of date.” Parent/Carer*

According to Healthwatch Liverpool survey data: 68% of parents/carers said that the EHC needs assessment and plan development was not completed within the agreed timeframes; 24% stated the timeframes were maintained. Review scores were more positive, with 64.5% of parents/carers stating that their child’s plan was reviewed regularly.

*“EHCP process was over timescales and subsequent amendments to the plan have occurred up to 9 months behind annual review...” Parent/Carer*

*“The process takes too long and during this long time period, children are struggling badly.” Parent/Carer*

*“I understand it is about educational officer resources, but a planning meeting doesn’t exist and would prevent delays or errors in information gathering that would be obtained from start.” Parent/Carer*

In the views of parents/carers, the EHCP process is seen as challenging and taking too long to complete. Any amendments to plans are delayed whilst reviews are pending, and this means they become outdated and no longer function correctly. There is the potential to seek advocacy for help with the process and this has made the process easier and outcomes more suitable for the parent/carers and therefore child/young person. However, advocacy appears to be limited in its availability/access as many parents/carers indicate a desire for this but are unsure where to find it, or have requested it but not received as much support as they’d hoped for due to limited resources.

*“We had to use complaints procedure to get plan reviewed.” Parent/Carer*

*“The review process has been done but the amendments that I have asked for have not been done within the correct time frame.” Parent/Carer*

*“Delays, drift and inexperienced workers producing poor quality plans means children’s needs are not being adequately met. Whole service is under-resourced.” Parent/Carer*

*“I can cope with the children’s behaviour but fighting the system is hard.” Parent/Carer*

*“Disabled children are not accepted in Liverpool. There is no help or support and as a parent I feel let down by all. It seems the more disabled you are the less help there is, everything is a fight and I get nowhere...referrals are terrible and too long, communication is dreadful, and appointments are shocking.” Parent/Carer*

*“Very poor experience, complete breakdown with school because of the way this process was managed. I requested an early help social worker to liaise with school and this is written into the EHCP, as is his EHAT (Early Help Assessment Tool).” Parent/Carer*

*“It is unacceptable to wait 2 years for an ASD diagnosis to then be told that your son is being referred to the ADHD pathway, and that the current wait is over 12 months, my son has been failed for the last 3 years by school and wait times and is now being failed again by healthcare by making him wait another year for support and medication to address any ADHD.” Parent/Carer*



The delays and exceeding of timescales are a paramount concern for the parents/carers who responded to the survey. There is a lot of criticism with regards to how the system works and what improvements need making; chief amongst these is communication, lengthy paperwork, long delays and lack of availability which leads to the delays. Parents/Carers are also frustrated by the lack of support and the combative nature of the process which leaves them feeling defeated.

Most comments from SEND practitioners were also relatively negative about timeliness - of the EHCP process in particular. Many of these were factual descriptions of how many assessments were delayed, particular pathways or parts of the process affected. Some mention very long delays and, whilst some indicate that only some cases are getting delayed, others indicate that timescales are missed routinely and that there are features of the process itself which cause these delays. Some mention waiting lists which may be a resources issue (see p38 below for further comments about resources):

*"Few plans are completed within timescale."* SEND Practitioner

*"High work demand on all services results in late advice or late writing of EHCPs."* SEND Practitioner

*"Waiting 18 months or more, sometimes several years is poor"* SEND Practitioner

*"I've been involved in reviews of EHCPs that haven't been amended a few months afterwards"* SEND Practitioner

*"Too long, too many steps"* SEND Practitioner

*"There are too many steps in the process, which leads to delays in children receiving support they need."* SEND Practitioner

*"The paperwork often gets in the way of meeting the needs of children. It is a long process of gathering evidence..."* SEND Practitioner

*'It takes a totally unacceptable amount of time, HUGE amounts of work and data and assessments are gathered and used before assessment is considered..."* SEND Practitioner

The practitioners predominantly acknowledge that timescales are being exceeded although experiences differ, with some stating that none have been completed within expected timeframes and others indicating that some exceed the timescales. Another theme is that the process itself is unnecessarily complicated, causing delays. Practitioners state the amount of evidence and data collection that is required prior to and throughout the assessment process is time-consuming, with too many stages of the process. There is acknowledgement that exceeding the time frames is having a detrimental impact on children/young people's development. Although lack of resources/personnel may be an issue, it is hoped that recent restructuring may address the 'backlog' but this needs to be monitored and any potential simplifications of the system that are identified should be introduced.

Some practitioners made comments which suggested that positive changes are already starting to be seen:

*"We are working to improve our timescales."* SEND Practitioner

*"Aware of difficulties in the past. Primary feedback raises examples of timeliness exceeding the statutory times. Recent restructure is encouraging."* SEND Practitioner

*"There is lots going on, with changes to the way things were done. Unfortunately, this is not quick enough for some families."* SEND Practitioner

*"I think we have made progress in relation to EHCPs but there is plenty more work to do around neurodevelopment."* SEND Practitioner

*"Additional resources and improved processes are improving service provision."* SEND Practitioner

***“The WSoA (Written Statement of Action) has geared all services up to improve and work with families.” SEND Practitioner***

***“I am aware that the service has suffered some staffing difficulties etc. and I am also aware that they have a strategy in place to address any issues.” SEND Practitioner***

It is encouraging to see that some practitioners are positive about the recent changes to processes. The introduction of additional resources, particularly within the Council’s SEND casework team, are likely to increase capacity and enhance the quality of service provision alongside procedural changes to improve efficiency. Awareness of new evaluation methods within the system to track and report on progress is evident and practitioners now have a more systematic monitoring procedure that can inform about and indicate successes and failures. There is some evidence that such practical changes have started to trickle down into the everyday workings of the process and have been adopted as an important component of the practitioners’ role. However, the majority of positive comments appear to have come from professionals in more senior or strategic roles, so it would be useful to see whether ‘frontline’ practitioners report positive changes in any future re-run of the survey.

As these changes are fairly new, we may not see the full extent of any improvements for some time yet, however, timeliness has clearly been identified as an issue that is improving. It is encouraging that feedback has resulted in these changes, but it is worthwhile noting that these comments relate directly to timeliness and this is not the only issue within the process. The heightened focus on this should not detract from other issues such as co-production; communication; lack of information etc.

Despite encouraging signs, practitioners also made a significant number of comments about failure to complete and implement reviews effectively in order to capture changing and emerging needs. Typical examples include:

***“Some plans are fit for purpose when issued but the review process needs to be more thorough to ensure emerging needs are captured and met.” SEND Practitioner***

***“Children’s needs change a lot throughout a year.” SEND Practitioner***

***“The initial EHCP is often very appropriate but the review process is not adequate and the time for reviews to be updated is currently very poor with schools being told that their reviews and amendments will not be actioned for a few months. The potential there is for the EHCP to be permanently unable to meet the learner’s needs due to weak processes.” SEND Practitioner***

Nevertheless, it was recognised that professionals continue to place children’s needs at the centre of the process.

***“Although slow to complete the process, meeting needs of children is still the primary driver behind all decisions.” SEND Practitioner***

## Importance of Early Years support and interventions

Families and professionals alike are aware of the importance of early recognition of the need for additional support, and the impact that delaying such support can have not only on the child's development but also on the physical and mental wellbeing of other family members (see p35). Liverpool has long recognised the strategic importance of early intervention, multi-agency working, whole family approaches, and the role of the Early Help Assessment Tool (EHAT) and is committed to improving outcomes. Nevertheless, the strategic commitment is still not always effective in practice.

*“[Colleagues] work hard to identify needs early as part of the Graduated Approach. We work with them to enable them to access appropriate support from external agencies in a timely manner.”* **SEND Practitioner**

*“Very rarely has the process been completed before a child starts school.”* **SEND Practitioner**

*“He has had a learning disability since Primary School. This has never been picked up on despite my concerns at Primary School. High School only screened him at my request and found that he had ‘mild’ dyslexia.”* **Parent/Carer**

*“I work in Early Years and support the early years Consortia which supports the PVI [People with Visual Impairments] sector in supporting children 0-5. It is about giving the children the right support in the right place at the right time for better outcomes.”* **SEND Practitioner**

There also appears to be a danger that early diagnosis may act to hinder as well as to help. If mainstream primary schools refuse those with EHCPs then early diagnosis may exclude a child from certain schools and this in itself could encourage the parent/carers to look for other methods, for example: home schooling, specialist schools or delaying assessment to ensure the child is not refused entry to school due to any additional needs.

*“A lot of primary schools will make an effort to deliver the support outlined in EHCPs, however the EHCP can at times act as a reason for schools to refuse a place for a child when they are looking to make the transition from nursery. If the needs outlined within the EHCP are high, there have been occasions when the school have read the EHCP and have stated that they will be unable to meet need despite the school being the parent's preferred setting for their child.”* **SEND Practitioner**

As outlined elsewhere in this report, resources are limited, and some respondents felt that there can be a general reluctance to begin the EHC assessment process before all other avenues of support have been explored.

*“In my role EHCP process is initiated but often refused by council as nursery have not exhausted all funding options.”* **SEND Practitioner**

*“We've been repeatedly refused my daughter's wish and request for Braille teaching by the sensory team (only offer awareness) for years whilst she was partially sighted until last year when she was registered SSI (Severely Sight Impaired). Bradbury Fields have arranged a volunteer Braille teacher. I feel the SEND team are very nice at saying NO.”* **Parent/Carer**

In relation to this last comment, learning braille while still partially sighted could help minimise disruption to education and other costs if it is known that sight will deteriorate.

## 2. Education, Health and Care Plans (EHCPs)

As might be expected, a significant proportion of survey comments related to Education, Health and Care Plans. These comments largely fell under the following 3 headings:

### a. EHCPs include unrealistic targets/aren't deliverable with existing resources

Parents/carers expressed frustration with the contradiction between what the EHCPs/health professionals stipulate their child/young person needs, and what is available in practice. This gap between expectation and reality causes anxiety for the parent/carer as they feel their child/young person is being let down and cannot function/perform to the best of their ability without the provision outlined by health professionals. There is a sense that the EHCP is worthless when not being followed directly, and that the school is to blame for this, causing friction between the parent/carer and the school.

*“School and Local Authority never follow EHCP and my daughter never had all provision in place stated in her EHCP throughout its duration.” Parent/Carer*

*“EHCP is not worth the paper it's written on. My child is still punished for having medical needs and health appointments.” Parent/Carer*

*“All provisions stated in EHCP never was covered and delivered. I feel totally let down with SEN system in Liverpool.” Parent/Carer*

Parents/carers feel there is only so much that can be done given the resources available to them. This means they are getting used to being told no and expecting to have to fight to achieve anything they require, often unsuccessfully. This leaves them disappointed and disheartened by the process as they seek support for their child/young person. The constant challenges and refusals make parents/carers defensive when dealing with professionals, and cynical about the process. In addition, parents feel they have to actively push for support or be ignored and can sometimes only get what is required when a professional intervenes on their behalf.

*“...3 senior schools, not one adequate to deal with her needs, ended up in [a specialist] school; damage done but this point. Went to college and was not supported, more damage done. Comes down to money and not the child's needs which results in damaging their chances of surviving in the world and gaining employment.” Parent/Carer*

*“Seedlings [emotional support for Primary years children]... but only because at an EHAT review my daughter's school and the attendee from EHAT South Hub forced the head teacher of my son's school to agree to a referral.” Parent/Carer*

*“Should have received Seedlings but [his school] did not put him on waiting list. He requires OT [Occupational Therapy] but not received that yet” Parent/Carer*

Nevertheless, some parents did refer to specific positive support or outcomes:

*“In her infant school she had lots of access to outside intervention, has seen educational psychologist as part of EHCP process.” Parent/Carer*

Another issue of concern was around preparation for the transition to adulthood and adult support services. According to our survey data: 71% of parents/carers feel that not enough information is provided in the EHCP to support their child during their transition to adulthood. Specifically, 85% stated that finding employment was a high/very high concern; 80% felt that being involved in the community was a high/very high concern; 78% said that their child/young person's ability to live independently in the future was a high/very high concern; and 75% said that transferring to adult care services was a high/very high concern.

*“What will happen when we go? Older daughter will never be able to live independently. Younger daughter will be able to live independently but will have problems with mental health, needs to believe in herself.”* **Parent/Carer**

*“Clear need for more support for SEN students for now and the future with all aspects of work and life.”* **Parent/Carer**

Only 6% of parents/carers who participated in the survey believed EHCPs supported their child/young person during their transition to adulthood.

SEND practitioners had mixed views about the efficacy of EHCPs. Practitioners’ comments suggest that they feel EHCPs do largely meet the child/young person’s needs due to the quality of the plan and collaborative work that has gone into the production. Some feel that the views of the parents/carers and children/young people have been recognised alongside those of all relevant professionals. The EHCP is largely seen as relevant at the time of production and there are felt to be ongoing improvements to the overall quality of plans.

*“If an EHCP is in place then my experience is the need is met – particularly by schools.”* **SEND Practitioner**

*“By the time they get to this stage, all agencies, practitioners and parents are on board.”* **SEND Practitioner**

*“Our EHCPs are of good quality when written...”* **SEND Practitioner**

*“Quality of EHCPs are improving all the time, we are getting better at ensuring education settings are meeting the needs identified in the provisions provided.”* **SEND Practitioner**

*“The initial EHCP is often very appropriate...”* **SEND Practitioner**

However, whilst many practitioners feel the process is largely adhered to and that parent/carer views are taken into consideration; others disagree and argue that resources/capacity do not allow for this to always be the case. Furthermore, issues to do with language and learning difficulties have been identified as barriers to this involvement.

*“Attend an advanced solutions meeting-face the parents ask them for honesty. I am also one of these parents and a professional. The system is an embarrassment.”* **SEND Practitioner**

*“Even with an EHCP I see many not accessing their entitlement unless advised to do so.”* **SEND Practitioner**

The SEND Practitioners survey also shows that most respondents are relatively confident in the standard of EHCPs. 51% gave a confidence score of 3 (‘average’) for how confident they feel that EHCPs meet the needs of the individual concerned. 27% are ‘fairly confident’, 0% are ‘very confident’ and 5% are ‘not at all confident’. 17% are only ‘slightly confident’.

Interestingly, practitioners as well as parents/carers recognise that variations exist depending upon factors such as which school the child/young person attends, who the caseworker is, or who authors the plan.

*“It depends on the school.”* **SEND Practitioner**

*“Depends on the person who has written it.”* **SEND Practitioner**



Practitioners also felt that there was a lack of consistency in respect of whether children/young people’s needs are best met within mainstream or specialist provision.

*“There are too many occasions where someone with significant needs is given an EHC naming a mainstream primary, where their needs cannot be met. ‘Best fit’ is not good enough for these pupils.” SEND Practitioner*

*“LCC EHCPs often result in specialist placement as opposed to supporting inclusion in mainstream.” SEND Practitioner*

Clearly, whilst each case is different, it is crucial that all views are considered, not least those of the parent/carer, and wherever possible those of the child/young person.

## **b. EHCPs are too vague and need specific/measurable details**

Parents/carers were critical of EHCPs for not being specific enough to match the unique/individual needs of the child/young person concerned. A common theme was having to battle for non-generic and quantifiable targets to be written into the Plan. Parents/carers sometimes felt that their only resort was to commission independent reports to challenge the local authority to get the support their child/young person required. Moreover, those unable to seek private help by commissioning independent reports or seeking professional legal advice feel they are backed into a corner and have to accept the EHCP being offered in order to give their child some form of assistance and to prevent any further delays to the education process. Feedback from parents/carers also highlighted that it’s difficult, or impossible, to monitor outcomes or evaluate the plan without measurable targets.

*“The EHCP is not clearly written and is confusing as it says one thing then says different. Clearly because of this my child’s needs are not being met and he gets no 1:1” Parent/Carer*

*“My child has a very specific and quantified EHCP following the independent reports that I commissioned. 2 draft, 1 final, 13 working documents and 3 final-final EHCPs to get the EHCP in a usable state.” Parent/Carer*

*“It doesn’t give clear enough strategies for college to employ to help my daughter.” Parent/Carer*

*“We have never been happy with the quality of the plan. We have brought this up numerous times during Reviews, particularly with regard to the need for provision to be specific and quantifiable and for outcomes to be SMART. However, we have felt that we have had to accept the proposed final versions of each amended plan in order to have ‘something’ in place.” Parent/Carer*

Whilst practitioners were generally satisfied that EHCPs were fit for purpose, they shared parents/carers feelings that they could be improved by ensuring that they were more bespoke:

*“They need to have more clarity on individual needs...” SEND Practitioner*

*“Not all targets are SMART and can be open to interpretation.” SEND Practitioner*

*“They are not specific enough and often it is unclear as to what is expected.” SEND Practitioner*

## **c. EHCPs seen as key to accessing any form of SEND support**

Despite concerns that EHCPs can sometimes raise expectations that aren’t met in practice, they are often seen as the only way to ‘legitimise’ parental concerns and unlock access to support.

*“My child needs an EHC [assessment] but school are refusing” Parent/Carer*

*“School have refused to support as “there are children worse than my son””. Parent/Carer*

It seems there is a disconnection between what/who is covered by an EHCP and who/what is covered with SEND support more generally; there may also be misunderstandings about the graduated approach to SEND support, indicating a lack of information available to parents/carers outlining what the differences are, the levels of support for each and what is most appropriate for their child.

Parents/carers will inevitably push for the highest level of care to support their child/young person's needs which it is assumed will be achieved with an EHCP. However, perhaps due to the resource issue that prevents EHCPs from being fully met, schools may be reluctant to push for this and believe that 'lower level' SEND support may be more appropriate or easy to facilitate for the child. If inadequate SEND support is being provided, then parents will push for an EHCP to get the support required but, from education staff's perspective, this is not necessarily the most appropriate approach.

Some professionals expressed concern about need not being met where there is no EHCP, stating that an EHCP should not be required in all cases in order for need to be met:

***“I am concerned that the need is not met without an EHCP - which should not in some cases be necessary.” SEND Practitioner***

Some comments by parents/carers and professionals indicate that initiating the EHC process may sometimes be unnecessary and that schools should be relied upon to make SEN provision without an EHCP. This is attributed to a lack of awareness or focus on SEN provision and/or concern that needs will not be met, or continue to be met, without an EHCP. Some note that they understand the reasons for this, but concern is also expressed that the system needs to ensure there is support without a plan where this is appropriate:

***“A lack of focus upon SEN support prior to EHCP and implementation of the graduated response results in parents/professionals escalating SEN to EHCP level/request. Parental feedback detailed that they are not aware of SEN support plans and the statutory requirement for them.” SEND Practitioner***

***“Parents are currently applying for EHCPs more readily, to ensure the support for their child/young person is always going to be available, rather than trusting the school/setting. This over-reliance on EHCPs means that money is being spent on assessments which could be better spent on supporting the child/young person but the parents need certainty. In these times of cuts and ever-increasing initiatives for schools to comply with, SEN can sometimes become lost.” SEND Practitioner***

***“There is some really good practice, but some settings are making parents feel that their children are unwanted as it is too much hard work and too expensive to meet the needs. I think it is inappropriate for Parents to be told by schools that they have to fund the first £6000 to access top up funding, it makes them feel guilty. Also, parents feel that if settings are short-staffed, the SEN support seems to be the first thing that is sacrificed.” SEND Practitioner***

Practitioners for the most part seem to support the perception that parents/carers find SEND provision inadequate and that a push for an EHCP is undertaken to ensure the child/young person gets the appropriate level of support. Whilst this may be increasing demand and causing delays/resource issues for those with or without an EHCP, until investment is ploughed into mainstream SEND provision the push towards EHCPs is likely to continue. It is a concern if parents/carers are made to feel that their child is a financial burden; this is likely to cause the parent/carer some distress and if the child picks up on this, there may well be an impact on their development and mental health too.

According to our survey data: only 15% of practitioners are fairly or very confident that a child/young person's needs can be met without an EHCP - the lowest confidence score across all components in the EHCP-related questions.

A further theme raised by professionals was monitoring and accountability:

***“Although the EHCP places a statutory duty on settings to deliver specific provision for individual children, no one is monitoring if this is actually happening... there is nobody working with these settings who can hold them accountable for the support they should be providing as part of an EHCP.” SEND Practitioner***

Nevertheless, overall, by a small margin, the majority of professionals (51%) had an average to high level of confidence that EHCPs meet the needs of the individual concerned.

There were different views about the quality of plans, with some focussing on the drafting and/or implementation of plans not meeting need, but one comment about some improvement already taking place:

***“More work needs to be completed to improve the quality of plans.” SEND Practitioner***

***“EHC plans in my experience don’t always match the needs of the child.” SEND Practitioner***

***“It is not looked at often enough.” SEND Practitioner***

The focus of a number of practitioners’ comments is on lack of resources to carry out the actions in the EHCP, particularly in mainstream schools. Some emphasise lack of space or equipment in these settings, and others focus on lack of specialist training or financial resources generally. One respondent commented that schools have to supplement resources themselves. Some comments from professionals are fairly neutral as to whether they view the problem as the level of resource or the expectations and actions included in the EHCP. The two things are linked and interdependent, but some comments emphasise one more than the other, characterising the problem and potential solutions in different ways. Some refer to unrealistic expectations for inclusion in mainstream schools, for example due to drafting of plans by non-education professionals, and others emphasise issues such as lack of funding for EHCP actions, over-reliance on special education, or a lack of choice or lack of emphasis on inclusion:

***“Usually the content is accurate, but sometimes the provision requested in a busy mainstream school, with no extra classrooms/breakout spaces, is impossible e.g. quiet spaces, access to specialist equipment.” SEND Practitioner***

***“Sometimes the demands of the EHCP are unrealistic for the school to provide due to expectation of required financial support from restricted budgets; lack of professional training to support the adults working with the individual child.” SEND Practitioner***

***“We often have to strongly challenge. Many pupils with significant and increasingly alarming levels of SEN have unrealistic targets set by authors of EHCPs who are not education professionals.” SEND Practitioner***

***“School spend a lot of their budget to ensure that they know their needs, and use their own budget to supplement poor high-needs funding quantities.” SEND Practitioner***

A number of comments focus on problems with interpreting the plans and with accountability for their implementation. Whilst there is one comment noting that the process is personalised, many of these comments focus on plans being too generic and/or lacking specific quantifiable actions, making it difficult to interpret and implement plans. Others mention lack of processes for monitoring and holding people to account if support is not provided.

***“Think they need to have more clarity on individual needs for example they say ‘Needs 1-2-1’ with no timescale, so parents/settings have their own interpretation of the meaning of this.” SEND Practitioner***

*"Concerns regarding the SMART objectives and lack of specific detail regarding who will deliver on the plan." SEND Practitioner*

*"Over the past 12 months EHCPs have been very generic and not very specific which leads to interpretation of outcomes and expectations." SEND Practitioner*

*"They are not specific enough and often it is unclear as to what is expected." SEND Practitioner*

*"Parents' views are taken into account when EHCPs are being developed." SEND Practitioner*

*"Meetings with children, young people and parents regarding the Draft/Final/Review of the EHCP do not appear to be standard practice at the current time." SEND Practitioner*

*"Our children are very young and their understanding of their needs are not always heard, although recorded." SEND Practitioner*

*"Information is gathered during the assessment process but then parents and children don't hear anything until a draft is written." SEND Practitioner*

*"Every EHCP should begin with a MDT [Multi-Disciplinary Team] with parents. Due to the number of requests for assessment and the resource available within SEN teams this is not possible." SEND Practitioner*

*"Parents are asked to complete a form to inform the EHCP Assessment and Draft EHCP, however they often don't have the opportunity to meet with the person compiling the EHCP. This could cause particular issues in gathering accurate information from parents who have difficulties with literacy, learning difficulties or those who speak English as an additional language. The same form is often used to gather the views of the child/young person which raises similar issues in terms of the literacy skills and level of understanding of the child/young person completing the form." SEND Practitioner*

Only one professional indicated that children/young people and their parents/carers show any indifference to the EHCP production process.

*"Children/carers never want to change anything as they either don't think they know enough to comment or they don't care enough." SEND Practitioner*

### 3. Communication

Communication issues between parents/carers and schools/social services are a common theme, as are communication issues between different professionals. Issues are also present around the duplication of forms and constantly having to provide the same information when attending services. The process of information sharing across services needs improvement, certainly in relation to children/young people who require ongoing access to a range of services. Professionals and parents/carers alike were aware that communication was not always good.

Not all parents are fully aware of what support their child is receiving at school and some feel that communication between SENCOS/education professionals and parents/carers could be improved. There is a lack of knowledge on the parent/carers part about what is available to help/support their child/young person as there is limited liaison between schools and families once support has been established.

As noted above, reviews do not always take place regularly and it can be difficult to find other opportunities for parents/carers to liaise with SEND staff to discuss improvements/issues. The clear message from parents/carers is that more information needs to be provided in a clear manner so they can fully understand what support their child is receiving, why this is happening and how it can be reviewed or challenged. Additionally, there need to be opportunities for parents/carers to have any points clarified or simplified should the language be too technical or unclear; and more information is needed on where parents can go to access advice or information.

*“I automatically thought the school did this, so I should have been more up to date with information as he did not get any extra help...” Parent/Carer*

*“We are wishing to apply for an assessment but not getting any support.” Parent/Carer*

*“It is very difficult to find out what is needed for the children.” Parent/Carer*

According to our survey data: 40% of parents/carers felt that the overall process of the EHCP was not explained; 23% felt it was only partially explained and 27% felt the process was explained fully. When asked if all sections of the EHCP are understood, the results are slightly better with 50% agreeing that they understand all sections. Parents/Carers feel that they understand the EHCP sections slightly better than the process.

Based on responses to our survey, communication between education professionals and parents/carers is, by and large, lacking and there is room for improvement. Some parents/carers had difficulties making contact with schools and reported negative experiences when they did, although others have had plenty of communication and positive experiences. There appears to be no consistency with communication between parents/carers and professionals involved in the EHCP process and this could result in unequal outcomes for children/young people concerned. Suggestions from parents/carers included simplifying and clarifying the language used in reports/correspondence as they may not understand technical terminology and this can lead to feelings of intimidation/anxiety about asking for clarification given the existing difficulties in making contact. The lack of contact also leads to the feeling that parents/carers views are worthless particularly if being told they have ‘no right’ to discuss their own child/young person’s needs.

*“Not sure exactly what support is given. [My son] was working with someone but that seems to have been stopped.” Parent/Carer*

*“Communication feels poor. My daughter has always been told to relay feedback on findings.” Parent/Carer*



*“Never had advice from an educational officer, even more I was told I have no right to speak with her on the phone – just wait for an outcome.” Parent/Carer*

*“I have tried calling the Education Officer and she will not return my call; I have no idea what is happening....” Parent/Carer*

*“The Education Officer was easy to contact; she always returned my emails and was open to suggestions.” Parent/Carer*

*“Form of EHCP document is very clear to understand but when local authority put their own comments/fill the form, it is not clear at all.” Parent/Carer*

*“Emails go unanswered and ignored. This is not just restricted to one EO but is our experience with both EOs that we have worked with and is suggestive of a wider problem.” Parent/Carer*

*“Many professionals work very hard for children with SEN but there seems to be a lot of lack of communication and clarity about what’s available. There is no openness about what is possible in terms of support.” Parent/Carer*

*“The special school our son attends are extremely poor at communicating with us.” Parent/Carer*

The issues, however, were not entirely confined to education providers. Health services can also be difficult to communicate with:

*“We have an EHAT that I requested to be sent to the GP, but GP declined EHAT info as they couldn’t save the form on their IT system. Information isn’t shared. For example, we are under Alder Hey for appointments, and Mersey Care, but they don’t share information.” Parent/Carer*

*“For the new strategy to work each service needs to communicate effectively with all others. Health and other services and schools should work jointly for the most vulnerable children in our city.” SEND Practitioner*

The centrality of good communication, parent/carer involvement and multi-agency working to ensure quality SEND support is very clear. This is largely unrelated to resources and funding but there is a suggestion here that if it is not addressed by the ongoing changes and reforms it could result in failure.

Nevertheless, strategic leads are confident that this is at the top of the local SEND agenda.

*“Improvements with communication between services. Focus within EHCP as a priority on local area WSOA. Data being built to inform on key performance indicators.” SEND Practitioner*

#### **4. SEND system isn’t sufficiently inter-connected**

There was some concern that each aspect of SEND provision still displayed a tendency to operate in isolation and was not sufficiently connected to other services or providers. This clearly relates closely to the structural problems with communication – both between services and between services and parents/carers. Signposting to advice, information and support tailored to individual need was not felt to be offered early enough or regularly enough. For instance, families would welcome signposting to sources of support whilst waiting for assessment/diagnosis, and then again at the point of diagnosis or discharge.

Again, one area where there were particular concerns about the system not joining up well was the transition to adulthood and adult support services. Parents/carers expressed concerns about how their child/young person’s lack of communication or social skills may prevent them from gaining independence and flourishing outside of education and into adulthood. The social isolation experienced by these children/young people within the education system was thought to have a lasting impact upon them in the future and potentially to aggravate any issues already present. Further

support with less academic aspects of education such as social skills could be beneficial in increasing the child/young person’s independence.

Parents/carers worry about the future/adulthood for their children at all ages; parents of younger children are no less concerned than those of teenagers or young adults. It is important that preparation for later life and independence is written into EHCPs and also considered where EHCPs aren’t in place. It is therefore encouraging that the SEND Co-Production Working Group is looking at all children in relation to access to support. The sooner parents/carers can start to plan and prepare themselves and their child/young person the better.

*“My son does not have social communication, so he is going to struggle with his future.” Parent/Carer*

*“Now socially isolated; the education system has failed her.” Parent/Carer*

*“He is incredibly bright but has no confidence in the community, doing new things and no support to help him do so.” Parent/Carer*

*“This is a long way off for my son, however I still want him to be able to access school, the curriculum and social activities and to be supported to build resilience so he will eventually be able to function independently in the majority of situations.” Parent/Carer*

*“...she struggles massively socially and interacting appropriately for her age and situation and I worry massively that she would be bullied in the workplace by other workers and actually whether she will secure employment at all and whether she will be able to live independently at all.” Parent/Carer*

*“Parents have to fight to obtain services in Liverpool. A change in SEND system will be welcomed.” SEND Practitioner*

## 5. Lack of co-production of EHCPs and other support plans

It is encouraging to note that co-production is given such a high priority by the SEND Partnership Board and that recent working groups have been led by parents/carers (co-ordinated by LivPaC) in collaboration with Liverpool City Council and NHS Liverpool CCG. All parties acknowledge that there is still work to be done to embed strategic aims within day-to-day practice, and this is reflected in feedback from professionals:

*“After the local authority Ofsted and working as part of the focus group (Send 4 Change) changes are slow to be implemented and more and more service reviews seem to be taking place. The outcomes were clear and joined-up thinking and co-production are key to change and success.” SEND Practitioner*

*“Parents/carers continue to express frustration at not being ‘heard’.” SEND Practitioner*

*“There is an action plan to address this to ensure the voice of the child and family are heard.” SEND Practitioner*

*“We can always work harder to ensure true co-production.” SEND Practitioner*

*“Parents appear to be happy - however that is because schools are doing the best for the child despite what’s on the EHCP at times.” SEND Practitioner*

*“The voice of the child and the young person’s family is now central to all of our processes going forward.” SEND Practitioner*

Some comments focussed on the need for meetings with children and parents/carers to happen consistently at key points in the process. However, some also emphasised that improvement is needed not just in terms of ensuring that there are mechanisms for listening to the views of children/parents

but also that their views are actually taken into account throughout the process i.e. that they not only influence the drafting of the plan but that they are kept informed about how their input has shaped it.

*"The idea of an initial meeting with all concerned hasn't happened."* SEND Practitioner

*"Children, young people and families are not routinely involved in the assessment and review processes in as effective a way as they should be."* SEND Practitioner

Other practitioners see high demand and/or lack of sufficient resources as the key barrier to listening effectively to parents/carers/children/young people:

*"The volume is the biggest barrier to a satisfactory level of involvement. The SEND reforms have not been adequately funded by government."* SEND Practitioner

*"Shortage of provision means that parents have very little choice and have to wait vast time periods before their preferred provision is available."* SEND Practitioner

*"Difficult to provide the necessary time for every child/parent/carer that each deserve with high caseloads."* SEND Practitioner

Some see a wider lack of involvement of all parties from the start of the process as the cause of the failure to listen effectively to parents/carers and children:

*"The process falls at the start by not organising a team around the child approach."* SEND Practitioner

*"Specialist teacher not involved to produce the draft which may lead to confusion in the provision."* SEND Practitioner

Parents and carers echoed the views of professionals, noting not only that family input was perceived to be prioritised less highly than the views of education professionals, but that health and social care professionals could seem less engaged.

Parents tended to feel that their involvement was often tokenistic or an afterthought. In other cases, they felt that if they had not driven the process themselves the EHCP would never have been fit for purpose.

*"My parent view was always ignored both in EHCP and review meetings."* Parent/Carer

*"I felt the meeting was based more about the teacher's perspective of the pupil, disproportionately, rather than 'listening' more to the pupil and his/her concerns/needs"* Parent/Carer

*"[The school] did not hold a planning meeting and did not include all comments. We had to rewrite a lot of the plan as the one written by the SENCO was awful."* Parent/Carer

*"EHC planning meeting actually happens at the end of the process with a completed plan."* Parent/Carer

Parents/Carers' frustration at not feeling heard is evident in the following quote, which also underlines this parent's experience of being 'kept out of the loop.'

*"My child was attending a mainstream school as I wanted him to. He has Higher Needs funding for 1-2-1 but instead the school used it to move my child against my wishes to a Sure Start nursery where he was in a tiny room. The school gave his place away and refused to take him back there. He waited 2 years for a SEN school. From there he's worsened significantly. I'm not told anything."* Parent/Carer

According to our survey data: Fewer than half (42%) of parents/carers felt their views and the views of their child/young person were considered during the EHC planning process. 36% felt their views had been partially considered and 21% (more than 1 in 5) did not feel their views had been considered at all.

Although the EHCP should consist of education, health and social care perspectives, there is a general feeling that education has the most input. Parents feel their involvement is not as valued as the professionals.

*“There is not enough listening to parents and carers and not enough change based on the listening to parents and carers.” Parent/Carer*

*“The EHCP replaced the Statement of Educational Need to incorporate the Health and Social Care elements, however, in my experience, it is generally school led and at no point have Health contributed.” Parent/Carer*

*“Mental health for children with SEND in mainstream schools needs addressing through collective co-production between Education, Health and Social Care. Budgets aren’t an excuse for not working together to improve the outcomes for our next generation.” Parent/Carer*

As noted elsewhere in this report, it is clear that all stakeholders recognise the importance and benefits of co-production (quite apart from their statutory duties) whilst highlighting the fact that implementing the necessary changes has been slow.

## Multi-agency working - issues arising

Effective multi-agency working is central to effective co-production. References in some practitioners’ comments to having to duplicate information gathered by others or having to start the process from scratch imply that they view the evidence gathering process as unnecessarily repetitive. Currently, a significant number of professionals see the evidence-gathering process as taking an unacceptable amount of time and the paperwork as often getting in the way of meeting the needs of the children. Feedback includes several instances of stakeholders blaming each other for delays to the process, comments about schools feeling not listened to, and the process being adversarial for parents and hard for them to navigate if they are not in the know.

Whilst the EHCP process requires input from all stakeholders there remains some opportunity for more effective joint working, whether or not an EHC assessment has been requested, or whether a Plan has been produced.

*“The voice of the school is often not asked for or disregarded. We often have a totally different view to the parent but are not part of the process.” SEND Practitioner*

*“We rarely get copied into paperwork from NHS - even when parents request this.” SEND Practitioner*

*“It takes a totally unacceptable amount of time, HUGE amounts of work and data and assessments are gathered and used before assessment is considered - however it appears that these are often disregarded by health or other professionals or have to be duplicated in order to get a result from assessment.” SEND Practitioner*

*“Health provide information and return within 6 weeks to SEND, however they inform parents when they are late in their processes that health are causing delay which is not the case.” SEND Practitioner*

*“Timeliness has significantly improved - health now support 100% of advice within the statutory timescale of 6 weeks.” SEND Practitioner*

There do seem to be some tensions between the range of professionals involved in the EHCP process and suggestions that co-production is difficult. Blame is placed with other services for causing delays and this indicates further the lack of collaboration across services. It is recognised that better relationships and communication between services will improve the outcomes but due to the multi-disciplinary nature of the work this is proving difficult.

***“Social workers withdraw as soon as they can. Health never turn up to meetings, always attempt to delegate to schools. EHCPs should just be called Education Plans as social care and health are usually nowhere to be seen.” SEND Practitioner***

***“Health services, especially Speech, discharge regularly and pass on responsibility for delivering and monitoring a therapy to schools/settings. If the waiting list were dramatically shorter this could work but as it stands there are lots of partially supported children with communication difficulties who have been discharged. This practice also does not allow for continuity of staff supporting a given child.” SEND Practitioner***

There are clearly some concerns expressed by Education professionals about Health and Social Care services. There is a sense that minimal support is offered and that some services are quick to “wash their hands” of the child and leave it to schools to provide support. However, the majority of professional responses we received (71%) were from Education practitioners which is likely to skew these findings. If this survey is repeated in the future it would be useful to attempt to elicit more responses from Health and Social Care practitioners.

***“Need a more consistent communication and processes between services so the plan reflects a well-rounded view of the child.” SEND Practitioner***

Just as parents/carers can feel dismissed by professionals, some professionals can feel under-valued by others.

***“There is an arrogance in some medical professionals that information gathered from schools or specialist teachers is inaccurate or uninformed and often assessments are rejected, dismissed or repeated without any collaboration.” SEND Practitioner***

***“There is little opportunity for review and mainstream schools, health services are not challenged enough in their support role. The ‘buck’ is continuously passed.” SEND Practitioner***

One respondent said that all parties tend to be on board by the time an EHCP is in place but others had the opposite view, i.e. that all stakeholders are not consistently involved or listened to:

***“By the time they get to this stage all agencies practitioners and parents are on board” SEND Practitioner***

***“Voice of the child not collected. Specialist services not always listened to.” SEND Practitioner***

***“The structure in the SEN team has changed and increased and this will see an impact of new assessments for families.” SEND Practitioner***

***“The EHCP process needs to be revised. We know that there are issues with the current system and we plan to make changes.” SEND Practitioner***

Some professionals reported that they were confident that the views of parents/carers/children/young people are listened to or taken into account most or all of the time. In one case, the implication was that parents at the school are listened to because staff take an active role in ensuring that this is the case. The comment did not detail how people’s views are taken into account or whether they are acted upon:

***“Parents in our school are very active and always listened to.” SEND Practitioner***



Other practitioners differed in their views of how closely or effectively they worked with other services.

*“My experience is that getting support in some schools is difficult - the inspection highlighted the offer in mainstream as inadequate.” SEND Practitioner*

*“Our school access a great deal of support from other services.” SEND Practitioner*

*“As services are being cut, we as schools are having to pay for many services with an ever decreasing budget. CAMHS provide consultation support through consortia, but we would rather it was spent with children and families.” SEND Practitioner*

*“There is a void between local authority services and NHS. They duplicate services rather than find out what is already available and add or extend it...e.g. ADDvanced Solutions, ASD Pathway. Trainers target same group, same provision competing against each other rather than working together. Costs would be much reduced and could be shared.” SEND Practitioner*

## 6. Variations in parental capacity to make the system work for them

Another issue which was raised by parents/carers and SEND practitioners was the varying capacity of parents/carers to navigate the system and advocate for their child/young person’s needs. It was recognised that as difficult as the system can be to navigate for even the most well-informed or well-connected parents/carers, the playing field is not level. Parents/carers can be at a disadvantage for several reasons, e.g. their own SEND support needs, mental health support needs, cultural or language barriers.

*“Many families I work with have EAL [English as an Additional Language] and therefore I worry that they may not understand all the paperwork.” SEND Practitioner*

*“Draft presented to family but not always understood...” SEND Practitioner*

*“Depends on how assertive the parents are.” SEND Practitioner*

*“Parents who have disabilities themselves? How do they access support?” Parent/Carer*

Parents/Carers recognise the difficulties which can arise when attempting to get support for children/young people with SEND and are concerned about how others manage to find their way around a challenging system. In addition, they feel that children/young people who do not have needs perceived to be ‘severe’ enough to warrant an EHCP can get lost if they do not meet specific criteria.

*“One final thing to mention is our worry about those families who, for whatever reason, lack the capacity to do what we have had to do - essentially rewriting our son’s EHCP. What happens to the SEND children in those families in our city?” Parent/Carer*

This is a prime example of why support needs to be made available to all, as not all parents/carers have the same resources or access to support and the outcomes for their children/young people should not be determined by their ability to fight for the provision needed.

*“With the right support and knowing how to access this then the process will be quicker.” SEND Practitioner*

*“Processes are long and difficult for those not in the know to navigate. Families feel like it is a fight rather than a supportive process to enable shared thinking.” SEND Practitioner*

Practitioners also suggest that parents/carers’ ability to advocate on behalf of their children/young people can affect outcomes, and the complicated system accentuates differences in parental ability. Accessing support is seen as essential to helping with the process but some parents/carers are not aware of where to go to receive this support and some have indicated that those identified as a point of contact do not communicate with them. Again, improved communication between practitioners and

parents/carers is required, as is a named contact for parents/carers to assist with and support throughout the process.

It is hoped that the planned recruitment of additional SEND Case Workers/Support Workers at Liverpool City Council will reduce each Case Worker’s case load to a level commensurate with other comparable ‘Core Cities’ and will enable them to have a more meaningful and engaged relationship with families; and that improved access to advocacy and support will reduce the length of time that the assessment process takes.

## Parents forced to pay for private support/assessments/reports

A related point is that some parents/carers report that they have resorted to paying for private advocacy, advice or service provision because waiting times are too long, EHCPs are poorly drafted, services are not available, or the quality of the service does not match up to what is required and expected. This raises concerns about the equity of the system in terms of potential outcomes for children/young people, the strain placed on families - financially and in terms of mental wellbeing - and the fact that not all families have the means to do this.

*“I understand there are too few speech therapists, but families are left frustrated and paying private is just not fair. If a child had CP [Cerebral Palsy] and needed regular physio this is needs-assessed and well resourced. SLCN [Speech, Language and Communication Needs] has such a long-term effect on academia, well-being, employment as an adult; it is a public health issue. Practitioners have seen an increase in ASD and communication difficulties over the last several years.” SEND Practitioner*

*“We have had to pay privately for therapies and support when our son has been discharged from services that he still desperately needs (e.g. SALT, Speech and Language Therapy) or that is not available in school or not providing to a high standard (e.g. Lego Therapy).” Parent/Carer*

*“We engaged a parent advocate to assist and guide us. Without his assistance, my daughter would not have been granted a plan and the process to gain an EHCP would have been a very long and hard experience.” Parent/Carer*

*“It is a full-time job to challenge LCC... So I have employed a lawyer, we go round in circles.” Parent/Carer*

*“We’ve seen a private practitioner who has been helpful but I’m sorry to say the NHS hasn’t been great.” Parent/Carer*

## 7. Mental Health

Mental health is an issue which is touched on throughout feedback from parents/carers, but is also picked up by professionals. Concerns can broadly be split into the following categories:

### a. Impact on parental mental health

Parents/carers are aware of the impact that having a child with additional needs (and in some cases the EHCP process itself) has on their own mental health. Parents report trying to maintain their mental wellbeing as best they can; yet, the constant battles they feel they must undertake with the system add pressure and increase their frustration and feelings of rejection/dismissal. This all contributes to poor mental health (e.g. stress, anxiety and/or depression) for parents/carers, which has a knock-on effect on the rest of the family. Parents/carers try their best, despite these concerns, to maintain a sense of normalcy or to keep up appearances for their children.

*“Some days I feel like ‘The Waltons’ when everything is in its place, but I have hit a low spot at the moment – which kids pick up on.” Parent/Carer*

*“The whole process is a challenge.... It’s so tiring and a struggle sometimes.” Parent/Carer*

*“The most stressful experience I have ever been through.” Parent/Carer*

*“Can’t go to the shop - make food - go out unattended. She relies on me all the time, I am exhausted, and I do not have a life of my own.” Parent/Carer*

*“Being a father of a child in the spectrum is always concerning.” Parent/Carer*

*“It’s not my kids that get me down it’s the stress of dealing with e.g. answering emails from professionals that stop me dealing with meltdowns... I am so bombarded with it all, it’s had a big impact on me, but I would do it for other parents.” Parent/Carer*

This last quote from a parent/carer emphasises the importance of peer support and a common wish from parents to help others who are also having difficulties navigating the system. It also underlines how stressful contact with professionals can be, highlighting the need for procedural changes. Focussing on reducing timescales and improving communication is likely to reduce stress and have a positive impact on parental mental health. This is a key point to consider with reference to the benefits of parents having some continuity in access to named contacts/advisors, and improved access to respite.

Practitioners are also familiar with the mental health pressures faced by parents/carers, as the following comment illustrates:

*“Parents are at their wits end with the wait for any sort of assessment, including neurodevelopmental conditions, speech and language and OT.” SEND Practitioner*

#### **b. Parent/Carer fear of being ‘blamed’**

Parents/Carers commented on the limited value or worth that they feel their opinions are given and how they feel they are perceived as being part of the problem if they raise an issue or concern with professionals. The counter to this is that parents who do not ‘interfere’ fear being classed as ‘not caring’. Those who wish to do the best they can, but are restricted through communication issues and a more limited capacity to advocate on their child/young person’s behalf, fear that they are failing their child/young person. Parents/carers often feel that they are in a ‘no win’ situation and this increases the stress they are already under. These concerns are closely linked to a desire to be more closely involved in co-production and to improved communication channels.

*“System is not fit for purpose. Parents are seen as interfering or difficult when they question the system.” Parent/Carer*

*“Now I feel totally isolated and worry that I am to blame if I haven’t filled the thing in properly.” Parent/Carer*

Parents/carers can feel very personally judged by those assessing their child/young person’s condition and/or support needs. One parent/carer felt they were perceived to be dishonest and exaggerating or dramatising their child/young person’s issues, as the child/young person did not display these at school as they did at home (See also p54 and p57). This parent was questioned by a professional as to whether they, themselves, had been assessed for ADHD, and they felt this was an attempt to ‘blame’ their child’s difficulties on them, when the purpose of the assessment should have been to focus on their child’s needs.

*“I may have it, but this is about my daughter, not me; this was my chance for him [the practitioner] to understand how it was for my family, maybe I was overwhelmed; I think they think I am lying.”*  
**Parent/Carer**

### **C. Impact on whole-family wellbeing**

Families (including siblings) are impacted both by a) having a child or children with additional needs, and b) the stresses of dealing with the system. Parents/carers state that they feel alone even though large numbers of their peers are going through the same process. This links to the need to continue supporting existing networks and online support groups to create a peer-supportive environment (including through commissioning Third Sector support groups) which can help mitigate some of the more damaging feelings of being lost/alone - and to enable new groups and networks to emerge, particularly those targeting minority groups or cultures who do not always feel well-represented by mainstream services or networks.

Statutory and voluntary sector practitioners are similarly frustrated that they cannot always fulfil their role and obligation to the parents/carers and child/young people involved. The support services which currently exist have very limited capacity given the enormity of the challenges faced in relation to family life and the emotional wellbeing of all family members.

*“We feel that our son is being let down and that we as a family are being let down. There is no support for the family unit. e.g. the impact on our son’s siblings is not considered or acknowledged. There is no disabled children social worker involved with our son. We feel alone in supporting our son and helping him to achieve his full potential.”* **Parent/Carer**

*“Both my son’s and my own mental health were at breaking point with the way we were being treated.”* **Parent/Carer**

*“I am watching families at breaking point, reaching out for support that quite simply does not exist. The strain placed on families, relationships, parental mental health and the home environment is evident.”* **SEND Practitioner**

### **d. Role of peer support**

This section has touched on the importance of peer support to all family members, and the negative impact it can have where it is unavailable. Lone parents/carers, in particular, reported feelings of isolation and despair. This was also a notable issue for parents/carers who did not speak English as their first language or who felt that existing support services did not recognise or understand their cultural needs (see also Point 10, below).

Where peer support was available to parents/carers, or to siblings, it was valued highly as it allowed individuals to feel understood and heard. It also provided access to informal advice, information and signposting, as well as to some respite and shared sense of humour.

However, existing services and networks were felt to be over-subscribed, over-stretched and not accessible to all. Even accessing online support is not something everyone is able to do, although those who did, including home-educators, found it very helpful.

*“In PDA (Pathological Demand Avoidance) forums parents discuss being on anti-depressants or going for counselling. In some ways it feels like health professionals feel that ‘the kids are a lost cause but maybe we can help the parents a bit.’ We don’t have any tangible help but at least online forums can offer an outlet and help you feel less alone.”* **Parent/Carer**

## e. Child/young person’s mental health

Both parents/carers and SEND practitioners commented that children/young people’s mental health could be overlooked where they had a diagnosis that wasn’t specifically mental health related. Or that once they were on the ASD Pathway, their psychological support needs could be neglected. Despite aiming to recognise children/young people as rounded individuals, the system can sometimes fail to see beyond an immediate ‘label’, to the detriment of the child/young person. The system was also thought to have other built-in biases which failed to take account of the child/young person’s needs, and the wellbeing of the whole family.

*“I have recently moved my son because of the poor SEND support he received. For the sake of this survey it is based on his previous school. As both my sons and my own mental health were at breaking point with the way we were being treated.” Parent/Carer*

*“...my biggest fear is my daughter’s mental health.” Parent/Carer*

*“So, our son is in now in his second year of Secondary school, without the correct provision to meet his needs for the second year running. What concerns me greatly is how this impacts upon his development: not just academic, but his ability to reach his full potential. We see him struggle daily because he is not receiving the correct support. It impacts on our family as a whole and it also impacts on our son’s mental health.” Parent/Carer*

*“My son’s social skills are not good, and he is afraid of outside life without adult supervision. His education is not at his year he is in and he does not thrive at school but do not care and this causes anxiety and upset for my son which causes him utter stress and no sleep. He is also called names at school and hit a lot for being annoying by children and school do nothing about this either.” Parent/Carer*

*“We are currently struggling to help him manage his anxiety as he is frightened of going to school. School have done as much as they can, but because it doesn’t count as a crisis, we have a 15-20 week wait for YPAS [Young Person’s Advisory Service].” Parent/Carer*

*“No idea of where the psych support is supposed to come from- not [ADHD] Foundation, not Paediatrics, and CAMHS don’t offer this - something psychological in Liverpool for ADHD!” Parent/Carer*

*“The remit of health services to discharge for DNA [Did Not Attend] is unfair and penalises the children of families who struggle to access support for either their own learning needs or mental health needs. This further disadvantages children who are already subject to family difficulties. It compounds an already frustrated issue.” SEND Practitioner*

## 8. Lack of resources/capacity/flexibility

Resources were a common theme in the majority of responses, and across all aspects of SEND support. There were many comments referring to a general lack of resources for SEND – financial, specialist training, space etc. - and some about complicated time-consuming processes to put support in place and/or secure additional resources. Some mentioned schools allocating higher budgets for SEND from reserves, commenting that this is not sustainable. Some focussed on the impact of wider budget cuts on SEND and the impact of lack of resources on children’s learning and on family wellbeing. The resource implications of increased numbers relying on EHCP assessments were also mentioned. Since the majority of responses from professionals were from people working in Education, most of the focus here is on the problems facing schools:

*“There are capacity and quality concerns regarding the commissioning of private additional services named in the EHCP. When a plan is high quality and specific the services are enabled to deliver more effectively and leadership is enabled to hold these to account.” SEND Practitioner*



*"We do the best we can with the limited funding that we have, but space is an issue for us. Our building limits what we can provide." SEND Practitioner*

*"Financial restrictions sometimes mean that provision has to be reduced as there is simply not the daily personnel/resources to move the learning and support on at a developmental pace." SEND Practitioner*

*"In my school we prioritise budget and staff for this. We are not funded for this, and are using some reserves, so this will come to an end at some point." SEND Practitioner*

*"Paperwork and evidence-gathering to secure top-up funding is extremely time-consuming and complex." SEND Practitioner*

*"The amount of support given is based on what school can provide not on what the child actually needs to progress. If support is provided it is often delivered by staff without the knowledge, understanding or resources needed for it to have a positive impact on the pupil." SEND Practitioner*

*"I think there is far too much variety within provision in mainstream schools/settings. Some settings/schools undertake great training and develop staff skills, taking advice from council support staff whereas other settings/schools are less engaged with the inclusion agenda and aim to establish ways that they cannot meet a child's needs rather than find ways that they can." SEND Practitioner*

#### a. Lack of specialist SEND support

Another theme which emerged was that there are not enough specialist services available in any sector, and that this is predominantly a resources issue. With demand increasing, practitioners felt that there needs to be a recruitment drive or incentives for individuals to specialise or re-train to ensure that demand can be met in the future.

*"The system is wrong - there is not enough choice or specialism available to meet need." SEND Practitioner*

Parents/carers also outlined considerable differences in how much tailored support has been available to their children/young people, with some having very positive experiences in relation to flexibility of support whilst others felt deeply frustrated.

*"In response to a recent crisis in which he was too anxious and distressed to come to school, he was allowed to come back on a mornings-only basis with some adjustments to his timetable in order to help him." Parent/Carer*

*"They did pay an MSI (Multi-Sensory Impairment support worker) to come to school for 2 hours every 3 months for my child who is deaf and blind." Parent/Carer*

*"They have never provided any support for me. School only. No home or hospital support." Parent/Carer*

This displays the divergence in levels of support available across institutions and the willingness to make reasonable adjustments to support SEND requirements regardless of EHCP. An institution's ability to provide is, of course, based upon the resources available to them and the demand already being placed on them but, in some circumstances, reasonable adjustments or offers of support do not appear to be forthcoming. Some positive experiences demonstrate how schools have made adjustments to the benefit of the child/young person and how this flexibility has been beneficial in allowing the child/young person to maintain academic consistency. Conversely, a young person transitioning into adulthood without the support required to help them at college, can result in self-exclusion from education with potentially serious impacts on future employability.

There is a sense amongst parents/carers that mainstream education is not able to meet the needs of their child/young person without additional support being available. In addition to this, there is limited support across the board for parents/carers and other family members who are also affected. As the support is already limited during the years of formal education, parents/carers worry about what will be available when their child/young person leaves education:

*"My sons struggle in a mainstream school, academically and socially." Parent/Carer*

*"There is no support for severely disabled children in Liverpool and no services that meet his needs and no respite or anywhere we could attend as a family. There is also no support for siblings or parents." Parent/Carer*

*"My feeling is that once he has left school, he won't receive any future support involving employment opportunities..." Parent/Carer*

According to our survey data: Council-led social activities and short breaks services score low on the satisfaction scale for parent/carers (0% and 27% satisfaction respectively), although demand for respite is high. Improvements to these provisions would be welcomed by parents/carers, as would greater access to Direct Payments and Personal Budgets, which would potentially offer greater control and choice for families.

However, one parent/carer, at least, felt that even with control over their child/young person's Personal Health Budget the services that they require are not currently available.

*"I could be in control, but the activities don't meet her VI [Visual Impairment] needs. No other specialist support for her needs. There are local adult services, not children." Parent/Carer*

This is a resources and recruitment issue with more investment required across education, health and social care services to ensure the supply is there to meet the demand.

*"My child needs a 1:1 but been told there is no funding." Parent/Carer*

*"My school puts a lot in place for my son and I am happy with the school's input but, with declining budgets they do struggle." Parent/Carer*

*"Since new SENCO has been in place, his support plan has been implemented and reviewed, however due to high staff turnover and lack of funding to education support, intervention could be better." Parent/Carer*

*"In my experience both of my son's schools have done what they could, but they lack the flexibility and resources to provide what he really needs." Parent/Carer*

*"Not enough places in SEN schools." Parent/Carer*

*"I am happy with the support my son is receiving in that the school are being as flexible as possible and offering as much support as they can given the limitations they are working within. However, I feel he needs more flexibility and support to be able to thrive at school. At the moment he's not thriving, he's just about coping." Parent/Carer*

These quotes illustrate that whilst some parents/carers are broadly happy with the level of support their children/young people receive, they understand that this is threatened by budget cuts and resource issues. The majority of respondents are, however, unhappy - and this is reflected through responses which state that their child/young person is not getting the level of support they require and that recommendations are not being followed. Again, lack of resources is widely blamed for lack of provision but when this is known by those involved in writing EHCPs or providing other types of assistance through the graduated support system, then parents/carers should be made aware that the implementation of recommendations may be subject to availability. Although this is far from ideal, it is

more realistic than implying a service will be provided where resources don't allow this to happen in practice.

Parents/carers noted a lack of resources and reasonable adjustments across all aspects of SEND provision, both locally and nationally, and some recognised that funding decisions made by central Government have a serious impact at the local level, with private provision sometimes being the only option, for those who can afford it:

*“Why are there no reasonable adjustments made in terms of waiting times at GP surgeries and walk-ins when a child with SEND is ill? I don't have to queue in Alton Towers when accessing for leisure, yet my severely disabled child is expected to wait when distressed or in pain.” Parent/Carer*

*“Why are parents waiting for months for wheelchair services yet Lifehouse always appears empty when you go there for appointments? And why is your child's referral closed each time and a new one needed next time? My child will always be a wheelchair user. Why is he not kept on their system as a user of their service?” Parent/Carer*

*“Why are city events not making adequate adjustments for disabled children?” Parent/Carer*

*“If there is no sectioned safe space for my child and other disabled people to be in large events such as firework displays, then he is excluded from being able to attend.” Parent/Carer*

*“I wish every child and young person could access to all the support and services on the same level and timing.” Parent/Carer*

*“The government needs to invest massive amounts into SEND provision so these children can achieve and prosper.” Parent/Carer*

*“My child receives private SALT and OT as described in the EHCP because the LA were not able to find anyone. This is paid from the top-up team.” Parent/Carer*

Some practitioners also identified lack of resources as the key reason for delays putting plans in place:

*“Insufficient resource.” SEND Practitioner*

*“There is less support for children with SEND and more is being expected of schools. We have children with needs which sometimes require an additional adult, which we have to put in straight away, yet it can take months to get the funding because we have to gather evidence.” SEND Practitioner*

*“There are not enough resources across the system to make the necessary improvement and meet parental expectation.” SEND Practitioner*

*“Demand for services is increasing but supply is not keeping up.” SEND Practitioner*

More pressure is being placed on schools as health and care services are increasingly unable to cope with the growing demand and this additional pressure and tension between competing budget priorities.

*“I understand the process, but it is getting more difficult to support children with services as the consortia process is stricter.” SEND Practitioner*

*“Not enough resource to honour what is in the EHCP.” SEND Practitioner*

*“Trying to speak to anyone, chase up referrals etc. is nigh on impossible.” SEND Practitioner*

*“Sometimes the demands of the EHCP are unrealistic for the school to provide due to expectations of required financial support from restricted budgets.” SEND Practitioner*

*“The EHCP names actions which are not well enough funded.” SEND Practitioner*

This all links to expectations vs realities. Funding, resources and practical considerations prevent practitioners from providing adequate levels of support and meeting targets. There is obviously a large amount of pressure being placed on all services and practitioners working within them, but there is a sense that this is not being acknowledged by those writing the plans. This links to effective partnership working and co-production; if all voices are equal in the process then plans should be more reflective of reality.

**b. Concerns that ‘less serious’ needs are neglected**

For the parents/carers who feel that additional support is required for their child/young person, there is a sense that schools are not doing enough and are, in some cases, refusing to comply with recommendations from health professionals. There is a belief that the more severe or visible a child/young person’s needs are then the more support they get; thus, many children are unable to perform to the best of their capacity without support but unable to get the support as they are not perceived to need it as much as others.

According to our survey data: 76% of those surveyed have a child/young person in receipt of SEND support at school and a further 76% of these are not happy with the level of support received.

*“I feel that more support could be given in classroom settings, there are not enough learning support assistants. I feel that those children with SEN who do not fit criteria of EHCP applications are missed.” Parent/Carer*

*“The school won’t follow all the recommendations from the hospital, when I complained they said he isn’t vulnerable enough to get help.” Parent/Carer*

*“School insist there is nothing wrong, that he is ‘fine’ in school, that there are no concerns and refuse to make reasonable adjustments.” Parent/Carer*

*“No support from school other than to check if he was okay – Safeguarding policy.” Parent/Carer*

*“They do their best with regards to speech and language but due to my son not having 1:1 support this cannot always be facilitated.” Parent/Carer*

*“Concerned he is not a priority having a ‘mild’ dyslexia. But ‘mild’ dyslexia is still dyslexia.” Parent/Carer*

There is a fear that those with less pronounced behaviours/symptoms are sidelined and lost in the system. These children/young people without an EHCP and with limited SEND support are greater in numbers but with mainstream provision barely coping, it is these who will be hit hardest by limited resources and a lack of specialist support/teaching assistants etc.

*“His condition makes it difficult for him to cope in the mainstream but isn’t severe enough for him to need a special school environment. He needs a small class size and a flexible timetable within a mainstream environment but that’s impossible. School has also been struggling with his lack of a diagnosis. Because early paediatric assessments recommended a wait and see approach, followed by a 2.5 year wait for ASD assessment, they haven’t known what to do. We’re now being told it could already be too late to get the extra time and adjustments he needs for his exams. He’s been totally let down by lack of capacity in the health service, and a lack of joining up across health and education services.” Parent/Carer*

There are concerns from parents/carers that those with conditions or support needs not severe enough to warrant placement in special schools will suffer in mainstream schools and be left behind or neglected as their needs do not manifest as an immediate or urgent concern. This is reflected also with academically talented children who do not get the support required as they are perceived to be coping and by the time support is required, it is too late. This could also link with prevention as the issues have been left to escalate until they reach ‘the point of no return’.

Nevertheless, some professionals point out that support should be available to these children/young people without the need for an EHCP.

***“Lots of children receive support without EHCP - often through EHATs or Top-Up applications - according to their needs.” SEND Practitioner***

### **C. Concerns that neurodiversity is neglected**

Several respondents expressed concerns that the breadth and range of neurodiversity is still not adequately recognised or supported - including access to mental health support - and that lack of appropriate signposting remains an issue.

***“The most serious cases I believe are covered. My concern is for those less serious cases - I don’t think enough is being done for those children and young people with a neurodevelopmental issue i.e. ADHD or ASD.” SEND Practitioner***

***“Went to speech therapist and ADHD appointment at Alder Hey. Went on courses which were useful, but after discharge re ADHD I was just given websites to look at. He is still three years behind. He is just starting to sing. I was upset with reception class staff who kept telling me ‘he’s okay’ when I knew he wasn’t. He cannot read or write, only now just writing ‘red bus’.” Parent/Carer***

***“ADHD Foundation offers no special or individualised help for families. Community Paediatricians offered medication as the only treatment - no advice offered except for being told to look on ADHD Foundation website. Only offer was 2 days of workshops for groups of parents - hard to justify 2 days lost income for general information when I have specific individual needs.” Parent/Carer***

***“it is unacceptable to wait 2 years for an ASD diagnosis to then be told that your son is being referred to the ADHD Pathway, and that the current wait is over 12 months, my son has been failed for the last 3 years by school and wait times and is now being failed again by healthcare by making him wait another year for support and medication to address any ADHD.” Parent/Carer***

Issues raised within Liverpool Parenting Strategy Working Group included a concern that difficulties with speech, language and communication may be linked to parents’ use of mobile phones, which prevent them making eye contact or engaging fully in conversation with their children. The Group is working with schools to encourage ‘hand to hand’ handover to parents after school. They are also concerned that increases in ASD referrals may be more related to Speech, Language and Communication Needs (SLCN). If this is the case, it can be linked to the need for further training about signs and symptoms for practitioners across education, health and social care.

### **d. Lack of skills/training (for mainstream professionals and families)**

***“As a teacher who provides support for pupils with EHCPs in both primary and secondary schools I am shocked and frustrated by how little regard is given by schools to the outcomes on the pupils’ EHCPs. Rarely have I been invited to an annual review or has it been arranged for me to meet with parents. Schools pick and choose targets which relate to the curriculum and/or their own priorities and not the needs of the pupil. For example young people with an autism diagnosis may receive literacy support but not support to develop their communication or social interactions. At secondary, young people with a dyslexia diagnosis do not have daily reading with an adult or teaching/practice of phonics and curriculum spellings, rather the focus is for an adult to scribe/***



*read for them in French for example. I think there needs to be greater emphasis and expectation placed upon school's working collaboratively with outreach services in order to support the needs of the pupil's with EHCPs rather than it being a tick box exercise. I feel that particularly at secondary, support and teaching staff are struggling with knowing how to support Y7 pupils who are working at Year 1 levels for reading and spelling and how to teach it.” SEND Practitioner*

The quote above illustrates the difficulties with providing adequate levels of support and of schools focusing on targets over a child/young person's individual needs. It also emphasises the importance of collaboration as a means of providing better support. Teachers working with and supporting children/young people on a daily basis do not always have the opportunity to meet with parents/carers or to attend reviews which is problematic and could be preventing children/young person from getting the help they need. The need for additional training for professionals is also noted by parents/carers.

*“Schools need more funding and more training.” Parent/Carer*

*“Mainstream schools need training.” Parent/Carer*

*“I do however think they need to have a more robust understanding of sensory processing and sensory diet and the importance of movement breaks.” Parent/Carer*

This fits with comments expressing concern about inequitable provisions and level of support as training/skills will impact upon this. Improved training and increasing training opportunities for staff to develop their skills could be useful but specialist support is still required as teachers will not be able to provide specialist support for all issues and this adds more pressure to those working in the education sector.

Some professionals felt that the situation had improved over the past 6 months, mentioning a number of factors which had improved their own practice.

*“More time to complete my role in school.” SEND Practitioner*

*“Accessing training, SEND newsletters, SEND literature and peer support.” SEND Practitioner*

*“Attending courses.” SEND Practitioner*

As those working within the EHCP/SEND environment become more experienced in their roles, they report becoming more confident in the processes as they learn and develop on the job. There are opportunities for training which recognise the need for continuous development, and peer support creates a nurturing environment for staff to succeed in. Given the pressure and scrutiny on practitioners, it is reassuring that some feel they are receiving relevant help and support.

However, other comments focussed on ongoing frustrations with the system over the past year:

*“Although a spotlight is on the issues I don't believe enough is being done to solve them.” SEND Practitioner*

*“Nothing has changed.” SEND Practitioner*

*“No change in waiting times.” SEND Practitioner*

*“Continue to be frustrated by the situation and no direction or apparent strategy.” SEND Practitioner*

*“Nothing appears to have currently changed.” SEND Practitioner*

*“Ongoing issue simply deteriorating.” SEND Practitioner*

*“Remains disorganised and underfunded.” SEND Practitioner*

*“I don't feel anything has changed.” SEND Practitioner*

***“Not much has changed in my experience.” SEND Practitioner***

Practitioners are aware of the recent changes aimed at reducing timescales for assessment and diagnosis, and improving the overall process; however, some feel not enough is being done and the process is, if anything, becoming more difficult. Many practitioners appear discouraged, and confidence in the EHCP process is weakened by this and their perception that they are experiencing no changes or improvements in their working environment. Those in more senior positions, who have been involved with decision-making on a strategic level, tended to have greater levels of confidence in the SEND timelines and in positive changes since the joint inspection.

The lack of co-production and communication between all parties is expressed as a factor that contributes to ineffective processes, and something which can be improved upon.

Practitioners themselves suggest that further training is needed and there certainly appears to be a need for greater emphasis to be placed on SEND for those training to teach in a mainstream setting.

***“Lack of professional training to support the adults working with the individual child.” SEND Practitioner***

***“The amount of support given is based on what school can provide not on what the child actually needs to progress. If support is provided it is often delivered by staff without the knowledge, understanding or resources needed for it to have a positive impact on the pupil.” SEND Practitioner***

## **9. Information, advice and support**

**a. Lack of parental awareness about how/where to get support AND how to ask for an assessment**

Some concerns were raised about parents/carers not knowing what their responsibilities are in relation to SEND assessments, or who is responsible for the process, and there can sometimes be a disconnect between parents and schools about who initiates the process, whether support is available during the assessment period and where to find information about what services/provisions children may need/be entitled to.

***“The processes of development and review do involve parents well, however parents need quality information to be able to know the most appropriate information to give. The opinion of C/YP is not as easy to gain and the C/YP would benefit from greater age/ability appropriate information and an advocate service, as used to be available.” SEND Practitioner***

***“Not enough support for parents and carers throughout the process.” SEND Practitioner***

An issue raised that may be preventing parents/carers from having the level of input they would like, or that is required, is the parent/carers limited knowledge around SEND/EHCP provisions. Support for parents/carers with a named contact to assist throughout the process still appears to be missing and preventing input from parents/carers. Even parents/carers who feel informed (often through self-education) do not necessarily feel that their voice/opinion is treated with any greater value in the process.

Results from the quantitative data show that the majority of respondents had moderate levels of confidence on this (rating it 3 out of 5) however, slightly more were not confident than confident. The qualitative comments were mixed although there were more comments about what could improve than there were wholly positive comments.

Parents/Carers indicated that they would value more support/information to deal with the transition into adulthood and also to assist with independence. This information needs to be made available as early as possible so parents/carers and their child/young person can prepare for this stage.

*"I have no knowledge of services that he would be able to access in adulthood."* Parent/Carer

*"No-one talks about it at this stage."* Parent/Carer

*"No help, no advice."* Parent/Carer

**b. Lack of key/named support for parents**

A consistent message from Parents/Carers was that they need an individual professional or One Stop Shop to contact for advice, information and general support with all issues relating to SEND/EHCP. An advice line may be beneficial, but parents/carers appreciate not having to repeat themselves each time they have a question, and online information is often too generic to reflect individual needs. Parents/carers stated that SEND professionals should assume that families need as much information that is relevant to their child/young person's situation as possible, rather than making an assumption that they can just search online.

Many parents/carers raise the point that once a diagnosis is received, attempting to get further advice or support can be challenging and they feel left in the dark about what to do next. Lack of communication between professionals and parent/carers leaves them wanting but there is limited support to be signposted to. Some services are singled out for their ability to assist but not enough individualised support is available for children/young people, parents/carers or the immediate family. Additional assistance from social workers may assist with the process as would additional short courses to support families with diagnoses. The existing Local Offer was viewed by some as too generic to meet individual needs. Some feel they have no support at all for navigating this complex process and this further supports the request from many that a named worker for contact would be beneficial.

*"Our son was diagnosed with ASD in August this year. We were really shocked to find that post diagnosis support involved giving us a leaflet with some website addresses on it and telling us we were now discharged and had to start from the beginning if we wanted any help... I would love for there to be a named person responsible for coordinating his education and health care needs who we could go to as a first point of contact for support."* Parent/Carer

*"LCC is a joke when it comes to child services and help. There is Fusion [short breaks service] or nothing. No short breaks for disabled at all. Even their website is full of lies. There isn't any support."* Parent/Carer

*"Since we had his diagnosis, November 2017 we haven't seen anyone."* Parent/Carer

*"With older daughter I had a social worker who helped me get DLA and backed me up 100% - always had good social workers. Now I am finding it difficult because I am very isolated."* Parent/Carer

*"Families should be allocated a social worker or support worker to support the parents and help them access stuff."* Parent/Carer

*"Words fail me that no one (GP for example) has encouraged or signposted extra support for my daughter's wellbeing and social needs."* Parent/Carer

*"We get our children diagnosed after a long struggle then dismissed from Alder Hey and left to fight for education only to be met by hostility and hate."* Parent/Carer

*"Why can I not access a person when I call the continence service? Why am I expected to play 'phone tag' for sometimes a week due to being a working parent?"* Parent/Carer

*"As a parent when you start out on this journey with you child it's very confusing. I often felt lost, not knowing where to go for help... I feel services should be better publicised so that parents can find the help and assistance that they often really need before they get to crisis point."* Parent/Carer

### C. Personal health budgets (PHBs)/empowerment

*“I could be in control, but the activities don’t meet her VI (visual impairment) needs. No other specialist support for her needs. There are local adult services not children.” Parent/Carer*

*“Older child gets PIP (Personal Independence Payment) - Used to get 3 hours a week for personal trainer. Empowering the individual is good.” Parent/Carer*

*“It is important for my daughter that she takes ownership of her medical treatment / appointments as part of our personal plan to encourage independence.” Parent/Carer*

This reflects how parent/carers are trying to promote independence and empower their child/young person through everyday activities such as attending appointments and money management/ paying for services. As many of the parent/carers are concerned with these aspects of growing up and many EHCP’s do not offer support for this; a potential way to achieve this is through access to PHB. Only one parent/carers did have responsibility for their child/young person’s PHB but 88% wished to have more control over this. However, control over PHB’s also comes with many additional responsibilities which can amplify any existing stresses and as such it may be more helpful to control this aspect of things for the parent/carers and children/young people. This lack of knowledge on the PHB is articulated in these quotes:

*“Never heard about this.” Parent/Carer*

*“I don’t have enough information regarding this topic.” Parent/Carer*

### d. Role of Third Sector

Third Sector organisations (including voluntary organisations, community groups, self-help and peer support groups, Community Interest Companies (CICs) and Social Enterprises) play a vital role in supporting children/young people with SEND, and their families, as well as reducing the burden on statutory services, yet they can be overlooked in terms of commissioning their services or grant support. Although some of them appear as part of the Local Offer, they may also be overlooked as part of routine signposting as potential sources of information, advice and support, or may not appear on the Local Offer at all. See also the feedback about Mary Seacole House (p48)

*“We have been very lucky, they (Bradbury Fields) have been a godsend and the whole experience would have been so much worse without them. I am really grateful.... A very stressful experience but the support was amazing.” Parent/Carer*

*“I have found ADDvanced solutions to be the best support available to my family.” Parent/Carer*

*“ADDvanced Solutions and LivPaC are good. LivPaC shares info on services on social media.” Parent/Carer*

*“SEND [team] emailed regarding support, I called SENDIASS re: jargon.” Parent/Carer*

*“More money invested in SENDIASS would mean a bigger overall spend for LCC and they may not see it as being cost effective, but it may have longer-term benefits.” Parent/Carer*

## 10. Issues for Black, Asian, Minority Ethnic and Refugee (BAMER) families, including those with English as an additional language/minority communities/cultures

A theme of particular concern was that families who have specific language or cultural needs appear to be less likely to have access to accurate information, advice and support about SEND, and feel that that they are systemically excluded from decision-making and the co-production process. This is particularly disappointing given that this issue was raised in the Praxis report on the ‘Together Project’ for NHS Liverpool CCG (Jan, 2016). The Together Project itself was funded during 2015 to work with organisations including Mary Seacole House, Chinese Wellbeing and Women Reach Women in support of Chinese, Bengali and Somali families with children in need of SEND support.

The Together Project report’s recommendations related to:

1. The importance of peer support for parents from BAMER communities
2. The ongoing challenges of stigma in some communities
3. Improved awareness, including cultural awareness, for SEND professionals
4. Improved multi-agency communication
5. Improved communication with families, including access to translation and interpretation where required
6. Improved awareness and understanding of the Local Offer amongst BAMER families
7. Funding for a dedicated worker to work with BAMER families and develop parent/carer support groups
8. A high-level champion to be identified within the City Council or CCG to ensure action is taken in respect of the above points

Feedback from parents who responded to the Healthwatch Liverpool survey indicates that these issues remain equally relevant five years later. The issues are highlighted in Case Studies 4 and 5 (See pages 77 and 78) but were also raised in a focus group held at Mary Seacole House and by parents attending an English as an Additional Language (EAL) group at Pinehurst Primary School. At present there is very limited support available to families with additional language or cultural support needs. Mary Seacole House are not specifically commissioned to provide this, yet they estimate they have a caseload of 50+ families from BAME and/or refugee backgrounds who rely on them for information/advice/support/advocacy around SEND issues. Specific issues raised in the Mary Seacole House focus group included:

a) A single parent who is Kurdish and speaks little English. She relies on a friend to interpret for her. She has two children, one of which is a 13-year-old who has autism and is non-verbal. The daughter attends a ‘special school’, however she does not feel her child has shown any improvements. The parent struggles to understand the system despite having a social worker who she rarely works with. The social worker brings an interpreter to any visits, but the parent still struggles to understand.

The family are in receipt of DLA and the child was attending Fusion however they can no longer attend as funding for transport was withdrawn and the family do not have access to a car and it would be too expensive to attend by taxi. The parent has to keep her child at home most of the time. When the parent wasn’t well recently and had to stay in hospital, she had to rely on neighbours for help as her social worker did not arrange any respite. She couldn’t understand why they wouldn’t help her out and this added to her stress. She asked what she would do if she was on her own and had no friends. She describes herself as feeling very depressed.



The school have indicated that the parent is “disruptive” and won’t engage. She says she’s desperate to engage but does not understand what she’s being told. It was also fed back that the social worker never answers the telephone and doesn’t get back in touch. The parent’s son deals with all of the calls, but she thinks he shouldn’t have to as he’s too young. The school keep getting back to Mary Seacole House saying “We can’t help as the parent won’t tell us what she needs”, even though Mary Seacole House have offered to tell them on her behalf (which she is happy with). The attitude of the school and the council seems to be “we’ve done our bit”.

When the daughter has appointments at Alder Hey, a translator is only provided sometimes. Sometimes translators don’t translate fully and the friend that the parent takes with her has to fill in the gaps.

b) Parent’s daughter attends a special school and has an EHCP. “I didn’t know what to put in the plan when I was asked and I didn’t know what to write to make sure my child would get the right help, so the school just wrote “Everything is fine, Mum is fine” and I didn’t get to see the plan again.”

“Mary Seacole House helped me to get hold of a copy of the plan in December 2019 and found out it was only three pages long and it should have been much longer. She’s also had the same plan since she was 3 years old and it was last updated in 2017. The school have complained to the council and the council have complained to the school so the buck keeps being passed backwards and forwards. I have asked for a speech therapist but haven’t got one. I do research online when I go home and generally do the best that I can. I watch YouTube Videos and found one which showed me how I could help my daughter develop her speech facial muscles.”

“When I have been to meetings with the school, they have only been ten minutes long and they just say, “well done, you’re doing great”. I don’t know who to write to in the city council.”

The daughter gets one-to-one help at school, but the class has 25 other children who are mostly non-English speakers. There’s only the teacher and one TA (Teaching Assistant) who is meant to be there specifically for the Parent’s daughter, not everyone else.

“If they had more support in the class from more staff, I think the TA would be able to provide better support to my daughter. My daughter has Down Syndrome. TA’s are meant to be only for my child, but they aren’t, they’re seeing to all the other children too.”

Communication between the school and parent was so poor that she hadn’t even realised that in order for the EHCP to be processed, she needed to sign the form first. The report was full of abbreviations which she did not understand.

The parent resorted to an appointment with the Law Clinic who advised her on what she is entitled to, but it still didn’t change things. Once Mary Seacole House was involved, things started to happen within 2 weeks. “Before this, the school would just keep saying “don’t worry, we’re taking care of it, goodbye”.

The parent also needed help with transport but was told she has transport of her own, so no help was available. She tried to explain that her husband needs the car for work and that as she needs to take her other children to different schools, it makes things impossible.

The parent described how everything makes her feel stressed, tired and upset. She doesn't feel she has time for herself as she's always trying to sort things out. "I'm not stupid; they just don't care and don't explain anything clearly".

The parent feels the EHCPs should be changed so that families can understand them; they're not just for professionals.

The school usually asks the parent to sign forms straight after their meetings without giving her time to read them. She described how the school have chased after her in the playground just to get a signature, telling her they won't get paid if she doesn't sign it.

She also didn't realise that she could apply for Direct Payments and decided to approach the school about it. When she did this, the school tried to discourage her by saying they need the money for the school. She is now trying to find another school.

The parent described how her other daughter doesn't get the same level of support from her which she finds upsetting. When her daughter with SEND was going to Fusion on a Saturday, she used to be able to take her other daughter to the cinema etc., but this ended due to a lack of transport. She described how Fusion had so much in terms of activities, both indoors and outdoors, and her daughter was happy there, but it was now inaccessible to her, so the whole family has suffered.

The parent also described how letters from schools are never translated into other languages (for example, parents' evening reports, school trip letters), so parents end up relying on other children who speak English. The parent feels the SENCO role should be much stronger and that she shouldn't have to find things out by accident. She feels parents should have more personal, emotional and social support. There is no information about how her daughter is performing in comparison to other children in mainstream school.

c) The parent is a single father with two children. The son is having problems as he cannot get into a school. He only speaks Farsi and when he does speak, he whispers. The son did attend a mainstream secondary school as they were still getting the Premium Rate for him; but he's now at home so benefits have been cut. "My son no longer gets child benefit as he is not in school". The son is nearly 18 years and has only recently had an EHCP. The school had the budget but said they couldn't find a translator.

"I am awake all night, so I don't sleep. CAMHS have been out to the home in the last 18 months. My son has autism, a learning difficulty and severe eczema. My son is bigger than me so I can't force him to go to school. We've asked for assistance so I can spend time with my daughter, but I keep being told "it's in process". My daughter has no social life and I have no social life. It's only because Mary Seacole House have got involved that anything has changed. My daughter now has a little bit of anxiety. She can't bring her friends home and it's getting harder as she gets older."

The parent has no friends and struggles with anxiety, but it is difficult for him to get to talking therapy appointments or even take care of his own health.

He is concerned about the son's transition to adult services as he will soon be 18. School haven't chased up the fact he hasn't been in school for 2 years. Three schools have refused to take the son. If anything were to happen to the parent, there are no other sources of care.

The parent often gets his daughter to school late as he can't cope, and she has ended up in detentions as a result. The school don't take any of the issues the family are facing into account.

The father thinks his son can understand more than the EHCP states. He feels that if he'd had the right support, he would also be more advanced at this stage. They haven't taken the time to do a full report. His reading age is probably better than the EHCP recognises as he opens letters from the council and gets upset, which suggests he understands what they say.

d) Parent had requested an EHCP for her 7-year-old child but hadn't heard anything back yet. Parent described how her child has mobility problems and is awaiting an additional diagnosis. Her child also has heart problems. They are on enhanced Disability Benefit and awaiting an OT assessment at their home. The house is in bad condition with internal structural damage, however even though there are 8 children within the household, this is not classed as an urgent repair job.

The parent has to provide round the clock care for her child. She described how she “just does it” as she doesn't want to bother anyone. Her eldest daughter has looked after the younger child when their parent isn't well but said she found this difficult.

The child now gets extra reading and writing help at school however they also home-schooled for two years because they could not get sufficient support from the school. The parent feels the child has “improved a bit” but things would have been much better if help had been offered sooner.

Overall, the experience of Mary Seacole House clients is that:

- + When using translators for EHCP meetings, large portions of information have been missing and the document the parents receive appears to be a summary of what has happened rather than a verbatim report. EHCPs are not translated and parents/carers express concern that schools play on the fact that English is not some of the parents' first language and give them things to sign without any clear explanation, or just tell them “Don't worry. We're dealing with it” but don't follow this up with any feedback. Jargon and abbreviations can be difficult to understand; however, it should be noted that one SEND Practitioner specifically stated “Parents view forms are obtained and we can support patents to complete if a language barrier”.
- + Some parents/carers reported that professionals, including social workers, had used Google Translate to translate documents, coming up with phrases such as “Put your daughter in the washing machine”, which clearly make no sense. Parents/carers asked why Language Line could not be used.
- + Many families do not claim DLA, Carers Allowance or Family Fund grants as they're simply not aware of them. Many parents have never had a Care Assessment and are paying for expensive items such as nappies and waterproof mattresses when they cannot afford to do so. In common with parents/carers more generally, there was a feeling that “only those who shout the loudest get the help”.
- + The lack of support for BAMER parents of children/young people with SEND is negatively impacting on parent/carer health. Mary Seacole House is trying to train volunteers to go out to the community to reach these people.
- + Some BAMER clients are choosing to home educate as they feel there are no other viable options. They feel the system isn't joined up; SENCOs do their best but don't suggest other sources of help, leaving parents to search online. Nobody takes ownership and everything is

left to the parents, whether or not they have access to relevant, understandable information.

- + Liverpool City Council website says that there are BAME support workers for education and families in the council but when families or Mary Seacole House staff ring up “nobody seems to know what we’re talking about.”

Beyond families known to Mary Seacole House, there was evidence from parents who responded to the Healthwatch Liverpool surveys that some groups are disadvantaged; including where traditional networks of support (family/friends) are not available or may not have the relevant information to navigate such a complex system. Language/translation support is essential for these families, as is recognition amongst professionals of cultural differences which may be relevant, and which should not prevent children/young people from getting adequate support.

*“Have spoken to other Black parents; we need a BAME support group. BAME communities think about these things in other ways. No idea how the system works.” Parent/Carer*

There is a strong case to be made for providing additional funding to specialist Voluntary Sector organisations, such as Mary Seacole House, which already have the expertise and the trust of under-served communities but which lack the resources to meet the demand being placed upon them.

Barriers to understanding are also highlighted by SEND practitioners as preventing effective involvement of children/young people and parents/carers in some cases. Some specifically mention barriers where people speak English as an additional language, and although some mentioned that they do provide support to complete forms, lack of an opportunity to contribute via a meeting was identified as contributing to difficulties in understanding.

*“Draft presented to family but not always understood.” SEND Practitioner*

*“Many families I work with have EAL [English as an Additional Language] and therefore I worry that they may not understand all the paperwork.” SEND Practitioner*

## 11. Education

### a. School uncooperative with parents’ requests for help/support

A recurrent theme from parents/carers was that schools could be uncooperative with their requests for support – whether with asking for an EHC assessment, explaining the assessment or how an EHCP would work in practice, reviewing their child’s progress, or listening to their own insights about their child’s behaviour. This was even more marked where parents did not have English as their first language.

*“We had the first EHCP plan declined... [the school] told us three times he would not get EHCP but requested... Due to school failing to provide appropriate help EHC assessment refused. I can’t get school to implement or document Ed Psych plans to the satisfaction of EHC assessors. I can’t get EHCP assessment because of school...” Parent/Carer*

*“School has not been helpful; they have said parents should do it.” Parent/Carer*

*“I’m concerned he won’t ever meet literacy targets as he’s failed to be supported in primary. I’m worried about the lasting impact on his educational attainment.” Parent/Carer*

Parents/carers believe the level of support differs across institutions and potentially disruptive school moves become more frequent.

*“I have recently moved my son because of the poor SEND support he received”. Parent/Carer*

Parents/Carers express frustration at mainstream SEND provision in particular, believing that head teachers have too much control/say in what support their child/young person receives and that this is not being monitored. There is recognition that schools are doing what they can but are restricted in what they can provide. Parents/carers are confused that school assessments have not captured their child's needs and support requirements.

*“Finally believing an EHCP can help only to find it gathering dust in a drawer never to be read. Having your child cry each day and night as he hates school and is full of bruises every day from being kicked or hit with chairs or bricks and knowing the school do not care is sad and heart-breaking. My son will never have 100% attendance due to his needs. My son is never picked for anything at school as he says “Why would they pick me mummy? I’m annoying”. The headmaster goes out of his way to make sure that the children who are not academic know they are not as he rewards 100% [attendance] and punishes the disabled.” Parent/Carer*

*“I feel like schools have far too many ‘tick box’ requirements to fulfil which takes away valuable time they have to ‘listen’ to and engage with the children. I believe [they] try their best, but like everyone else they seem to be under pressure from above to comply with so much paperwork, that the important things in life for our children are ‘lost’”. Parent/Carer*

*“3 of my kids have been missed in school; private assessment and diagnosis have saved their lives.” Parent/Carer*

*“Get daughter moved to suitable provision. Daughter describes school as poison.” Parent/Carer*

*“The LA needs to have more control over SEND provision in schools. Head teachers can do what they like and not be questioned. Governors only hear what the head teacher tells them. Interventions - just a tick box exercise therefore waste of money/time and not supporting the child. The LA need to speak with and support parents.” Parent/Carer*

*“They [special school] are also not following best practice of producing an IEP [Individual Education Plan] and assessing and reviewing throughout the school year.” Parent/Carer*

*“The systems of moving children who are in mainstream schools are under reported and extremely detrimental to the child.” Parent/Carer*

There are some highly negative comments about schools in the findings but with unequal numbers across each institution it is difficult to statistically analyse these differences - it would be useful to explore this in greater detail to identify best/poor practice and the factors that contribute to this. One parent felt that the survey did not allow adequate opportunity to provide feedback on schools.

*“There’s nothing in this survey about schools - this is where we have the biggest difficulty. SEND support in mainstream schools is really poor in this city.” Parent/Carer*

## **b. Parents and schools see different behaviour**

A recurrent theme from parents/carers was that their child/young person could often behave significantly differently at home than they did within the school environment, causing teachers to doubt the parent/carer's descriptions of how problematic the situation could be, or the types and levels of support that their child/young person required - both in and out of school. Parents/carers described the huge efforts that their children/young people made to stay calm, appear ‘normal’, concentrate and focus on their work or avoid potentially stressful situations with staff or fellow classmates/students in order to survive the school day; and the subsequent ‘meltdowns’ at home, which the children/young people required as a counter-balance or coping mechanism. One parent noted that they had videoed their child's behaviour as evidence but that not all professionals were willing to look at the footage. Nevertheless, professionals had changed their opinions/diagnoses/treatment based on such evidence.



Some parents/carers felt that professionals should be more aware of the ways in which children/young people with some support needs falling on the SEND spectrum can seek to ‘cover up’, disguise or minimise their ‘difference’, and that parents/carers expert, first-hand, accounts of their child/young person’s behaviour and support needs, as well as personally-tailored ways to minimise or prevent distress and disruption should not be so easily dismissed or ignored.

*“Feel like the school think I am making it up as she is so well-mannered in school and that frustrates me.” Parent/Carer*

*“Daughter doesn’t display in school but coming home her mental health isn’t good. Impacts on rest of family. Older sister is autistic and sensitive to noise so has bedroom in attic. 5-year-old also upset by meltdowns and is also on the pathway. If she becomes upset this can aggravate the situation.” Parent/Carer*

### C. Variations in commitment of school leadership/education staff

The level of support a child/young person receives appears to vary markedly depending on which school they attend, with some schools seemingly more willing to go the extra mile to provide the help and support needed. Whilst parents/carers are understandably frustrated about this, pressure on resources and staff training and experience is also likely to add to these inequalities.

*“I would like to say the support from [the school] has been amazing...since my child has moved school... in September 2019, he has had a better experience, the school have a better understanding of Autism and ADHD, and he is more at ease in this school, they are also more approachable, the SENCO has a good understanding and is sympathetic and believes what I say... unlike [the previous school]....” Parent/Carer*

*“I would just like to say that my daughters Primary school refused to acknowledge that my daughter was struggling, they refused to accept what I was telling them and didn’t help her in any way... when she transferred to secondary school she had a much better experience.” Parent/Carer*

*“I feel a parent’s experience of the SEND process is really impacted by the school your child attends. If the school is fully engaging and willing to seek outside help and advice, it can make the parent and child’s experience so much better. If the school sees your child as a problem, it makes the whole process very hard and very isolating.” Parent/Carer*

There is further evidence to suggest that there are variations in outcomes, interpretations and resources depending on which mainstream school a child/young person attends. There is also an indication this becomes more problematic as a child advances through the education system and other aims and targets take precedent. School’s decisions on how to prioritise available budgets and resources inevitably have an impact. It is concerning that parents/carers and practitioners agree that there are variations depending upon which school an individual attends and there does not appear to be any consistency in practices. Further exploration of these differences could be informative to determine what works and what does not but also why we are seeing this and why variations appear to be accepted as normal. The onus is on those involved in the EHCP/SEND process to monitor and ensure this is not a reflection of socio-economic differences and that provision/support is not restricted to those financially able to fund their own services or advocate for themselves.

*“As a school our SEND budget is very high and used effectively to meet their needs before an EHCP assessment is requested.” SEND Practitioner*

*“For those children in early years settings, SEND support is often very good. These settings appear to take a more individual approach to support for children and so they often work hard to make the reasonable adjustments needed for individual children. This appears to change a little once children go to school as other agendas such as achievement targets and attendance targets can*

*take priority, there is also a higher volume of children so the individual approach can get a little lost at times.” SEND Practitioner*

*“Delivery of support identified in EHCPs is sometimes inconsistently delivered by schools.” SEND Practitioner*

*“My involvement starts only when a request for EHCP has been received. My understanding of provision is that before this stage it is mixed: some schools/settings are very inclusive and meet needs very well, however some are less responsive to needs.” SEND Practitioner*

#### d. Home Education

Some parents/carers stated that a school environment is not necessarily the best place for children/young people with SEND. Whilst schools always attempt to provide as much support as possible to children/young people with specific educational needs, resources are increasingly scarce and specialist knowledge or support is not always available. Some parents/carers feel that schools are not only unable to provide the support that their child/young person needs but that keeping them at school may be harming their progress/wellbeing.

Home schooling appears to be an increasingly attractive alternative to parents/carers who feel that schools are not equipped to cater to their child/young person’s specific needs for reasons including lack of understanding or recognition of the diagnosis or condition (e.g. Pathological Demand Avoidance (PDA)) or for cultural or language reasons. Some parents had home educated for periods of time, or were actively considering doing so, but felt under pressure from professionals not to do this, and afraid that they would be viewed by ‘the system’ as damaging their child’s prospects rather than providing support tailored to their child/young person’s individual need. Others were much more positive about the benefits for the child/young person, whilst stating that the impact on their own wellbeing could be considerable.

*“Our experience with her mainstream primary school was that they supported but didn’t accommodate. They listened and believed there was a problem but they didn’t have the money to get the staff she needed, because she wasn’t violent or aggressive. They basically said ‘Because your child is ‘nice’, we can’t help her.’ We felt that kids were being treated as ‘a difficulty’, not celebrated for what they can do. Having her at home has definitely been better for her. She has fewer meltdowns and recovers more quickly; you can respond to her whenever she’s ready to learn - so we can do her 9 Times Table at 8.00pm rather than in a 9.00am maths class. But this flexibility for her comes at an economic and emotional price for us. We can’t both go out to work, we have to buy all the educational resources she needs, we get out together as a couple maybe twice a year.” Parent/Carer*

Liverpool City Council figures show that 470 local children were home schooled in 2018/19 (up from 350 in 2017/18; a 34% increase over 12 months) – not all have SEND but it appears to be a factor in some cases.

It’s recognised that this may potentially be a vulnerable group which can be excluded from services, but there appears to be positive movement. As Healthwatch Liverpool understands it:

- a. If families are struggling with support for SEND at home but have taken a principled decision not to keep their child at school, SENISS [Special Educational Needs Inclusion Support Service] can offer support.
- b. If families have chosen to home educate specifically because schools don’t know how to support their child/young person’s specific needs, but they’d like help to re-integrate at school, this can also be supported.

- c. The SEND Partnership is looking at the possibility of offering specialist teacher support to families which home educate.
- d. School Improvement Liverpool has also started to consider this issue.

It is important that this cohort of families are not overlooked and that support is provided to them, including to BAMER families, as noted on p51. One suggestion from a parent/carer was that:

*"There should be a swap/loan Home Education Library, for books and other resources."* **Parent/Carer**

e. Role of SENCOs and school mentors

Families' experiences of the education system were often closely aligned to the relationship they had with their SENCO and other support staff within a school. Parents/Carers were mostly aware that SENCOS and related staff were under pressure with teaching responsibilities and workload but also reported frustration at not being able to contact them or not receiving timely (or any) responses from them. This lack of consistency and availability was also noted by other SEND Practitioners who had also experienced variability of support.

*"Support can be variable, being affected by the significant workload of SENCOs/staff and their priorities."* **SEND Practitioner**

*"The SENCO has never been in touch with me regarding anything about my son, but his school mentor has been fantastic throughout his senior years. He and I would never have got through it without her."* **Parent/Carer**

*"SENCO visited her having meltdown and only comment was "I see you have a nice house" and wanted to take her off pathway - but then she was diagnosed with ASD."* **Parent/Carer**

*"Since new SENCO has been in place, his support plan has been implemented and reviewed, however due to high staff turnover and lack of funding to education, support and intervention could be better."* **Parent/Carer**

*"The SENCO has to be chased continuously as the communication between the school and the parent is very poor."* **Parent/Carer**

*"I would like to say that I couldn't fault them [the school] in any way, so much support and understanding, good communication between myself, her Year Head and the SENCO. They really should be applauded for their effort to try and meet the needs of girls and help them to achieve."* **Parent/Carer**

*"SENCOS and SENISS are the most consistent support."* **SEND Practitioner**

Whilst it is encouraging to hear positive reports from some respondents it is clear that support for SENCOS needs to be increased if they are to have the capacity to truly make a consistent difference in children/young people's lives and thus, by extension, in the lives of their families. This is undoubtedly a matter of national concern and a major policy and resourcing issue (particularly in relation to protected time for undertaking SENCO duties in addition to other duties within the school) but should, nevertheless, remain a high priority at a local level.

## 12. Health

As has been noted elsewhere in this report, the vast majority of survey responses from professionals came from people working in education. Although parents/carers and children/young people commented on health and social care issues, the majority of their input also related broadly to education. This is a finding in itself and it may, perhaps, be useful to look at why this is, as well as to try to engage more proactively with health and social care professionals who work primarily with children/young people who have SEND support needs, as well as with more generalist health and care professionals.

In terms of the feedback to the Healthwatch Liverpool survey, the main input in relation to health included:

### a. Role of medication

One concern raised by parents/carers was that medication was sometimes offered as the only option for their children/young people and that they felt that whilst this may have an important role to play it should not be the only response. Parents/carers were understandably wary about the potential negative side-effects of medication, or of the impact of the wrong medication being prescribed. Some felt that alternative options should be available, and others felt poorly informed about the advantages and disadvantages of medication and of ‘medicalising’ the issues faced by their children/young people rather than considering social models and the impact of wider environmental factors. There was also a concern that diagnoses could be reliant on agreement to medicate.

*“...Community Paediatricians offered medication as the only treatment - no advice offered except for being told to look on ADHD foundation website.” Parent/Carer*

*“Paediatrician asked if we’d consider medication but we want to stick with mindfulness. She was diagnosed by the paediatrician with ADHD but that’s being questioned because she doesn’t display in school. The diagnosis would have stuck if medication was used but now there’s no diagnosis.” Parent/Carer*

Lack of information and support once diagnosis is received is mentioned frequently in survey responses and parents/carers are concerned that they have been left to find the relevant information and services to support their child/young person without adequate support.

### b. Role of medical professionals/health sector

The NHS, like education, is generally accepted to be under-funded, under-resourced and under pressure in all specialisms and disciplines. This is particularly relevant in relation to Community Paediatrics, SALT/SLCN [Speech, Language and Communication Needs] and CAMHS services.

*“Think the capacity within the health service provision is a big issue; national shortage of Community Paediatricians.” SEND Practitioner*

*“[My] negative comments around SEND reforms are in regards to experience of SEN Team and EHCP process and NHS Speech and Language service who are dealing with heavy caseloads and can only offer minimum service on the care aims model. This fails the 10% of the SLCN children with a developmental language disorder which the service cannot be responsive to needs. This is highlighted in much public health research at present (like Bercow 10 years<sup>4</sup>) that the poor outcomes from SLCN will continue to adulthood.” Parent/Carer*

4 ‘Bercow: 10 Years On - An independent review of provision for children and young people with speech, language and communication needs in England’, March 2018, I Can/Royal College of Speech and Language Therapists.

However, advice and support from GPs can also be variable.

*“The GP just blamed her eczema for the fact that she refused to wear clothes, and tried to imply that she was ‘misbehaving’ because she was an only child, and that we should ‘Let her wear pink, girls like pink.’ We had to fight past the GP to get a CAMHS referral and then wait months to be told that we could probably teach the professionals some stuff, and then discharged and referred back to the GP. The whole system seems circular.” Parent/Carer*

### C. Role of Public Health/preventative approaches

The above mention of public health research underlines a specific concern raised in respect of the role of Public Health, early awareness and preventative approaches - which relates back to issues around early diagnosis and intervention, as discussed in Theme 1 above (p21).

*“The service is at breaking point. The wider determinants of health i.e. poverty levels in our city are impacting upon everyone. Greater investment into public health intervention for prevention is required.” SEND Practitioner*

However, Public Health has also faced considerable reductions in funding over recent years<sup>5</sup>.

## 13. Social Care

### a. Role of social care professionals/sector

Social Care was also under-represented in terms of responses to the survey and feedback from parents/carers and children/young people. Indeed, some respondents expressed concern that these services were not sufficiently engaged or integrated within the SEND system.

*“Why is it only school that appear prominent in the process? This whole process could have remained a statement of SEN if the expectation was for schools to do all of the work and be the key contributor. Health and Social care are failing in their duty to input appropriately to these processes.” Parent/Carer*

*“School are always involved in review, health and social are less engaged with this process.” Parent/Carer*

*“The social care only provides waking nights for one HCA (Health Care Assistant) and I’m the second hand. It does not take into account the needs of the family.” Parent/Carer*

*“Social care, early help and family support is completely insufficient.” SEND Practitioner*

*“Social workers withdraw as soon as they can. Health never turn up to meetings, always attempt to delegate to schools. EHCPs should just be called Education Plans as social care and health are usually nowhere to be seen.” SEND Practitioner*

Again, it would be potentially useful to look further as to why Partnership working at senior/strategic level does not yet seem to be reflected at all levels.

<sup>5</sup> Since this report was compiled, the principal public health focus has been on Covid-19, and plans have been made to replace Public Health England.



## Input from Children and Young People

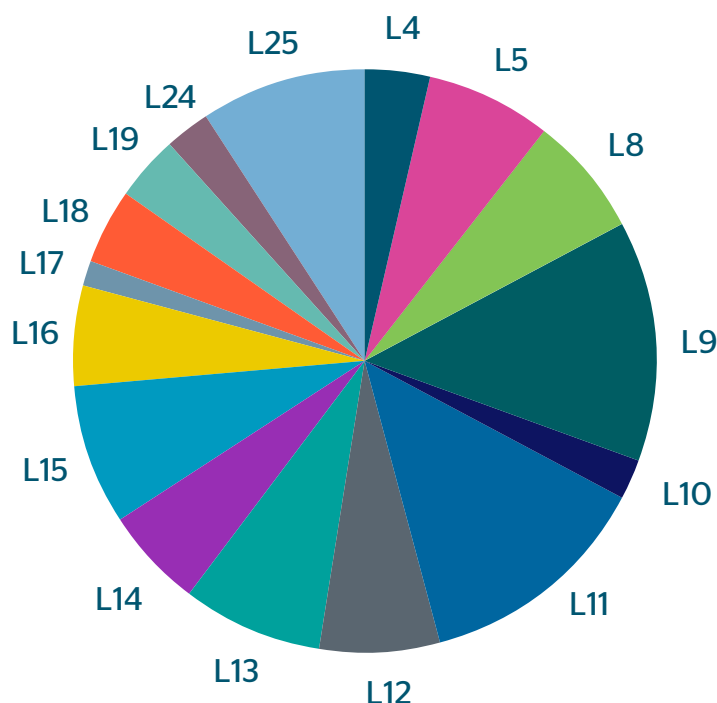
When designing surveys for children and young people we were aware that these would not be suitable or appropriate for all children/young people with SEND and we looked at other potential ways of seeking feedback, including working with a group of peer researchers. To this end, we commissioned the Liverpool Safeguarding Children Partnership (LSCP) Young Advisors group to conduct focus groups with children and young people on our behalf.

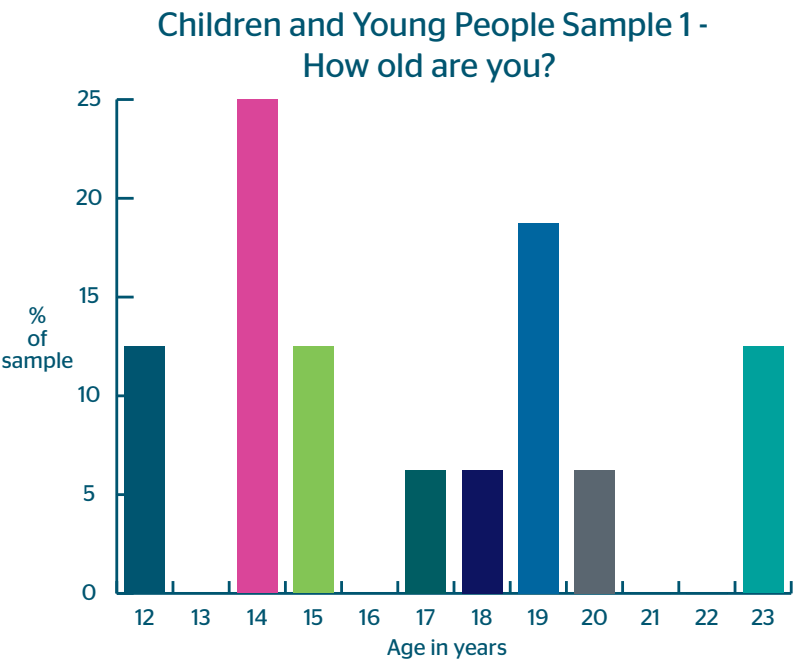
Young Advisors are a group of young people aged 15-21 (or up to 24 with additional needs) who bring unique expertise and knowledge about being young to strategic planning, decision making and marketing across business, health, local authorities, justice and charity sectors. They delivered 6 focus groups for children and young people aged 11-19 on our behalf, using a slightly modified version of Healthwatch Liverpool’s survey questions, which made them more suitable for group discussion.

In total we gathered opinions from 72 children/young people. Sample 1 consists of 16 participants who responded to the Healthwatch Liverpool survey either online or by hand. Sample 2 consists of 56 participants aged 11-19 years old who took part in the 6 focus groups facilitated by Young Advisors.

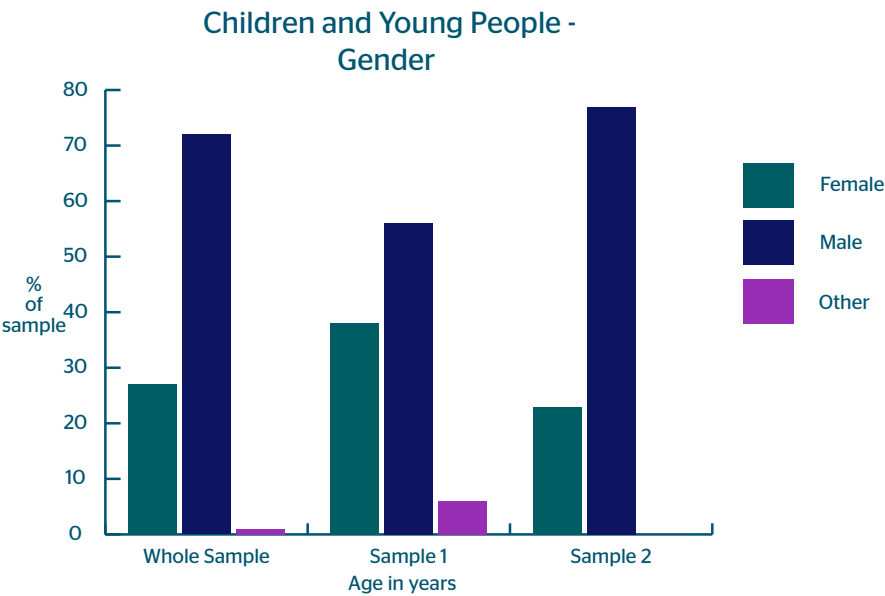
Where possible, the samples have been combined to show the total result. Where questions differed slightly, 2 charts have been created to show the results from each sample. Demographics for both samples are provided, where known.

**Postcodes of Children and Young People participants**

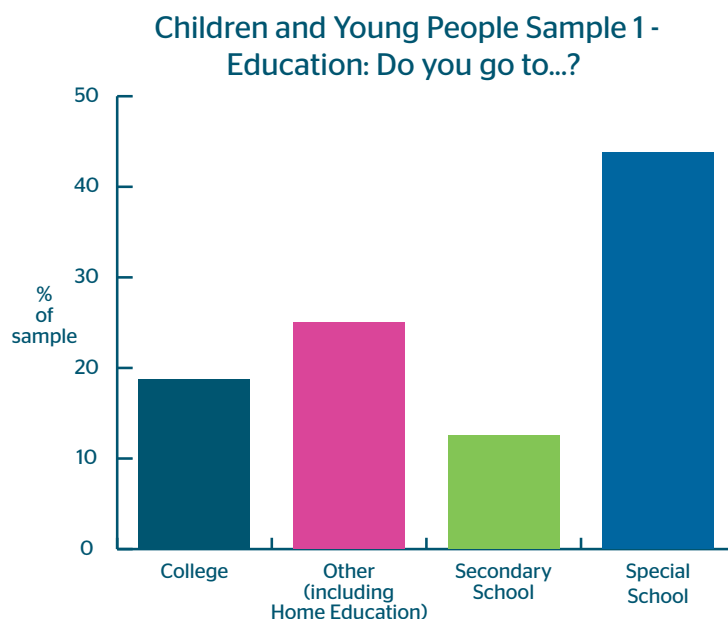




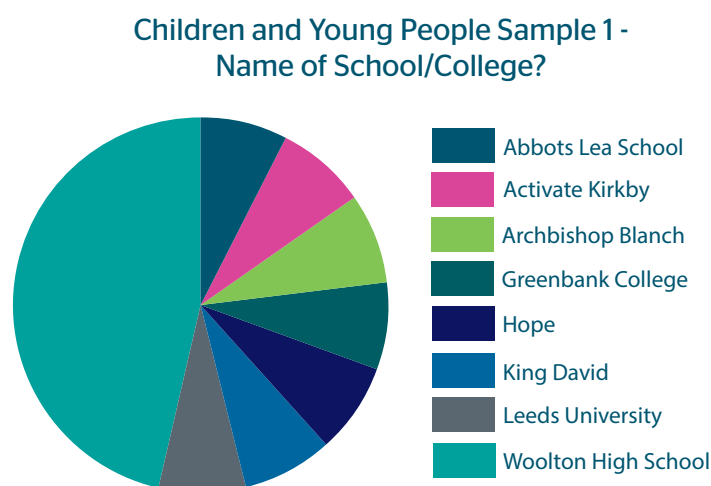
Sample 1 was relatively small but shows a similar spread of ages (12-23) to Sample 2 (11-19).



Both samples included more males than females, with nearly three-quarters of participants being male overall.

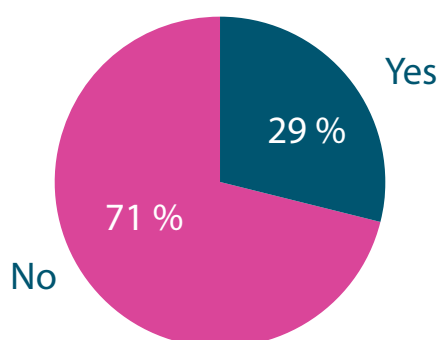


Where we have information on the type of education participants were involved in, they were most likely to say they attended Special Schools.

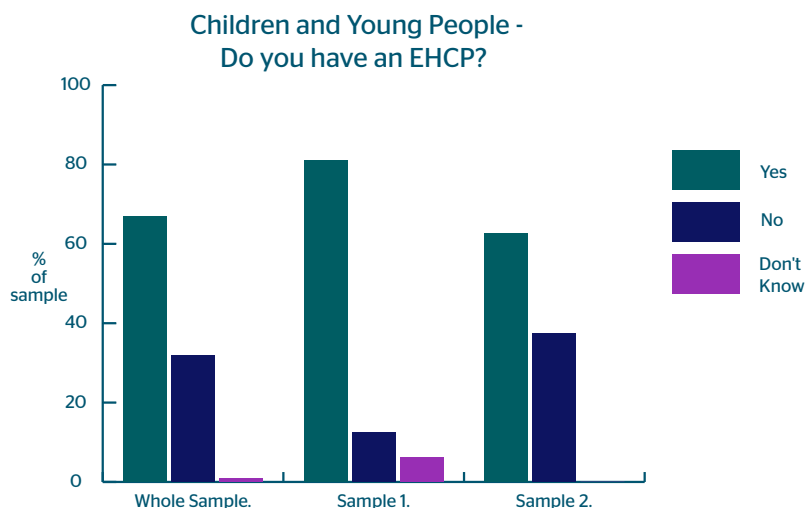


Where educational establishments were named, they showed a diverse range of institutions from Special Schools to mainstream schools, colleges and universities. However, in these particular samples, almost half attended Woolton High School.

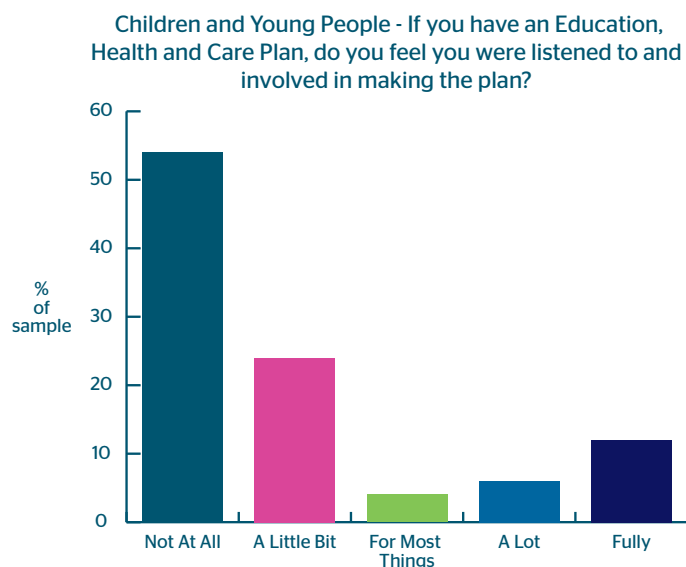
Children and Young People Sample 2 -  
Do you know what an EHCP is?



Of those who answered this question, less than a third (29%) knew what an EHCP is.

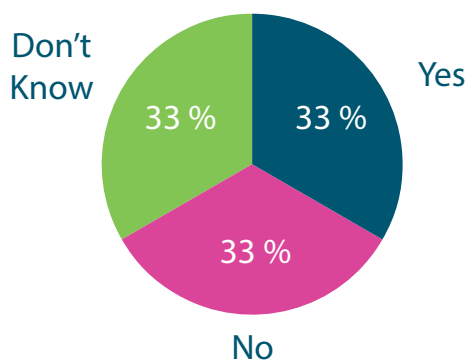


However, a clear majority of respondents in both Samples, were aware that they had EHCPs in place.

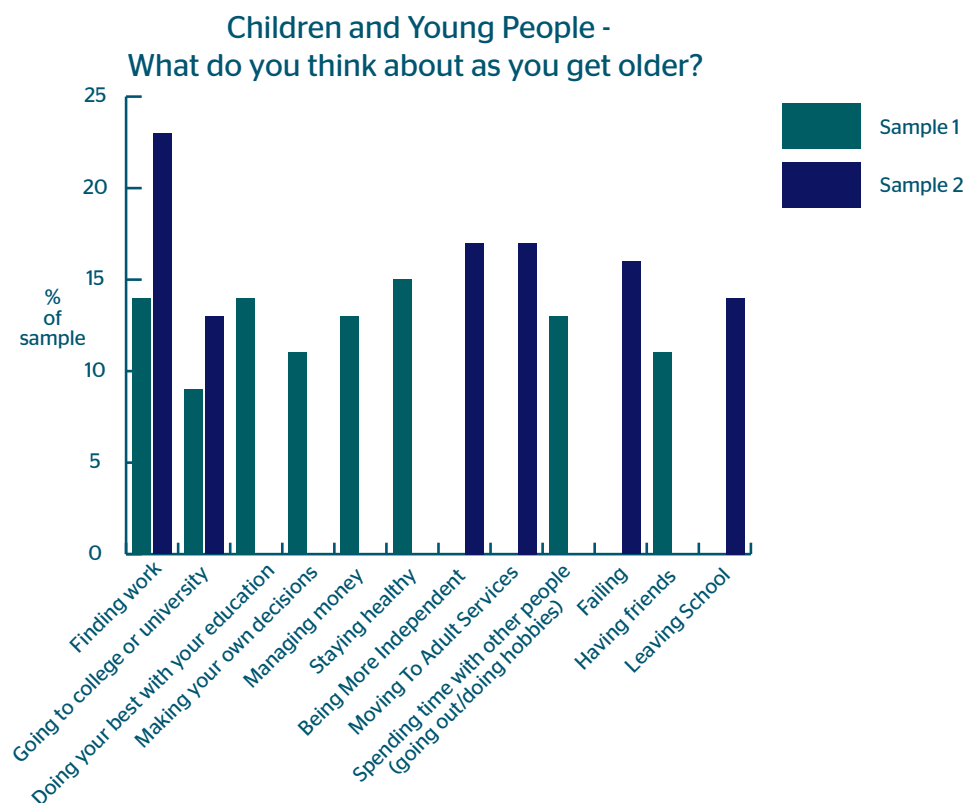


Significantly, over half of the children/young people with an EHCP felt that they had not been involved in making the plan at all.

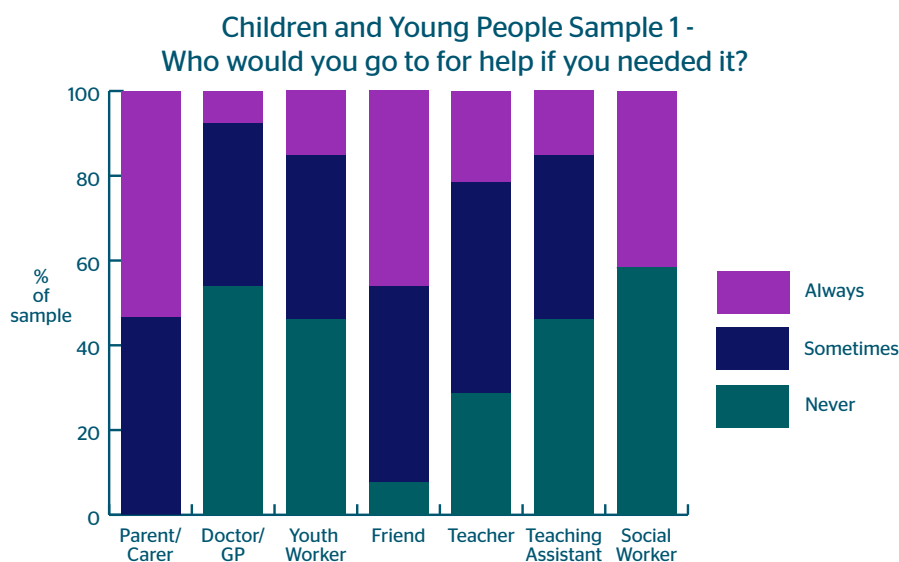
Children and Young People Sample 1 -  
If you don't have an EHCP, do you have any  
SEND support at school or at home?



Amongst those who said they did not have an EHCP, there was a completely even distribution between those who said they received some SEND support, those who said they received no SEND support and those who didn't know whether they did or not.



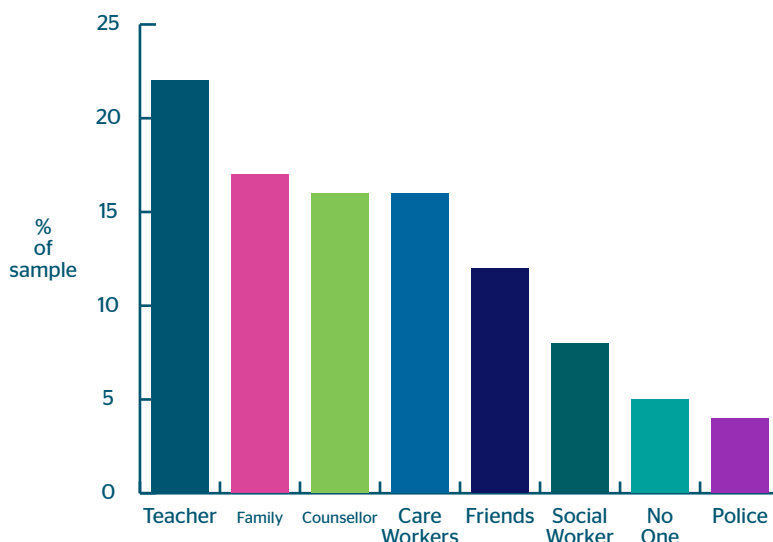
Overall, participants' main concern as they got older was 'finding work'. However, 'being more independent' and 'moving to adult services' were also of particular concern to Sample 2, as was 'failing'. Sample 1 also mentioned 'staying healthy'.



Sample 1's biggest source of support was 'parent/carers', followed by 'friends'. Although 'teachers' were also largely trusted. 'Social Workers' and 'Doctors/GPs' were the least likely to be confided in.

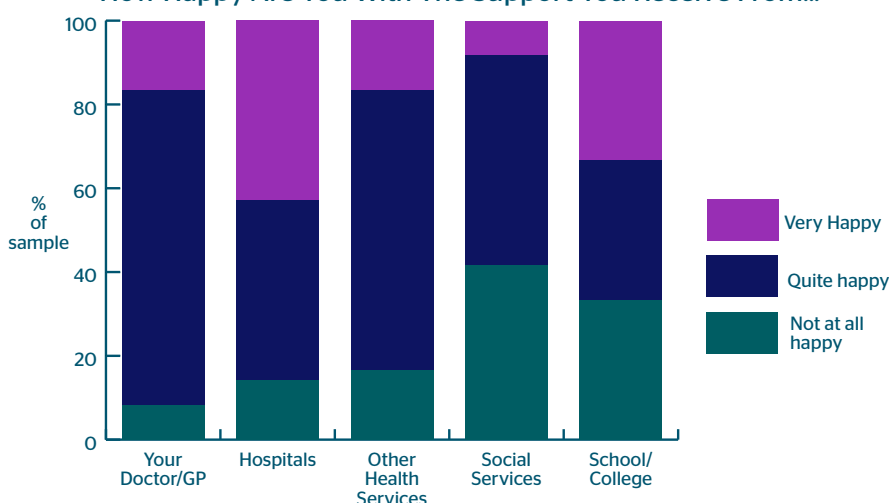


Children and Young People Sample 2 -  
Who would you go to for help if you needed it?



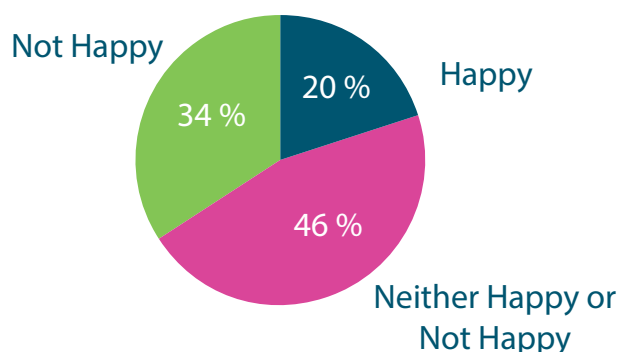
Sample 2 were most likely to seek help from ‘teachers’ or ‘family’ and least likely to confide in ‘Police’. However, 5% also said they had ‘no-one’ to go to for help.

Children and Young People Sample 1 -  
How Happy Are You With The Support You Receive From...

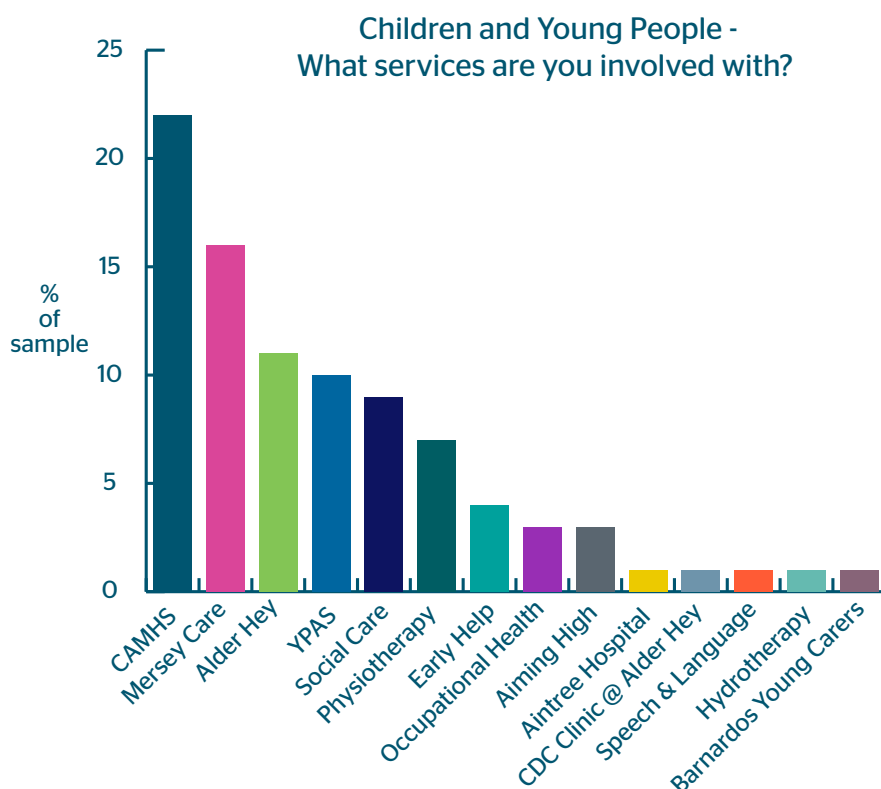


In both Sample groups, participants were moderately happy with the support they were receiving overall. Sample 1 were least likely to be happy with ‘Social Services’ support, and most happy with support received from ‘Hospitals’.

Children and Young People Sample 2 -  
How happy are you with the support you receive?



Sample 2 were asked a more generalised question but almost half said they were ‘neither happy or not happy’ with the support they received. However, just over a third said they were ‘not happy’ at all.



Across both Sample groups, CAMHS was the most frequently cited service that children/young people were involved with (used by almost a third of respondents), and Mersey Care was the second most predominant, also suggesting that mental health was a particularly important factor in their lives. The third most engaged-with service was Alder Hey.

In addition to the quantitative data summarised above, we also received some qualitative comments from children/young people which have been grouped/summarised below.

## Role of the parent/carer

There was some evidence that children/young people can be aware of the hurdles their parents/carers face in trying to access appropriate support for them, and of the stresses this can put on them, as outlined by parents/carers themselves elsewhere in this report.

*“I wouldn’t be where I am today without the support of my Mum... she has fought every obstacle on my behalf.”* **Child/Young Person**

*“I’ve never been offered a social worker to help me with my social skills. I rely 100% on my Mum. Who has supported me all my life.”* **Child/Young Person**

## ‘Less serious’ needs neglected/importance of tailored support

The following quote provides an excellent illustration of the importance of individually tailored educational support, regardless of the perceived severity of support need:

*“When I was at infant school, I really didn’t like reading or writing. I used to get upset when I was asked to write because it was so hard. The school didn’t do anything, and my family ended up getting me assessed outside school. This report helped the school understand but it was still really left to me and my family to deal with. At school I had to concentrate much more than other people, which was really tiring, and I often came home from school feeling unwell and going to bed. I also found it hard if there was a lot of noise in the classroom and when teachers put writing or PowerPoints on white backgrounds. The glare made it harder to focus. When I first started at my*

*secondary school the SENCO was nice and if I'd needed help, she would have been willing to. By then my reading was not too bad and I could cope reasonably well in most lessons. That SENCO was helpful to my brother when he needed it. She left and her replacement was much less helpful, they seemed to assume that because I was in top sets that I was coping fine and didn't need any help. People who are 'clever' can still be dyslexic and need support. She didn't understand that I was working extra hard to do well despite my dyslexia and that some things were still really hard for me. I didn't get any support with planning my next steps or explaining my needs to my university, she just gave me a link to a long form to fill in to get reassessed. Forms and paperwork are the hardest thing for me so that wasn't really helpful. It has taken me my first term to try to get that sorted out.”* **Child/Young Person**

Children/young people also expressed a desire to have their educational support needs balanced with appropriately challenging work. One young person told us they wanted

*“A school that can meet my needs as an autistic person but has work at my level.”* **Child/Young Person**

It is clear that SEND can present difficulties for children/young people, whatever their strengths and abilities. SEND students can sometimes be assumed to have lower academic capabilities than they actually have, whilst those who are seen to be ‘coping’ academically can have their additional needs dismissed, adding to their stress levels.

## The need for Specialist Training

Input from children/young people supports the ‘need for more training’ theme which was also identified by parents/carers and practitioners. One young person, for instance, told us that what they’d find helpful would be

*“More specialist carers who are trained in using my communication aid.”* **Child/Young Person**

Although it is, understandably, difficult to ensure that all staff across education, health and social care can be aware of all specialist support needs or use all specialist equipment, it is important that they have access to as much training and awareness raising about as many conditions or support needs as possible to reduce the likelihood of children/young people missing out, and so that they are aware of where to signpost children/young people and their parents/carers for more specialist advice, information and support, as appropriate.

## The need for improved information about EHCPs

Children and young people who attended focus groups facilitated by LSCP Young Advisors requested a one-page document, explaining their EHCP aims and actions. They suggested that this should be provided in addition to a detailed explanation, both before and during their appointments, outlining:

- + what the meeting is about
- + what will happen at it
- + how it's designed to help them
- + how they can provide feedback about whether or not EHCP actions or support plans are working well for them.

*“Get more of a say in my care plan.”* **Child/Young Person**

## What else would be useful?

Other comments from children/young people tended to echo themes also identified by parents/carers and practitioners. These included:

- + struggles and concerns around mental health
- + money management
- + finding employment
- + living independently
- + developing social skills
- + help with/access to transport to enable improved participation in educational opportunities and social activities

*"I struggle to manage my money, look after myself properly and struggle with my mental health on a daily basis."* **Child/Young Person**

*"Finding a job when I'm 18."* **Child/Young Person**

*"Help with my social skills and offering transport to attend social events."* **Child/Young Person**

*"More accessible Educational facilities in Liverpool."* **Child/Young Person**

## 3) Word Cloud

As part of the survey, we asked parents/carers to sum up the local SEND experience in 2 words of their own choosing. The results were as follows. Although some chose positive words, such as 'good', 'great', 'helpful' or 'friendly', or more neutral words, such as 'patchy' or 'varied', the vast majority chose words which express their frustration with the system and which summarise the experiences which they outlined in greater depth in their survey responses, including in the quotes selected to illustrate the findings outlined in this report; 'poor', 'slow', 'inadequate', 'underfunded', 'disappointing' and so on:



## 4) Case Studies

The information and feedback provided by parents and carers fell into a number of broad themes, as outlined above. Many of these themes are illustrated in more depth in the following five case studies which are based on semi-structured interviews with parents/carers.

### PARENT 1

Parent 1 has a 7-year-old son. She first noticed a ‘difference’ in him when he was 3. Her son was seeing a speech and language therapist. Parent 1 was given a list of support providers and was referred to the Autism Pathway. SALT services then discharged her son. Nobody mentioned the word ‘autism’ but all the providers on the list were autism specific.

Parent 1 felt that her son shouldn’t have been discharged from SALT and suspected that he’d been discharged purely because he’d been put on the autism pathway. An autism diagnosis was made at age 5, after a wait of 18 months.

The school put some support in place but Parent 1 did not feel it was enough. Parent 1 asked the school for an EHCP assessment but they “said they were busy” and asked the parents to request the assessment instead. The assessment was refused, and they chose mediation.

Assessment for an EHC Plan was refused because a) school should apply for more funding b) the child had made good progress with speech and language c) the mediation report’s recommendations were being followed. However, the following day, the decision was reversed and LCC agreed to assess, due to the wording of an Educational Psychologist’s report.

Parent 1 felt largely on her own when navigating this process. “The Local Offer website is not very good. The tabs don’t work. It’s not where I’d look first for information. I look when I remember to. ADDvanced Solutions and LivPaC are good and share info on services on social media. Social media is more helpful than the Local Offer site. Alder Hey are good. SENDIASS had some involvement but didn’t have the resources to attend meetings. Once discharged from the ASD pathway you need an ADDvanced Solutions follow-up appointment, but you just get leaflets. What you really need is an official introduction and handover meeting.”

Parent 1 prepared a statement and advocated for herself. “I was lucky to have the skills, knowledge and resources. Not all parents do.”

Parent 1 made a complaint to LCC because everything in the EHCP was late. She asked for a SALT re-referral but LCC refused. The parents then took their concerns to the Local Government Ombudsman.

Negotiating IPSEA (Independent Advisor of Special Education Advice) and SOS!SEN was “a Special Needs jungle” but an EHAT was eventually written into the EHCP and an Early Help Social Worker is now required to attend all meetings. “Support is needed at 3 or 4 – not at 7, 9 or senior school. It prevents crises and costs, and mental health problems. Children are seen by health visitors, nurseries etc who could identify issues early on – but it’s important how you ‘sell’ it to parents. You scare them if you mention social services involvement.”



The relationship with the school had completely broken down but is now good and Parent 1's son now has full-time 1-2-1 support. “I had to get a judge to get the Education Officer to confirm that my son should stay in mainstream school. We named the school we wanted and were offered another school, which we refused. We held out for our preferred school or my son's current school.” Parent 1's son is now very happy at school and has friends, “He's oblivious to the issues.”

The draft EHCP was full of spelling and grammatical mistakes and inaccuracies. Parent 1 made corrections to it and LCC eventually accepted her amendments. By the time of the Tribunal they were on Working Document Version 13. Even the Final Document contained omissions, despite all the previous versions and conversations. Court hearings had to be postponed 3 times whilst trying to get paperwork correct. The Social Care section came back as ‘Not Known’, “Which isn't a reason in law. They MUST do an assessment.”

Parent 1 asked for 1-2-1 support for before and after school but was offered respite (via Fusion) instead.

Parent 1 is happy with the level of support she's getting for her son, and as a family. The Autism Show in Manchester turned the family's life around. They spoke to solicitors and educational psychologists who advised them to get their own reports done. They hired an Educational Psychologist and Speech Therapist and “never looked back”. LCC accepted all their advice. Before this, the EHCP was not specified or quantified and was offering nothing Parent 1's son did not already get.

The child spent 3 months at Mab Lane for Intensive Speech Therapy and saw an Educational Psychologist there too. “They all said he ‘would benefit from...’ but none said ‘he should have...’ X, Y or Z”

Now that the right support is in place the fight is to keep it there. “His teacher says how well he's doing now, he's doing well BECAUSE of the support!”

IPSEA and social media were helpful but more intensive help from SENDIASS would have been preferable. She did have an IPSEA volunteer to assist with her tribunal. More money invested in SENDIASS would mean a bigger overall spend for LCC and they may not see it as being cost-effective but it may have longer-term benefits.

Parent 1 also sought support from a local Councillor and MP to help support her case. Parent 1 has now asked for reimbursement for the money she's spent on private reports.

Within 12 months, Parent 1's son has gone from being unable to read or write to being able to read ‘The Faraway Tree’.

“The stress on the family is huge. I was off work for 7 months with stress. We had no family time. I spent all my time researching. Even our holidays were ruined by the research work I was doing. Not all children have such a supportive background. The playing field should be level.”

## PARENT 2

Parent 2 has an 11-year-old son with ASD, PDA (Pathological Demand Avoidance), ADHD and severe anxiety. He has been involved with CAMHS since he was 2, was diagnosed by Alder Hey at 4 and has been on medication of various kinds since he was 5. He was an inpatient at the Dewi Jones Unit (Alder Hey mental health unit) for some time, aged 7, and was restrained during that time, which has increased his anxiety and continues to act as a trigger for him. He has frequent meltdowns in addition to self-harm, suicidal ideation/suicide attempts, and regular nightmares. He has an EHCP “but they’ve never said ‘yes’ to me first, always said ‘no’. I finally got him one 3 years ago. School didn’t listen to what I said, and professionals stick together and dismiss the parent and child. It was disgusting.”

Parent 2’s son has attended 3 schools, but none have been suitable for him. He was out of school for 2 years between the ages of 6 and 8. LCC offered the choice of a school that Parent 2 felt was unsuitable, but she was threatened with being taken to court for neglect if she did not accept the place. He’s now, therefore, on the roll at a special school where “children are restrained on a regular basis and it triggered his anxiety. He was also bullied” but he has not attended since September 2018. A reduced timetable was negotiated but the school chose the time (9am – 11am, to cover English and Maths) and this did not work best for her son. No alternative educational options have been offered.

Parent 2 says that no professionals take her son’s needs seriously and that she has been threatened with prosecution because of his non-attendance at school. Her GP refused to write a letter of support about her son’s anxiety and his inability to return to school and, for some time, CAMHS were also unwilling to give support, “It breaks you.” Parent 2 paid for a private psychologist to write a report on her son, which concluded that he was not fit to attend school, but this was disregarded by local authority and NHS staff.

The relationship with the school is very poor and Parent 2 says that the school rang Social Services to say that “I’m depriving my child of an education.”

The school asked whether there is an anniversary of a trauma every September which makes it particularly difficult for her son to return to school, “But, no. He doesn’t want to go because he’s been away from that stressful environment over the summer holidays!”

“The school is aimed at children who need high boundaries, but that’s the complete opposite of what he needs. He needs flexibility. They have a very mainstream approach. It made him so ill. I don’t know how I’ve managed to survive this far. I’m strong but I don’t know how I keep going. It’s scary how quickly professionals can take over. There shouldn’t be ‘sides’ but I’m on one side and the school is on the other.”

At the time of interview, Parent 2’s son had been out of school for almost 12 months, but she’d asked for a referral to ACE (the Alder Hey School). She hoped he’d be able to start there in September, but she was not sure he’d ever be able to cope with full-time education again.

An LCC officer told her the Council doesn’t have to provide a school place as she’s chosen to take her son out of school. She had made a complaint to the Ombudsman and was awaiting the outcome. She made a previous, unsuccessful, complaint several years ago and “the Ombudsman met with the LCC SEN team but not with me.”

“I was going to home educate but they said I couldn’t. I think they suspect he’s at risk. I know so many who’ve had to home educate as there’s no provision. But it’s expensive. It’s not ideal for us as we’re isolated. He needs to be with people like him and away from me. I worry he’s too dependent.”

Parent 2 attended Alder Hey with her son (then aged 10) at 1.00am one morning when he thought he had an infestation of worms inside him. They were left in a room for 6 hours whilst he had panic attacks. Eventually a Dr said they could get her son a bed but this offer was withdrawn, and they were sent home with instructions to return at 3.00pm to see a CAMHS worker. It was “a complete waste of time”. The CAMHS worker told Parent 2 to “call the police next time it happens.”

Parent 2 is particularly unhappy with the attitude of a Consultant Child and Adolescent Psychiatrist, who she feels “was inept and patronising... refused to write in support of removing my son from school because [the Psychiatrist] didn’t want to ‘get into the bureaucracy’. They gave him useless games to play, like pretending he was biting into a big piece of cheese every day; and kept increasing his anti-psychotic medication”. When Parent 2 asked for a blood test because she was concerned about the side-effects of the medication, her request was refused.

However, a neurologist who saw her son because he regularly passed out when he had meltdowns, thought the issue was “brain flooding” and said that he should have a blood test. The test showed raised levels of prolactin which could result in her son producing breast milk, if left unchecked. He is now therefore being weaned off his anti-psychotic medication and is on anti-depressants.

The psychiatrist sent a letter to Parent 2’s GP saying “the mother’s anxiety is being passed on to the son”, so Parent 2 feels she is being blamed for her son’s condition. “I’m worried and concerned and want to protect my child, and for him to have an education. Yes, I’m anxious. They’ve made me anxious and they’re pointing the finger at me.”

Alder Hey were reluctant to allocate a different psychiatrist but this has now happened and “the new psychiatrist is better but still won’t support us about my son’s inability to attend school.”

Social workers visited for 3 hours and said “they’d never seen a child so distressed” and that he “shouldn’t attend school” but the school started sending taxis for her son at 7.30 every morning and these didn’t stop until April 2019, when CAMHS finally told the school to cease sending them.

CAMHS won’t accept PDA as a diagnosis so won’t consider any support or activities which Parent 2 feels would be beneficial to her son. Instead, they offer activities which increase his anxiety. “He was invited to Forest School, but they don’t see that a child with severe anxiety won’t want to be in a circle, get to know people and join in. A child could have run that group. It was so patronising. It’s a great facility but wasted on children with anxiety. He was so disappointed, sobbed all the way home, had nightmares, and feels he completely failed.”

Parent 2 feels she has no support networks. She goes to CAMHS once a fortnight for a Lighthouse Parenting programme, “Some of it is useful but I understand my child’s needs more than they do. I go along with them just to keep them happy”, and she’s part of Fusion (which aims to direct disabled children and young people into mainstream play and leisure provision within their community) but doesn’t feel they’re suitable for her son as the places that they visit are “just sensory overload, and things like bowling are too competitive”. Other than that, “I get no support, no respite, he’s with me 24/7 and he doesn’t go out. I have no family; it’s just me, my daughter and my son. I’m trapped in the house every day, I do on-line shopping, I don’t have free time except that my daughter will mind him for a few hours sometimes. No one reaches out to the likes of me because my son looks ‘normal’ – I hate that word – but if he’s in a group of children with severe physical disabilities, all the attention is on them. I

understand that they have severe needs, but they don't read his notes and see that his needs are big too.”

“I've been in touch with support groups, but I don't feel like I fit in, so I don't get the help. I need someone to attend meetings with professionals with me, because they're savages, but there's no help available. Do they help everyone or only who they choose? There was a North West PDA Group on Facebook and they used to meet once a month but when we went, he lasted 10 minutes. I tend not to mention PDA because it puts people off. I just say, 'demand avoidance.'”

“Papyrus (young suicide prevention charity) and Young Minds have been helpful and supportive and not judgemental on the 'phone” but “He's just offered medication, not therapy. He had art therapy years ago and it was good, but he's had nothing like that since he was 6 or 7. Counselling and CBT aren't helpful.

In Parent 2's opinion, the best form of therapy for her son would involve cats or other animals, which he bonds with, or time in nature. “Animal therapy would help him and being in nature. Birds and forests. Looking at things, not sitting in a room and chatting. It's scary. Sometimes he doesn't know how he feels and it's triggering to be asked, so he turns in on himself. But he's funny – hilarious! Has me in stitches! I feel his childhood's been robbed. He's been discriminated against. I get told there's nowhere for him. He's been labelled SEMH (Social, Emotional and Mental Health) but I want that taken away. It's not a diagnosis, it's a label.”

Parent 2's son was currently getting re-assessed. CAMHS were supporting the removal of SEMH as the main issue in his EHCP and replacing it with autism.

“It's relentless. I can't get a break. I've tried 4 times for Respite, but he doesn't fit the criteria. The social worker said he's severe but 'the wrong kind of severe' – because he can talk. My life doesn't exist anymore. I used to have a life and a job, but it's affected me, big-time. I'm on anti-depressants but I'm scared to mention it, in case they hold it against me. I don't trust professionals.”

“If I'm not there it could get really serious. The impulsivity, the harm. Being able to live independently, and what will happen if something goes wrong. I know not to talk to him about what will happen to him as an adult. There's been a lot of talk from him about not wanting to be an adult.”

## PARENT 3

Parent 3 is parenting a Looked After Child (LAC) aged 9 - who has been with her for the past 6 years. He is nonverbal and has no expressive or receptive language skills. He is also a wheelchair user and needs to use nappies. Health care is provided from local budgets but because the child is Looked After by LCC on behalf of another Authority, as an out-of-area placement, social care is paid for by the other Council. However, Parent 3 feels that access to early help is not good enough, across the board. “In Liverpool a Child in Need, under the terms of Section 17 of the Children Act, should be identified via the EHAT process. According to S17, every Child in Need is entitled to provision but, in reality, very few children ‘in the middle’ are receiving social care support. Legally they should all have that status.”

Parent 3 noted that LCC have an ASD training team and offer 6-week courses. The city has fought to keep this provision - which is admirable - but they offer dates and times which aren’t flexible for working parents, and general support is limited. “During the assessment process you meet with a neurological practitioner over an extended period (where a ‘sit down’ test is impractical), and information is drawn together from family, educational psychologists, community paediatricians etc., and then goes to Panel. Then you’re given a diagnosis (or not) by the neurological practitioner and sent on your way with a wallet of leaflets and information. At this point there is a gap in provision for families with ASD. There’s lots to navigate - EHCP, benefit entitlement etc. - and very little guidance.”

Parent 3 also feels there are many families with children on a huge spectrum with limited access to support. Professionals want to help but mainstream and holiday-based activities can’t accommodate her son’s needs. “On Saturday mornings my child is up at 5.00am and desperate to get out of the house but most activities only run from 9 to 10am - and wet days can be especially difficult. You need to think about the risk to other children because of his movements - throwing and spinning - he can easily hit other children accidentally.”

In Parent 3’s experience, the infrastructure of the city is not conducive to life with a severely disabled child. “I recently had a problem with the Showcase Cinema because their disabled toilet facilities are not big enough for a wheelchair AND the 2 people required to change a nappy, and the only other space offered was upstairs, which was inaccessible. On the other hand, the Odeon and the swimming baths have made reasonable adjustments and allowed for dignity. The Mayor wants Liverpool to be autism friendly, but we have a long way to go! Places can only be as accommodating as the people who work there - regardless of the physical facilities. Staff in one restaurant refused to mop the floor in the toilet even though it was covered in piss and I needed to use the floor in the changing process. Liverpool One’s ‘Changing Places’ facility is the only useable place in the city centre. Otherwise, you need to be assertive and quote legislation about dignity and respect. And not everyone is able to do this.”

Parent 3 gave further examples of the lack of parity of access to sport and leisure facilities. “We go to Wavertree (swimming pool) every week but if they have a gala (without adequate notice to parents) it takes precedence and disappoints the child, who has a meltdown. There are similar problems at Everton Park. Peter Lloyd has great staff who couldn’t be more helpful, and they have a good-sized changing room but it’s dirty, so we’ve stopped going. The staff are also great at Wavertree. My gripe is - why only one hour a week? Non-disabled children can go any time. The therapy and independence of swimming are so important. I’ve now chased this up with the Council and had assurance that protected swims won’t be affected by other events.”



In respect of health care, there is much to be thankful for. “Health are great in general. We use many Alder Hey services, including Inpatient, A&E, Sensory Room... The staff are fantastic, and the Play Therapy Service is brilliant. The worker really understands sensory needs. We use the service frequently. We’ve also been dead lucky with our GP surgery. Each GP is really thoughtful and understanding.”

Nevertheless, not everything about the NHS was helpful for Parent 3 and her son. “Health is the elephant in the room. He’s banged his head for 4 years and I’ve been increasingly convinced that it’s pain-related, not about his ASD. The neurologist, ear and eye test people and Community Paediatrics all said it’s “just” ASD but I’m convinced it’s pain-related.” The neurologist we saw said “I’ll print you off a leaflet if you like”. I felt like saying “I’ll WRITE you a leaflet!” I asked for a second opinion and I made sure I took the school nurse, community paediatrician, social worker etc. with me for support. We saw a different neurologist and I showed him a selection of different film clips of my son’s daily behaviour in different settings. Within 2 minutes, everything had changed, and the doctor agreed that my son was in pain. After 4 years! It was an awful journey for 4 years, then a total change because of a change of professional. This was just 8 weeks ago. He’s being tried on a new medication, there’s no change yet but there are 6 possible medications to try. I want them to do more tests – he’s already had a CT scan and an MRI but I’d like to have dye tests and an EEG.”

Parent 3 had also experienced unhelpful attitudes when attempting to access Walk-In health care, which she had challenged and which had led to changes. “We went to the Paediatric Walk-In Centre and were told the wait was 1 hour 45 minutes. I asked for a quiet space where autistic people could wait, but they didn’t have one. As a reasonable adjustment I requested that we could wait in the car and that someone would tell us when we could be seen. But they told me “If you wait elsewhere, you’ll go back to the end of the queue.” In the end I called 111 and got a quicker appointment with a doctor elsewhere. It does seem ridiculous that autistic children will be given preferential treatment in a Theme Park queue but not in a Health Centre. I made a complaint to Mersey Care, which they accepted. They said they would change their policy on fast-tracking and the next time I used the Paediatric Walk-In, we were in and out within 10 minutes.”

Parent 3 reported that the Continence Service had improved recently in terms of ordering, but that they are still only entitled to 4 nappies a day when her son needs 7 or 8 per day. Nappies are delivered 3 or 4 times a year in bulk and you’re not allowed to re-order even one day ahead of your allocated date, which can make it difficult to plan for e.g. Christmas holidays. PALS have had to be involved in ensuring sufficient supplies were delivered. Her son takes 3 or 4 nappies with him to school each day and, if unused, these are added to the school’s general stockpile, which means that he can also use someone else’s ‘spares’ if necessary. This practical arrangement was praised by Parent 3.

Parent 3’s son has used a wheelchair since he came to her, aged 3. She reports that the Lifehouse building is well-stocked but feels very empty/under-used in terms of activity. A problem with the system is that every time a new chair is required it is recorded as a new referral and “they don’t keep you on the books”. When her son needed a new chair there was a 20 week wait. Parent 3 contacted the CCG and asked to speak to the relevant commissioner, after which she was given an appointment and provided with a new chair within 5 days. “The service could be more dynamic. There seems to be a gatekeeper element that holds things up. The chairs are ready quickly once an appointment has happened but how does the backlog build up?”

Parent 3 was particularly pleased with the OT support her son had received. “The Council OTs are phenomenal. If I won the Lottery, our OT would be first on the ‘never needs to work again’ list!”

“Our OT applied for a Disabled Facilities Grant for a downstairs shower, which will change our day-to-day world. We’ve also made a bid for an electric bed like in Changing Places, so I don’t have to change him on the floor. His bedroom’s being renovated to be a safe space. He bangs his head on hard surfaces, so it’s being turned into a soft play space, with sensory lighting. Things like this can prevent smaller stresses from becoming massive.”

In her experience, the OTs at the Lifehouse also provide a good service – separate to the Council OTs – however, “At the moment there’s no funding for OTs to do sensory stuff – we’re reliant on charities like the Isabella Trust.”

Parent 3’s son attends a Special School and she couldn’t wish for a better school, or system. Even so, some aspects of mainstream schools are not replicated by specialist providers. “Why can’t children have access to breakfast and after-school clubs in Special Schools?”

Parent 3 is grateful that her son’s school provides access to orthotics (shoes), OT (to match what happens at home), Speech and Language support, and physio. “I couldn’t be more thankful for the journey we’ve had through school. EHCP and LAC reviews take place at school and the School Nurse is always on site. I was worried about his weight, so now they weigh him every week. His medical and social needs are all met. The Head is outstanding – a breath of fresh air, so caring. When I was desperate, without respite for 2 years, she’d listen and give me a hug. She has an open-door policy and the school app is really useful and we can send private messages on it. Class sizes are 8 students with 4 or 5 staff to each class. He gets a school bus with an escort and the escort is also brilliant. He went to school full-time from 3 years old as nurseries can’t cope. He’s had the same escort throughout. The consistency from the SEN Transport Team has been excellent. They put taxis in place for 2 weeks after my son’s knee operation. It’s been seamless. Great strategic management.”

Parent 3 relies on family and peer support for her own wellbeing, and finds that her difficulties tend to be practical rather than emotional. “I tend to go out with a friend and her child (who also has ASD) as there is safety in numbers and a shared humour. It feels easier to navigate societal attitudes and cultural beliefs when you’re with someone else in a similar situation. A good friendship circle and a supportive partner makes a huge difference. Because I have these in place, I think I need practical help rather than emotional help from SEND services. Getting him in and out of the bath daily – having a seat to be able to so that is worth 50 conversations about “How are you feeling today?” But I know this isn’t the case for everyone. Having gates installed on the stairs and into the kitchen was a massive help, as was a ramp to the front door.”

In terms of access to welfare support, Parent 3 felt that the system was stacked against families and weighted towards preventing access to benefits they are entitled to, rather than towards helping them secure those benefits. “DLA is a postcode lottery. Not all support agencies are as good as each other. It depends how good you are at describing your child’s needs. Decisions seem random. It feels like there’s a policy to refuse applications, on the basis that “If we refuse 100 then only 50 appeal and, of those appeals, only 30 get upheld. So there’s a 70% reduction in potential benefit pay-outs”. It’s a minefield.”

Moreover, Parent 3 feels that bureaucracy and lack of resources make life unnecessarily difficult for parents across all aspects of the SEND landscape. “In terms of my life as a carer... don’t make me run AND jump. Take away the hurdles and the unnecessary hoops. Make processes easier by TALKING to parents. Life is hard enough. The child is not the issue. The issue is the procedures, policies and practices that the system puts in place. The hurdles. I despair sometimes.”

For example, she waited 9 months until a respite foster family could be found. Then, when they stood down, she waited another 2 years for a replacement foster family. She didn’t have a single day off in

those 2 years. Her son’s needs are beyond what can be supported by Fusion. “I need a weekend where I can sleep uninterrupted for 8 hours - not just 2 hours to go shopping. Friends and family can’t just have him for an hour. Life with a child with SEND is... everything, all the time.”

In common with other parents who participated in this project, Parent 3 had grave concerns about her child’s future. “He’s going into Year 5 now, and then it’ll be his transition year [to Secondary School]. I’m terrified. I can ask for a preferred or named school on the EHCP and they will try to prioritise. Because he’s LAC he will be top of the queue, so that doesn’t worry me so much. I’m worried about how he will cope with the transition. He finds holidays hard. He struggles after 3 weeks [away from his routine].”

“I have a HUGE worry about what will happen when I’ve gone. My fear is what happens beyond adult services, not just beyond transition to adult services. It’d be right to give him some level of independence and then he wouldn’t miss me so much. Who will advocate for him when I’m gone? Every parent with a child with special needs worries about this. There’s no platform for speaking about it. It’s not a sadness, it’s a fear. There’s nowhere you can sit down, have a cup of tea and talk about the future.”

Parent 3’s final message to commissioners and providers summarises the frustrations and anxieties expressed by many parents who participated in this project.

“Show respect for parents and carers. Don’t belittle or talk down to us. Don’t refer to me as ‘mum’ when you’re talking to me or about me. I’m not your mum! We are professionals and experts in our own lives – you are the facilitators, thanks to our taxes. I feel confident and professional in my work life but helpless and hopeless and shit at home. Amateur. Even though I’m a good parent and carer. I can’t be the only one in the city that feels that way.”

## PARENT 4

Parent 4 has 3 children, all with different support needs. They are a family of mixed heritage. The family’s experience has differed markedly with each child; for instance, access to social work support has not been consistent. The oldest child is now an adult (aged 27) but still lives at home and requires support. “My older daughter had a social worker who helped me get DLA and backed me up 100%. I always had good social workers. Now I’m finding it difficult because I’m very isolated. I was on training courses all the time and did voluntary work. Now I and worry that I’m to blame if I haven’t filled things in properly. My youngest daughter cries if there’s any change and my older daughter needs ongoing support. There’s a lack of empathy and support from the system. Families should be allocated a social worker or support worker to support the parents and help them access stuff.”

There has also been a lack of capacity across other support agencies, including within the voluntary sector, which has left Parent 4 feeling stressed, anxious and isolated – particularly in relation to the family’s cultural support needs. “SENDIASS don’t have capacity. I rang them 2 years ago and never got a response. I only got a response when I tried again the next year. PSS used to help with EHCPs – but not now. ADDvanced Solutions tell me that there are children with worse problems and disabilities. I’ve done all their courses but that’s it, there’s no ongoing support. I went on a parenting course with YPAS and the leader was lovely. I need people to support me in meetings and that’s what Parent Partnership used to do. There’s a need for online forums, even nationally. And what about BAME meetings once a week at LivPAC? I can only do evening meetings. The Brain Charity helped with the PIP form and were very good. I’m so bombarded with it all. It’s had a big impact on me.”

Parent 4 also raised concerns about the lack of support for her children as they transition to adult services. “With my oldest daughter there was a safeguarding issue with a homeless guy who asked her for money, and asked to meet up with her. I ‘phoned the police because she was a vulnerable adult but they only took it seriously when the Brain Charity intervened. Then she felt listened to. What will happen when we go? My older daughter will never be able to live independently. My younger daughter will be able to live independently but will have problems with mental health. She needs to believe in herself.”

Health care support has also been patchy in Parent 4’s experience. Her children have had involvement from Seedlings, but mental health support has been hard to access otherwise, typifying issues raised by other parents about a lack of joined-up support in relation to mental health and neurodiversity. “CAMHS were awful, flip-flopping. They didn’t want to touch my daughter’s case as it was an ADHD issue.”

Parent 4’s older daughter was seen twice a year by Paediatricians until she was 19, but her younger daughter has not had the same level of support. “Now you get your diagnosis and are not seen.” The older daughter was given a Statement automatically and had one throughout education but was more academically gifted than younger daughter who hasn’t been automatically given an EHCP. Parent 4 sees this as an indicator of resources being cut. Where children have older siblings and/or friends with EHCPs or diagnoses it puts additional pressure on them and adds to their anxieties about the support available to them. “My younger daughter is already asking “Will I go to the same secondary school as my friends and am I on target?”

## PARENT 5

Parent 5 is Polish and has recently moved to Liverpool from a local authority area in Greater London. She speaks very little English and has a 13-year-old son with Selective Mutism. In their previous area, Parent 5's son had an EHCP and attended a mainstream school where he was happy and where he and his mother had a good relationship with the Polish-speaking SENCO. He received one-to-one support as well as Sliding-In Therapy and some Art Therapy. The son appears to understand both Polish and English and can respond to 'Yes' or 'No' questions by nodding. He can also indicate things by pointing.

When they moved to Liverpool, Parent 5 was told her son would not be able to attend a mainstream school but would have to go to a Special School as “that's the way it's done in Liverpool”. She was given no option but to send him to a school of the local authority's choosing. He is very unhappy there and Parent 5 says that nobody has explained why he is only expected to attend from 8.45am - 12.30pm. As far as she is aware, he is offered no specific support, “He just sits and does nothing.” However, she says she's had no interpreters provided to help her speak to teachers or LCC staff (although she has requested this) and has had to rely on her 15-year-old daughter to interpret for her. At the time of interview, she had only ever spoken to school staff by telephone (with her daughter's assistance) and had asked the SENCO to call her to discuss her concerns but had never had a call back. There had also been miscommunication when she made a complaint to LCC via an online form.

Parent 5's son was referred to Alder Hey for a CAMHS assessment in 2018 and received a written reply stating that they could not offer support but would pass the referral to PSS Spinning World but Spinning World did not make contact.

Parent 5 contacted SENDIASS who did not have the capacity to provide support beyond signposting back to the (non-responsive) SENCO. Eventually Parent 5 did arrange a meeting with the school but felt they were putting the blame on her son for being uncooperative. “In [my previous area] I could always speak to my Family Support Worker but [the new school] have refused to refer me to a Support Worker here. I'd like ANY kind of help I can get for my son. He'll be 14 in March and I'm terrified that he only has me to rely on at the moment. He can't write or read, and I'm scared that he'll finish school and never find a job. I've told the SENCO about who he is and that he needs basic help with reading and writing so he has some sort of start in life but, unfortunately, the school isn't helping at all. I'm desperate now at the lack of help. He doesn't like going to school. He's not happy there. Maybe he should stop going - at least the Council might take notice! I can't see any other solution. He needs to continue his therapies. When the previous school realised he had Selective Mutism, they knew immediately what to do and they had someone who could support him. The SENCO here had never heard of Sliding-In Therapy. My son takes going to this school as a punishment for not being able to speak. He feels very bad at this school. To this day, the school has not given any therapy for my son so he can start to speak. They are waiting for him to start talking by himself! I believe that no one cares what is written in the EHCP. The school said that he would not have a psychologist at school and would not have a speech therapist (however) they will try to find someone for Sliding-In Therapy.”

The interview with Parent 5 was conducted with the help of a Polish interpreter.

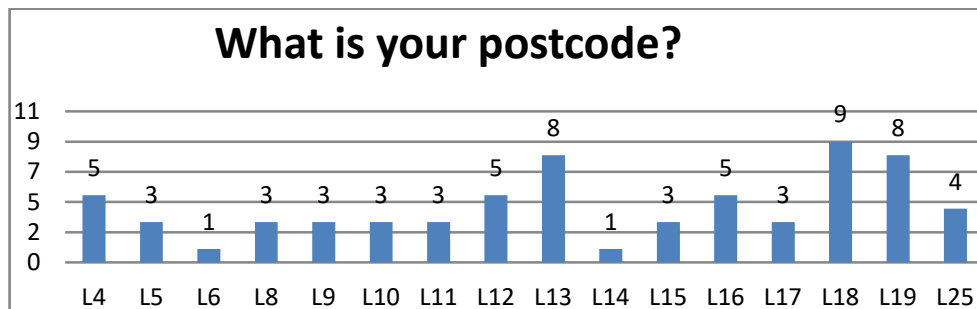


# Appendix A

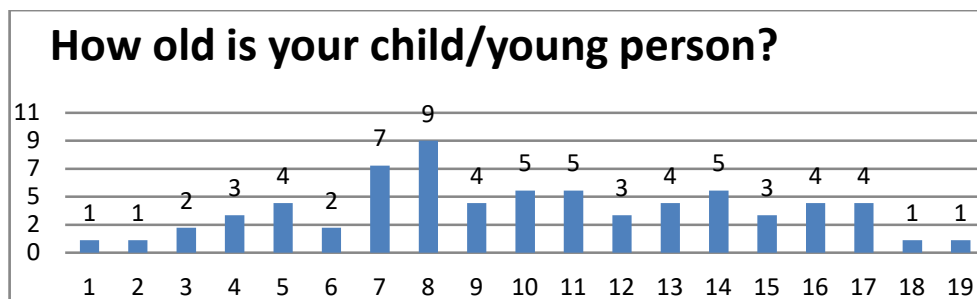
## Parents/Carers - Quantitative Data

Survey information was provided by 70 parents/carers but, as this was a self-selecting sample, some caution should be exercised when viewing the data, as it may not be wholly representative of parents and carers experiences in Liverpool.

### Q1. What is the first part of your postcode?

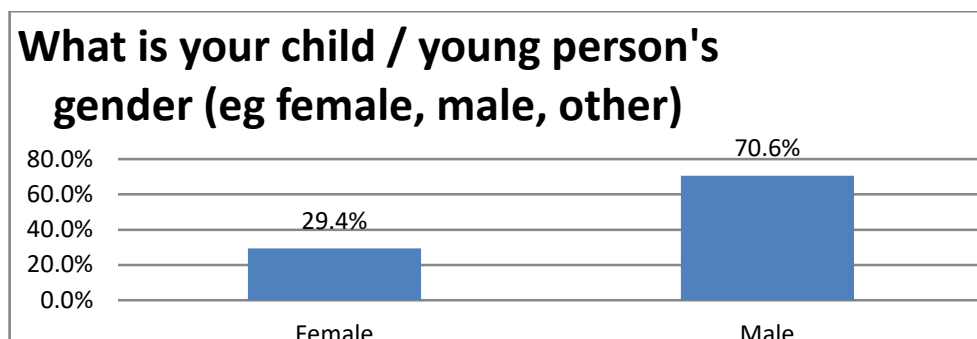


### Q2. How old is your child/young person?



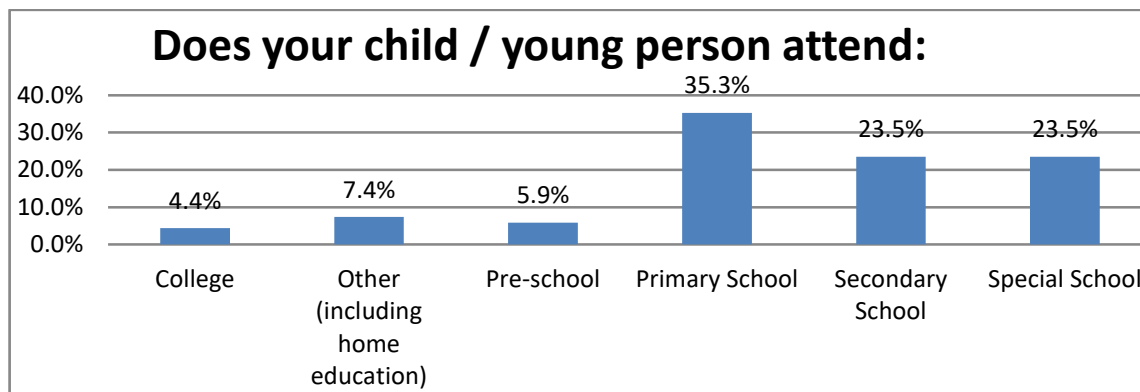
The average age of the child/young person is 11 years and 8 months.

### Q3. What is your child/young persons gender?



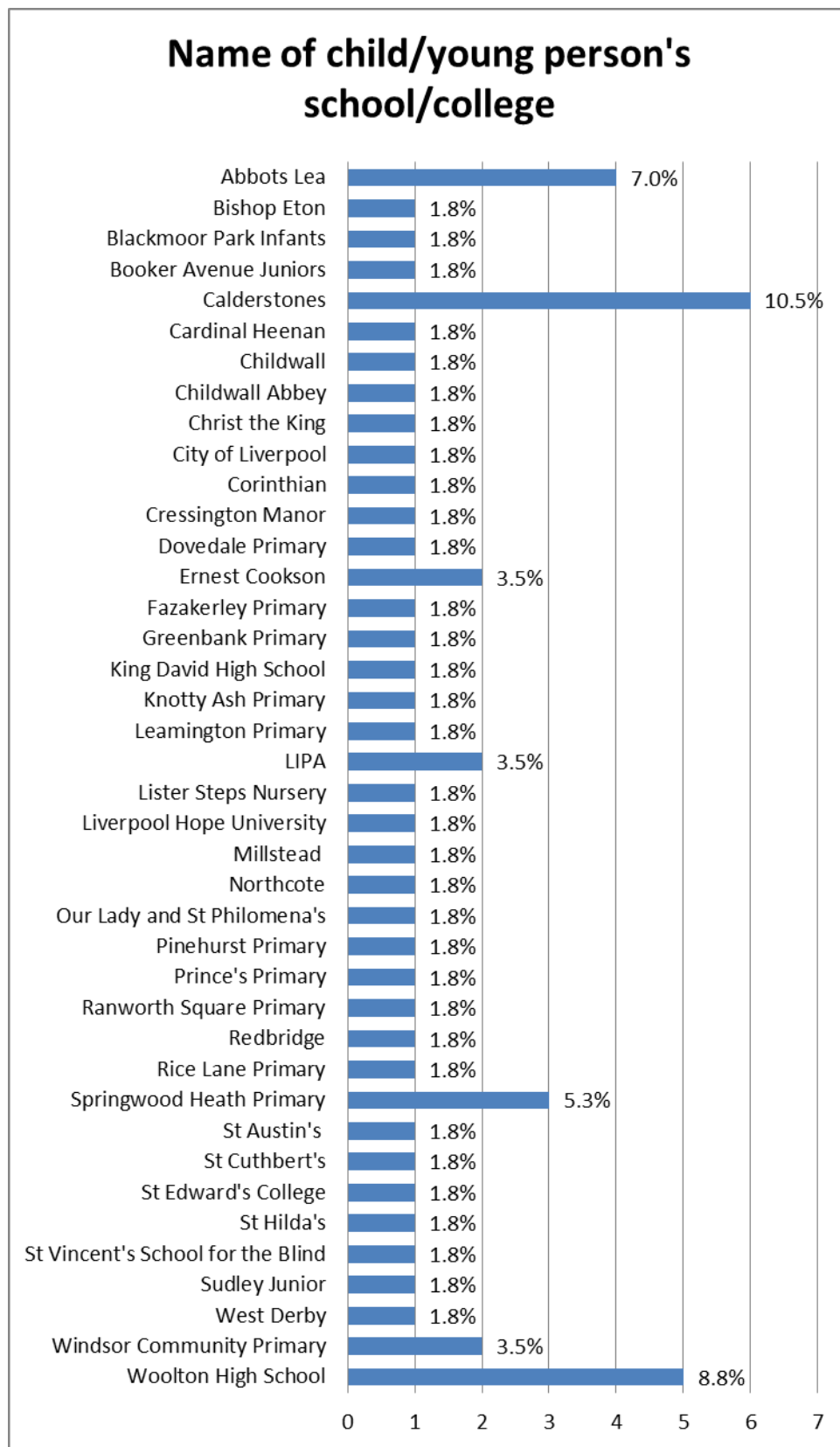
The majority (70.6%) of parents/carers who participated in this survey have a male child and 29.4% a female child with SEND.

**Q4. Does your Child/Young Person attend....?**



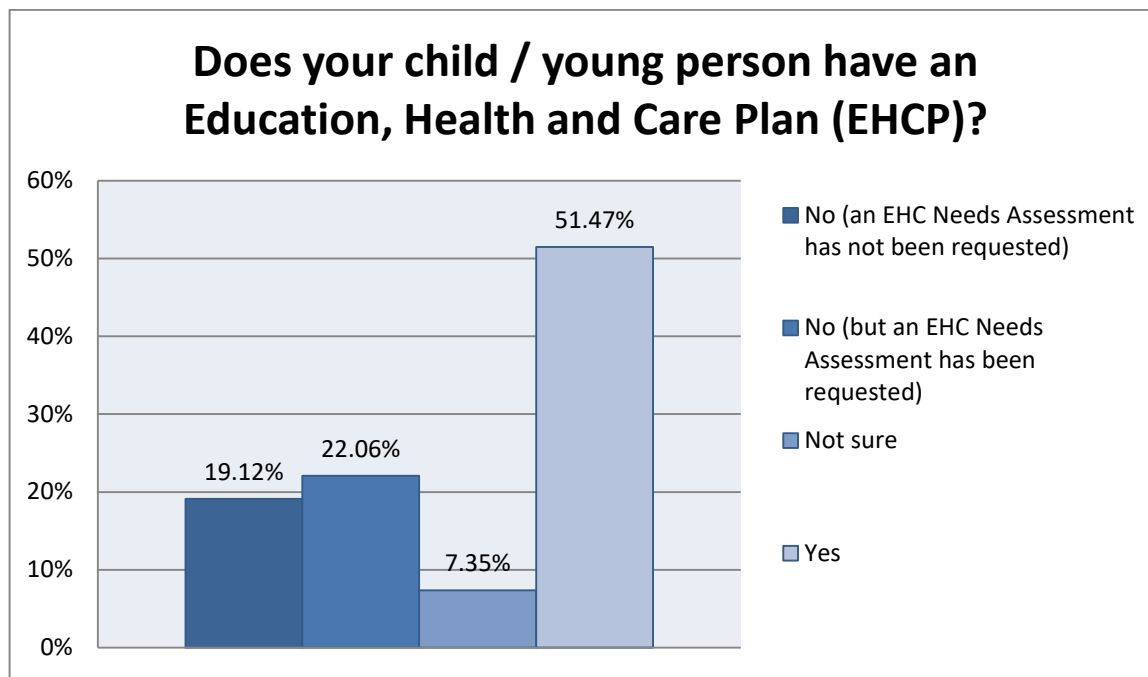
Over a third of respondents' children/young people were attending Primary School but close to a quarter attended Secondary School or Special School. Almost 6% were pre-school age, and 4% were at College. 7% fell into the 'Other, including Home Education' category.

**Q4-B - Please give the name of the school if you wish?**



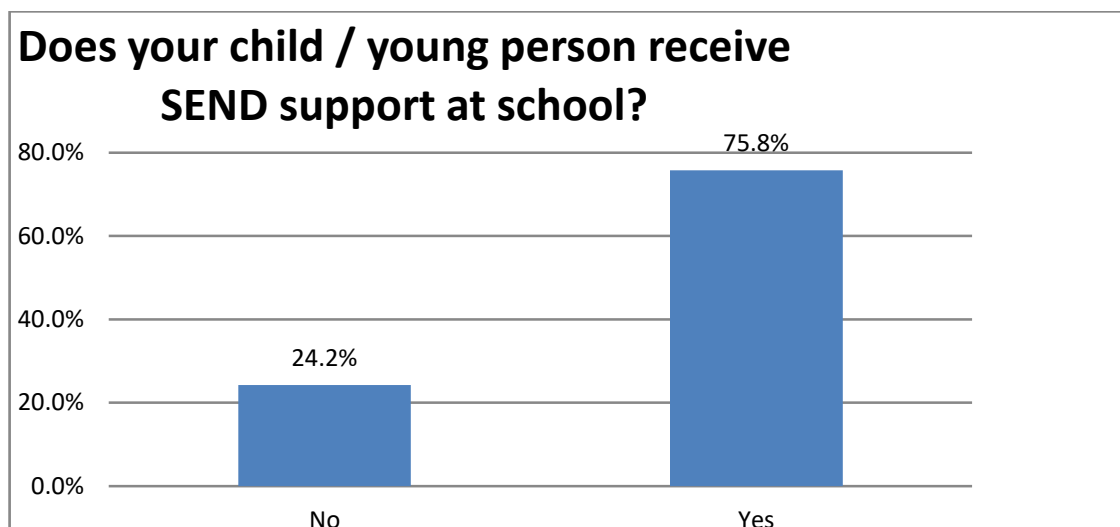
Our respondents' children attended 40 different educational establishments and the most frequent responses were in relation to young people attending Calderstones or Woolton High School.

**Q5. Does your child/young person have an EHCP?**



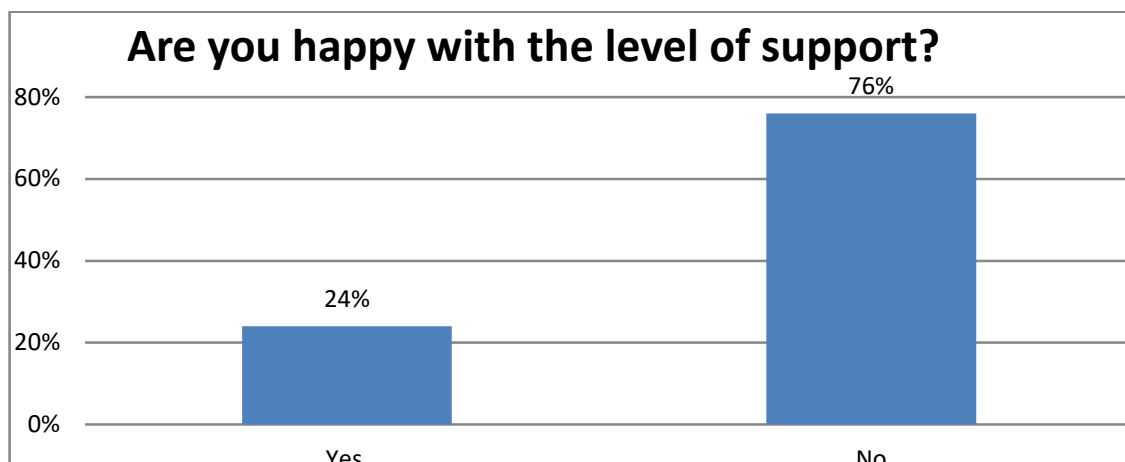
More than half of these parents/carers had a child/young person with an EHCP (51.5%). 22.1% were awaiting an assessment and 19.1% had not requested an assessment. 7.4% of parents/carers were unsure whether their child/young person had an EHCP.

**Q6-A. Does your child/young person receive SEND support at school?**



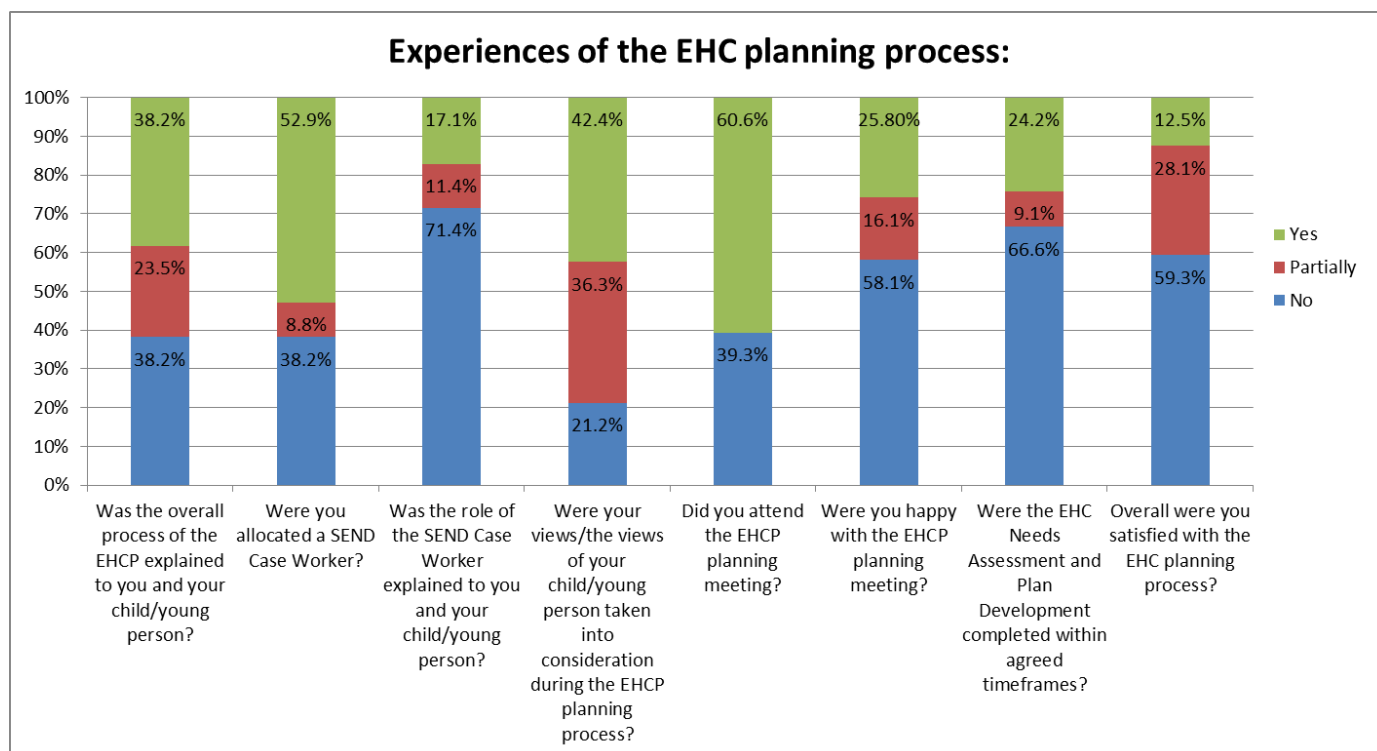
Of those children/young people without an EHCP, three-quarters (75.8%) received SEND support at school and a quarter (24.2%) did not.

### Q6-B. Are you happy with the level of support?



For the parents/carers of children/young people without an EHCP but in receipt of SEND support; 76% were not happy with the level of support but 24% were happy.

### Q7 (A- H) Experiences of the EHC Planning Process



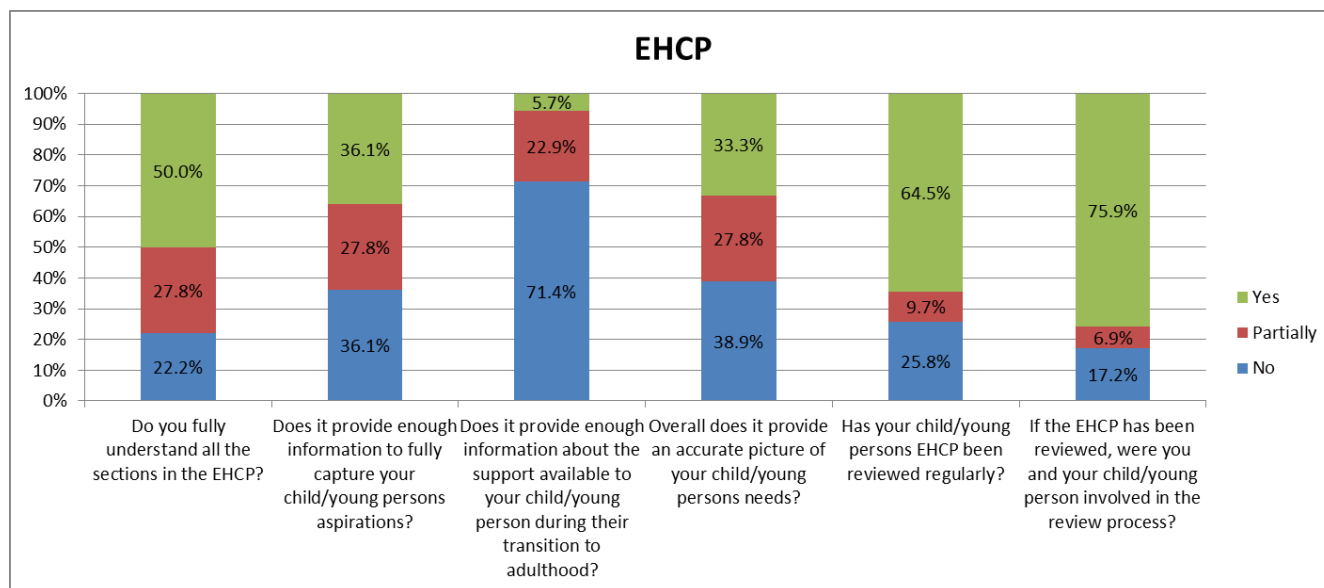
Experiences of the EHC planning process varied but some key points include:

- Exactly the same amount of parents/carers (38%) said the EHCP process had been explained to them and their child/young person as said it hadn't.
- Only just over half (53%) said they'd been allocated a SEND Case Worker; of these, 71% felt that the role of the Case Worker had not been sufficiently explained to them.



- Whilst the majority felt that their views and those of their child/young person had been considered (42%) or partially considered (36%), over a fifth (21%) felt that their views had not been considered at all.
- Whilst the majority (61%) attend EHCP planning meetings, a considerable number (40%) did not.
- The majority (58%) were not happy with the EHC planning meeting, 16% were only partially happy and only a quarter (26%) said they were happy.
- 67% stated that the EHC needs assessment and plan were not completed within the agreed timeframes, with only about a quarter (24%) reporting that the agreed timeframes were met.
- Overall satisfaction with the EHC planning process was poor, with only 12% satisfied and 28% partially satisfied. The remaining 59% of parents/carers were not satisfied with the overall EHC planning process.

### Q8 (A-F) Satisfaction with the EHCP

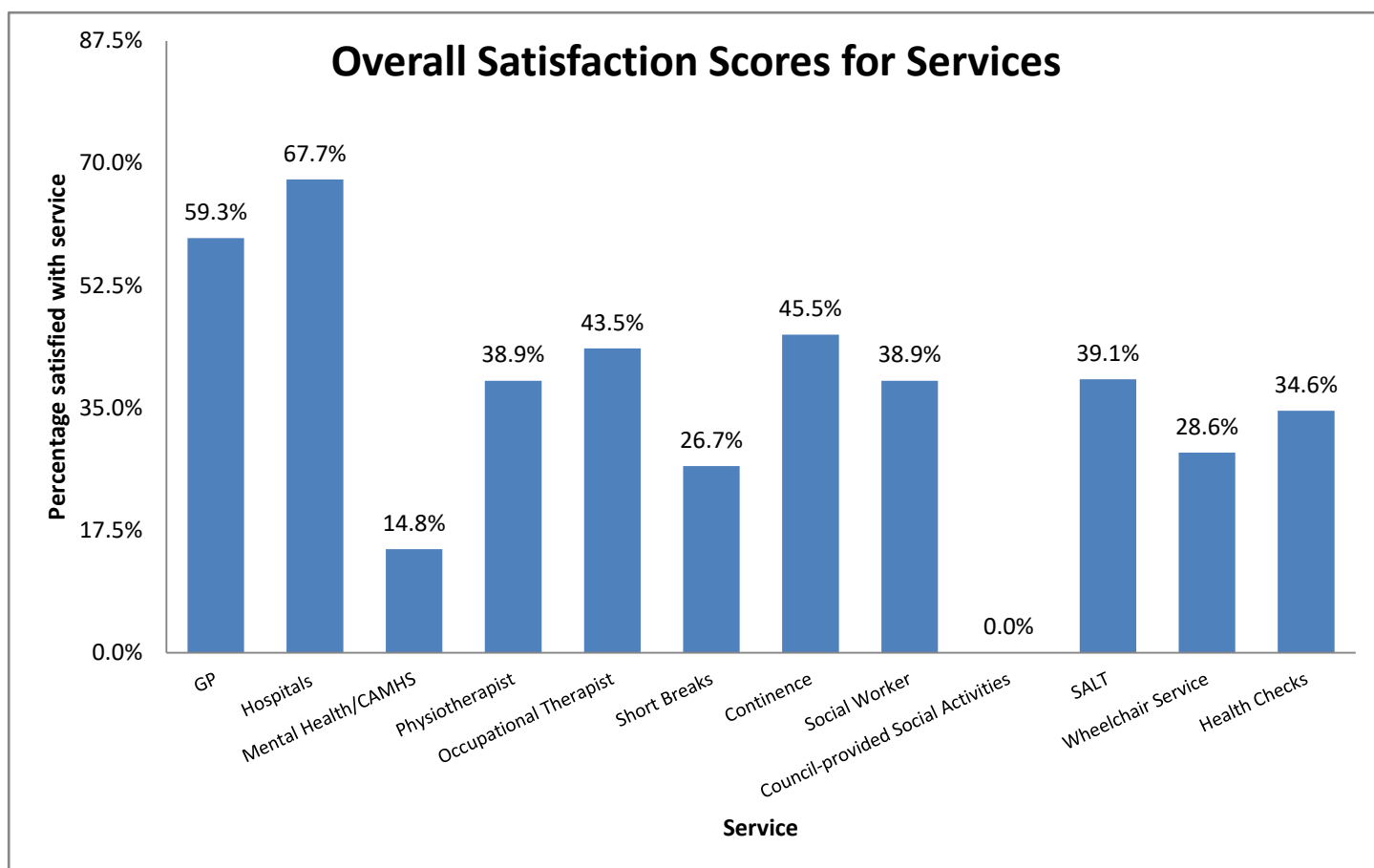


### Where an EHCP was in place,

- Only half (50%) of the sample felt they fully understood all the sections of the EHCP. 28% only partially felt they understood all sections, and 22% stated that they did not fully understand all aspects of the plan.
- 36% felt that there was enough information to fully capture their child/young persons aspirations but exactly the same percentage felt that this was not the case. 28% felt their child/young person's aspirations were only partially captured.
- A worrying 71% of parents/carers felt that not enough information was provided in the EHCP to support their child/young person during their transition to adulthood. 23% believed this was only partially covered. Only 6% agreed that the plan provided enough information about the transition to adult services.

- 39% felt the EHCP did not provide an accurate picture of their child/young person’s needs, whilst 33% felt it did. 28% felt that the EHCP provided a partially accurate picture.
- The majority (65%) of parents/carers reported that regular reviews of their child/young person’s EHCP took place and 10% partially agreed with this. However, approximately a quarter (26%) said their child/young person’s EHCP was not reviewed regularly.
- Where reviews had taken place, over three-quarters (76%) of parents/carers said they and their child/young person were involved in the review process and 7% felt they were partially involved with the review. 17% had not been involved.

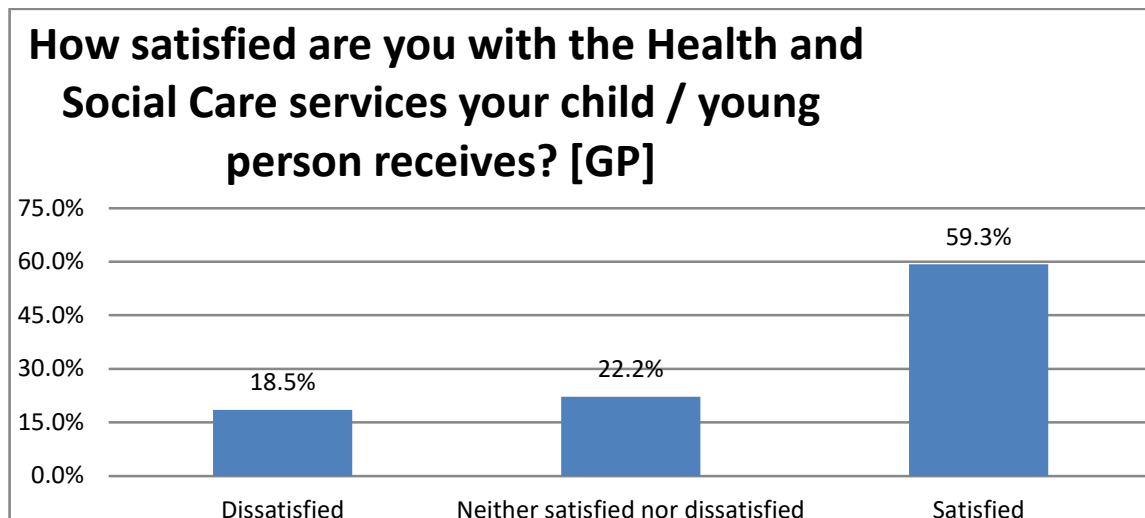
## Q9: Services



Parents/Carers were most satisfied with the services provided by Hospitals (68%) and GPs (59%), and the lowest satisfaction scores were for Council-provided Social Activities with 0% of the sample being satisfied and only 15% satisfied with Mental Health /CAMHS.

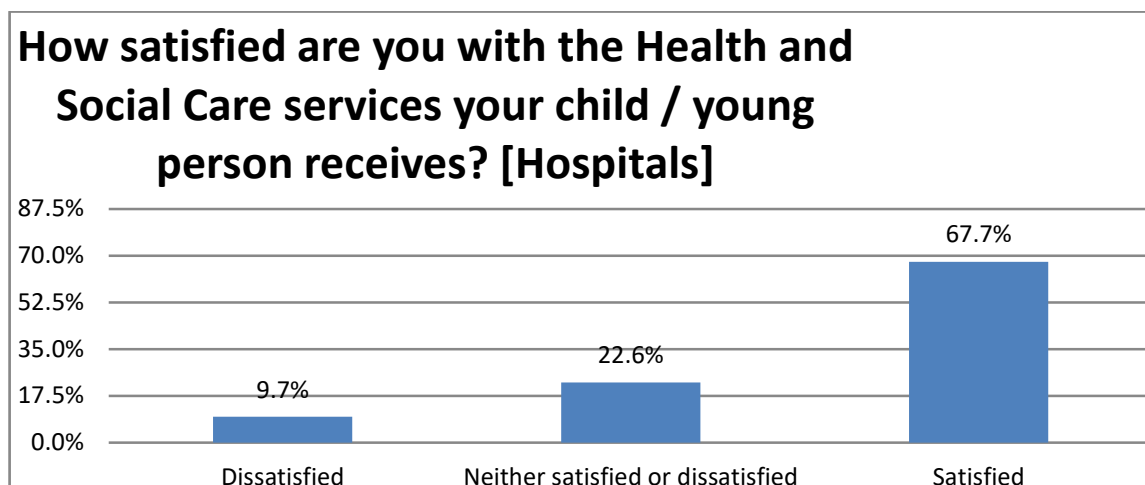
## Individual services

### Q9-A. How satisfied are you with the Health & Social Care services your child/young person receives? GP



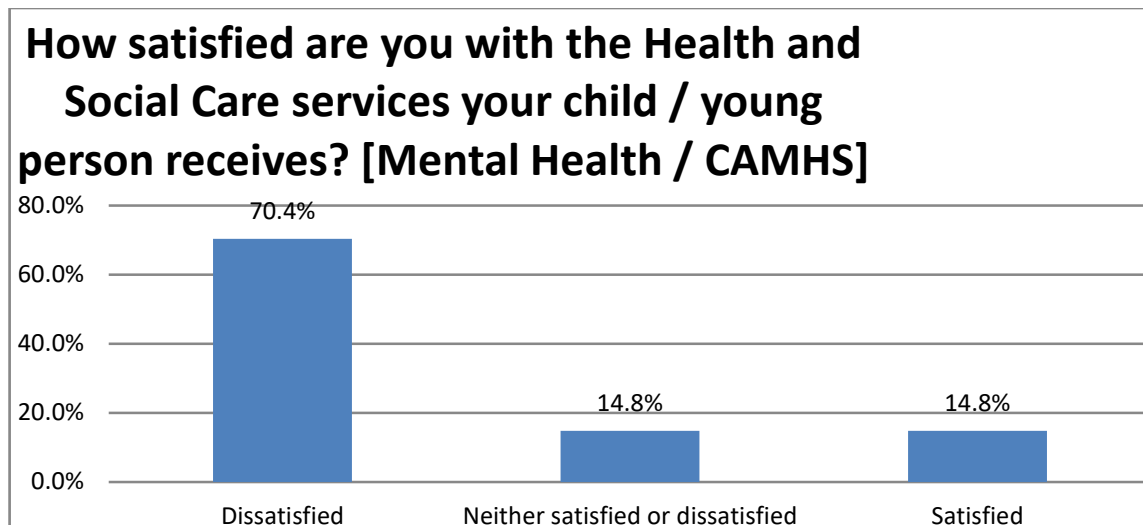
The majority (59%) were satisfied with GP services, however nearly a fifth of respondents were dissatisfied with the support provided by GPs.

### Q9-B. How satisfied are you with the Health & Social Care services your child/young person receives? Hospitals



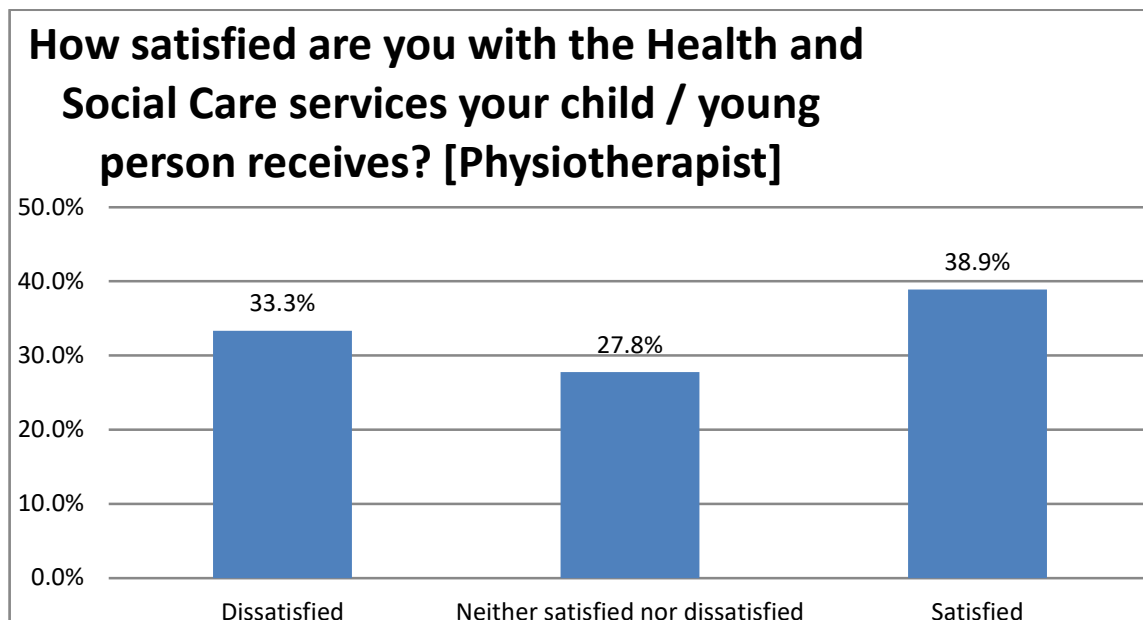
The majority (68%) were satisfied by hospital services, but 10% were dissatisfied.

**Q9-C. How satisfied are you with the Health & Social Care services your child/young person receives? Mental Health/CAMHS**



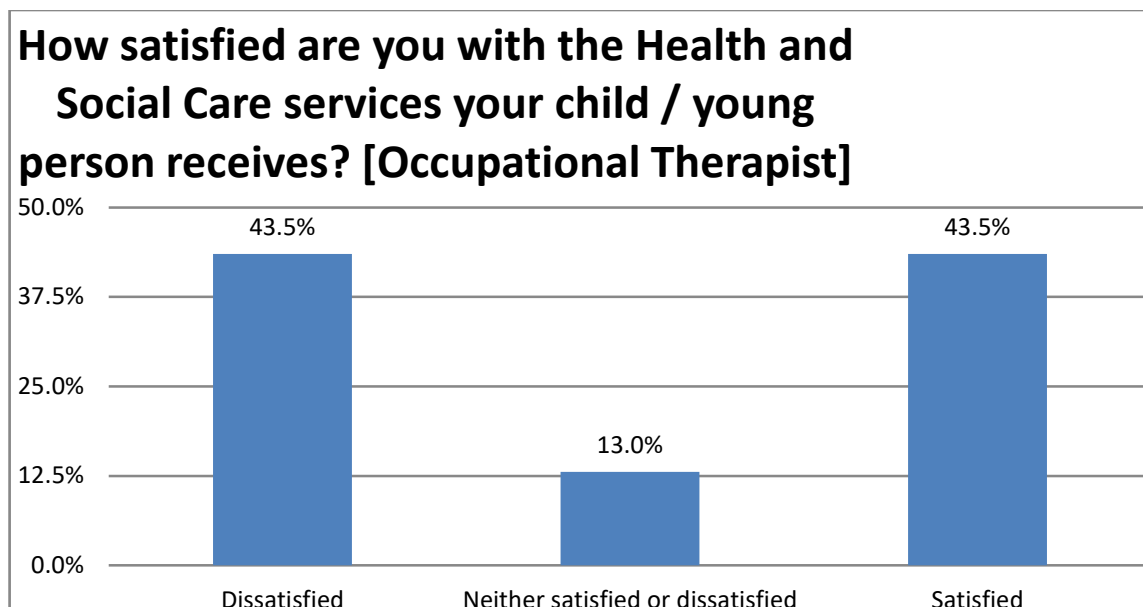
Mental Health services received a high dissatisfaction level (70%), with only 15% entirely satisfied.

**Q9-D. How satisfied are you with the Health & Social Care services your child/young person receives? Physiotherapist**



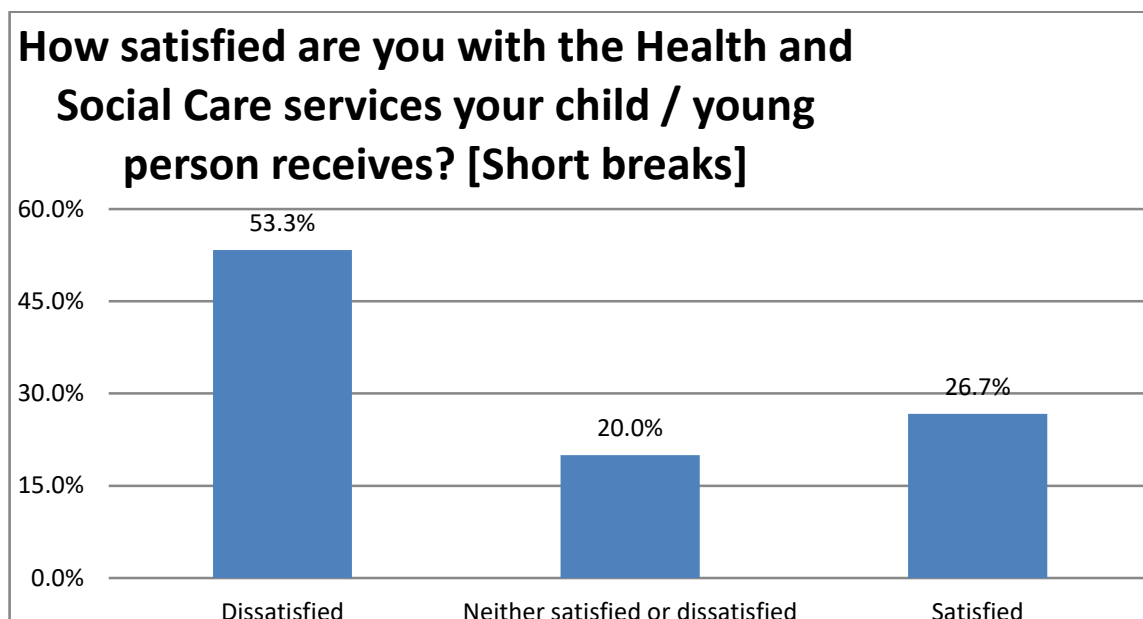
There was a relatively even split between Physiotherapy satisfaction levels, with 39% feeling satisfied and 33% dissatisfied.

**Q9-E. How satisfied are you with the Health & Social Care services your child/young person receives?**  
**Occupational Therapist**



There was also an even split in respect of Occupational Therapy, with 43.5% of respondents feeling satisfied and dissatisfied.

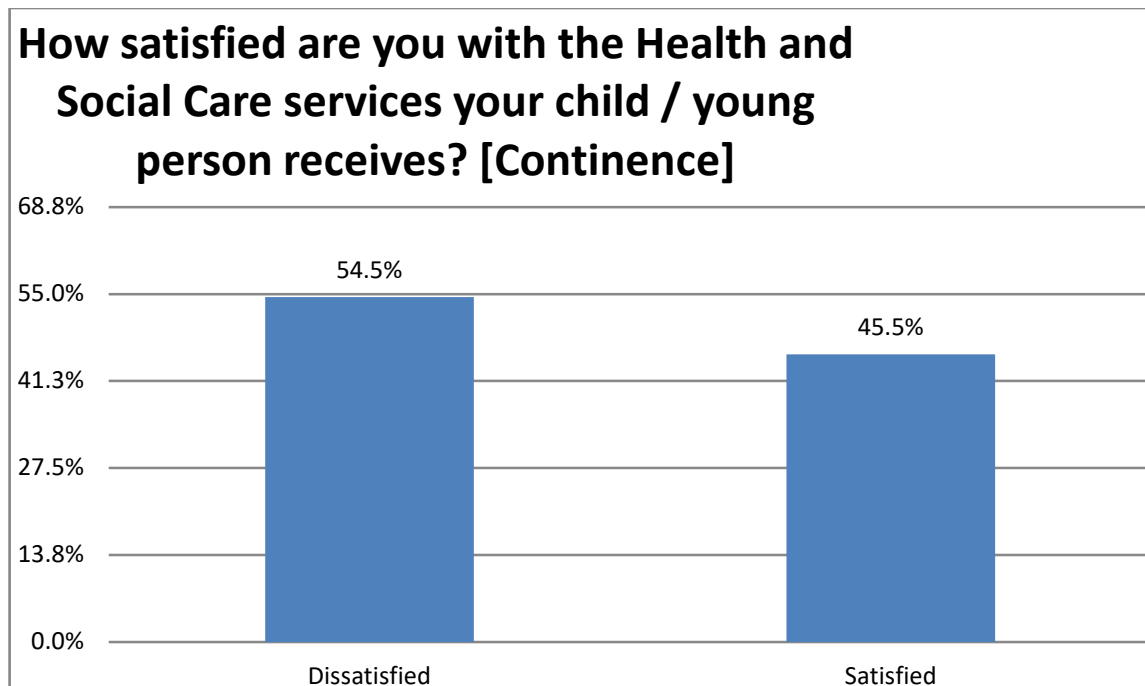
**Q9-F. How satisfied are you with the Health & Social Care services your child/young person receives?**  
**Short Breaks**



The Short Breaks service received a dissatisfaction rate of just over half (53%) whilst only just over a quarter (27%) felt completely satisfied.

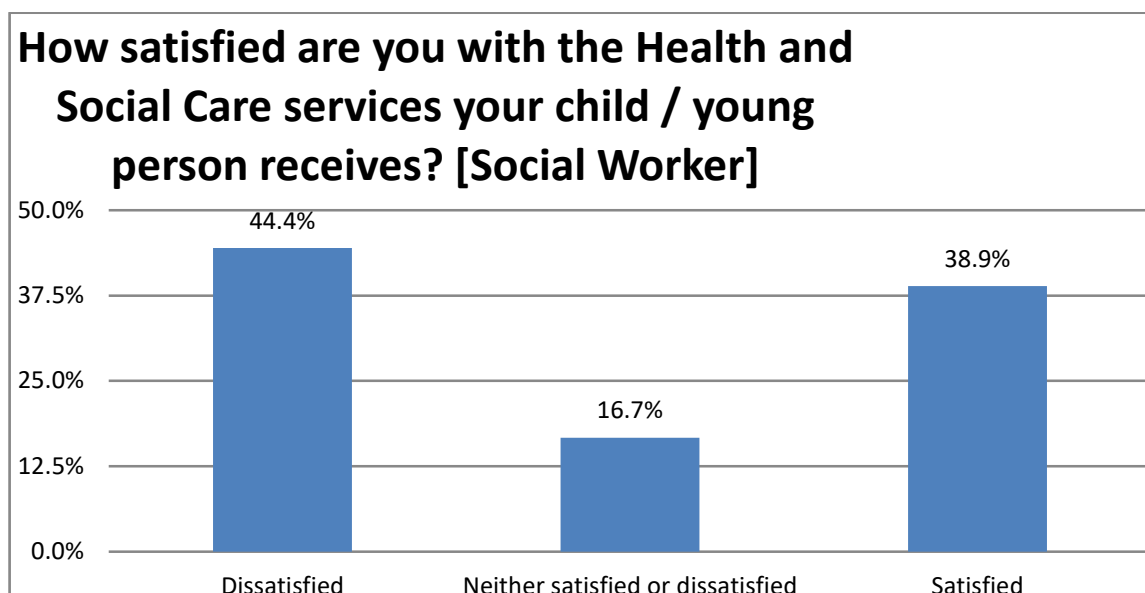


**Q9-G. How satisfied are you with the Health & Social Care services your child/young person receives? Continence Service**



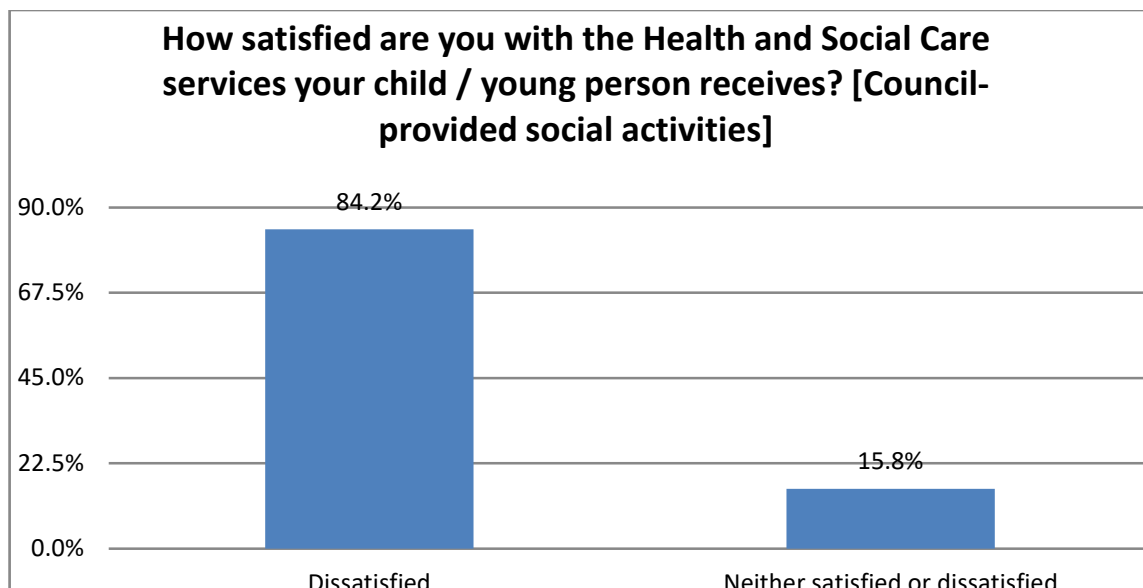
Over half of survey respondents (54.5%) were dissatisfied with the Continence Service, with just under half (45.5%) feeling satisfied.

**Q9-H. How satisfied are you with the Health & Social Care services your child/young person receives? Social Worker**



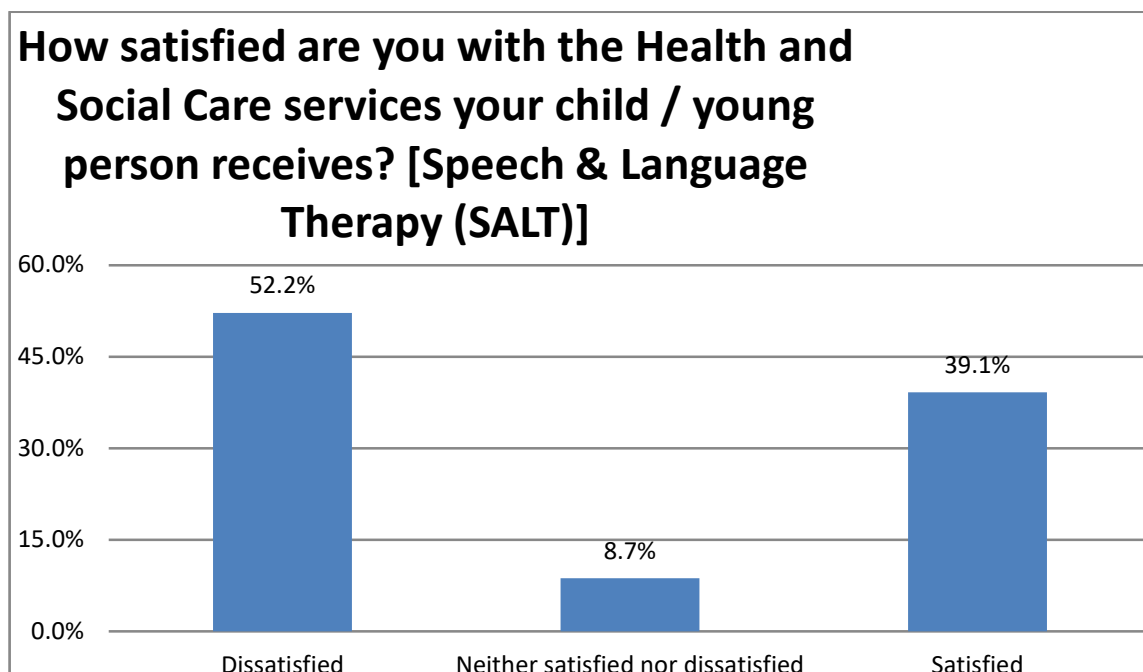
Only 39% were satisfied with the service they received from Social Workers, whilst 44% were dissatisfied.

**Q9-I. How satisfied are you with the Health & Social Care services your child/young person receives?**  
**Council-provided Social Activities**



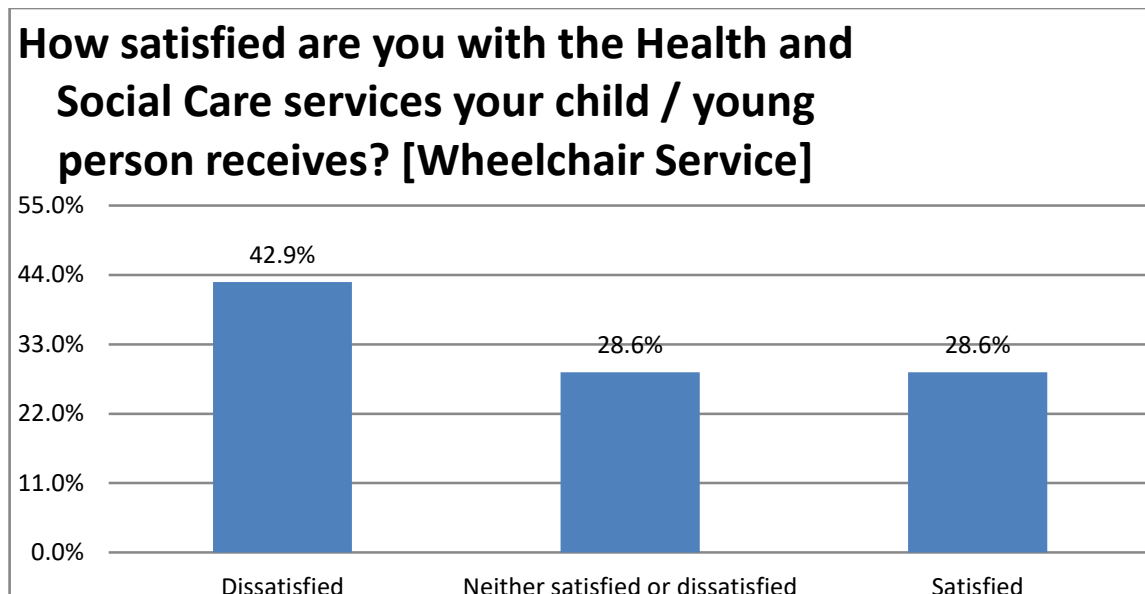
Council provided social activities received the highest dissatisfaction rating (84%), with only 16% satisfied.

**Q9-J. How satisfied are you with the Health & Social Care services your child/young person receives?**  
**SALT**



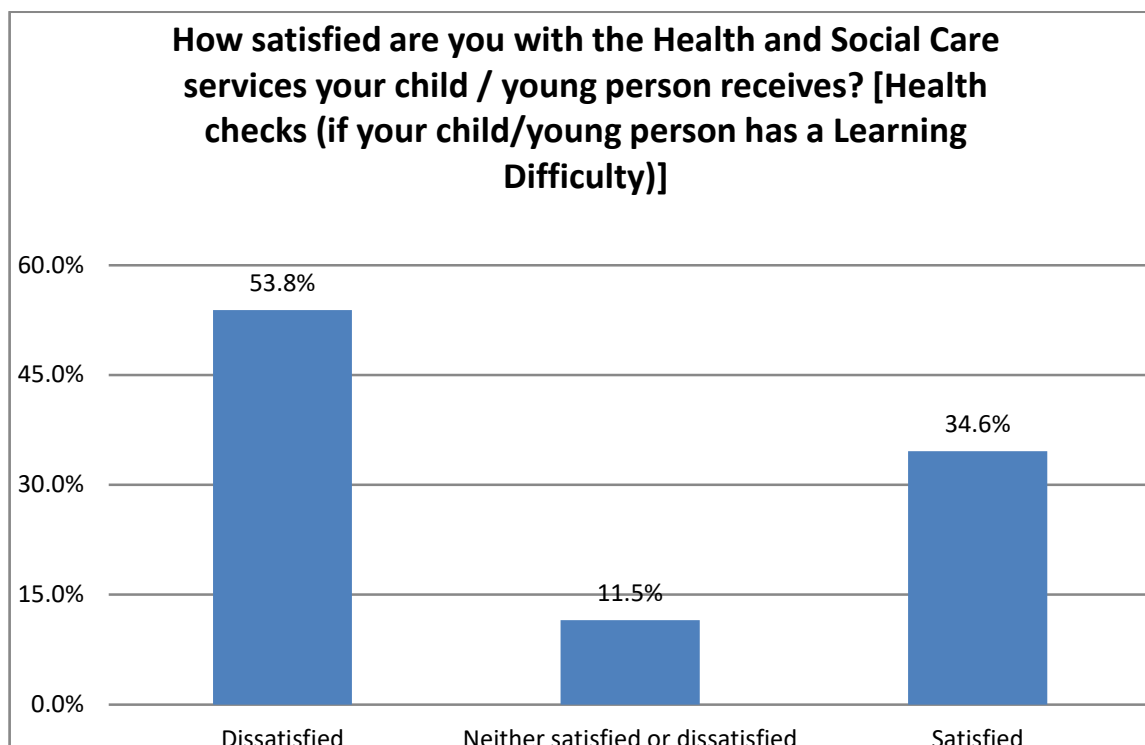
Over half of respondents (52%) were dissatisfied with SALT services, and only 39% were satisfied.

**Q9-K. How satisfied are you with the Health & Social Care services your child/young person receives?**  
**Wheelchair Service**



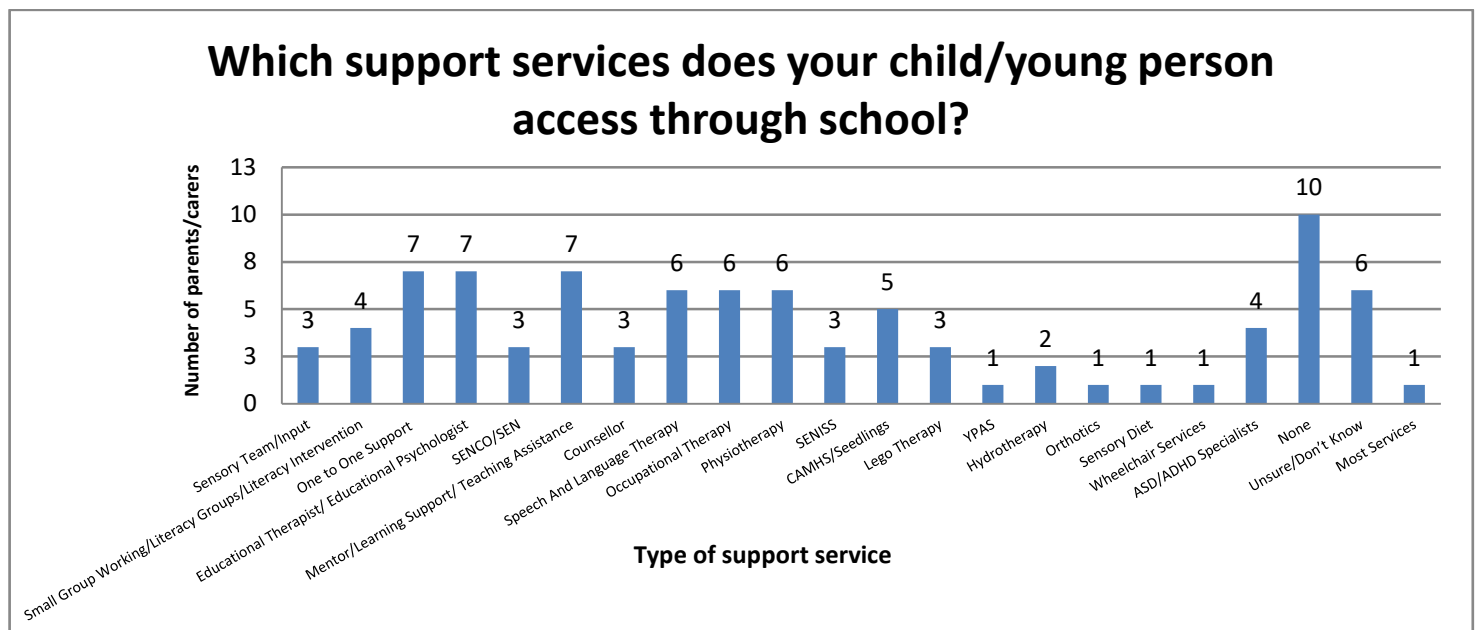
Survey respondents were only 29% satisfied with the Wheelchair Service, with 43% dissatisfied.

**Q9-L. How satisfied are you with the Health & Social Care services your child/young person receives?**  
**Health Checks (if your child/young person has a Learning Difficulty)**



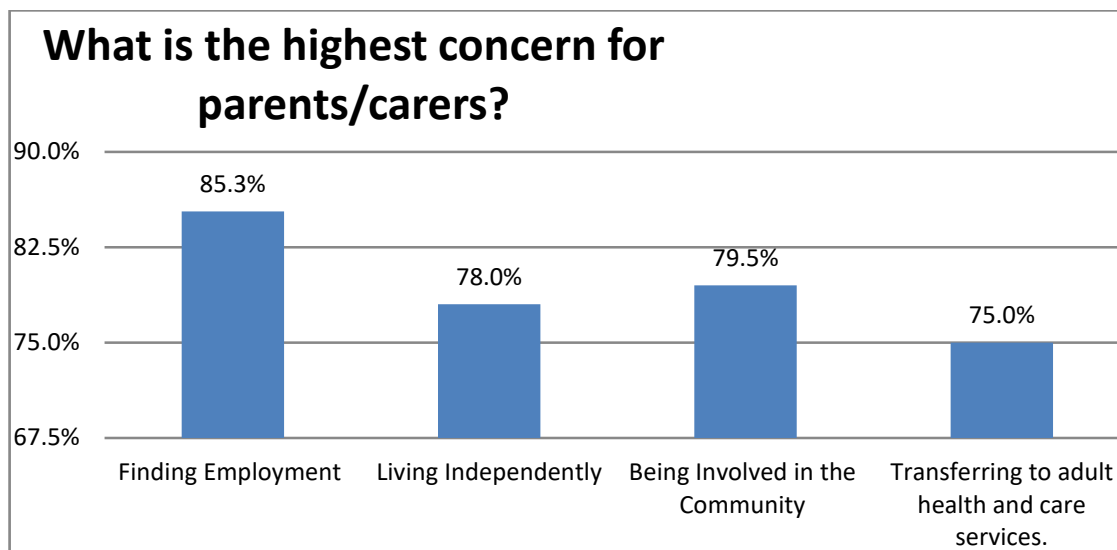
Over half of survey respondents (54%) whose child/young person had a Learning Disability were dissatisfied with Health Checks, whilst 35% were satisfied.

**Q10. Which support services does your child/young person access through school?**



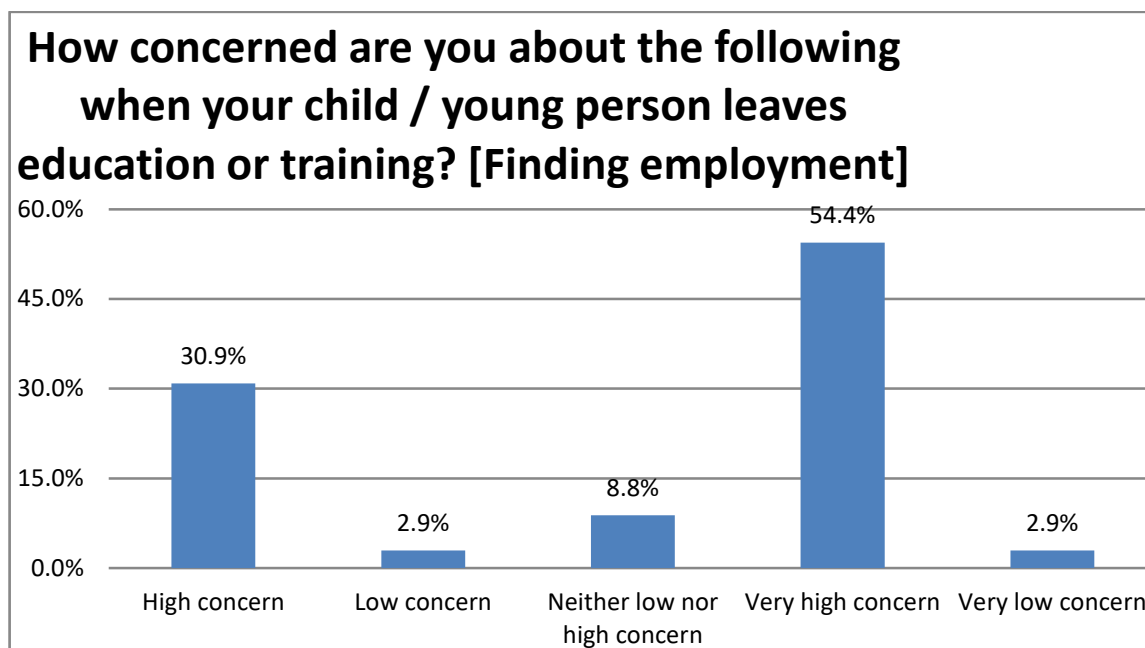
Parents/Carers reported that their children/young people accessed a wide range of services through their schools. However, a significant number said they were unsure or didn't know.

**Q11 – Overall Concerns**



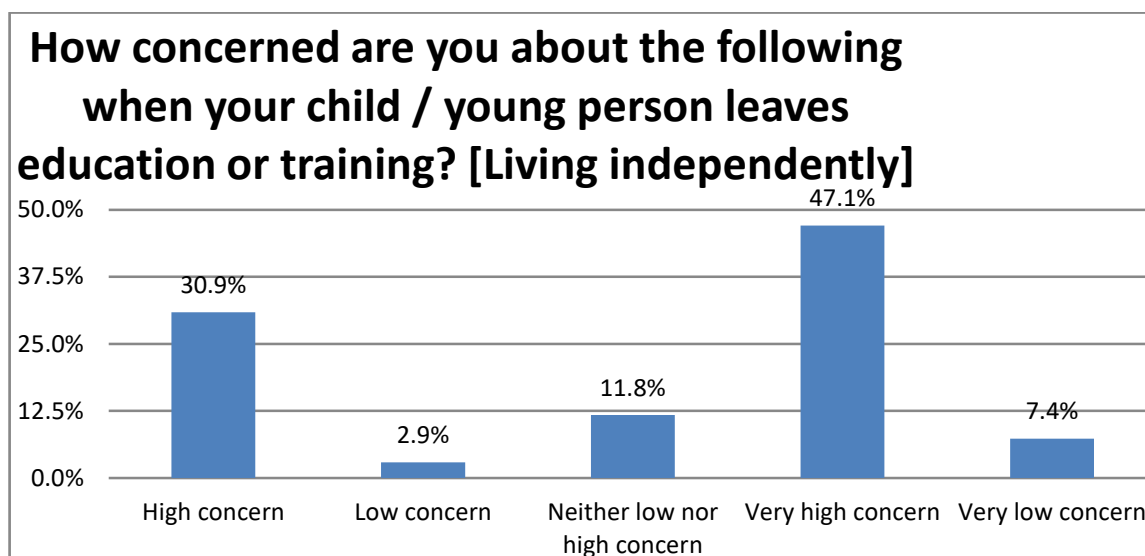
The biggest concern for parents/carers (as for children/young people, see p63) was about their children/young people finding employment as they grew older (85%). However, 80% were also concerned about Being Involved in the Community, 78% expressed concerns about Living Independently and 75% were worried about their child/young person transferring to adult services.

**Q11-A. How concerned are you about the following when your child/young person leaves school? - Finding Employment.**



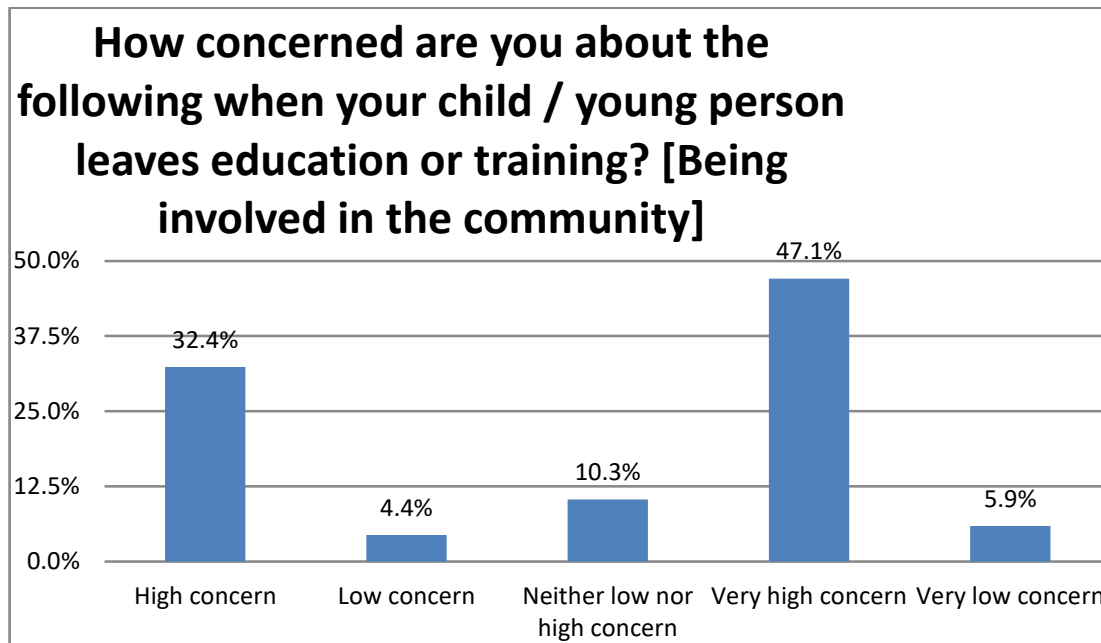
Their child/young person finding employment in the future was a very high concern for over half of parents/carers (54%).

**Q11-B. How concerned are you about the following when your child/young person leaves school? - Living Independently.**



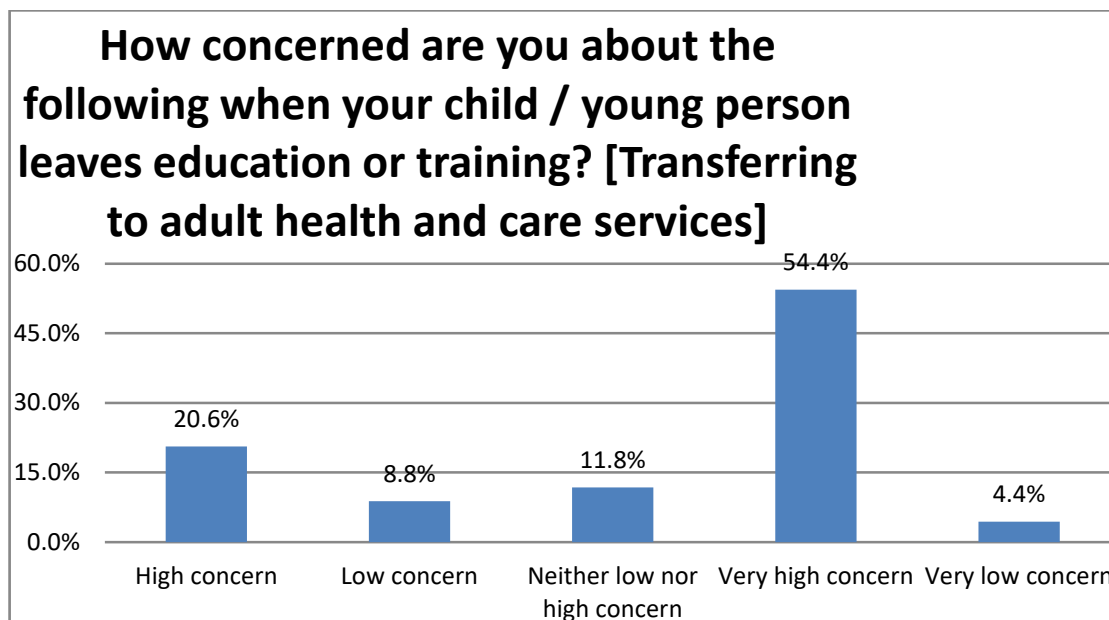
Almost half (47%) said that their child/young person’s ability to live independently in the future was a very high concern.

**Q11-C. How concerned are you about the following when your child/young person leaves school? - Being Involved in the Community.**



Almost half (47%) said that their child/young person's ability to be involved in the community in the future was a very high concern.

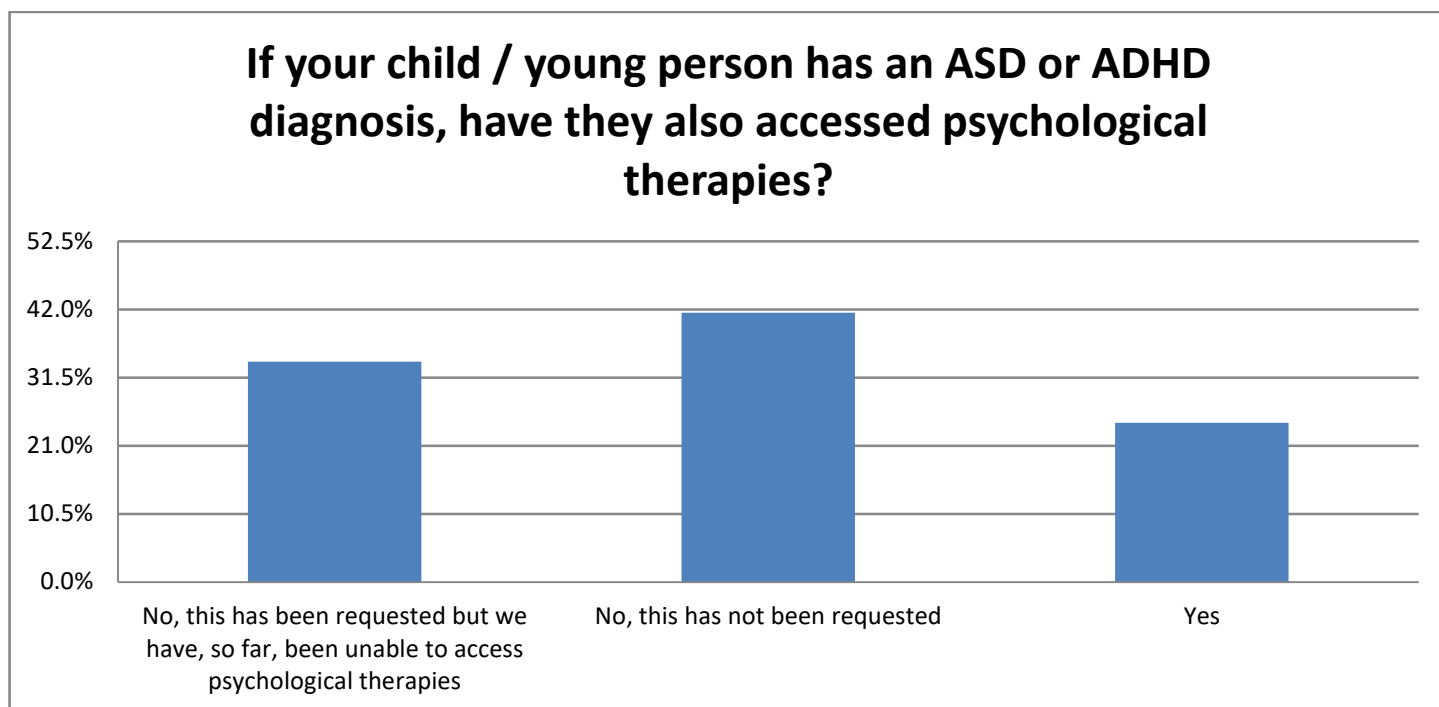
**Q11-D. How concerned are you about the following when your child/young person leaves school? - Transferring to Adult Health & Care Services.**



Over half (54%) said that the transition to adult services was a very high concern.

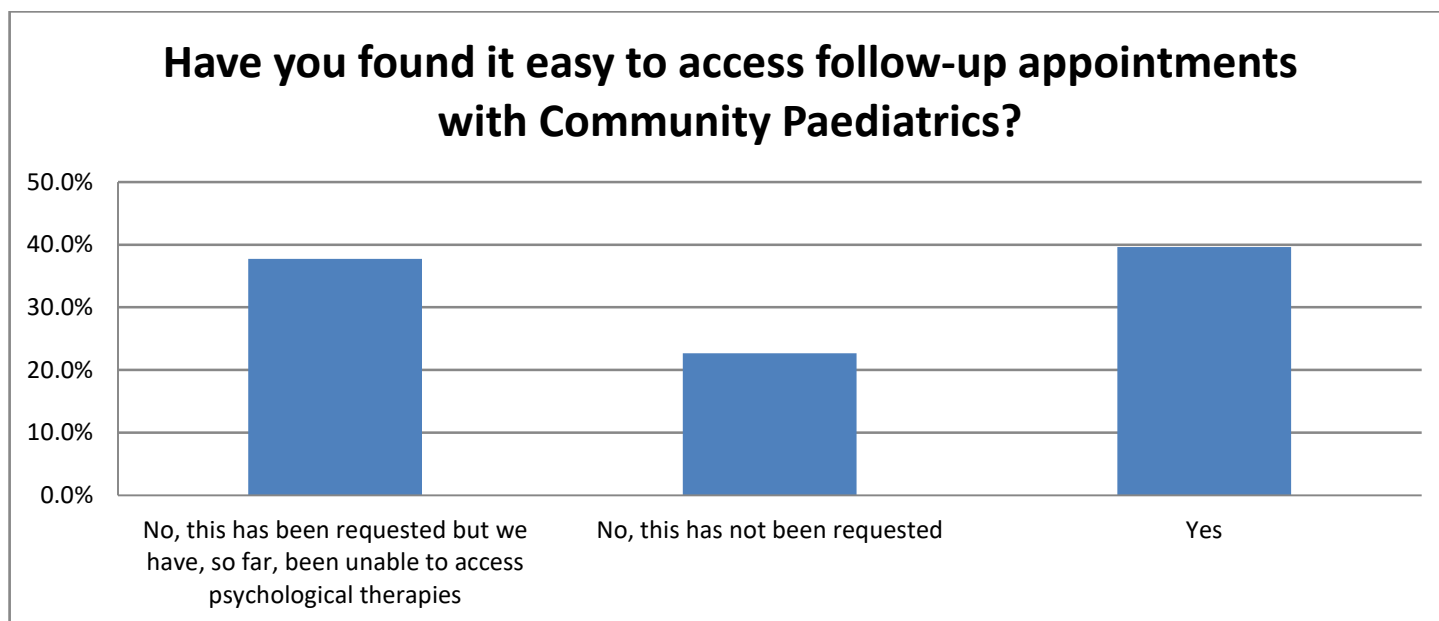


**Q12. If your child / young person has an ASD or ADHD diagnosis, have they also accessed psychological therapies?**



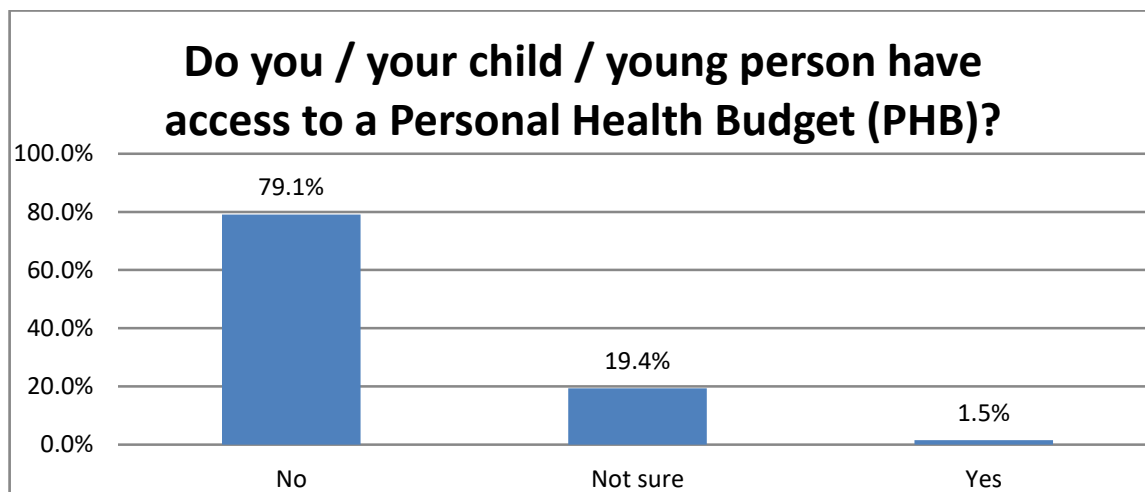
Where children/young people had an ASD or ADHD diagnosis, almost a quarter (24.5%) had also accessed psychological therapies, but these services had been requested by a further 34% of families.

**Q13. Have you found it easy to access follow-up appointments with Community Paediatrics?**



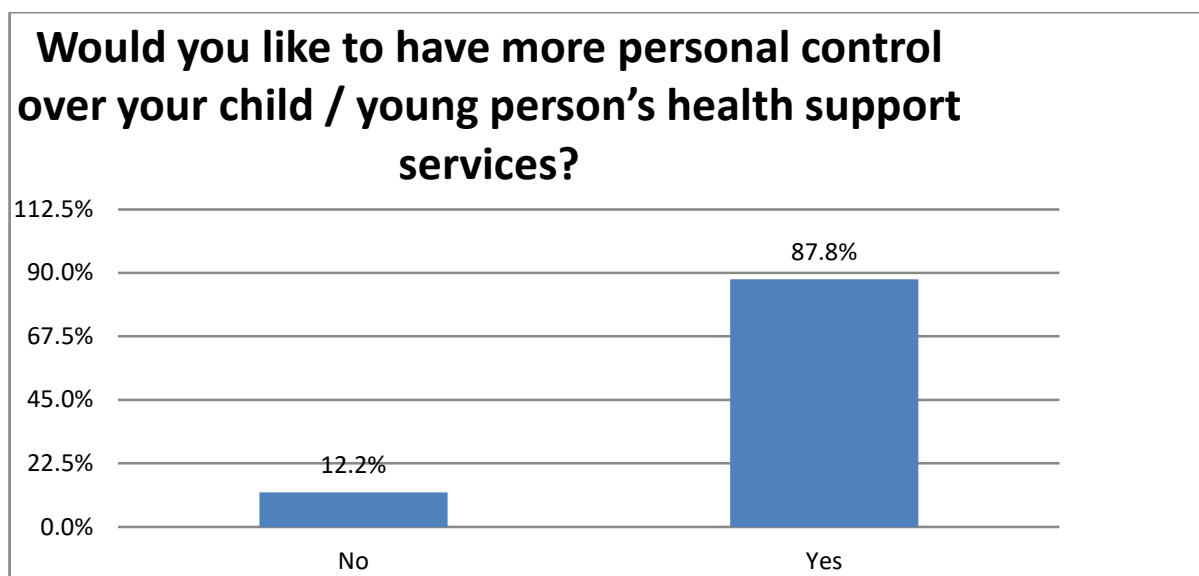
Whilst 40% of parents/carers had found it easy to access follow-up appointments with Community Paediatrics, a further 38% of families had not found this easy.

**Q14. Do you / your child / young person have access to a Personal Health Budget (PHB)?**



The vast majority (79%) had not had access to a Personal Health Budget, with only 1.5% saying they had access.

**Q14-B. Would you like to have more personal control over your child / young person's health support services?**



However, 88% of respondents said they would like to have more personal control over their child/young person's support services.

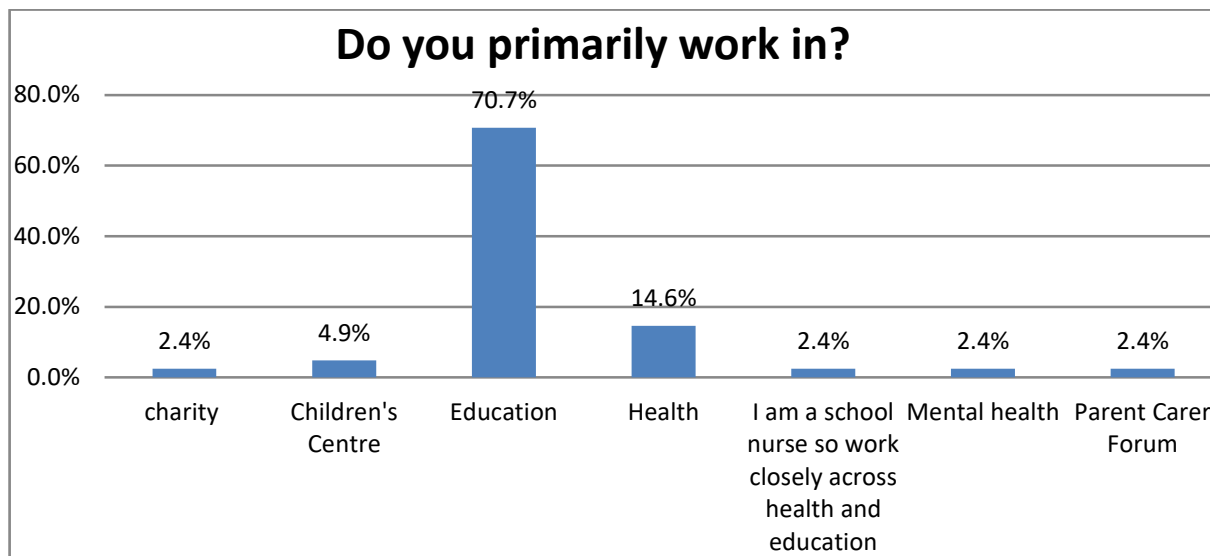
# Appendix B

## SEND Practitioners - Quantitative Data

Survey information was provided by 61 professionals working with children and young people with SEND. This was a self-selecting sample so some caution should be exercised when viewing the data, as it may not be wholly representative of SEND practitioners’ experiences in Liverpool. It is particularly important to note that although attempts were made to circulate surveys across all relevant sectors, 71% of responses came from people working in Education, so the sample will inevitably reflect their viewpoints in particular.

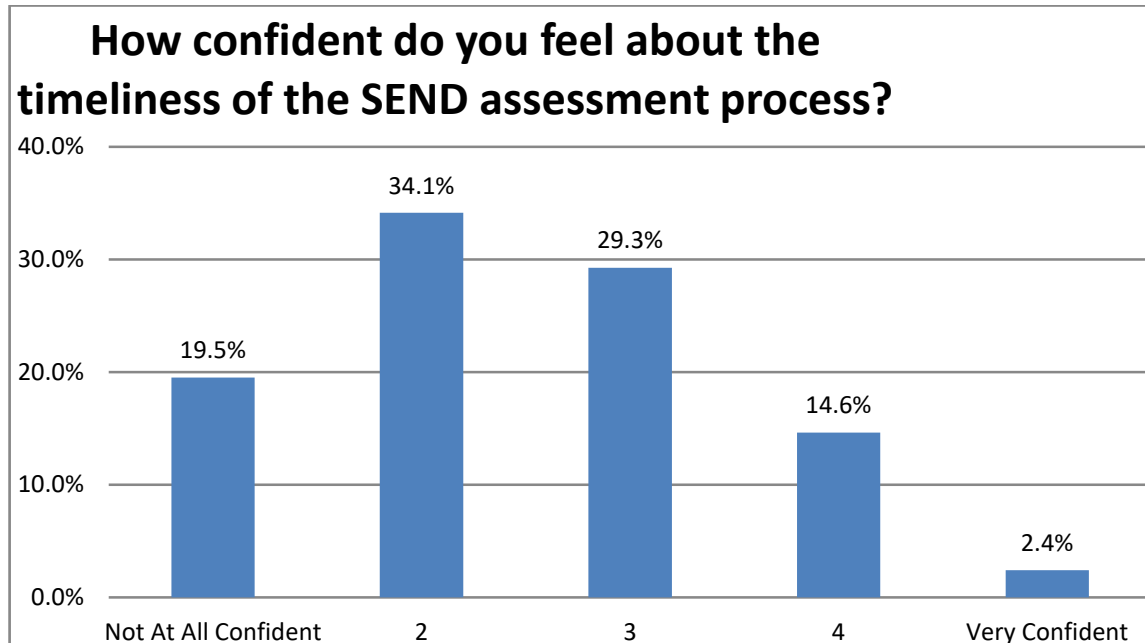
### Descriptive Stats

#### Q1. Do you work in....?



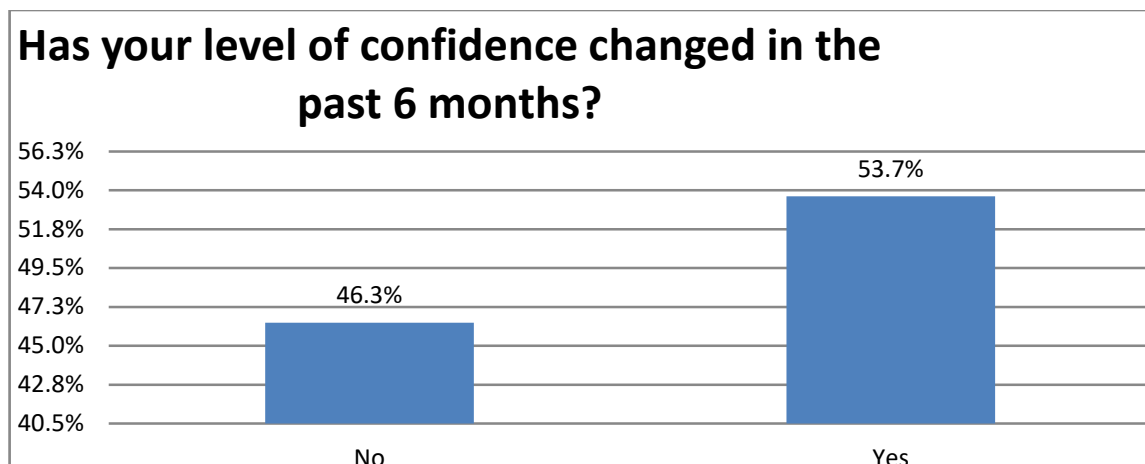
The majority of respondents, 70.7% worked in the education sector, 14.6% worked in the health sector, 4.9% worked at Children’s Centres and 2.4% each worked in mental health, as a school nurse, within a parent/carers forum and for charities.

**Q2. How confident do you feel about the timelines of the SEND assessment process?**



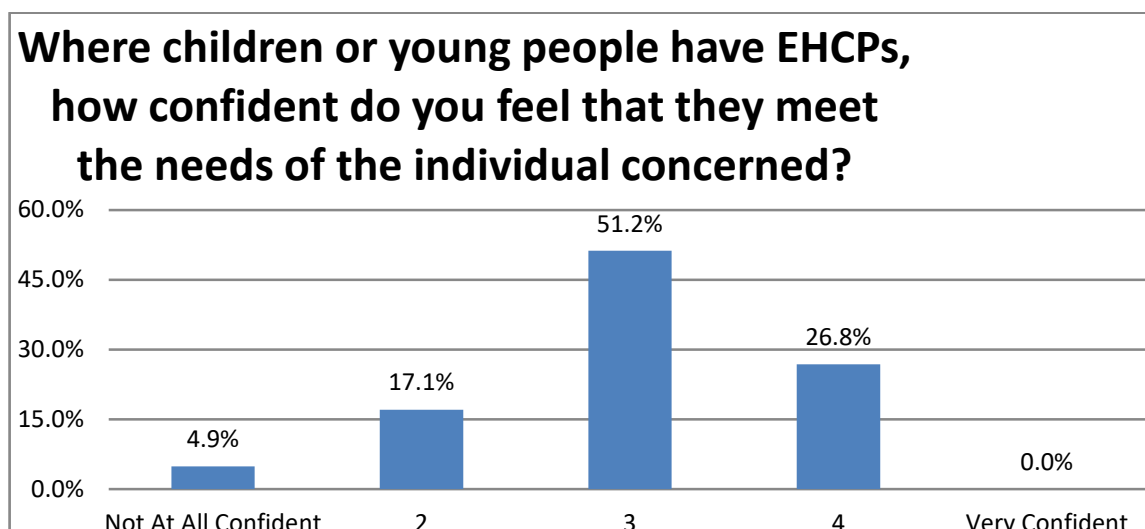
The majority of respondents were not confident about the timeliness of the SEND assessment process; 20% were ‘not at all confident’ and 34% rated their confidence levels as 2/5. 29% gave a 3/5 rating for their confidence. 15% rated their confidence as 4/5 with only 2% expressing that they were ‘very confident’ about the timeliness.

**Q3. Has your level of confidence changed over the past 6 months?**



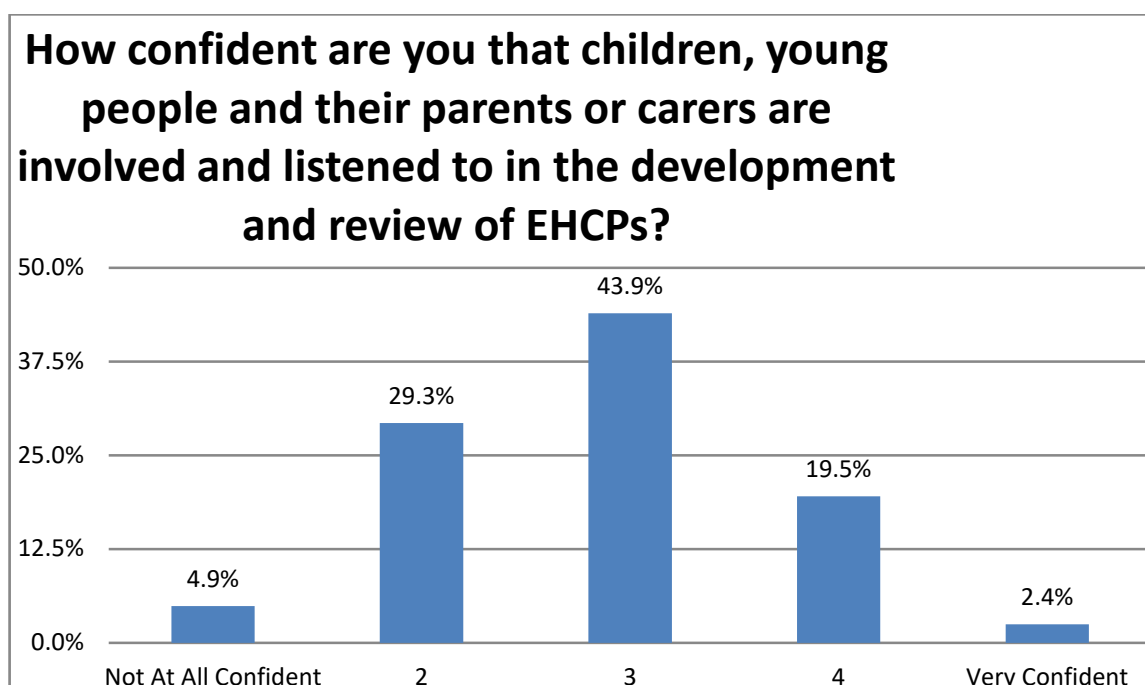
54% felt their level of confidence had changed over the past 6 months.

**Q4. Where children or young people have EHCPs, how confident do you feel that they meet the needs of the individual concerned?**



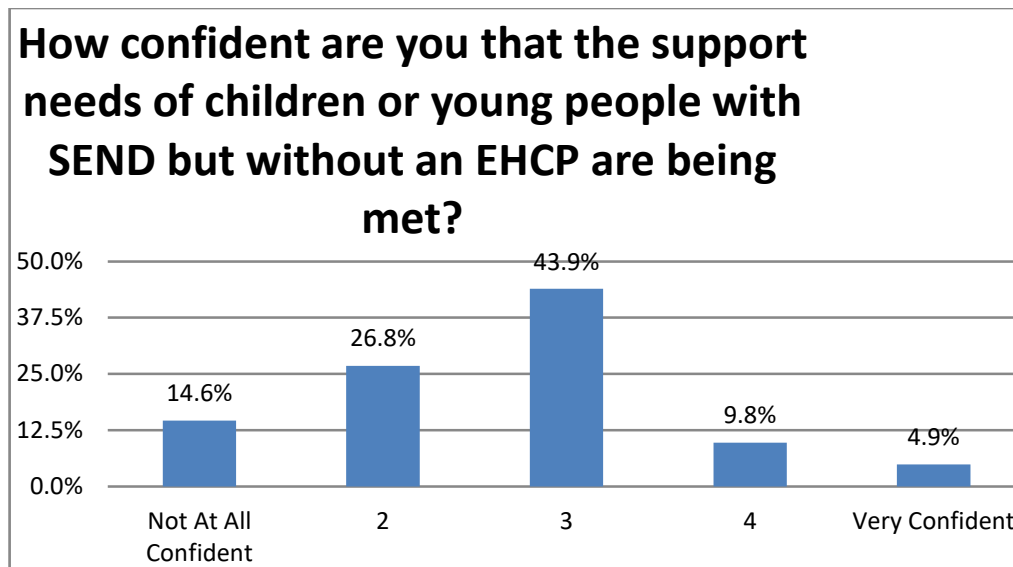
The majority of respondents (51%) gave a confidence level of 3/5 that EHCPs met the needs of the individual concerned. 17% stated 2/5 and 5% were ‘not at all confident’. 27% were more confident at 4/5 but 0% of professionals who completed the survey were ‘very confident’ that the needs of the individual were being met with an EHCP.

**Q5. How confident are you that children, young people and their parents/carers are involved and listened to in the development and reviews of EHCPs?**



Whilst 44% of respondents had medium levels of confidence that children/young people and their parents/carers were involved and listened to, 29% had slightly less confidence 2/2 and 5% were ‘not at all confident’. 20% rated their confidence 4/5, but only 2% were ‘very confident’ in this aspect of the process.

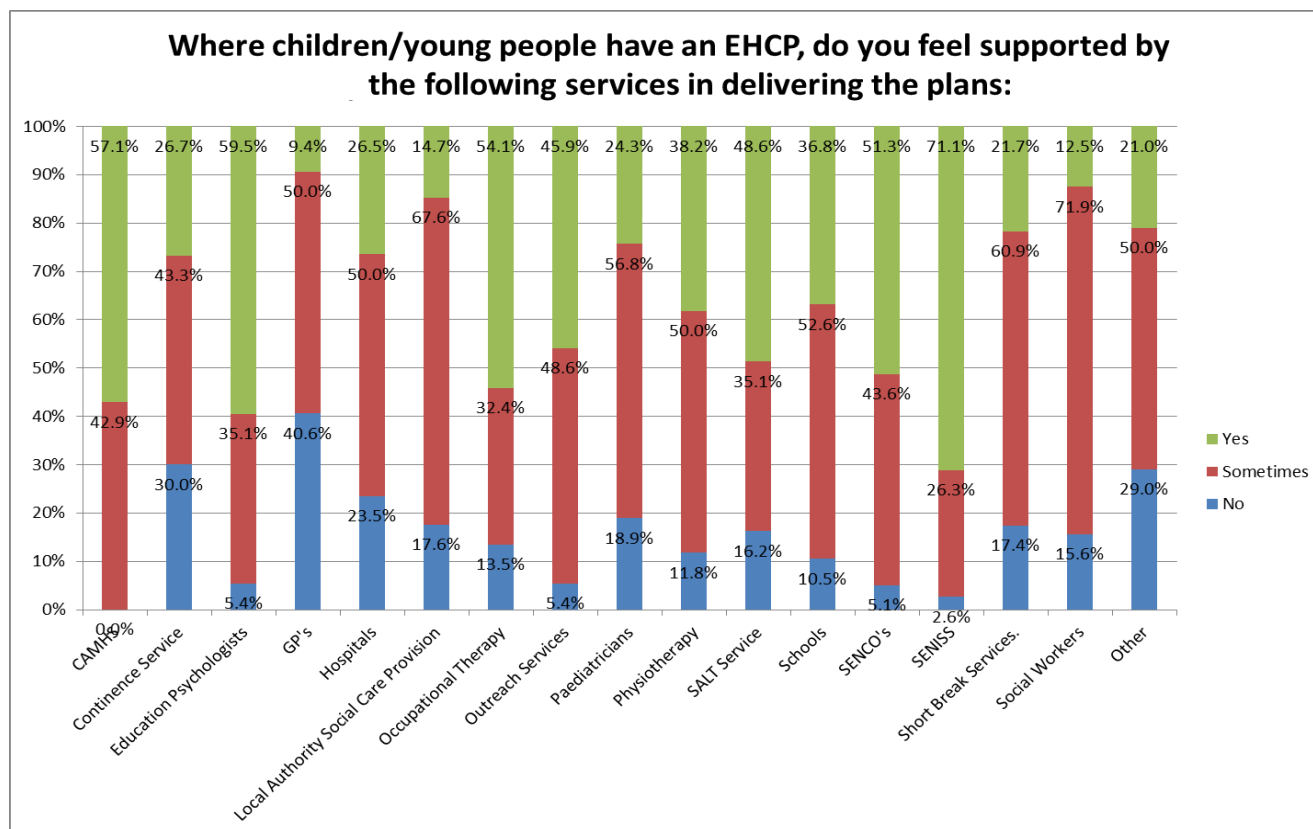
**Q6. How confident are you that the support needs of children or young people with SEN but no EHCP are being met?**



44% had average levels (3/5) of confidence, 10% had slightly more confidence with 4/5 and 5% were ‘very confident’ that those with SEND and no EHCP were having their support needs met. 27% were not very confident about this and scored 2/5, whilst 15% were not confident at all about this.



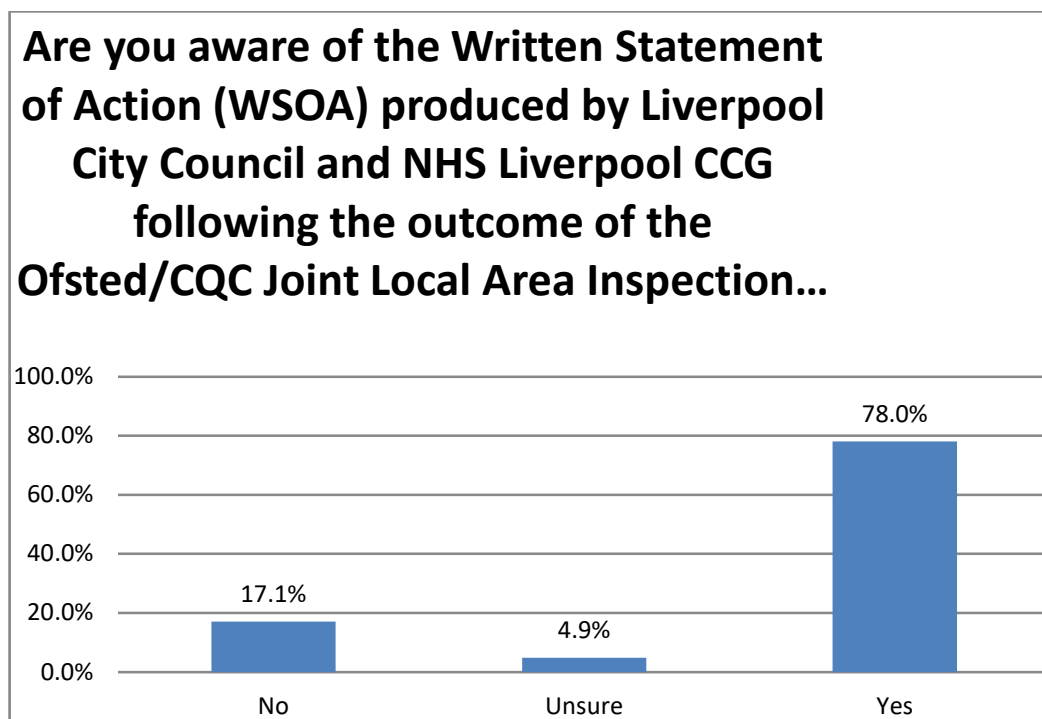
**Q7(A-Q). Where children/young people have an EHCP, do you feel supported by the services listed in delivering the plans, including your own service, where applicable?**



- 57% stated 'Yes' they do feel supported by CAMHS in delivering the plans. 43% said that 'sometimes' CAMHS supported the plans and 0% stated 'No' they were not supported.
- 30% said 'No' they did not feel supported by the Continence Service in delivering the plans. 43% agreed that the Continence Service 'sometimes' supported the plans and 27% stated 'Yes' they were supported.
- 5% stated 'No' they did not feel supported by Education Psychologists in delivering the plans. 35% said that Education Psychologists only 'sometimes' supported the plans and 60% stated 'Yes' they were supported.
- 40% said 'No' they did not feel supported by GPs in delivering the plans. 50% said that GPs only 'sometimes' supported the plans and 9% stated 'Yes' they were supported.
- 24% stated 'No' they did not feel supported by Hospitals in delivering the plans. 50% said that Hospitals only 'sometimes' supported the plans and 26.5% stated 'Yes' they were supported.
- 18% said 'No' they did not feel supported by Local Authority Social Care Provision in delivering the plans. 68% said that Local Authority Social Care Provision only 'sometimes' supported the plans and 15% stated 'Yes' they were supported.
- 14% stated 'No' they did not feel supported by Occupational Therapy in delivering the plans. 32% said that Occupational Therapy only 'sometimes' supported the plans and 54% stated 'Yes' they were supported.
- 5% said 'No' they did not feel supported by Outreach Services in delivering the plans. 49% said that Outreach Services only 'sometimes' supported the plans and 46% stated 'Yes' they were supported.

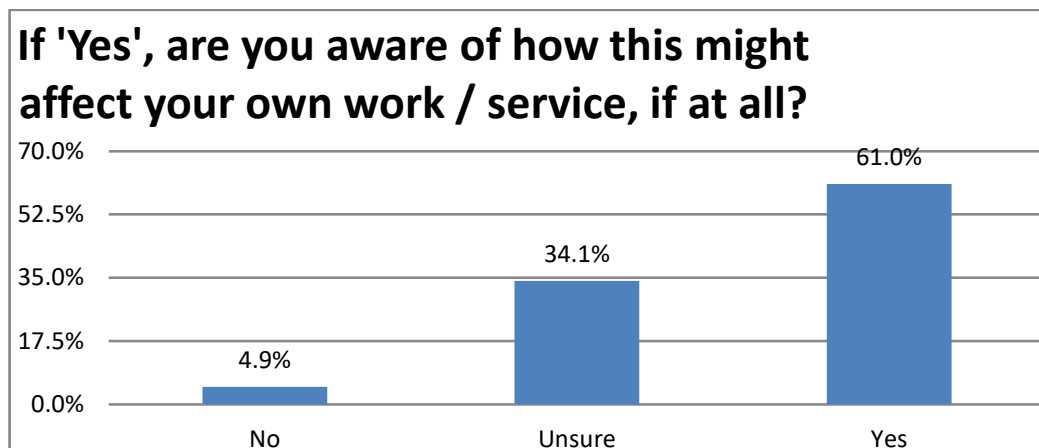
- 19% stated ‘No’ they did not feel supported by Paediatricians in delivering the plans. 57% said that Paediatricians only ‘sometimes’ supported the plans and 24% stated ‘Yes’ they were supported.
- 12% stated ‘No’ they did not feel supported by Physiotherapy in delivering the plans. 50% said that Physiotherapists only ‘sometimes’ supported the plans and 38% stated ‘Yes’ they were supported.
- 16% said ‘No’ they did not feel supported by the SALT Service in delivering the plans. 35% said that the SALT Service only ‘sometimes’ supported the plans and 49% stated ‘Yes’ they were supported.
- 11% stated ‘No’ they did not feel supported by Schools in delivering the plans. 53% said that Schools only ‘sometimes’ supported the plans and 37% stated ‘Yes’ they were supported.
- 5% said ‘No’ they did not feel supported by SENCOs in delivering the plans. 44% said that SENCOs only ‘sometimes’ supported the plans and 51% stated ‘Yes’ they were supported.
- 3% stated ‘No’ they did not feel supported by SENNIS in delivering the plans. 26% said that SENNIS only ‘sometimes’ supported the plans and 71% stated ‘Yes’ they were supported.
- 17% said ‘No’ they did not feel supported by the Short Breaks Service in delivering the plans. 61% said that the Short Break Service only ‘sometimes’ supported the plans and 22% stated ‘Yes’ they were supported.
- 16% stated ‘No’ they did not feel supported by Social Workers in delivering the plans. 72% said that Social Workers only ‘sometimes’ supported the plans and 13% stated ‘Yes’ they were supported.
- 29% said ‘No’ they did not feel supported by Other Services in delivering the plans. 50% said that Other Services only ‘sometimes’ supported the plans and 21% stated ‘Yes’ they were supported.

**Q8. Are you aware of the Written Statement of Action (WSOA) produced by Liverpool City Council and NHS Liverpool CCG following the outcome of the Ofsted/CQC Joint Local Area inspection of Liverpool’s SEND provision in January 2019?**



78% were aware of the WSoA, 17% were not aware and 5% were ‘unsure’ whether they knew about this.

**Q8-B. If 'Yes', are you aware of how this might affect your own work / service, if at all?**



61% of those who knew about the WSoA were aware of how this might affect their own work. 34% were unsure and 5% were not aware of how this may have an impact on their role.

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# About Healthwatch Liverpool

Healthwatch Liverpool is the independent champion for people who use health and social care services in Liverpool. We're here to make sure that those running services put people at the heart of care. One of our main purposes is to understand the needs, experiences and concerns of people who use health and social care services and to speak out on their behalf.

As part of a national network made up of local Healthwatch organisations in every local authority area of England (and Healthwatch England, the national body) our work contributes to a nationwide perspective of health and social care services.

At Healthwatch Liverpool we also provide a dedicated information and signposting service which helps to put people in touch with services and activities that can help maintain and improve their health and wellbeing.

This report is available online at [www.healthwatchliverpool.co.uk/news-and-reports](http://www.healthwatchliverpool.co.uk/news-and-reports) If you require a copy of the report in another format or language please contact us and we will do our best to help.

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