Improving parent carer participation and co-production in Haringey

an independent review by Amaze

commissioned by Contact and Haringey Council

July 2020

Executive Summary

Amaze was jointly commissioned by Contact and Haringey Council to undertake a review of parent carer participation, with the intention of making a series of recommendations about how this can be improved. Our review included a survey and focus groups with a total of 89 parent carers and interviews with 25 professionals from different sectors.

One of the aims of the Children and Families Act 2014 was to fully embed individual and strategic participation, placing children with SEND and their families at the centre of SEND processes and services. Nationally, progress to implement these sweeping reforms has been very variable and significant challenges remain for many areas. In 2019, the Education Select Committee published a report reviewing how effective the 2014 reforms had been across England and it found that many of the aims were yet to be realised. It also highlighted the ongoing plight of parent carers across the country, who often have to 'wade through a treacle of bureaucracy, full of conflict, missed appointments and despair' and concluded that, alongside significant funding, a systemic cultural shift would be required to deliver the outcomes children need.

Our research found many of these findings reflected in Haringey, with further complexities due to its very diverse population and high levels of deprivation. We found a lack of continuity in leadership, repeated movement of the SEND team between portfolios, staff turnover and inconsistent practice, which have hampered Haringey's attempts to deliver the systemic cultural changes that have been needed over the last six years. Most parent carers we spoke with told us they had to fight to receive services for their child(ren) and some had a low level of confidence and trust in the authority to deliver services in a timely and accessible way. We heard many examples of families in Haringey who needed more support from key services such as respite and social care, as well as more accessible information to enter and navigate the SEND system.

There is currently no formal route for parent participation in Haringey as the parent carer forum, Haringey Involve, was decommissioned in 2019. While there has been some participation it has been difficult for all involved. Engagement has lacked the necessary structures, policies and process and has also been limited in its reach. In our view, previous attempts to develop a Parent Carer Forum (PCF) have been hampered by insufficient local investment and because other priorities have pushed participation down the list for some professionals, and families say following their input there has been little in the way of action, follow up and tangible results. Parents reported other challenges including a lack of joined up working, poor customer service and communication, and a lack of empathy or understanding of their situations. Clear structures are not yet in place to invite a diverse team of parent representatives to input to agendas at an early stage in a planned way, so it is not surprising that 63 per cent of respondents to our survey said they did not feel at all involved in shaping local services.

Despite these difficulties, the vast majority of parent carers we spoke to were keen to play an active role in participation opportunities particularly if they could see how their input improved outcomes and services for their children. Most feel it is essential to set up a new PCF which is governed and led by a steering group with a diverse membership including key support groups. Parent reps will also need training and support to lead on particular areas of work feeding into key decision-making boards. Parents at our focus groups also want boundaried pieces of work and flexible ways to get involved – at different times and using different formats – so a varied menu of activity needs to be developed going forwards.

Professionals were also keen to do more engagement with families and senior leaders have indicated a strong commitment to facilitating change in the borough to improve participation. But there is much to overcome, including the defensive culture of some professionals, a lack of capacity in their roles, and agreement around ways of working and codes of conduct. They said that the differing aims and priorities amongst parents were sometimes difficult to navigate and they felt they needed closer working relationships with a wider range of parents. Many also felt they would need more time and training on co-production and participation techniques.

Since our research phase with parents, the Covid-19 lockdown has had a huge adverse impact on families. In times like these, the strong collective voice of a forum would have been incredibly helpful to service leaders, with parents co-producing emergency policies and solutions. Therefore, it feels urgent that Haringey responds positively and swiftly to our recommendations, including the 'key ingredients' that we have found to be essential to participation, to co-produce an action plan and statement of intent with the community. This will need to be led from the top, with local investment made in setting up and supporting a new PCF, with training for all staff around participation co-delivered by parents, embedding participation expectations into staff work plans and celebrating and sharing the impact of successful participation to families via strengthened communication channels.

Finally, it's important to note that some parents we spoke to did report having good experiences, which happened when they, and their children, were listened to and their knowledge and expertise was recognised and used in decision-making. This was often on account of the actions of one or two individuals in the system with whom they have developed a positive relationship. All professionals working in Haringey need to engage parents as equal partners, who can make informed and valuable contributions to the design, delivery and review of services. If done well, true co-production has the potential to effect real change and ensure services meet, and are responsive, to the varied needs of the local community.

Acknowledgements

Our grateful thanks go to the following people for their time and contributions to our report:

- Parent carers who were so generous in giving up their time to attend our focus groups, online webinar or fill in our survey
- Leads from various parent support groups and voluntary organisations in the borough, who were so helpful in promoting our review and sharing their views.
- Hornsey Vale Community Centre and the four Haringey schools that accommodated our focus groups.
- Staff at Haringey Council, the CCG, schools and other services who kindly gave up time to speak to us.
- Heather Tarbuck, Contact

A note about terminology

For the purposes of our report, the word 'child' has been used as shorthand to cover babies, children and young people aged 0 to 25 years who have special needs and disabilities (SEND). This has been done to avoid clumsy sentences, endless repetition and to make the text as accessible as possible.

We acknowledge that 'parents and carers' is the preferred terminology of some organisations, however in order to be as clear and concise as possible we have used the term 'parent carers' in our report. The *Children's and Families Act, 2014* defines a parent carer as being:

'a person aged 18 or over who provides or intends to provide care for a disabled child for whom the person has parental responsibility.' (97, 2).

This term is also widely recognised by families and professionals working in the community with disabled children and young people. Therefore, in our report the term 'parent carer' also covers families where the child's main carers are grandparents, kin carers or foster parents, for example.

Disclaimer: this report reflects the events and experiences of many professionals and parent carers in Haringey since the 2014 SEND reforms were implemented. Any quotes in the report are the subjective views of individuals, whose opinions will have been shaped by many experiences during this time. Quotes have been used as examples where we have gathered evidence from several sources and similar themes or issues have emerged as being common experiences of multiple families or professionals. These opinions are not necessarily shared or endorsed by Amaze and must be considered within the wider context of the full report rather than taken as facts in isolation.

Introduction

This independent review of parent carer participation was jointly commissioned by Contact and Haringey Council. Its aim is to find out how participation and co-production can be strengthened in the borough so that parent carer voices, and those of children and young people, shape and inform the design, delivery and review of services to meet the needs of the local SEND community

Why Amaze?

Amaze is a Sussex-based charity originally formed from two parent carer support groups. It provides a range of services for families including: the Information, Advice and Support (IAS) service in Brighton and Hove and East Sussex; the Compass disability register and discount leisure card in Brighton and Hove and West Sussex; numerous projects supporting parents and young people, as well as delivering regular workshops and training.

Since Brighton and Hove's parent carer forum, Brighton and Hove Parents and Carers Council (B&HPaCC), was set up in 2008, Amaze has hosted the forum, providing strategic and back office support. Twelve years on and B&HPaCC has established itself as a truly representative voice for the local SEND community and been cited as an example of good practice by Ofsted for co-production and its approach as a 'critical friend' to the local authority and other service providers.

In 2016, Amaze carried out a review of parent carer participation in East Sussex on behalf of the county council and Contact, which generated a report published in early 2017. Effecting change has taken some time, but in 2019 East Sussex Parent Carer Forum (ESPCF) was established by the chairs of two parent carer support groups in the county, with Amaze providing back office support in a similar model to that which has worked so effectively in Brighton & Hove.

In late 2019, Amaze was approached by Contact and Haringey Council, who wanted to carry out a similar review in their borough and were looking for an experienced organisation to carry out the review. In order to deliver this piece of work

Amaze has employed the same freelance writer and researcher who is also a parent carer, to ensure that the review is as objective as possible.

What is participation?

It is more than fifty years since US academic Sherry Arnstein developed a 'ladder of participation[1]' (see Appendix 1) to explain the relationships between those in power and citizens who are affected by their decision-making. She described the least effective levels as those where citizens have no say at all, while the most effective levels of participation, towards the top of the ladder, happen when citizens and professionals work in partnership in planning and decision-making and in some cases citizens are delegated to make the decisions and run services themselves.

In the context of special educational needs and disabilities (SEND) parent participation was brought to the fore over a decade ago by the 2009 Lamb Inquiry[2], which said there was an urgent need for parent carers of children and young people with SEND to have a stronger voice in decision-making. The report emphasised that good communication between parents and professionals was key to developing partnerships and trust:

Face-to-face communication with parents, treating them as equal partners with expertise in their children's needs is crucial to establishing and sustaining confidence. (Lamb Inquiry, 2009[2])

Five years later, the *Children and Families Act 2014*[3] brought in sweeping reforms to the SEND system in England. The duties of local authorities to children and young people with SEND are set out in Part 3, section 19 of the act. One of the aims of the reforms was to fully embed participation both on an individual and a strategic level by placing children and families at the centre of SEND processes. It was hoped that better participation would improve long-term outcomes for families on an individual level and on a strategic level would ensure that services meet the needs of the local SEND community.

The statutory duty of local authorities to consult with parent carers at a strategic level is set out in the *SEND Code of Practice 2015*[4], which says:

> *At a strategic level, partners must engage children and young people with SEN and disabilities and children's parents in commissioning decisions, to give useful insights into how to improve services and outcomes... (SEND Code of Practice, 3.18)*

What are its benefits?

Effective participation can strengthen partnerships between families and professionals by opening up a two-way dialogue, allowing parent carers the chance to voice their views and share their experiences in a constructive way so that professionals gain a better understanding of their service users' needs. It also allows parents to understand the challenges professionals face in service design and delivery and why sometimes tough decisions have to be made. Effective partnership working by parents and professionals can effect real change and ensure that services are appropriate for the community and adapt over time to meet changing needs. It can also ensure that resources are used efficiently and as effectively as possible.

Participation can empower parent carers so that they feel actively involved in the planning and provision of services they use and therefore ensure their children's needs are met. It can also allow families to connect to others in similar situations, thus providing opportunities for peer-to-peer support, which can improve resilience and enhance the wellbeing of the community.

The evolution of parent carer forums

In 2008, the Government's Aiming High for Disabled Children programme asked local authorities to consult with parent carers, disabled children and young people so they could provide short breaks that met the needs of the local SEND community. Funding was provided to enable participation and so to facilitate it parent carer forums were established in numerous areas across the country. Many service managers and commissioners found that by working with parent carers, and children and young people with SEND, they were able to deliver better services and allocate funding more effectively.[5]

The majority of local authorities across England now have parent carer forums, each playing a vital role in ensuring that services are planned, commissioned, delivered and monitored to meet the needs of children and young people with SEND and their families. However, this has not been without its difficulties, as highlighted in Contact's most recent annual report *Parent Carer Participation 2018-2019: The Next Decade of Supporting Parent Carers' Voices*[6], which highlights the need for professionals to strengthen their commitment to joint working with parent carers:

> ***Evidence shows that co-productive partnerships make the best use of people's time and money, whilst also improving outcomes for disabled children. It is the gold standard of working. However, it means that strategic partners must make a commitment to engage with Parent Carer Forums to shape and develop their services.***[6]

The Department for Education's *Tenth Special Educational Needs and Disability (SEND) Reforms Implementation Survey for Parent Carer Forums*[7] asked parent carer forums to give examples of good practice 'specific to the engagement of children, young people and parents in strategic planning and co-production of SEND services.'

Forums reported parent carer involvement in many services and areas at a strategic level, including

EXAMPLES OF SERVICES/TOPICS WITH PARENT INPUT AT A STRATEGIC LEVEL

- *0-25 social care service,*
- *Adult social care team*
- *CAMHS*
- *Capital funding*
- *CCG/Health*
- *Co-production strategy/charter/MOU*
- *Diagnostic pathways*
- *Education*
- *Educational Psychology*
- *High Needs*
- *Home to school transport*
- *Learning Support Service*
- *Jointly produced guidance, comms and newsletters*
- *Local area inspections: before, during and after*
- *Local Offer*
- *Personal budgets*
- *Preparing for Adulthood*
- *Recruitment/interviews (to director level*
- *SEND Mediation*
- *SEND strategy co-production/ consultation/documents*
- *Short breaks*
- *SENDIASS*
- *Therapies (OT, SALT, PT)*
- *training for staff/practitioners/schools*

EXAMPLES OF GROUPS/PANELS/BOARDS WITH PARENT REPRESENTATION

- *Autism Development Group/ Partnership Board/Pathway/Hub*
- *Birth - 25 service collaboration group*
- *Children's Trust Board*
- *Community Paediatrician Steering Group*
- *Co-production Board/Communication and Participation workstream/ communication*
- *EP (Educational Psychologist) parent group*
- *Health therapies meetings/working group (SALT, OT, PT)*
- *High Needs Strategic Review*
- *Inclusion Programme Board/task force*
- *Joint commissioning strategy panel/ multiagency steering group and engagement policy/Co-production and SEND evaluation group*
- *Local Offer working / evaluation groups*
- *PfA Development Board/ Supported Internship Board*
- *Process Governance Group*
- *Quality Assurance/Evaluation/Review panels*
- *SEND Behaviour Strategic Partnership Steering Group*
- *SEND Challenge group*
- *SEND development groups/boards/ meetings*
- *SEN Moderating Panel/Moderation Group*
- *SEND representative group*
- *SEND work streams*

The survey[7] also explores the value in joint commissioning arrangements and asked parent carer forums to explain the reasons for their success. Joint commissioning arrangements are a requirement under the Children and Families Act 2014 to ensure that commissioners in education, health and social care work holistically with families of children with SEND and providers of services so that services meet the needs of the local community and improve outcomes for children with SEND.

Parent carer forums said that the following were necessary for joint commissioning to be a success:

JOINT COMMISSIONING ARRANGEMENTS ARE SUCCESSFUL DUE TO:

- *joint strategic meetings, strategy boards and action plans*
- *panels for complex cases, pooled budgets and joint funding*
- *multiagency assessments*
- *data-sharing agreements*
- *having a Designnated Medical Officer (DMO)*
- *Joint Strategic Needs Assessment (JSNA)*
- *having a Quality Assurance Team*

However, despite these important steps forward, parent carer forums identified that there were still signicifant barriers and challenges to overcome in order to develop and embed co-production. They highlighted that there are multiple factors at play, affecting everything from professional culture to communication all of which make parent carer participation challenging at times. The examples given[7] include:

ONGOING BARRIERS TO PARTICIPATION:

CULTURE/STAFF

- *culture*
- *attitudes*
- *reluctance to adopt co-production*
- *entrenched practices*
- *own agendas*
- *capacity issues*
- *officers'/clinicians' lack of availability*
- *no joint commissioning manager*
- *lack of social care representation in joint commissioning*

ONGOING BARRIERS TO PARTICIPATION continued

COMMUNICATION/TRANSPARENCY

- *lack of transparency*
- *lack of joint working*
- *lack of communication*
- *silo working/thinking*
- *defensiveness/protection of own areas*

TIME / GEOGRAPICAL BARRIERS

- *time pressures*
- *pressure on staff to meet statutory timescales*
- *geography (travel/accessibility etc)*

FINANCIAL BARRIERS:

- *budget/resources not pooled*

BARRIERS IN PROCESSES:

- *lack of strategic management*
- *lack of defined processes*
- *lack of accountability*
- *inconsistency*
- *problems with data gathering*
- *no review of outcomes*
- *lack of follow-up between services*
- *inaction*
- *differing systems, policies, processes and language across agencies*
- *conflicting priorities for joint commissioning teams*
- *prioritisation of other areas, i.e. older population*

Although at a national level there has been some progress in parent carer participation since the 2014 reforms, there is much variation between local authorities and significant challenges remain at a local level.

Participation is not a tick-box exercise

Faced with these considerable challenges to participation, it can be tempting for service providers to push it down the priority list, resulting in hasty and poorly planned 'consultations' towards the end of projects, with ad-hoc discussions limited to one or two hand-picked parent carers so that the 'participation box' can be ticked. But this is not an acceptable substitute for engaging a representative sample of the SEND community in true participation from a project's outset, so that the voices of parent carers, and ideally those of children and young people feed in to the entire process and shape outcomes.

It is equally poor practice to request that parent carers give up valuable time to take part in a project when a decision has already been made behind closed doors.

Both of these scenarios can be extremely damaging to relationships with the wider SEND community. If parent carers feel that their time has been wasted, or that their participation is tokentistic and they have no real influence on decision-making. This can lead to frustration and resentment, as well as distrust on a strategic level and also on an individual level. Parent carers are unlikely to want to engage in future opportunities, however well-planned, as they will see them as a futile exercise which has no value or bearing on the final outcome.

Therefore, in order to ensure participation is effective and to overcome the challenges outlined above it is essential that participation opportunities are planned properly with honesty and transparency before a project or piece of work commences. Professionals and parent reps from the SEND community must sit down together and agree how things will proceed from the outset – with the scope of the piece of work clearly outlined so that all concerned have a clear understanding of a project's aims, what can be achieved and its limitations.

Also, it is crucial that parent carers receive prompt feedback from their work, so they understand what has resulted and how their input has effected change, as this often encourages further participation by other members of the community.

Success stories: Somerset Parent Carer Forum

Aim: to redevelop the forum and grow membership

In 2015, when Somerset Parent Carer Forum reformed they found that the membership records were unclear.[8] Although 250 people were signed up to the forum, it appeared that some were in touch via social media only.

In order to address this, the forum visited local support groups to talk about their work and offered parent carers a variety of ways in which to engage through Facetime, Skype, conference call and by streaming the steering group meetings over Facebook.

In 2019, forum reps attended more than 350 meetings and their membership had grown to 1,945 people. The steering group stream had a peak audience of 554 people on Facebook and they also live-streamed the CCG's AGM to an audience of 2, 600 people, during which the forum challenged the decision to change the community paediatrics criteria.[9]

The national picture

In 2019, the House of Commons' Education Committee published its report after an 18-month formal inquiry to review whether the 2014 SEND reforms had been successful, how well they had been implemented and the extent to which they have addressed the needs of children and young people with SEND.

The Committee heard oral evidence from many professionals and parent carers, as well as receiving many written submissions. In its summary, it concluded that these ambitious reforms were largely still to be realised and:

> *Let down by failures of implementation, the 2014 reforms have resulted in confusion and at times unlawful practice, bureaucratic nightmares, buck-passing and a lack of accountability, strained resources and adversarial experiences, and ultimately dashed the hopes of many.*[10]

The report highlights that the reforms were correct, but their implementation had suffered due to poor administration and a challenging funding environment for local authorities and schools. It also highlighted a lack of accountability within the system, and the need for greater oversight, stating:

> *The distance between young people's lived experience, their families' struggles and Ministers' desks is just too far.*[10]

It goes on to highlight the plight of parent carers, who have to 'wade through a treacle of bureaucracy, full of conflict, missed appointments and despair', while finding that many local authorities have struggled with the reforms, which in some cases has 'led to unlawful practices.'

In addition, it also flagged that there has not been sufficient joint working between education, health and social care and that there is the need to develop a joint outcomes framework to measure how effective health support is for children and young people and ensure that the serious gaps in therapy provision are addressed.

It also highlighted that one of the main issues was a significant shortfall in funding. It said this is:

> *...a serious contributory factor to the failure on the part of schools and local authorities to meet the needs of children and young people with SEND. However, unless there is a systemic cultural shift on the part of all parties involved, additional funding will make little difference to the outcomes and experiences of children and young people with SEND.*[10]

Against the backdrop of these difficulties, it is not surprising that the success of the reforms has been hampered and the support parent carers receive is a lottery, based not only on the borough or county in which they live, but also on their own level of education and social capital and which professionals they meet as they navigate their way through the system. The report goes on to say:

> *In some cases, parental empowerment has not happened. Children and parents are not 'in the know' and for some the law may not even appear to exist. Parents currently need a combination of special knowledge and social capital to navigate the system, and even then are left exhausted by the experience. Those without significant personal or social capital therefore face significant disadvantage. For some, Parliament might as well not have bothered to legislate.*[10]

The challenges wrought by the SEND implementation reforms underline that it is critical for professionals and parents to work in full partnership, otherwise there is little hope of achieving true change It also highlights how essential it is for each local authority to have an effective parent carer forum to ensure that the views of the wider community can be gathered in a structured, meaningful way and that voices of the wider SEND community are heard by commissioners and service providers. This is particularly vital for families who are at a disadvantage because of language, cultural, social or geographical barriers, whose views may not otherwise be heard. These are essential ingredients in ensuring that the services in the area meet the requirements of the population so that every child and young person with SEND and their wider families get the support they need to have the best possible outcomes.

The local picture

Haringey, is a north London borough covering an area of 29.6 square kilometres (11.4 square miles)[11]. In 2018, its estimated population was 284, 288.[11] It is a highly diverse borough – according to the local authority's November 2019 report, *Haringey at a glance: state of the borough.*[12] 38 per cent of residents are from Black, Asian and Minority Ethnic groups, 26 per cent of people identify as 'white, other' and more than 180 languages are spoken. In the borough, 30 per cent of the population do not speak English as their main language, the sixth highest percentage in the capital. Of those whose main language is not English, 24 per cent do not speak English well, or do not speak it at all, which is the third highest proportion across London.

Language barriers will present significant challenges for the successful engagement of parent carers across the borough, as difficulties accessing and understanding information, particularly if key information is not translated into the most common languages, is likely to mean that families are reliant upon others in their community to share information or translate it for them.

Deprivation is another key factor which can be a barrier to participation and this is a significant issue in Haringey. Despite having extremely affluent areas in the west, it is still the fourth most deprived borough in the capital. It also has a larger number of employment benefits' claimants than the London average and the second highest proportion of residents whose earnings are below the London Living Wage[12].These factors will also influence parent carers' ability to participate, as they may not have the time or resources to devote to this when daily living is a challenge. Therefore, engagement opportunities must be carefully planned to ensure they meet the needs of the local community and are culturally appropriate as well as being socially accessible to all.

According to the Department for Education's annual *National Statistics on Special Needs in England for 2019*[13], there are 42,402 children and young people in education in the borough. Of these, 6,397 children, or 15.1 per cent of the total number on the roll have had Special Educational Needs identified, slightly above the average of 14.9 per cent for England. 3.1 per cent of these children have an Education Health and Care (EHC) Plan, while 12.0 per cent receive SEN Support, with the

average in England being slightly lower at 11.9 per cent, see table 1. It is important to note that although the number of *children* in education with SEND can be used as an indicator of levels of SEND, it is not a precise figure for the number of *families* that need support because some families have more than one child with SEND. Others will have children who are not of educational age, or have yet to have their SEND officially identified, and are therefore not counted in this data.

	Total pupils	Pupils EHC Plans		Pupils on SEN Support		Total pupils with SEN	
	Number	Number	%	Number	%	Number	%
Haringey	42,402	1,314	3.1	5,083	12.0	6,397	15.1
Inner London	522,834	17,382	3.3	65,238	12.8	82, 620	15.8
England	8,819,289	271,165	3.1	1,047,163	11.9	1,318,328	14.9

Table 1: DfE, Special Needs in England, January 2019[13]

According to the Department for Education's report, *Statements of SEN and EHC Plans: England, 2019*[14], in Haringey, between 2015 and 2018, the percentage of new EHC Plans completed within the statutory 20 week time frame was consistently lower than the average for both London and England. When compared with the six surrounding boroughs – with the exception of Enfield in 2017 and 2018 – it had the lowest percentages of plans delivered on time, see table 2, below.

The most recent figures for 2019[15] show a significant improvement on previous years, with 70.1 per cent of new EHC Plans delivered within the statutory time frame, as opposed to 25.8 per cent in 2018.

New EHC Plans issued within 20 weeks by local authority (including exception cases)

	2015		2016		2017		2018		2019+	
	No.	%	No.	%	No.	%	No.	%	No.	%
Barnet	128	25.0	288	42.4	253	90.9	277	91.0	301	93.0
Camden	114	68.4	152	50.0	139	56.1	165	62.4	131	93.1
Enfield	122	45.1	234	32.5	339	11.2	363	3.6	659	47.2
Hackney	130	70.0	241	30.3	263	34.2	229	42.4	449	40.3
Haringey	88	8.0	155	9.0	185	22.7	240	25.8	345	70.1
Islington	31	48.4	130	40.0	193	41.5	185	69.7	157	75.8
Waltham Forest	193	93.8	283	30.0	339	41.3	308	70.5	265	47.5
London	4,583	64.2	6,066	52.7	7,170	52.4	8,348	54.6	8,967	60.2
England	24,216	55.0	36,109	55.7	41,250	61.3	48,543	58.0	53,327	58.7

Table 2: DfE, Statements of SEN and EHC Plans: England, 2019[14]
+DfE, Education, Health and Care Plans (reporting year 2020)[15]

Good information, advice and support is essential for building confidence and parental trust (see figure 8, page 46). Research commissioned by the Department for Education has also shown that parent carers are more likely to be positive about their involvement with the local authority if the 20 week statutory guideline is met:

> *Where the 20-week... deadline was met, it was more common to rate involvement in the process as very easy/easy; and views on specific aspects of the process (e.g. communication during the process, the amount of time and work involved) were more favourable ...parents and young people were more likely to report that staff involved had been knowledgeable about the process; that different services had worked together to make the EHC plan; and that it had been very easy/easy to agree on the EHC plan content. Within this group there also tended to be more positive perceptions of both the outcomes already achieved; and the likelihood of future outcomes being achieved.*[16]

The above quote, taken from a research report commissioned in 2017, outlines some of the ingredients that are key to successful participation– namely good communication, ease of process, knowledge of staff and joint working as being important for parental experiences and them feeling that they've had a successful outcome from the EHC assessment process. Getting participation right on an individual level by ensuring that parent carers are at the centre of processes and feel that their views are valued and listened to sets the tone for future involvement and also the perceived levels of trust families have in a local authority. This can only happen if participation is embedded in day to day systems and teams so that individual staff can build lasting relationships with families.

It must also be emphasised that pressure to improve the percentage of EHC Plans within the statutory time frame should not reduce the involvement of children and families or the quality and accuracy of content. Consequently, there is a need to ensure that teams are able to deliver plans of a consistent high standard and have the necessary structures, training and systems needed to facilitate this.

So whilst it seems positive that Haringey has significantly improved against the 20 week statutory time frame, this needs to be looked at alongside the quality of EHC Plans and involvement of families to ensure these are not compromised.

The lower percentages of EHC Plans completed within the statutory time frame in previous years is likely to be a reflection of the state of flux in Haringey at the point when the 2014 SEND reforms were implemented. In our interviews with professionals they described to us that in common with many local authorities there was a lack of preparedness for the enormity of the work that was needed to implement the changes demanded by the reforms. It was reported to us that the casework teams had been reorganised prior to 2014, and that the Head of SEN had retired in the summer of 2014, both of which had a negative effect on the team and its ability to deliver plans on time.

Perhaps the biggest barrier to delivering the reforms, however, has been the fact that the SEND team has moved several times between Assistant Directors' portfolios leading to an inconsistent approach and a lack of ownership and prioritisation, which have hampered Haringey's ability to deliver the systemic cultural change required. When combined with the national picture of a lack of investment from central government, this difficult landscape will have been a significant factor in implementing the reforms including embedding co-production.

Delivery of health and care

Barnet, Camden, Enfield, Haringey and Islington CCGs have come together to form the North Central London CCG, which is responsible for commissioning some health services using a mix of approaches, at borough, cross borough and NCL levels. However, responsibility for wider care services and delivery of health services still takes place at a borough level within Haringey. The majority of paediatric health services are delivered locally at the Whittington Hospital, although some families are referred to specialist centres such as Great Ormand Street Hospital (GOSH) as required.

Recently, a new Borough Partnership has been formed in Haringey, which sits under the Health and Wellbeing Board. This partnership will oversee work across adult and children's services and consists of representatives from the council, CCG, NHS partners, voluntary and community sector organisations, HealthWatch and other statutory partners. Additionally, the Director of Children's Services chairs the 'Start Well Board' and professionals told us that they feel this meeting will provide a useful space to reset priorities and to discuss avenues for co-production and reinforce borough level decision making within Haringey, which is a key focus for all teams.

We are aware that parent carers have had input in a number of health-based groups in the borough. These will be discussed in more detail later in the report, but examples given to us include: the Moving On Transitions Reference Group, which originated in the Adult Social Care team and is now chaired by Public Voice Haringey, and a task and finish group around autism provision in the borough.

Haringey Involve

Until it's decommissioning in 2019, Haringey Involve was the parent carer forum in the borough. During the time it was in receipt of DfE funding, its back office support was delivered by two organisations in the borough, firstly Markfield and latterly by MyAFK. The forum and back office organisations also received additional support from a representative from Contact, which administrates the DfE grant nationally.

Despite this support and the hard work and commitment of the parents involved, there were considerable challenges for the forum. As has been stated and will be elaborated upon further, co-production is not yet successfully embedded and there are no clear routes for effective parent participation at a strategic level.

Another key factor for the forum was its limited funding. Nationally, it is common practice for parent carer forums to receive additional funding from their local authority and CCG to top up the DfE annual grant of £15,000. However, Haringey Involve did not receive any additional funding, which significantly restricted their capacity to operate

We wanted to find out how the funding for Haringey Involve compared to other parent carer forums around the country. Contact told us that nationally, forums last year had an average of £28,959 from local authorities, and £17,500 from health. In London these figures were £14,314 and £12,500 respectively.

We also looked at the 2019 accounts for ten parent carer forums registered with the Charities Commission and found that the average income was £45,976, while the highest was £92,379. Not all forums are registered charities, but this does convey some advantages to groups, as it allows them to apply for additional funding in the form of charitable grants on top of the monies received from statutory partners.

Consequently, trying to bring together such a diverse community that already faces multiple barriers to participation with the limited funds available placed Haringey Involve at a significant disadvantage.

DfE funding for forums[+]:	£15,000
Av. Local authority funding[+]:	£28,959 (£14,314)
Av. Health authority funding[+]:	£17,500 (£12,500)
Average forum income[*]	£45,976
Highest income[*]:	£92,379
Four out of ten had income[*]:	> £50,000 p.a
Seven out of ten had income[*]:	> £25,000 p.a

+ Contact, grant monitoring information requested June 2020 (figures for London in brackets)
* 2019 accounts for ten forums registered with the Charities Commission[17]

The forum also faced difficulties in recruiting members. Although we were told that it had around 100 prior to its decommissioning, many were not active, which meant that the considerable workload fell to two or three parent carers. The difficulties in growing an active membership meant it was not possible to develop a representative steering group, and so the development of the forum's structure, governance and its ability to represent the wider community effectively was also stifled.

Without adequate financing and in the absence of a solid foundation on which to grow membership, the hard work and best efforts of the committee could not overcome these issues. There was also a lack of clarity around roles and difficulties in reaching a consensus on a forward plan, as we were told there were also differences of opinion over fundamental decisions. Ultimately, the multiple factors at play proved insurmountable. Unfortunately, there are other cases around the country where parent farer forums have or are struggling. The expectations of multiple stakeholders can be great and the pressure on parent carers significant. For a forum to succeed, it is essential it is properly supported and sustained.

In our survey, we asked parents how many were members of Haringey Involve, with 21.6 per cent saying they were, while 75 per cent said they were not and 1.9 per cent didn't know. We also asked our focus groups what they felt about the previous forum. Although many said they had not been actively involved, a couple of attendees said they felt the previous forum was 'quite political' and they said this had been 'off-putting.' There is a need to be mindful that the main function of a forum is to represent members of the SEND community, and so it should remain non-partisan if this is to be successful. However, in reality this can be challenging because SEND issues are so closely connected to local and national policy and with such a diverse group of families, all with differing opinions, it is difficult to strike a tone that will be right for everyone.

Co-Production channels in Haringey

Routes for co-production in Haringey are quite limited for parent carers at present. Until recently, parent carer input was sought at the SEND Co-production Group, which met every six weeks. Staff at the council informed us that this group feeds in to the SEND Executive, which in turn feeds in to the Health and Wellbeing Board. Senior professionals tell us that the SEND Executive is the overarching partnership group and has seats for representatives from education, health and care, as well as the voluntary and community sector but acknowledge that currently it does not have representation from parent carers. This is something that should be developed as part of its commitment to improving participation and we would suggest that seats should be allocated for two parent carer reps once the forum is up and running. We would also suggest that there needs to be clarity and understanding around the remit of its group and its partnership status.

A limited number of parent carers had some input into the Children's and Young People's Scrutiny Committee review of SEND in 2019, the purpose of which was to 'examine and review the role and the effectiveness of the current service children with Social, Emotional and Mental Health (SEMH) issues and autism receive.' The review made numerous recommendations in terms of improving SEND provision, many of which are still underway in the borough. We believe there are some other partnerships in place where parents are represented and inputting, such as the CAMHS Executive and the Transitions Reference Group, the latter of which feeds into the Joint Partnership Board for Adults and Health.

The SEND Co-production Group's meetings have paused to await the publication of our report. We are also aware that the amalgamation of the five north London CCGs and the need for local authorities and CCGs to review their committees and groups as a result of Covid-19 may result in other changes for Haringey over the coming months.

Haringey also has many voluntary organisations working in the borough, such as Markfield Community hub, which also delivers SENDIASS for the borough; Bridge Renewal Trust, which is also the Council's Voluntary Sector Strategic Partner; myAFK; Open Door, a mental health service for young people aged 12 to 25 and parents; Challenge Group, which supports families of pre-school children with SEND; and WAVE group. Additionally there are numerous parent carer support groups, which include Haringey's branch of the National Autistic Society (NAS); Mums in Mainstream; sendPACT; and Step by Step. Close working relationships and forum representation for these organisations will be key to maximising reach in the borough, ideally via the SEND Executive Board or a new Partnership Board.

Our review

Our review is based on a sample of the community but it's important to emphasise that future participation projects in Haringey will need careful planning to ensure that they are inclusive. A variety of methods and channels will need to be used to provide opportunities for all families across its diverse community to be involved.

When planning our review, we wanted to ensure we could reach a representative cross-section of parent carers whose childen come from all age groups and have different types of SEND. We wanted to speak to families who have children in mainstream education as well as those who were in specialist settings, home or further education, so that we have a representative sample of views from families whose children receive SEN Support, those who have an EHC Plan and also those who may have SEN but are still awaiting a diagnosis.

We also wanted to explore whether parent carers had the information and support they needed in order to be able to participate. This is particularly pertinent in Haringey due to the fact that 30 per cent of its residents do not speak English as a first language. We wanted to explore whether parents needed more support to participate and a greater variety of engagement options, such as time-limited pieces of work and different methods of capturing their voices to faciltate wider participation across the borough.

A 360-degree review

Participation is a two-way process that demands commitment from parent carers and professionals alike so, in order to understand the current situation in Haringey, it was essential that we sought the views of professionals from the local authority and health, as well as parent carers. We wanted to establish whether staff understood the benefits of participation, how much training they and their teams have had on parent carer engagement and to what extent co-production is embedded in their processes.

Due to the low uptake on our 'professionals' survey in our East Sussex review, we decided against sending out a survey to staff at the local authority and health in Haringey and instead opted to hold telephone interviews with professionals. Our interviews included key service managers and commissioners, whose views have added further clarity to our findings.

We also invited headteachers and SENCOs from a number of schools and senior staff at a number of key voluntary organisations to feed into our review via interview, so that we could understand some of the challenges facing the SEND community in the borough.

We have researched some recent examples of good practice at other parent carer forums around the country, as well as inviting East Sussex Parent Carer Forum, which was set up as a result of our 2017 review, to reflect on some of the challenges and successes they have faced in creating a new organisation to be the voice of parent carers in the county (see page 77).

We held five focus groups across the borough during school hours. Four of the five groups were held in schools, while the fifth was held in a community centre. We aimed to choose locations that were within easy reach of public transport for parent carers and also in walking distance of other local schools so that they were convenient for pick-up and drop-off of children.

To accommodate working parents and those whose caring roles meant they could not attend a face-to-face meeting, we held an evening online focus group on Zoom and a survey, which was open online for four weeks as well as being available in paper form (see Appendix 2).

Reach

In order to reach as many parent carers as possible for the review, it was essential for Amaze to work collaboratively with Haringey Council, local organisations and parent support groups, especially as we hoped to hear from parent carers who may not have had previous experience of participation/voice work.

We designed two flyers advertising our focus groups and survey, and drafted an introductory email, which we asked the local authority to distribute to education settings, health, social care and other organisations via their existing communication channels. It should be noted that at the time of the review the local authority had yet to establish an online social media presence, although they acknowledge that this is something they are working towards, in order to increase communication with families.

In addition to asking the local authority to circulate our email, we approached many support groups and voluntary organisations working in the borough to ask them to publicise our review. Paper copies of the flyers and the survey questions were mailed out on request. We also publicised the review via our own social media channels, tagging a variety of local and national organisations.

At the time of our review, the council was still developing a contact list of parent carers in the borough and it will be some time before it is in a position to collate the rich demographic data often recorded on a detailed disability register. Therefore we were unable to ascertain how widely our email had been distributed or identify which communities had the highest rates of SEND to target them directly. This highlights the value in developing a more extensive disability register as more sophisticated targeting could be achieved. Haringey Council is aware of the advantages of developing one and staff reported that they would like to build to build up a more comprehensive data set about SEND families.

To ensure that our focus group attendance was maximised, we approached education settings directly and also emailed children's centres, the child development clinic at the Whittington, health visitors and Portage to ensure that they shared copies of our flyers. We kept in regular contact with various support groups who publicised our review on their social media pages, websites and at face-to-face meetings they held in the borough.

Confidentiality

In order to encourage all participants to be open and candid, our review has been conducted on a confidential basis. All survey findings, focus group and webinar comments have been anonymised, along with feedback from local authority officers, service providers and support group leads.

The impact of Covid-19

Our focus groups were completed just prior to the Covid-19 lockdown, which began in mid-March. Many of the organisations involved in our review, including schools, local authorities, CCGs, and our own team, were placed in a situation where huge changes had to be implemented very quickly and therefore for a number of weeks senior staff were unavailable for interviews.

As a result, our review faced a number of delays while new measures were put in place. Some time had elapsed since the focus groups, so we felt there was a need for a check-back process with previous participants to ensure that we had captured views correctly in our report.

We invited previous participants to join us via two online sessions, where we presented a summary of our headline findings for discussion and feedback to check for accuracy and ensure that we had captured the key issues around participation. Feedback from these meetings has been immensely useful in shaping our final report and our recommendations.

Our findings

We had 63 responses to our parent carer survey (see Appendix 2), 11 of which were incomplete and have not been included in our results. The majority of respondents who completed the survey have a child with several additional needs or disabilities.

More than 96 per cent of respondents have children with SEND of school age (5 to 16 years) with 11.5 per cent having young people aged 17 to 24 years as some respondents have more than one child with SEND. We had no responses from parents of children with SEND aged four and under, which might be explained by the fact that many children's additional needs are not identified until they start school, while other parent carers who are still coming to terms with a relatively new diagnosis may feel unable to engage at such an early stage in their journey (see The Parent Carer Journey and Insider's Guide to Parent experience, Appendix 3 for reference.)

Thirty-nine families said they have children in mainstream schools (including units). In this group, 26 children have EHC Plans, while 14 receive SEN Support (as some respondents have more than one child with SEND) and two said their children were not receiving any support but that it was needed, while one parent was not sure what support was in place. We also heard from 15 families who have children at special schools or private specialist settings; three with children in alternative provision; and two who are home-educating. All of these children have current EHC Plans. Two of our respondents also had young people who had finished education.

Our focus groups were attended by 37 parent carers. They included stay-at-home and working parents, home educators and parents who have disabilities themselves, or were also the primary carer of an older person. Several of our attendees have pre-school children with SEND. Parent carers have children in a variety of placements, from mainstream to special schools and alternative provision. Several have children who are educated out of borough, while others have young people who were not of school age. One attendee had a child who was out of education, as their current setting could not meet their child's needs.

A number of parent carers we met highlighted that they are currently or were previously employed as SEND professionals in education, health or at the local authority. They shared their own experiences of the difficulties navigating the SEND system, despite their extensive knowledge and experience of it in a professional capacity.

Data gathered from diversity monitoring forms at our focus groups showed attendees ranged in age from 25 to 35 years up to 56 to 65 years. A range of ethnicities were represented, as shown below:

		Focus groups (%)	Haringey 2018 (%)*
Asian/Asian British 29.0%	Indian	3.2%	2.2
	Pakistani	0%	0.7
	Bangladeshi	9.7%	1.5
	Chinese	3.2%	1.7
	other Asian	12.9%	3.3
Black/Black British 19.4%	Caribbean	9.7%	5.8
	African	6.5%	8.2
	other black	3.2%	2.6
Arab		-	0.9
Mixed 9.7%	White and Black Caribbean	6.5%	1.7
	White and Black African	0%	1
	White and Asian	0%	1.5
	other mixed	3.2%	2.3
White 41.9%	British	22.6%	33.6
	Irish	3.2%	2.8
	Traveller (Irish Heritage)	0%	25.9
	Gypsy/Roma	0%	
	Any other white background	16.1%	

Table 3 Source: *London DataStore: London Area Profiles[18]

How involved do parents feel?

The Department for Education's *Tenth Special Educational Needs and Disability (SEND) Reforms Implementation Survey for Parent Carer Forums*[19] asked parent carer forums across England how well engaged they felt parents were in strategic planning and co-production. They said:

69% of forums agree that parents are either largely or fully engaged in strategic planning with their local authority[19].

In our survey, Haringey parent carers indicated that they did not feel as involved in the planning, shaping and evaluating of services for their child(ren). As the pie chart (see figure 4) shows, just 3.8 per cent of respondents said they felt 'very involved', while 32.7 per cent said they felt slightly involved, and 63.5 per cent said that they were 'not at all involved'.

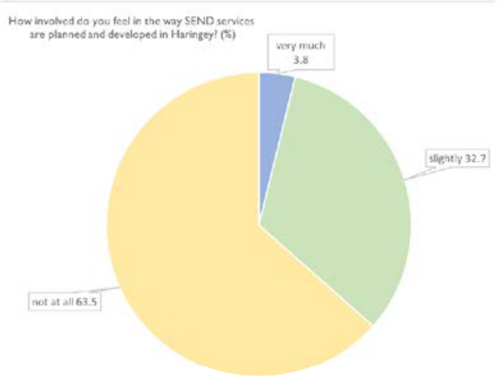

Figure 4: Amaze survey of parent carers in Haringey, March 2020 – how involved do you feel?

The fact that the majority (96.2 per cent) of parent carers say they are only slightly involved or not at all involved at present is no doubt partly the result of the current absence of a parent carer forum but also due to the other challenges facing the borough. These will be explored in depth later in the report.

For the sake of balance, we also asked parent carers to share positive experiences. Feedback in our focus group showed that without exception, parent carers had faced enormous challenges while navigating the system. However, some parents were able to share examples of empathetic professionals who took a person-centred approach when engaging with their family.

What makes a good experience?

Although we were given only a limited number of examples at a strategic level due to the ad hoc nature of engagement opportunities and the absence of an effective parent carer forum, parent carers did share some positive experiences they'd had.

'There's a massive difference in the way that adult services behave with us and the way they communicate. They're still not there yet but you see they're willing, which is half the battle.'

– focus group comment

A number of professionals and parents involved at a strategic level referred to the Transitions Reference Group which feeds into the Joint Partnership Board. This board is attended by senior officers but chaired by users and voluntary sector representatives, and administered by Public Voice Haringey. The Transitions Group evolved as staff wanted to devise a pathway for families moving on to post-18 SEND services, but, in order for this to be successful they knew that they needed to embed co-production in the process. Therefore, they invited stakeholders, set up terms of reference (ToR) for the group, as well as a code of conduct and listened to what the community wanted. This was not a smooth process and staff told us that there was a need for reflection, researching best practice in other boroughs and taking on board feedback throughout. However, their willingess to listen to parent carers and take an open-minded approach to the project allowed progress to be made and we feel that it is important that the council learns from this example and the way in which parent carers were approached to inform practice in other teams across the council as both parents and professionals reported that they would like to develop a similar format for children's services.

On an individual level the positive experiences parent carers reported are the exception rather than the norm, and so they must be viewed in the wider context of the current situation in the borough, which is very challenging for families. The examples of good practice we did hear about mainly came from health services and education settings, with the experiences parents have driven by the empathy and skill set of the professionals they work with.

Real participation feels like a partnership where you are listened to and respected, with good communication and expertise

–focus group comment

Good practice needs to become the norm rather than the current examples which sit in isolation in an otherwise difficult landscape.

When asked to give us positive examples

of participation, carers said:

Markfield do a lot, but they are so overstretched.

[school refusal] I was totally part of the plan. [Special school] worked out who [child] was and understood my views. Focused on [their] needs and recognised my expertise.

[What made a difference] was having the decision-maker in the room and an effective support plan from a third agency who personally knew my child and were on board

School teachers are complete heroes... they communicate well; come up with strategies to help with specific issues... tell us what they're doing.... [They] treat my son as an individual.

Smooth transition to another primary school in the borough

A member of Haringey SEN team came to our home to ask us questions about [child's] EHCP... it was a one-off and it's not happened since. That was amazing!

Paediatrician gave us a longer [diagnosis] appointment, brought in support to play with my child, listened to us as parents, accepted a private report, contacted school and explained situation, which changed their views.

School teachers: treat my [child] as an individual who is a valuable member of the class. They work with me and my [partner].

OT was amazing – very committed and even offered to train the school in Lego therapy.

School SENCO listened to me, engaged my child and made sure provision happened.

Whittington hospital's asthma team know [child's] needs and call in a community nurse who supports visits so I can focus. We're treated with the upmost care, it's like they're my family... I know the nurses. I feel like a person. They ask after my children.

Being listened to, feel my input is valuable. They ask questions: 'How do you do this at home?' to learn from me. They've tried everything I've suggested and are open to trying things, which feels very important.

The message from parents at our focus groups was unequivocal. They have good experiences when they and their children are listened to, when they feel like they play an equal and active role in processes and decisions and when their knowledge and expertise around their child is respected by professionals and used in order to ensure there is a person-centred outcome for their child.

Parents said that good practice happens when professionals follow up on their concerns in a timely manner. They want professionals to be understanding, committed and patient when dealing with them. Most of all, they want a two-way dialogue. A number of parent carers told us that what matters most is how things are dealt with. If they know that the professional is trying their best for the family and that they are honest and prompt in communications this can go a long way to help families deal with delays and bad news. This is why it is so important that professionals understand the parent carer journey (see appendix 3) and meet with SEND families so they can gain insight into the challenges of being a parent carer and ensure that they have a compassionate, person-centred approach to their role.

Professionals also shared what they felt were positive developments in the borough,such as the Huddle, a group that runs at the Pembury Children and Family Centre to support families whose children with SEND may not be ready for nursery. The Huddle allows small groups of parent carers who may be isolated for language or cultural reasons to meet others in a similar situation so that they have peer support. This can be a real issue for SEND families in Haringey. A professional related that a parent had described immense barriers in their journey, as their language does not have a word to describe their child's condition. Therefore, it was incredibly difficult to open a dialogue with family and friends, but they had met other families in a similar situation via the Huddle. Once the new forum is established, it will be essential for professionals and parent reps to ensure that families attending such intiatives can connect to the parent carer forum. This will ensure that parent carers who may be isolated can feed in their views so the forum is truly representative of everyone in the borough and that their families can have further support from the SEND community at an early stage in their journey.

Despite these positive examples, they were outweighed in our focus groups by the negative and challenging experiences of parent carers. One attendee neatly summed up the views of those in our focus groups, saying Haringey had 'an avalanche of things to address' before consistent joint working will be possible between parent carers and professionals in the borough.

Challenges faced by parent carers

Although our attendees were a diverse selection of parent carers from across the borough, they shared many of the same concerns when it came to engagement and participation, as shown in figure 5, below, which summarises the headline themes from our findings:

Figure 5: summary of participation challenges for Haringey parent carers (on an individual and and a straregic level)

1. Structures and processes

> *'Parents struggle to navigate the system. We don't know who to speak to.'*
> *– focus group comment*

Parent carers spoke of the difficulties they had in identifying clear routes through the SEND system, and that it was a slow and exhausting process, due to the lack of joined up thinking within and across services.

Many referred to the fact that they were often passed from person to person in teams and also from service to service, meaning that they had to share their child's history again and again, instead of being able to 'tell it once'. They also highlighted delays and bureaucratic red tape, which placed them under extra strain due to the additional admin involved in chasing teams and the huge volumes of paperwork involved.

Many of our attendess found the transition from Statement of SEN to EHCP fraught with difficulties and said they felt the process had not been person-centred as there was no consultation with the family. Others highlighted the delays and slow admin as being a cause for concern, with four parents across two focus groups saying that they had waited three years for EHC Plans to be updated, while a further two parents said that their draft plan had been lost by the SEND team, which concerned them due to the sensitive nature of the content. Another parent carer said it had taken seven years to secure an EHC Plan for their child.

Parents also expressed exasperation as they felt their caseworkers were not proactive in communicating and updating them. They said they felt it was difficult to open a dialogue as they found their phone calls and emails did not elicit a quick response while other parents present said they did not receive any reply.

Our attendees also felt there was a lack of transparency around SEND processes, and many felt that it would be extremely helpful to have flow diagrams to help them to understand the steps so they could join the dots and understand what should happen and when. It is posittive to hear that recently the SEND team has consulted with parent carers to produce new parent guides around the EHC process and annual reviews and hope that these will bring clarity for parents who are new to the system – it is important to flag that this should be an ongoing participation process so that the team can gather parent feedback on the guides and implement changes where necessary to ensure that they are meeting the needs of families.

Parent carers felt that there was a lack of consistency across services and also within them, as parents with more than one child in the SEND system had variable experiences depending on which member of staff handled their children's cases.

> *'This panel. Who are the panel? Who are these people? Where do they sit? These people all discuss our children but we don't know them. [They] are reading files on my children that I haven't even accessed.'*
>
> *– focus group comment*

At every focus group, the majority of parents said they were uncomfortable with the lack of transparency around the panel process for EHC assessments, largely because they did not know which professionals sit on the panel and they were not allowed to attend to represent themselves or their child.

Almost a quarter of parents at our groups told us that they were extremely concerned because they did not have access to the files that went to panel, and three flagged that they had later found out the information that professionals had sent to panel was out of date or innaccurate. Attendees were unanimous in their feeling that the panel and its processes must be demystified for the community and that they would be keen for parent voice to be represented at the meetings.

Inclusion of parent carers on decision-making panels is often a concern for local authorities, due to the sensitive nature of the information and the need to ensure that confidentiality is maintained for the children and families being discussed, particularly as there is a risk that the family may be known to a parent forum rep.

However, once a new parent carer forum is well-established in Haringey and has the necessary robust policies and procedures in place and parent reps have a proven track record in maintaining confidentiality, it would be a very positive step for the local authority to trial panel representation with the forum to show there is buy-in at a senior level and a commitment to transparency and partnership working with the SEND community.

In Brighton & Hove, parent carers are succesfully represented at the panel by members of the parent carer forum, B&HPaCC. Forum reps abide by the robust policies and procedures that are in place, developed jointly with Amaze. As reps are employed via Amaze they are also covered by the charity's policies.

If the local authority remains hesitant due to the issues outlined above, they could look at an innovative reciprocal arrangement with another borough so that parent reps from Haringey go to panel meetings at another borough and vice versa.

> *'At the transport event they talked AT us and eventually I couldn't listen anymore… that's the difference today – you lot are listening to us.'*
>
> *– focus group comment*

In addition to the need for processes to be clearer, parent carers said they felt that there was a lack of structure or follow up to participation opportunities. The recent SEND transport consultation (held 5th February 2020 and attended by approx. 100 parent carers) was raised as an example at every focus group. Parent carers expressed disappointment and frustration because they felt that a month had passed without an update so the consultation had been tokenistic and their time had been wasted. Unfortunately, the lack of prompt follow up explaining the next steps to parent carers led to many concluding that the transport consultation was nothing more than a tick box exercise and that there would be no tangible outcomes from it, which might discourage engagment in future participation opportunities.

Subsequently, the local authority confirmed to us that a report had been commissioned but parents were unaware of this. In our interviews some professionals told us that there is a tendency in the local authority to avoid communication with parents until all matters could be addressed in full. They acknowledged more flexibility was needed in situations like the transport consultation. Tasks could be divided into 'quick wins' and those that need more work. Giving families immediate updates on the former and progress updates on the latter would help families to feel that their input is valued and effective, as they have waited several months to hear back, but we understand from senior leadership that the report has now been published. On a strategic level, we are aware that parent carer input has effected change as the council had planned to bring in external consultants to aid in the redesign of the home to school transport service, but parent carers came together to challenge this decision and this plan has now been shelved.

Developing their existing parent contacts into a comprehensive disability register and establishing a social media presence would enable the local authority to improve its reach. Prompt communication and regular progress updates build trust and show parent carers that their voices are being heard, both of which are key ingredients to effective participation.

Parents indicated that at times some local authority staff seemed unclear about what constituted participation and how it should be embedded fully in all processes and that sometimes professionals regarded a chat with parents they had selected as being a consultation. Many of the parent carers we spoke to knew how successful participation should happen, even if they had not been involved at a strategic level themselves. They understood that true participation involved parent representatives bringing the views of the wider community to the table in a planned and structured way from the beginning of a project, so this schism between expectation and reality has also contributed to their frustration and disappointment.

We were given an example where boundaries around consultation were blurred because some staff had filled in a parent carer survey from a professional perspective, with one saying it had been done 'for balance.' It is important that professionals buy in to the benefits of seeking feedback and other engagement activity and don't see it as threatening. This underlines the importance of framing consultations at the start so that everyone understands and respects the purpose of the exercise.

In our interviews with professionals, we established that the local authority has yet to implement training on co-production and participation and this no doubt is a significant factor in the examples mentioned above. Staff need to have a solid understanding of the principles of co-production to ensure they can implement them on a day to day basis, which requires management to ensure structures and processes are developed to fully embed participation across their teams. Both require buy-in from senior leadership so participation is prioritised and training is provided for all staff across services. We understand from our interviews with the local authority, management know this needs to be an urgent priority once the new parent carer forum is in place and able to play an active role in this work. Organisations offering suitable co-production training for professionals include Contact, the Social Care Institute for Excellence and the New Economics Foundation Consulting.

2. Communication issues

In our focus groups, parents said communication with education settings was mixed, with some families having excellent experiences while others said it had been variable depending on the culture of the establishment, and the attitudes of individual members of staff, particularly SENCOs. Some families said the only information they received came from their child's school and the Markfield Community hub, while others mentioned that the good communication and information they had had at primary school had fallen away when their child transitioned to a secondary setting.

When considering the local authority and health, multiple communication difficulties were highlighted. Many parents said they struggled to open a dialogue, having problems reaching professionals as phone calls or emails were often unanswered, which led them to feel that communication was one-way and that staff were dismissive and discourteous by not responding to them. Two attendees said that they had experienced staff hanging up on them mid-call.

Attendees across our focus groups felt professionals did not listen to them and that there was a lack of honesty and clarity in communications, particularly with the local authority. They said they felt that staff often talked at them, rather than wanting a two-way dialogue and several made reference to the SEND transport consultation as being an example where they felt this had been the case.

One attendee said that it had been so difficult to get the local authority to engage that the family had resorted to contacting the media in order to get a response. Another highlighted the difficulty of getting the Speech and Language Therapy team to engage with them and, although professionals from two other teams had insisted support was needed for their child, the family was unable to make any headway in opening a dialogue with the team.

Some parents at our focus groups said that, when they managed to speak to local authority staff, they often felt they were abrupt or rude, or made them feel bad for troubling them stating that they were very busy or short-staffed. Several parents also expressed frustration at the lack of a joined up approach, which meant that communication between teams was often slow and disorganised. In all our focus groups, the home to school transport team was highlighted as being particularly problematic in terms of the way parent carers were spoken to, and in one egregious example a parent carer said that a member of the team had responded by saying, 'You're wasting my time. What do you want me to do about it? You're lucky you're getting transport.'

> *'They say, "I can't deal this now, do you realise how busy/how short-staffed and underfunded we are?"'*
>
> *– focus group comment*

While this is just one example, its seriousness means it should not be dismissed, as it would be unacceptable in any client-facing role and this needs to be addressed as a matter of urgency to ensure that parent carers' queries are dealt with professionally and appropriately by all staff. We would suggest that as part of staff inductions new recruits receive training in the parent carer journey. When we mooted this suggestion in our check-back with parents and professionals, a parent carer suggested that some families could record video clips, to use alongside face-to-face talks by parent carers. We feel this would be extremely beneficial as it would also allow families who cannot commit to attending training in person to share their experiences with officers and foster a greater understanding of the challenges families experience.

During our telephone interviews, one local authority employee shed some possible light on the lack of responses some parent carers mentioned. They said that if they had already addressed the parent's query with their colleagues, they felt they did not need to go back to the family, as the matter was closed. But, from the parent's perspective, they would have no idea if their email had been read or acted upon, so it is unsurprising that this disconnect leaves parents feeling angry and frustrated.

Another local authority professional we spoke to in a different team had a good understanding of the need to build relationships with parent carers, and the importance of good communication. They knew that they needed to open a dialogue over the telephone so they could understand the family, their circumstances and level of support required. They said they had developed their own systems to deal with their workload, but felt that more structure was needed so staff had the necessary tools to be able to deescalate situations with good communication rather than shutting conversations down, which 'raised tensions and resulted in an adversarial atmosphere.'

It is difficult to ascertain from a handful of examples whether communication difficulties are a result of heavy workloads or a lack of training, but we suggest there is a need for this to be explored further and addressed by management within the local authority to ensure that parent carers receive courteous and timely responses from all staff in all departments in Haringey. This will help to rebuild parental trust in the authority, which in turn will encourage parent carers to participate.

In order to increase parental engagement there is a need to improve communication so parent carers are informed of consultations as many parents told us that they were often unaware of engagement opportunities. Currently families depend on voluntary organisations, their schools or fellow parent carers to spread the word.

In one of our focus groups a parent mentioned a consultation for families of children with Autism and ADHD that was happening the following week. They had heard about it via a charity but others present who had children with autism and ADHD had not, despite the significance of the consultation as it would feed in to a new model that Resources for Autism hoped to roll out across five London boroughs. These parents were exasperated by this scattergun approach to communication, as it meant they had missed out on the chance to feed in to the process. Again, development of a detailed disability register would be advantageous for future consultations, as it would allow for targeted communications with families.

Naturally, once a parent carer forum is established in the borough they will be able to develop communication channels with the SEND community to ensure that participation opportunities reach families whose children will be affected by changes to services. However, to maximise the reach of the forum there is a need to utilise as many communication channels as possible. A disability register would allow the local authority and forum to take a targeted approach towards planning participation opportunities to ensure that they are truly representative of the Haringey SEND community. Undoubtedly social media presences for the local authority and forum will also be an essential part of maximising their reach.

Both the forum and professionals will also need take an innovative approach in engaging parent carers to give families greater flexibility in sharing their views in a way that suits their circumstances. This will entail using a variety of methods such as online polls via social media, surveys and webinars, plus face to face opportunities such as focus groups with interpreters if required. It will also involve developing relationships with community leaders and elders so that families can participate in ways that are culturally appropriate.

At a strategic level, participation in Haringey has mostly been face to face, but the recent Covid-19 lockdown has shown many organisations that it is possible for digital methods to be used, which could be an additional avenue for parent carers who cannot travel to a meeting because of their caring responsibilities, to feed in online via Zoom or Microsoft Teams. It is essential that these avenues do not replace face to face participation and alternative methods of consultation, due to the risk of digital exclusion for some families. Likewise, there is a need to offer evening sessions so that working families can also share their views.

3. Lack of information

A number of attendees across our groups said they had to rely on schools and voluntary organisations such as the Markfield Community Hub to share information. In our survey, we asked parents which organisations they would turn to for information and signposting, asking them to check all options, shown in figure 6:

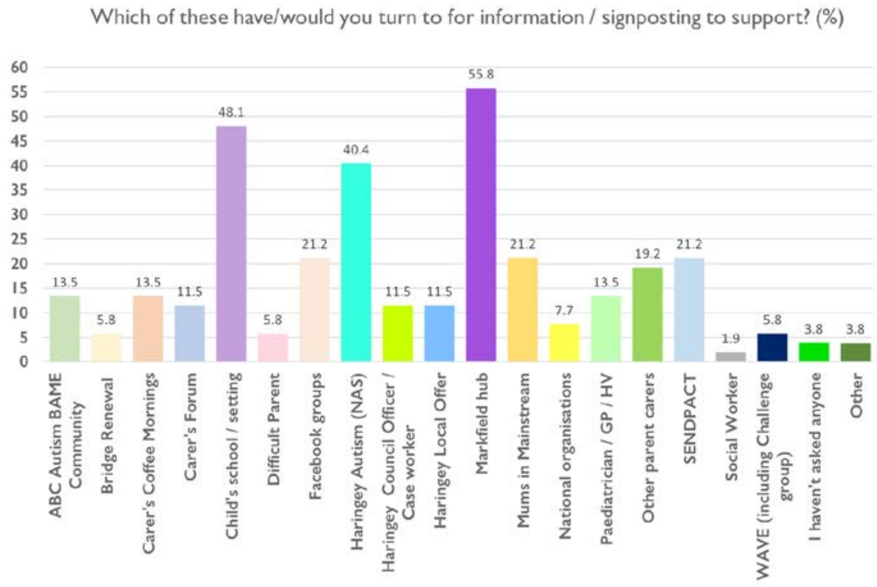

Figure 6: Amaze survey of Haringey parent carers, March 2020 – where do you turn for information/sign-posting?

55.8 per cent of respondents would use Markfield, while 48.1 per cent would use their child's education setting. Parents would also turn to local support groups, Facebook groups or other parent carers.

Fewer would seek support from professionals,– 11.5 per cent would speak to a local authority officer, or use the Local Offer; 13.5 per cent to a paediatrician, GP or health visitor, while 1.9% would talk to a social worker. This may be explained in part by the challenges parents described in reaching professionals and opening a dialogue with them. They may also be reluctant to use professional channels, as parents at every focus group said they felt that the information that they do receive from them often contains complicated and anachronistic language that is difficult to absorb.

We were interested in the fact that just 11.5 per cent of respondents would use the Local Offer for information and signposting. In May 2020, Markfield SENDIASS also conducted a survey[20] of parent carers. They found that 53 per cent of respondents were unaware of the Local Offer, while a further 22 per cent were aware of it, but had not found it useful. Respondents were asked what they felt about the website and highlighted that some links led to dead ends, while another comment highlighted that parent carers had to find the information themselves, which was reliant on them being aware of it in the first place.

In our survey, parents said that due to the multiple demands on their time, they would prefer websites and flyers to be simplified so the information was quickly accessible. This sentiment was echoed in the Markfield SENDIASS survey, in which parents said they would like information via email, text, Whats App, post and social media.

A number of attendees were concerned about information barriers for the many families in Haringey who have English as a second language or do not speak it at all. Several at different groups said they had helped others in their community with information from professionals, as often it is not translated. Given the complex nature of SEND information and where Haringey is in terms of implementing SEND reforms, it is not surprising that this has come up as a challenge. in the borough.

Parents said that the families they helped in the most vulnerable minority groups were unaware of the help and support on offer, or that they should have a voice. Likewise, they were concerned about the challenges faced by parent carers who have additional needs in accessing information and support. Attendees felt that these problems must be addressed to ensure that all parent carers could access support and have their voices represented at a strategic level.

The development of a detailed disability register would allow the local authority and health to address this with a targeted approach to information and translation needs for families in Haringey, as well as supplying easy read formats for parents and young people to access, if required. It would also allow for targeted translation of key information for SENDIASS and the Local Offer, to help vulnerable minority groups access information and support.

In our survey, we asked parent carers to tell us about their information needs:

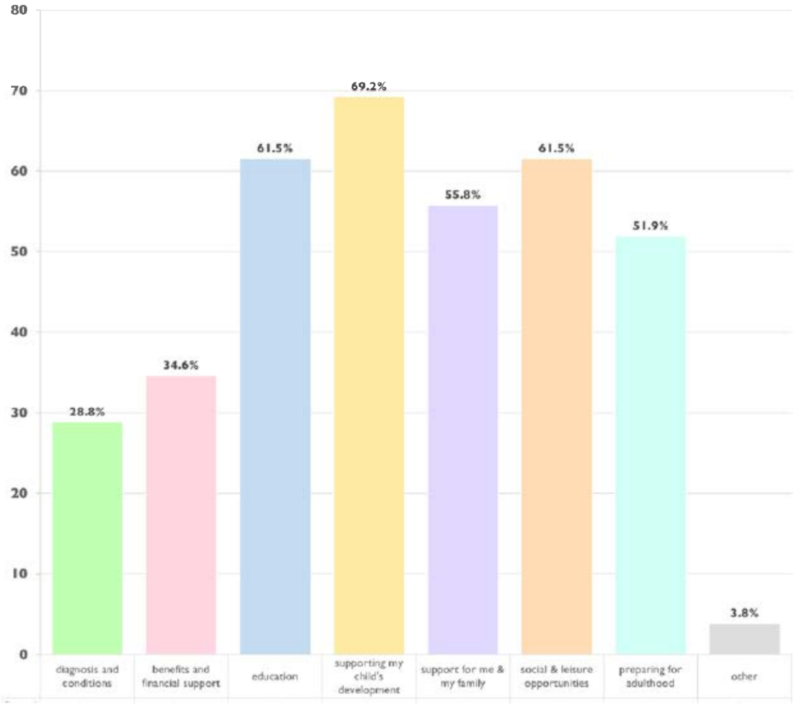

Figure 7: Amaze survey of Haringey parent carers, March 2020 – for which SEND topics would you like more/better information?

As figure 7 shows, many of the families polled wanted more information on SEND topics, with almost 70 per cent of families needing more about supporting their child's development, followed by education; social and leisure opportunities (61.5 per cent respectively) and support for families (55.8 per cent.) Over half of our respondents (51.9 per cent) wanted information about preparing for adulthood, while around a third wanted information about benefits and financial support (34.6 per cent) and diagnosis/conditions (28.8 per cent). A further 3.8 per cent of respondents asked for information about mental health and navigating the SEND system.

Good quality information, advice and support at an early stage in the parent carer journey is essential for parent carers, as it promotes a positive cycle which builds confidence and parental trust, see figure 8, below.

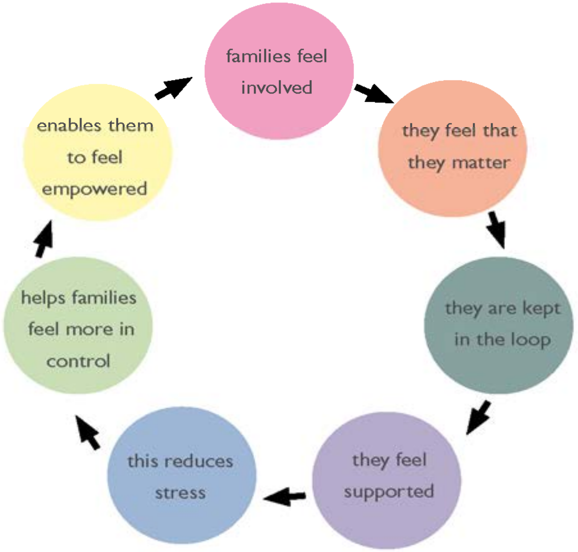

Figure 8: Cycle of how good information makes a difference to parent carers[21]

Haringey parent carers spoke very positively about their local SENDIAS service, which is delivered by Markfield. However, they also said that the organisation was under huge pressure due to the overwhelming demand for the service, so we would suggest that the local authority needs to consider the budget envelope for SENDIASS and whether it is adequately resourced and jointly commisisoned across the LA and CCG to ensure that all Haringey families can access the good quality information, advice and support that Markfield provides.

It will be critical for the new parent carer forum to be able to work in partnership with the current SENDIAS service and the local authority to improve information delivery, as this is an essential ingredient for improving participation.

Markfield already hosts training workshops for parent carers, which could be co-produced and co-delivered with parents from the forum along with developing programmes of peer to peer support for parent carers. With more funding, Markfield could also look at the possibility of developing bite-sized fact sheets in a similar vein to the ones that Amaze has published. They cover more than forty topics, from disabilities and conditions, to support around benefits, behaviour and education and sign-posting for families to local and national organisations. It would also be beneficial if additional local authority funding can be found to expand casework capacity to meet the overwhelming demand for support in the borough.

4. Culture, practice and training

In our focus groups, many parents said they felt the current professional culture is a barrier to participation, due to the power imbalance and lack of trust between families and professionals. Parents tended to feel that their involvement was something of an after-thought, and said that the behaviour and language used by professionals made a huge difference as to whether they had a positive or a negative experience.

> *'[the local authority] are suspicious of parents, they think you are asking too much and that you're not reasonable, that you don't know what your child truly needs, how can you because you're not a professional?'*
>
> *– focus group comment*

Parents were concerned that for some professionals there was a culture of suspicion towards them and a tendency to

'The local authority is meant to come to the North London Adoption Consortium, but never attend... they don't have a mindset of joint working

– focus group comment

'divide and rule' rather than encouraging a cohesive approach in the borough. One parent went as far as asserting that for them the relationship with the local authority has broken down.

Some parents said they were concerned about consistency of practice in the borough. Almost all parent carers at our focus groups agreed that their experiences with professionals were variable and inconsistent, with one parent sharing an example where staff were dismissive when contacted.

The parent had spoken to school transport as they were concerned about excessive journey times for their child who is a young primary pupil. The parent reported staff had told them it 'did not matter' how long the school journey took, only that the child was taken to school. Although the parent carer was unaware of the statutory guidance around transport, the local authority officer would have been aware from their training in relevant legislation that for primary aged children there is a recommended maximum journey time of 45 minutes and should have listened to the parent carer's concerns and acted on them.

In our interviews with professionals, several felt that there is a defensive atmosphere in the local authority, which may be in part due to the impact of high-profile cases and the coverage they received in the media. To move forward in the borough, there seems to be a need for a cultural shift so that staff are compassionate and respectful in their dealings with families and that they have the confidence to deal with issues via open, honest dialogue.

Similarly, parent carers said they felt there was a 'blame culture' with some professionals being quick to assume that issues for children were down to poor parenting rather than undiagnosed additional needs. Often, parents said they had to jump through many hoops in order to get support for their children, which could take many months, or years in some cases.

Many parents told us that the traditional unequal relationship between parent and professional, with the latter the default decision-maker, is still common despite aims of the SEND reforms to place parent carers at the heart of processes, alongside their children, as the experts in their care. Even so, some professionals still view parents as 'just a mum or dad'. This is often perpetuated by them addressing them by these titles rather than by name, which reinforces the power imbalance.

Parent carers at our focus groups also pointed out that many of them are also professionals working in teaching, finance or health, who have a great deal of expereince in senior level meetings and organisational processes. However, when it comes to the SEND system, some said their knowledge and skills are often dismissed and their suggestions do not carry the same weight. In one example that was shared with us a parent carer with a professional background in health was asked to attend a parenting course as part of a diagnostic pathway for a different condition to the one she suspected her child had. Even so, the parent was placed in the seemingly absurd situation where they had to attend a twelve-week course with facilitators that they had trained in order to move the diagnostic process forward. This lack of flexibility and refusal to acknowledge a parent's own expertise achieved nothing except for delaying the diagnosis and relevant support for the child.

'We cant support our children and do our jobs, because of the frustrations on a personal and professional level.'

– focus group comment from a parent / SEND professional

Understandably, these examples of the focus on parenting and some professionals' dismissive attitudes is exasperating for all parent carers. In three out of five focus groups we heard from parents who were also professionals working in the SEND system in a range of roles. They highlighted that the strain of fighting for support for their own child meant that they were less resilient professionally and some feared that they would eventually 'burn out' due to the stress of their personal circumstances.

Social care in Haringey has recently been in the spotlight due to a case which was heard in the family courts. Reporting restrictions on the case were lifted by Justice Hayden, who highlighted 'root and branch failure' of social work in safeguarding two children, one of whom is profoundly disabled. He added that, 'The social work failures are, in isolation, concerning. Cumulatively, they are profoundly troubling. They signal, to my mind, a need for significant retraining.[22]'

Haringey's Director of Children's Services reported that they have been working hard to improve the social care team as a result of this case, the recommendations made by Ofsted in Inspection of Children's Services in 2018[23], and their focused visit in late December 2019[24]. In their revisit, Ofsted said, 'Leaders are tackling staff competence issues and helping social workers and their managers develop the requisite skills to take forward essential improvements more quickly. They are establishing strong foundations to ensure that the children supported across all teams consistently benefit from services'

'The amount of times I've done these [RAS] forms and been told 'there's children more severe than your child!' It makes you feel like you are begging for basic things.'
– focus group comment

However, in our focus groups we heard several examples that highlighted ongoing difficulties with social care for families of disabled children. Parents shared examples of huge challenges in acccessing support from social care. Many parents reported that the thresholds were extremely high. One of our focus group attendees had no previous involvement in strategic level participation but felt compelled to come along to our review as they were desperate to make their voice heard in relation to their difficulties in accessing social care. The parent told us they have a severely disabled child with multiple complex needs and have been struggling to access support for their child since birth. A decade later they were still trying to get the support, respite care and equipment that they and their child needed, which was having a significant impact on the whole family.

Another parent carer at our focus groups reported being repeatedly refused a social worker as 'the child was not at risk'. This raises questions of whether parent carers are using the correct route to access support for their disabled child via the children's disability team and whether there is more to do in achieving a shared understanding and transparency around eligibility thresholds.

The above examples from our focus groups suggest there may be some work to be done in the borough to ensure that all families with disabled children receive the support they need.

5. Staff and services

Many parent carers acknowledged that many professionals worked very hard to help families access the support they needed, but also said they experienced many changes in staff, which made it hard to build effective working relationships and access the right services for their children.

Some parent carers at our focus groups reported that speech therapists 'were hired at band 5 and trained up to band 6 or 7, when they would leave.' Two parents said that their children had missed part of a six week therapy block because staff were out training. Parents also flagged that other neighbouring boroughs paid inner London weighting, which they felt placed Haringey at a disavantage in terms of retaining and attracting higher band staff. There was a perception amongst parents in the focus group that there was a 'constant cycle of Haringey losing their most experienced therapists' when the band 5 staff qualified then left the area.

'Most of our [speech] therapists are part-time and the problem is we lose the experts.'
– focus group comment

We asked senior management in health for their feedback and they said that, 'there have not been cuts to funding of therapy services or posts in recent years.' But they acknowledged that capacity had been impacted as a result of increasing demand. They went on to explain that speech therapy always had movement of band 5 staff, as good staff retention at bands 6 and 7 means that there are no higher band vacancies once band 5 staff complete the relevant training, so therapists would leave the borough to find a suitable band 6 position. They acknowledged that other boroughs do pay an inner London weighting, which resulted in 'some movement of staff to Islington and Camden' but they do not feel this is a significant factor in the recruitment and retention of speech therapists.

One parent carer was concerned about the 'constant changes of senior management' at the council, while others gave the educational psychology service as an example of a 'rotating door of expertise' as they felt there was a lack of continuity in staff. Parents also highlighted concerns around accessing occupational therapy; at one focus group parents said that the occupational therapy team had 'halved' and that 'remaining therapists are hard-pushed to meet the needs of families in the borough.'

We queried this with senior health professionals, who emphasised that there have been 'no cuts in occupational therapy', but said there had been recruitment issues recently, which resulted in reduced staffing. This is a reflection of the staffing shortages in this specialism at a national level. They went on to say that the OT team is now 'almost fully staffed', with one current vacancy and that a 'new autism-related post was also created around 18 months ago.'

However, it is important to emphasise that for parents what matters is their ease of accessing services and therapies. When they have difficulties – whether it is a due to higher demand and staff capacity issues or because of cuts to teams – the result for families is the same; they face longer wait times and feel services are harder to access for their children.

Parents at our focus groups were concerned that difficulties accessing therapy meant children were not receiving sufficient support to develop the life skills they needed to live as independent adults. One parent said the council was 'borrowing from the future' because young people with SEND would require more support and interventions from adult services as a result.

> *[This is an] opportunity for Haringey to own it and be inclusive through action. They are the sort of borough who want that.... [They] need to start rebuilding trust and relationships and move in the right direction.*
>
> *– focus group comment*

Parents highlighted the need for prioritisation and creativity around how services are planned and delivered, which is something that parent participation and co-production can facilitate. Often, parent carer are best placed to identify the flaws in a service and by collaborating with professionals can ensure that innovative solutions are found, especially when increased demand is a problem, to ensure that services best meet the needs of the local community.

Understanding the role of a forum

In our survey, we asked parent carers if they knew what a parent carer forum did and gave them several choices, from which they could pick more than one. From their answers, the majority of parent carers had a good understanding of the role of a parent carer forum, see figure 9.

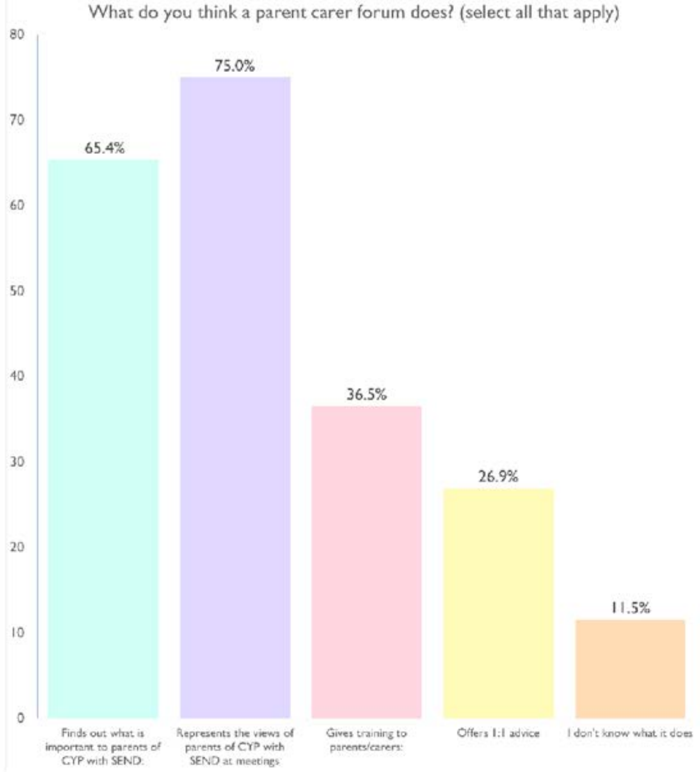

Figure 9: Amaze survey of Haringey parent carers, March 2020

The majority (65.4 per cent) knew that a parent carer forum's role was to find out what was important to parent carers of children with SEND, while three quarters (75 per cent) knew that a forum represented parents/carers at meetings attended by professionals. Over a third of parents (36.5 per cent) said that a forum may offer training. while a quarter (26.9 per cent) incorrectly believed that a forum also offered one-to one advice and 11.5 per cent said that they did not know what a parent carer forum did. This illustrates how important it is for parent carers to have easy access to good quality information so that all families are clear about the role of a forum and how it can help them and their children.

Do parents want a new forum?

In our focus groups, the vast maority of parent carers felt that a new forum is essential if the voices of the SEND community are to be heard.

> *'We need to find a way to have a dialogue: the local authority will not be able to work with us if we just shout at them.'*
>
> *– focus group comment*

Many were mindful that because of the previous challenges for parents and professionals there is a need to find a way for both groups to come together to work constructively and positively by setting aside past difficulties. Several felt that an overly critical dialogue would only result in further barriers, which is admirable given the extremely difficult experiences many have had.

Others were clear that to be successful, the forum needed the support of the wider SEND community. They acknowledged that this might be difficult at times due to the diverse nature of the borough and different priorities for families, which can make reaching a consensus tricky. Some parents told us that they felt the local authority used this as a way of avoiding participation, by saying that it was 'too difficult' because 'parents cannot agree' or that they 'only hear from one group of parents.'

> *We desperately need a forum... simply having the discipline of public meetings where we could have relevant representatives from the council, NHS, sendiass to present topics and take questions would be a fantastic start.*
>
> *– survey comment*

However, at our focus groups, many parent carers were keen to work collaboratively – as one attendee said, 'We have to learn to support each other. How can we pretend to offer support to all parents if we can't even support each other?'

To represent the wider community a steering group or committee must have a representative range of parents to ensure that the needs of all families are heard at a strategic level. There is a need to strike a balance so that families in mainstream and specialist settings are heard; that those on SEN Support and those with EHC Plans are represented and there is fair representation of different conditions and needs, for example.

Additionally, a forum must take a strategic, organised approach to planning its priortities and areas of focus by seeking input from the wider community so key concerns and common goals can be identified. For work around particular topics or disabilitues the forum can use a targeted approach to seek feedback from its members. Likewise, it is essential that the local authority and health reach out to the forum to seek the views of particular groups in a targeted way when input is needed on services and also ensures that this is communicated to families through its own channels. This is where having a detailed disability register can be so valuable to commissioners and the forum.

These steps can help to ensure all views are gathered and themes presented, but they will only work if professionals at the local authority can also take action to change by moving away from the defensive culture described and foster open and honest relationships with a new forum and SEND families.

What do parent carers want from a forum?

Some focus group attendees thought it was important that an independent organisation was appointed to oversee forum development and provide timescales for implementation. They wanted the support organisation, parent forum and professionals working in partnership to embed co-production across services to bring about cohesion, joint strategy and partnership in the borough.

> *'I like the idea of a collaborative approach and moving forward together to help SEND children and families'*
>
> *– survey comment*

> *'It would be amazing to have a parent forum that could represent parents' voices in a fair way, with training and information events running alongside..'*
> *– survey comment*

Parents told us that it was essential for the new forum to be representative and inclusive of all in the SEND community, especially more isolated families and those who may be excluded by language barriers.

The majority of attendees wanted flexibility around methods of engagement so they could feed in their views in a way that suited their families, so they were keen for the new forum to to offer a variety of consultation methods. They suggested online surveys, Whats App groups and online options for meeting attendance, such as Zoom and Microsoft Teams. Other parents said they would prefer to attend meetings and focus groups in person and a few highlighted the need to ensure that families without IT access could feed in via other means.

Parents told us that if involvement was to increase, careful consideration was needed around the timing of face to face meetings. Several working parents said that they do not have the opportunity to participate unless they take time off, which isn't usually possible, especially if meetings are arranged without much notice. The usual practice of some forums is to arrange meetings between 10 am and 2 pm to fit around when children are in school but offering evening events is also needed to give working parents opportunities to engage.

Some attendees wanted the option to work with the forum on a project-by-project basis as and when their caring commitments allowed, so that they had boundaried pieces of work.

Attendees also wanted the option to link in to the forum via existing groups within the community. They gave examples of the Challenge Group, WAVE Cafe, sendPACT and Mums in Mainstream. Others suggested that parents could also link in via schools. We are aware that the Vale Special School has a parent group and that Bridge Renewal Trust is also establishing school forums (open to all parents). Additionally, three parent ambassadors have been appointed to shape the work of health's Positive Behaviour Support project. By using existing community links, the forum can grow their membership and strengthen engagement in the borough.

Parents underlined the importance of capturing the views of children and young people, and suggested setting up groups to help them feed in to the new forum and strategic meetings, as they may have different views to parent carers. This was outside the scope of our review, but we suggest this could be facilitated by linking to existing groups for young people in the borough such as MyAFK's youth council and youth ambassadors, and by building additional participation opportunities for children with SEND.

The majority of parent carers were keen for paid roles for key positions and reps. They said reimbursing parents for meetings, travel costs and childcare would help families who are less financially secure to participate

Parents emphasised that one of the key difficulties for past engagement had been the last-minute notice of meetings and circulation of paperwork. There will need to be a cultural change in working practices, as participation needs forward-planning and proactive thinking so that parent carers have time to make arrangements for their family and can digest the information to ensure meetings are productive and resources are used efficiently.

Focus group attendees wanted more transparency around what could be achieved in projects, which is good practice to set out at the start of every project. East Sussex Parent Carer Forum (ESPCF) has achieved clarity around this by co-producing two simple documents with the local authority (see Appendix 4). The first, the co-production procedure document outlines the process for co-production. The second, the co-production brief and working document is used for individual pieces of work. It sets out who is involved, agrees parameters for the work and how it will be credited, as well as having sign-offs at key stages. These are extremely useful monitoring points for all involved and mean that everyone comes to the table with a clear understanding of the project and its aims.

Parents were also keen on the idea of the forum, local authority and CCG holding joint meetings where parent carers would have the chance to feed in their views face to face. They suggested that with careful facilitation, a series of surgeries could be held, to enable parent carers to raise issues they may have.

We asked our survey respondents how they thought a new forum could make things better for families, see figure 10:

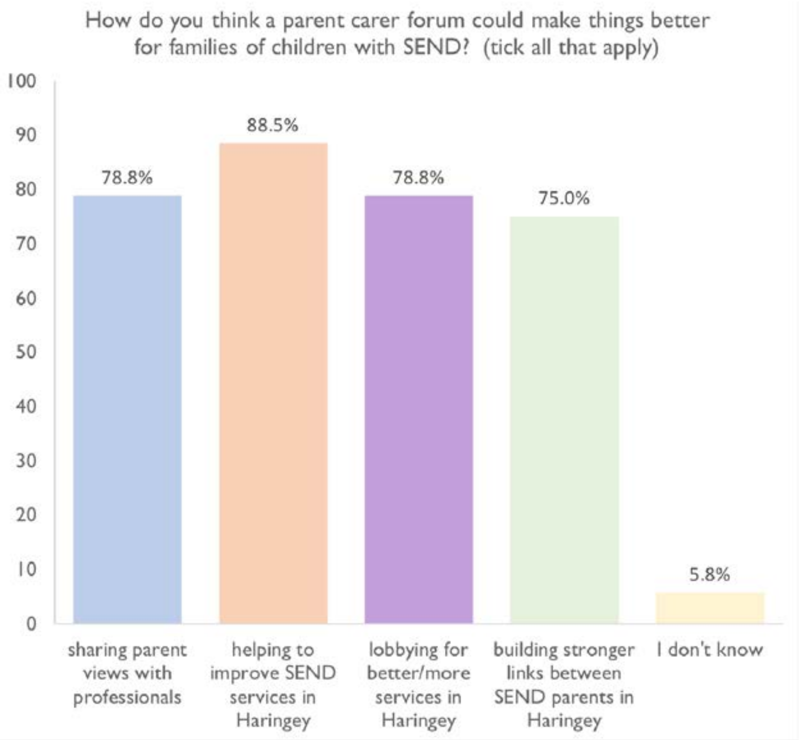

Figure 10: Amaze survey of Haringey parent carers, March 2020

78.8 per cent said by the forum sharing parent views with professionals; 86.5 per cent that the forum could help to improve SEND services, 78.8 per cent said it could lobby for better or more services in the borough; 75 per cent thought it would build stronger links between parents; while just 5.8 per cent didn't know.

Persuading parent carers to get involved

Figure 11 below shows our survey respondents said there are five ingredients which are vital to persuade them to participate:

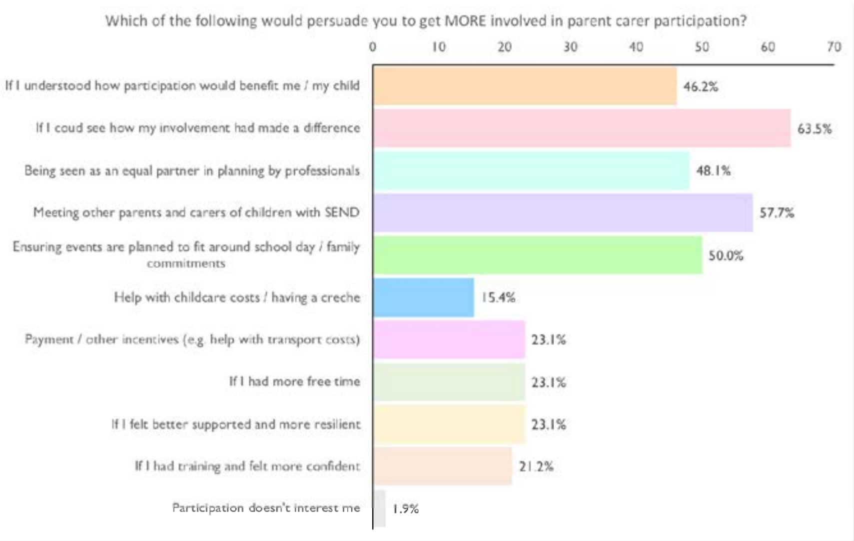

Figure 11: Amaze survey of Haringey parent carers, March 2020

63.5 per cent of parent carers said it was if they could see how their involvement makes a difference; 57.7 per cent said meeting other parent carers would also encourage them; 50 per cent by ensuring events are timed around family commitments ; 48.1 per cent wanted to be seen as an equal partner in planning by professionals; while 46.2 per cent said if they understood how participation would benefit their family.

Knowing that parent carer input has led to changes and successful outcomes is essential to sustain engagement, as other parent carers are more likely to get involved if they hear about successful outcomes in improving services. Brighton and Hove CCG ensures parent carers are aware of the impact of their input, by using the 'you said... we did' format to summarise issues raised and action taken as a result. It will be helpful for the new forum and professionals to adopt a similar approach to swiftly communicate successes to parent carers.

We asked respondents how they would like to be involved, (see figure 12).

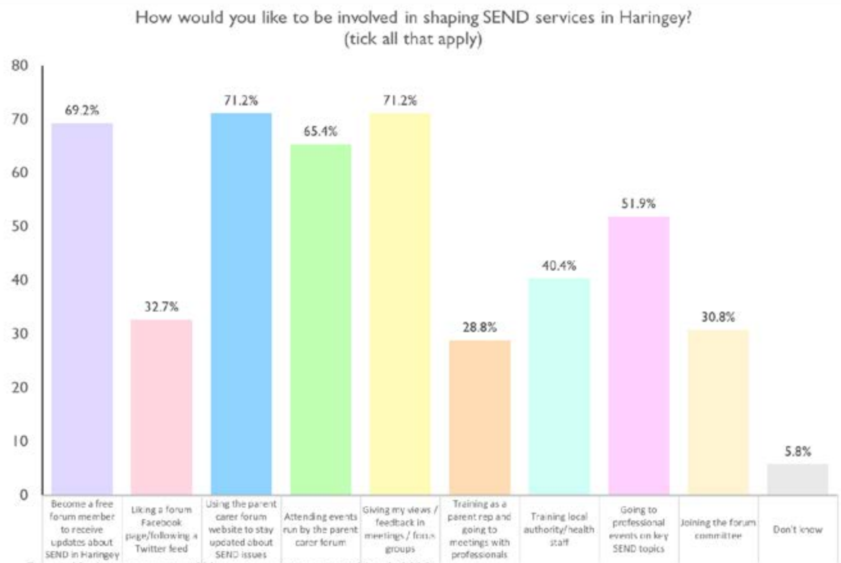

Figure 12: Amaze survey of Haringey parent carers, March 2020

Almost 70 per cent said they would become a forum member; 71.2 per cent said they would visit a forum website or give their feedback in meetings and focus groups; 65.4 per cent they would attend forum events; 51.4 per cent would go to professional events on key SEND topics. 40.4 per cent said they would like to be involved in training professionals, and 30. 8 per cent would join the forum committee, while 28.8 per cent said they would train as a forum rep.

We also asked our survey respondents to tell us which area is most in need of parental involvement and is one they would consider participating in (see figure 13).

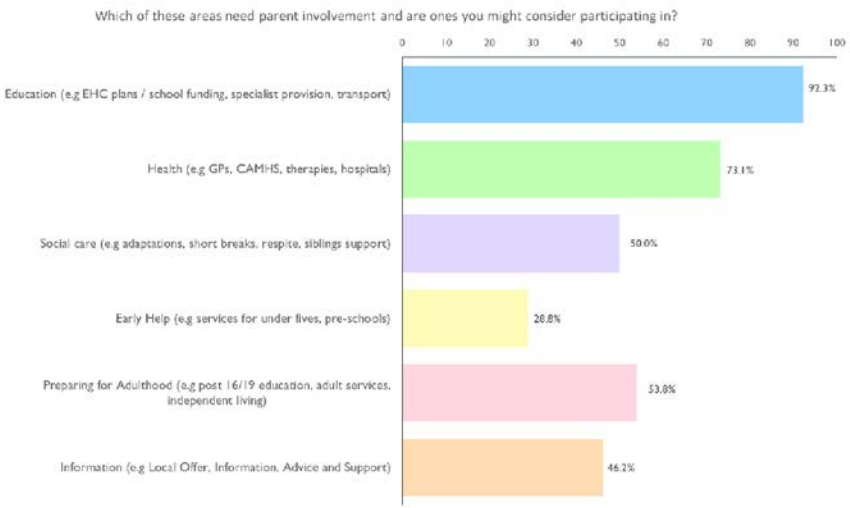

Figure 13: Amaze survey of Haringey parent carers, March 2020

The overwhelming majority (92.3 per cent) said education, 71.3 per cent said health; 53.8 per cent preparing for adulthood; 50 per cent social care, 46.2 per cent for information, advice and support, including the Local Offer and 28.8 per cent said Early Help.

These findings echo those of our focus groups, in which education was their key concern, followed closely by health, social care and preparing for adulthood. As we know, parent carers were also concerned about having accessible information, advice and support, especially parent carers who might be struggling to access and navigate the system. Increasing the availability of this should help parents engage with a new forum.

What are their concerns?

We also asked our focus group attendees to share their concerns. They said

how long will it take to change?

too much pressure on schools

feel alone

it's bafflingly slow!

council can't cherry pick parents – need to engage with all of us

fear of adult services being even worse

Can't see anything changing – concerned about families' mental health

we need more people to join in

will this bring parity with other boroughs/ where children get more support?

Council can't pretend we're not here – they must engage to have a positive, productive result. It's very, very basic.

broken by the fight

will a forum help with more effective use of resources?

will our input make a difference?

will it have an impact?

anxious for the future

will anything change?

there are no resources

exhausting

skeletal services

I feel like I'm the only one... being [a SEND parent] in mainstream is a lonely journey.

What would parents get from participation?

Finally, we asked our focus group attendees to summarise how a new forum and better participation would make a difference. They said:

equality

accountability

collective voice

connect to professionals

advocacy for the vulnerable

mutual respect

better use of resources

better support

clarity

improved health/ wellbeing

clearer pathways

communication

positive step forward

change

parents are prevention: we can prevent many problems

cohesion

to be heard

connecting existing groups

peer support

empowering

shared knowledge

partnership working

good practice

transparency

fairer services for all

information

honesty

A final word on our focus groups

Despite parents' frustration with the current situation in the borough and the extremely challenging journeys many of them have had, all our focus group attendees expressed a strong desire to help improve things and want an open and honest dialogue with the local authority and CCG. Their determination to make their voices heard must be recognised by professionals as an opportunity to rebuild trust and relationships with parent carers. In our view, it is essential that professionals respond rapidly and proactively to this review's findings and co-produce an action plan to share with the community to ensure that things move on in the borough as quickly and as constructively as possible.

Success stories: Brighton & Hove PaCC

Over the past 12 years, Brighton & Hove's Parent and Carer Council (B&H PaCC) has built a strong presence in the city and developed open communication channels with the local authority, CCG and SEND families.

PaCC deals with issues by gathering and setting out the community's views on a case by case basis. This articulates the needs of the SEND community and highlights the obligations of the council to ensure statutory and equalities duties are met. It is able to maintain relationships with all concerned while a challenge is in place by holding regular face to face meetings with professionals and by having wide-reaching engagement with the SEND community.

In 2019, Brighton & Hove Council re-tendered home to school transport provision, which had an extremely negative impact on many SEND children, young people and their families. As a result of local press attention, a campaign group formed, which worked with PaCC to highlight issues with officers and councillors.

PaCC was able to work effectively with all parties by being transparent around their ask for a fit for purpose home to school transport service and an adequate transport budget to ensure a safe service was provided for families. Its clarity and transparency demonstrated a commitment to the community and also to ensuring excellent working relationships were maintained with the campaign group and professionals.

By working collaboratively, delivery issues were addressed, an independent review was completed and co-production processes defined for service planning, with the aim of placing children at the heart of future decision-making so their families' needs are met.

Professionals and participation

We conducted telephone and online interviews with 25 professionals across key teams, services, voluntary organisations and support groups. We spoke to a cross-section of professionals working in education, including senior management, case workers and educational psychologists as well as those in health, social care and transport. We also spoke to school heads, SENCOs and voluntary organisations, as well as support groups operating in the borough. The headline themes from our findings are summarised below in figure 14:

Figure 14: summary of participation challenges for Haringey professionals (on an individual and and a straregic level)

How involved are parents in SEND services?

- *15.8% – not at all involved*
- *63.2 % – slightly involved*
- *5.2 % –very involved*
- *15.8 % –don't know*

Have you or your team received training on on how to support participation?

- *0 % – yes, me*
- *7 % - yes, my team*
- *64 % – no*
- *43 % – don't know*

How can participation can be improved ?

79% said:

- *more training for us on participation and how to facilitate it*

86% said:

- *better understanding of its benefits*
- *more support for parents*

93% said:

- *increase its priority by senior managers;*
- *parents being seen as equal partners*
- *offering a range of ways to participate*
- *wider cross-section of parents represented*
- *closer working relationships with parents*

Culture

Several local authority professionals indicated that they felt the overall council culture had been resistant to engagement due to a somewhat rigid top-down approach and a resistance to listening to the community.

> *'Trying to change a council takes time. It is a bit like trying to turn an oil tanker round– it takes ages to change direction.'*
>
> *– professional comment*

A recent example where the community felt their voices had not been heard happened late last year, when proposals were tabled to consider involving an external agency to assist with redesigning the home to school transport service. In any situation where changes to a key service are being considered it is essential to seek the input of parent carers at all stages and that changes are co-produced to ensure that the service meets families' needs. This had not happened, so parent carers and councillors were able to successfully challenge this proposal, with a result that the outsourcing has been shelved.

Professionals tell us that in recent months their focus is shifting away from outsourcing towards one to one of delivering in-house, building their own team to provide the service. As part of this they are growing their in-house teams to meet capacity. However, in addition to developing a delivery model it is important for this to go hand in hand with a cultural change to foster a more open and transparent approach to parent carers, so that their input is sought at an early stage and is valued by professionals.

Routes for engagement

All staff that we spoke to said that they wanted parent carers to be more involved in future and that they are committed to improving participation in Haringey. However, they said participation has been hampered by a lack of clearly defined routes for parents to feed in to, especially when compared to adult services.

Several professionals also felt that levels of participation were impacted because of the fact that they had lost the confidence and trust of parents and they acknowledged that part of the reason for this was that when parents try to engage there is no follow up to show that their input has been effective, or if it has been used at all. A recent example of this is the transport consultation, whch had left parent carers at our focus groups feeling frustrated and disappointed due to the lack of updates or tangible outcomes.

This view was reinforced by a parent carer at our check-back session, who expressed that the limited number of parent carers involved in strategic level participation is a direct consequence of the wider issues in the borough and the fact that parents have been left feeling that participation is a fruitless exercise.

Consequently, the weight of responsibility to participate at a strategic level is carried by a very limited number of parent carers who are still willing to try. It is also important to note that they have done this without the backing of a forum. Parents need the strength in numbers, necessary governance, and financial, emotional and practical support that a forum brings. In Haringey parent carers have continued to attend meetings without this support network to help them. and they have remained tenacious in their efforts, despite the challenges involved.

The majority of staff we spoke to reported not having training in facilitating participation. We also heard from staff who felt the SEND Co-production Group had struggled to facilitate this activity as it doesn't yet have structures and routes for engagement.. In the face of these challenges, it is hardly surprising that the co-production meetings have become a difficult arena for all attendees, and seem to have lost their focus, buy-in and direction.

In order to move on, we feel it will be essential to establish new routes for participation, including identifying decision-making groups for parent reps to attend. We suggest some of these meetings are held in community venues and not always at council premises.

We are aware that some parents are extremely concerned that co-production has come to a standstill during lockdown, but it is important that the next steps are well planned and a solid foundation of support is built so that new co-production routes can be effective.

Our recommendations will set out a suggested pathway and timeline to achieve this.

As we outlined earlier in the report, there are additional challenges to engagement due to the diverse population in the borough, and staff also feel it is important to have a variety of ways for parents to feed in. Several in education referenced projects to support families who may be facing particular challenges linked to their language needs so it will be important that the new forum links in with these groups so their voices can be represented. During lockdown we have seen how technology can assist some parents to engage as they can join meetings from their homes, so we hope staff can convene meetings that can be attended either in person or online depending on which is easier for the parent rep.

Many professionals agreed that the transport consultation had been eye-opening because it revealed that a large number of parent carers were keen to input their views on service planning and policy. It had also shown professionals that it was critical to have more face to face contact with families as the chance to talk directly helped them to understand the issues more clearly and that as well as parent carers coming to meetings it emphasised the value of one to one conversations, too. They also recognised that there was a need to build relationships with families that were long-lasting, rather than confined to isolated feedback.

'Adversarial' atmosphere

Issues around SEND are incredibly emotive, especially when things have gone wrong for families, as what might seem like a relatively 'minor' issue to a professional can have a huge impact on a whole family.

In the absence of absence of a commissioned forum, responsible for gathering and presenting parent carer views, it is difficult for families to make their voices heard. Those that have fed in on a strategic level told us they have often been left feeling frustrated, as their input is not acted on, despite their best efforts.

> *'If we had training [in participation] then it would be in our psyche rather than us making it up as we go.'*
>
> *– professional comment*

Parent carers needing to 'fight' to access services and feeling they are not being listened to, alongside professionals face increasing demand and limited resources means it is unsurprising that a number of people we spoke felt there was an 'adversarial' atmosphere in Haringey. One special school head told us that they were seeing the impact of this on a day to day basis, as mounting pressures and difficulties accessing support meant parent carers were increasingly stressed, and as a result staff were receiving more complaints as their worries and frustrations often spilled out at school.

Stress and frustration has also had an impact in meetings. One staff member said there had been occasions when they felt parents' language or behaviour had been inappropriate while others said that at busy events, such as the transport consultation, they were concerned that quieter and less confident parents struggled to have their say.

In our check-back session a parent carer said they felt it was difficult because there was so much negativity around the council and she did not feel it was particularly helpful when participating. At our focus groups, two parent carers said they had been deterred from getting involved because Facebook posts had made it seem 'adversarial.' Other parent carers in our focus groups said they feared that getting involved in participation and 'rocking the boat' with professionals might affect their ability to access services for their children.

The above points need to be viewed within the wider context of the challenges mentioned in our report and noted as a consequence rather than a reason for the current difficulties in the borough.

Without an effective engagement platform for parents and an established forum to develop the necessary robust policies and procedures, strategic level co-production has lacked the usual governance, including a code of conduct to ensure meetings are respectful and constructive for all.

Education

A number of staff we spoke to in education at the council acknowledged that participation was still in its early stages in the borough, with many describing it as 'embryonic'. They acknowledge that the focus has been on dealing with the massive changes wrought by the SEND reforms, with participation seen as less of a priority rather than an integral part of strategic and individual level processes.

Many made reference to the challenging landscape for the council since 2014 as Haringey's SEN team had been cut leading up to the reforms, so the team found themselves 'on the back foot' when they were implemented. The upheaval in senior management and movement of the SEND team between portfolios also resulted in a lack of continuity and direction for the teams. As a result, some work to transfer Statements to EHC Plans was outsourced, which led to variable quality in the plans produced and delays in completing the transfer process for existing Statements of SEN. One professional told us that until recently, there had been an operational focus on getting EHC Plans in place, on time, rather than co-production being prioritised.

At the time of the review, all the staff we spoke to, with the exception of educational psychology, said that they had not received training on co-production. It is incredibly difficult to implement good practice in co-production without a solid understanding of the benefits and principles behind it and without the necessary strutures and processes to ensure that it is embedded in day to day work. It is unsurprising, therefore, that in this landscape participation has been very ad hoc in its approach.

There are other areas where we identified a possible need for staff training. Many professionals we spoke to acknowledged that the recent transport consultation meeting had shone a light on the dismissive attitude of some officers towards parents and the way that some issues were minimised rather than being addressed. Senior management acknowledged that further training was needed with staff to ensure that they had an empathetic approach and take ownership of issues. One member of staff also highlighted that it would be useful for staff to have training in de-escalation techniques, to ensure that problems could be resolved rather than exacerbated.

Asking parent carers to participate in training of new staff will build relationships and foster greater understanding. Inviting a group of parent carers to meet with officers during their induction or team-building days to talk to them about the parent carer journey would give staff some understanding of the challenges of life as a parent carer. It would also be extremely beneficial for officers to meet parents with their children so that they can understand more about the 'people behind the files' sitting on their desks. All of the above will be important factors in rebuilding parent carer trust in the council.

Professionals in education highlighted transport, annual review forms, experiences of the EHC assessment process and preparing for adulthood as being key areas in which they were keen to have more parent engagement in the immediate future.

Health

Like educational professionals, staff working in health felt the challenging atmosphere in the borough added to the difficulties around participation, especially when parents had differing priorities and concerns they wanted to raise. As has been covered previously, seeking clarity at the start of a piece of work is key to successful participation so that everyone understands the aims, process and what can and cannot be achieved. By developing clear documents such as a co-production brief and working document (see appandix 4) professionals and parents can agree clear parameters and proceed with confidence.

As with the transport review, health professionals also highlighted that sometimes it would take time for parents to see tangible differences to a service after a review, as staff tended to focus on resolving the 'difficult stuff' rather than actioning the things that are easy fixes. It would be helpful if staff could communicate a few 'quick wins' speedily to families, and explain they may need a bit longer on the complex changes.

Staff working in health told us that co-production in adult health seemed more straightforward, possibly as there were clearer routes and structures. They gave examples where they had had good engagement from all stakeholders such as in the commissioing of adult day opportunities, nursing homes, and homelessness.

In children's health, there were some examples of successful engagement and consultation. The CAMHS trailblazer project had seen parents and young people engaging and giving feedback to shorten the waiting list to four weeks. Feedback on Occupational Therapy training sessions for parent carers at Markfield had resulted in positive changes being made as a result.

The CCG had also asked a Transitions group to review parent carer experiences around transfer to secondary schools and mental health. The focus group was so successful that parents wanted to continue meeting for support. This is a great example where a one-off piece of participation work has evolved into something more concrete and long-term for families in the form of a peer to peer support group. A forum can play a pivotal role by seeking out and linking up with a variety of groups such as the example above, to facilitate a two-way flow of information between the wider community and commissioners.

In future, health professionals said they wanted parents to be represented on the new body of amalgamated CCGs, as although Health Watch have a seat, parent carer voice would also be welcome.

Additional priorities for parent carer involvement at the time of our review included alternative SEMH provision and therapies, however it is likely that the impact of Covid-19 will see some reajustment in groups and a resetting of these priorities over the coming months.

Social Care

As previously covered in our report, social care has been mostly been focused on improvements after the findings from Ofsted during its 2018 Inspection of Children's Services and also the judgement in the recent case heard in the family courts. However, professionals tell us that SEND services and participation are also a high priority for the immediate future.

Perhaps the most successful piece of work for the social care team to date has been the 'Moving On' Transitions Group, which we previously referenced.

A professional in social care highlighted that special schools were an important route for participation for families and therefore should also feed in to the new forum. This view was reinforced by a head teacher at a special school, who told us that they often held events in the school for parents and they were usually quite well attended.

Social care could not identify future engagement opportunities at the time of our review, however, we would suggest that, based on our focus group feedback, a review of thresholds and some aspects of staff training could be helpful co-production projects in the near future

A final word on professionals

We were struck by the honesty of the professionals we interviewed, who were very open about the difficulties in the borough and the huge amount of work that lies ahead. Many said they accept that this will also need a significant cultural shift in order to bring about the change required, both to embed participation across services and also to build trust with SEND families.

During our check-back process, SENDIASS told us that many of our headline findings replicate and represent the conversations they are having with parent carers. Several professionals also expressed how emotional they felt reading the summary. One said, 'It just hits you seeing it. The figures: 6,397 children and our co-production hasn't been at that level.' while another said they felt 'overwhelming sadness' at the 'disconnect between leadership and parents' and the 'majority of parents feeling that they haven't got a voice and can't navigate the services.'

In one of our sessions, a parent carer felt that to move on there was a need to avoid a 'blame game' and the pull of past difficulties. They felt that, while there was a need to acknowledge what had gone before, there was also the need to work positively and constructively to build something better in the borough.

They suggested that a joint statement from parent carers and professionals, or a 'peace and reconciliation' meeting to set out a new vision with the recommendations and timeline from the report might be helpful as a first step in achieving this. This was welcomed by professionals and the majority of parents at the check-back sessions. However, it will be up to the wider Haringey community to decide if they wish to proceed in this way.

Life during lockdown

Just after our focus groups were completed, the UK entered lockdown due to Covid-19. This unprecedented situation has had a huge impact on the SEND community, with children and young people out of education and parent carers in many families left without respite or support. Other families, who have young people with SEND living in residential placements have been unable to see them for many weeks, which has been extremely distressing. Faced with juggling their family, caring and work commitments many already stretched families have been under unbearable strain in the past few months.

Many Haringey parents reported that they felt isolated and overwhelmed by their caring responsibilities during lockdown. Parent support groups running virtual meetings with parents told us that they were concerned for many of their members, as without support many families were falling into crisis due to the immense pressure they were under. Some were also angry and frustrated as there are currently no channels through which to raise their concerns, which in other areas had been taken up on behalf of families by their parent carer forums.

In our check-back groups, parent carers said they felt the onus was always on families to seek information and help, whereas what they needed was proactive support. One parent carer pointed out that after almost two decades in the SEND system, they had never been contacted by the council to find out what support they needed and what would help. Many parent carers need a proactive approach as the 'complete maze' of the SEND system is just too difficult to navigate. We floated the idea of a comprehensive disability register with parents and they were keen on the idea, as long the information gathered was used in a proactive way to support families, including the carer and wider family members.

Nationally, we found many examples of ways in which co-production has supported families during lockdown. Gloucestershire and Swansea parent carer forums worked with their local authorities to co-produce accessible information for families, while Cornwall parent carer forum held virtual coffee and chat sessions and peer to peer support online.

In Suffolk, the parent carer forum offered free family support boxes with a range of items inside, including sensory bags, colouring books, items for siblings and information in support. They shared the data collected from this and other initiatives on a weekly basis with the health and local authority to commission services such as VCS organisations to respond directly to the needs the PCF identified with an almost immediate start.

In Brighton & Hove and East Sussex, the parent carer forums have been meeting with local authority officers every week to discuss issues affecting families. This consistent and frequent contact has supported officers in having a good understanding of the issues, with regular information dissemination, and constructive challenge to service providers to change, redirect or increase the support available.

This support for families from their forums has been vital for many SEND communities, as parents and support organisations reported to the Education Committee[25] that families have been 'utterly abandoned' during lockdown, because closures to schools and other services had seen support 'fall off a cliff.'

Restrictions on travel and mixing with other households mean that families have been unable to access support from family or friends, while most short breaks and other respite services have also been closed. Additionally, many children with disabilities have health issues that place them in the vulnerable or shielding group, which means they have been forced to stay indoors. Many families of children with challenging behaviours have also reported that these have escalated due to the disruption and stress of lockdown. One parent said during a BBC interview, 'Unless you have a disabled child, you will never understand how it affects your life - and then this is ten times worse, because there is no let up, no let up whatsoever.'

The Special Educational Consortium reported to the Education Committee that many families had been hit by the relaxation of legal duty on schools to provide support for SEND pupils., which has been temporarily replaced with a requirement for schools and local authorities to make 'reasonable endeavours' for children with EHC Plans.

Although children with EHC Plans are classed as vulnerable and therefore should be able to return to school, at a local level many parents, including some in Sussex and Haringey, report that this has not been possible, often because schools say they are unable to accommodate their needs.

Witnesses giving evidence to the committee highlighted that the lockdown had exacerbated the existing inequalities for families of children with SEND and that this will have a deep and long-lasting impact on children and their families and that a catch-up plan is needed so that children receive additional emotional and therapeutic support. This is in addition to working out practicalities such as home to school transport, as more vehicles may be needed to ensure social distancing and staggered start and finish times can be put in place.

What is clear is that many SEND families will come out of lockdown with more needs, as it has pushed some parent carers to the limit in terms of their own health and wellbeing. Therefore, it is essential that Haringey puts a strong and robust plan in place to ensure that needs are identified quickly and families supported going forward. A parent carer forum will play a critical part in feeding in the views of the community and representing parent carers at a strategic level, but this is only part of the jigsaw and professionals have to recognise the challenges ahead. What is needed is a bold approach to ensure that Haringey families receive the best possible support so their children can achieve the best possible outcomes.

Success stories: East Sussex parent participation

Aim: to develop a new forum and grow membership

In November 2019, a new parent carer forum was established in East Sussex. An interim committee of six members was formed from two support groups, one in the west of the county and one in the east. This brings benefits of established links to the parent carer community and knowledge of the challenges facing families, as well as the working practices of the local authority and health, and existing services within the county.

One of the biggest barriers we faced was that historically the area had not had a strong parent carer forum, therefore parent participation had become disjointed and almost non-existent, with parent support groups 'going it alone' and setting up to support each other and find information – this, in some cases had created a barrier to the suggestion of parent carer participation.

It is hugely important to research and establish the most effective way of communicating with parent carers to maximise reach, be accessible and inclusive. Get to know groups who already meet, introduce the forum, invite them to take part and value their input; hold a roadshow and offer something parent carers may find useful eg a guest speaker; look at what 'others' are doing in the area to benefit parent carers; and use a variety of communication tools - facebook, twitter, email, phone or face to face.

With support from Amaze, we spent time developing our forum policies and created a website and flyer with a very simple sign-up page, as well as paper copies for those not online. Both options had to be accessible and quick for parent carers to do and it was instrumental in building our membership.

It was important to establish trust with members and understand that many may have felt very alone, let down and isolated. We are getting to know our families via active listening and our engagement coordinator is building relationships with forum members.

We have developed clear lines of communication and regularly feedback to families so they feel involved and trust the team. During lockdown we called every member to find out how they were coping, sign-posting to appropriate services where needed, which has been very positive in developing relationships and helping members feel supported.

Jo Nye, Interim Co-chair, East Sussex Parent Carer Forum (ESPCF)

Recommendations

Our report has demonstrated that while there are pockets of good practice amongst professionals there is much to be done in Haringey to develop participation and foster closer working relationships between professionals and parent carers.

The tables below outline our key recommendations, grouped by the themes identified in our findings section. Beneath these, we have provided a diagram to outline the initial steps to help the borough begin to formulate a plan of action.

For the recommendations, 'professionals' has been used as shorthand to cover staff working in commissioning and leadership roles at the local authority and health, as well as those working in education, health and care. Leadership across these sectors will need to identify and take ownership of specific recommendations relating to their teams and drive forward their implementation, as the change required can only be achieved by a proactive, cohesive approach in the borough.

1. Professionals

A. CULTURE AND PRACTICE

A1	Senior management at the council to lead on fostering a collaborative culture of honesty and transparency by being in the first tranche of staff to be trained on participation and ensuring partnership working is embedded across teams and processes. Contact, SCIE and NEF consulting offer training of this nature.
A2	Co-produce a training programme about participaton with parents for delivery to all client-facing staff and include participation techniques, customer service, as well as training on the parent carer journey. This should be co-delivered with parent carers and include them sharing their stories face-to-face with staff and also via bite-size video clips. This should be mandatory for all new staff as part of their induction and offered over a defined period to all existing staff.
A3	Ensure sufficient time/capacity is built into staff work plans and project plans to support a variety of participation activities. This should include time for senior management to meet with the PCF and hear from parent support groups. Delivery of this activity must be reviewed as part of an individual's annual appraisal..
A4	Have standard agenda items at all key decision making meetings, such as: *Update from the PCF* / *What needs to be shared with the community* and *What do we need to co-produce going forwards*, for example

1. Professionals

A5	Local authority and CCG to provide a joint grant (ideally for 3 years initially) to both the the new PCF and their support organisation which sets out clear expectations and KPIs for engagement activity

B. STRUCTURE AND PROCESSES

B1	Review the existing SEND Executive Board and consider whether this is the correct route for a SEND partnership, or if a new group is needed. This will require the involvement of all stakeholders and representation from the local authority, CCG, voluntary organisations such as SENDIAS and spaces for two parent reps from the parent carer forum.
B2	The SEND Executive/new Partnership Board should be allocated responsibility for governance and commissioning for SEND services and given decision-making powers, feeding up into other appropriate governance structures, i.e. the Health and Wellbeing Board, Start Well Board, or Borough Partnership meetings. The Chair of the new PCF should also be invited to sit on the Start Well Board.
B3	Other subgroups, or shorter task and finish groups, should report into the SEND Executive/new Partnership Board structure for example the High Needs Block sub-group, the Transport Review.
B4	Once established, the PCF Chair should be offered the opportunity to co-chair this board, which should have clear Terms of Reference. It would also be very useful to have a diagram of what meetings are going to happen going forwards and reporting lines between each. We understand this is being worked on currently.
B5	So that this board is developed with input from SEND families we would suggest that it should be paused until the forum's interim steering group has been appointed (see back office support recommendations).
B6	In the meantime, there will need to be a temporary channel through which parents can raise concerns. We would suggest that the local authority and CCG set up an email address so that parents have a point of contact and views can be collated. Urgent queries and issues can be forwarded to the necessary teams while topics and concerns that need further consultation with the community can be collated for presentation at the SEND Executive/new Partnership Board. Although this is not ideal, it is essential in order to put the right foundations in place.

1. Professionals

B7	Meeting dates to be agreed in advance and PCF reps involved in agenda setting.
B8	Minutes, agenda items and other relevant documents should be shared at least one week prior to the meeting, to allow parent carers time to prepare.
B9	Standing agenda item at meetings to include update from PCF on priorities in the SEND community

C. PARTICIPATION PROJECTS AND COMMUNICATION

C1	Professionals to plan ahead for consultations and engagement oppportunities, with an ideal minimum of three weeks' notice for meetings and six for consultations.
C2	Parents should be involved from the outset to help determine what type of engagement activity would be most effective. As part of this planning, have discussions around the needs of families who do not have English as a first language and whether translated materials or interpreters to access the opportunities can be provided.
C3	Utilise social media, websites, text and WhatsApp to communicate upcoming engagement opportunities, plus emails and flyers via schools and Markfield. Once established, partner with the PCF to promote events and other opportunities to participate. Provide flexible participation methods, such as face to face meetings, focus groups, online participation via Zoom, surveys, meetings at existing support groups and voluntary organisations, and via email.
C4	Agree the scope of pieces of work by developing a co-production document and a brief (see appendix 4) to bring clarity to the process and manage expectations.
C5	Ensure there is timely follow up to pieces of engagement work and consultations, starting with an email to thank participants. If there are many things to resolve, split them and communicate what has happened with easily resolved points, by using a 'you said... we did' format. Let families know that other more complex issues are being looked at and further communication will follow. Give regular updates via social media, the newsletter and so on, so parents know that their input has been valued and contributed to change.
C6	Council to consider developing a comprehensive disability register, possibly with a partner organisation – see below – so that detailed data can be gathered to help plan services for families.

1. Professionals

C7	Consider joining up a leisure discount card to the register scheme to offer an incentive for families to share their personal data. Co-produce the project to develop the scheme so that families can say how much data they would be prepared to share and service commissioners and managers can consider what data they would find most helpful. Look at outsourcing the scheme to an independent organisation, as families might be more willing to share their data. Amaze is commissioned by Brighton & Hove Council and West Sussex County Council to manage the Compass Register and Card schemes and we would be happy to share our experience if you decide to develop this.
C8	Use register to identify translation needs and most vulnerable families in the borough and plan for targeted services to meet these needs, including some of the IAS intiatives mentioned later.

D. SERVICES AND STAFFING

D1	Training, as described in A2, for all staff who are in client-facing roles to ensure courtesy, prompt responses and excellent communication with families.
D2	Management to develop evaluation processes and protocols to ensure there is consistency in the quality of services provided, and feedback from families is regularly sought and used in performance reviews.
D3	Give staff the appropriate tools and support to ensure they have the confidence and skills to de-escalate situations and successfully resolve issues for parents.
D4	Training for teams to encourage open two-way dialogue and transparency when dealing with parent carers and ensure staff value the knowledge of parent carer
D5	Ensure prompt assessments from social care and that families are signposted to the children's disability team to access support. Work to improve shared understanding and transparency around eligibility thresholds for families.
D6	Provide information which helps parents to understand the EHC panel process and work towards parent representation at meetings.
D7	Collectively review intelligence from a variety of sources such as the PCF, SENDIASS, Disability Register, service evaluations and service feedback to help determine priorities together.
D8	Make increasing co-production a standard objective in personal development plans for all staff.

2. The parent carer forum

There is an urgent need to establish a representative voice for parent carers in Haringey by setting up a new parent carer forum. We hope that the recommendations we outline below will help parents and professionals in the borough to build a solid foundation for a new forum.

A few parent carers have voiced concerns around whether a parent carer forum can work in Haringey. However, it is our view that participation has not been a challenge because the parent carer forum model is flawed. The reality is that there are much wider difficulties at play so without all the challenges we have highlighted being considered and addressed, any alternative participation model is likely to face same outcome.

In our opinion a forum model has the most chance of success – as long as there is a cohesive, strategic approach with proper planning and implementation in order to build solid foundations for its development. While it is not our intention to prescribe a precise model, we have come up with the key elements that we believe are needed for a forum to develop and operate successfully.

2. The parent carer forum (PCF)

E. INITIAL STEPS IN DEVELOPMENT

E1	Independent panel to draw up a specification and seek expressions of interest (EOI) from voluntary organisations to provide back office support to a new forum. Specification to include expert understanding of community development, co-production and ideally parent participation. If not a SEND specialist, provider will need to demonstrate how they will develop the necessary SEND knowledge eg co-production requirements of SEN Code of Practice. This could be through buddying/training eg from Contact or Amaze
E2	Independent panel to score EOI against a procurement matrix and appoint back office support provider organisation accordingly.
E3	Support provider to engage parent carers in developing its work plan and ensure necessary SEND expertise/knowledge of PCF good practice in place..
E4	Invite interested parties from the Haringey community to submit expressions of interest (EOI) to the same independent panel, this time hosted by the support provider. EOIs to outline proposals to develop an interim steering group, including a structure and their aims and objectives for the new PCF.

2. The parent carer forum (PCF)

E5	Panel to assess EOIs and appoint an interim (caretaker) steering group for a forum.

F. INTERIM STEERING GROUP (ISG) PRIORITIES

F1	Secure DfE funding from Contact by submitting grant application and sign off interim budget
F2	Interim steering group (ISG) to spend time before launch developing relationship with support provider defining roles, key priorities and a budget for spending on engagement activity, including agreed contributions from LA and CCG.
F3	Identify a forum structure – longer-term the PCF might become a stand alone organisation but for its first year at least we suggest it functions as a project hosted by the support provider.
F4	Use stakeholder mapping to prioritise groups to target for membership
F5	Develop a work plan for the forum and map steps towards the creation of a permanent steering group.
F6	Support provider to advise ISG on strategic development of a PCF and put in place all back-office requirements such as admin processes, HR, finance (including reimbursement of volunteers' expenses and reps fees), IT, office space, for example.
F7	ISG to meet with Haringey Council, CCG, SENDIASS and key representatives to agree structure and format of the SEND Executive/new Partnership Board and develop ToR, Code of Conduct and draw up a new co-production policy/charter to identify where and how parent carer views should be fed in to ensure that parent voice is heard at groups/boards with decision-making powers.
F8	Map out key stakeholders including the local authority, forum, SENDIASS and parent support groups) for the ISG to begin developing constructive relationships facilitated by the support provider

G. SOFT LAUNCH

G1	Membership: invite a number of support groups to nominate a parent rep to sit on the ISG to ensure representation across diverse groups in the community.
G2	Initial 'soft launch' of forum with an online social media presence via channels such as Facebook. Focus on attracting members by using the page as a friendly and helpful information-sharing platform to generate interest with parent carers.
G3	Recruit members to forum by asking them to sign up to be involved/provide data on their families' needs and priorities to inform Forum's first workplan.

2. The parent carer forum (PCF)

G4	If the ISG decides that paid staff roles are needed, draft job descriptions, person specification, and advertise roles for these positions, e.g. chair/admin/engagement officer. Develop Volunteer Task descriptions for any roles to be undertaken by volunteers.
G5	Selection and interview process for key paid or voluntary forum roles.

H. COMMUNICATION

H1	Create a forum leaflet and identify groups who need information in other languages. Ask existing members and volunteers for help with translation, or see if translation services can be provided by the council.
H2	Create an e-newsletter with short articles to communicate forum activities, input, outcomes and successes. Focus on different communities within the borough to foster understanding and strengthen relationships in the SEND community.
H3	Formulate a joint comms strategy looking at the relative roles of the LA/SENDIASS and PCF to agree what should be communicated, who should do it and which channels should be used.
H4	Use the forum membership database to send targeted communications to families around consultations and topics of interest.
H5	Conduct a skills analysis of parent reps and canvas contacts to identify any parent carers who have previous marketing/comms experience and encourage their involvement to develop social media presence for the forum.

I. DEVELOPING THE TEAM

I1	Ensure a diversity of reps are in place i.e. of different conditions/needs, ages of CYPs, education settings, geographical areas of the borough. Ensure reps have boundaried pieces of work.
I2	Utilise Contact training for reps as much as possible and clarify who decides when a rep is 'meeting-ready' and has oversight of their input and their reporting back of key themes/actions via forms.
I3	Identify ways for reps to offload and debrief, through rep surgeries or similar.
I4	Develop a succession plan for handing over from ISG to permanent steering group.

J. CONSULTATION METHODS

J1	Use online methods to consult with the local community, including quick one question polls via Facebook, Survey Monkey for longer consultations and more innovative approaches such as using WhatsApp which many parents mentioned was a preferred method of contact. Have accessible/paper forms or ways to input for those who are digitally excluded or do not want to feedback online.

2. The parent carer forum (PCF)

J2	Consult with members annually to find out what is important to them – gather views via a range of methods e.g. online surveys, focus groups, interviews, Zoom meetings, and via existing parent support groups/school forums.
J3	Collaborate with community workers and community leaders to increase reach by using existing outreach projects and building relationships with communities.
J4	Look at existing school forums to see if a parent carer rep could sit on each to represent SEND children at the school and feed in to the forum on behalf of those families.
J5	Build relationships with early years services, and parent groups via engagement sessions on relevant topics as building a core of contacts with younger children will encourage those parents to get more involved with the forum and provide new members in the long term.
J6	If the council develops a disability register this could be also used for targeted consultations with families.
J7	Collaborate with neighbouring PCFs as necessary, for example on health services which are commissioned across 5 boroughs as part of the new North Central London CCG.

K. RECORDING ACTIVITY AND MONITORING

K1	Clarify reporting/monitoring requirements and design monitoring and evaluation framework.
K2	Develop reporting forms to document meetings and summarise feedback from parent carers to professionals and report back to parent carers.
K3	Collate and document information in a consistent, quantifiable and structured way via reports, position statements or case studies.
K4	Use reporting forms to track activity, to feed in to newsletter updates and articles in order to celebrate successes and keep parent carers membership updated.
K5	Quantify feedback from parent carers to professionals e.g. 'We spoke to 100 parent carers, 80 said they needed more information about transition to adult services.'
K6	Use monitoring information to build a picture of consultations by: age; condition; school provision etc. This could link to development in the breadth of data gathered by the council if it creates a more comprehensive disability register.

2. The parent carer forum (PCF)

L. FORUM SUCCESSION PLANNING

L1	Develop a succession plan for training and mentoring junior members of the forum steering group with a specified time frame for stepping up into senior roles
L2	Capacity should also allow for reps to step down temporarily for other reasons if they choose, such as when there's a conflict of interest due to a dispute with the council over their child's provision and the case is going to tribunal, for example.
L3	Agree a fixed term for each of the key roles of the forum e.g. 3 to 5 years, to avoid over reliance on individuals and possible burn out, and ensuring the forum remains innovative and representative of a changing community of families.
L4	Develop longer-term plan for PCF, such as a fundraising strategy and independent governance arrangements/legal structure

3. Information, advice and support (IAS)

M1	Review current funding levels to increase spend to meet demand for SENDIASS in the borough and secure additional funding from health.
M2	Parent carer forum and SENDIASS to look at co-producing and co-delivering rolling training workshops for parent carers including topics that families identify are important e.g. accessing DLA/PIP, mental capacity and setting up power of attorney, building resilience, and so on.
M3	Look at developing a range of bite-size information products such as factsheets, to give families an overview of conditions and common themes. In Sussex, this has been extremely successful, with Amaze co-producing more than 40 fact sheets with a West Sussex charity, Reaching Families. In 2019, they were downloaded 10,000 times across the two charities, providing a valuable stepping stone to many families trying to navigate the complex SEND system.
M4	Consider what information products can be translated into the most common languages needed by the SEND community.

Conclusion

The changes we've recommended will require a strong commitment from parent carers and professionals alike, with those most senior at the council and CCG reaching out to listen and build relationships across the SEND community in Haringey. This will require better communication, open dialogue and transparency around policy, as well as changes in culture, strategy and day to day working practice.

While it is important to identify the challenges both that have gone before, and those that still exist on the ground, Amaze's role is not to apportion blame as this would be an overly simplistic explanation for a complex situation which has developed over many years. It has been necessary to identify the difficulties in order to understand the context and to make the best recommendations for building strong foundations for participation in the future.

We hope that the community, commissioners and service providers can come together and use our recommendations as a plan to bring about the change thats needed to improve experiences for families of children and young people with SEND in the borough.

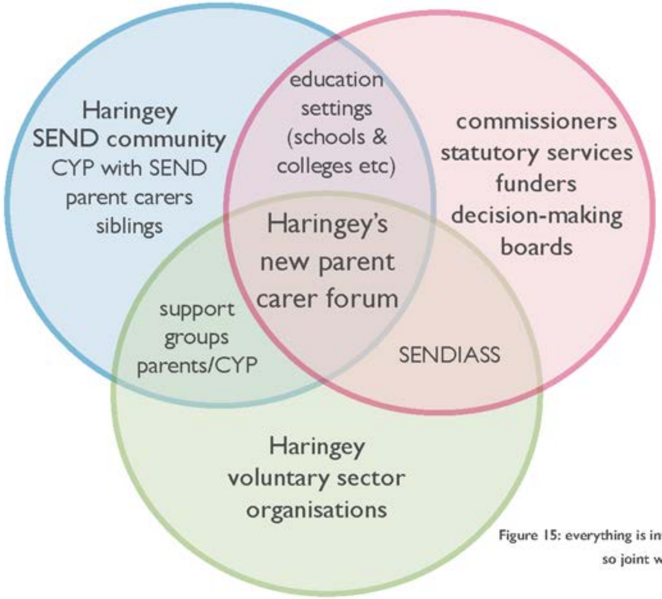

Figure 15: everything is interlinked in SEND, so joint working is essential.

Suggested timeline for forthcoming months

Panel and tender process to appoint support provider organisation
COMPLETE BY END OCT 2020

Tender process and appoint Interim Steering group
COMPLETE BY END DEC 2020

ISG SET UP AND STRATEGY
by MARCH 2021

DEVELOP existing SEND EXECUTIVE or a new PARTNERSHIP BOARD
progress co-produced by all stakeholders including ISG/parents

GROW PARTICIPATION IN BOROUGH
- *commence staff training*
- *embed participation in teams*
- *ISG to start comms with community*

ONGOING

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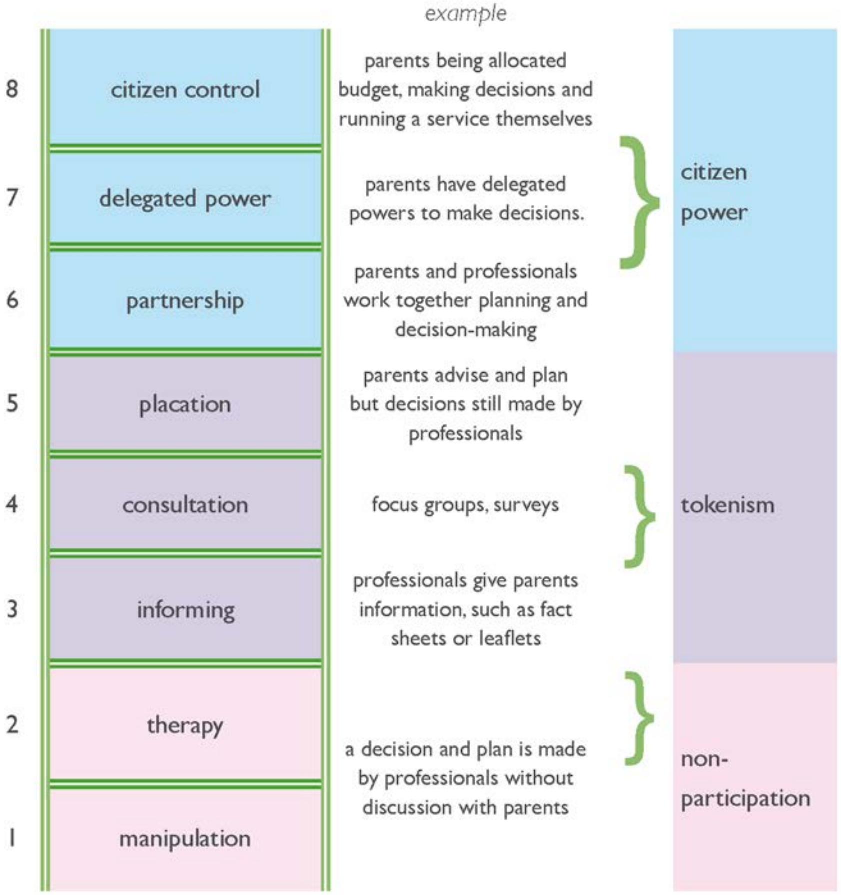
Appendix 1 – ladder of participation

The ladder of participation was developed in 1969 by US academic Sherry Arnstein to show the different degrees of citizen participation.



		example	
8	citizen control	parents being allocated budget, making decisions and running a service themselves	citizen power
7	delegated power	parents have delegated powers to make decisions.	
6	partnership	parents and professionals work together planning and decision-making	
5	placation	parents advise and plan but decisions still made by professionals	tokenism
4	consultation	focus groups, surveys	
3	informing	professionals give parents information, such as fact sheets or leaflets	
2	therapy	a decision and plan is made by professionals without discussion with parents	non-participation
1	manipulation		

Arnstein's Ladder (1969) Degrees of Citizen Participation[1]

Appendix 2 – Parent carer survey questions

1) Where do you live?

- Alexandra
- Bounds Green
- Bounds Green
- Bruce Grove
- Crouch End
- Fortis Green
- Harringay
- Highgate
- Hornsey
- Muswell Hill
- Noel Park
- Northumberland Park
- Seven Sisters
- St Ann's
- Stroud Green
- Tottenham Green
- Tottenham Hale
- West Green
- White Hart Lane
- Woodside

2) What is the main language you and your family speak at home?

3) Number of children living at home

- 1 to 2
- 3 to 4
- 5 to 6
- 7+

4) How old is your child with SEND? (if you have more than one child with SEND, please select all that apply)

- 0 to 4
- 5 to 10
- 11 to 16
- 17 to 19
- 20 to 24

5) What kind of additional needs does your child(ren) have?

- ADHD/ADD
- autistic spectrum condition
- hearing impairment
- moderate learning difficulty (MLD)
- multi-sensory impairment (MSI)
- Physical disability
- Profound and Multiple Learning Difficulty (PMLD)
- Severe Learning Difficulty (SLD)
- Social, Emotional and Mental Health (SEMH)
- Specific Learning Difficulty (SLD)
- Speech, Language and Communication Needs
- Visual impairment

- Other– please say

6) How involved do you feel in the way SEND services are planned and developed in Haringey?
- Very much
- Slightly
- Not at all

7) If you said in question 6 that you DO feel involved developing services, which ones are they? (please select all that apply)
- Education
- Paediatrician / GP
- Other health services (e.g wheelchair service, physio, continence, OT, SALT)
- Short breaks / respite
- Social care
- Other (please state)

8) What do you think a parent carer forum does? (please select all you think apply)
- Finds out what is important to parents / carers of children with SEND
- Represents the views of parents and carers of children and young people with SEND at meetings
- Gives training to parents / carers
- Offers 1:1 advice
- I don't know what it does
- Other (please specify)

9) Were you a member of Haringey's previous parent carer forum, Haringey Involve?
- Yes
- No
- Don't know

10) How do you think a parent carer forum could make things better for families of children with SEND?
- Sharing parent views with professionals
- Helping to improve SEND services in Haringey
- Lobbying for better/more services in Haringey
- Building stronger links between SEND parents in Haringey
- I don't know
- Other (please specify)

11) How would you like to be involved in shaping SEND services in Haringey? (please select all that apply)
- Becoming a free member of a new parent carer forum to receive email updates and newsletters about SEND in Haringey
- Liking a parent carer forum Facebook page/following a Twitter feed
- Using the parent carer forum website to stay updated about SEND issues
- Attending events run by the parent carer forum
- Giving my views / feedback in meetings / focus groups
- Training as a parent rep to be the voice of the SEND community at meetings with professionals
- Training local authority/health staff so they understand how important it is for parents to be fully involved in shaping services
- Going to professional events on key SEND topics
- Joining the forum committee
- Don't know
- Other (please say)

12) Which of the following would persuade you to get more involved in parent / carer participation?
- If I understood how participation would benefit me / my child
- If I coud see how my involvement had made a difference
- Being seen as an equal partner in planning by professionals
- Meeting other parents and carers of children with SEND
- Ensuring events are planned to fit around school day / family commitments
- Help with childcare costs / having a creche
- Payment / other incentives (e.g. help with transport costs)
- If I had more free time
- If I felt better supported and more resilient
- If I had training and felt more confident
- Participation doesn't interest me
- Other (please specify)

13) Which of the following areas do you think are most in need of parent / carer involvement and are ones you might consider participating in? (please select all that apply)
- Education (e.g assessment / EHC plans / funding for SEND at schools, specialist provision, home-school transport)
- Health (e.g GPs, CAMHS, physio, OT, SALT, wheelchair service, hospitals, sensory support teams)
- Social care (e.g adaptations, respite, short breaks, direct payments / personal budgets, siblings support)
- Early Help (e.g services for under fives, pre-schools)
- Preparing for Adulthood (e.g post 16/19 education, adult services, independent living, employment / training)
- Information (e.g Local Offer, Information, Advice and Support)
- Other

14) Please use the box below to add any other comments / suggestions about parent / carer participation

15) What education support does your child receive?Â Â If you have more than one child with SEND tick all that apply for them.
- EHC Plan
- SEN support
- None, but it's needed
- I don't know

16) Where is your child(ren) with SEND educated? (please select all that apply)
- Mainstream school / college
- Unit within a mainstream school
- Special school / college

- Private specialist provision
- Alternative provision
- Home educated
- Not of school age

17) Which of these have you/would you turn to for information / signposting to support? (please select all that apply)

- ABC Autism BAME CommunityCare for Carers
- Bridge Renewal Trust
- Carer's Coffee Mornings
- Carer's Forum
- Child's school / education setting
- Difficult Parent
- Downright Awesome
- Facebook groups
- Haringey Autism (NAS)
- Haringey Wheelchair User Group
- Haringey Council Officer / Case worker
- Kith and Kids
- Haringey SEND Local Offer
- Markfield community hub
- Mums in Mainstream
- MyAFK
- National organisations
- Paediatrician / GP / Health Visitor
- Other parent carers
- SENDPACT
- Social Worker
- Step by Step
- WAVE (including Challenge group for pre-schoolers)
- I haven't asked anyone
- Other

18) Have you ever used any of the following services for specialist advice? (please select all that apply)

- A law firm specialising in SEND
- National organisations such as IPSEA, SOS SEN or Contact
- People or local groups offering SEND advocacy services
- Haringey's SEND Information Advice and Support Service (SENDIAS)
- None of the above

19) Which topics do you need more / better information on?

- Diagnosis and my child's condition
- Benefits and financial support
- Education
- Supporting my child's development
- Support for me and my family
- Social and leisure opportunities

- Preparing for adulthood
- Other – please say

21) Please select the top three ways you prefer to access information

- Books
- Fact sheets
- Helplines
- Websites
- Haringey Council's Local Offer
- One to one advice
- Training courses
- Support groups / other parents
- Other – please say

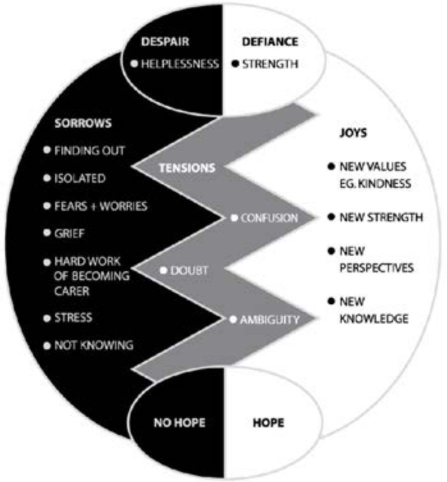
22) Please use the box below to add any other comments/suggestions about this survey.

Appendix 3 – The parent carer journey

Early stage	Middle stage	Later stage
anxiety and effort to secure diagnosis	coping with conflicting advice	reframing 'normality'
shock and feelings of helplessness	realising things cannot always be fixed	drawing on range of expertise
denial	noticing unsustainable physical and emotional effort	developing confidence
guilt	emergence of chronic sorrow	connecting with other families
crisis as life will now be different	navigating service systems	advocating for services
eagerness to put child in hands of expert	exposure to disability discrimination and lack of opportunities	
isolation		

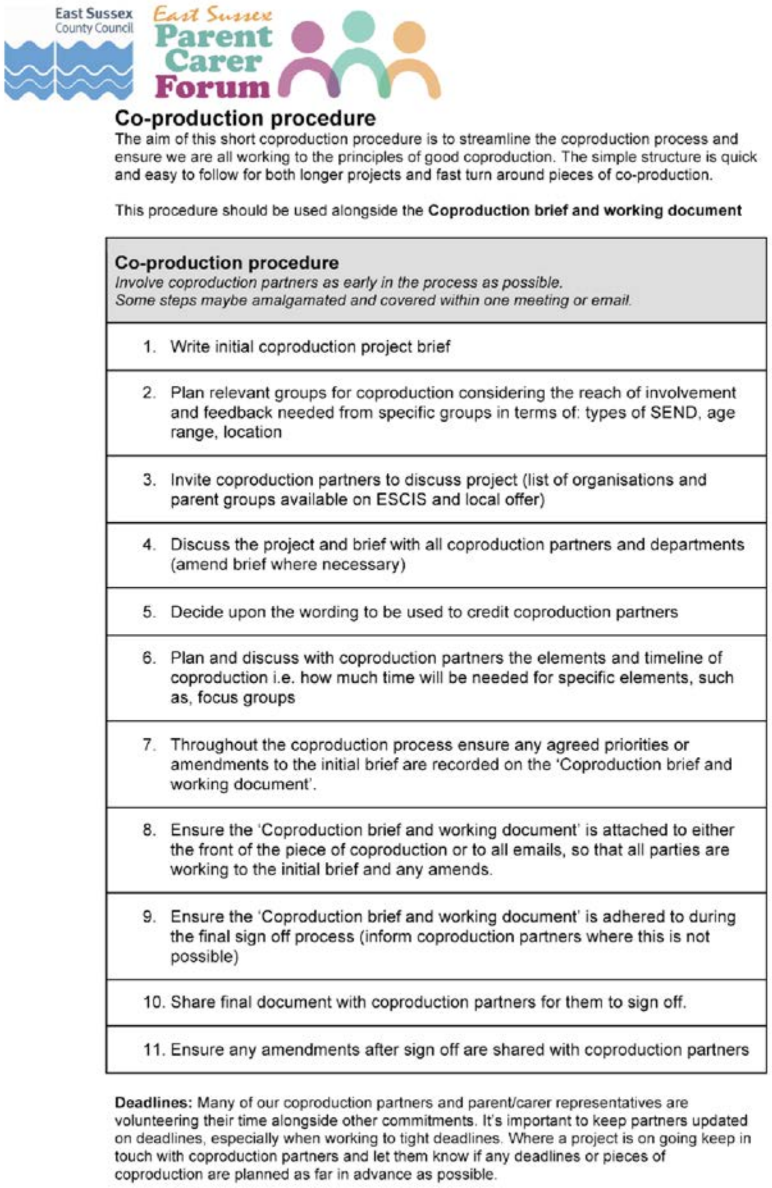
NB: Every parent carer's experience is unique, but for all the journey is not linear – over the course of time parents may switch between stages, most typically if their children receive additional diagnoses, or at times of transition, for example. Parent carers in the middle and later stages are more likely to be able to take part in participation opportunities.

Insider's guide: model of parental experience



Appendix 4 – East Sussex Parent Carer Forum

Co-production procedure document



East Sussex
County Council

East Sussex
Parent
Carer
Forum

Co-production procedure

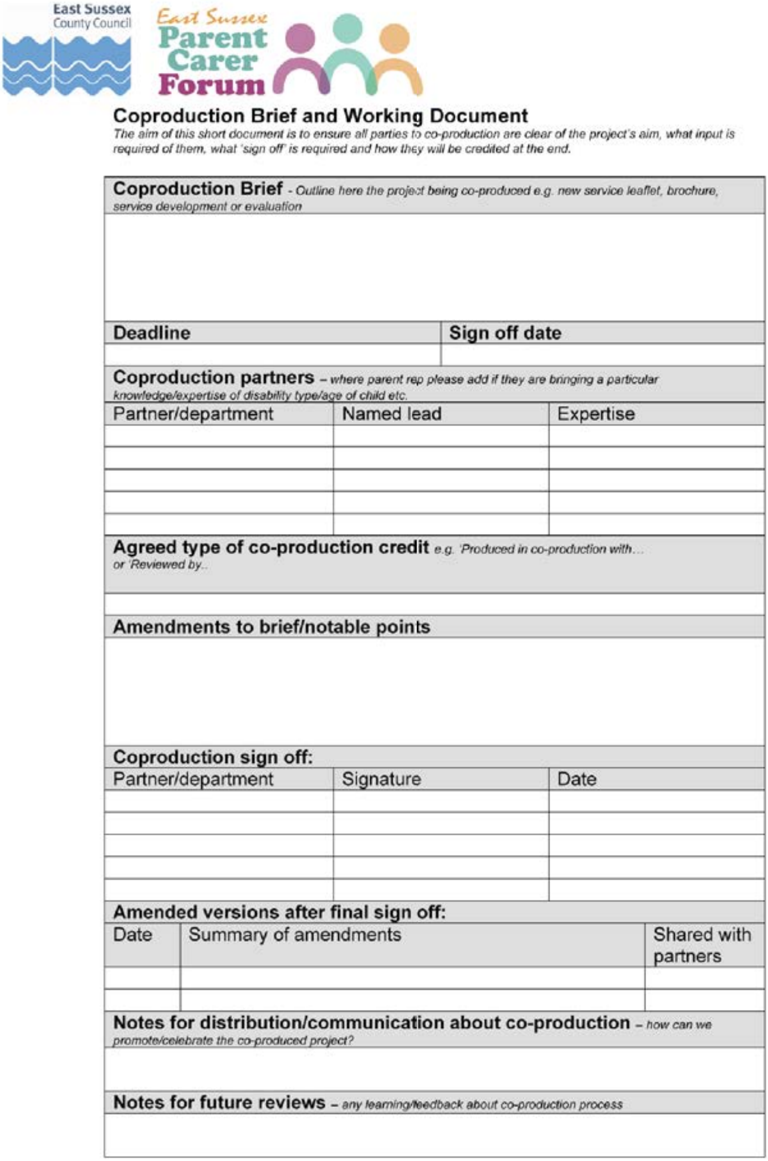
The aim of this short coproduction procedure is to streamline the coproduction process and ensure we are all working to the principles of good coproduction. The simple structure is quick and easy to follow for both longer projects and fast turn around pieces of co-production.

This procedure should be used alongside the **Coproduction brief and working document**

Co-production procedure *Involve coproduction partners as early in the process as possible.* *Some steps maybe amalgamated and covered within one meeting or email.*
1. Write initial coproduction project brief
2. Plan relevant groups for coproduction considering the reach of involvement and feedback needed from specific groups in terms of: types of SEND, age range, location
3. Invite coproduction partners to discuss project (list of organisations and parent groups available on ESCIS and local offer)
4. Discuss the project and brief with all coproduction partners and departments (amend brief where necessary)
5. Decide upon the wording to be used to credit coproduction partners
6. Plan and discuss with coproduction partners the elements and timeline of coproduction i.e. how much time will be needed for specific elements, such as, focus groups
7. Throughout the coproduction process ensure any agreed priorities or amendments to the initial brief are recorded on the 'Coproduction brief and working document'.
8. Ensure the 'Coproduction brief and working document' is attached to either the front of the piece of coproduction or to all emails, so that all parties are working to the initial brief and any amends.
9. Ensure the 'Coproduction brief and working document' is adhered to during the final sign off process (inform coproduction partners where this is not possible)
10. Share final document with coproduction partners for them to sign off.
11. Ensure any amendments after sign off are shared with coproduction partners

Deadlines: Many of our coproduction partners and parent/carer representatives are volunteering their time alongside other commitments. It's important to keep partners updated on deadlines, especially when working to tight deadlines. Where a project is on going keep in touch with coproduction partners and let them know if any deadlines or pieces of coproduction are planned as far in advance as possible.

Co-production brief and working document



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Coproduction Brief and Working Document

The aim of this short document is to ensure all parties to co-production are clear of the project's aim, what input is required of them, what 'sign off' is required and how they will be credited at the end.

Coproduction Brief - *Outline here the project being co-produced e.g. new service leaflet, brochure, service development or evaluation*

Deadline	**Sign off date**

Coproduction partners – *where parent rep please add if they are bringing a particular knowledge/expertise of disability type/age of child etc.*

Partner/department	Named lead	Expertise

Agreed type of co-production credit *e.g. 'Produced in co-production with… or 'Reviewed by..*

Amendments to brief/notable points

Coproduction sign off:

Partner/department	Signature	Date

Amended versions after final sign off:

Date	Summary of amendments	Shared with partners

Notes for distribution/communication about co-production – *how can we promote/celebrate the co-produced project?*

Notes for future reviews – *any learning/feedback about co-production process*