East Sussex County Council

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Building parent/carer participation in East Sussex

In December 2016, East Sussex was subject to a Local Area Inspection of Special Educational Needs and Disabilities (SEND) by Ofsted and the Care Quality Commission (CQC). The results of this inspection were largely positive and we have been able to see from subsequent inspection reports of other Local Areas that we have much to be proud of in the way that children and young people with SEND in East Sussex have their needs identified and met across Education, Health and Social Care.

One of the areas highlighted for improvement in the inspection report was the way which professionals work with parents and carers to shape, review and improve our services. East Sussex recognises that we need to do much more in this are to improve levels of parental satisfaction with our processes and confident in our provision.

All Local Authorities have a local parent and carer forum which acts as the main consultative group for developments around SEND. In East Sussex, the East Sussex Parent and Carer Council (ESPaCC) undertake this role and are designated as a representative group of all families of children and young people with SEND across the county. Although separate from the Local Authority, the local parent and carer forum does, therefore, share some responsibilities for ensuring that parents of children and young people with a full range of SEND across the full range of ages are well-represented and able to engage in development opportunities.

As a result of the inspection, East Sussex County Council commissioned Amaze (a local charity with extensive experience of working with parents and carers) to undertake a review of current parent participation across East Sussex, with a focus in two main areas:

1) What can the Local Authority do to ensure that it has appropriate processes in place to facilitate and improve parental participation?
2) What can the local parent and carer forum do to ensure that it is representative of all parents of children with SEND and improve parental participation?

East Sussex stipulated in the commissioning of the report that we wanted it to be broad in its consultation, engaging with parents and carers from all areas of the county, as well as those already participating with ESPaCC. The outcome of this is a broad set of recommendations, which has been co-produced by parents/carers across the county.

East Sussex County Council is committed to working with partners across Education, Health and Social Care to deliver the recommendations outlined in this report and we will be working together to ensure that we use this report as a springboard to improving our work with parents/carers.

Finally, the Local Authority would like to thank all parents and carers who took the time to engage with this consultation. We will ensure that we circulate, in due course, the action points we will be working on to make improvements in this key area.

If you have any comments on the content of the report, please send them to ISEND.Comms@eastsussex.gov.uk.

Kind regards,

Nathan Caine
Head of Service, Inclusion Special Educational Needs and Disability Service (ISEND)

Building parent carer participation in East Sussex

An independent review by Amaze

commissioned by East Sussex County Countil

November 2017

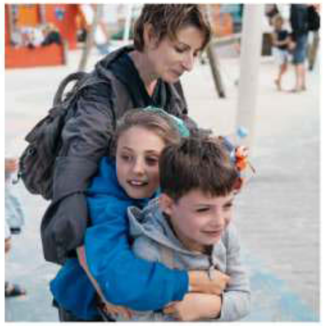
Executive Summary

Over the past year, Ofsted and the Care Quality Commission's (CQC) Local Area SEND Inspections have been assessing how changes to SEND services, which were brought about by the *Children's and Families Act 2014,* have been implemented by local authorities and other service providers.

In East Sussex's Local Area Send Inspection, Oftsed and the CQC found that, as is the case for many counties, there is still much to be done to ensure that professionals involve parent carers of children with SEND and young people with SEND in the design, development and review of services so that resources and services are used to meet the needs of families in the area. As a result of their findings, Amaze was asked to perform a 'critical friend/peer review' of parent carer participation, with the intention of making a series of recommendations about how it could be improved in the county.

Our review involved surveying parent carers, professionals and a selection of parent carer forums nationally. We held focus groups for parent carers, interviewed key service managers and commissioners and collaborated with the parent carer forum, ESPaCC.

Our findings indicate that parent confidence in East Sussex is quite low, because families had not had access to sufficient Information, Advice and Support (IAS) and feel that they have had to fight for services for their child. This was certainly the case among parent carers at our focus groups who, almost without exception, had had extremely challenging experiences. Many parent carers felt that some professionals do not seek – and therefore don't seem to value or act on – their input, which has led to an overwhelming sense of frustration.



It is clear that many parent carers in East Sussex require more support and information to help them to navigate the SEND system. Although some professionals are already committed to co-production and do seek the input of parent carers, there is a need for a cultural change to ensure that this happens across the board so that all professionals view parent carers as equal partners who can make valuable contributions to the design, delivery and review of services.

The *Childrens and Families Act 2014* requires close working across education, health and care services and, as a result, in East Sussex, the SEND strategy is overseen by the SEND Governance and Commissioning Board, which meets termly.

This group is relatively new and there is a need to increase its frequency so it meets on a quarterly basis, and also to clarify its agenda and role in decision-making in relation to the Children's and Families' Steering Group.

There is a need for East Sussex's parent carer forum, ESPaCC, to expand its existing management committee and grow the diversity of membership across localities, age groups, disabilities and ethnic minority groups, to ensure that it has better capacity and that the forum is truly representative of the East Sussex community. A review of the meetings attended, by which reps, and identifying key areas of focus will also help ESPaCC to maximise their impact.

Sharing its input, outcomes and successes with parent carers will be a key factor in motivating existing members to participate and encourage new members to join, while documenting feedback to professionals in a structured way will help the forum to feed into service redesigns, including pathway reviews, which could open up funding for one-off pieces of topic work from CCGs.

We believe there is a great opportunity to develop a communications strategy for how the county wants to communicate across a variety of channels with parent carers. For instance, by improving the scope of both the Children's Disability Register and SENDIASS service so they can be used to regularly communicate with families and help them to feel part of an informed and included community, as well as help to plan services and identify areas of focus for ESPaCC.

However, improving parent carer participation also requires a cultural change with some professionals. There should be a spotlight on the benefits of co-production from the moment new staff join, with participation expectations firmly outlined by senior managers and also placed on the agenda at all meetings and performance reviews with clearer mechanisms for reporting back how decisions and services change as a result of parent carer input. Professionals engaging in more face-to-face work with families will also help to establish better personal relationships and rebuild trust with parent carers.

Parent carers and professionals both expressed a desire to improve participation in East Sussex and in the first instance it is essential that professionals respond proactively to our recommendations and co-produce an action plan to share with the community. It is hoped that this will build on the existing foundations and good examples of co-production to improve participation for the benefit of all children with SEND and their families living in East Sussex.

A note from East Sussex County Council:

In December 2016, East Sussex was subject to a Local Area SEND Inspection. The outcomes for this were largely positive and recognised the very effective work that has been done across the area. One issue for improvement that was highlighted was to improve work with parents and carers. East Sussex County Council places the highest priority on this and have commissioned Amaze to undertake a review of parental engagement across the county. The findings of this review will be used to inform the next steps to driving improvement in the area.

Acknowledgements

Our grateful thanks go to the following people for their time and contributions to our report:
Parent carers who gave up their time to come to focus groups or fill in our survey
The management committee of ESPaCC for their time and input
Kerry Baldwin, ESPaCC Administration Lead, for her hard work and support
The five East Sussex schools that accommodated our focus groups
Care for the Carers, East Sussex
The Greek Orthodox Church of St Mary Magdelene, St Leonards
Danielle Morley for her help in organising our meetings with professionals
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Tina Brownbill and Anne Domeney – for creating and managing our survey
Emily Sanders, iContact
Jo Egan, Care for the Carers
Gail Walshe, Head of Parent Participation, 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 used by the East Sussex Parent and Carers' Council (ESPaCC), 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.

– Sue McMillan, independent writer, researcher and parent carer

Introduction

This independent review of participation and current arrangements to engage with parent carers in East Sussex was commissioned by East Sussex County Council in the summer of 2017 as a result of the local SEND area inspection by Ofsted, which was carried out in December 2016.

Amaze's mission:
Parent carers, children and young people with special educational needs and disabilities are informed and supported to build their resilience and ensure their voices are heard.

Why Amaze?

Amaze is a Brighton-based charity originally formed from two parent carer support groups that now works across Sussex.

The charity provides a range of services for families including: the Information, Advice and Support (IAS) service in Brighton and Hove and East Sussex; Independent Support (IS) across Sussex; the Compass disability register and discount leisure card in Brighton and Hove and West Sussex; a DLA Project; and regular workshops and training. Because of its IAS and IS work in East Sussex, it has some reach to families who may be receiving services, but might not be involved in participation.

In 2008, Amaze helped the Brighton and Hove parent carer forum, B&H PaCC, to set up and still hosts and supports it. Over the years, this work has included running a variety of parent and carer engagement activities and has necessitated much trial, error and learning from testing different approaches. B&H PaCC has 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.

Both Amaze and B&H PaCC have worked with ESPaCC, attending SE7 Pathfinder and now SE19 events, as well as collaborating on a series of workshops for parents about the EHC Needs Assessment and planning process. In addition, the three organisations have collaborated with West Sussex Parent Carer Forum and Hampshire Parent Carer Network on a partnership project and report entitled *What Works for Us*.

We wanted to build on this and work collaboratively to make recommendations about how East Sussex parent carers and professionals could work more closely in the future to improve participation and co-production in the county. We chose to employ a freelance writer and researcher who is also a parent carer (living outside East Sussex) to undertake this piece of work to ensure that the review was carried out objectively on behalf of Amaze.

What is participation?

In the context of special educational needs and disabilities (SEND), participation is the involvement of parent carers of children with SEND, and young people with SEND, in the design, development and review of services so that service providers can ensure that resources and services are used to meet the needs of families in the area. The rights of young people with SEND to participate are set out separately in the *Children's and Families Act 2014* and should also be taken into account by East Sussex service providers, however our review has a specific focus on parent carer participation and how this can be improved.

Participation recognises that parent carers are the experts when it comes to their children and that their input and knowledge is invaluable to professionals. By working with parent carers, professionals can understand what families' needs are and develop flexible, person-centred services to meet these needs.

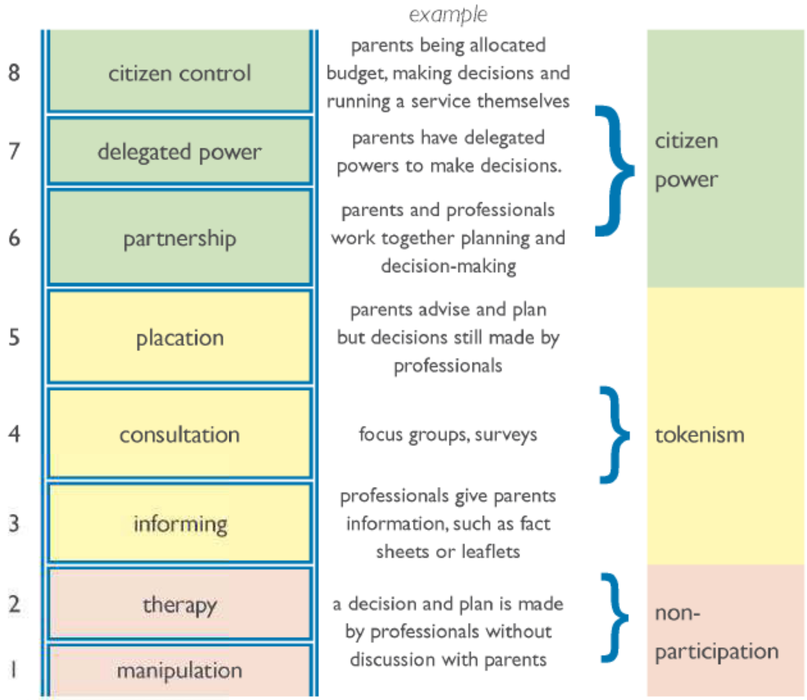
Participation also gives parents an opportunity to air their views and wishes in a constructive way, which can help to build stronger relationships between families and professionals. It also means that parents have a chance to understand some of the challenges faced by professionals and to see why some tough decisions are made.

By working in partnership, parents and professionals can effect change and ensure that services are appropriate and that they will meet the needs of children and young people in the area. Participation also ensures that resources are not wasted providing services that are not required by families.

As well as improving services and the lives of disabled children, young people and their families, participation can also empower parent carers, so that they feel actively involved in planning and provision. If children and young people's needs are met, this can also help to reduce the stress of parent carers.

How does participation happen?

In 1969, US academic Sherry Arnstein described participation in the form of a ladder below), which showed the different levels of involvement that people could have in planning processes. This ladder is still in use today and can be used as a tool to see how involved citizens are in the planning, development and delivery of services.



		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]

Of course, in practice, levels of participation will vary and recognising which type of participation is appropriate at the outset is vital.

For example, setting up a tokenistic exercise in participation with parent carers for a planning decision already been made by professionals behind closed doors would be extremely poor practice, as this could lead to frustration and reduce trust. It also wastes time, which for parent carers is a particular concern as they will have given up precious free time to take part on a voluntary basis.

It is vital, therefore, that participation opportunities are planned properly, with clearly defined boundaries set out for parent carers so that they know what is expected of them. There must be transparency and honesty, so that participants understand what influence they have, what can and can't be changed and most importantly, participants should receive feedback so that they know the final outcome.

SEND reforms and participation

In 2009, the Lamb Inquiry emphasised that it was critical for parent carers of children and young people with special educational needs and disabilities (SEND) to have a stronger voice in decision-making. It highlighted that communication between parents and professionals was key to developing good 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])***

The recommendations made in the Lamb report were key to the SEND reforms that followed five years later with the enactment of the *Children's and Families Act 2014*[3].

Part 3, Section 19 of the *Children's and Families Act* defines the duties of local authorities towards children and young people in England with SEND. It highlights the need to place the child or young person and their parents or carers at the centre of the process, ensuring that they can participate as fully as possible in decisions to achieve the best possible outcomes.

The need to consult with parent carers is also emphasised in the *SEND Code of Practice 2015*[4], statutory guidance that sets out the duties of local authorities and partner commissioning bodies to commission services to meet local needs and support better outcomes. It 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)***

There is an onus on local authorities and their partners to consult parent carers of children with SEND and young people with SEND on a number of levels; individually in order to benefit the child or young person, but also collectively at a strategic level.

The role of parent carer forums

In 2008, the Government's Aiming High for Disabled Children programme was launched. This funded parent participation and also gave money to local authorities to develop short breaks for disabled children.

To do so, local authorities were expected to consult with parent carers and disabled children and young people in order to provide breaks that met local needs.

During the course of the programme, many parent carer forums sprang up across England to support parent participation. In many local authorities, service managers and commissioners found that working with parent carers, and children and young people with SEND, they were able to deliver better services and also spend funding more effectively.[5]

There are now more than 150 Parent Carer Forums, across England, covering almost all local authorities. As representative groups they play 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.

In their joint report, *Strengthening Parent Carer Participation The National Picture*[6], Contact and the National Network of Parent Carer Forums (NNPCF) concluded:

> ***The immense commitment and support shown by many parent carers across England who are active members of their forums, or involved in feeding in their views, is having a significant impact. These outstanding efforts are making a real difference, supporting service providers and commissioners to ensure that provision for disabled children and families are the best they can be, which ultimately promotes the wellbeing and life opportunities of disabled children and young people[6].***

The Department for Education's *Ninth Special Educational Needs and Disability (SEND) Reforms Implementation Survey for Parent Carer Forums*[7], asked forums the following:

Reasons known to your parent carer forum to explain where things are going well with joint commissioning arrangements within their local authorities:

- integration
- multi-agency working groups and panels
- shared budgets

What are the most significant barriers and challenges to joint commissioning?

STAFF:
- *turnover and attitudes*
- *difficulties with buy-in from the top*
- *capacity issues (social care staff)*
- *nobody to champion*
- *lack of leadership and too many*
- *levels of hierarchy*

FINANCIAL:
- *reluctance to pool budgets*
- *gate-keeping of budgets*
- *funding*

OTHER PRESSURES:
- *pressure on education to deliver*
- *time scales*

LACK OF UNDERSTANDING *of co-production and responsibilities/accountability in health staff*

INCONSISTENCY:
- *in criteria*
- *in methods of delivery*
- *in methods of measuring outcomes/progress towards them*
- *different priorities*
- *competing priorities*
- *of agendas*

COMMUNICATION AND INFORMATION SHARING:
- *compatibility issues with IT systems*
- *lack of transparency between agencies*
- *lack of guidance on personal budgets*
- *families not at the centre and views not always represented*
- *silo working*

Local area SEND inspections

In the December 2016 *Joint Local Area SEND Inspection report for East Sussex*, Ofsted and the Care Quality Commission stated:

> ***'leaders recognise that there is more work to do to increase the participation of parents, carers and children and young people in assessing the work of the local area.[8]'***

This was highlighted as a challenge that many areas still face in Ofsted and the Care Quality Commission's recent report, *Local Area SEND Inspections: one year on*[9] They found that over a third of local areas did not involve children and young people or their parents sufficiently in co-production. This report goes on to say that local area leaders were unaware of the depth of frustration among local parents and what their concerns were about. This is a significant challenge for many local areas, including those that were judged to have implemented the reforms well.

The report goes on to highlight other concerns, including parents feeling that there was lack of transparency in the decision-making process and that their voices were not heard, particularly if there was a disagreement between professionals and parents on decisions. There was also dissatisfaction amongst parent carers around the way in local areas work with them to develop plans, make decisions and agree outcomes.

In contrast, the report also highlighted that where strategic co-production has been most successful, the local area's parent and carer forums have sought and used the views of parents to inform their discussions with leaders and their role in co-production. It cites Brighton and Hove as an example where good co-production is in place:

> ***The forum draws on its members, keeping them informed of meetings, consultations and imminent changes in provision using a range of social media and other devices. This means that parents are represented at all partnership meetings between leaders in education, health and care .... Local area leaders are clear about and sensitive to the impact of decisions and changes on families. They take this fully into account when planning strategically for the future. Parents feel valued and part of the improvement planning for provision in the city, including understanding the reasons why decisions are taken.[9]***

Good practice:
Gloucestershire Parent Carers

Aim: to represent the views of a greater number of parent carers, including those in rural areas and ethnic minorities.

#1: encouraged parents to set up local support groups, which nominated representatives to sit on the forum's steering group.

#2: consulted membership and broadened methods for parent carers' input. Offered to reimburse travel and childcare to encourage parents to attend.

#3: organised a road show of events targeting isolated rural areas.

#4: collaborated with community workers and leaders of BAME communities to run targeted consultations that were culturally appropriate.

#5: produced new promotional and publicity material with photos representing a diverse range of parent carers, children and young people.

#6: improved communication around successful outcomes and the benefits of participation to encourage parents to join.

Outcome: membership doubled from 500 to 1,000. The steering group now includes a diverse range of parent carers and is recognised by parents and professionals as being a truly representative group.

Key point: the forum is supported by a part-time-care coordinator funded by the local authority and hosted by Carers Gloucestershire, without which they would not have the capacity needed to run these new initiatives[10].

Good practice:
Hull Parents Forum

NHS Hull Clinical Commissioning Group (CCG) funds a parent participation coordinator to support the forum. In return the forum agrees to carry out engagement and consultation with members regarding health services*. Successes over recent years include:

#1 The Wheelchair service: two parent reps were involved in the procurement of a new wheelchair service.

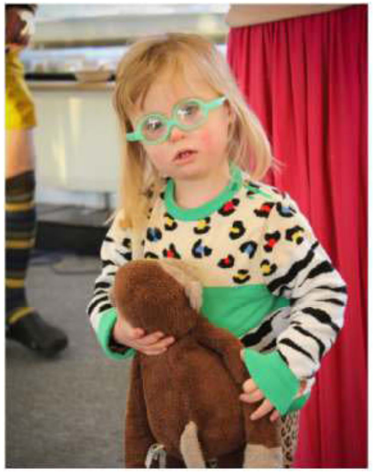
Outcome: service improvements, reduced waiting lists, an improved maintenance and repair service, fewer complaints.

#2 Autism assessment and diagnostic pathway: parents helped to draft a leaflet describing the pathway and a covering letter sent to parents whose children were referred to the service. Focus groups ran by the forum allowed them to seek parental feedback and make changes to the leaflet before it went live.

Outcome: the lead commissioner for children's services meets fortnightly with the forum to provide updates about the service and it is performing. More children are diagnosed earlier and appropriate support is put in place for families[11].

* Note: Brighton and Hove CCG funds B&H PaCC to research and report on four health topics each year. Recent topics include: mental health, A& E and GPs.

The local picture



East Sussex covers an area of 1,725 square kilometres (666 square miles)[12] and in 2016 had an estimated total population of 547,797 people[13]. The county consists of two boroughs: Eastbourne and Hastings; and three districts: Lewes, Rother and Wealden[12].

The county is predominantly rural, although the majority of the population is concentrated in urban areas and market towns. East Sussex's large area and it being the county with the highest levels of deprivation in the South East both present challenges for the successful engagement of parent carers, who may not have the time or resources to travel to parent carer events, especially due to the relatively poor transport infrastructure in the county[12].

In January 2017, the Department of Education's annual school census[14] showed that in East Sussex of the 73,414 children and young people in education, 9,779 children, or 13.3% of the total number on the roll have had Special Educational Needs identified[15] with an above average number having needs requiring an EHC Plan.

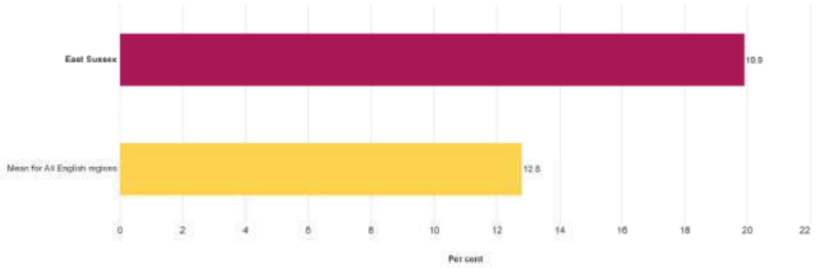
	Total pupils	Pupils EHC Plans/ Statements		Pupils on SEN Support		Total pupils with SEN	
	Number	Number	%	Number	%	Number	%
East Sussex	73,414	2629	3.6	7,150	9.7	9779	13.3
England	8,669,080	242,184	2.8	1,002,069	11.6	1,244,253	14.4

Source: DfE, Special Needs in England, January 2017[14, 15]

In addition, the county also has an above average number of children in need with disabilities. According to the DfE's *Local Area Send Report* 2016/17[16], 19.9% of school-age children in need* have a disability, compared to 12.8% in all English regions.

** Children in need are defined in law as children who need local authority services to achieve or maintain a reasonable standard of health or development, need local authority services to prevent significant or further harm to health or development, or are disabled*

These figures suggest there's more pressure on education, health and social care, and more investment and support may be required to meet the needs of these children and their families. Consequently, there is a need for this to be taken into account and reflected in funding levels and investment in both services and in creating opportunities for engagement or co-production of service development in the county.


% of children in need with a disability (2015/16)

Source:
Metric ID: 2246, Department for Education, Characteristics of Children in Need in England

Powered by LG Inform

Delivery of health and care

Three Clinical Commissioning Groups (CCGs) are responsible for commissioning hospital and community health services in the county these are: Hastings & Rother; Eastbourne; Hailsham and Seaford; and High Weald, Lewes, and Havens.

The SEND Governance and Commissioning Board consists of professionals from across education, health and care and parent reps from the East Sussex Parent and Carer's Council (ESPaCC). This board meets termly and is viewed by professionals as one of the key routes for the parent carer forum to influence and engage in co-designing and co-producing all services for children with SEND in East Sussex, including health and social care.

However, the board is relatively new and there is a need for further clarity around its role in decision-making, as there is a perception by ESPaCC that some key decisions are taken outside of this meeting or at a higher level at the Children's and Families' Steering Group.

In addition to the SEND Governance Board, there are also two programmes running with a focus on adult health and social care. The East Sussex Better Together programme, which covered Hastings & Rother and Eastbourne, Hailsham and Seaford CCGs is currently in a period of transition to the new East Sussex Better Together Alliance, which aims to provide more integrated health and social care. This has resulted in eight integrated locality teams being set up (appendix 3) consisting of nurses, therapists, social workers and care practitioners, which are aligned to a small number of GP practices. In future, it's planned that service users will have a care co-ordinator as their main point of contact who is responsible for ensuring their needs can be met.

Connecting4You is also running as a separate programme for some services in High Weald, Lewes and Havens CCG and there is a need to clarify how this will fit into the strategic picture, particularly as a number of partnership boards have been replaced by the East Sussex Collaborative Health and Wellbeing Stakeholder Group, which will have 15 seats for community representatives.

These programmes are currently limited to adult social care, which means that although the parent carer forum has a seat on the Collaborative Health and Wellbeing Stakeholder Group to represent young people aged 18 to 25 with SEND, the SEND Governance Commissioning Board will continue to be the most suitable forum for discussing the health and care needs of children with SEND aged from 0 to 18 years.

East Sussex Parent and Carers' forum (ESPaCC)

East Sussex Parent and Carer Forum (ESPaCC) was established in 2011. It is funded by the DfE and a joint funding agreement with ESCC and the three East Sussex Clinical Commissioning Groups (CCGs).

Until recently ESPaCC consisted of a management team of eight people, three of whom have prior experience supporting parent carers through Parent Partnership/ Parent Link and as parent supporters. Recently, two members of the management committee stepped down due to their care commitments, but they continue to have occasional input in the forum as associates. Of the six current members of the Management Committee, two are non-voting members since they are paid for their part-time roles with the forum.

ESPaCC in numbers

6: management committee
(two non-voting)

16: active parent reps

506: families reached

317: completed contact forms

284: Facebook likes

619: Twitter followers

ESPaCC is based in Eastbourne and currently 317 of their contacts have completed a form with additional information such as location, age of children, type of SEND and so on, which means targeted engagement by area, age or need can be carried out.

The forum has sixteen active parent reps, two of whom are also involved in running parent support groups within the county. Between them, the reps have 18 children with SEND ranging between 3 and 19 years, with the majority (14) aged under 14. The children are educated in a variety of settings, including mainstream schools; facilities within mainstream settings, special schools and several are home-educated.

ESPaCC feel that partnership and co-production was at its height between 2012 and 2014 in the county and that during this time they had a meaningful role in shaping services. Shared training and effective meetings meant that parents and professionals worked together as equal partners, with transparent decision-making.

Since 2014, the implementation of the *Children's and Families Act* has placed additional pressure on local authorities, particularly due to the additional work created in transferring all Statements of SEN to EHC Plans by March 2018. ESPaCC say this has resulted in a number of challenges in their engagement with professionals:

CHANGING GROUPS AND RESPONSIBILITIES:

- *there is a perception that parent reps are not invited to all senior meetings*
- *reps spread across too many groups*
- *staff turnover – new relationships must be built from scratch*

PRESSURE ON PROFESSIONALS:

- *staff taking on extra roles/responsibilities*
- *less time to attend meetings and engage with parent reps/parents*
- *fast turnarounds mean less time to seek parent carer views*
- *short-notice for meetings/ consultations*

COMMS AND PLANNING

- *less notice for meetings*
- *some meetings held at times when parent reps are unavailable*
- *short deadlines for document review*
- *inconsistency of parent carer input*
- *parent carers not on board at start of some new projects/processes*
- *no chance to feed into some important documents e.g. transport survey; iSEND services demand.*

Good practice in East Sussex

Recent successes for ESPaCC include their role in supporting the Local Authority to secure the appointment of a Designated Medical Officer (DMO) to improve links between the Local Authority, schools and health services.

Other successes include the ESPaCC rep for the Information Advice and Support (IAS) steering group undertaking a snapshot survey of contacts regarding the new IAS service in order to feed parent carer views into a meeting. In a 24-hour period, there were 71 responses, which shows that the forum can have good reach and provide information for professionals on a very tight schedule.

In addition, ESPaCC, the local authority and CCGs have drafted a Memorandum of Understanding (MOU) which, at the time of writing, was awaiting final sign-off by all parties. The MOU sets out how ESPaCC, the local authority and the CCGs will work together to ensure there is effective parent carer participation in the shaping of services, provision, information and support. It also sets out the roles and responsibilities of each party in ensuring that co-production happens and there are effective outcomes in the planning and delivery of SEND services for children, young people and their families.

We suggest there is an opportunity to review the delivery against the MOU annually and report back families how the MOU is being met and to celebrate good practice with the relevant professionals. Showing commitment to parent carer participation by signing off this document will reassure families, so we would recommend that this is signed off as soon as possible.

Case Study:

Autism Pathway Review and Implementation Group (APRIG)

This short-life group was formed from representatives from education, health and parent carers; including two from iContact, an autism specific parent support group in the county. Additional iContact parent carers formed a working group to feedback directly on the three documents produced: the autism spectrum diagnostic pathway; post-diagnostic support; and a leaflet for the Scott Unit explaining what to expect at appointments.

During the project, parent carers and professionals collaborated positively. Good communication enabled honest and transparent working relationships to be established, which meant that potential pitfalls were quickly identified and overcome in partnership.

Outcome: the deadline for finalisation of the pathway has been met and the three supporting documents were signed off. This could not have been achieved without the full participation of all representatives. An ongoing group of iContact members, ESPaCC parent reps, health and education will meet regularly to review parental experience of the pathway and make further improvements as required.

This positive co-production experience and the learning from this project can be used by parents and professionals to inform future partnership working.

Our review

For our review, it was essential that we spoke to a representative cross-section of parent carers, whose children have different types of SEND, across all age groups from birth to 25 years.

We wanted to hear from families of school age children who have an EHC Plan, as well as those who receive SEN Support. We felt it was essential that parents whose children attend mainstream schools or specialist settings made their views known, as well as those who home-educate.

Our review also aimed to understand what elements need to be in place to facilitate better parent carer engagement . Consideration was given to parent carer resilience and whether this is a factor that influences their capacity and ability to participate. We wanted to understand whether there are stages in the 'parent carer journey' (see appendix 8) where they might feel more able or willing to engage.

A 360-degree process

Participation is a dynamic process which involves commitment from both parent carers and professionals. We sought the input of ESPaCC and Nathan Caine, Head of iSEND to shape the review's focus. We also felt that it was essential to canvas the views of professionals as well as parent carers. We wanted to find how widely the benefits of participation and engagement are understood by professionals and whether there is the vision to achieve co-production across the board.

We also wanted to talk to other parent carer forums to see what was working well for them and incorporate their learning and reflections to inform our recommendations.

Consequently, we supplemented our parent carer survey with focus groups. We also held meetings and update sessions with ESPaCC. In addition, we ran concurrent surveys for professionals and parent carer forums. In addition, we also held one-to-one meetings with some key service managers and commissioners, whose views have added further clarity to our findings.

Reach

Amaze worked collaboratively with ESPaCC and parent support groups in East Sussex to reach parent carers with children and young people of all ages, including those who may not have been involved in parent participation/voice work before.

Our survey and focus groups were widely advertised using both paper and e-flyers via the following channels: ESPaCC newsletter, website and Facebook page; East Sussex support groups and their Facebook pages; mainstream, special and independent schools; the disability register, iSEND team and Care for the Carers. Paper flyers were also mailed out to a number of local organisations for their service users, including child development clinics, health visitors, libraries and children and family centres.

Focus groups

Five of our focus groups were held at a selection of education settings across the county, covering mainstream, special, alternative and private independent provision. Focus groups were open to all parent carers, not just those with children and young people attending the settings.

Two additional focus groups were held in community settings. Most focus groups were held during the day, with one evening group for working parent carers.

Confidentiality

In order to encourage all parties to be open and candid, our review has been conducted on a confidential basis. All survey findings and focus group comments have been anonymised.

Our findings

Who responded?

Our parent carer survey had 142 responses. The majority of respondents have children with a number of different additional needs or disabilities. Sixteen participants have more than one child with SEND.

More than 80% of respondents have children with SEND of school age (5 to 16 years) with a further 15% having young people aged 17 to 24 years. Only 5% had children with SEND aged under five, but this was expected as some children's additional needs/disabilities may not be identified prior to a child starting 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.

We heard from an almost identical number of families of children educated in a mainstream settings as those who have more specialist placements requiring an EHC Plan. We also heard from a smaller number of parent carers whose children attend alternative provision, are home-educated or not of school age.

Of the children in mainstream settings, 56% receive SEN Support, while a further 30% did not receive support but parent carers felt it was needed. Just 11% had children with EHC Plans in mainstream settings.

Just over 50% of parent carers indicated that their children have EHC Plans, the majority of whom are educated in specialist placements, including special schools and colleges, mainstream units and private specialist provision.

*Where are participants' children or young people educated?**

66 – mainstream setting
65 – mainstream unit, special school/college or private specialist provision
6 – alternative provision
9 – home-educated†
9 – not of school age

† includes a number of children who are currently at home awaiting a suitable placement to be agreed

** note, raw values given, as some families have more than one child with SEND*

In addition to the survey, our focus groups had 73 attendees and included a range of parent carers, from stay-at-home mothers and fathers, grandparents, working parents, home educators, to parent carers with additional needs or disabilities of their own.

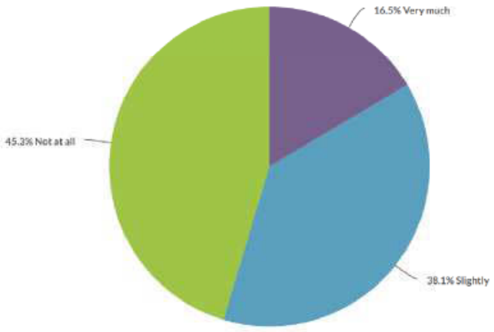
Six attendees had preschool children, three of whom said that they felt the support and advice they had received from early years services meant they were better informed and therefore able to participate at an earlier stage than might be usual for parent carers.

How involved do parents feel?

In the *Ninth Special Educational Needs and Disability (SEND) Reforms Implementation Survey for Parent Carer Forums, Spring 2017*[7], parent carer forums across England were also asked how well engaged they felt parent carers were in strategic planning and co-production. They said:

> *‘64% of forums feel that parents are largely or fully engaged in strategic planning with their local authority.’*[7]

In our survey, we asked parent carers how involved they felt in the planning, shaping and evaluating of services for their child(ren):



How involved do you feel in planning, shaping and evaulating services for your child?

see appendix 7 for a large version of this chart

Just over half (54.6%) of parent carers indicated that they feel very much or slightly involved and 45.3% of parent carers said that they were ‘not at all involved’.

It is difficult to make a direct comparison between our survey and the findings of the SEND Implementation Survey, due to the differing samples and point scales used. However, our survey results suggest that parent carers in East Sussex may feel less involved than the perceived levels of participation reported elsewhere by parent forums nationally.

This suggestion is supported by the views expressed by focus group attendees. We asked them what came to mind when we said, ‘participation.’ They said:

“This is the first time I’ve been asked to participate. It’s a game-changer!”

“Participation has a power dynamic to it – are we an equal partner?”

“Disjointed. We don’t work in partnership and it’s not joined up.”

“a tick-box exercise”

lip-service

“I don’t know how you become aware of participation opportunities. I havent had any information”

lack of communication

“We’re not being listened to!”

frustration

complex

Do parent carers understand 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.

The majority (98) knew that a parent carer forum’s role was to find out what was important to parent carers of children with SEND. Just under half (69) of those surveyed knew that a forum represented parents/carers at meetings attended by professionals. Over a third of parents (55) said that a forum may offer training.

However, 30 of our respondents said that they did not know what a parent carer forum did, while 37 incorrectly believed that a forum also offered one-to one advice. This means that collectively, just under half of those responding were unclear about the role of a parent carer forum.

Do parent carers know about ESPaCC?

Just over half (78) of our survey respondents had not heard of ESPaCC and, as responses to the previous question show, many of our respondents were also unclear as to its purpose. In a later question, 82.8% of parent carers said that they found accessing information in East Sussex 'very' or 'quite difficult'.

> *I had no idea there was a forum, no one has mentioned it to me*
>
> – survey comment

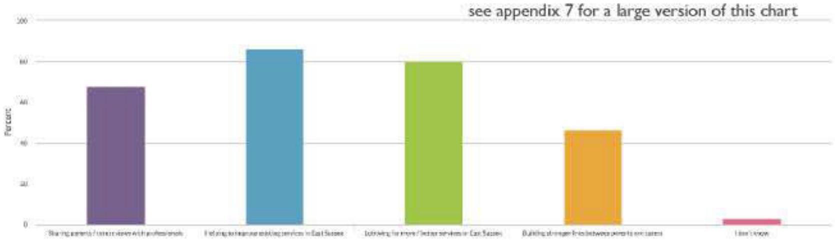
These findings highlight a need to improve information delivery for parent carers, which local authorities have a statutory duty to provide via SENDIASS. This service should signpost families to alternative and additional sources of advice, information and support locally and nationally. In its new role delivering SENDIASS in East Sussex, Amaze will continue to work collaboratively with the forum and other service providers to improve parent carer knowledge and empower them so they feel able to participate.

Increasing awareness of the forum and its role will provide ESPaCC with the opportunity to grow its membership. As was shown in the survey, of the 62 parent carers that had heard of the forum, more than 80% had signed up to become a contact, with around half engaging with ESPaCC's Facebook page, website and attending an ESPaCC event. More than half had also considered becoming more involved with the forum.

Of the parents that had heard of ESPaCC, 60% said the views of parent carers in the county were represented 'very well', or 'OK' by the forum, with 18% saying they felt that their views were not represented by the forum.

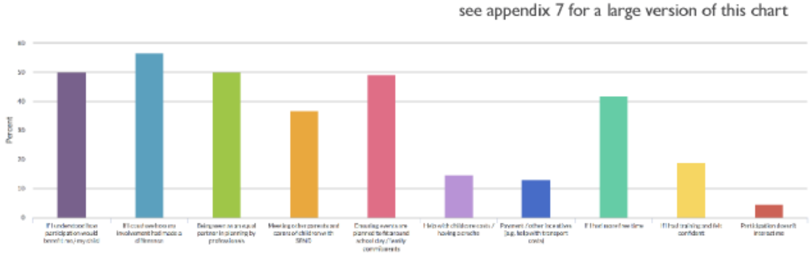
The findings illustrate that in East Sussex, a high proportion of parent carers who know about the forum sign up, which is very positive and shows there is a willingness to engage once parent carers are aware of its existence and its role.

What do parent carers want their forum to focus on?


see appendix 7 for a large version of this chart

The majority of parent carers surveyed (121) want their forum to help improve existing services in East Sussex, and (112) lobby for more/better services in the county. Many respondents (95) also wanted the forum to share parent and carer views with professionals, while almost half those surveyed (65) also wanted their forum to build closer links between parent carers.

Persuading parents to get more involved in participation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As the above graph shows our survey respondents said there are four ingredients which are vital to persuade them to participate: 56% of parent carers said it was seeing how their involvement makes a difference; 50% wanted to understand how participation would benefit them and their child; 50% wanted to be seen as an equal partner in planning by professionals; while 49.3% of parents wanted events planned to fit around the school day/family commitments.

Knowing that parent carer input has led to changes and successful outcomes is essential to sustain engagement. It also ensures that parent carers feel that their time and feedback is valued by professionals. Gloucestershire parent carers found that this was a particularly important factor in encouraging fathers to join the forum, as they were more likely to do so if they heard about successful outcomes in improving services[8].

The 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 to as a result. ESPaCC could look at asking professionals to report back on parent carer feedback using this format, to show parent carers how their input has effected change.

Parent carers at our focus groups were also emphatic on this point. Most of our attendees wanted to participate in future, provided there were clear parameters around the piece of work they were contributing to. They wanted to know how their contribution could make a difference and for there to be transparency around what could be changed or achieved. They highlighted the following as factors which would help them to get involved:

"Inform parents that they can participate in a variety of ways."

"Flexible ways of working, such as Facetime for meetings."

"Clear boundaries about the work."

travel expenses

"a clear agenda"

"Meetings in local satellite venues."

feedback

honesty and transparency from professionals

"will my input have an impact?"

"If you knew you were being listened to you would commit."

"They need to be upfront about what they can change."

mentoring

flexibility

Parent carers emphasised that they would get more involved if they understood how participation would benefit them and their children – again, this is something which could be achieved by improving information delivery so that parent carers understood the role of their forum and how their engagement could improve services for their children.

It is also vital that professionals understand that parent carers have very limited spare time. To improve rates of involvement, professionals must give careful consideration to the timing of meetings so that parent carers can attend. Some working parent carers in our focus groups highlighted that they do not have the opportunity to participate unless they take time off, which isn't usually possible. Most parent carers need meetings to take place between 10 a.m. and 2 p.m. but having some participation events in the evening would ensure that working parent carers can contribute, too.

In order for this to happen, it involves a certain amount of cultural change in working practices. Allowing more time for participation needs proactive thinking to facilitate better planning for all parties and will ensure that parent carers are consulted at the start of each process in order to use resources as efficiently as possible.

It is also important to parents and carers that they are seen as equal partners in planning by professionals, with 50% of respondents choosing this as a key factor.

In our focus groups, parent carers said they felt some professionals did not value their knowledge or expertise, although they knew their children better than anyone else and therefore could – and should – be seen as experts in their child's condition.

> '...many of us are, in our own working lives, just as experienced, qualified or 'professional' as them, yet simply because we have disabled children we are patronised and belittled.
> This continuing problem – particularly with the LEA – makes it hard to want to engage...'
>
> *– survey comment*

In several groups, they expressed frustration that they were often addressed as 'mum' or 'dad' in meetings rather than by name, which they felt diminished their position as equal partners and also devalued their knowledge and contribution.

What would parent carers get out of participating?

We asked our focus group attendees what they would get out of participating. They said:

"I would feel empowered."

"Helping the next generation of children and their families."

"We are an untapped resource, which could save resources."

"Making a difference, even a small one!"

knowledge

More compassion from professionals.

cohesion

possibility

"a more organised system"

change

"The campaigning strength in collective voices."

joy

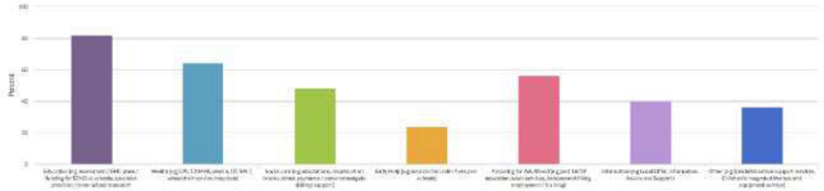
"We are so cynical, all of us, because we've had so many bad experiences. I would like to go into something positively, knowing the right things will happen."

improved services

Which services are most in need of involvement and which would parents consider participating in?

We also asked our survey respondents which services they thought were most in need of parent/carer involvement and are ones they might consider participating in. They said:

See appendix 7 for a large version of this chart



Respondents' top priority was education, with 81.8% stating it was most in need/the area in which they would consider participating, closely followed by health (64.2%), preparing for adulthood (56.2%) and social care (48.2%).

> ### *How do parents wish to participate?*
>
> *69% – via surveys*
>
> *46% – meetings and focus groups*
>
> *39% – professional events on key SEND topics*
>
> *33% – training as a rep and going to meetings*

We also asked parent carers how they would like to participate, shown left. The majority were happy to provide feedback/views via surveys, while almost half said they would attend focus groups and a third said they would go to professional events on key topics, or consider training as a forum rep and attend meetings.

A final word on our focus groups

In all focus groups, there was an overwhelming sense of frustration from parent carers. It was clear that with one or two exceptions, they had had extremely challenging experiences and many felt cynical about whether our review would improve things in the county.

> Trust needs to be built within SEND parent carer groups... I feel parents will only participate if/when they feel their voice is being heard and a consistent line of communication is built up.
>
> *– survey comment*

However, despite their doubts, their strong desire to improve services in East Sussex meant that they were still willing to give up their time to ensure they could participate in our review.

Many had travelled long distances or struggled to get childcare. Their determination to ensure that their voices were heard and their hope that things will improve must be recognised by professionals. This is an opportunity for professionals to rebuild trust and relationships with parent carers. It is essential that professionals respond proactively to this review's findings and co-produce an action plan to share with the community.

Our parent carer forum survey: key points

We spoke to seven forums; three were interviewed / completed online telephone surveys; four responded to an online survey.

15
largest steering group/ management committee

350 to 1,500
membership size, smallest forum to largest

10
average size of steering group/ management committee

6
smallest steering group/ management committee

2
average number of paid part-time staff

£13.86
average hourly rate for paid staff

£33,000*
average annual budget
(* data from 6 forums)

challenges

- increased demand – need to prioritise involvement
- capacity of steering group/ management committee
- staff turnover in local authority/ other service providers
- persuading some professionals that participation is beneficial

Parent carer forum findings

We consulted seven parent carer forums, gathering information via interviews and online surveys. We found that in spite of their different locations across the country that there were many similarities in the challenges they identified.

For the majority, cuts to services, increased demand from parent carers and pressures to attend a constantly growing list of meetings means that forums are often over-stretched particularly those who have limited budgets and mostly rely on the DfE grant.

However, one flagged that their steering group produces a yearly workplan with the local authority and health, which helps to plan parent rep commitments.

Three forums reported that their local authorities have comprehensive disability registers, while three others stated that they had limited ones. Only one is using the disability register to communicate with families, which increases their reach from 350 families to 2,000 and means that some communications or requests can be targeted to specific groups by age, geographical area or condition, for example.

The forums we spoke to reiterated the findings of the Department for Education's *Ninth Special Educational Needs and Disability (SEND) Reforms Implementation Survey for Parent Carer Forums*[7], which highlighted the following actions as ways to break down barriers to participation:

> ***Formal working agreements with joint visions, processes and pooled budgets; workforce development; strong, united and effective leadership with buy in from the top; and improved communications and information sharing were the most prevalent suggestions for action. The need for attitudinal change and of having families at the centre of outcomes-driven decisions being made about them, were also cited.***

Good practice:

Bristol Parent Carers

Bristol Royal Children's Hospital has embedded parent participation in many areas of its work with children with disabilities. Examples include:

Working groups and feedback to management: parents work together with professionals on working groups focused on particular areas/topics. They are also invited to give feedback to the management team at board meetings.

Parent involvement in pathway development: parents and young people are involved in developing pathways for different conditions to support a person-centred approach by professionals.

Meetings, planning and flexibility: a meeting schedule is sent to parent reps in January to allow time for planning. There is an open meeting annually for any parent, carer or support group to give feedback. Thought is also given to childcare – when a parent rep had to attend a working group meeting in the holidays, the hospital arranged for the play specialist to care for her child so she could attend.

Family fun day: held annually, this event is a chance for parent carers to give feedback, get information from staff, including hospital managers, while their children engage in music, craft and other activities[17].

Professionals and participation

For our review, we invited 24 professionals to take part in our research, with 15 agreeing to participate. Eight professionals filled in our survey and a further seven were interviewed face-to-face.

Professionals said...

100% – said they had strong links with ESPaCC

6 – had heard of the Co-production Memorandum of Understanding (MOU)

Are all members of your team aware of stated commitments to participation and co-production:

YES: 57% NO: 29% DONT KNOW: 14%

Had received training in supporting parent participation:

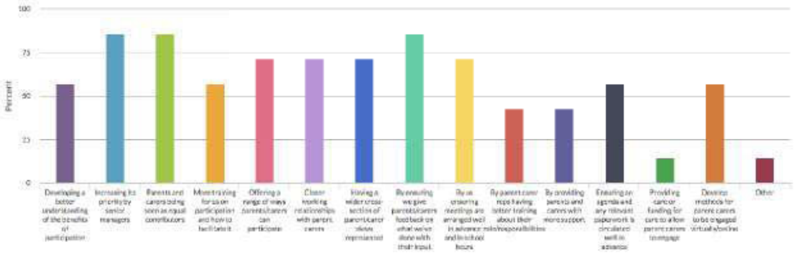
3 – me 2 – my team
3 – No 1 – don't know

How well is parent carer input used to inform your team's decision-making?

VERY WELL: 14% QUITE WELL: 57%
NOT WELL: 29%

We asked how they thought participation could be improved. They said:

see appendix 7 for a large version of this chart



Top priorities for the respondents were: ensuring parent carers had feedback on what had happened with their input; increasing participation as a priority with senior management; and parent carers being seen as equal contributors.

Other key factors that were identified were ensuring meetings were arranged well in advance and in school hours; offering a range of ways for parents to participate; closer working relationships with parent carers and having a wider range of parent carer views represented. Although our sample size was small, the professionals who did respond were very much on the 'same page' in terms of what they saw as the key ingredients to improving participation of parent carers.

In the subsequent survey question, 'what are the difficulties in involving parent carers' professionals identified what they felt were the barriers to participation. 43% said they felt parent carer reps were spread too thinly across too many groups, while 57% said that they felt that staff do not have enough time or capacity to seek parent carer input.

In fact, our case study on page 22 regarding the Autism Pathway Review and Implementation Group (APRIG) shows that this need not be the case, as parent carers were involved at every stage without it impacting on the deadline. This suggests there may be a need to change staff perceptions of working with parent carers and its importance.

We think the publication of this report will provide an opportunity for East Sussex County Council to give a renewed focus to the importance of co-production with professionals as well as the community of families.

Interviews

We conducted face-to-face or telephone interviews with seven senior members of staff from education, health and care.

All staff that we spoke to indicated that they were committed to improving participation in East Sussex. Several acknowledged that there is the need for a cultural shift in attitudes towards parent participation, but that it would take time for professionals to move from the existing model, which is consultation-based with limited feedback, to true co-production with parent carers.

The success of the Autism Pathway Review is an excellent example of what can be achieved by working with parent carers. It is hoped that the learning from the pathway will also encourage professionals to plan co-production opportunties on a wider scale in future.

Education

'we want to be allies, not enemies"

– parent carer comment

Professionals working in education suggested that participation was harder in East Sussex due to the lack of parental trust in the SEND assessment system. It was acknowledged that change was needed, but this will take time and a particular challenge is achieving co-production on an individual case level, and on a day-to-day basis, such as in SEN assessment and planning.

The need for partnership working was also highlighted by the majority of parent carers at our focus groups. They expressed a strong desire to work collaboratively with professionals, but they felt that this was a struggle at times.

This may be partly due to legacy of a period where there were high levels of staff turnover in the iSEND team which led to a lack of capacity to maintain good communication with parent carers. This has contributed to a reduction in trust and a perceived lack of honesty and transparency. However, the Head of iSEND now feels that the team is more stable, case workers are taking ownership of issues and improving communications is a top priority. The challenge is to ensure that new entrants to the system have better experiences, but the local authority acknowledges that there is also a need to rebuild relationships and confidence with parent carers who have had negative experiences.

We would suggest therefore that it might be helpful for the local authority, ESPaCC, SENDIASS and some parent support groups to have a meeting to discuss ways in which relationships and confidence could be rebuilt as this will be an important step in encouraging wider participation within the county.

Professionals also spoke about some positives, such as the Autism Pathway and they thought that there was a good level of parental involvement with the Communication, Learning and Autism Support Service (CLASS) so there is a need to build on these successes and make co-production the norm and an important factor in this will be more face-to-face work with parent carers.

Professionals emphasised that when they had been involved in workshops and other opportunities to speak to parent carers they found the face-to-face work extremely useful and that in a number of instances they had picked up helpful information and ideas from parent carers.

We also asked professionals for their feedback on the parent carer forum. Some felt that ESPaCC needs more diversity in the management committee, as currently there is a perception that many have young people aged over 16 who are in specialist settings. They suggested that there is a need to broaden membership of the management committee to bring in parent carers who can represent younger children and those educated in mainstream settings, as well as to target minority groups to ensure that their views are represented, too.

As is shown on page 20, amongst the active parent reps the group is more representative of younger children and those who are educated in mainstream settings but we suggest there is a need for this to be reflected in the management committee as well as the wider membership.

Several professionals flagged that there is some reluctance amongst more junior members of staff to meet with parent carers from the wider SEND community face-to-face due to the present atmosphere in the county, which is felt to be quite adversarial.

We discussed how this could be managed and we suggest one way to overcome this could be asking parent carers to participate in training of new staff. This could be done by 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 (appendix 8) and foster additional understanding. It would also help if staff could meet their children, too, to build their knowledge and confidence and the trust of parent carers.

Health

In East Sussex, it is complex navigating and influencing health services due to the fact that commissioning services are split between three CCGs.

As with educational professionals, the somewhat adversarial atmosphere in the county was highlighted as sometimes being a barrier to participation and one professional from health said that this tends to lead to a retreat by professionals, who feel less willing to engage with parent carers if they feel that there is hostility.

It is important that professionals and parent carers do overcome this hurdle, however, as the professional went on to emphasise that parent carer input is vital for many reasons, but predominantly as their voice reminds professionals that there is a need for compassion and empathy in their work. Indeed, when parent carers and professionals have worked together constructively, there have been some extremely positive results.

Professionals expressed a strong desire for better engagement with parent carers and highlighted two areas where they felt that there was the opportunity to work more closely with them.

The first is commissioning reports from ESPaCC on specific topics, like CCGs do in other areas, and the second would be identifying and delivering joint training to professionals and parent carers, which would also provide much-needed opportunities for professionals and parent carers to engage face-to-face and work in partnership.

Some focus could also be given to the launch of the eight new locality networks integrating health and social care. These networks are each aligned to a smaller number of GP practices and consist of nurses, therapists, social workers and care practitioners. Service users will have a care co-ordinator as their main point of contact who is responsible for ensuring their needs can be met.

The networks will bring together the community and stakeholders together to raise issues and create locality plans. ESPaCC will be feeding in the parent carer perspective, thanks to its position on the new stakeholder group, although presently this will be restricted to young people aged 18+ with SEND, as the networks will focus on adult health and social care.

Care

At present in social care, it seems much of the engagement work being done is at a consultative level, with emerging opportunities for partnership working. Professionals who had engaged with ESPaCC and also attended support groups to speak to parent carers said that they found opportunities for face-to-face engagement invaluable.

More forward planning, and the identification and prioritisation of co-production opportunities could help. There are also issues around the fact that budgetary restraints and scope mean parent carers are not part of the new Carers Health and Wellbeing Engagement Group, which primarily focuses on the care of adults and the elderly.

As a result of ESPaCC identifying the need to support families of young people aged 16 to 25 with SEND transitioning to adult services,

'Improving Carer Experiences (ICE)' in functional mental health conditions has been asked to design a course targeting parent carers who have young people with mental health issues.

This resulted in two workshops in Hastings and Eastbourne. There will be a feedback process at the end, but again, capacity issues mean that evaluation and co-production is an ongoing struggle.

In Brighton and Hove, Amaze has just been funded to co-produce new separate support courses with the parent carers of young people with autism, ADHD and anxiety, which could also be shared in East Sussex, subject to funding.

ESPaCC has also been involved with user-testing the adult social care assessment tool, FACE RAS, which will be filled out by parent carers themselves or via triage through Health and Social Care Connect. The software is geared to adult care and restricted in terms of changes that can be made to it, but ESPaCC's feedback is helping to ensure that the assessment is as relevant to parent carers as possible. At the same time user-testing has also been carried out in Brighton and Hove.

In future, there may be opportunities for PaCCs to work together or share their learning/input on issues across Sussex to share findings and avoid work being duplicated.

A Carers' Prescription on SPFT GP/Hospital Intranet is also being worked on with Care for the Carers. This will be used by GPs to identify carers and used as a gateway for signposting and referral to other services. The triage process will generate numbers and data for professionals and could be used to link parent carers identified via their GPs to the forum and other services such as IAS, for example.

A final word on professionals

The insights we have been given by professionals indicate that there is a commitment towards improving participation in the county, but also recognition of the fact that things cannot be changed overnight. The fact that parent carers and professionals are on the 'same page' in terms of their desire to work together to change things is a positive. However, there are many barriers to be overcome and one of the first steps will be to regain the trust of parent carers, many of whom report that they have had very challenging journeys.

As a first step, once this review is concluded and the report published, the most pressing thing will be to make sure that professionals communicate with parent carers so that together they can decide upon a strategy to improve participation, using the recommendations below as a starting point for discussion.

Our recommendations

It is clear from our findings that while some good things are happening, there is a lot of work that can be done in East Sussex in order to improve participation and foster closer working relationships between parent carers and professionals.

i. Professionals

Forward planning

It would be extremely beneficial for ESPaCC, health and local authority to meet and produce an annual plan to identify engagement priorities for the forthcoming year. This would allow ESPaCC to highlight key concerns from parent carers and also allow professionals to identify key topics that they want ESPaCC's help with.
This will enable ESPaCC to seek feedback/input from its contacts about particular key topics or issues to feed in to certain workstreams and will also ensure that parent reps can be given plenty of notice to plan their attendance at the most relevant meetings. In turn, this will also mean that some reps may have capacity to take on ad hoc pieces of work reading documents, writing surveys or reports.

In addition, professionals need to seek ESPaCC input regarding consultations, service redesigns, evaluations service development and the best time to carry these out. For example, the post-16 transport consultation was held over the summer holidays, which is a time when it is very difficult for parent carers to participate.

The SEND Governance and Commissioning Board

While it is is good that East Sussex professionals have established a dedicated SEND Governance and Commissioning Board, it is still relatively new and currently only meets on a termly basis. We would suggest that over the forthcoming year it would be advisable to increase these meetings so they are held quarterly outside of the school holidays.

We also believe that it is important for senior managers from across education, health, social care, and the community and voluntary sector to attend. It will be necessary for them to liaise with parent reps attending the group to clarify the decision-making scope of the group and also to establisj when and what type of decisions need referring up the chain to the next level.

There also needs to be regular items from across all three topics, along with updates from other sub-groups and working groups reporting in to the board. We would also recommend that there is a standing item on co-production and communication with parent carers on every agenda. This will help to ensure that consideration is given to items where co-production should take place and also that updates are

fed-back to parent carers on a regular basis.

Joint events

One of the suggestions that professionals were keen on was running joint focus groups on specific topics for parent carers and professionals, with an independent facilitator to draw out parent feedback and the professional perspective, in order for the group to come up with co-produced solutions or ideas to effect change.

A constructive meeting with a neutral facilitator would foster a feeling of equality and help to rebuild trust and positive dialogues between parent carers and professionals.

Professionals felt that this type of input would be beneficial, as it would complement the contributions made by parent reps in meetings and would also allow them to build relationships with a wider cross-section of parents.

Short term aim: plan a focus group on short breaks, or another identified key priority topic, to trial the idea in East Sussex.

Long-term aim: if the first group is deemed useful, then plan to schedule three focus groups covering different topics and hold over the course of a year, varying localities for each to ensure parent carers around the county have a chance to participate.

Recruitment and training

For certain key strategic posts there should be a commitment on the part of the local authority and CCGs to ensure that a parent rep is invited to sit on interview panels to demonstrate they value parent carer views. For example, in Brighton and Hove, both B&H PaCC and Amaze sat on the interview panel to recruit the Head of SEN and both have been involved in the selection process to recruit Executive Heads for the new special school hubs.

Once key staff are in post, we feel it would be helpful if their induction includes an element about the importance of co-production and why and how it needs to be encouraged. This could include a session on the 'parent carer' journey delivered by the forum, for instance, as well as basics such as making sure meetings with parent reps are scheduled well in advance and during hours that they can attend (between 10 a.m. and 2 p.m.) it is also vital that their training embeds co-production as a key part of their role, to ensure that over time there is a cultural change within organisations so that co-production is considered as a matter of course rather than on an 'add-on' basis.

Long-term aim: ESPaCC and the local authority and CCGs should collaborate on an introductory document for all new staff members to outline co-production expectations and to ensure that they are aware of the forum and ensure that they are included on relevant pieces of work.

Leadership

For professionals' appraisals if this does not already occur we think it could be beneficial to ask SEND managers to illustrate how they are putting the views of children, young people and their parent carers at the centre of their decision-making so that it becomes a standard objective in personal development plans and therefore an essential part of every role.

East Sussex ethos

By making co-production a standard point on the agenda for meetings, the local authority could ensure that it becomes an essential consideration for all officers so that they remember to consider if there are areas or items where co-production would be beneficial. This would foster a person-centred ethos, which firmly places families at the centre of all decision-making in East Sussex.

It is really positive that iSEND services are asking for feedback from parent carers, regarding, amongst other things, how involved they felt (see appendix 4). iSEND has shared aggregated responses for a number of key services with us for the purposes of this report, some of which look very favourable. It would be beneficial if these figures were broken down for each service and shared with ESPaCC on a regular basis, and discussed at a partnership meeting each quarter. If there are services where parent carers are reporting lower levels of involvement/co-production, then these could be identified in partnership by the local authority and ESPaCC as priority topics where ESPaCC could seek more feedback from parent carers in order to improve things.

Short term aim: data on parental involvement and levels of satisfaction to be shared by iSEND team with ESPaCC on a quarterly basis, to recognise where results are good or identify where improvements could be made or more data is needed. This will enable key priorities to be identified so ESPaCC can do surveys/focus groups to find out what improvements can be made.

Meeting parent carers and families

In the long-term, consideration could be given to the case study we used on page 36, regarding the fun days held at Bristol Children's hospital. In West Sussex, the short breaks team runs Family Fun Days at Leisure Centres around the county.

These could be adapted and run as a 'meet the family, meet the team' day, running in the school holidays, where parent carers and their children could come along to meet professionals.

Many junior officers at the local authority may not have much experience around children with SEND and by meeting the children and participating in the activities on offer (usually crafts and sporting activities) they would get a snapshot of life for families in East Sussex which would increase their understanding.

In addition, if managers were in attendance, there could be 20-minute 'meet the manager' slots for parent carers to discuss concerns they have and for managers to gather quick feedback about their services face-to-face. This would go a long way towards strengthening relationships with parent carers.

Communications and promoting the forum

The local authority also needs to reiterate its belief in parental engagement as many of our focus group attendees voiced their frustration as they felt that they were shuttled between the local authority, education and service providers. One suggestion could be to provide a clear single point of contact who will support that and ensure that a satisfactory outcome is reached.

> ***My latest caseworker phones me regularly, even if nothing's moved on. I feel kept in the loop.***
>
> *– focus group comment*

For example, when an EHC Needs Assessment is underway, some parent carers at our focus groups highlighted that they had had frustrating experiences, which they felt was in part due to a lack of regular communication. They indicated that they would prefer to have regular updates from their caseworkers via email or text, even if it is just a quick 'check-in message' when nothing had moved on. Having this open channel of communication is important to keep parent carers informed throughout the process.

We also think that there may be more opportunities for professionals to help to promote the forum to families as they move through services, thus increasing their participation and ensuring their voices are heard.

We understand that the East Sussex Children's Disability Register is held by the Customer Services Customer Relations Team and this is used to communicate some messages with families including the circulation of the e-newsletter, *Parent Voice*. ESPaCC reported that they used to be able to ask for articles to feature in this newsletter but that this is no longer possible.

The local authority recognises that their communication strategy needs updating and recently appointed a new officer in a dedicated post to do so. We would suggest it would be beneficial for ESPaCC and SENDIASS to co-produce a parent carer comms strategy with the local authority, setting out which channels can be used, which are most appropriate for different messages, how frequently these should happen and who should take the lead on particular aspects of communication. This should take account of the variety of ways in which parent carers prefer to access information, from social media to emails, face-toface briefings, workshops and printed newsletters.

We feel there is a lot of potential to improve communication with the wider community of families through the Disability Register, including expanding the data collected from families, which would increase the ability to provide targeted information to families.

We think it would also be helpful to review how the Disability Register is being used and if there are more ways that it could be used to share information with families, including about the benefits of joining ESPaCC and what their impact has been.

Memorandum of Understanding (MOU)

As set out in the agreement, this should be reviewed on an annual basis by the local authority, CCGs and ESPaCC. We suggest that this needs to be clarified by deciding which meeting will be used to review the document and scheduling a date to do so.

ii. The parent carer forum

Members of the ESPaCC management committee are committed to improving participation in East Sussex and have worked hard to improve things over the past

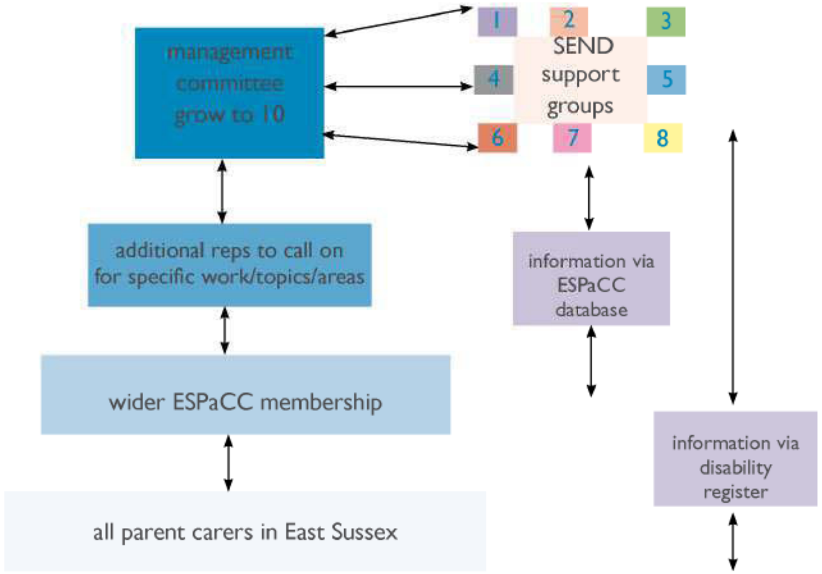
year, often on a voluntary basis. They should be congratulated for how far they've come. It is hoped that the below recommendations we make for the forum will improve things, but they are only part of the overall picture and should not be viewed as the only solutions needed to increase participation.

Structure

Currently, there are six members on the management committee, plus the two members who recently stepped down, who will be called upon from time to time as associates. It has been a struggle for ESPaCC to attract new parent carers to join the management committee, which is crucial to the long-term success of any type of organisation. Of the parent forums that we surveyed, the ESPaCC Management Committee was one of the smallest and there is a pressing need to recruit new members.

ESPaCC has good connections with many East Sussex-based support groups for parent carers and two of their parent reps run their own groups. In the case study we evidenced on page 15, Gloucestershire Parent Forum invited members from each support group to nominate a representative to sit on their steering group. This is something that B&H PaCC also does.

Linking with support groups covering different areas and disabilities can also ensure that the management committee has a balanced profile in terms of the community they represent. As much as possible this should aim to cover as many disabilities and age ranges as possible from 0 to 25. Ideally, the management committee should represent both children with EHC Plans and SEN Support in a range of education settings, including mainstream, specialist settings and home-education (although this is more challenging, as home-educators may not be able to attend day-time meetings) Additionally, having support groups represented on the management committee, immediately opens up a two-way process, whereby a wider group of parent carers can be canvassed for information and feedback via the support groups, the representatives can also facilitate improved communication with parent carers by cascading information and findings back from the forums to their membership, as shown in the diagram below:



It should be noted that several parents at our focus groups mentioned that their schools had set up support groups – again, a representative from these groups could be invited to sit on the management committee.

Short-term aim 1: invite a number of East Sussex parent carer support groups to nominate a parent representative to sit on the ESPaCC management committee. Alternatively the committee could look at recruiting one rep per locality area or by type of disability (see Appendix 3).

Long term aim 1: collaborate with community workers and leaders of minority communities to increase membership diversity of overall ESPaCC membership.

Long term aim 2: build relationships with early years services to encourage the engagement of new parent carers via engagement sessions on relevant topics – building a core of contacts with younger children will hopefully encourage those parents to get more involved with the forum and provide new members in the long term.

The disability register could be also used to target parent carers of under fives and seek volunteers.

Reps' matrix

A common concern at the focus groups was that due to the rural nature of the county, many parent participation events tend to be concentrated in the Eastbourne area. This has led to some parent carers feeling very isolated.

The introduction of the new CCG locality networks suggests that it may be worthwhile identifying parent reps who are able to gather and put forward views about their locality based on the map, see Appendix 3. However, there is also a need to have reps who can lead on specific topics or issues, so there is a need to adjust the rep matrix to fulfil all of these requirements. For instance, there should always be a parent carer of a children or young person with ASC representing the forum at an ASC meeting.

Succession planning

There is also a need to build in succession planning, particularly as it has been necessary for members to step away from the committee because of their caring commitments. We would suggest that ESPaCC aims for its management committee to serve fixed terms to avoid 'burn-out' of committee members.

In addition, there should be built in capacity to allow reps to temporarily stand down from the management committee or their forum duties when their caring role needs to take priority, or when a conflict of interest arises, for example, when they are in a dispute with the local authority over their child's provision and the case is going to the SEND Tribunal.

Long-term recommendation: once membership of management committee has grown, look at training and mentoring junior members of the committee so that they can step up to senior roles within a specified time frame, with members serving a maximum term of five years, or stepping down once their young person reaches the age of 25, whichever is soonest..

Priorities

One of the biggest difficulties the forum faces is the ever-increasing number of meetings, groups and documents it is expected to manage. It is clear to us that currently reps are spread too thinly across too many areas, which dilutes the impact that they can have.

This is a challenge that has faced other forums we spoke to, and limited capacity has meant that it is vital that priorities are identified so that attention can be focused on key areas, because an important part of their work is spending time gathering views from the community and feeding them in in a written or verbal format. Other local organisations such as Care for the Carers have adopted this approach.

The forum could, as is the case with others that we spoke to, allocate a set amount each year for the cost of reps. Setting out the number of 'rep hours' available in a twelve-month period would show professionals what could be covered in terms of meetings with the funds available.

Short-term aim 1: a review of which meetings parent reps can attend. The forum, health and local authority to meet and produce an annual plan to identify priorities for the forthcoming year.

Short-term aim 2: map costs of 'rep hours' available in a twelve-month period, look at current funding to identify shortfalls which need to be addressed.

Contacts or members?

At present, the ESPaCC database has just over 300 parent carers who have filled out 'contact forms' with more information about their families, their location and the needs of their children. These parent carers are currently known as 'contacts' by ESPaCC. However, we find this is slightly misleading, as ESPaCC reps have also had contact with an additional 200 families on a one-off basis.

The word 'contact' implies that the parent carers who have given information to ESPaCC have a passive role in the forum, whereas we've heard from parent carers who are keen to get actively involved in delivering change or improvements.

In order to clarify that there is an ongoing relationship with the families who have given information and would like to play a part in forum activities we would suggest that it would be much simpler to use the term 'members' as is the case for the majority of parent forums. People who have only been engaged with the forum on a one-off basis could then be known as 'contacts'.

This may seem like a moot point, but we believe it could help parent carers to understand that 'for their membership and to effect change' they will be called on to input to surveys and will hear about what happened as a result.

Short-term aim: use the word 'members' for those who are on the database and can be consulted on a regular basis. Use the word 'contacts' for families spoken to on a one-off basis.

Recording activity and monitoring

Currently, ESPaCC tends to report back their views and findings verbally to professionals. By collating and documenting information in a consistent, quantifiable and structured way via reports, position statements or case studies (see Appendix 5 for a B&H PaCC example), ESPaCC could start to present it in a way that can be more easily followed up or monitored, or to encourage new members to join.

At present, due to budgetary constraints it is difficult for CCGs to do additional work with the forum such as commissioning them to write reports on specific topics or to provide joint training for parents and professionals. However, they have indicated that if the forum was to document their activity it could be fed into pathway reviews to show what the forum has achieved, which may allow more funding or grants to be made available. This may allow for one-off pieces of additional work to be commissioned, such as undertaking a survey about health services to illustrate where key concerns are.

Short-term aim: ESPaCC to identify how their current reporting forms can be used to track activity, to then feed in to newsletter updates and articles in order to celebrate successes and keep parent carers membership updated on current 'hot topics' and developments within East Sussex.

Additionally, when presenting feedback from parent carers to professionals there is a need for it to be quantified effectively – for example '*at the meeting, which was attended by 26 parents, 18 said they were unhappy with their school transport service*'.

Long-term aim: Reporting format for monitoring future parent participation could aim to build a picture of consultations by: area; age; disability type; gender; ethnicity and so on. This could link to any development in the breadth of data gathered on the disability register.

Communications

Both the local authority and ESPaCC acknowledge that there is a need to improve communication around sharing the impact of good participation work with the wider SEND community.

The existing ESPaCC electronic newsletter to contacts has a clear format, but could be used more often to communicate with parent carers about the forum's work, outcomes and their successes. We would suggest that the forum looks at producing an e-newsletter based around school terms, so that each edition is published at the start of a six-week half term with content promoting the term's new topic or focus and reporting back on the previous term's work and impact.

ESPaCC's administrator could use the bulleted information from parent reps to summarise the forum's activities over the six-week period in short, snappy articles to inform members about current focuses.

We have attached an example of articles from B&H PaCC's termly newsletter, see appendix 6. The articles show how B&H PaCC communicates to parent carers that it is listening to them, using their input and how it is making a difference to services in the county.

In addition, we would suggest that the newsletter could have a 'forward focus' highlighting topics or areas coming up over the next half-term with a particular emphasis on highlighting engagement opportunities in East Sussex (surveys, focus groups etc).

If the forum were to produce six newsletters across the year, reps with responsibilities for different topics or areas could be asked to produce a short article for each, which would also help members to get to know their reps and help to spread the workload.

Amaze would also like to produce a newsletter for the wider population of families, if additional funding could be found. This could include inserts or articles written by ESPaCC in a similar vein to those written by B&H PaCC for Amaze's Brighton and Hove families.

Short-term aim 1: improve communication with parent carers, about ESPaCC's work and successes. This can partly be achieved by cascading information back via parent representatives from support groups, but also making better use of social media, particularly Facebook to share successes with parents.

Short-term aim 2: publish the e-newsletter on a half-termly basis; look at writing articles to communicate forum activities, their input, outcomes and successes.

Short-term aim: conduct a skills analysis of parent reps and canvas contacts to identify any parent carers who have previous marketing/comms experience or those who feel at home using social media and encourage their involvement to publicise positive results. ESPaCC is also keen to find parent carers with finance or legal skills who would be happy to contribute to their work.

Medium-term aim: look at simplifying the leaflet about ESPaCC to explain in more basic terms what the purpose and aim of the forum is, focusing on the benefits of joining for the parent carer and their families rather than what they have to do. At present it sounds quite daunting and involved for new parent carers, which some said was off-putting, so start with the basics. Also look at increasing diversity of children and families represented in the photos.

Seeking feedback

Short-term aim: ESPaCC could plan to ask its members every year what is important to them and gather views using more surveys and supplement with feedback from parent groups.

Medium-term aim: ESPaCC to trial using online survey tools to offer parents the opportunity to respond digitally to surveys. This will save time in data entry and also means more parent carers are likely to respond because there is less paperwork/effort involved. Suggest ESPaCC picks the element that is most urgent for their members and designs a simple survey to seek the views of parent carers.

Reps' training and ongoing support

ESPaCC reports that it has recently introduced a 'buddy system' pairing new reps with members of the management committee, with the aim of sharing knowledge and skills, which is a great idea, but there are some areas where new reps may still need additional assistance. For example, it is important that reps understand that social media can be a potential minefield and there is a need for discretion and professionalism, even when 'off duty' as parent reps are ambassadors for ESPaCC. While parent reps already receive training from ESPaCC and a job description and parent carer agreement, some new reps may need more support in terms of what to expect at meetings and guidance on the 'ESPaCC' position on tricky or sensitive topics.

The Chair of B&H PaCC's offers 'rep surgeries' in which they can off-load/debrief, in addition to reporting to the steering group via a simple form. Reps use the surgeries as a chance to discuss how meetings are going and identify which key messages they should be feeding in.

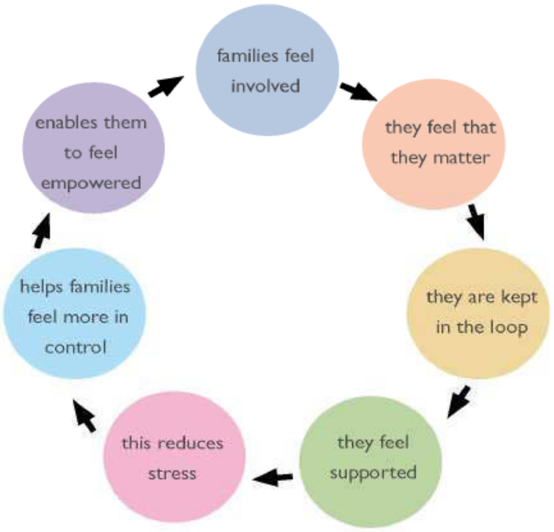
Short-term aim: Contact provides training for reps, so it would be good to utilise this resource as much as possible. There also needs to be more clarity over who decides when a rep is ready to go to their first meeting and who oversees their input and checks the meeting went well, so that any queries or stumbling blocks can be dealt with.

Medium-term aim: once the management committee has grown, look at ways to support reps, such as providing 'rep surgeries'.

iii. Information provision

One of the current barriers to participation in East Sussex is the fact that so many parents need better information, advice and support, with 82.8% of parent carers saying that they found it 'very' or 'quite' difficult to access information.

Investing in a good quality SENDIASS can help to increase parental trust and confidence at an earlier stage in their journey. It makes a difference to parent carers for the following reasons, below:



Cycle of what parents said makes a difference to them about information[iii]

Amaze took over SENDIASS in September 2017, and plans to try to improve information delivery to parents to try to empower parents so they feel more able to engage. However, currently it is restricted to a helpline and web-based service as the IAS budget in East Sussex is at 47 pence per capita, one of the lowest nationally.

In Brighton and Hove, IAS is funded at £1.09 per capita. which means Amaze can offer Brighton and Hove parents 1:1 case work, face-to-face support and a range of workshops and training.

Improving information delivery is an essential ingredient for improved participation – as was seen in our survey of parent carers, around half of our respondents had not heard of ESPaCC, while many others were unsure of its role. Changing this will take time as well as better investment and good partnership working between service providers, SENDIASS and ESPaCC.

ESPaCC has previously delivered information events on topics such as personal budgets, the Local Offer, EHC Plans, and transport. We would like to discuss how a rolling programme of workshops could be co-produced and co-delivered by SENDIASS and ESPaCC. Recent workshops, which were organised by ESPaCC and delivered by Amaze Independent Support and involved the local authority's Principal Educational Psychologist were an excellent example of co-production and how this could work in the future in East Sussex.

Earlier support for parents

A key factor in engaging families is to ensure that there is good early intervention and support. It is hoped that the new autism pathway will improve waiting times and speed up access to support for children on the autism spectrum, for example, but parent carers suggested that more support is needed across the board for all disabilities to build relationships and dialogues with families from the start of their journey.

Long term aim: supporting parent carers by investing in face to face support and other parent support groups, along with resilience building courses such as the Insiders' Guide workshops (last held in East Sussex in 2016) could help to build parental trust and confidence so they feel more able to participate at an earlier point in their journey. As these are delivered by a professional and a parent carer they also offer a great opportunity to showcase co-production.

Better information about families

Developing East Sussex's Children's Disability Register so that it is more comprehensive possibly including additional data around the additional needs of children, young people and their families, would provide more information to service commissioners to improve planning and delivery of services to ensure they best meet the needs of the SEND community. This data could also be used by ESPaCC in their representation work and in planning their workload to help them to identify issues of concern/needs in the wider SEND population.

By ensuring that contact information is kept up-to-date, with families re-registering every two years, as is the case in Brighton and Hove, the register could also facilitate easier communication with families. If this is planned so that ESPaCC can send information out via the disability register team, they could promote their engagement work to a wide or a targeted population of families and encourage others to sign up to the forum. We found that several of the parent carers who came to our focus groups had heard about them via emails from iSEND, which shows that it can be a good way of communicating with parent carers, especially at short notice. Gathering additional data would allow for better targeting of information too, for instance asking for parent carer input to service developments based on disability type, age or area.

We understand that further development of i-Go offers for the discount scheme is on hold and we suggest that it would be worthwhile performing an evaluation to see how the card is used by families and what benefits they feel they get from their child being on the register. Amaze currently operates the Compass Register and card in Brighton and Hove and West Sussex and has over 4,000 children and young people registered now, with over 160 providers offering leisure discounts. An independent survey of the Brighton and Hove scheme highlighted significant financial savings that families can get from using their Compass Cards, but also many softer benefits around feeling better informed and included in their local community. Amaze has also found that families like the fact that the Brighton and Hove disability register is held independently in the voluntary sector.

We would be happy to share with East Sussex County Council details about the extensive data stored on the Compass Registers to see if extending the East Sussex children's disability register could be of greater benefit to families and commissioners. Better pan-Sussex disability data may also be helpful to service providers, especially health, to ensure services best meet the needs of local families.

Table of draft recommendations

For convenience we have provided a summary of all the recommendations mentioned in the body of this report.

We suggest agreement is needed by professionals and ESPaCC as to which of these are desirable and if so, when they should aim to be completed by and who will take ownership of ensuring they are implemented.

However, we are really aware about the limited capacity both within ESPaCC and with the range of professionals. If these recommendations are accepted, capacity will need to be found/released or resourced to ensure these can be achieved.

RECOMMENDATION	*to be agreed by*	*aim to complete*
PROFESSIONALS		
ESCC and CCGs to clarify the role of the SEND Governance Board in decision-making	ESCC/CCG	
Review membership of SEND Governance Board, its agenda and frequency of meetings	ESCC/CCGs/ ESPaCC	
ESCC, CCGs to identify with ESPaCC where and how parent carer views should be fed in to ensure that parent voice is heard at groups/boards with decision-making powers.	ESCC/CCGs/ ESPaCC	
ESCC and CCGs to meet with ESPaCC to identify priorities and produce an annual plan for engagement work	ESCC/CCGs/ ESPaCC	
Ensure co-production is a standard agenda item for all ESCC/CCG meetings	ESCC/CCGs	
ESPaCC budget to be reviewed and protected so no risk of reducing	ESCC/CCGs	
identify a topic and plan a joint focus group for professionals and parent carers	ESCC/CCGs/ ESPaCC	
Using the new co-production policy as a template, collaborate on an introductory document for all new staff members to outline participation expectations	ESCC/CCGs/ ESPaCC	
plan an initial focus group with the aim of scheduling three covering different topics and over the course of a year, varying localities	ESCC/ESPaCC	
SEND managers's performance reviews to ask how they're incorporating views from parent carers and children and young people in service development	ESCC	
make increasing co-production a standard objective in personal development plans for all staff	ESCC/CCGs	
ESPaCC reps to be invited to join senior staff recruitment/ selection panels	ESCC	
parent carers to participate in training of new staff. Invite a group of to meet with staff at training/induction days to talk about the parent carer journey and foster understanding	ESCC/CCGs/ ESPaCC	
plan a 'meet the family, meet the team' fun day	ESCC/ESPaCC	
iSEND data on parental involvement/levels of satisfaction to be shared with ESPaCC on a quarterly basis to identify key priorities for surveys/focus groups	ESCC	
develop the disability register and the scope of information it holds, also hold a review of the i-Go scheme and how it is used by parent carers in East Sussex.	ESCC/ESPaCC	
use the disability register and other partner mailings lists/ social media and newsletters (e.g.. Parent Voice) to promote the forum	ESCC/ESPaCC	
review the MOU annually in terms of co-production and highlight successes to report back to ESPaCC members/ identify areas where collaboration could be improved	ESCC/CCGs/ ESPaCC	

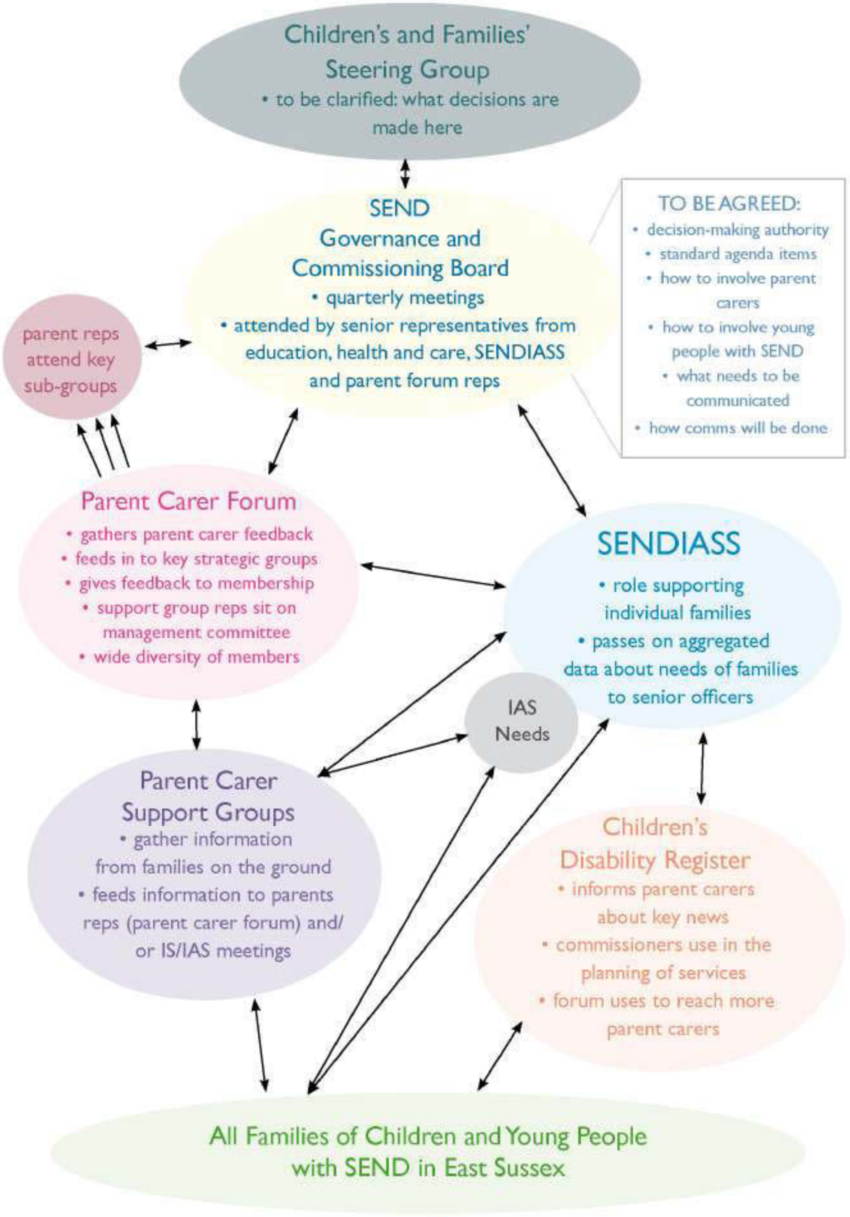
RECOMMENDATION	to be agreed by	aim to complete
co-produce a parent carer comms strategy setting out which channels can be used, which are most appropriate for different messages and frequency	ESCC/ESPaCC/ SENDIASS	
the local authority, ESPaCC, SENDIASS and parent support groups to discuss ways to rebuild relationships and confidence with parent carers who have had negative experiences.	ESCC/ESPaCC/ SENDIASS/ support groups	
ESPaCC		
Diversity of membership: invite a number of support groups to nominate a parent rep to sit on the ESPaCC management committee.	ESPaCC	
collaborate with community workers and leaders of BAME communities to increase membership diversity	ESPaCC	
build relationships with early years services and hold engagement sessions for parent carers of <5s	ESPaCC	
use disability register to target parent carers of under fives and seek volunteers.	ESPaCC/ESCC	
Reps: identify parent reps who are able to gather and put forward views about their locality/topic/issue	ESPaCC	
a review of which groups parent reps attend, mapping costs of 'rep hours' against current funding to identify how many meetings can be attended and any shortfalls	ESPaCC/ESCC/ CCGs	
look at mentoring junior members of the management committee to prepare for senior roles	ESPaCC	
utilise Contact's rep training for reps as much as possible and clarify how reps are assessed as 'meeting ready'	ESPaCC	
identify ways to support reps so they can off-load/debrief	ESPaCC	
Structure: develop succession plan for key roles	ESPaCC	
consider changing 'contacts' who have filled in details and are on database to 'members' to make parent carers feel they have an active role in the forum	ESPaCC	
Comms: communicate ESPaCC's work/successes by cascading information back via support group parent reps on management committee	ESPaCC	
make better use of social media, particularly Facebook to share successes with parents	ESPaCC	
simplify ESPaCC leaflet and increase the diversity of children and families represented in the photos	ESPaCC	

RECOMMENDATION	to be agreed by	aim to complete
ask for volunteers, among reps, who can update social media to publicise positive results	ESPaCC	
publish electronic newsletter on a half-termly basis, look at writing articles to communicate forum activities, their input, outcomes and successes.	ESPaCC	
Reporting: ESPaCC to look at the way in which current reporting forms are used to document meetings to feed information back to parent carers and also to quantify feedback from parent carers to professionals	ESPaCC	
trial using online survey tools to offer parents the opportunity to respond digitally to surveys	ESPaCC	
consult with members annually to find out what is important to them – gather views using more surveys and feedback from parent groups	ESPaCC	
INFORMATION DELIVERY		
increase investment in SENDIASS	ESCC	
ESPaCC and Amaze SENDIASS team to discuss possibility of a rolling programme of jointly delivered workshops	Amaze/ESPaCC	
invest in resilience building courses such as the Insiders' Guide workshops and develop other types of peer support	ESCC	
develop the disability register so that it is more comprehensive and usable by ESPaCC and commissioners	ESCC	
perform an evaluation of how the i-Go card is used and consider Amaze extending Compass scheme into East Sussex	ESCC	

To conclude

Improving parent carer participation in East Sussex will not happen overnight, However, it is clear that both parent carers and professionals want change. There will need to be cultural change in the way in which the local authority and health services work and the need to be proactive rather than reactive.

We have made the recommendations listed above for professionals and ESPaCC to consider and in the following diagram we have summarised how parent participation needs to fit into the whole SEND system in future:



Children's and Families' Steering Group
- to be clarified: what decisions are made here

SEND Governance and Commissioning Board
- quarterly meetings
- attended by senior representatives from education, health and care, SENDIASS and parent forum reps

TO BE AGREED:
- decision-making authority
- standard agenda items
- how to involve parent carers
- how to involve young people with SEND
- what needs to be communicated
- how comms will be done

parent reps attend key sub-groups

Parent Carer Forum
- gathers parent carer feedback
- feeds in to key strategic groups
- gives feedback to membership
- support group reps sit on management committee
- wide diversity of members

SENDIASS
- role supporting individual families
- passes on aggregated data about needs of families to senior officers

IAS Needs

Parent Carer Support Groups
- gather information from families on the ground
- feeds information to parents reps (parent carer forum) and/or IS/IAS meetings

Children's Disability Register
- informs parent carers about key news
- commissioners use in the planning of services
- forum uses to reach more parent carers

All Families of Children and Young People with SEND in East Sussex

The final word in the report should go to parent carers who attended our focus groups and what they want from future participation:

understanding

consistency

forward-planning

to help other parents

invest early – it will pay off

better links with other parents

proactive professionals

mutual respect

communication

tangible objectives

cohesion

accountability

child-centred services

change

better resource management

a cultural shift from the top

better outcomes for our children

experienced staff

hope

action

feedback

a voice

involvement at all stages

empathy

transparency

a joined-up approach

equality

Appendix 1 – survey questions

i) Parent carers' survey questions

1) What is your nearest town or village?

2) Main language spoken or read at home

3) Number of children living at home

4) How old is your child with SEND?
- 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?
- Learning difficulty
- Autistic spectrum condition
- Physical disability
- Sensory difficulty
- Behavioural or emotional difficulties
- Other - please say

6) How involved do you feel in planning, shaping and evaluating services for your child?
- Slightly
- Very much
- Not at all

7) If you have answered that you feel involved in developing services in Question 6, which services do you think seeks the input of parents and carers?
- Education
- Paediatrician / GP
- Short breaks / respite
- Social care
- Other (please state)

8) What do you think a parent carer forum does?
- 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) Have you heard of your county's parent carer forum, the East Sussex Parent and Carers' Council (ESPaCC)?
- Yes
- No

10) Have you:
- Filled in ESPaCC's contact form to receive emails / newsletters
- Liked ESPaCC's Facebook page
- Used ESPaCC's website
- Attended an ESPaCC event
- Become an ESPaCC parent rep
- Thought about joining ESPaCC

11) How well do you think the ESPaCC represents the views of parents and carers in East Sussex?
- Very well
- OK
- Not at all
- I don't know

12) What would you like your parent carer forum to focus on?
- Sharing parents / carers views with professionals
- Helping to improve existing services in East Sussex
- Lobbying for more / better services in East Sussex
- Building stronger links between parents and carers
- I don't know
- Other (please specify)

13) 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 could see how my involvement had made a difference(please select all that apply)
- Being seen as an equal partner in planning by professionals(please select all that apply)
- Meeting other parents and carers of children with SEND(please select all that apply)
- Ensuring events are planned to fit around school day / family commitments? (please select all that apply)
- Help with childcare costs / having a creche (please select all that apply)
- Payment / other incentives (e.g.. help with transport costs)(please select all that apply)
- If I had more free time
- If I had training and felt confident
- Participation doesn't interest me
- Other (please specify)

14) If you were to get involved in shaping East Sussex services, what might interest you?
- Becoming a contact (member) of ESPaCC
- Giving my views / feedback via surveys
- Giving my views / feedback in meetings / focus groups
- Training as a parent rep and going to meetings with professionals
- Going to professional events on key SEND topics
- Helping out at meetings / events
- Helping out with admin support (photocopying etc)
- I'm not interested in getting involved / more involved
- Other ideas (please specify)

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

15) What education support does your child receive?
- EHC Plan (or Statement)
- SEN support
- None (and support is needed)
- None (and support is not needed)

16) Where is your child(ren) with SEND educated?
- Special school / college
- Private specialist provision
- Mainstream school
- Unit within a mainstream school

- Alternative provision
- Home educated
- Not of school age

17) Which of these have you / would you turn to for information / signposting to support?
- Amaze's Independent Support Service (for transfer from Statement and new EHC Plan)
- Care for Carers
- Child's school / education setting
- SENDIASS
- Embrace
- ESPaCC
- Facebook groups
- Families for Autism
- iContact
- National organisations
- Paediatrician / GP / Health Visitor
- Parent carers
- Social Worker
- I haven't asked anyone
- Which do you find most helpful?

18) Have you ever had advice from the following?
- Individuals / groups offering SEND advocacy services
- A law firm specialising in SEND
- Neither

19) How easy do you find it to get information to support your child's SEND / your family?
1. Very Easy
2. Quite easy
3. Quite difficult
4. Very difficult

20) 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

21) Please select the top three ways you prefer to access information
- Books
- Fact sheets
- Helplines
- Websites
- East Sussex County Council's Local Offer
- One to one advice
- Training courses
- Support groups / other parents
- Other

22) Please use the box below to add any other comments/suggestions about the information needs of families in East Sussex, or any comments/suggestions about this survey.

ii) Professionals' survey questions

1) What is your role?
2) What is the name of your team and/or the organisation that you work for?

3) Can you tick which (if any) you think is happening currently with parent carers in your team/organisation? Please choose all that apply and where applicable give an example of this.
- Information
- Consultation
- Engagement
- Co-production
- None apply

- Information Example
- Consultation Example
- Engagement Example
- Co-production Example

4) Have you (or your team) received any training about how to support parent carer participation?
- Yes, me
- Yes, my team
- No
- Don't know

5) If yes, who was it delivered by?

6) Senior leaders at East Sussex County Council and the three East Sussex Clinical Commissioning Groups (CCGs) have all recently signed up to a 'Co-production Memorandum of Understanding' with the East Sussex Parents and Carers Council (ESPaCC). Are you aware of this document?

7) Do you have strong links with ESPaCC (the East Sussex forum for parent and carers)?

8) Do you understand the role of ESPaCC (the East Sussex forum for parent and carers)?

9) Do you think that all members of your team are fully aware of your organisation's stated commitments to participation and co-production?

10) To what extent do you think your service/area of responsibility seeks and uses the views/input of parent carers in the following? (choice for each: all of the time / most of the time / sometimes / hardly ever / not at all)

- Service (re)commissioning
- Service evaluation
- Staff recruitment
- Staff training/induction
- Strategic/policy developments

11) What methods do you use to seek the views/input of parent carers? Please choose all that apply.
- Asking parent carer reps to attend meetings

- Asking for input on documents/letters/leaflets
- Inviting parent carer reps to speak at events
- LA officers attending parent carer events
- Evaluating services together
- Commissioning reports from ESPaCC

12) When setting up a new meeting, project or work-stream, how do you decide whether to invite a parent carer rep to attend or undertake any other means of engagement?

13) Can you think of a time when parent carer input has led to a positive change in policy/practice/service design?
- Yes (please specify)
- No
- If yes, please give details

14) When do you feel it is NOT appropriate to involve parent carers?

15) How well does your team use parent carer input to inform their decision making?

16) How do you think parent carer participation can be improved in the future? Please choose all that apply.
- Developing a better understanding of the benefits of participation
- Increasing its priority by senior managers
- Parents and carers being seen as equal contributors
- More training for us on participation and how to facilitate it
- Offering a range of ways parents/carers can participate
- Closer working relationships with parent carers
- Having a wider cross-section of parent/carer views represented
- By ensuring we give parents/carers feedback on what we've done with their input
- By us ensuring meetings are arranged well in advance and in school hours
- By parent carer reps having better training about their role/responsibilities
- By providing parents and carers with more support
- Ensuring an agenda and any relevant paperwork is circulated well in advance
- Providing care or funding for care to allow parent carers to engage
- Develop methods for parent carers to be engaged virtually/online
- Other

17) What are the difficulties with involving parent carers? Please choose all that apply.
- Parent carers don't understand what Parent Participation is
- Many can't participate due to their caring commitments
- Some parent carers aren't interested in shaping services
- We only hear from unhappy parent carers
- Reps are spread too thinly across too many groups
- We need better feedback/data from our parent forum reps
- Parent carers aren't available to attend meetings at short notice or outside school hours
- We don't have enough time/capacity to seek their input
- Parent participation can make more work for us
- Other (please specify)

18) Thank you for completing our survey. Is there anything else you would like to add?

iii) Parent carer forums' survey questions

1)What is the name of your Parent Carer Forum?

2) How many parent carers sit on your management committee or steering group?

3) How many parent carers are in your wider membership?

4) What is your forum's total annual budget?

5) How is your forum funded?

- Local authority
- Clinical Commissioning Group
- Department for Education
- Other

6) Have you had a review or any major changes to the forum's structure recently?
- yes
- no

7) Do you employ paid staff?
- yes
- no

8) If yes, could you tell us what their roles are and how many hours they work?

9) Does your forum use parent reps?
- yes
- no

10) If yes, how many parent reps from your forum who attend strategic/partnership meetings?

11) In the past year, do you feel that achieving co-production with strategic partners / service providers has:
- Greatly improved
- Improved
- Stayed the same
- Deteriorated

12) If possible, can you tell us about when your forum's work has had a positive impact, made a change or influenced policy and practice?

13) Please tick any of the following roles that are included within your forum's structure
- Chair
- Vice-chair
- Co-chairs
- Subgroups

14) Do you know roughly what proportion (%) of your management committee and overall membership have a child with an Education, Health and Care Plan or Statement of SEN, compared with those who are receiving Other SEN Support?

- % with EHC Plan or Statement – Management committee members
- % receiving Other SEN Support - Management committee members
- % with EHC Plan or Statement - Overall membership

- % receiving Other SEN Support - Overall membership

15) Do you know what proportion (%) of your management committee and overall membership have a child who attends a special school compared with a mainstream school?
- % attending special school - Management committee members
- % attending mainstream school - Management committee members
- % not attending school or college - Management committee members
- % attending special school - Overall membership
- % attending mainstream school - Overall membership
- % not attending school or college - Overall membership

16) Is your management committee remunerated for attending meetings?
- No
- Yes, vouchers
- Yes, childcare costs
- Yes, travel costs
- Yes, hourly rate paid
- If yes, hourly rate paid, how much per hour?

17) How many strategic meetings are attended by your parent reps per year?

18) What type of meetings do your parent carer reps attend?

19) Do your parent carer reps attend meetings on their own or in pairs
- On their own
- In pairs

20) Do your parent reps help input to interview panels for the recruitment and selection of key statutory/service staff?
- yes
- no
- don't know

21) If yes, please list the types and levels of roles.

22) Do your parent reps help with inductions and training of key statutory/service staff?
- yes
- no
- don't know

23) How does your forum collate opinions and gather feedback from the local community of parent carers and families?
- Online surveys
- Paper surveys
- Facebook surveys
- Online discussion groups/forums
- Holding events/information sessions/focus groups
- Running training events
- Running or linking in to parent support groups

24) Does your forum feed in parent carer views verbally at meetings it attends?

25) Does your forum write up views for submission to managers, commissioners or publications?
- Written reports
- Website news
- Emails
- Third-party Facebook pages, publications or newsletters
- Local Offer
- Other

26) Does your forum document when your input has made an impact, altered a decision or changed policy/practice?
- yes
- no

27) Does your forum share any influence you've had or changes you've brought about with your wider membership?
- Facebook
- Twitter
- E-bulletins
- Events
- Newsletters
- Annual report
- Local Offer

28) Does your forum hold events for your membership (and wider) to attend?
- Conferences
- Training
- Focus groups
- Information events
- Other

29) If yes, does your forum rotate the event locations across the geographical area you cover, to ensure they are accessible to as many members as possible?

30) Does your forum pay members' expenses such as travel or childcare when they attend your events?

31) How your forum decide which themes or topics to focus on?
- By seeking members' views on what is important to them
- Focusing on what commissioners or managers ask us to
- The forum's management committee decides
- Other

32) Which aspects of your forum's work do you think has the most impact on services and for families?

33) Do you feel that as a group, your forum has influence with councillors?
34) Do you feel that as a group, your forum has influence with the local press?

35) Does your forum.....
- have its own website?:
- send your membership regular emails or newsletters?
- hold regular open meetings?

36) What do you estimate to be your forum's total reach to parent carers (including members and non-members)?

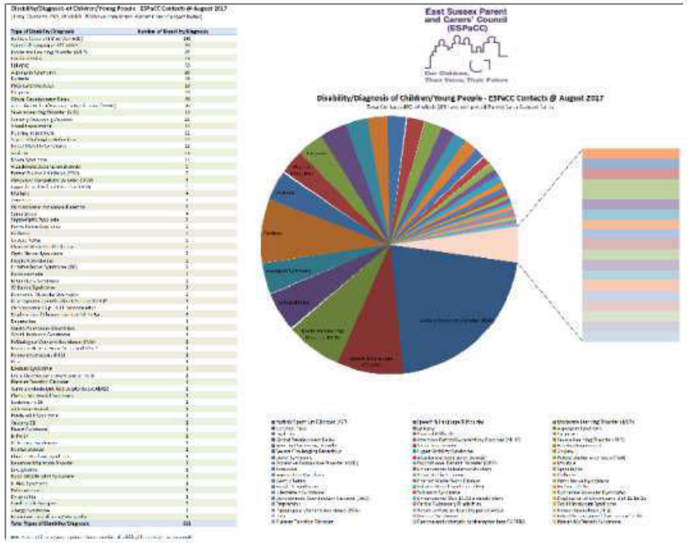
37) Does your forum work closely with or communicate via your area's SEND Information, Advice and Support (SENDIAS) Service?

38) Does your local authority have a Disability Register?
- Yes, it's comprehensive and has a wide reach
- Yes, but it is limited and doesn't have a wide reach
- No
- Don't know

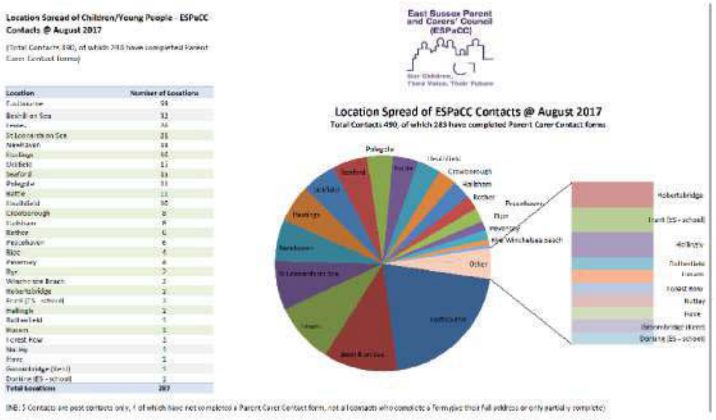
39) If yes, does your forum utilise the register to communicate with families?

Appendix 2

ESPaCC – disability/diagnosis of contacts' children



ESPaCC – contacts by locality



Appendix 3 – Locality networks

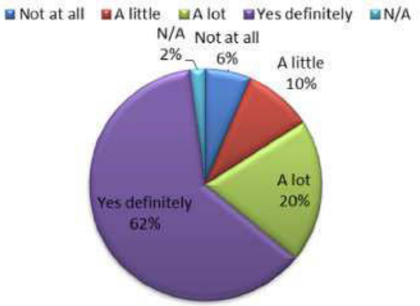
October 2017

Appendix 4 – iSEND Parent Evaluations, 2016-2017

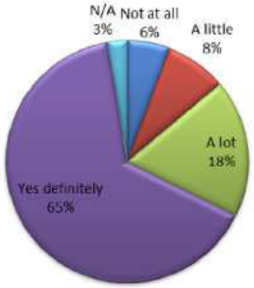
East Sussex County Council's iSEND team sends out evaluation forms to parent carers. Figures below are aggregated for 2016-2017 for the following services:

- CLASS (Communication, Learning and Autism Support Service)
- EALS (English as an Additional Language Service)
- Early Years' Service
- EPS (Educational Psychology Service)
- ESBAS (Education Support, Behaviour and Attendance Service)
- SNS (Sensory Needs Service)
- STLP (Specialist Teaching and Learning Provision)
- TLP (Teaching and Learning Provision)
- TLP - GRT (Teaching and Learning Provision – Gypsy Roma Traveller)

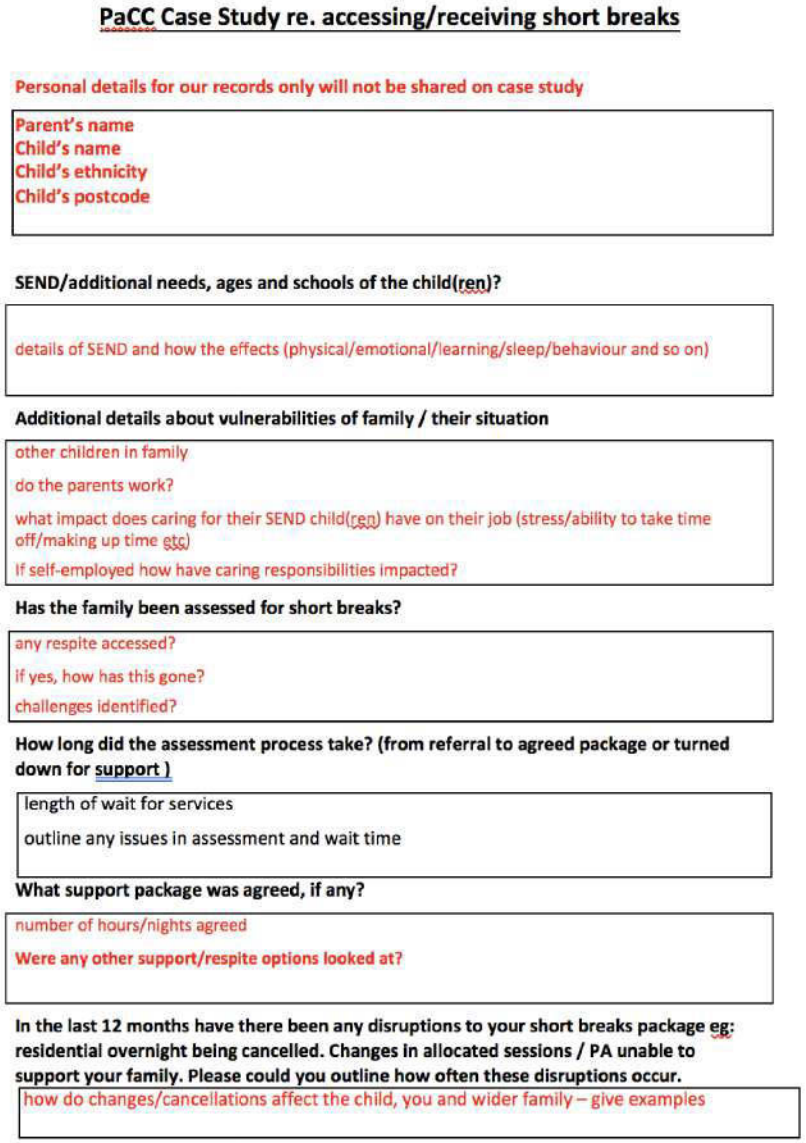
Were you asked your views/involved in the planning of the support for your child? (425 Responses)



Were you listened to and your views taken into account? (418 responses)



Appendix 5 – B&H PaCC case study



PaCC Case Study re. accessing/receiving short breaks

Personal details for our records only will not be shared on case study

Parent's name
Child's name
Child's ethnicity
Child's postcode

SEND/additional needs, ages and schools of the child(ren)?

details of SEND and how the effects (physical/emotional/learning/sleep/behaviour and so on)

Additional details about vulnerabilities of family / their situation

other children in family

do the parents work?

what impact does caring for their SEND child(ren) have on their job (stress/ability to take time off/making up time etc)

If self-employed how have caring responsibilities impacted?

Has the family been assessed for short breaks?

any respite accessed?

if yes, how has this gone?

challenges identified?

How long did the assessment process take? (from referral to agreed package or turned down for support)

length of wait for services

outline any issues in assessment and wait time

What support package was agreed, if any?

number of hours/nights agreed

Were any other support/respite options looked at?

In the last 12 months have there been any disruptions to your short breaks package eg: residential overnight being cancelled. Changes in allocated sessions / PA unable to support your family. Please could you outline how often these disruptions occur.

how do changes/cancellations affect the child, you and wider family – give examples

If Direct Payments, have they been able to find a PA? If yes, was this challenging? If no, where have they looked or has family not got capacity/skills to do this for themselves? If so what support do they need?

how were PAs found? challenges in identifying/recruiting suitable people

In the last 12 months has the lack of a suitable support package for your family's needs led you to worry about about key areas of your life. eg: Risk of split with partner. Risk of mental health difficulties or worsening of existing problems. Risk of having to leave employment. Lack of opportunity to return to employment. Lack of opportunity for your child/young person with SEND and their siblings to access the community.

Financial:
Social/Educational:
Family:
Health (mental and physical):
Personal Relationships:
Holidays:
Summary:

Using their story – please tell them the following

PaCC may wish to use their story to illustrate the needs of families to local politicians or service managers. **Is the client happy to be a case study that we may use to promote Amaze's work in our internal and external literature (annual report, website blogs or features, fundraising applications, newsletter)**

☐ Yes, using their real first names *

X☐ Yes, but must be anonymised

Photos?

* If they are happy for us to use their real names, would they let us take their photo or to use one they have taken to illustrate the case study?

☐ Yes – (if yes, the Comms team will contact them separately to complete a separate photo consent form)

☐ No

Appendix 6 – B&H PaCC newsletter

Parent Carers' Council

out of amaze NOV 2017 • 9

Inclusion in mainstream schools

Working together to help our children succeed.

PaCC repeatedly hears feedback about the struggles of children and young people in mainstream schools, as well as how difficult it is for parents to get their voices heard. PaCC has been particularly struck by the variability across the city.

PaCC has identified work with mainstream schools as one of our priorities.

PaCC has therefore identified work with mainstream schools as one of our priorities. In the context of funding pressures on schools, where cuts can disproportionately hit children with SEND, it is increasingly important to ensure the voice of parents and carers is heard in all schools.

Since PaCC does not have the capacity to work with every school, we have taken steps to work across schools. Our reps now attend both the primary and secondary SENCO forums and, earlier this year, we hosted a PaCConnect all about inclusion in mainstream schools. A large number of parent carers came along, as well as representatives from the local authority, Councillor Vanessa Brown, and SENCOs. The aim of the session was to gather parent views on what works around inclusion in mainstream schools, and what doesn't. These valuable views have been compiled into a report, which is being shared with the SENCO forum, heads forum, and the SEND Partnership Board. Read the full report on our website at www.paccbrighton.org.uk/resources/reports.

We're currently identifying areas for future strategic work with schools and the local authority, such as ensuring children with EHCPs are more able to attend their local school, and embedding co-production between schools and parent carers. PaCC is also asking for a city-wide commitment that cuts to provision do not disproportionately affect children with SEND.

We see this work as the start of a process to improve consistency of inclusive practice across Brighton and Hove, to do all we can to ensure our children reach their full potential.

Your views on pharmacies and medicines

Just before the school holidays we asked parent carers about their experience of using pharmacies. Specifically the role of pharmacies around prescription and management of medicines and how parent carers and their children could be more included in this.

We found out that the majority of parents were happy with the explanations of what medicines are for, what they do and possible side effects. However, considering that many parents and their children take multiple medicines they would like to know **more about interactions between different medications.**

Parent carers are confident enough to ask their pharmacist for more information about the medicines, and 79 per cent of parent carers can easily find and use an open pharmacy when they need one. However some parent carers suggested the quality of information and advice could be improved. They also felt having **a private space where they could speak confidentially** with the pharmacist would be useful.

Whilst the majority of parent carers are aware of many of the different services that a pharmacy can provide, only 42 per cent knew that the pharmacist can review and help manage their medications and/or provide health checks. We also found that just over 10% of parents who took part in the survey preferred to take alternative remedies or not to take medicines at all when they are ill.

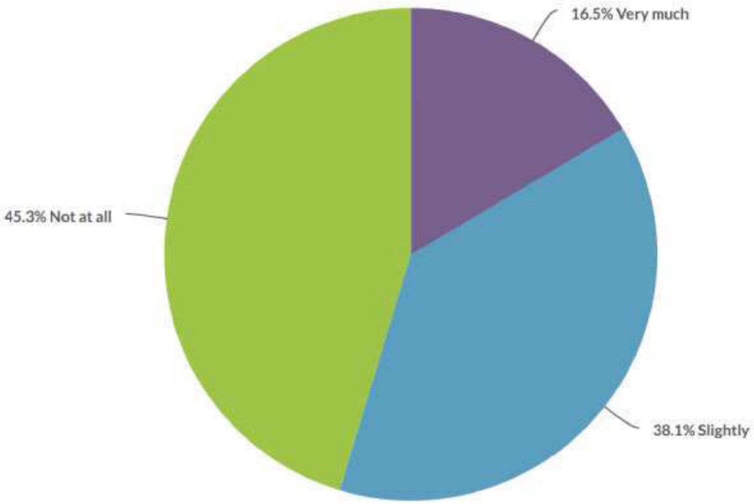
Overall parent carers are satisfied with pharmacy services. However, parent carers find the management of repeated prescriptions very challenging. **Better communication between GP and pharmacy**, and coordination of the different agencies involved could resolve some of these issues.

This report was sent to the local Clinical Commissioning Group and Brighton & Hove City Council who, through their Brighton & Hove Communities and Third Sector Investment Prospectus (TSIP), fund Amaze and PaCC to gather information and recommendations on health care and social care services.

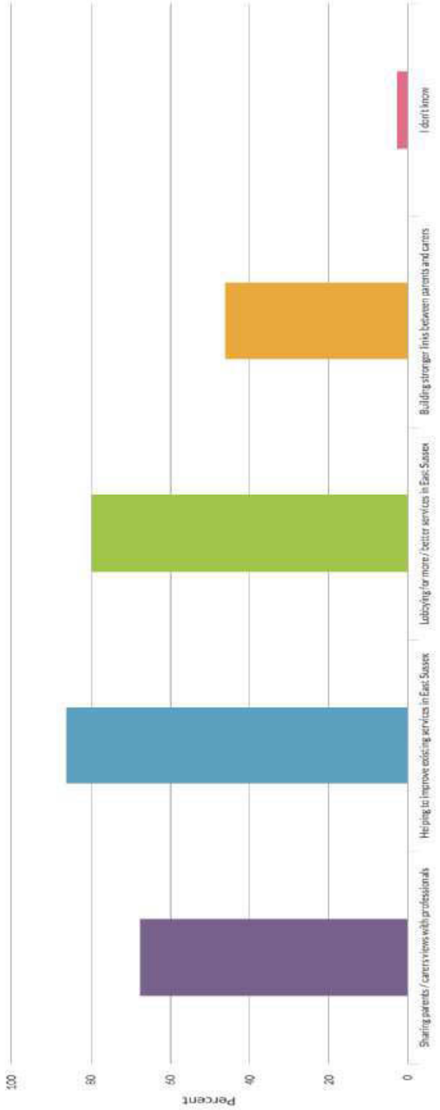
Read the full pharmacies report at www.paccbrighton.org.uk/resources/reports

Appendix 7 – charts and graphs

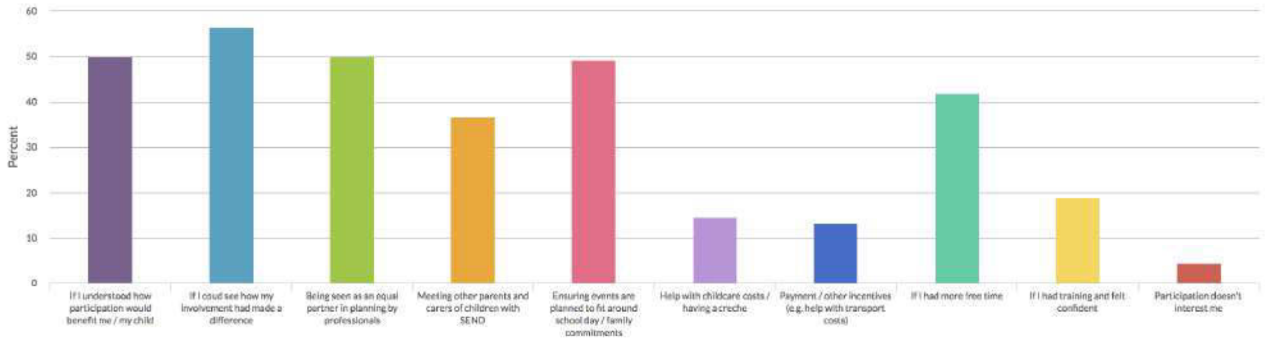
How involved do East Sussex parent carers feel in the planning, shaping and evaluating of services for their child(ren)?



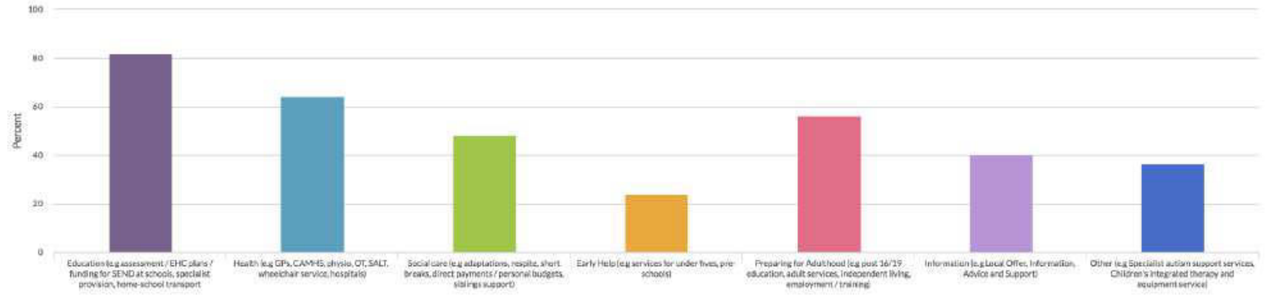
What do parent carers want their forum to focus on?



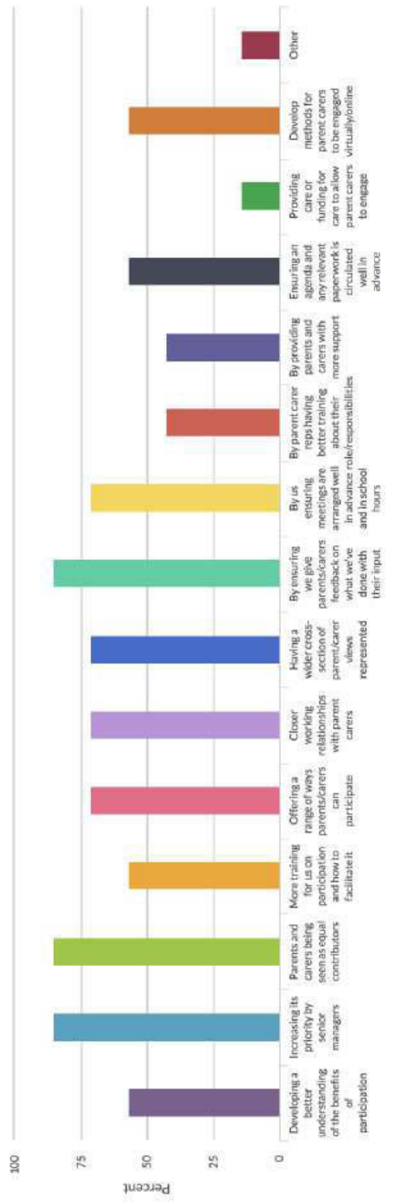
What would persuade parent carers to get more involved?



Which services are most in need of involvement and which would parent carers consider participating in?



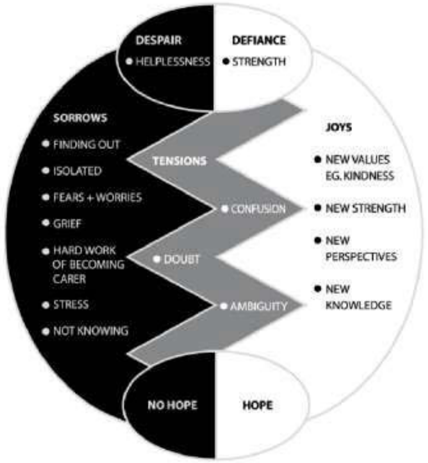
How do professionals think participation could be improved in East Sussex?



Appendix 8 – 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		

Insider's Guide model of parental experience



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