

Proposed changes to Support services for Education

A parent carers view



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Summary

This independent report has been prepared following the Children's & Families Policies scrutiny meeting in March 2018. The report outlines the feedback from parents on proposed changes to Support Services for Education. The report will show how many families feel that their voices have not been heard and they have not been able to influence the move forward to a new look service. It will demonstrate that currently there is a lack of clarity around the role of the services, particularly in connection to the delivery of Augmentative and Alternative Communication (ACC). It will also evidence the negative effect that has resulted from accurate information not being shared in a timely and appropriate manner and how this has been detrimental to the opportunities for parent carers, children and young people to influence changes which will impact on their lives. The report will conclude with recommendations to help move forward in a productive way.

Introduction

2014 brought changes for children, young people with Special Education Needs and or disabilities and their families. The Children and Families Act 2014 placed duties on Local Authorities to involve children, young people with Special Education Needs and or disabilities and their families in decisions about individual provision. There was also a requirement that children, young people with Special Education Needs and or disabilities and their families should be involved in the shaping of services through, participation, engagement, consultation and co-production. The SEND Code of Practice (2015) similarly placed duties on partner agencies so they "must work together in local Health and Wellbeing Boards to assess the health needs of local people, including those with SEN or who are disabled".

This is further supported by the United Nations Convention on the Rights of the Child (UNCRC 1989) article 12, namely that every child has the right to express their views, feelings and wishes in all matters affecting them, and to have their views considered and taken seriously. It is against this backdrop that the following report aims to share the views families hold on the current proposed changes to Support Services for Education, referred to as SSE in this document.

Background

In November 2017 the forum were advised by the Support Services for Education that an internal consultation was taking place with staff within SSE. They were further advised that an impact assessment had been undertaken on proposed changes and this had revealed there would be minimal impact. Following HR guidelines the consultation with staff would take place until the end of January and then a series of engagement events would take place with families.

Within 24 hours of this happening, staff from within those teams contacted the forum expressing concerns. Furthermore, information from the confidential internal consultation was shared on social media. In addition to this on the 20th December 2017 information from the “confidential internal consultation’ was shared by the Union on their website page. This caused concern and upset for many families and therefore Somerset Parent Carer Forum approached SSE and Somerset County Council for clarification and issued a statement on their social media (Appendix A).

Lots of information continued to be circulated; some accurate, some not. A report on SSE was presented to scrutiny on 16th March 2018 and 7 families rightly asked for further clarification.

Following the scrutiny meeting, Somerset Parent Carer Forum met with representatives of Somerset County Council, to discuss engagement events for parents carers who currently get support from the Support Services for Education. Due to time pressure of needing to report back to scrutiny on the 20th April, it was proposed we held 4 events around the county and provided an online platform for parents to be able to feed back. Simultaneously, Somerset County Council staff would meet with families on an individual basis and families would receive a letter explaining the current situation and reassurance around transition arrangements.

Section 19 of the Childrens and Families Act (2014) identifies “the importance of the child and his or her parent, or the young person, being provided with the information and support necessary to enable participation in those decisions”. Due to a substantial proportion of information being shared being factually incorrect (e.g the Autism and Communication Team being disbanded), part of the sessions would involve presenting a clear and transparent picture of the proposed changes (please see SPCF website for presentation). We felt for parents to be able to comment on the proposed changes they needed to be able to picture what the service would like before and after (see appendix B).

Proposed changes

Somerset County Council provided the forum with data on the current structure and the proposed changes. We were also provided with data which contributed to the proposals that had been made. The data was then put into a format which we felt may be easier to understand and analyse. This was supported by national data and examples in other areas to give a bigger picture. See also Appendix B.

AREA OF SSE	Structure beforehand	Proposed structure
Autism and Communication service	6.8 FTE	7.4 FTE
Physical Impairment and Medical Support Team	6.9 FTE	2.4 FTE
SENATAS	1 FTE	1 FTE
Learning Support Service	9.4 FTE	9 FTE
Vision Impairment Team	4.67 FTE	4.74 FTE
Hearing Impairment Team	13.2 FTE	11.38 FTE

Engagement events

The forum ran events in Bridgwater, Taunton, Frome and Yeovil also attending the Bridgwater parent support group. An online option for parents to feed back their views was set up as not everyone could get to the events. The events were split into the following 3 sections based on questions families had been asking.

1. Providing background Information on Local And National changes that impacted on the proposed changes.
2. Discussion on the current situation and the proposed changes
3. Opportunity to reflect on the information, share thoughts, feelings, experiences and ask any further questions.

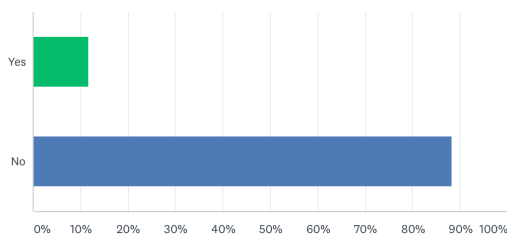
In addition the Special Educational Needs and Disability (SEND) Information, Advice and Support (SENDIAS) were invited to attend all the sessions to help support families and provide independent advice and suggestions on next steps.

In total 79 families fed back their views. Of these, 28 attended the engagement events, 44 completed the survey (only 1 of these had attended an event) and 7 contacted us via social media. Collectively they have experience of all the SSE services (Please see Appendix C)

Parent carer views

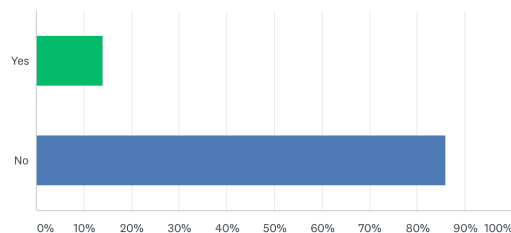
The importance of listening to and having regard for the views, wishes and feelings of the child and his or her parent, or the young person and their participating as fully as possible in decisions relating to them is underpinned by UK and International law.

The Childrens and Families Act 2014, makes it clear that the Local Authority, in carrying out their functions under the Act, in relation to disabled children and young people and those with special educational needs (SEN), must have regard to: the views, wishes and feelings of the child or young person, and the child's parents.



We asked parents if they felt this has been achieved regarding the SSE proposed changes? 88% of the survey respondents felt this had not been achieved.

Do you feel that you have been able to participate? 86% responded No and 14% Yes



Nobody has met my son to see him and what his needs truly are.

My child hasn't been asked anything

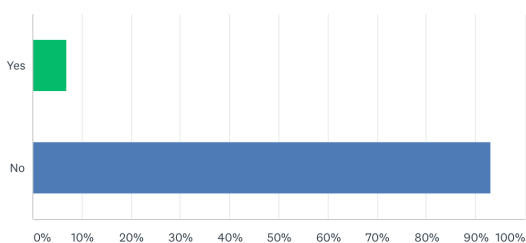
These views were in the majority supported by families who attended the engagement events. Families expressed concerns asking how an impact assessment could be done fairly and accurately without speaking to parents and children who use the services? The overwhelming feeling of families was that the decision had been undertaken before engagement had started.

"Unfortunately, the decision has already been made to reduce the PIMST so why the consultation. What meaningful contribution can any of us make to a decision that has already been made?" A Parent.

We've had some information and views from county.

Section 19 of the Childrens and Families Act (2014) identifies “the importance of the child and his or her parent, or the young person, being provided with the information and support necessary to enable participation in those decisions”. Families were asked their experience of the current changes through the online survey and at the beginning of events.

“I don't feel very informed about what's been going on its only been because of social media but county really haven't said much”

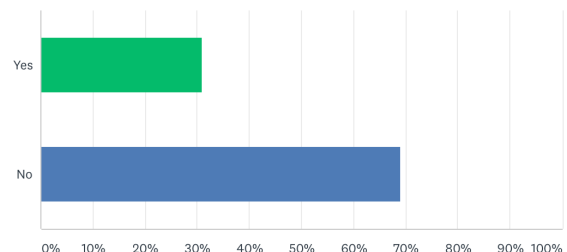


Do you feel that you have had enough information about the proposed changes to Support Services for Education?

93 % No 7% Yes

Do you feel the information has to been clear and timely?

31% Yes 69% No



Parents agreed that when sharing information there cannot be a one style fits all approach, and that various media should be used (see appendix D). Parents are very keen to be informed from an early stage. This was evidenced by a lot of families that attended the events interest, in how the funding structures work, the changes in policy at a national level and how this had a knock on effect to Somerset. For a lot parents it was the first time they had seen this level of detail and they found it enlightening. They were pleased to hear that Somerset in analysing the impact of services and making sure the money spent is getting positive outcomes for children and young people. They also were surprised at how much of the high needs budget can be taken by independent schools, with many suggesting more support should be given to our own schools to help keep our children local. Families are very understating that budgets are shrinking and that we need to make the most of what resources we have; they just want to be involved in the choices.

The following 2 sets of data were the most discussed at the engagement events. The data which revealed that 46% of the caseload of PIMS (a service funding from high needs block) consisted of children who do not have high needs funding raised concerns (please see comments). As a forum this raised the following queries for us-

1. Have these children not had their needs clearly identified?
2. Should these children be receiving high needs funding and schools have not applied or failed to get this?
3. If the child should have high needs funding and does not, are they being denied the protection of an Education Health and Care plan?

	Number of pupils	% of caseload
Can't Find Child on Capita	6	1.3
EHE	2	0.4
Special School	8	1.7
No HN Funding	224	46.8
EY Provision	45	9.4
MSBM	29	6.1
MSB1	22	4.6
MSB2	31	6.5
MSB3	39	8.1
MSB4	33	6.9
MSB5	19	4.0
MSB6	11	2.3
MSB7	10	2.1
TOTAL PIMST CASELOAD	479	

Parental comments and questions

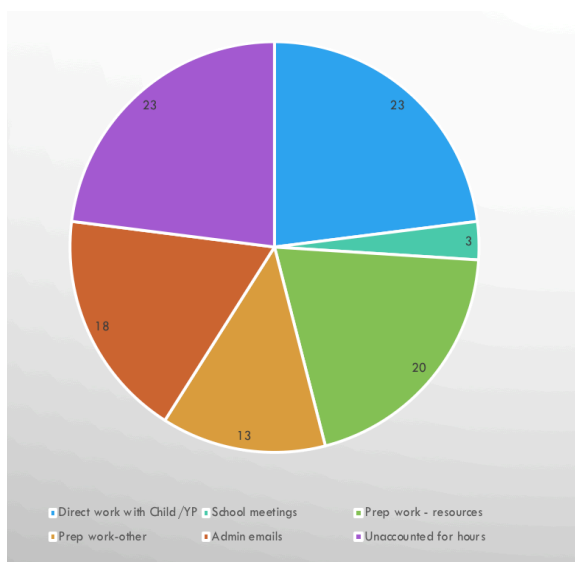
“Why are they working with children who do not meet the threshold?”

“There appears to be a lack of governance in the service”

“If the 6 kids are in independent why are we paying twice?”

Snap shot of use of time

This slide represents the data collection over 1 term within the PIMS team as shared by Support Services for Education. The information was to give a flavour of how staff were currently deployed. Families expressed that they felt the preparing resources was vital and should not be undervalued as this enables children to be able to access the curriculum with their peers. Others felt these highly experienced staff could be used more effectively. They also expressed concerns that people making the decisions did not have a clear understanding of what the staff do or how complex the needs of the children are.



Parents Comments were mixed

“Is it best use of advisory teachers?”

“Resources sounds low level and actually the resources are very high level and unique, which the team should do.”

One of the key messages that came from the survey and the engagement events was how highly the individual staff within the PIMS team were valued. We heard how they liaise with schools, the Bristol communication hospital, act as advocates for families and show school staff how to support the children. Parents are worried about the cuts and feel these individual members of staff and the expertise cannot be replaced. One of the things frequently asked was who was staying and who was going, the feeling was this was not about roles but individuals. There is a great fear that children will be forced out of mainstream schools. Although the forum shared the relevant information and the reassurance from Somerset County Council that this was not the plan, there was a sense of lack of trust by some families; others were clearly relieved.



One of the things that became very evident during the engagements was that it was not clear who did what. Many families were surprised that In April 2013, NHS England became responsible for commissioning services for those with the most complex communication needs. This has seen developments in the way

specialist services are commissioned and funded, with a national service specification for AAC and the identification of 15 specialised centres including Bristol.

“If SSE had been able to produce something like this at the outset, it would have saved some families from stress and worry because their children's services aren't being cut at all, and would have given a more honest picture of what it means for PIMs service users.” Parents view of SPCF graphics

Families also were unaware that under the Department for Education guidance on support children with medical needs, the schools governing body should ensure that medical plans are reviewed at least annually, or earlier if evidence is presented that the child's needs have changed. They should be developed with the child's best interests in mind and ensure that the school assesses and manages risks to the child's education, health and social well-being and minimises disruption. This is reinforced under the SEND code of Practice 2015 which places duties on schools to ensure they meet these needs. The general expectation is that the role of centrally funded services is to support schools in meeting the needs of pupils through an advisory role, with the direct support to pupils falling under the remit of schools.



There are concerns that if the PIMS team were no longer going to do some of the things they had previously covered, that come under the health remit, and could not see how that would work. Families repeatedly stated that health were unable to supply Occupational therapists and speech and language therapists due to capacity issues. Another area discussed was access to support all year round. If PIMS, a term time only service (39 weeks a year), are delivering all the support, how do families managed outside of term time. Families felt a more joined up service across agencies could help to address this.

The service currently covers children up to the age of 16 and we heard multiple accounts of families waiting for a diagnosis for it to come too late for them to access the service. There was a high level of frustration around this especially as the SEND Code of Practice cover 0 to 25.

Within Somerset the vision is that “is for the 110,000 children and young people in Somerset to be safe, healthy, happy, ambitious for their future and to develop skills for life” (Somerset County Council 2016).



We ask you to read through the following case studies and learn about the world from the view of our young people. There is a lot of information but these stories deserve to be heard.

Name of Company	Somerset Parent Carer Forum
Contact for enquiries	help@somersetparentcarerforum.org.uk
CASE STUDY	
Summary	The Support Services for Education is a service that combines lots of teams together. It encompasses the Hearing Impairment Team (HI), Visual Impairment Team (VI), Autism Communication Advisory Team, SENATAS, Learning Support and the PIMS (which encompasses the AAC) Team. There is a continual overspend and the team were asked to make savings across the board.
Issue to be resolved	<p>The issue is that High Needs Funding is currently £5.2 million over spent and savings need to be made across the whole range of services. Other projects like banding for example are already taking place in other areas. It is against this backdrop that Somerset County Council have requested SSE make necessary reductions in budget.</p> <p>The objective? To reduce overspend now that money cannot be moved between the funding blocks, due to government guidelines, unless permission is sought by the LA to central government.</p>

Name of Company	Somerset Parent Carer Forum
Insight - Ettie, Max and Gracie.	<p>Ettie - To give you some insight to the use of technology and Ettie, please see her video that was filmed 2 years ago by Somerset's SEND Participation Team - https://www.youtube.com/watch?v=WJTRUCyKrsM&feature=youtu.be</p> <p>Ettie is 13 years old and now attends a special school over the border in BANES. She lives with her Mum, Alison and her Dad. Her mum is a secondary school English teacher and her Dad works in IT. Alison thinks that Ettie is extremely lucky as they are in a position to function (update etc) the technology, which usually is carried out by the AAC.</p> <p>She was born, after a normal pregnancy but was subject to a traumatic birth where the labour was not monitored and Ettie was starved of oxygen, as the cord was wrapped around her neck. Due to her brain being starved of oxygen, she was diagnosed with Athetoid Cerebral Palsy, which means that she has very little control of her whole body, because all her muscles are affected, including swallowing. She still cannot sit upright, unsupported by herself. In her early life, she was unable to feed, but fortunately the nurse that was looking after the family in special care baby unit, gave the family a special bottle, normally used for babies with a cleft palette and this enabled her to start to learn to swallow.</p> <p>As she grew up, she attended the Frome Opportunity Playgroup and it was they who started the process, firstly with MAISEY. Through MAISEY meetings Ettie was able to start a mainstream school within her community. There was a really good handover because of the support that MAISEY gave.</p> <p>PIMS involvement started when she started school.</p> <p>Speech and language was initiated, though this wasn't right for Ettie. Because she couldn't speak or form words, this was when PIMS team were involved. Parents were concerned that cognitively Ettie may not be able. So when the PIMS started their work via a Specialist communication adviser, who then started introducing symbols on cards, like yes and no, giving her choices to be able choose. Ettie responded really well by touching the cards, giving Ettie communication for the first time in her life at the age of 4. It then progressed to a communication booklet, which included photos of her peers in the classroom, which gave her choices to play with her peers and make friends, this was the first time that Ettie was fully included in her school life.</p>

Name of Company	Somerset Parent Carer Forum
	<p>Her sentences in the book were made more complex as she grew older. These books then were developed to differentiate her learning. As she grew up the booklets became books and were developed to a 70 page laminated book. As Ettie grew the books became more complicated and were coloured with coloured references and the TA was essential to sit next to Ettie, so she could be able to communicate.</p> <p>The electronic device was initiated in year 2/3 with a trial. This caused issues, as for the first time Ettie had found her true voice, where she could press a button and it would speak whenever she pressed the button. The issues arose where it was new, and it was used inappropriately by Ettie, so AAC were instrumental in teaching her of when to use the device within school. This made a huge difference, made it more inclusive. A high-tech device was then introduced, but again, due to the involuntary movements, the device had to be started with 8 tiles and over time the AAC have initiated more and more tiles. It took weeks for the parents and PIMS team to develop the tiles, so she could communicate, using her arm and the device, this can cause issues over time with her shoulder as the movements are repetitive.</p> <p>So an OT needs to be there when they progress to an eye gaze, to make sure that she is sat in the right position.</p> <p>The communication books become more complicated when Ettie has to sit her SATS etc, as they are specific to what they are learning, so that she can be included within her classroom environment, giving her the same opportunities as all her other classmates, which is essential to Ettie, as she likes to be the same as everyone else.</p> <p>Year 6 SATS she achieved a level 2 in science, only because the papers were accessible and the TA from PIMS came in and met with Ettie and the school and she took a typical SATS paper and made it accessible to Ettie, so she could take part.</p> <p>If another child like Ettie came into the service, they will benefit from the work that they did with Ettie, however, curriculums change as do the children's needs.</p> <p>PIMS were able to devise an AAC users of IT book, so she could communicate emails etc.. so that she could start to send emails, another way to communicate and another thing we take for granted.</p> <p>5 sentences in an email can take Ettie 40 mins.</p>

Name of Company	Somerset Parent Carer Forum
	<p>Another issue that Ettie also faces:</p> <p>Gators - for sitting a long time, body gets deformed, Ettie has a physio in school and health are supposed to provide it as it's in her EHCp in her health section. The Physio, is based in Mendip, is the only one who is based there and is supposed to attend one session per half term in her plan, she's not been attending. Parents have now resorted to paying for her to have a private physiotherapy and has now discovered that because she had no physio and that Ettie is growing, her hamstrings have shortened. This could quickly end up to her having surgery to cut her hamstrings and ligaments. Out of desperation they borrowed some gators as they were £80-£90 to buy them online, as it was going to be 3 months to get an orthotics appointment and potentially be 6 months for these gators to arrive through the NHS.</p> <p>By having the AAC /PIMS team involved they have realised that Ettie has capacity to decide and the cognitive potential to learn and develop in her own right. There is a possibility now that Ettie can live a fulfilled life doing what she wants to do, whatever that may be. Ettie wants to go somewhere her parents aren't and she loves the idea of going off and doing things and have opportunities without her parents. She wants to live by the sea and would love to go to university and wants to do sports too, so watch out special Olympics! Without these devices and the people (including her amazing parents) who support them, Ettie would not be where she is!</p> <p>It is a lengthy process. The systems change as does language and it is very time consuming, but the commitment from the team and the parents has made it worthwhile as without them Ettie would not have a voice.</p> <p>There are real concerns that the service stops at 16 and may need to be re-issued post 16.</p>

Name of Company	Somerset Parent Carer Forum
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Max’s Story: Please look at this video to give you an insight into what it means to say the word Daddy:



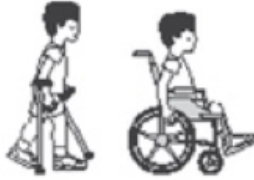


<https://1drv.ms/v/s!Aks7iPjVJ4Dh3EtABWUIAXL-wont>

Max is 10 years old and is the eldest child in his family with Mum Gemma and Dad Adam, He has a 6-year-old sibling. Mum went into labour at 26 weeks, where she stayed in hospital for a week after they tried to stop labour. He was born at 27 weeks and 4 days - although breathing they ventilated him straight away, and he was diagnosed with dystonic cerebral palsy at about 5 months.

They were told that Max wouldn’t be able to talk, move his arms, or walk and that there was no hope. The doctors couldn’t predict his future and he is a level 5.

GMFCS for children aged 6–12 years:

Descriptors and illustrations

	<p>GMFCS Level I Children walk indoors and outdoors and climb stairs without limitation. Children perform gross motor skills including running and jumping, but speed, balance and co-ordination are impaired.</p>
	<p>GMFCS Level II Children walk indoors and outdoors and climb stairs holding onto a railing but experience limitations walking on uneven surfaces and inclines and walking in crowds or confined spaces.</p>
	<p>GMFCS Level III Children walk indoors or outdoors on a level surface with an assistive mobility device. Children may climb stairs holding onto a railing. Children may propel a wheelchair manually or are transported when traveling for long distances or outdoor on uneven terrain.</p>
	<p>GMFCS Level IV Children may continue to walk for short distances on a walker or rely more on wheeled mobility at home and school and in the community.</p>
	<p>GMFCS Level V Physical impairment restricts voluntary control of movement and the ability to maintain antigravity head and trunk postures. All areas of motor function are limited. Children have no means of independent mobility and are transported.</p>

Name of Company	Somerset Parent Carer Forum
	<p>To get some answers, the parents paid to attend a private clinic that specialises in CP in London and the tests found that Max is cognitively aware, and his biggest strength was his communication. Max was referred to a speech and language advisor and it was deemed that Max's communication needs are as such that it was deemed not appropriate and this was when they referral to AAC.</p> <p>Max attended TOG and then he attended a mainstream pre-school where he had portage. PIMS, along with the AAC were involved before the transition to primary school. He was using the books/ cards upon entering school. He was assessed for an eye gaze and was given one in the January 2014 year 1. All instigated by AAC</p> <p>Kate (AAC) has done the reading assessments and he can read with pictures - he uses eye gaze. As part of this training and assessments he played games and then he built up his time and then it was built where he has families and different screens allowing him to build up his words to have a massive resource like a dictionary but unique and important to Max.</p> <p>Certain pages in the machine has subjects that is unique to his learning, i.e. all his science topics that he is doing in that term is loaded by AAC and then is subsequently changed by the AAC</p> <p>If the computer breaks parents ring the suppliers.</p> <p>Gemma is concerned that the TA's are already trained as Gemma states that Kate has already trained them.</p> <p>Max cannot speak so the only way he can communicate is through the eye gaze device.</p> <p>These children are so few with the most needs, that although PIMS is a big service, actually those people who support them are so unique, that Gemma feels that Max would be better supported if he were blind...as the visual impairment team or hearing team are yet to be affected by the cuts and feel that using staff from VI or HI to support Max is short sighted. Communication should be a statutory service as everyone has the right of a voice, and Gemma feels that it is equalities act.</p> <p>Needs to be kept as it is - doing what it does best as it has changed lives - training needs as this is a short</p> <p>Transition to secondary will he be accepted? Without this support? He is due to go to BCA a mainstream in Bridgwater.</p>

Name of Company	Somerset Parent Carer Forum
	<p>Gracie's Story:</p> <p>Gracie is 12 years old and lives with her Mum, Dad and her older brother.</p> <p>Mum had a normal pregnancy, and at one point, due to a blood test they thought Gracie had Down Syndrome, mum and dad refused a amniocentesis. It progressed to a normal birth and she came at her due date.</p> <p>The first they knew that something wasn't right was when she kept falling over and wasn't walking by one. Her brother was more advanced, but they thought that she was a late developer and it wasn't until she was in pre-school at 18 months that they agreed that something was wrong. She went to GP as he thought it was her hips and then went to see paediatrician in Musgrove, who then sent her to Bristol and it was then backwards and forwards for lots of trips. and eventually she was diagnosed in 2008 at the age 3, with ataxia 18 xia telangiectasia, a genetic condition.</p> <p>Children with this condition do not normally live past their teenage years and whilst they have periods of time well, they also have phases where the condition progresses and something else is lost.</p> <p>PIMS were involved once she started at TOG and MAISEY were involved when she was about to start school.</p> <p>Gracie was able to speak and could move around without a wheelchair, however in year 4 she went to the toilet and what looked like she lost focus, there was nothing. They called mum and because this was part of the progressive nature of the condition, however she lost her ability to speak and to walk permanently, because of another progressive disease called cerebellar dysarthria associated with anarthria, this is a neurological condition.</p> <p>Pam was the key worker who helped Gracie use clicker and an iPad etc, until another progression episode meant that these communication aids were not enough. They brought Kate in, as it became apparent that Gracie's communication was as such that AAC was needed.</p>

Name of Company	Somerset Parent Carer Forum
	<p>Symbols and STC were used and the iPad was used with speaking apps. At transition to mainstream secondary, Kate made a referral to Eye gaze (who are based in Bristol) and the referral was made in July and the appointment came through in December. Gracie started mainstream secondary in September and unfortunately the WIFI wasn't given and the work that Gracie did on the iPad couldn't be printed off.</p> <p>She didn't sit her SATs at primary school but is doing assessments at secondary, with a reader.</p> <p>Gracie had issues at the start of the secondary years as she didn't have the eye gaze and so was unable to communicate properly.</p> <p>She is currently under review with the eye gaze with a joystick on her wheelchair and she is really getting on with it. Kate and Pam need to be present with the review as Pam goes into School and Kate knows the equipment more than Pam.</p> <p>The family are in limbo as they are unsure if the staff will remain.</p> <p>Pam is currently going into the school nearly every week to support both Gracie and the school, as this is new to Gracie and with her progressive condition, every time she has an episode, it is almost as if a whole new communication aid is put in for her.</p> <p>Without the support the school have already said they are unsure of how they are going to cope or how Gracie is going to cope. The secondary school education is with many teachers and to train every single one in Gracie is going to be costly and time consuming.</p> <p>Sheryl has said why...we fight for our kids every day, why are we fighting for their communication, their ability to speak. This is what everyone takes for granted.</p>

Name of Company	Somerset Parent Carer Forum
Next Steps	<p>It is hard for parents and the children to visualise this service without the key members of the AAC team that sit within the PIMS team. They have a mammoth amount of knowledge that has been learnt over the years along with their TA's. They understand that cuts need to be made, however, the AAC and her team have such a unique set of skills, they cannot be learnt quickly by anyone else. These unique sets of skills, help, support and give something that we take for granted to a unique set of people. How would we feel if we were unable to talk? Speech and language hasn't worked with all of these children and so a unique service is needed for these unique and individual children.</p>
Other Information	<p>For more information on Alternative and Augmentative Communication can be found here:</p> <p>http://www.inclusive.co.uk/articles/alternative-and-augmentative-communication-aac-a280</p> <p>And in the words of Stephen Hawking -</p> <p>"Without the ability to say what we are thinking we lose our dignity, our independence and the very essence of what makes us human. But with the gift of communication, there are no boundaries to how we can influence and participate in the world around us. With a voice, we have the power to be who we are."</p>

Areas of Concern

"Parent carer participation is when parents and professionals work together, recognising each other's expert knowledge, to make informed decisions about children's services that make the best use of people's time and money"(Contact 2018). The feedback from families indicates that they do not feel this has taken place. Over half also feel the information provided was not transparent and easy to access. The engagement events and graphics have enabled families to understand better, information has alleviated much anxiety.

While acknowledging that this has been an upsetting and challenging time for all involved, it could be argued that the unprofessional behaviour of some staff

members has led to misinformation being shared and parental anxiety being raised; a lot of which has been unnecessary. Peoples lives have been affected and some families including children, have experienced extremely high levels of distress. This has also impacted on parents and young people having a full opportunity to engage in shaping the service as this has been a barrier to effective coproduction.

There is no national guidance around the PIMS service. Our research as a forum has identified that the delivery across England is very variable. Some areas are funded by education, some from health and others do not have a service at all. This makes it very challenging for commissioners and families when trying to shape a service. The report Bercow Ten years on (2018, p.18), highlights good practice in Liverpool where the council and CCG have jointly commissioned the service for children needing Augmentative and Alternative Communication (ACC). The SEND Code of Practice (2015) section 3.46 states “The **DMO** provides the point of contact for local authorities, schools and colleges seeking health advice on children and young people who may have SEN or disabilities,... The DMO can support schools with their duties under the ‘Supporting Pupils with Medical Conditions’ guidance”. Within all the reports, impact assessments and presentations there has been no indication that the DMO has been involved or consulted in the changes. While we appreciate the service is an education service provided by Somerset County Council under the spirit of the Children and Families Act (2014) and the SEND Code of Practice there is an expectation that this would have taken place. Our concern is echoed by parents.

Nasen (2014) have published excellent guidance on effective adult support. This highlights research into the danger of over reliance and some of the negative impacts this can have on confidence and resilience within children and young people. As mentioned previously parents placed an overwhelming value on the expertise of the individual staff within the services. While we whole heartedly agree they are very dedicated and highly skilled members of staff this does not come without risk. This is a relatively small team and at some point those staff may retire or choose to move on. We need to ensure we are building the resilience in children, young people and their families to manage these transitions effectively while maintaining an appropriate level of support. As an area we need to value this expertise and grow it in others to ensure the sustainability and equal access moving forward.

It appears that the Impact assessment has been completed without full regard to the feeling of families and the emotional impact changes may have. We would have like the assessment to have taken into consideration the impact on the social interactions of the children and young people who are using the services that are being proposed to change. Although the services focus on the education of the child or young person this is not something that only happens at school and impacts on the whole family.

Conclusion

The highest level of concern has come from families who have children with complex needs who require access to Augmentative and Alternative Communication (ACC).



It is evident that the Human Resources constraints and the requirements of the Children and Families Act 2014 do not necessarily align. Balancing these 2 areas is a challenge that needs to be managed moving forward to mitigate any risks this brings.

Ten years ago a review of speech, language and communication needs was undertaken, led by RT HON. John Bercow MP. This acknowledged that “the most fundamental life skill for children is the ability to communicate. It directly impacts on their ability to learn, to develop friendships and on their life chances (ICan 2018, p. 4).” Support Service For Education is an essential service that supports schools to differentiate the curriculum and adapt to support the needs of a wide range of children. They support children and young people to be able to communicate and try to allow them to access the world as their peers do. As an area we need to value the support and expertise these staff have and ensure this is shared, empowering and enabling schools to support the needs of all children and young people with SEND.

It has been clearly evident that everyone who has been involved in these proposed changes be it parents, support staff, teachers, SENCO's, commissioners or senior leaders with the council, they are all endeavouring to support children to get the best outcomes. Each group has different experiences, priorities and pressure to manage while doing this and many have lost more than a few nights sleep trying to see a way through. While there are lessons to be learned and changes need to be made, we must endeavour to do so together.

Recommendations

In light of this report and discussion with families we would like to make the following recommendations.

1. A workshop is held between Human resources, the SEND department, commissioning and Somerset Parent Carer Forum. We need to find a way forward which will allow the duties of HR to be preformed while enabling meaningful participation on parents at the earliest point. Without this there is a risk we could experience this again.

2. There is a multi agency group to look at the impact of the proposed changes and to explore how this service can be jointly funded. Drawing on examples of good practice such as Liverpool.
3. There is a renewed commitment to the refreshed SEND Engagement and Participation strategy (appendix E) which places the voices of children, young people with Special Education Needs and/or disabilities and their families at the heart of decisions.
4. Scrutiny have oversight of the strategy on at least an annual basis and monitor its implementation
5. There is a review of the information services. Families who attended the events were unfamiliar with procedures, their rights and what to do when things are not going as planned. There also needs to be more clarity around the roles and powers of boards and committees with Somerset County Council and the Clinical Commissioning group.
6. Engagement events take place 6 months after the changes to measure the impact.

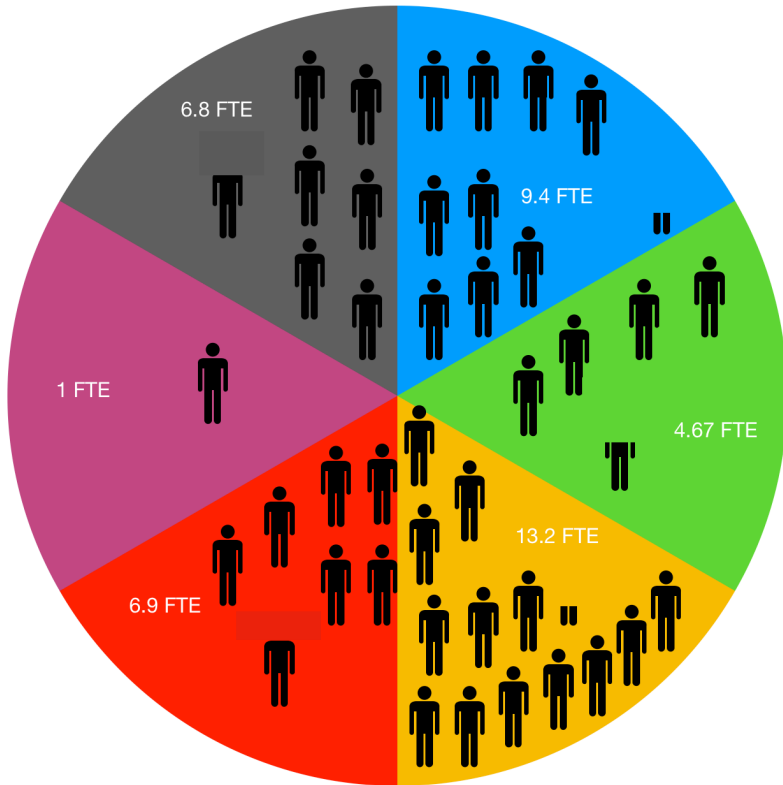
Appendix A

Statement shared On Somerset Parent Carer Forums social media December 2017

We have been contacted by members concerning information that has been shared recently on social media regarding Support Services for Education. As a forum we are not involved in any consultation regarding SSE, and we know there are no public consultations taking place currently, so have approach Somerset County Council on behalf of our members. The following is their statement which hopefully will clarify the situation for families.

"SCC is currently in consultation with some of their staff regarding potential changes which may affect some of their staff within Support Service for Education (SSE). This is an internal staff consultation which is necessary due to the likely reduction in funding due to budget pressures. SCC is facing significant financial pressure and must respond to this. The need to reduce the overspend has been outlined to schools over the past academic year and is in relation to the wider SEND review taking place to ensure pupils in Somerset with SEND receive consistent support."

Appendix B



Support Services for Education before proposed changes.

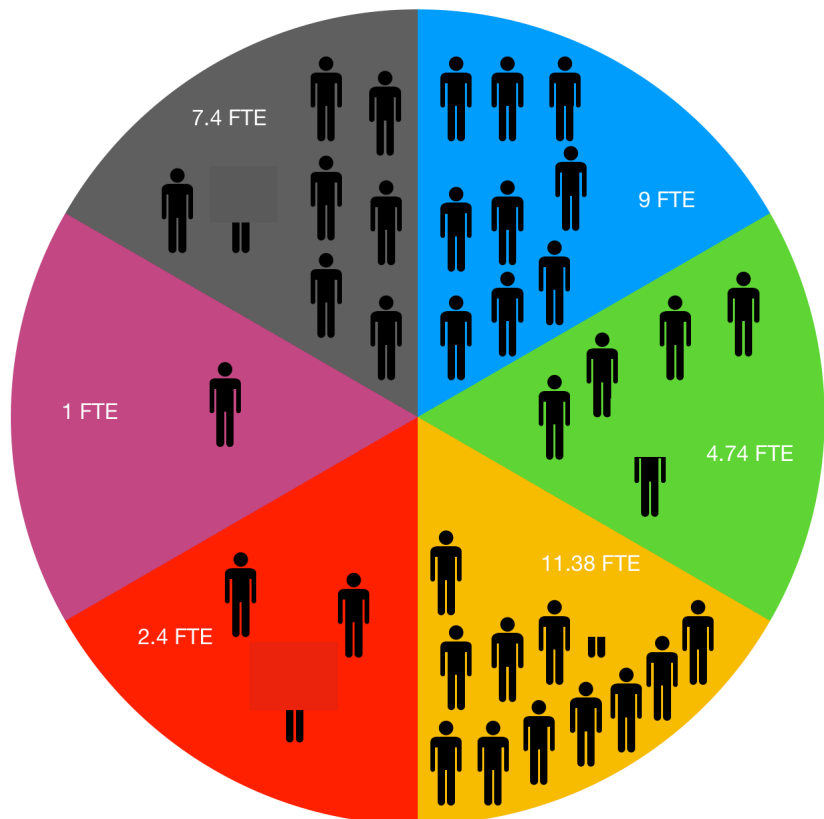
FTE = Full time role.

Support Services for Education after proposed changes.

The manager from Learning Support services has left. Moving forward the manager of the Autism and communication team will cover this role.

Hearing impairment and Vision impairment (statutory services) are currently under consultation with families who use the service.

Higher Level teaching assistants from Vision and Hearing will support the PIMS team under the proposed new structure.



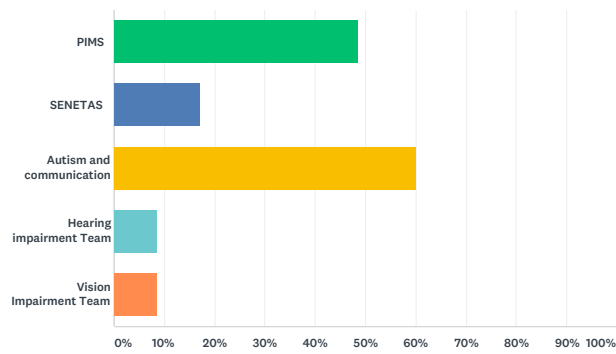
- Learning support
- Vision Impairment
- Hearing Impairment
- PIMS
- Sen assisted technology advisory service
- Autism and Communication team

Appendix C

PIMS Engagement Survey

Q1 Which of the following Support Service for Education does your child use or has used previously

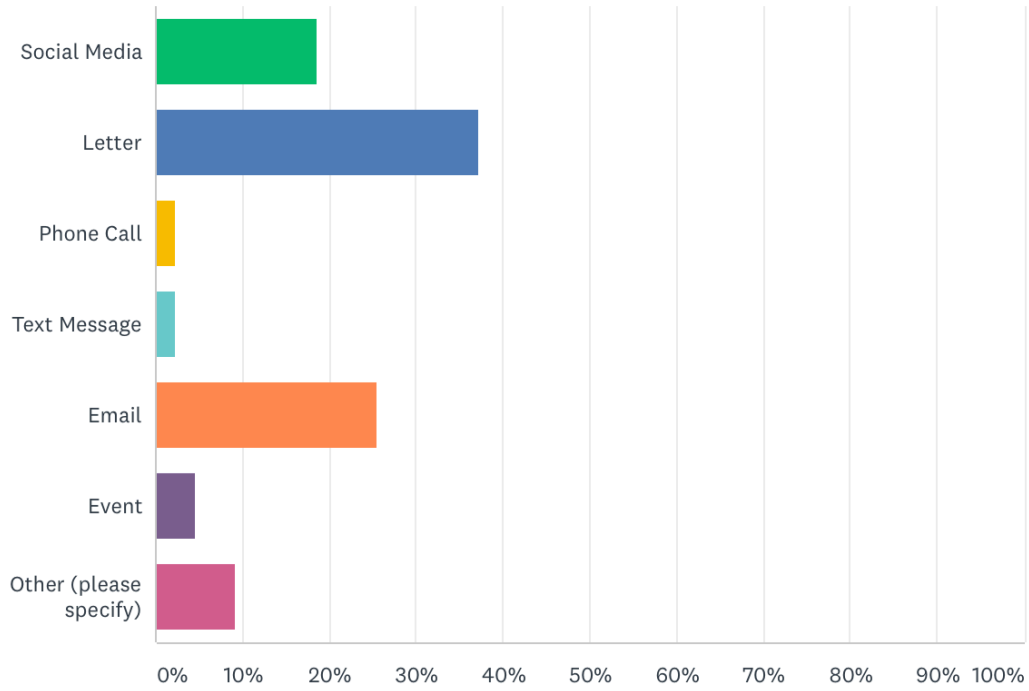
Answered: 35 Skipped: 9



ANSWER CHOICES	RESPONSES	
PIMS	48.57%	17
SENETAS	17.14%	6
Autism and communication	60.00%	21
Hearing impairment Team	8.57%	3
Vision Impairment Team	8.57%	3
Total Respondents: 35		

Appendix D

Best ways to share information.



Appendix E

Somerset Special Educational Needs and Disabilities Engagement and Participation strategy 2018-2020

What is participation and why do we do it?

Participation is involving children and young people and their parent carers in the decisions that affect them. Every child and young person has the right to be involved in decisions . Some might need more help than others.

Vision

We want every child and young person to have the greatest possible opportunity to be the best they can be, to be happy and have choice and control over their lives.

SEND strategy 2016-2019

Why are we here?

In Somerset, we believe that there should be no decision made about you without your involvement.

The law also tells us that we must listen to the views wishes and feelings of a child and his or her parent or the young person.

How are we going to do it?

- ⇒ Make sure there are tools to support participation.
- ⇒ Good quality, simple information that everyone can use so that people can make decisions.
- ⇒ Create opportunities and a safe space for people to share their views.
- ⇒ Good feedback- "you said we did"- people can see what happens as a result of their feedback.
- ⇒ Things that are working well are shared– We celebrate success!
- ⇒ Share information between services to make changes.
- ⇒ Involve children, young people and their families in planning and reviewing services.
- ⇒ Enable people to communicate their views in the way they want to.

Priorities

Children Young People and families are encouraged to participate in decision making about their own lives.

Services are designed with people for people.

Working together– Education, health and social care .

How will we know its working?

- ⇒ Children and young people will feel safe and happy at home, college, school and work.
- ⇒ Children, young people and their families are happy to speak up and feel that views are valued.
- ⇒ Children and young people have the skills they need to be as happy and independent as possible in these five areas:

How can I choose my next school or college?

How can I find a job and keep a job?

How can I live more independently?

How can I find things to do in my spare time?

How can I stay safe and healthy?

- ⇒ Services are designed with the families that use them leading to better outcomes.
- ⇒ Strong communities that are able to support themselves and each other.

References

Great Britain. Department for Education (2015) *Special Educational needs and disability code of Practice; 0 to 25 years* [online] available at <https://www.gov.uk/government/publications/send-code-of-practice-0-to-25> (accessed 18 April 2018).

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Somerset County Council (2016) children and young peoples plan. [online]. Available at: <http://www.somerset.gov.uk/policies-and-plans/plans/children-and-young-peoples-plan> (Accessed on 17 April 2018)

Nasen (2014) *Effective use of Adults* [online] available at: <http://www.nasen.org.uk/resources/resources.effective-adult-support-inclusive-practice.html> (accessed 10 April 2018)

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