

**PaCConnect**  
**13<sup>th</sup> November 2018**  
**The SEND Strategy Review**

In attendance; Carolyn Bristow – Head of SEN and disabilities, Carl Campbell – head of Social Worker Services, Georgina Clarke-Green Assistant Director of Health, SEN and Disability, Fiona England PaCC Chair, Diana Boyd PaCC Vice Chair, several Parent Reps from PaCC Steering Group and Parent Carers

**Setting up SEND strategy – Key Points – Georgina Clarke-Green**

- System wide and co-produced, involving health social care, education, FE (ask GCG for power point)
- Identify key priorities
- Local offer
- Profiles of need have right services  
Transitions  
Health – cutting waiting list. Making sure services are working together not multiple pathways
- Adulthood and beyond
- Intersectionality – children with send not just send – recognising the whole person – look at other communities the child with SEND is part of. Whole life
- Governance – who holds us to account? Are we delivering on these priorities – need to have a parent critical friend who will work with priority leads to make sure families are in mind when delivering – strategy. Smart targets and priorities – priority leads responsible for delivering back to SEND partnership board. Measurable and achievable targets. Aiming to have strategy in place by Summer 2019.
- Once priorities are set – we will let parents know and look into volunteers/PaCC reps being critical friends – (Fiona England - PaCC reps will ensure other members of the community will be included)
- Also look at how do we get CYP involved
- Fiona England – thinking about how we include the whole community – outreach for example. Similar sessions will be held at the outreach coffee mornings in Moulescombe, Hangleton and Whitehawk

*Parent Question – what about current SEND strategy?* The LA to evaluate with input from PaCC. The last one will be evaluated but we are focusing on looking ahead.

## **Sufficiency Plan – Georgina Clarke-Green**

Purpose of sufficiency plan

- Identifying resources to ensure we have efficient resources going forward.
- System wide – need to involve health and social care partners. Able to identify service information sharing agreement – we knew where we'd need therapeutic and educational input. Making sure that we don't just tackle one part but all of the system.
- Analyses of data – strong evidence base. Show very clearly what is needed and what it will cost. Look at all the trend data in BH council and also data from national statistics so we can create a range to make sure we're checking everything out and getting it right. This will inform Commissioning intentions.

*Parent Question – how detailed will the plan be – will we be looking at every single child? What level of detail will you be looking?*

GCG – look at individual need – every child should be recorded as having an additional need – then further detail such as EHCP – then should be able to predict this many places, for this area of this city of this age.

## **What do PaCC do? Diana Boyd – Vice Chair of PaCC**

Key points:

- Looking after parent carers needs. Many parent carers are not having carers assessment – reason being doesn't lead to anything
- Respite – focuses tends to be on just children with learning difficulties
- Training for Parent carers
- Improving inclusion in mainstream.
- Treating parent carers as partners
- Mental Health
- Falling through the gaps – not just in education but every area. Hidden children
- Post 16 – lack of provision – very limited options – we would like that to be included

## **Questions for Parent Carers to Consider Georgina Clarke-Green**

1. What do you think are the key priorities that need to be included in the strategy?
2. What data sets do we need to be looking at for the SEND Sufficiency?

What is a data set – eg - numbers of families of children with downs syndrome, numbers of children moving to the city with SEND, numbers of CYPs who have moved from mainstream to specialist, numbers of tribunals, exclusions etc

## **Parent Carer Comments**

### ***EHCPs***

*EHCPs to represent child better and not be wishy-washy.*

*My Child (and I) need dedicated caseworker attached to our child and not the school (EHCPs caseworker)*

*Lack of provision for children with SEND who don't have EHCPs*

*Maintaining support for children with SEND but no EHCPs*

*Legal checks of EHCPs by external neutral parties -moderation*

*Total transparency of EHCPs*

*EHCPs should include home too. SEND review was supposed to address home support and hasn't yet.*

*Have the capacity and opportunity to think and plan beyond the day-to-day. But EHCPs annual review tends to focus just on year-by-year.*

*My child's progress needs to be maintained e.g. when change of school.*

*SEND strategy needs principals e.g. parent's voices have parity with professionals.*

*Communication needed from school on what aspects of life skills are being covered. And need support for parents on supporting YP with life skills development, e.g. consent, sex education, appropriate behaviour etc.*

### ***Inclusion/Education***

*I want my child (10 years) to be confident at school and feel well looked after regarding her still not diagnosed special needs. I want the SENCO at school should be held accountable for refusing to refer children due to lack of funding (if a child is diagnosed with SEN the school won't be able to provide support through a TA due to funding cuts.) I want my child to be supported in secondary school and given a chance to show her full potential.*

*I would like there to be clear info on what provision is made for dyslexia in MS secondary. Currently none is given and no idea what is available. Provision not just for low attainers, but also higher attainers who are not meeting potential. (13 year old).*

*Support with dyslexia in secondary- none provided "Not bad enough". Yet time spent in classes used by watching videos not providing specific support for dyslexia.*

*Dyslexia – schools refusing to carry out / commission assessment.*

*I would like ADHD to be fully understood. Many staff in schools see it as 'bad behaviour', and if there is no bad behaviour, there is no need to meet. It is a lot more complex and encompasses anxiety, poor organisational skill, poor executive function which have big impact on learning (son 13 years).*

## **Training**

*Support for parents and training for demand avoidance selective mutism and social anxiety*

*Training for GPs to help them support SEND*

*To ensure schools can access training e.g. just right, speech and language, ASC*

*Using what's available e.g. Down's syndrome training for teachers*

*Help educate parents as well as teachers*

*Training for teachers about using special interests as an educational tool not a problem*

*I want my child to be understood to open more doors for him so he needs providers trained to understand his condition*

*All school staff need training not just teacher; dinner hall staff and office staff needed to.*

## **Social/community/leisure**

*Trained PAs who are able and willing to do manual handling, driving, transporting and supporting for clubs and social activities*

*I want children to be able to access leisure facilities sports opportunities, drama clubs etc - outside school. They need training for providers and peers and deaf awareness.*

*I want my child to access wider community and learn social skills so he needs skilled professionals 11 yrs*

*11-year-old wants to have friends so he needs support groups and intervention to do this*

*Have continuous peer associations through college and beyond at on-site provision bases*

*Specialist trained childcare workers*

*My son wants to stop using nappies he needs CBT which is tailored to working with ASE because he's fallen through the gaps*

*Fairness of offer/respice/clubs*

*My child wants to be liked so she needs to be taught social skills to help with friendships*

*For her to be able to spend time with family without us which isn't possible at the moment due to her ASC mental health and especially separation anxiety*

*I want my son to do more physical activity but there are so few clubs etc that are truly inclusive and appropriate for my 11-year-old. He is at a special school*

*My child is year eight with Down's syndrome in mainstream secondary. She wants an age appropriate social life independent of her parents she needs PAs to access Social interaction with support.*

*Year 9 EHCP-mainstream, ASC, plus hearing impairment. My child wants to go out to gigs and have a social life so she needs a young person to take her out and hang out with.*

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*My child has quadriplegic Cerebral Palsy and is in mainstream. My child wants to be seen as an individual and not clamped in with all SEND for convenience. She is a very self-aware teenager struggling with her identity and physical difficulties.*

*Callum has been offered fun literacy games for an iPad for one hour in local café three times a week with a TA. So far refused.*

*My child wants to be acknowledged and respected by his peers so he needs to have adults who model and nurture this when he is with other kids. Age 5 SEND.*

*My child wants to be known and greeted and socialise with people in our community so he needs our local school to cater for his differences so is he is passed all the social opportunities throughout the school day.*

*My child wants to be a valued member of her community so she needs meaningful opportunities to contribute and mix with her local community. ASC, hearing impairment, year nine mainstream EHCP*

*Mail-aged 14 non-verbal SLT, epilepsy, autism, requires one-to-one support. Goals more opportunities. To socialise with peers outside of school. To be more active access supported activities-horseriding, trampolining, dog walking, loves animals.*

*To access our club, messy activities, music-in a social situation which allows facilities and individual creativity. To learn to feed and dress himself to not wear nappies. For the future-to be safe loud happy individual as full as possible, to live in a supportive community, to be respected, stimulated, socialise. To access activities experience age appropriate activities, cinema and Tesco's with someone his own age.*

*Allow CYP with SEND to fulfil creativity and recognise value to community and for CYP to have sense of achievement and worth*

## **Education**

*I would like my son to feel he can say he has ADHD. He hides his diagnosis for fear of bullying from peers. He also would prefer teachers not to know all day than do a zero tolerance on his behaviour which is totally counter-productive and makes assumptions about him based on the lack of knowledge. This would be solved by up-to-date training on ADHD for all school staff head teacher of school said he was not aware of any ADHD training for his staff-either delivered or available. 13 year old*

*Year seven mainstream EHCP - I want my child to be taught by teachers at his level so that he can access the curriculum and specifically improve maths and English. He needs teachers to differentiate his learning. He needs specialist teachers in maths and English. He should not have his work differentiated by the TA. I want him to be part of his community but also get the right teaching so that he reaches his potential academically.*

*My child wants to learn about his passions explore and learn, space transport, animals, local places, so he needs a local school to have high expectations and recognise his passions and know-how to help him to learn - different to mainstream approach.*

*I want my child-year nine with Down's syndrome in mainstream-to be able to read when she leaves school. In order to achieve this, she needs syndrome specific teaching and better methods of monitoring progress.*

*My child wants to communicate so he needs adults who support him to switch on and use his communication aid-app on iPad-not leave it in a drawer all day. Age 5*

*My child wants to do his best so he needs rest. Flexibility about punctuality, attendance, time off in term time without it reflecting badly for the school.*

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*Mainstream and special schools to communicate with each other more to provide strategies and support for inclusion of SEND students.*

*For schools to be more inclusive of multi diagnosis and staff to be better trained. My child needs better trained TA to support children with epilepsy - reading, writing and social skills.*

*Early intervention in schools - for families to be listened to and helped earlier.*

*My son likes music and Internet he likes his own time. But he struggles at school because he can't have quiet time and he finds it difficult to engage.*

*Mainstream schools to provide support as provided by special schools.*

*Mainstream aged 13, EHCP. Through effective partnership with the school leaders and whole school approach outcomes presently being met well.*

*I want my deaf child to feel comfortable about going away with the school-/sports group. He will need staff and peer group to be educated and how to help him and he'll need an adult to understand his technology. Brackets bracket (Aged 11)*

*All schools should be inclusive and working to the same standard with send.*

*I want there to be good communication between parents and schools at secondary school. We need parent groups formed in all secondaries.*

*I would like my son to leave secondary school with the GCSEs he is capable of. To do this he needs his additional needs recognised and then worked with by the school. Currently he may well achieve a few GCSEs at low grades, not the 8 GCSEs level 6+ that his at psychologist profile says he is capable of (son is 13 years old)*

*I want schools to read and consider independent educational psychologist reports. Often parents have to go independent as they are never top of the list for LA ones. The professional reports are then ignored by the school (son 13 years old)*

*My child is autistic aged four. Has high anxiety. Allow to pursue his interest/that this is accommodated at school so he feels he is successful, of worth. Rather than he'll be measured by grades/able to have a job etc.*

*For my child to have a full education broad and balanced curriculum and be able to access it.*

*Ensure special school cohort reach their fullest potential.*

*Parity of the SEND offer in mainstream ASC schools in the west and east of the city.*

*Parents being fobbed off or ignored by SENCOs.*

*Need of advocate when relationships break down between parent carers and schools.*

*Partnerships between good schools and those who could improve their practice.*

*Education in mainstream school, strong partner groups, increased parental confidence.*

*Better working with school, parents and LA working together.*

*Saint Lukes infant primary school operates autism friendly lessons.*

*My child needs to - fulfil his potential - maintain his self-esteem-continue to receive support from the sensory needs team at BHISS. So he needs - to be seen as an individual not a label*

- ongoing support from BHISS despite his not having an EHCP this is essential for his progress.

### **Mental health**

Lots of mental health issues could be avoided if our children are made to feel a valued part of their community/school and well-being.

Acceptance that current trends in educational conformity are driving kids to a SEMH crisis, and 'be kind' in the city.

Consistent support and access to mental health provision for children and their families living with physical disability. It gets increasingly challenging for everyone and you have to be at breaking point before you are even assessed for help.

Mental health to be addressed with early intervention.

Children getting sectioned, their mental health is not assessed properly. More training for professionals would help!

CAMHs to be better at dealing with children - my child came out of the meeting with them thinking he was going to die (at age 8) As they did not speak to him in a way he could understand. (Now 13 years old)

I need CAMHs to be more responsive, more frequent appointments and offer more than medication e.g. CBT, stuff for anxiety-not just when CYP are suicidal/self-harming. To do this we need more staff, less pressure, job satisfaction and staff retention. (13-year-old)

Joined up services or contributing to EHCP, especially CAMHs who are disjointed and don't know how to contribute.

More access to mental health services for SEND -both specialist and mainstream schools.

Ensure that CYP's are aren't forced to break before help is even offered.

Affordable accessible and inclusive treatment for mental health issues.

My child who is ASC with SEMH needs access to adapted CAMHS (tier 3) therapies but this does not exist in the city.

Mental health risk assessment of educational setting for all kids with identified as CMH. Legislation Exists (has at work for employees)

### **Post 16**

My child wants to be as independent as possible when she is grown up so she needs opportunities to become self-reliant. Day release in school to college or apprenticeship to work. (Year nine autism, hearing impairment, mainstream)

My child wants a job when she's older so she needs support pre-16 and to be able to study what she wants post 16 (as above)

SEND children should be able to study what they want post 16, not have to fit in to the local offer and study something they don't want.

Parents shouldn't have to give up their job to fit in with 16-hour full-time offer.

My child year 9 with Down's syndrome in mainstream education wants choices about her post 16 option. She needs a personalised and flexible transition plan.

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*My child you nine Down's syndrome in mainstream education needs a menu of post 16 choices and access to other providers. Not just the Met, East Sussex or Plumpton. She needs access to mainstream provision which is differentiated to meet her needs.*

*My child year nine with Down's syndrome at mainstream wants to be included and valued for her contribution she needs meaningful post 16 provision that extends beyond 16 hours of education. She needs and wants more opportunities and not just being babysat for the remainder of the week.*

*I want my child to have access to the courses he wants with support of his own when he is 16+ in Brighton and Hove or out of the area, and not have to do a different course first. (Age 7)*

*My child year 9 with Down's syndrome wants an enriching and meaningful life - in order to achieve this she needs more opportunities such as day release from school, work experience, Department of education award etc.*

*I want my child to have the freedom and independence to choose where she wants to study or work and have the physical and emotional and practical support to achieve it. Not all provided by me!!*

*I want my child to learn to drive so he may need specialist help (14 years old)*

*My child who is 15 years old needs to have clear plans for the future in terms of mental health and education but these are not available.*

*My child needs support with her social anxiety and selective mutism to be able to fulfil her dream of being a teacher*

*My child who is year 10. Independent specialist needs to know the next steps in their education but this cannot (Apparently) be confirmed by education department.*

*My child wants to be a SENCO and will need clear pathway is to enable this written into EH CP.*

*Transfer from DLA to PIP for under 18s is fully supported and advocated for.*

*For her to have a job, be able to live independently, have a family and a wide circle of friends.*

*My child wants a job, he needs colleges to be considerate to sensory needs and make reasonable adjustments.*

*My child as an adult will be able to pursue and sustain a career of his choice and make a positive contribution as an autistic.*

*My child wants to work one day. He needs work placements and careers advice and support into work later on.*

*My child needs to have other advocates in the professional sectors to avoid loss of knowledge of their needs as they move into adult heard.*

*I want my deaf child to feel confident about his future-now and in the next five years. He will need good deaf role models to show the success that is achievable (age 11)*

*Giving our children proper aspirations and life achievements.*

*Provision-college courses-independent learning? How? Transport*

*Transition-apprenticeships-work experience-parent/carers filling in the gaps?. Courses available and colleges that mention options in year 9.*

*Schools to link in with colleges to pass on information about the young person and their needs and their aspirations and how they could become a reality for the young person.*

*Year 12 ASC SEMH.*

*I want my son to live independently of his family and be supported into work. He needs work experience to get ideas what to do and supportive work environment, supported living environment with peers and support workers.*

*My daughter in mainstream wants to be able to hang out with peers and access after-school clubs. In order to do this she needs access to extended day support (currently not available in mainstream secondary)*

*I want my child to learn life skills/social skills/danger awareness, so he needs training bodies (14 years old)*

*My child wants to-do drama theatre make up as a career, to live independently/to drive/to have a job that she loves-more bespoke post 16 package, to have a college life like her peers - parties, social clubs, being included. To fulfil their aspirations by courses being available. Work experience, PAs to give her independence away from mum, learning about transport etc. and living independently to achieve and enrich her life.*

*Down syndrome in mainstream. Needs to be able to fulfil their own aspirations from options/careers advice, early interaction with the LA. So they need meetings with the LA in annual reviews from year 8, working with colleges to help facilitate wants and aspirations, the right courses available.*

*Post 16-continue to have a happy life and exhibit no characteristics of aggression or violence outside the home environment.*

*Planning for the future of CYP is scary, sometimes too difficult to think about. Parent carers need to vocalise fears about future and have support to discuss-e.g. Cedar centre to have parents group? More coffee mornings? Opportunity to talk through fears.*

*I want my child to be happy. Don't overlook this in search for education or employment or independent living.*

*Impact of benefit cuts drives the focus on being economically active, and this might not make the CYP happy or enable them to be active. CYP ends up confined which has long-term implications.*

### **ASC, ADHD, PDA.**

*PDA and SPD to be understood by schools NHS, LA cams and SSB*

*ADHD-lack of provision*

*My young person wants to become a dentist and did brilliantly at her GCSE. She doesn't get enough support for her on diagnosed autism and depression as assessment takes ages she needs to get support to make her dream come true!*

*Primary school teachers and nursery teachers should be more educated and aware of autism as a spectrum condition so they can make the referral. The sooner the children get referred the bigger the chances they get to get help. Teachers should recognise the whole array of autism, from severe cases to Asperger's.*

*Why is the LA pursuing the ASC hub expansions when they don't have data sets and the info they do have already shows waiting lists exceeding capacity as it is? Recognition in planning that ASC diagnosis in girls is increasing and plan accordingly.*

### ***Falling through the gaps***

*I would like all SEND to be funded and recognise lower-level needs children are being let down. Solution - more funding and interest in education of school staff in (often) hidden disabilities (13-year-old)*

*Why don't you wait open Patcham house to capture demand from the "hidden children"?*

*Hidden SEMH (who comply at school) having needs met*

*Schools have to concentrate on obvious needs. Missing children with a lower level need - needs may increase - child does not make potential (let alone challenging aspirations)*

### ***Parents and family support***

*Provision for family-training-SEMH*

*What my other children need - support and recognition for their struggles in living in the same household as a traumatised SEND child.*

*PAs-we need more and need help to find them-higher wages to attract more applicants*

*Stop putting young people in ATU when they need help to stay with their families and cope at Home*

*Childcare so I can work. Mainstream school clubs/childminders need to cater for all needs*

*My child needs me to be calm and competent so our family need training and support and strategies for coping*

*Care pathway for carers upon diagnosis*

*No support for parents trying to negotiate direct payments.*

*Direct payments have been extremely difficult to negotiate and understand. An added stress for parent carers when it's meant to be a help. We need more support and help with direct payments.*

*Parent carer community facilitation.*

*What about restricted outcomes for parent carers? Opportunities to talk through this - can no longer be teacher. Impact on parent carer of caring responsibilities. Can't access development opportunities and extended day etc.*

*What I (parent) need is the ability to trust services who should be supporting my child*

### ***Other***

*Every CYP's needs are understood (not just those with higher level SEND) and heard*

*I want my child to pursue the things he enjoys to feel a sense of self-fulfilment (relevant to all CYP with send)*

*What I need is a clear set of expectations of all professionals to do no further harm to my child.*

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*Support with her restricted diet and her sensory control difficulties with the food*

*Assessment becoming whole child, all environmental*

*Better screening and assessment process at all points of access*

*What areas or priorities are working well and what can be learned by other strands?  
For the support she is receiving to continue and for it to only change if it's based on her needs changing and not because of other factors*

*For her to reach her full potential be happy and not be held back because she hasn't had suitable provision*

*My child needs a mentor to help them achieve their goals in life academically and professionally*

*Boy 13-autism and epilepsy. Wants to build a fully working tardis! Finds reading writing and adding up impossible because of epilepsy. Very bright, no social games*

*Referral time and diagnosis time is ridiculously long (About 14 months!) And meanwhile children and young people don't receive any support.*

*SEND support not being provided for children with identified SEND*

### **Local authority perspective**

*So we need to - build networks - be open to learn from others - know what goes well so we know what is working well*

*LA prospective - need to share best practice more - through parent/carer groups - through SENCO networking - through different local areas*

*As LA professional, manage transitions for young people in a more effective way. This is for social care, health and mental health*

*As LA professional-child, young people and families feel that the local authority is supportive.*

*As LA professional, ensure that the right children get the right support. This involves a broader range of support.*

*LA prospective - Want Brighton and Hove to be the best - professionals to want to work here including PAs - want OFSTED to say we are the best!*

*LA prospective-want all stakeholders to have a positive experience of going through the EHCP process*

### **LA Related**

*All parent carers of children and young adults with SEND to have a chance to contact The council online to raise their concerns.*

*Learn from independent specialist and mirror within LA.*

*Honest approach to cutting acknowledged within services*

*Visible higher commitment from your local authority to SEND. To listen to expert parent carers groups*

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*LA perspective - want flexible provision that is responsive to changing needs*

*LA perspective - want mainstream schools to be able to be their inclusive best - lots of good practice but lack of consistency*

*LA perspective - want parent carers to have confidence in the system - so what we need is better communication, especially about what we mean and want to do - fixing things faster - understanding need better*

### **Audiology support**

*I want preschool deaf children to have excellent social and learning opportunities. Need support in training staff and peers at nursery and deaf awareness (early years)*

*I want to preschool deaf children to have excellent social and learning opportunities. They need support in training staff and peers at nursery and deaf awareness. I want deaf children to have the best possible experience of paediatric audiology. We need this excellent department moved out of old unsuitable premises into the Alex as soon as possible - this will allow more appointments to be delivered in a safer and more relaxing environment.*

*I want deaf children in Brighton and Hove to achieve their academic potential - with or without EHCPs. Then technological support "sound field" systems in all classes that benefit everyone - classrooms that are acoustically treated.*

*Have access to good and appropriate child friendly facilities to have audiology test.*

*The only audiology department to have accommodation in the range with physical proximity to the ENT department*

*Services for children with hearing loss are in general felt to be positive and effective by parents. As a parent group we want the services to be maintained and not compromised.*