# Special Educational Needs and Disability (SEND)

# Your voice questionnaire

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# Special Educational Needs and Disability (SEND)

## Introduction

The Local Area is determined to work in partnership to transform the way that they work with children with SEND and their families. That means creating a new relationship with parents/ carers which is open and transparent, and characterised by increased levels of trust, with a commitment to genuine consultation, partnership and co-production. This approach will characterise every area of our improvement journey.

The first step of this journey was to get a good understanding of our families’ experiences of accessing and using SEND services and what they would like to see change through this questionnaire. The response has been comprehensive with 660 respondents and a variety of views from, “this questionnaire is a start” to feelings of it is a waste of time and tokenistic as no one will read it and nothing will change.

When the whole picture of our families’ experience is explored in more depth it is easy to why there is the level of scepticism within our SEND communities. However, the initial findings of this questionnaire have been shared with the first Kent PACT training session on 19th September and at various IASK Launch events and drop in events through October and November. Parents responded to the presentations by telling us that they do feel that they are beginning to feel heard.

This in is itself is a good start, but it will amount to nothing if it isn’t followed up by a change in the way we work together with children, young people and families. We need to better support inclusivity in schools; we need to improve the Education Health Care Plans process, quality and delivery; and we need to work together to govern and commission services and improve our service delivery timescales. These improvements can only be achieved if we work in partnership with children, young people and families.

The breadth of the questionnaire has allowed us fully hear what our families are feeling about our services from, “everyone has my child's best interests at heart” to “I am crying just doing this survey that you even believe the support is out there, there is no support at all.” It is clear reading each and every one of our families responses that when the system works for children, parents and carers are happy with their child’s progress and where it is not working- which, for the large proportion of our respondents to question seven, it is not- then the impact on families, children and young people is grave.

## Methodology

As outlined in the introduction, the questionnaire was designed to get a real and an in-depth understanding of children, young peoples and families' journeys through the SEND system- what has gone wrong, and what we need to do to improve this. It went out through schools, the parent charities, IASK, and a range of other avenues. The most successful route was through the SENCOs in schools

The questionnaire was anonymous, allowing us to hear a whole range of stories, experience and ideas on how to improve. However, this approach did not allow us to collect data recording the diversity of our respondents. We do not have details of how many of our respondents represent different faith, black and ethnic minorities groups and various socio-economic backgrounds. In order to ensure we are reaching and being responsive to all sectors of Kent's population we will need to understand this better. Therefore, further shorter more targeted questionnaires will follow which will not only show us whether we are having an overall impact, but that we are reaching all of our SEND communities fairly. These questionnaires will be very similar to this one but will not progress past question seven. Any progress against question seven onwards will be tested through the Parent Forum, Kent PACT and a range of other engagement events and opportunities which have already begun.

Section one of this questionnaire's purpose was to find out about who our respondents were and what services and support they were accessing. There were then three lines of inquiry. The first being our family's feelings about the services they had experienced so far and ends at question seven. Question seven is to test respondents' confidence in services from KCC, education, health and care and future questionnaires in this coupled with the demographic information will give base line data to identify levels of progress made as we continue to work together to improve the services

The next two sections are unique to this questionnaire and won't be repeated in future questionnaires but will be assessed though wider engagement and participation activities. The second line of inquiry was around the Vision. The third being what actions we needed take together to improve on each of the areas of weakness as identified in the Inspection

The findings in the report follows the structure of the survey and gives detail against all the questions asked. We were told continuously, and throughout, that the voice of families is missing, and therefore the findings have been presented with the actual quotes given to us by our respondents. These responses have been sampled by IASK for objectivity and lack of bias. The findings were that the analysis fairly represented the views of the respondents

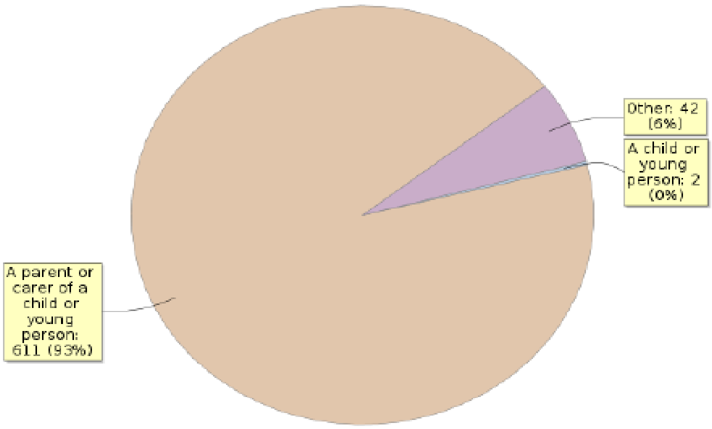
This report will be then published widely through the Local offer and other forums that will help publicise the findings of this report. The findings will be presented to the SEND Improvement board to inform our journey towards improvement.

## A Single Voice speaking for the many

Perhaps spending less on fighting parents at tribunal and employing highly paid tribunals managers and barristers would enable the LA to employ some of the services so desperately needed. The current provision seems to be based on an expectation of fighting parents and ensuring funds are available for that rather than ensuring the process is undertaken properly in the first place.

## Section 1: About you

Section one of this questionnaire's purpose was to find out about who our respondents were. Overall these were parent carers of children and young people with SEND. The highest number of respondents had children in Primary, Infant or Junior school with the next highest groups in Secondary school or Special schools. Around 30% of children and young people were under the care of a paediatrician and just under a quarter were accessing therapeutic services. 22% of families received direct payments around, 20% accessed Social Work Services and or Early Help. The percentages of families accessing services or support is commented on by our families throughout the questionnaire with a common theme being that there are not enough therapies or support available with funding and more staffing being cited as a concern.

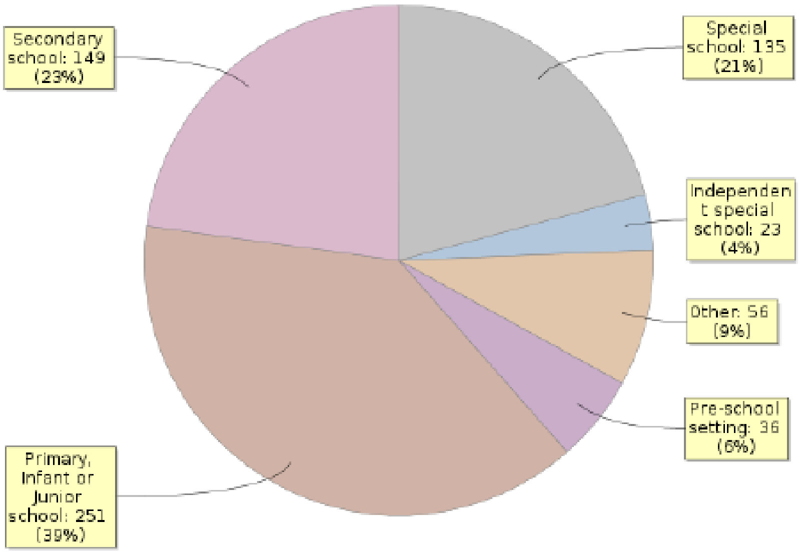


Most respondents are parent carers. Amongst others, there is a mix of grandparents, friends and educationalists. A few who responded had no direct contact with SEND children or families but have been able to share their ideas for improvement of our SEND services. This demonstrates that this is a whole community concern and lending weight to the adage that it takes a village to raise a child.

It is echoed throughout the responses that a whole community approach is needed, with services and families working together in equal partnership to build services rather than families being merely the consumers of services. In the absence of this whole community approach the families report a devastating sense of isolation.

Throughout the questionnaire we have been told not only what has gone wrong and what needs to change, but ideas on how we need to change our services. By harnessing this wealth of expertise of our families- the 'experts by experience'- we can ensure we have a child focused system which takes into account the views, wishes and feelings of the child. Parents, children and their parents will be able to fully participate in decisions, and we can ensure there is appropriate support to facilitate the development of the child and help them achieve the best possible educational and other outcomes, preparing them effectively for adulthood.

## Q2. What type of education do you or your child currently access?



The highest single group of respondents are parent carers of children attending primary, infant or junior schools. The ‘other’ category encompasses schools that are a mix of special college; children who have fallen off the cliff-edge; home tutors; and no provision

As with the range of responses regarding who answered the questionnaire this section was also diverse reflecting the wealth of our community of education provision in Kent. We had ASD units within Primary Schools, Grammar Schools, community provision that had grown from a Special school, and children and children not currently in schools.

The responses were equally as varied with approximately half telling us that they felt confident that the settings had the skills and knowledge and were able to meet their child’s needs. With the other half feeling that the settings did not have the skills and knowledge and were not able to meet their child’s needs.

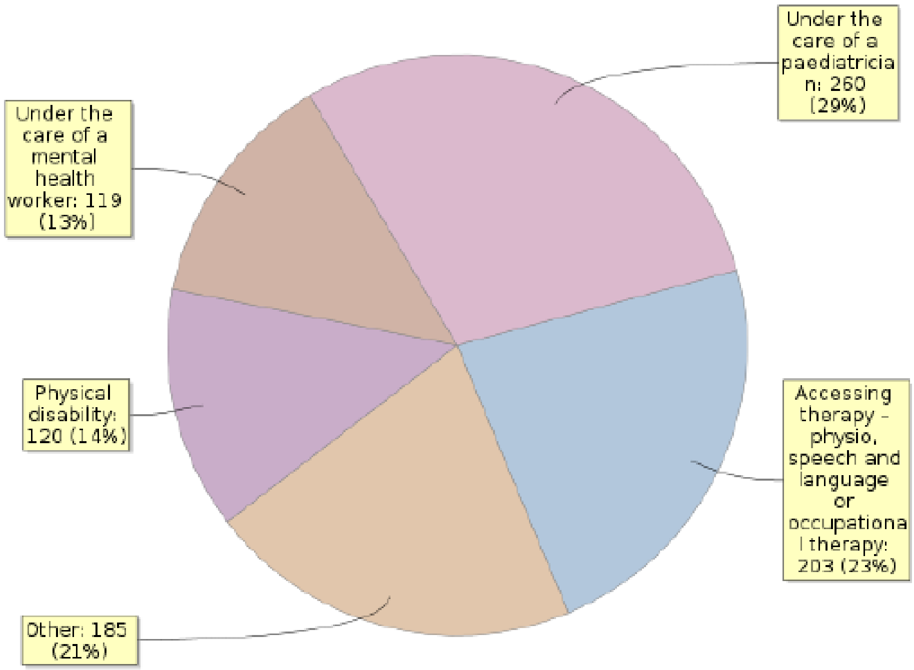
When education was working well, we were told that, “…my son’s present school has an excellent understanding of his needs” and that families welcomed, “good conversations between the parents and the school.”

However, when this was not working well the impact was profound: “my son’s school has continually let him down the entire time he has been there”, and “lack of progress = lack of understanding of the child and their condition and needs”.

We were also told what our families wanted from schools in order for their children to thrive, that is to listen more, “please, please acknowledge and follow up parental contact” and for us to have a better understanding and greater aspiration: “Imagine where he would be now if he was encouraged to grow, not chastised for his different abilities. Three years to get it right is totally unacceptable”

Parents would like a more joined approach to support schools to be more inclusive, including improving communication and partnerships with both health and social care, for KCC to hold schools to account more and parents to be recognised for their ‘expertise by experience’.

### Q3. Are you or your child currently accessing a health (physical and/or mental) service or have a disability?

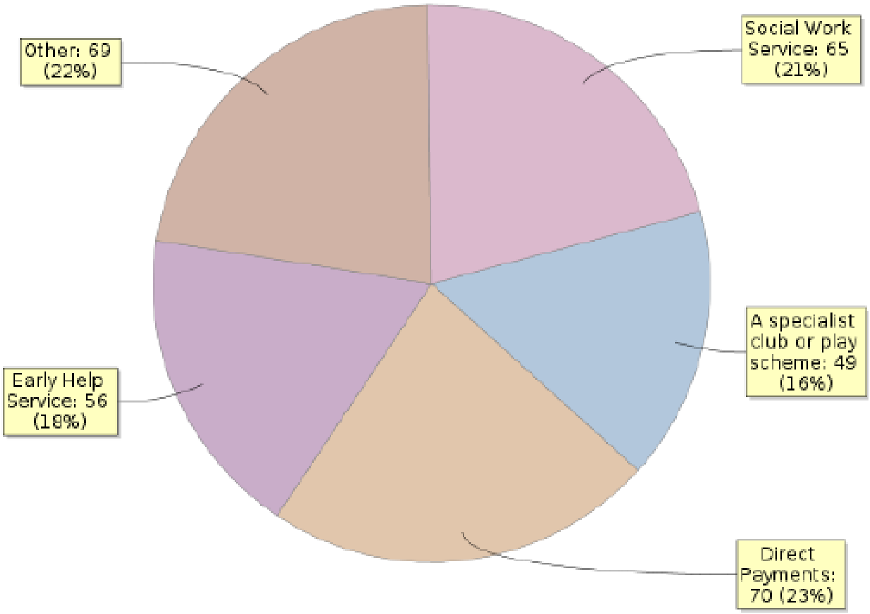


The responses given in this section tell us the range of services our families are accessing. Included in the ‘other’ category, were responses such as not accessing anything; having support from a dietician; support for autism; and waiting for care to be put into place

There were 255 responses and sampling those where none of the drop box choices were ticked, parent carers tell us that they have been denied access to services, or on a waiting list for services, and are lack of citing funding as a concern- for instance, one respondent “has been referred to CAMHS but we have heard nothing”… “Still waiting for ASD assessment after 2.5 years.” This reporting of waiting times being problematic and frustrating for families was a theme continued throughout the questionnaire.  It is possible that some of the 65% who did not complete this section did not complete this section because waiting times and lack of resources mean that many of these respondents have not been able to access the services they need, and therefore we are unable to get a full picture of what good health provision would look like for these respondents.

Where a service was being accessed, this covered a wide range from dyslexia to supported living. Of the services being accessed we were told that where it is not working well there were stories of services "……. neglecting my child & failing to make a diagnosis, my son has failed to get the care, help & support he needs…. had to go under the private mental health team as he had attempted suicide last week." The experience of accessing private support due to the lack of available local support was heard throughout the questionnaire, "…doesn't take into account the amount of families having to pay for private assessment and provision.

## Q4. Are you or your child currently accessing a social care service?



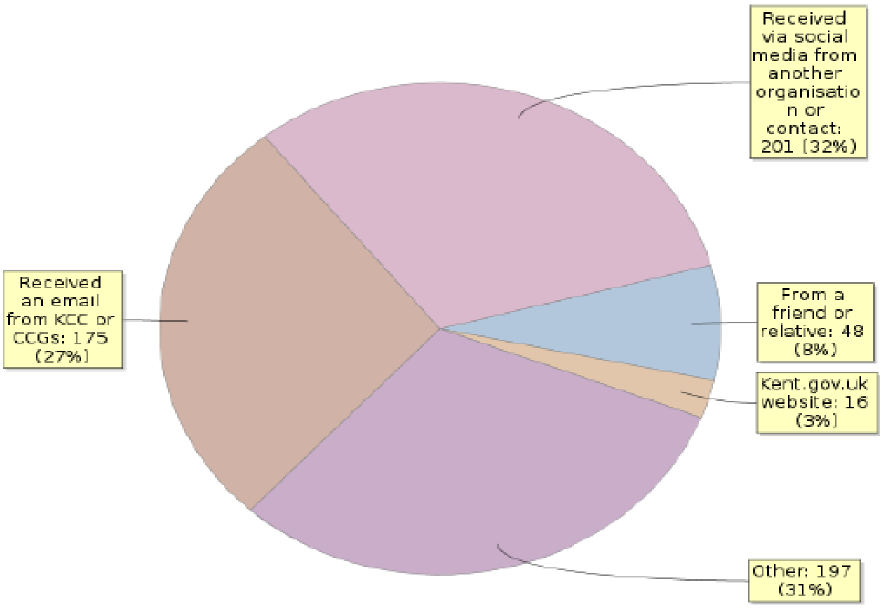
There were 309 responses to this question and respondents gave a range of answers including being on the waiting list and trying to get help, "First referred aged 2.5. Formal diagnosis received just shy of 8th birthday" to, ", "None (support) was offered which was terrible!" These build on the experiences described in question three about accessing health provision 16% of our respondents are accessing a specialist club or playscheme.

However several respondents elsewhere in the questionnaire told us that they would like to see more of this provision particularly for children described as being in the middle, those needing a bit more support before or instead of accessing universal provision and those who don't meet the threshold for specialist or statutory intervention

The frustration of families not having support of services could be felt in one response, “Apparently they (Social Services) don't consider my son to be disabled enough.” In addition, many parent carers reported experiences of poor communication, with one saying they “…can never reach anyone”

However, third sector support such as charities and commissioned services for example Space2beme, SNAAP, Imargo and Salus (others were named and their omission here is due to space only) were described as invaluable support, “Without them we'd be lost.” This adds to the need to use all our community assets in a joined-up approach to ensure we can deliver the right services at the right time to the right people.

## Q5. How did you find out about this questionnaire?



The questionnaire went out through schools by way of Kent Association of Headteachers, SENCOs, Specialist Teachers and Language Teaching Services and Ksend. It was also shared via Kelsi, parent charities and Kent PACT, Healthwatch, IASK and the Local Offer
There were 234 respondents who shared where they specifically heard about the questionnaire- 162 of which were from schools including SENCOs, 32 from Kent Autistic Trust and the rest forwarded by friends, charities etc.

This will help us not only strengthen our future communications but indicate where more specifically where we need to improve things such as having an improved and co-produced Local Offer.

Information regarding this report will be send to the same partners to help share this message and we will be attempting to employ a more targeted approach by collecting some key demographic data will help us understand more about who we are reaching with this style of consultation

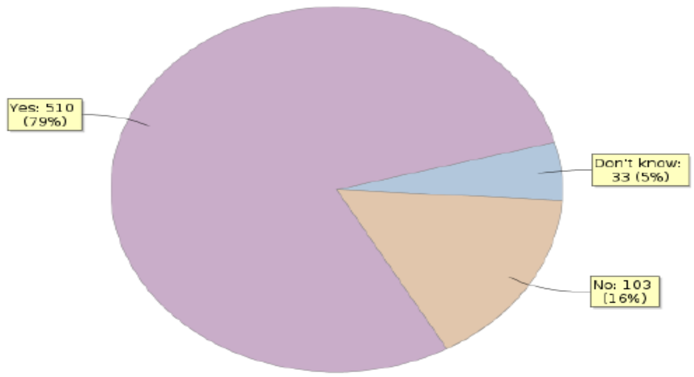
We will be testing whether we can see improvements in the areas identified in the inspection by rerunning elements of this questionnaire in six months and twelve months' time.

The difference with the repeat of the survey is that we will be exploring service specific information and including a more targeted approach such as using part post code digits to examine whether we are reaching all pockets of the community and to test whether the same cohort can see a difference in subsequent surveys.

In this survey however, some of our respondents see this questionnaire as tokenistic, "as long as KCC has consulted with the parents they have "ticked that box". While others have found this a useful start in changing the way we do things, saying, "this questionnaire is a start".

## Section 2: Your experiences of our services

Families were asked if they had SEND support in place, if they had an Education Health Care Plan and / or were they in the process of having a statutory assessment These responses were collated in the chart below.



> I don't have much more fight left in me. my mental health is now suffering.

In a similar pattern to earlier views this covered a wide range of experiences from, "Our experiences are horrendous" to, "Since the help was put in place, I have seen such a difference". Within all these stories came a clear picture of when it works well there are child centred outcomes, and families feel included, "(We are) Pleased with our meetings, with the LA responding to our child's needs EHCP informative, helpful and we felt listened to regarding our son's needs" but when support or provision is not there, not only do families feel isolated but the impact is keenly felt on children especially when the right setting is not found or available , "all he understands is he is a little boy and no one wants him"

To get support families describe having to have a fight. For instance, "getting an EHCP was difficult …everything felt like a constant battle" and told us of an adversarial culture, "absolute shocking behaviour…who told us outright lies" and there are lots of examples of families having to go through tribunals first in order to get any support.

Lack of support is similarly cited both pre and post diagnosis and the need for support to be in place for working parents at times and places they can access.

We are told that we need to work in a more open and honest way with families; we must stick to the timescales; we must make sure we are joined up with other services; and we need to have strong and clear leadership to hold services, provision and settings to account and to set the tone for child focused outcomes with ambitions for children. Families want better information and support through the Local Offer

Some of our families felt that schools were aware of their child's needs and are trying their best to support the children, but lack of funding and / or lack of accountability has an impact on putting support in place with examples given of an individual child's Teaching Assistant being used for whole classroom support.

Early support when a need emerges and solid inclusive are fundamental to supporting good outcomes.

There is a consistent theme of the slow response of services and or provision across all pathways, this includes slowness to assess, to diagnose and to put provision in place. Mental health support is cited as being too difficult to access or when accessed children and young people are often discharged at the earliest opportunity.

## Q7. To what extent do you agree or disagree with the below statements?

Respondents were then asked to what extent do they agree or disagree with set statements. There were approximately 650 responses for each statement. These represent our baseline data for comparison within our Written Statement of Action. When we rerun this in six and 12-months' time, we should see incremental move to more positive responses.

| **Statement** | Strongly agree | Tend to agree | Neither agree nor disagree | Tend to disagree | Strongly disagree | Don't know |
|---|---|---|---|---|---|---|
| I found information on KCC's website about SEND (Local Offer) useful | **22** | **102** | **181** | **124** | **121** | **97** |
| I am confident that the setting, school or college has provided appropriate provision to meet my or my child's SEND needs | **147** | **148** | **62** | **108** | **167** | **20** |
| I am confident that the setting, | **132** | **153** | **63** | **108** | **166** | **27** |

| | | | | | | |
|---|---|---|---|---|---|---|
| school or college have the skills and knowledge to fully meet my or my child’s SEND needs | | | | | | |
| I am confident that my or my child’s SEND support / provision through health is being appropriately met | **70** | **108** | **108** | **120** | **197** | **27** |
| I am confident that my or my child’s SEND support / provision through social care is being appropriately met | **54** | **69** | **144** | **91** | **169** | **88** |
| I was happy with the length of time we waited for an assessment (if your answer relates to a specific service, please state this in Q7a below) | **27** | **54** | **76** | **78** | **349** | **48** |
| I felt fully included in the planning of my or my child’s provision | **85** | **134** | **96** | **125** | **164** | **35** |
| I am confident that I am or my child is making appropriate progress | **109** | **142** | **95** | **96** | **184** | **17** |

### Q7a. Please add any additional comments on the above statements in the box below.

This question has been answered 303 times and we can clearly see when we have got it right- “My son was diagnosed aged 2 and early intervention really was the key as to why he is doing so well now.” However, this was the exception and in virtually every other comment were stories that bore out the findings of Ofsted and CQC, describing the difficulties our families experience trying to find their way through the SEND services and provision. The below quotes were echoed by many respondents.

- Local Offer out of date and not that useful
- The local offer is a joke- look at the autism pages- there is nothing there- respite for your child links through to adult support. 2 or 3 playschemes in the whole of Kent. There should be holiday provision in every town

Families tell us that the Local Area is not abiding by the SEND Code of Practice Principles. The following quotes tell a very stark story of why we need to abide by the Code of Practice and what the consequences are for families are when we do not abide by the Code of Practice.

**The participation of children, their parents and young people in decision- making**

- My son got diagnosed with ASD over the phone
- My daughter was in mental anguish for more than 7 months thanks to your irresponsible and inadequate Independent Placement Panel. It was obvious to everyone else involved, that she had to go to this independent special school. But I ended up having to appeal which wasted 7 precious months; a lot of taxpayer’s money and caused me a near mental breakdown.
- I might have been present at the meeting, but my views were not heard or dismissed and at worst ridiculed.
- KCC appear to have no regard for the child whatsoever and do not include the parents at all.
- I felt my opinions in the wording and content of the EHCP were given much less weight than professional reports even when the professional did not know my daughter.

**The early identification of children and young people’s needs and early intervention to support them**

- My son has been out of education for 2 school years due to his anxieties and I don't feel that I was being heard when I first noticed a problem emerging. I feel that if I had been listened to and the appropriate support put in place early on, we would be in a better position now
- I am very unhappy with the length of time it is taking for my son to get the help he needs at school. It was made aware when he was at nursery that he had learning difficulties and special needs, but he is almost 6 now….
- We were denied help from CAMHS on numerous occasions as our child did not meet the criteria. It took for the situation to get really bad before we were accepted.
- Had my child been given the necessary help in a timely fashion some of the issues he is now dealing with could easily and cost effectively been avoided. The protracted process made his life hell in the wrong schools and consequently we are faced with extreme anxiety issues.
- If he'd had the help he needed back when he was younger, it's likely his problems would never have got as bad as they are, and they are only getting worse as we wait and wait to

be seen by CAMHs. I feel like I have been battling this entirely on my own now for 10 years. It is exhausting and depressing.

**Greater choice and control for young people and parents over support**

- Giving parents and child the right choice is an individual choice but local authority seem to want to battle you adding extra stress that is unwarranted to child and parents.
- I wasn't listened to by KCC about what was right for my child and KCC failed my child
- My son was neglected in his care and we had no choice but to look after his needs ourselves financially.
- KCC / SEN West and they school they chose for my child have caused educational, social health and mental wellbeing and even his confidence to decline with such a devastating effect on him
- We were pushed into making a decision with no knowledge or information.

**Collaboration between education, health and social care services to provide support**

- Education and social services take too long to process paperwork and react to requests or queries. Officers do not meet statutory time frames over annual review yet expect parents to comply to strict response times
- There is woeful lack of support from Educational Psychologists, health, OT, CAHMS, physios, speech and language, social care, etc. Schools are left to do the whole lot
- My child's academic struggles are being managed extremely well in his school setting. However, we have no support for his mental health - despite presenting at A&E recently when he tried to take his own life, there has been absolutely no follow up.
- Transition arrangements for CAMHS to Adult Mental Health are CRAP
- Many of the services we access tend not to communicate effectively with the school. I have attended numerous appointments where the paediatrician has not got the schools latest report and recently establishing that our son’s latest paediatrician has no knowledge of the school our son attends.

**High quality provision to meet the needs of children and young people with SEN**

- Even though they get funding for him they took him out of the classroom permanently and put him in a small room on his own with a different teacher every hour. They will not let him at school full time, so he is on a part time timetable. He also eats lunch in the same room so has no contact with other children.

- My child currently only attends mainstream 1 hour a day - council cannot offer any other placement.
- Children's Mental Health services are inconsistent in both provider and provision. For neurodevelopmental support this is a pure medication review, with no wrap around support for my child or family unit to access the intervention he needs.
- I want my child having more access to the community and real life and more therapy time to prolong mobility.
- I found them (NELFT) to be incredibly rude and made me feel like I was an idiot for wanting my daughter to receive the help she clearly needs.

**Focus on inclusive practice and removing barriers to learning**

- School don't want her, but sorting the new school is taking time. Her mainstream school keep threatening prosecution for non-attendance. The stress levels are very high.
- …she falls apart on sports day and then self-harms afterwards. She won't be attending sports day from now on - I shall keep her home, and if I get fined, so be it. Her health comes first.
- My child feels under pressure at school to be at the same level as everyone without any additional support except from her family.
- My son has not attended school for five years now and no one seems to care
- My son was excluded from mainstream school on several occasions. It turned out these were discriminatory (as tested by tribunal). He was also subject to an illegal reduced timetable, meaning he missed several months of education in years 8 and 9.

**Successful preparation for adulthood, including independent living and employment**

- Family therapy abruptly ceased when she reached 18.
- He has gone backwards in real terms since Y6, and now at Y8 is unlikely to be able to fulfil his dream of going to university to study science. I am beyond livid with KCC and he has been badly let down.
- I took my son to a taster session/interview for a course recently. I wish I had filmed it because it would make a classic example of how NOT to behave with ASD students. Huge training need identified.
- Lack of input from any social worker speaks volumes about an overstretched service.

- KCC originally refused to assess son, so had to take this to tribunal…. son did not want to attend school at that point they refused to do an EHC assessment that would have allowed education to age 25 (I understand). He has gone downhill since then and has been in hospital for the last year having treatment for his mental health.

The fragmented service identified by the inspectors can be recognised in the experience of respondents who reported "…..worker inept – said that my son could walk and was in mainstream nursery when he can't walk and is in the PMLD Class at nursery- and then she got angry at me when I questioned her!", and "KCC's website was a standard fact sheet that initially had no substance behind it. Any telephone numbers didn't go through to anyone and emails where never responded too. When eventually finding a support organisation for EHCP they said they didn't know much and were not in a position to help."

The consequences of this fragmentation and staff being over capacity have resulted in professionals not being able to do their job that they came into these services to do and in turn lets down our children, young people and families, with one respondent saying, "every organisation that is there to assist children is greatly understaffed and overworks. Therefore, nothing seems to be completed effectively."

The next three questions were in response to the statement, "Kent is changing how we work with parents, carers, children and young people to make sure you are at the centre of all decision making about the choice and control over the support you receive."

Families were asked what you feel is working well with our SEND services, provision and support, what you feel is not working as well with our SEND services, provision and support and what you feel needs to change with our SEND services, provision and support.

Combined responses in what is not working and what needs to change tell us that parents want better leadership driving forward culture change to deliver child focused outcomes along with shorter waiting times.

## Q8. Tell us what you feel is working well with our SEND services, provision and support.

This question has been answered 489 times. The answers range from 39% of respondents telling us that nothing is working well, "NOTHING - there is no area that I feel is working well …" to detailed evidence of what is working well including individual named staff. "You have some amazing dedicated staff (named)"

41% of respondents felt the greatest strengths were when schools were truly inclusive and could see progress of their children when this worked well- "My son is receiving exceptional care from all involved which is aiding his development.” It was recognised that these schools are “working hard to support SEND pupils despite facing increasingly insurmountable challenges”. We were told that what made the difference was that there was a “variety of interventions offered in school”, and that skilled, knowledgeable and compassionate support was key to getting this right- “care and classroom assistants are usually fantastic and are the main deliverers of professional recommendations and they work without the necessary training and back up in my opinion.”

The importance of having the right staff with the right skills and outlook recurred throughout the survey and in this section 13% of respondents felt that this is what  made a difference to them and told us that, “You have some amazing amazing dedicated staff who was incredibly supportive and helpful above and beyond her role.” And while systemically it is recognised that there are great concerns across all service areas, “the front line, the specialists who you eventually get to see have always been kind and understanding”

Specialist teaching support was respected “We get 3 visits per year from a Specialist Teacher of the Deaf and this works well.” And recognised that they are, “Highly skilled, knowledgeable and excellent at sharing their knowledge”

Children being in Special schools were key to success for a number of parents and the quality of these settings was noted- ”You have outstanding special schools in this area and the people who work there are extremely skilled and know how to adapt the curriculum to support the child.” This parent- along with others- felt that we should be sharing this good practice, “More of these people need to be put in mainstream settings as SENCOs because in my experience there is a serious lack of knowledge at this level.” Not only being able to access a Special School was valued but the level parental contribution that these settings offer allow parents to feel that their child’s needs are being well met, “The specialist setting my child is at meets his needs well and I have input into his care and support there.”

Having the child’s needs met well through good and effective parental involvement, however is necessary across all settings and provision, but sadly this seems to be the exception- “Once you find someone who will listen, talk straight to you, not make empty promises and actually listen to the professionals opinion. keep hold of them, the children need to be put first, some are but usually money is instead.” It is evident that “when support is received it tends to be useful and helps produce better outcomes for the children.”

As well as good engagement and partnership working with parents the importance of having Education and Health Care Plans was noted- “The ability to work through the EHCP with my children's school works very well for us as a family. I am given fantastic information about my children's needs at school via their teachers and as a team, we all discuss and decide what the best way forward to tackle any situations that have occurred or are due to happen in the future. Without the EHCP both children would not have this continued level of support that has for them had successful results.”

Overall health was viewed positively- “The consultant we saw … was fantastic. He didn't rush and took us through what was needed to be talked over.” However, the general consensus throughout the survey felt that diminishing resources meant that there just wasn’t enough health provision to meet need. Similarly, the support offered by commissioned services was prized- “My daughter really appreciates her visits from her Project Salus worker. We are so grateful for these.” But elsewhere in the survey families are crying out for this type of support. This could mean that either there isn’t enough of this to go around, or joint commissioning in equal partnership with users of these services, the parents, children and young people need target these services better, in the right places, for the right people.

## Q9. Tell us what you feel is not working as well with our SEND services, provision and support.

This question has been answered 538 times and “it honestly is too much to list” typifies the responses in this section with several reporting that “everything is not working well. You don't even see us in the system. We are invisible parents with SEN kids having to make our own way through this, supporting each other because you won't”

Almost a third felt the system, culture and practices were not child focused contributing to this sense of invisibility, “Children are being lost in the system and parents are not receiving the support that they need.” The devastating consequences of these children being lost in the system can be heard in this parent’s desperate plea for help- “Leaving my child by the end of year 3 pushed to the limit so far he got a knife and put it to his chest & wanted to die! has been suicide for 3 weeks. Still no help from anyone from: Paediatrics, CAHMs GPs, young minds, ChildLine, NSPCC, Early help etc.”

The lack of child focused services, where efficiency and logistics are placed before welfare is concerning- “Transport times for some children to special schools is inhumane and unacceptable. It is not ok that 5-year olds spend 1.5 hours on a minibus each way to get to school.” While data driven decisions are important the wider principles of needing to, “take the child's well-being into account” must be kept central. “Children are only children for a short time and so we want quick action for our children's education needs. The sooner they get the right help with the right tools the quicker they can overcome/manage the problem.”

Compounding the feelings of isolation, frustration and distress is the length that children and young people must wait. “Everything takes far too long to sort out. We are wasting our children's education years.” It is not only the wait for standard provision that is a concern, but it is alarming to note that even emergency care is not timely, “My eldest son has waited 12 weeks for help to be put in place when he was in danger and crisis.” This lack of timely responses to requests for help and support have driven some families, “to get a private diagnosis for our child. We were on waiting lists for CAMHs and an assessment. Could not wait any longer as our child had now developed mental health issues on top of his existing needs.” What then does this mean for families for whom this route is not feasible, “(we are) Still waiting for help. And my daughters got much worse in the process. Very sad to witness. Feel quite helpless.”

One of the reasons families felt that waiting lists were too long is the lack of appropriate local support and provision that is available. There are, “Far too few Ed Psychs and very limited access. Too little SALT available. No OT for sensory integration needs. Absolutely no specialists in speech and language at secondary level.” Perhaps this lack of available support is why for some “There is a lack of specificity in provision mentioned in section F of provision plans which means children miss out on vital support.”

There is a reasonably common consensus that lack of funding is the cause of waiting times and lack of provision leading some to conclude that failure to assess and implement resources is a deliberate attempt to delay and hence save budgets, “SEND staff are being encouraged not to diagnose dyslexia to save school budget”. The financial strain on schools some fear lead to more data led than child focused decisions, “These student are placed where there is space rather than where is suitable and yet had mainstream not had to make drastic staff cuts, the students could have thrived there.” With funding being stretched ever tighter and demand increasing changes in practices, outlook and culture are needed so we no longer hear stories such as:

- My son is sharing the TA that I was led to believe would be his support.
- Because he is the better behaved one, he just gets left to it! He is already delayed so this is just going to hold him back even more.
- Autism and ADHD is usually recognized and supported, but many students fall in between these categories. Therefore, many of these young people end up permanently excluded.

Lack of funding isn’t the only factor in poor support and delivery. There are lots of examples cited where not having the right staff in place is detrimental to children and young people getting the help and support, they need, with respondents stating that “Staff are poorly trained/supported or incompetent”, and “teachers do not have training in dyslexia issues. I am having to pay £400 to have my child assessed for dyslexia and dyscalculia so that school can understand what provision they need.” “Lack of understanding of children's conditions makes it difficult to get the understanding and support". “and probably not achieving any qualifications.”

Other ways in which the wrong, or poorly trained and or supported staff impact on families experiences of the services are the staff managing the processes with respondents reporting that “SEN team members appear either to have little understanding of SEN issues and the law and are overruled by other team members who have had little or no involvement in the assessment process. Officers appear to view parents as ill informed, overly demanding or irrelevant, and attitudes can appear patronising and adversarial”

This feeling for the need of a culture shift right across all of the services and in every part of these services can be heard loudly throughout the survey.” Being heard and helped with compassion and empathy understanding” may seem obvious but when services are under real strain, compassion and empathy can be in short supply.

“My case worker … was beyond rude, when I was frustrated that the EHCP process had taken longer than 20 weeks with no end date in sight and no communication or explanation for the delay I said I would be escalating to a manager. She told me to do what I liked and put the phone down on me.”

Capturing information wrongly or misunderstanding information can be a common occurrence, but when staff are under pressure, or not supported it moves from being an error to an escalation: “My son's EHCP said we had elected to home educate when we had not and when I complained I was simply told to take it to tribunal.” These may be isolated incidents or not, but they make people feel that we, “don't listen to parents, specialist provisions, social workers etc. You sit on reviews and lie to people. You lie when you phone, email send letters etc. You get the wrong people to respond. You don't follow out what you are asked to do and what you say you are going to do. You don't respond to phone calls etc.”

The feeling that there is. “TOO MUCH TACTICAL DISHONESTY BY KCC EMPLOYEES.” is too often heard to be ignored and must be a contributing factor to why families have lost trust in the people and provision. Families want this to change- “It would save money and make a huge difference to families like ours if the Caseworker actually met with the child and built a relationship with the family. They would then understand the SEN needs much more and it would not all feel like a huge fight.” They feel that there are, “Too many faceless people making decisions without the young person having anyone to advocate for them at key meetings. – ‘The Panel’ ‘The Brokerage Team’”

What is being described is more than services being , “Dismissive of Parent's opinion” there is the feeling that, “services are too quick to judge the parents and blame them.” and the , “attitude seems to be "we run the show - parents must comply with anything we suggest otherwise we will call in the Social Workers".

This feeling of judgmental attitudes is exacerbated by a wide range of poor communication where, “the child does not feel to be at the centre of the provision”: “The Caseworker assigned to us did not get to know my child or our family. She only knew about my child from his paperwork. The only thing she did was coordinate the gathering of information and very often it was quite obvious that she did not understand the information. She was always unavailable and almost never returned phone calls or responded to me unless I escalated my requests to her more senior colleagues”. The common theme here is that families need to be kept in the loop. “Not knowing is worse than being told honestly that the waiting list is x long, or that provision is not available.”

It is not just lack of communication that is frustrating, but the style of communication: “At times it can feel rather adversarial between KCC and parents. The language currently being used by KCC regarding "raised parental expectations" (Item C1, Scrutiny Committee, 9th July 2019) in relation to the 2014 SEND Code of Practice is somewhat insulting, when all parents want for their children with SEND is their needs to be met and a suitable education provided.” and “Personal transport letters are overly aggressive. These are children that have serious illnesses and days off school are inevitable. We don't mind not being paid but why do you have to be so threatening.”

When we asked in this survey what is not working with our SEND provision the 538 respondents added much detail to the statement made by Inspectors that Kent doesn’t care. In the final five sections of this survey however we have been given numerous ways to change this and start getting it right. If we are to deliver the vision agreed in this document all we have to do is listen and act upon it.

> Everything this whole process has left me very stressed and ill

## Q10. Tell us what you feel needs to change with our SEND services, provision and support.

This question has been answered 513 times and to a large extent mirror what we were told wasn’t working well. The similarities between the two sections even extend to the weighting given to most of the themes identified. For instance, more respondents felt what wasn’t working was that the systems and culture isn’t child focused, and here, in what we need to do better we are told that we need a better trained, child focused workforce.

We were told that the culture needed to change, we needed a, “more approachable attitude. More training when dealing with parents. Not a flippant negative unhelpful attitude that I have received. Which caused me even more stress …..which added more stress in my family.” Having more creative working practices is required to be more inclusive, “and regular training for mainstream school staff, this may help children manage in mainstream better rather than damaging children when it is dealt with wrong.” In addition, knowledge around specific areas is seen as lacking and we need, “info and training for professionals regarding specific learning profiles for children with conditions such as Downs Syndrome and Autism.” There are lots of examples where it is thought that teams don’t have the necessary understanding of specific conditions- dyslexia and ASD being to two most commonly cited along with being a continuously learning workforce, “People that work in SEN need more regular, ongoing training in line with new scientific discoveries and research.”

Respondents urge us to follow the **SEND Code of Practice** across a number of areas: “You need to start listening to parents, we have a lot of expertise in this area. You need to start being involved with the young people you are supposed to support so you know them. You need to collaborate with social services and health. You need to stop making parents feel guilty and putting them under such stress and build supportive and trusting relationships. You need to give those going into post 19 education a guarantee of more than one year as long as they make progress. Other authorities don't do this.”

**Child centred**

We have to become child focused, “need to think about and see the child. Not a case number.” For instance, when considering settings for children, “come on KCC please invest in these young people. They will go on to lead independent lives if you give them the right placement.” Similarly, there is the requirement that these settings are meaningful and, “should not be treated as childcare and children should not be just looked after but should be taught. They all have a right to learn.” Not only is the concern that children have the right to an education, but as the inspection discovered, we need to have more ambitions for our children and young people, “It was very hard to comprehend the total lack of care or desire to see children in the SEND system achieve. My child has complex social and emotional issues caused by ASD but no intellectual impairment – with the right support at this stage there is no reason he should not go on to be a tax payer for many years but this will only happen if he is given the support he needs to go on to be an economically active adult. The SEND system could not see this big picture and were keen to minimise any spending on his education – regardless of the long-term cost to him and wider society.” We hear of children feeling like a burden because of their disability- “School trips are so difficult to attend that my child is now not wanting to go as feels his wheelchair is too much hassle for everyone else – this is extremely poor.”

**Timescales and better joined up working**

Timescales are an area where respondents told us we went following the SEND Code of Practice and is an area of great discontent- “It should not take nearly so long to get the support that vulnerable children desperately need.” Similarly, there is a great deal of frustration that services are not joined up- “Services need to work together to support our vulnerable young people” and that we need, “More continuity and collaboration with other sectors and providers, with earlier diagnosis and action.” Families are exasperated because they, “shouldn't have to explain and repeat ourselves to a million different services. They should communicate with each other.”

**Local Offer**
We have been told that if, following the SEND Code of Practice the Local Offer was better, families would have a, “clearer understanding of who to go to when things don't go well. There should be a page on the KCC website of who to contact at each service as I am often told "I'm sorry I can't help with that" but never told who can.”. To achieve this we need a, “Friendlier website - it looks official. It is probably more helpful for professionals.” And that is should, “widen its scope to voluntary sector and connect more: sports, leisure and community opportunities. My son is 12 and there is nothing in the offer he would want to access, although we access lots including sport, the voluntary sector, which could be part of the local offer” As well as improving the content we need to change the tone of the Offer, “Please be mindful on the wording of your website. It can feel very negative in some areas. Applying for funding does not come easy to all of us- many of us have had to give up work, prioritising the needs of our children, families and our sanity (no exaggeration). Government guidance tells us when financial support is appropriate, please don't make us feel like scroungers.”

**Co-Production**
Families are telling us that they are not given the opportunity to participate in decision making and planning for their children and that co-production is, “non-existent …. I had to provide evidence and learn Sen code of practice / C&F act in order to get right placement - I had to push for info about the process.”
We are urged to work more collaboratively and in partnership with parents- “The biggest change would be to start working with parents, rather than seeing parents as an obstacle. This will help everyone identify the best way to meet the needs of all children, improve the effectiveness of provision as well as potentially identifying synergies and cost savings that could be achieved. This isn't about budget, this is the basics of engagement – responding to emails, listening and acknowledging the views of parents and professionals and being true to your word.” Failure to get this right means that children are, “often forced into a school placement which they know is not right and often breaks down leading to mental health difficulties for the child.

**Specific, Measurable, Achievable, Realistic and Timely (SMART) Education Health Care Plans (EHCPs)**
Education Health Care Plans are covered in more detail under question 14 Workstream 3: Quality of Education, Health and Care Plans. Nevertheless, SMART EHCP are enough of a priority in this section it would be remiss to not mention them here too. Families want EHCPs to be, “shorter in length” “Needs definition needs to be accurate and capture needs.” “Provision specified (section F) should address the needs described” and we have to ensure there are more “KCC staff with better training so that the EHCP plans are more specific and delivered on time”

Once again, the need for culture change is addressed- “the whole culture in the SEN department needs to change. It needs a complete overhaul.” “Staff often seem cynical and dispirited. Instead of trying to achieve what is best for the child or young person, they seem focused on managing the expectations of parents. The message often seems to be ‘oh, you will never get that, don't even bother trying’. Complaints are largely ignored. Staff are often unavailable.”

Parents tell us that the children's workforce needs to be more knowledgeable- for instance, "recognise that ASD is a spectrum & a child that is rule driven & behaved at School still needs support to grow."

And they tell us we need to be less adversarial- "Stop fighting parents and SEN kids and making the whole thing adversarial and instead partner with parents with a view that you should be helping us not fighting us- i.e. stop recruiting lawyers to fight tribunals and instead spend the money on providing services and therapies."
The issues of the volume and the perceived default of a tribunal led service has been a constant theme and we are told we need to, "need to reduce the number of Tribunals as these are costly and time consuming leaving no room for the everyday stuff to happen. You need to employ staff that are skilled, competent and knowledgeable (or provide training for this)."

The sad truth here seems to be that a small number of respondents- 5% of those answering this section felt that "probably everything" needed to change. When asked what was not working a similar percentage- 8%- felt that nothing was working. Although the numbers are small, the sentiments expressed are common to the general feeling that this survey has uncovered: "The whole process needs to be reformed. It is not remotely child centred. At no point did I feel anyone was trying to find the right solution for my son or have any concern about his education. It was very adversarial. It felt like the Council were trying to commit to as little as possible at all times." And the feeling that we, "have not accepted the OFSTED report at all. I feel your apology basically said, "we are as bad as all the others failing SEND" rather than a heartfelt apology."

## Section 3: Your thoughts on our future vision

**The draft vision**
Services will work with families to improve outcomes and achievements for children and young people with SEND.
Families can reach the right people at the right time to support their children.
Children and young people with SEND in Kent feel happy, safe and supported while they learn and grow.

### Q11. To what extent do you agree or disagree with the below statements?

| **Statement** | Strongly agree | Tend to agree | Neither agree nor disagree | Tend to disagree | Strongly disagree | Don't know |
|---|---|---|---|---|---|---|
| The vision is clear | **97** | **246** | **125** | **62** | **72** | **40** |

| | | | | | | |
|---|---|---|---|---|---|---|
| The vision says what I would like it to say | 109 | 233 | 139 | 65 | 61 | 30 |
| The vision includes the right ambitions for the future | 97 | 235 | 132 | 77 | 61 | 36 |

Respondents were asked to what extent do they agree or disagree with the statements presented these were:

- Is the vision clear?
- Does it say what they wanted it to?
- Does it include the right ambitions for the future?

There were approximately 650 responses for each statement. The highest responses across all statements was that most tended to agree that it was clear, said what they wanted and contained the right ambitions: “The intentions are clear and good …” and “The vision is great…” However, here was a strong feeling that it was meaningless: “…but I'm not confident that it will be achieved” as “the Local Authority is not able or willing to deliver the best for our SEND children”… “I don't believe Kent has the commitment to follow through what it's visions states.”

Therefore, the Local Area must work together across its all of services and with parents as equal partners to change the perception of, “It's all well and good having a vision. If that vision isn't then implemented, it means nothing.”

To help implement and embed the Vision the Local Area has produced a Written Statement of Action identifying five workstreams to address the inspector’s areas of concern. All workstreams need to be co-produced in partnership with parents and carers and therefore to begin to understand more about what is going wrong and what we need to improve on in detail which will shape these workstreams the respondents were asked what actions should be taken within each workstream

## Section 4 – Your thoughts on our Written Statement of Action workstreams

when is this surveys results going to be published in English for us tired parents?

In the final five questions in each free text box, there were between 309 and 511 responses. The largest number of responses being the Parent Engagement workstream and the fewest responding to the Joint Commissioning and Governance. These responses have been sampled by IASK for objectivity and lack of bias. The findings were the analysis fairly represented the views of the respondents. Each workstream response is represented initially as a work cloud demonstrating the themes identified in each. The text appearing largest in each wordcloud responds to the weight it was given by volume of responses. The larger the word appears, the more responses identified this as a theme

## Workstream 1: Parental engagement and co-production

Ofsted highlighted the following weaknesses:

- The widely held concern of parents that the local area is not able, or in some cases not willing, to meet their children’s needs.
- The limited role parents and carers have in reviewing and designing services for children and young people with SEND.

Most felt that the Local Area needs to listen and work with parents in an open, transparent and inclusive way: “LISTEN!!! And stop making everything such a monumental battle and being so obstructive to parents’ views.”

“When parents say a placement is not working actually listen to them, I was told my son would have to fail again by the education authority before appropriate placements would even be looked at this is not acceptable, better funding for placements that actually meet needs, be listened to in reviews”

We have to “do outreach to the families who are not in a position to complain and appeal and really get an insight into what their lives are like.”
As well as listening we need to value the parents as equal partners by communicating better- “The phone needs to be answered & emails acknowledged. Parents being left in the dark causes extra stress.” Failure to do so creates unnecessary anguish for parents- as one respondent says, “lack of communication for anyone is horrible.”

Putting children central to our services and supporting their good outcomes is seen as a key weakness and that the children’s workforce at best don’t know the children: “decisions made by managers with little consideration for the individual child”; and at worse, don’t value the children- “treat our young people like something you have on the bottom of your shoe. We are human beings and have rights just the same as you.”

There are lots of ideas about how things can be done better and be more inclusive such as:

- (kids) sitting at the front of the class to avoid distractions.
- Group sessions are an option, not just 1:1 support
- After school clubs not just special needs but small groups to (be) integrated.

Having a flexible approach to learning to allow children and young people to achieve was also discussed with one respondent asking us to “allow children with SEN to access qualifications other than GCSEs in order that they feel they can achieve", and another calling for "a more varied support to meet the age of the child/ teenager/adult."

There is the feeling that the Local Area is a long way off achieving this and in order to get there, parents want us to "hire compassionate kind people, pay more attention" as currently there is the feeling that there is, "institutional discriminatory behaviour in Kent" with "fraudulent paperwork, illegal exclusions, children present on registers but not actually in school, children quietly dropped by schools to forcibly make the children home-educated."

Respondents described "our kids being seen as sub-human", and families feeling they are a problem, and we are urged to "Be more approachable - more professional and friendly in your interactions. I do not care how many other children you also have. At that point in time I care about mine, and at the point I am talking to you, he should be your only focus; do not make them feel as if they are one of many and do not matter as an individual."

Parents, children and young people need to be not only heard- "I wrote a lot of information about my children in the EHCP and was told as I wrote it, this couldn't be included in the plan. Talk about feeling marginalized"- but valued as equal partners and encouraged and enabled to take a part in a meaningful way in the decision making: "There is absolutely no point in calling a meeting a co-production meeting if a decision is then made by a single manager who does not understand the legislation."

Respondents called for "Co-production meetings and decisions taking place BEFORE the issue of a draft EHCP - after issue, it's not co-production, it's argument."

Parents tell us they are keen to help, and to improve things we could "involve parents in training. We all go to networking places to learn from other people. No need to be constantly reinventing the wheel." And we could have a "reference panel of SEN parents and older children to review all policy and operational changes."

An element of Co-production that was discussed a lot in the survey and will be explored in more detail in question 15 Workstream 4 Joint Commissioning and Governance was that of the need for more and better provision in the right place at the right time. However, this also featured strongly in this section and we are told that we need to ensure that, "there is adequate provision across the county so that all children and young people are able to access an appropriate provision for their needs, without excessive travel." Specific provision was thought to be lacking for instance, "KCC need to listen to all of the parents of dyslexic children and provide services for those dyslexic children so that they are not failed by the education system!" Without the help of parents in joint commissioning and governance there is the fear that we will continue to, "force square pegs into round holes by designating an unsuitable provision, or pressuring schools to take children whose needs they are not equipped to meet, merely to make the numbers fit." We are told we need to ensure there are, "more variety of school placements" more "playgroup/youth groups" and better access to therapies, "more support for children that includes physio, OT and SALT." It was argued that if we stop, "spending millions in legal fights, (where a) high percent of tribunal cases that KCC lost." We have more money to spend on improving local services allowing, "more Kent children stay locally." Several charities were noted as being particularly helpful but there was concern that these were not well known and had to be sought through word of mouth- “Not from any professionals telling me.”

This leads on to communication being inadequate as discussed in what needs to change, question 10. We are asked to, “Please, please acknowledge and follow up parental contact. So often parents feel they have to fight to get the right support, and it's emotionally draining.” However it is not just that we need to communicate more and better, but be more transparent, “ There should be a clear analysis of how conclusions are reached when making decisions as at the moment it is like a dictatorship where subjective opinions are acted upon rather than fact or professional advice.” We also need to involve parents in the evaluation of services- “Never have we been asked our opinion. Reports from NELFT on customer satisfaction are a joke, we were never asked! You want to improve, write to all families this affects, be genuine, give everyone the opportunity/”

As a part of better communication more and clearer information and guidance is needed- “if the Local Offer was more accessible and family friendly that would help.” This would include having a range of services posted on the Offer including, “children centre's sessions or support groups.” And, for instance, if “most parents aren't even aware of HealthWatch Kent”, the Local Offer needs to be wide in scope and give sufficient information and guidance to “make an informed decision”

Families tell us they want a better trained workforce- “Train your staff properly don't fudge or do it on the cheap. Get outside experts to evaluate practices and assumptions e.g. the national autistic society. Insist schools train their staff appropriately” and this needs to be fit for purpose- for instance, “training for new SENCOs on the code of practice. SENCO accreditation courses are mainly aimed at theory and SENCOs still need support with day-to-day expectations of their role.”

We are told we need to be flexible and creative to engage more widely and inclusively: “Find ways of getting communication with parents. Not all are willing or able to go to a large meeting but would prefer questionnaires or meeting 1:1 or small focus groups.” To enhance inclusivity we should encourage, “schools to have celebration days about SEND. Educating and being very open about the SEND issues. Some parents who have never heard of\met anyone with Asperger's should be told what it is. Schools should dedicate a page on website to explain how the school will meet each need.”

If we are told that, “SEN officers need to be trained to keep in touch with parents and keep them involved in what is happening” then this, worryingly once again points to the encompassing view that culture change is needed to bring about a competent, family focused workforce. There is understanding that we need to improve, “retaining decent staff - caseloads are too high.” And that without this we will not be able to, “honour (our) duties and responsibilities as set out in the SEN code of practice and education act.” Respondents tell us change needs to happen at the top, that we need to , “recruit senior staff that actually know that they are doing and that are competent and are properly held to account - not on 'narrow stats', but on genuine criteria that indicate quality of service and engagement with stakeholders”, and respondents call for a “review of job competencies in SEN teams.”

There are examples of how we can learn from what works- “I have not been supported by any KCC service and stumbled across SNAAP when on the early bird course and at rock bottom. They answered the call straight away, was honest what they can do, visited me at home and listened then helped me to get back on my feet and give me a support group so I don't fall back into the situation I was in. Whenever I call someone can help me and if they can't they say that and say what they will do and by when and they do it! I have never had that from KCC."

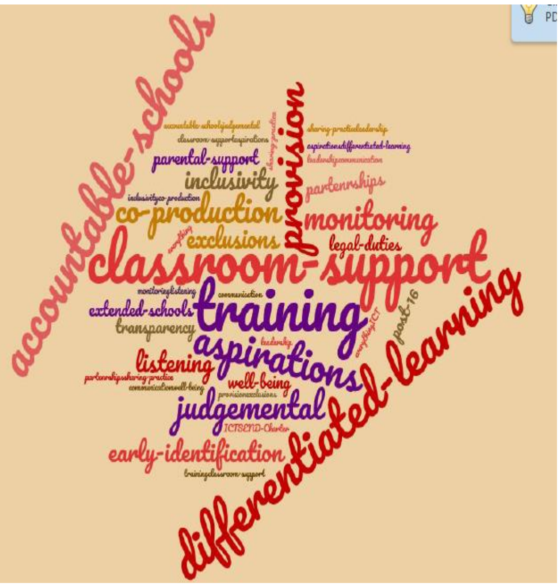
The culture change required needs to ensure parents feel heard, and stop feeling that they are judged and marginalised- "I was made to feel like an idiot and that I was imagining the way my daughter was and was just pushed aside with everything and not included. I was made to feel like I was stupid, and this should not happen." Parents tell us that they understand the constraints services are under and are keen to be a part of helping solve the problem- "KCC is underfunded and that could be its biggest problem. If you encourage parents to fundraise / raise awareness for their children's plight while listening to those concerns, we may be able to turn it all around. But by treating parents like ungrateful simpletons and turning backs to society's".

## Workstream 2: Inclusive practice and the outcomes, progress and attainment of Children and Young People

### Q13. Please tell us what actions you feel we should take together to improve these areas of weakness?

Ofsted highlighted the following weaknesses:

- The variable quality of provision and commitment to inclusion in schools, and the lack of willingness of some schools to accommodate children and young people with SEND.
- The poor standards achieved, and progress made, by children and young people with SEND.
- The lack of effective systems to track and improve outcomes for those children and young people whose progress to date has been limited by weaknesses in provision.



This question has been answered 467 times. Most felt that in order to address this area of concern the Local Area needs to support schools with effective and accessible training to help increase schools' knowledge and understanding. Not only should "Teachers … be given the training to recognise the different learning styles of our children and be able to support them to achieve their full potential." But there should also be, "Better (training for) early years practitioners to identify the need for medical assessment of needs. Recognise and act on the need to support the emotional and mental wellbeing of those in early years and primary education who are affected by SEND. Encourage health visitors to recommend GP visit rather than a 'wait and see' approach." Specialist training is also required as, "there seems to be a lack of understanding of the needs of those on the autism spectrum. It is not enough to train the SENCo - all staff need this knowledge." For instance, "Greater training for governors on what SEN discrimination looks like". And governors are key to holding schools to account- for instance regarding the issues of complaints to school, "separate complains system for SEN kids as governors rarely see the issues." We are also told that the Local Area needs to, "Monitor all schools on an individual basis to assess outcomes between SEN and non-SEN schools and encourage partnerships and learning across schools to address deficiencies"

Families would like to see a wider range of classroom support available including, "help and services for dyslexic children", that there is, "not enough provision for speech and language." Families would like more provision in school rather than having to access this separately, asking us to "Provide other services in schools such as ed psych, occupational therapy and speech and language therapy. Take a whole school / class approach to these things to improve standards for ALL children."

Support for emotional well-being was very high on the list to help, "to minimise distress rather than pressure to enhance it." Flexible approaches, such as appointing, "'visiting' assistants that go from school to school, … would really help."

Working together to improve classroom support "across health, social and education systems to facilitate improved understanding of children's needs and an integrated approach." And to remove uncertainty "If a child is in a private provision because no other place can meet their needs, then guarantee the funding post 16 so the parents don't have the worry each year. This is insecure for the young person."

There was strong feeling that we needed to have, "More ambition for our kids." With a strength-based approach so children and young people can, "access the education they deserve and not be defined by their diagnosis" for instance, "Deaf children should not expect to achieve less than their peers because they are deaf. the provision around them are failing them if that happens." We are told that "Our kids want to achieve the highest education possible NOT to just be put somewhere that's "adequate " to meet there needs !" and "Our kids deserve to thrive not to just exist until they age out of education!"

Better transitions into adulthood were explored with the plea that we, "need to demand that special schools are more concerned with long term education goals of individual children. Targets should be in place to best prepared children for long term education and future employment not just concentrating on social skills.” Regarding mainstream provision, “a 6th form for children with autism would be helpful” and “Links with industry and the workplace, so that autism is seen as a strength.” As, “with the correct support they have the potential to excel.” But one respondent spoke of “Children out of education have no hope and no outcome other than the dole. Thanks KCC for destroying young lives”

Respondents told us that on the whole “SEN children in schools should be encouraged. It's good for society, in the long run, if children are used to working with children who are different from them in some way.” but for this to happen, schools need more support:

- Support in training: “KCC SEND must work better with schools - enable teachers to have access to training (make it compulsory if working within a SEN team).”
- Support regarding funding: “More money for specialist resources & support staff. More money for evidence-based therapy services within mainstream schools with time to work jointly with teaching staff.”

We are told that without any extra support, schools are struggling and unable to adequately accommodate SEND children in their schools: “I as a parent have been told many times by school that they cannot afford to get another key worker, that they cannot afford equipment. that they cannot differentiate the curriculum for a child.” Some told us that supporting SEND children in mainstream schools would be easier if there was, “the inclusion of more special education units in mainstream, where children with mild learning disabilities, mid-range functioning autism etc can join mainstream lessons such as PE, art, music etc

However, it is not just external support that schools need to better accommodate SEND children. There needs to be the recognition that academic outcomes need to be only part of the measurements of success for children and young people and the, “need for 5 GCSEs and above is unachievable for some kids.” Failure to recognise and act on this, “is damaging to their self-esteem and confidence in their own powers. They have the ability to be a precious asset to our society and contribute in their own unique ways, but you are losing them and killing their will to integrate with the pressure at school since young age to conform with the NORM!” We should consider the creation of, “a new charter for send children where academia is not the only route to success”

Where schools are not meeting their duties and being inclusive, we are told they need to be held to account, “Poor standards and progress needs to be properly analysed at a granular level and reported upon appropriately. Where settings re unable to cater for a child's needs, they need to be upfront about this and work with parents and the LA amongst others to establish best ways forward.” Equally, “Don't let schools force off rolling or reduced timetables” As a part of this we need to ensure that schools are implementing the support as outlined in the EHCP, “involvement from council to check that provision is in place when a diagnosis is given. An easy to find contact for parents who feel their provision is not adequate.” For instance, “Don't get funding on one child's EHCP and then share it with multiple others.” And that there is quality assurance, “more input in compelling mainstream schools to provide interventions and all special needs children should be monitored to make sure they are being educated rather than just babysat.” Some felt that the Local Authority should have greater oversight over schools’ policies to ensure there is no inadvertent discrimination, “has been made to miss out on a recent future trip to Thorpe park because he cannot get 100% attendance due to his epilepsy. This is disability discrimination please tackle this. They have been very supportive, but this one thing is affecting his mental health. They say it's their policy, but this policy discriminates against a disability that he has. He will never have full attendance so does this mean he should miss out when educational wise he is hard working and trying his best despite his epilepsy."

This section also made reference to the need for culture change, "stop the blame culture... schools blame LA and LA blame schools.. this is of no help at all and not constructive. everyone needs to work together." More frequently expressed in this section in regard to culture change is that families want more understanding and less judgement, and we need to "challenge this culture of hostility to parents." We have been told that in some cases that schools are not working in partnership with parents and even, "made me feel my son was feral, that there was no hope. Indeed, in an inclusions meeting they even said that my options would open if I sent him in to get him permanently excluded." Some parents feel that "Pupils that fit the norm are priority. My son was described as the naughtiest they had ever had."
In order to counteract this, we are told we need to, "Train teachers. e.g. don't constantly shout at kids with ADHD" and where children are not attending school for reasons relating to their SEND we need to, "…work together and remove the threat of prosecution"

Failure to both improve inclusivity and listen to parents means we are "ignoring the suffering of children. You also have to stop taking the statements made by schools as gospel truth.", we need to, "Ban isolation rooms / booths" And "No child should be forced into a special school by mainstream schools unwilling to take them on making them feel like a burden." We are told that the emotional wellbeing and welfare of children with SEND is being harmed, "A special needs child is never fully included and often feels very much alone and are an easy target for bullies", and "because she doesn't fit into the 'norm' I feel she has been isolated in her learning."

## Workstream 3: Quality of Education, Health and Care Plans

Ofsted highlighted the following weakness:

- The inconsistent quality of the Education, Health and Care process; the lack of up to date assessments and limited contributions from health and care professionals; the poor processes to check and review the quality of Education, Health and Care plans.

### Q14. Please tell us what actions you feel we should take together to improve on this area of weakness?

Please write your comments in the below box.

This question has been answered 458 times. In lots of the other sections, culture change and leadership have feature, but this is the first section where this was the priority issue with a third of respondents telling us they would like better leadership which holds professionals and services to account and lead a less adversarial, more child focused culture.

This change is seen to be required with a sense of urgency and needs, “looking at sooner without all the fighting” and that the “whole process must be overseen by effective project managers; get rid of those under-performing.”. It has been requested that staff have, “have strong legal training so that much of the time, energy and resources currently being wasted by front line staff objecting to entirely legal and correct requests would be dramatically cut.” by more specifically, “IPSEA training for all KCC staff”

There is the sense that some of this attitude has been stuck in a blame culture and there are, “people hiding their mistakes for fear of reprisal.” If this is case then respondents also have solutions to this which mirror accepted theory on tackling a blame culture.

**Lead by example and take accountability:** “nobody ever says it's my fault and all the time it is the most vulnerable child that suffers”

**Seek to improve the situations by finding solutions rather than getting caught up in the blaming:** “Follow statutory guidelines correctly, support families in making sure the provision is delivered, hold schools accountable when it isn't, ensure the professionals carrying out assessments have the right experience to assess the needs of the children they are assessing rather than a one size fits all approach

**Embed a learning culture within teams:** “The LA should have properly trained staff and should start caring about the needs of our children and listen to the parents. We know our children best.” Therefore we have to, “Train and recruit staff that have the passion to complete their job. Ensure all SEN School staff are fully trained and are available to the children and parent’s needs”

In addition, a learning and growing culture has strong lines of accountability, clear about direction and expectations and works together to produce outcomes. Therefore when we are told that parents want us to develop, “standards that are applied consistently” that plans “should have set deadlines for review (which) are flagged up if they are not done in a timely manner” that, “health sections need to be more comprehensive to include descriptors of the condition and how it effects the child rather than bullet point diagnosis” and, “Ensure all schools are aware of the need for an updated EHC.” We must accept that we are being told that we must change the culture from one of blame to one of growth and accountability

As a part of learning and growing there are specific areas that we are told need improvement:

- “Teach health, social care and educational establishments how to fill in the forms, what their statutory duties are, what information they need to supply” “Train staff” to complete EHCPs to a readable and high standard- “Not a data input clerk. When EHCPs are written, all documentation should be used. Not cherry picked by an inexperienced member of staff.”
- Families have received “Empty EHCPs with all the content removed, delivered over a year late.”
- “Stop recording changes on EHCP's by highlighting, crossing out and adding new text. It makes it very difficult to read and understand the information.”
- “Caseworkers to not cut and paste”…“My son had three different names in one draft.”

Timeliness, usefulness and quality of EHCPs is a big concern. The length of time families are left waiting is a cause of much frustration: “Assessments used are several years old which is often the case.”

We need to ensure “that up to date assessment is needed no later than every 18 months - 2 years. And individually based for each child.”. If the assessment is up to date, “yet the process takes so long that it gets to the point when another one is required.” then little or no progress is made.

They are not felt useful when the “…plan is poor. Not followed through.”
We must, “Make sure all the professionals involved in the child's care plan either attend the reviews or give up-to-date evidence to be written into the reviews.” Joined up holistic plans are a must, “Health and care professionals just don't contribute. It is mainly a Tick box exercise even if they do which is a rarity. They don't follow through.” The ability of a plan to be affective can only work if co-produced, “Any changes made by a child's parents and the schools needs to be acted upon, or at least responded to.” otherwise they become tokenistic. Equally they need to be meaningful and accurate, “School did minimal amendments and made facts up without checking e.g. SALT said he made good progress in September when they didn't start until November. I corrected all of them supplying detailed supporting evidence of all medical reports and updated in accordance with guidance from IPSEA Sossen and the NAS. Set it all out on a plate. 7 hours work overnight. KCC had virtually nothing to do but I still haven't had it back yet. They are a bit short staffed in SEN …apparently.”

Quality of plans was seen as generally being very poor, and we are told that, “Poor ones should be returned and re-done.” And even, “Our sons EHP was blank. KCC staff don't know how to write them. Our Barrister wrote ours with our sons Speech OT and ABA consultant.” To improve this leadership needs to ensure we have, “Have the right people checking and changing EHCP. At the moment it is hit and miss. We are told our plans are not SMART enough when respondents identify the following key requirements for EHCPs

- “Appropriate assessment e.g. if a child’s main priority is listed as SEMH/anxiety an assessment by CAMHs should be included”
- “Needs to be reviewed more often than yearly to reflect changes in child.”
- “Should be done in line with NEED and not what NHS can currently provide.”
- “Show a genuine commitment to provide plans that meet needs and not try to save money resulting in an impossible situation for families and a dreadful impact on their mental health
- “Updates… things are not happening within timeframes, plans are weak, lack of clear communication with parents”
- “Annual reviews should be signed off by SEND within an agreed mandatory number of weeks to ensure that plans remain timely and appropriate.”

As discussed above, for plans to be useful or effective they need have a true integrated approach, but “Education and health do not work together in our experience. Health professionals should be made to attend annual reviews or technologies used such as skype to enable an accurate EHCP.” Currently the feeling is, “everyone seems to work in isolation and there is a distinct feeling no one wants to take responsibility as it will cost them money.”
Additionally, there is the sense that it more than simply working together, but a better joint understanding is needed, “GP's and health workers need to be better trained so that they know how to listen to parents coming in with concerns about their children. They need to recognise the descriptions given by parents, and parents' concerns need to be taken seriously.”

Currently, “Disconnect and delays between health professionals and support services leave us in limbo for long periods of time.”
Better and more streamlined ways of joint working need to be found.

It would simplify the documentation if we started to “…number the pages!” and make “the document smaller, clearer and concise.” But we also need to simplify the process: “The process is complex and involves too many people from different bodies. It's slow as a result and opaque to outsiders.” We are told that, “your systems are shocking. A simple database can organise who needs reviewing when.” Solutions to this include, “How about a website that is accessible to parents and professionals showing an example EHCP so that everyone is clear about the process and what actually needs to be on the plan?”

When systems and process are unwieldy and broken the child gets lost and process are driving work towards outputs rather than child focused outcomes as outlined in Professor Eileen Munro’s review of Child Protection: a child centred system In Chapter three she talked about a system that values professional expertise rather than an over reliance on procedures which can, “lull people into a passive mindset of just following the steps ….and can reduce …motivation to become skilled at a job” (Department of Education The Munro Review of Child Protection; A child Centred System May 2011 (3.3 pg. 40). In order to bring about a more child centred and less process driven system we are told that we need , “Trained staff working as case worker rather than admin people, proper assessments from professionals in all areas” and that, “ensure the professionals carrying out assessments have the right experience to assess the needs of the children they are assessing rather than a one size fits all approach.”
Otherwise, “the only person to suffer is that child.”

YOU NEED TO SACK MANAGERS IN PROBLEM AREAS AND GET PEOPLE IN WHO CARE AND WANT TO GENUINELY HELP OUR CHILDREN AND WHO GENUINELY WANT TO COMPLY WITH THE LAW. KCC HAS A CULTURE AMONGST ITS EMPLOYEES AND MANAGERS THAT IT IS OKAY TO LIE AND DELIBERATLY MISLEAD PARENTS. I COULD GIVE ENDLESS EXAMPLES OF THE LIES WE HAVE BEEN TOLD DURING OUR INTERACTIONS WITH KCC.

## Workstream 4: Joint commissioning and governance

Ofsted highlighted the following weaknesses:

- The inability of current joint commissioning arrangements to address known gaps and eliminate longstanding weaknesses in the services for children and young people with SEND.
- The governance of SEND arrangements across the Education, Health and Care system at strategic and operational level and absence of robust action plans to address known weaknesses.

## Q15. Please tell us what actions you feel we should take together to improve on these areas of weakness?

Please write your comments in the below box.

This question has been answered 324 times and along with question 14 puts leadership and culture change as its highest priority, “Kent in general seems to not care” and we need “Better leadership, not just the same old people rotating in the same old senior roles without real vision or passion,.... shake up the KCC rusty, complacent machine for once.” Similarly, like question 14 change here needs pace and purpose, “take action we've been complaining for years all it does is fall on deaf ears… You have known for years what has to be done so get on and do it.”
There is a general feeling that totally new ways of thinking and doing things is needed, “Everyone is too committed to 'we've always done things this way' and are unwilling to change. This needs to change”

The families tell us that the problems are well known and long standing, but they also tell us what we need to do to improve, we need to, “look to other regions that provide different or additional assessments and support. In the absence of changes to the provision in Kent these major gaps will remain.”
We need to improve joint working and decision making, “How often do senior leaders or even team managers meet to discuss issues? Other than to argue over who funds complex cases and continuing care.”

We are asked, “Why have a health and wellbeing board if it never discusses this?” Is this because there is no trust that there is sufficient accountability?
We are told to “ensure the NHS equality impact assess all their policies. Their SALT and IT policies are in breach of the law. I complained they won't even do it now. Public sector equality duty?”. But scrutiny is needed across all areas including education, “better governance and checks over schools and how their SEN funding is being put to use.” and equally internal KCC scrutiny, “by robust HR procedures - make senior staff accountable. Stop the presentations, networking, meetings and all that faff - actually get managers working from the bottom up, not top down.”

We are told that leadership is disconnected from the day to day service and needs to understand the impact of decision making to delivery. Therefore as well as listening to the families we also need to listen to the teams at the forefront of delivering these services we need to involve, “Frontline staff in decision making” Because when we don’t “ever ask SENCOs- as they are doing the job, day in, day out!” we miss not only their expertise, but the changing need gaps that they are usually first to see. To support this trend spotting and to give SEND local focus and priority, “Each Kent area should make this a standing item agenda on the Local children's partnership group.” This will help us to, “understand where you are at- grass root level.”

The leadership changes outlined above need to be in place to bring about the culture change that we are told is needed, leaders need to, “Take on some people who are able to inspire teams to produce results and remember that your staff are your single biggest asset.” Where his hasn’t happened, families tell us they have been faced with an adversarial approach from teams, “I was forced to name xxxxx as my sons post 16 as XXXXX coerced me by saying I just have to put anything down this can be changed later. Lie! Again, she just wanted to get through her paperwork deadline and did not care whether that school was not suitable despite me coming to her with my issues and concerns crying my eyes out. Horrid people. Tell staff to stop lying about procedures and to provide parents with all options they can consider not avoid communication at all costs because you can never get hold of anyone and when you do, they fob you off. This is clear lack of training and staff numbers”

Respondents tell us that we need to support these teams to have a more child outcome focused approach: “Lessen the workload of all those involved so they can actually provide the child with special needs with consistent support.” This would include spending more time with the child, understanding them, getting their wishes and feelings and including them in decision making in line with the SEND code of practice principles, “…why are the people on the panels who make the decisions on the child's placement or funding never once in contact with the actual child? I think that's wrong. Children should be at the panel so that where possible they can have their voice heard.” This is one example of where children are not included, but it is felt they should be; however, it equally applies to the whole system, “I found that the whole thing runs on looking at reports and statistics. This process never 'sees' the child in question.”

Child, or person centred approaches need co-production to be integral to their ethos to turn this from the feeling that professionals are the experts who are here to ‘fix’ the problem, to one where all parties work together in equal partnership to find the right solution: “Create a culture where every SEND employee genuinely cares and builds a trusting relationship with parents and wants the best outcome for the child” We are told this needs to be led from the top- “At the highest levels, conversations with service users and providers need to be held where a realistic, relevant and partnership-based LA wide strategy is discussed and formulated - one where users and providers feel partnered, and listened to, rather than done unto and an inconvenience. The LA needs to demonstrate publicly a desire to actually do the best without excuses that they possibly can. Focus should be on action, rather than spending large amount on action planning.”

There is a lot of eagerness from parents to help us solve this problem and improve SEND services for all children, “I would be willing as a parent of a child with SEND to sit on panels to give views from parents side.” We could also, “think about training passionate parents to work with alongside you. You will never understand the impact living with these additional needs unless you live it, breath it.”

What is being described here is that we are missing the full picture of the families’ circumstances and needs if we exclude the ‘experts by experience.’

Genuine co-production would remove the need for practitioners to feel they have all the answers and move to a model where they are valued for the individual specialism they bring to the table and working together with all partners to improve outcomes. The sharing of the load of decision making not only improves the decision made but improves the capacity of teams to work with families as together decision making can be swifter and more comprehensive.

Parents have offered to support us to improve at every level, “Get the right commissioners in place. Have parent volunteer commissioners who work alongside the commissioners - who would work much like volunteer school governors do. If you really want to involve parents, then embed them in every part of the system. Let us scrutinise every decision and be part of every decision.”

We could, “set up an independent committee to address these issues. this should include parents, professionals and Sen lawyers to ensure all aspects are covered” which would, “Create proper independent oversight which involves parents / parent groups and has some enforceable power over the council / schools to drive progress.”

Without this level of scrutiny, the view will persist that, “CCGs are running around wasting money in their haste to just spend, no insight work is completed, just a handful of people making a decision based on not a lot clearly! Find your best staff, so best practice, and get them to guide the CCGs so you can plug the gaps...”

This unmet need is a key concern- “The LA should insist the NHS fund OT and SALT with CCGs and somebody to ensure that the processes are met.”

How to achieve better service provision had no main consensus.

Some felt we should, “Run services in-house rather than commission them. This would give total control over them; you would have end-to-end visibility of processes and should eliminate people focussing just on 'their bit' and not having accountability of the whole provision. It should be about the child, not about trying to patch together a provision based or different providers.”
Whilst others felt that to improve, we need to have, “KENT wide service level agreement OT, S&L, Physiotherapy, Paediatric, wheelchair/hoists, sensory processing, Audiology, Vision, CAMHS, school nursing, Learning Disability nursing for 16 to 25-year olds, continence services.”

To achieve this, “Join budgets with health and KCC” are needed as more joined up decisions, “It feels like school, health and send are all on different pages. Everyone says that one of the others is responsible for something instead of working together.” And better decisions, “Commissioners need to be involved and engaged in service transformation. They need improved understanding of the risks attached to current provision, to participate in service redesign, and to understand the benefits of best practice models elsewhere within the UK - from individual, service, and systemwide perspective.”

Nevertheless, having better service provision available to meet needs has to be communicated well “In our own case, we would like a directory of ASD services here. We found a youth club on a Friday for young people with ASD. This has been a life changer for our son and for us. Yet we discovered it by chance. We also discovered IMAGO by sheer luck when someone mentioned it to us.”

So, there is the question asked here that perhaps it is not just more services that are needed but a better, more comprehensive and usable Local Offer that incudes local directories of all services currently available. This would not only stop the risk of duplication in providing too many of the same type of services and allow for a better understanding of where the real gaps are.

## Workstream 5: Service provision

Ofsted highlighted the following weakness:

- The unacceptable waiting times for children and young people to be seen by some health services, particularly Child, Adolescent and Mental Health Service, tier two services, Specialist And Language Therapy, the wheelchair service, and Autistic Spectrum Disorder and Attention Deficit Hyperactivity Disorder assessment and reviews.

### Q16. Please tell us what actions you feel we should take together to improve on this area of weakness?

Please write your comments in the below box.

**There's a growing suspicion as I complete this increasingly time-consuming questionnaire, that you may go through every point raised by Ofsted and in doing so cause parents to give up filling in this questionnaire....**

This question has been answered 496 times and as the quote above indicates, the sheer volume of responses received in this “time-consuming questionnaire” could result in a loss of reputation. In this section, it is true that a lot of ground has been covered in previous sections, so to avoid this while themes such as the need for a more child centred approach, strong leadership and culture change will be covered only in reference to the identified area of weakness around service provision.

As such, the most recurring theme in this section is the long waiting times and the need to improve on these, as they are, “are completely unrealistic and failing the children's needs.”. In failing the child’s needs we hear of situations deteriorating and becoming critical- “CAMHS have taken over a year to see my child, although my child’s self-harming has become extreme.”
Many parents felt compelled to self-fund the help they need due to waiting times, “The wait was so long I took my children private as they were excluded from school due to SEN needs but were awaiting assessments” Though this option is not available to everyone and there are no other options left but to wait, “My son has been going through this process since he was 4 years old (he was forgotten about at one point) and we are on the ASD pathway. He's now 10.5.”

Early support and intervention are required to avert worsening situations and crisis points being reached and to provide better outcomes for children, “many children would benefit from services being offered when the child is much younger. It would make a huge difference to the child and would probably be much more cost effective as it would mostly be required for a much shorter time than when the child is older and problems more ingrained and difficult to help and may well have caused other problems as well. Plus, the education of the child will also have suffered far more than if help is offered far earlier.”

As one parent tells us their fears that due to the delays in help their child is, “very behind and will never catch up. I truly believe early diagnosis would have helped” Creative solutions to intervene could include, “Training for the workforce to provide interventions prior to requiring specialist intervention”

It is not only the waiting times in themselves that are causes for concerns, it is the lack of support offered at the end of the process, “We got an ASD diagnosis after a year of being referred. You get the diagnosis and leaflet but left to get on with it.” And the lack of communication throughout, “We waited 2.5 years in total for our diagnosis, during this time there was no communication.”

To reduce these waiting times, “More staff needs to be trained, with incentives to stay rather than go private as soon as they have enough experience.”

Without better staff retention, “Frequent staff turnover means professionals do not get to know the child so appointments are repetitive going over the same things so appointments are not as effective as they could be.” And more effective staff recruitment, “If education and health professionals don't want to work in this area for some reason the council needs to be offering a more attractive package and positively the advantages of living and working here.”

Greater efficiencies can be made by having, “a one stop shop for services at a community hub, so all the professionals are in one place and autistic children don’t need to be put under undue stress with seeing multiple health professionals in different settings. This will save travelling time for professionals and their time can be better spent in assessment and advice.”

Alongside needing more staff, underfunding was seen as the cause for many delays: “There needs to be a better funded mental health service for children and young people. Children are only seen if they're an immediate danger to themselves which is unacceptable.” Better funded services is seen as crucial not only to reduce waiting times, but underfunding is seen as the reason for the need of such high thresholds in order to access services, “CAMHS IS UNACCESSIBLE TO MANY CHILDREN WHO NEED IT. MORE MONEY NEEDS TO GO INTO IT, TO WIDEN ITS PROVISION.”

Here again the case for earlier help through better funding is made, “Clearly funds need to be allocated to ensure appropriate provision of services. Without timely access to services children will fall further behind and suffer further disadvantage which may be more difficult to reverse and allow them to fulfil their potential.”
With the rationale that better funded children’s services save costlier interventions later in life, “More investment is needed. We spend very little on children compared to older people. The money that we spend on younger people has a far greater impact on them and society. Time in prison or in a care home, if independence is not achieved for example in someone with SENs is extremely costly.”

Lack of early and appropriate intervention does not just lead to greater financial costs later, but greater costs to quality of family life: “My son and I tried for 12 years to get someone to listen to us. It was picked up at 6 and he was finally diagnosed at 18 1/2, and an adult in College. His life would've been much easier with help and support in school, that goes for mine and his sisters too…”

This again leads to need for child focused outcomes: “If families could access services and support if a need is recognised it would reduce the demand for assessments that usually tell you what you already know but just give a label (at that point the child as a person is lost as they become a child with a label and another statistic). If less time was spent on labelling children for what is already known, more time could be spent on helping them / interventions)”

Many feel the services needed are just not there for them currently: “I am going to have no help now I imagine with his severe head banging and nil communication until he is diagnosed which will probably be in 3 years’ time. Meanwhile my whole family suffer. I am a mother of 8 children, with no family around. Just myself and husband. Please help.”

When there is the inability for the specialist provision to respond in an appropriate and timely way there is the concern that less well-equipped services are left to plug the gap, “Early Help pick up the pieces of the CAMHS wait times. So far, we are two years in on our waiting list to get a diagnosis. With a diagnosis more doors open for support. Early help cannot do the diagnosing and are only allowed a short time with a family. So personally, I feel like I'm trapped in a pinball machine bouncing off GP, CAMHS, KCC and Early Help.”
We are told that strong leadership, vision and direction is needed to redress this:

- “KCC needs to be more proactive with the commissioners of these services. My personal experience of CAMHS is diabolical.”
- “KCC really need to keep pushing this, the community is behind you, please do it and let us help you raise awareness.”
- “CAHMS not even bother as I found out when my son almost killed himself!!!! And I was then informed by CAHMS he did not meet their criteria!! They are mental health services. he has mental health issues and he has ASD ... I have little to no faith in CAHMS... they are a waste of time and they don’t seem to want to help anyone!!... my experience tells me that CAHMS doesn't give a toss about children or adolescents… CAHMS don’t care!!!! Prove me wrong! Actually start doing your jobs CAHMS need to start proving that my son’s welfare matters... what they need to do is their job and start caring about more than a paycheck!!!”

Specific providers of these services are seen as not able to deliver: “Get rid of NELFT. At least PSICON provided a friendly service. NELFT can’t even work together across departments, let alone the wider system. Oh, and here's a biggie, Tell the CCGs to stop wasting money on good health matters (it’s terrible) and use it to employ more staff. Oh, and telling parents diagnosis isn't necessary is appalling, that tactic for reducing waiting times remains the most shocking! Man up, invest, and do right by these kids.”

We have been told how we need to improve in this area- more staff, more funding, child centred cultures and strong and effective leadership, but we are also told what needs to improve. We have heard that mental health services are not delivering a good enough service to a great cost to children and young people’s well-being, but other unmet needs are also identified. We should get “a panel of salt and OT experts in. Yes, it will cost more, but I bet your Tribunals go down and kids will get personalised support from independent experts. Investigate the access to services to see if they are fair and lawful before you rely on them don’t assume that the NHS are better.”

We are told that

- “The wheelchair services have been a constant problem since Millbrook has taken control. Repairs, reviews and replacements are taking far too long.”
- “ASD support is non-existent so I would suggest a specialist ASD support team across Kent, comprising of Health, SLT , behaviour specialists and Mental health support who would work with parents and educational settings in a holistic way , improving outcomes for the young person at school , at home and in the community.”
- “No Dyslexia specialists seem to be available unless you can afford to pay for it.”

Along with types of support required we are told we need to reconsider the way in which services are delivered: “Parents should have choice about where health provision is provided - I have been told ‘if your child goes to that school they must be taken to that clinic (only)’, but from a parent's point of view another NHS facility might offer a quicker or better service. Schools should not be able to force parents to go to a particular clinic against the child's interest and with the threat of calling in the Social Workers if parents don't comply (this has happened to us).” Or we could consider services coming, “… to the school rather than inviting the child and family to the clinic.”.

## Conclusion

**The use of the parental voice throughout it not just important in ensuring true representation, but it is interesting to note that not all families are saying the same thing. For instance, some want more special school places to be available while others want mainstream school to be more inclusive and stop forcing kids with SEND to Special schools. Some want KCC to stop commissioning all its services and bring these in house, while others want more robust and coproduced commissioning. If anything, this makes the case stronger for co-production at both an individual level and a strategic level. Without this we risk prescribing a one solution fits all approach which we have been told throughout doesn’t work.**

Co-production as an ethos and method of improvement and delivery is being increasingly recognised in public sector reform. This works by shifting the balance of decision making and planning from individual groups of specialists to working together with all relevant specialists including the receivers of these services to plan and deliver and has a wide range of positive outcomes. In times of austerity and stretched provision, services don’t have to do this on their own, they can share the load and funding. By involving the service user as an equal partner, we ensure we have the widest range of expertise around the table to inform decisions and design and delivery of provision. By using the knowledge of the ‘experts by experience’ we enhance the professional learning with knowledge and skills based on lived experience. And finally, in changing the dynamic from services being prescribed and delivered by professionals to families, to one where families have active roles in planning and delivering, we can build healthy, sustained change, and a fairer system and good governance.

**In adopting and embedding co-produced service delivery and design we will ensure we move from an adversarial to a child focused culture. We know that this will have happened when we stop asking, ‘have we met the legal framework’ and start asking ‘have our decisions and action improved the outcomes for the child?’ In the words of Professor Eileen Munro “doing the right thing instead of doing things right” in her 2011 report** The Munro Review of Child Protection; A child Centred System

None of this can happen without being led from the top. Leaders need to work together to both hear the voice of the families and how badly they have been failed, and to hear the voice of the children’s workforce* across all service areas who are not able to deliver effectively efficiently without service design and reform. All of which can and should be done in equal partnership with children, young people and families. Finally, we are told our families want our leaders to hold failing services to account, set high standards and have aspirations for our children and young people.

In all the five workstream responses some common themes have emerged; o-Production already discussed, is seen as being essential for success, featuring high in every workstream and came highest in the Parental Engagement workstream.

Co-production here covered a range of areas from parents offering to sit on Steering Groups and undertake joint training with teaching staff and other professionals to being listened to and not judged. Parents are asking to be believed and treated as equal partners in the planning and decision around their children.

A Child focused service that identifies need early and ensures appropriate local support was high on the agenda for all and putting the child's voice central featured heavily throughout. This is both in terms of ensuring the child's wishes and feelings were heard and understood to having high aspirations, and a positive rather than deficit model to planning and decision making

Good Leadership and driving forward culture change were other common themes throughout all the five workstreams. Parents want leaders to give strong direction towards a family and child focused workforce to holding teams, services and joint commissioning to account. Better integration of services is called for, ensuring good and locally accessible provision us available. There was a strong emphasis put on better communication both with families as equal and trusted partners and across all service areas.

It is clear to see that that there is a reluctance to believe that anything will change and perhaps why there is so much scepticism around the vision when we hear, "More should be done with in schools and not keep fobbing us parents of .my child education has been failed so far just like my 26 year old was, nothing has changed in all this time no matter how much a parent complains it just a constant fight with no result .it has to change."

If we fail to take this opportunity to hear what we have now been told and act on this then we run the risk that this level of scepticism and mistrust will not only remain but grow.

Some felt that the SEND area needs greater mainstream attention which would not only ensure greater inclusivity in practice but reduce stigma at a personal level. To achieve this, it was suggested we could start by making SEND everyone's business, by perhaps ensuring that SEND should be a standard item on Local Children's Partnership Groups

*****Children's workforce used anywhere in this report should be taken to mean any teams working directly with children and young people in the Local Authority, educational settings and across health

## Recommendations

Listen to parents and young people, involve them, empower them to speak up about services.

In this report we were told by the respondents that the reason the Local Area across Education, Health and Social Care were failing to meet the needs of their children, young people and families is that we are simply not following the SEND Code of Practice

**Principles underpinning the SEND Code of Practice**

Section 19 of the Children and Families Act 2014 makes clear that local authorities, 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

• the importance of the child or young person, and the child's parents, participating as fully as possible in decisions, and being provided with the information and support necessary to enable participation in those decisions

• the need to support the child or young person, and the child's parents, in order to facilitate the development of the child or young person and to help them achieve the best possible educational and other outcomes, preparing them effectively for adulthood

It is recommended that the following seven statements which the Principles of the Code of Practice are designed to support should underpin all improvement plans and decisions as outlined in the five work streams in the Written Statement of Action

- The participation of children, their parents and young people in decision-making
- The early identification of children and young people's needs and early intervention to support them
- Greater choice and control for young people and parents over support
- Collaboration between education, health and social care services to provide support
- A focus on inclusive practice and removing barriers to learning
- Successful preparation for adulthood, including independent living and employment

## Workstream A

Parental Engagement and Co-Production
**Senior Responsible Officer: Stuart Collins**

Central to the SEND code of practice is to fully involve children, young people and families in decisions about their support and what they want to achieve and to change the experience of families from a confrontational, adversarial one to one that is inclusive, collaborative and efficient. We have heard across all our family's voices in this questionnaire that this isn't happening in Kent

Kent needs to move to a model and ethos of co-production which will involve changing working practices, principles and language, Instead of seeing our children, young people and families as clients, customers, students or patients we need to move to a model where all services are working together and alongside our children, young people and families as equal partners

To embed sustainable participation and co-production is not a quick fix and needs time to understand and establish. Relationships and trust need to be built which means the approach needs to be collaborative and transparent using tools like Hart's ladder of participation will help understand the differences between consultation and co-production

The children's workforce needs sufficient support to understand the principles of co-production, have the time to build relationships with children, young people and their families and have the skills to work in a person-centred approach.
Co-Production training has been designed and delivered by young people in Virtual School Kent and has been delivered to Local Children's Partnership Group Chairs, Cabinet and various teams within KCC. The consideration should be made that that this training is rolled out to all of the Children's Workforce

All service areas need to have a common understanding of what Co-Production is, and what it isn't, and what it means for children, young people and families. Devices like designing a Kent SEND Charter for Co-Production could facilitate this

Person-centred approaches work best when there is a stable and continuous workforce and the families know who their contact is and can early reach them and be confident that their calls will be returned. Good open and transparent communication is key to building trust and delivering a person-centred approach.

Children and young people and their families need to be involved in decisions about their support. The services and children's workforce need to ensure that children and young people can express their views about these decisions, and they must be considered in a way that it is appropriate for that child or young person to do so.

Responsive engagement is needed and not a one size fits all approach, for instance the children's workforce will need to have  a good understanding of the impact of transitions on that child or young person, the context of family, school and wider community life for that child or young person and understand the need for reassurance.

A different approach to listening to families when they first raise concerns is needed, including greater choices available. Families have told us that weren't listened to early enough resulting not only in wasted time which can leave their children and young people further and further behind, but also results in families feeling not believed and judged. This goes back to building a more centred approach and supporting the children's workforce to grow and develop so they can confidently deliver a truly child centred approach. This means earliest possible diagnosis intervention and in the Early Years, but to equally respond well to new and emerging needs as children move through transition stages and or have changing circumstances requiring support. Better training for staff including greater understanding between presenting diagnosed or undiagnosed needs and Adverse Childhood Experiences.

Good impartial information advice and guidance must be made available to children, young people and families to allow them to make active and informed choices about their plans and support through the Local Offer. Following feedback from families Kent may decide to brand its Local Offer differently, but it must be collaborative, accessible, comprehensive, up to date and transparent if it is to support children, young people and their families to know what they are entitled to, how to get this and what support is available. It needs to:

- Allow children, young people and families to easily find out what services are available for them from universal to targeted across all ages and stages.
- Allow children, young people and families to easily find out what specialist services are available and whether these are available to be bought through direct payments
- Allow children, young people and families to easily find out what other provision there is in their area that may support their needs.
- Allow children, young people and families to easily find out how they can engage with service transformation and commissioning to improve service delivery and design
- Allow children, young people and families to easily find out what is the Early Intervention offer
- Allow children, young people and families to easily find out how services will work together with them to provide improve outcomes and meet aspirations
- Allow children, young people and families to easily access information by considering speech, language and communication differences

The Local Offer must be co-produced with children, young people and families

## Workstream B

Inclusive Practice and the Outcomes, Progress and Attainment of Children and Young People
**Senior Responsible Officer: Keith Abbott**

It is no surprise that the experiences of children and young people in this questionnaire are told largely through school settings- both good and bad- as schools are where children and young people spend a great deal of their time, or are meant to where it is working well.

Good SENCOs with enough capacity and support to do their jobs and support families well, we are told are very important in getting this right. If we are making the case for early identification and intervention being a priority and SEND being everyone's business, then it stands to reason that SENCOs are an important resource in understanding and getting this right. We are advised in the questionnaire to listen to SENCOs. The Local Area should consider setting up a forum, working party or task and finish group to support the work in a co-produced manner

Part of the work in supporting schools to be more inclusive is around building capacity and confidence for schools to be able identify and implement reasonable adjustments, so that children can thrive and achieve without fear of discrimination within these schools.

Too many parents have told us within this questionnaire where this hasn't happened. Families have felt disbelieved by the school, children have been bullied and children and young people's needs have been misunderstood and they have been shouted at, labelled the naughty children and excluded. We have heard of the wasted childhoods that some of these children and young people have had and therefore they have at best not been able to reach their full potential at worse their experience has traumatised them and their emotional well-being has suffered. Schools must work better with all families however difficult this may be, so no child or young person goes through this and no family feel they are not being understood or heard by the school.

There are instances where schools have refused to support families by completing an EHCP for the child or young person. Families tell us that they are often told that it will be a quicker process if the family apply themselves. This is not only untrue but adds to the sense that there is an unfair system with parents who are able to undertake this process making more headway than those, who for whatever reason are not able. To ensure there is equality if access to ECHPs where they are needed schools must reverse this trend of parental application and work in cooperation with parents where an EHCP is appropriate and offer advice, guidance support where it isn't. This will include working with the family in exploring all reasonable adjustments, other available support, agencies and tools to help our children and young people thrive and achieve.

The Local Authority needs to work together to ensure schools are supported to meet their duties under the Equalities Act 2010 as discussed above under collaboration. Schools need to feel confident with the help of health they can manage health needs. They also need to feel confident that with the help of KCC and other services that they can meet the social needs of children.

Schools need to feel as they may do currently that they are not in this alone and together we can support and deliver a more inclusive school system for the children and young people of Kent.

## Workstream C

Quality of Education, Health and Care Plans
**Senior Responsible Officer: Sarah Hammond**

Education and Health Care Plans where they are required need to be of a much better quality. They need to be specific, measurable, achievable, realistic and timely and delivered with pace purpose and transparency. Families have given us a wealth of information of what is not working, what is and what needs to change regarding the quality and process of EHCPs

A great frustration for parent carers is that communication throughout the process has been poor. Families would like to be able to discuss easily the progress of their plan with the person responsible for pulling this together- it is not acceptable that calls and e-mails are not returned in a timely manner if at all. This has contributed to the feeling that some families have of the local authority not caring about their children. Similarly, there is a need for greater transparency about every part of the process from reasons for delays to clear explanations for decision making.

The paperwork needs not only simplifying and having page numbers included but written in clear, jargon free language. The plan needs greater attention to detail and quality and not just having been cut and paste from a series of other documents. Reviews, additions and amendments need to be correctly included and not added on in different colour text. The result of the contents being of a poor quality further add to the feeling that the child or young person is not important, equally they can be so difficult to read in some cases that it excludes families from fully being able to take part in the process as the sense of the documents become meaningless.

The plans and reviews need issuing on time and in advance of transitions. Families tell us of the struggles some of our children and young people have particularly around the autistic spectrum with managing change. Decisions and plans issued at the last minute add to this stress and hinder successful change planning for families.

The plans need to involve the children, young people and families wishes and feelings. There needs to be real meaningful involvement in the process and not just a tick box exercise, we have heard families tell us they voiced their views but then they were not included in the final plan. Co-production is central to the SEND Code of Practice and needs to be embedded fully within the whole children’s workforce.

Language must be accessible, age specific and plain, ideally written in the first person and using the child, young person and families own voice. They need to have clear lines accountability where individuals, agencies and services are clear about who is responsible for actions and delivery and clear plans for collaboration between agencies.

While there is concern that if the child or young person’s strengths and achievements are included then decisions may be made that support is not required. This should be addressed in the whole children’s workforce culture change recommendation that we move to a person-centred approach which is a strengths-based approach using a social rather than medical model of disability. Plans must be outcome, not output focused with realistic and aspirational considerations for future transitions and independence, social interactions and employment.

## Workstream D

Joint commissioning and governance
**Senior Responsible Officer: Karen Sharp**

We are told that services are fragmented and not working together. This results in families having to repeat themselves repeatedly to each individual service. Services, especially when under pressure, have inflexible thresholds which can result in children and young people falling through the gaps if they don’t quite meet that criteria. Families feel that schools are trying to do it all and health and social care provision are not flexible or responsive enough to work collaboratively with the schools. We are told services are patchy- what might be available in one area may not be available in another. Provision is not responsive enough, for instance there are groups and activities children who can access universal services in Children’s Centres and Youth Centres. There are also services for disabled children with specialist needs, but the is a big gap we are told for those children in middle who are not able to access universal, but don’t meet the threshold for specialist services.

The Local Area must ensure that Education, Health and Social Care work better to identify more fluid thresholds where there are no gaps for children and young people to fall through and that they work jointly across these. This could mean that the agency that has the greatest involvement with the child regarding their needs holds the hand of the child or young person throughout the navigation of these services (NB this isn’t just down to the school who will see the child more across the school day but who may not have the greatest involvement in meeting their needs). Or it could mean that there are casework navigators to help link these services up. Whatever solution is co-produced we will know it is working when we no longer hear, “that is not my job.”

Services need to work better to pool budgets and develop an understanding of need by using jointly available data to identify unmet need in the first instance, and then develop co-production to develop and deliver services. Data led decisions lead to outputs where co-produced decision lead to outcomes. The development of a single Kent CCG will help this and provide a county overview which will go some way to avoid wasteful duplication and ensure a wider fairer coverage of provision.

But this should go further. Education, health and care needs of a child or young person should be seen as a fluid continuum that do not have delineated lines between them. For instance, a medical condition treated by a GP for instance shouldn’t be seen in isolation from how this may impact on education, learning and socialising, all of which contribute not only to development but well-being. This can only be done if all services understand the wider environment of the child or young person. Consideration could be given to equip all the children’s workforce to work together to understand what will help the child or young person thrive by working with that child or young person around domains-based conversation. KCC uses resilience-based conversations through

Headstart already in some schools This could be considered as a wider unified children's workforce approach

A suggestion made in the questionnaire is, "Employ a Strategy Coordinator who is sincere dedicated and patient. Someone who understands the diversity of children and young people with SEND."

## Workstream E

Service Provision
**Senior Responsible Officer: Rachel Jones**

The evidence for the importance of early identification and intervention is widely available and known, yet the stories presented to us in this questionnaire tell that the common experience of too many delays and missed opportunities to support children and young people to thrive at the earliest opportunity.

Delays due to long waiting lists and services being over capacity are just storing up greater problems down the road. For instance, speech, language and communication needs are nationally 23% of the most common primary need according to the DoE SEND in England stats January 2019, but other evidence suggests that in the wider population this statistic may be even greater. The Royal College for Speech and Language tell us that 60% of the of young people in the justice system have speech, language and communications needs. Kent's Youth Justice Teams are being funded by the Clinical Commissioning Groups to commission Speech and Language therapist for their Youth Offending teams and nationally specialist training will be provided for 1,000 health visitors who will work in some of the most deprived communities in England, but this needs a wider approach if we want our children and young people to fully participate in their decision making. We need to make sure we focus our training, joint commissioning and wider improvement journey on empowering children and young people to communicate well. If they can tell they are not understanding something in class or are not able to concentrate due to something that has happened at home, would this perhaps reduce fixed term exclusions?

A person-centred approach to all areas of service provision is needed. This needs to move away from data only led decisions leading only to outputs to an approach that, through co-production has better consideration of impact and delivers outcomes. For instance, we hear of primary aged children who are reliant on SEND transport to get to and from school having round trip journeys of a couple of hours a day. While the decision on what route to take and what children to include on that route may have been based on sound financial and logistical information it does not have the child central to those decisions. Where is the consideration for child's individual needs? Is the time spent on those journeys constructive and nurturing? if they have sensory issues is a taxi or minibus with a lot of other children appropriate or harmful? If the child has had a rough time at home, or not coping with something how do the families let the school know this if they are not able to accompany them to the school gate and meet the teacher as other parents do? What is the impact on families of disabled children requiring school transport when they are not able to accompany their children to school? When do the normal day to day conversations that take place between the children and their families on the school run take place? How do families meet other families to share ideas and build up social links and strong resilient communities if they are not able to accompany their children to the school gate? These questions can only ever be fully answered when service provision is person centred and co-produced.

PUBLISH your findings clearly and let us know what you have changed AND what you are not able to change (even if that is disappointing, it's better to know that be sent round the houses...)

Thank you for sharing your experiences with us and the Local Area regrets the impact that this has had and by using this survey as a benchmark and starting point and working with you we pledge to improve our SEND services and provision

**Work has begun on all five workstreams outlined above and they can only be successful and bring about the desired change when co-produced with our children, young people and families. Some of this work has started and the main co-produced activities have been supported though the Parent Carer forum, Kent PACT. Other engagement opportunities through workshops and focus groups are also being developed.**

**If you would like to join and support SEND transformation in a strategic way then you can do this by joining Kent PACT simply go the Kent PACT website.**

**You could be involved in wider health service scrutiny by becoming a volunteer for Kent Healthwatch, to this go to the Healthwatch website.**

**Other opportunities for becoming involved will be published on Kent's Local Offer webpage which itself is undergoing transformation through co-production**

**If you can think of any other way you may like to be come involved you can let us know on the Local Offer Page under Local Offer, Your Voice.**