

Appendix 2

Southwark Council Developing the Southwark SEND Strategy 2022-25

Consultation Feedback Report

July 2022

Southwark Council

Developing the Southwark SEND Strategy 2022-25

Consultation Feedback Report

1 Introduction

Southwark Council and partners are developing a new SEND Strategy and asked the Institute of Public Care (Oxford Brookes University) to support them in undertaking a consultation process to ensure it is informed by all those involved in the SEND process. This has involved the views of children, young people, their families and carers as well as schools and other professionals who have responsibilities and accountabilities for the SEND process.

The consultation process was undertaken between March and June 2022 and gave as many people as possible an opportunity to be involved in a range of opportunities to express their views. Views were collated and analysed. These are summarised in this report together with suggested changes and recommendations to finalise the SEND Strategy.

It is encouraging that overall, there was a consensus that the strategy was a move in the right direction and that it was an opportunity to bring people together to address issues. There was some debate about the rationale and vision but considerable discussion around each priority and these are summarised together with suggested changes.

Inevitably there are challenges in developing a strategy and determining how it will make a difference. This was discussed during the consultation and a range of issues raised. These are summarised with the intention that they will assist in implementing the strategy.

Most importantly the voice of parents and carers must be heard. Although the number of individuals directly involved was low their contribution was rich and varied. Their key messages are reflected in the body of this report together with their comments regarding the key themes of the strategy, but such is the importance of hearing what they have to say more detail is contained in a separate report (Appendix 1).

Likewise, the numbers of children and young people views received were few, but it is important to capture them to give an insight into what is important in their lives, hence Appendix 2 gives a summary of the responses we received to a simple pictorial questionnaire sent to schools and some parents.

There is no doubt that there are many committed professionals involved in the SEND process, many schools wanting to do the best for their children and young people and parents/carers who have had positive experiences. There can be a tendency in a

consultation process to focus on what needs to improve so it is important to reference what has worked well. These are referenced as a positive reminder and incorporated into recommendations.

Summary of feedback follows the structure of the consultation document with comments given for each element of the strategy. Recommendations regarding changes in wording and content are detailed. To be transparent, suggested deletions are highlighted in yellow with suggested amendments/additional wording in red. Where actions have been moved to other priorities, this is indicated.

A revised version of the consultation strategy is attached for consideration with the intent that this could form the basis and a proposed framework for the final strategy. (Appendix 3).

2 Valuing your views – our approach

A strategy needs to be clear and focussed to be understood and 'owned' by everyone to confidently set the future direction of service development. Together with partners, Southwark Council had developed a draft strategy which was then condensed into a consultation version which created a consistent basis for the consultation process.

A range of consultation activity was undertaken

- Parents/carers – in depth face to face consultations with 10 parents (6 in person and 4 online).
- Children/young people – 13 children and young people fed back via schools.
- Portal - 55 responses including 18 members of the public and 35 parent/carers.
- Internal questionnaires - 20 responses from individual professionals involved in the SEND process.
- 2 focus groups with 16 professional stakeholders including paediatricians, educational psychologists, youth justice and a range of Council SEND staff.
- 3 focus groups with 29 stakeholders from schools which included senior teachers and SENCOs from primary, secondary mainstream, special schools and academies.

Hence a total 143 professionals, parent/carers, children and young people gave their views during the process.

3 Key messages from parent carers

During the consultations, we heard lots of compelling illustrations from the parent carers regarding their lived experience. We feel it is important to fully capture what parents told us and hence a comprehensive summary of the parents' views is detailed in Appendix 1. We have also included in the main body of this report the views that the parent carers expressed in relation to each of the themes in the strategy.

In addition, at each consultation session, we asked each parent/carer to tell us at least one key thing or message that they wanted Southwark Council and partners to focus on. These are quoted below.

“More information, collated together, to help parents start in the right direction”

‘Communication is key’

‘Parents and teachers working together to make things happen - keep us up to date with what is happening and any changes that will impact on my child’

‘Who is there to phone now he is 25? – need details of who to contact now’

‘Communication between the key stakeholders involved with the child, coming together and planning together’

‘Make sure children don’t go unnoticed, don’t nullify the challenges the child has if not as visible’

‘Parents need to be able to speak to people comfortably and feel listened to, not judged, it is important how professionals treat you, we need support and encouragement - not sympathy’

‘Easier to access respite and short breaks desperately needed for complex needs’

‘Why is it the child has to conform, why aren’t we conforming to them?’

‘Access to peer-to-peer opportunities and support to feel less isolated, alone and scared’

‘Invest in more schools so that children with different profiles aren’t bungled in together – right choice, right school’

4 General themes

There was a consensus from all those involved in the consultation process that the strategy in general terms was important and focussing on the right issues. However, there was a range of general and overarching issues that were consistently raised as discussion points and challenges which need to be incorporated throughout the strategy and in delivery plans as they progress. These are described below but are also reflected in more detail and referenced in the rationale, vision and priorities.

- **Strengthen and have a more proactive approach regarding inclusion** and specifically reference inequalities and discrimination that BME children and young people with SEND experience.
- **Improve communication between all involved** – schools, professionals and most importantly families/carers who can feel excluded. Communication was a key theme raised by the parents consulted.
- **Simplify systems and processes** – all considered them overly cumbersome, often felt duplicating report/information resulting in delays – parents/carers feeling it is a struggle and overwhelmed. Some parents considered the complexity of the process was in effect being used as means to deter them and ration resources.
- **Clarity about roles/responsibilities/accountabilities** – consistent sense that not always clear frustrating decision making and progressing plans.
- **Improve skills/knowledge** – whilst acknowledging that there are many skilled and experienced staff around there was a view, including from several parent/carers, that more was needed for staff (in schools particular) to feel confident about managing a range of needs – particularly for children with multiple/complex needs.
- **Recruitment and retention** – all stakeholders raised this as an issue. Whilst recognising the importance of improving the skills and developing existing staff there were real issues around the recruitment and retention of staff and that this was having a real impact on what could currently be delivered now and potentially in the future. Parents informed us that this also impacted on them and their child in being able to form meaningful and consistent relationships with key staff.
- **Focus/improve resources** – everyone questioned how changes/improvements could be made when it was considered there is a shortfall in resources.
- **Understand the impact of the Covid 19 pandemic** – all felt there was an impact that needed to be recognised/addressed – particularly around waiting list for assessments and delayed access to services.
- **Better information and analysis to inform commissioners and track improvements** - develop an understanding about need, what is meant by ‘good’ and ‘quality’ and clarity around baseline positions.

5 ‘Why are we doing this’ – feedback comments and recommended changes

5.1 Feedback

- Generally little comment was made about the rationale.
- Some wording changes were suggested.

- Several specific suggestions were made to strengthen the rationale. These included emphasising the need for change given the financial pressures, making specific any gaps in service together with a need to reference working with parents and carers and streamlining processes.

5.2 Recommendation

The statements detailing the rationale should be amended to reflect wording changes and a stronger emphasis in some areas. These are described below

Why are we doing this?

- We are ambitious and want to do better. Our special schools and mainstream settings are doing well but we can do more to make our services more inclusive.
- We want to keep pace with demand and practice innovations improvements. There are increasing numbers of children and young people with more complex needs requiring EHC plans. We need to think how we can practically and creatively meet these needs.
- We want to make sure that we have the best possible arrangements in place to make the right plans with our children and young people. Partnership working with key agencies can be challenging but we must work together
- We want to work more collaboratively with children, young people, and their families and improve their experience of the SEND system so it is clearer, equitable and more responsive.
- We know that we are living in financially challenging times so we must make the best use of our resources to make a difference. Costs are increasing and we want more local quality provision.

6 Vision

6.1 Feedback

Comments were limited but a number were made about strengthening reference to inclusion, prevention and wellbeing. Transfers to each of stage of education were described by many of the parents consulted as a key stress for them in finding the right place and ensuring that the next placement understands and can meet their child's needs.

6.2 Recommendation

The vision should be amended with amendments/additions noted as before.

Our vision is to improve life chances for our residents.

For our children with SEND this means we want to:

- Improve and further develop our continuum of provision for all children and young people of all ages.

- Have a stronger commitment to early intervention, prevention, assessment, planning and support through working with partner agencies and the voluntary and community sector.
- Make sure that our early years' settings, mainstream and special schools, as well as post- 16 settings, are more effective and inclusive in ensuring children and young people with SEND make good progress in their learning, personal and social development.
- Enable all our children and young people to transfer successfully to the next stage of their education, the world of employment, to live independently wherever possible or for those with the most complex needs to have quality experiences that enhance their everyday life.
- Reduce the disproportionality of children and young people from BME background assessed as needing and receiving SEND support.

N.B It also may be appropriate to reference the Council Vision which is to:

- treat residents as if they were a valued member of our own family
- be open, honest and accountable
- work for everyone to realise their own potential
- spend money as if it were from our own pocket
- make Southwark a place to be proud of
- always work to make Southwark more equal and just
- stand against all forms of discrimination and racism

7 Priorities – comments and recommended changes

Overall, the five priorities generated considerable debate. There was a consensus that these were important, but a range of constructive comments and suggestions were made to improve their focus and impact.

7.1 Priority 1 – Engagement, co-production and wellbeing

7.1.1 Feedback

- The overwhelming view was that this priority was more a statement of values/principles and a desired approach rather than a specific priority.
- It should include reference to the importance of effective communication between all but particularly with families so they can navigate the system and supporting them at different stages of their child/young person's journey from 'diagnosis' to adulthood.
- Important to be creative in our approaches and reaching out to families who find it hard to engage – going the 'extra mile'.
- One frequent issue raised was the importance of being more explicit about the issues of discrimination.

7.1.2 What parent/carers told us

- Communication is key – the importance of keeping parents informed, even of small changes.
- The importance for parents to be involved and contribute equally, to be listened to, recognising the experience the parent has and acting on their concerns.
- Parents to be given respect and encouragement to support their child and recognition that they are an active person in the child's life.
- The importance of parents and professionals working together to make things happen and understand what can make a difference for the child.
- Decisions about placements being made very late and parents not clear what is happening.
- Difficulties in accessing extra care support hours, activities and breaks for child during school holidays, particularly for complex need or personal care, and the importance of these for family life.

7.1.3 Recommendation

It is suggested that this is not described as a priority but retitled to reflect a statement of intent involving values/ principles which thread through all the priorities. This is described and amended below.

Our statement of intent

We want to better engage and work together with every child/ young person with SEND and all other agencies involved in supporting them to ensure that the wellbeing of the child or young person is central to the way that we work together.

We will:

- Make sure that children and young people with SEND and their families are included in all decisions about their support.
- Provide high quality, accessible, information, advice and guidance in a range of formats to support children, young people and their families at key transition points.
- Develop new and flexible ways of engaging children, young people and their families and carers in the co-production and commissioning of services.
- Create bespoke pathways as young people develop towards adulthood that recognises that they need support to make their own choice.
- Improve awareness with parents and partners to understand and take into account when assessing and supporting children/young people and their families the impact of Adverse Childhood Experiences (ACEs); including the impact of racial discrimination on peoples everyday lives and mental health issues.
- Enhance and improve family wellbeing by improving the short breaks and extra curricular activities/holiday activities offer for children and young people with SEND and the use of and access to personal budgets for all.

7.2 Priority 2 – Services for children and young people with autistic spectrum disorder (ASD)

7.2.1 Feedback

- There was a considerable debate and a consensus amongst professionals and parent/carers that this priority was too narrow and that should consider broadening this priority to reflect complex/multiple needs (including neuro developmental conditions).
- Agreement that ASD need addressing but views from some experienced internal and external stakeholders as well as parent/carers that it is an undue focus on ASD to the detriment of other conditions. A diagnosis of ASD was sometimes seen by parents and staff as a passport to services.
- Consensus was that this priority should reflect complex/multiple needs – specific reference as made to neuro developmental conditions, speech and language disorder and dyslexia. Strong view that ASD needs important but taking a social model approach presenting and other needs may be having a greater impact on a child/young person development and life chances.
- Strong view that should not use the word disorder as it has negative implications and that should consider using the term Autistic Spectrum Condition (ASC) rather than ASD, as latter is dependent on diagnosis and many children with needs have long wait for the diagnosis.
- Need to reference those young people known to youth justice system where those with SEND needs are over-represented.

7.2.2 What parent/carers told us

- ASD is important but definite need to understand/support other conditions which child may have in addition, and which have considerable impact on daily living and support needs for child at school and in the family home.
- Too much focus on ASD will take away from provision and awareness for other conditions and these needs may get unnoticed.
- Teachers (in special and mainstream) having more training around the range of complex needs as often children have more than one condition.
- Experience of having difficulty getting early diagnosis and support for girls with autistic traits as presents differently.
- Need to be alert to discrimination in both special and mainstream schools about identifying as autistic/disabled.

7.2.3 Recommendation

Given the overwhelming view from stakeholders and parents that this should have a broader application it is recommended that this priority is retitled to reflect this together with the amendments/additions indicated.

(N.B Consideration may however be to be given on to the exact terminology i.e complex/multiple/neuro-developmental needs – below reference is made to complex/multiple needs including those with ASC).

We want to improve provision and support across the age range for children and young people who have complex/multiple needs; including those with ASD/ ASC (Autistic Spectrum Disorder/Condition)

We will:

- Continue to develop a wide range of services closer to home and community.
- Improve early years provision and transition to specialist primary school provision to reduce exclusions.
- Continue to increase capacity in our special primary and special schools for our children and young people with the most complex/multiple needs.
- Work with all new/ expanding schools and providers to ensure friendly and appropriate learning opportunities for those with complex/multiple needs (including ASC).
- Increase the provision in our mainstream secondary schools for young people with complex/multiple needs (including ASC).
- Work more closely with young people and their families to match provision to their needs and aspirations.
- Provide parents with more choice and create new/strengthen existing, high quality educational pathways for complex/multiple needs. (moved from priority 3).
- Continue to return proactively to their communities those children and young people in out of borough provision.
- Support the needs of those young people complex/with multiple needs (including ASC) who are in or at risk of entering the youth justice system to improve their chances of living in the community and reducing their offending behaviour.

7.3 Priority 3 – Early identification of children with SEND

7.3.1 Feedback

- Big debate from internal and external stakeholders and consensus that early identification doesn't mean early years which was the presumption in the actions for this priority.
- This priority should apply across all life stages i.e. possibly to include pre/post-natal support, then babies/young children prior to going to early years education/settings and then those involved in youth justice or early identification of needs arising at later stages, e.g. examples of year 12,13, 14 arriving who have not had needs identified, no EHCP and needing assessment.
- Parents spoke eloquently of their anxiety of having to navigate a complex system at a time when they were having to come to terms with their child's special needs or diagnosis.

7.3.2 What parents/carers told us

- Parents need time to come to terms with a diagnosis and to begin to navigate the system and deal with professionals, possibly particularly for parents less familiar/confident with the education and care system.
- Parents are not aware where to go to get help and support, need to spread the word and give more information.

- Parents experiencing hurdles or difficulties getting their child referred for assessment, and then not sure what happens after an assessment.
- Need to recognise the needs of the quieter child who isn't demanding but who needs support and make sure they don't go unnoticed.
- Teachers (in special and mainstream) having more training around the range of complex needs.
- Some conditions only become evident at later ages hence need to make sure these children are supported and don't fall through the net.

7.3.3 Recommendation

This priority should be on timely identification of need with early years being referenced in an amended Priority 4.

We want to provide more timely high-quality provision for young children and young people with complex /multiple needs and their families throughout their life journey.

We will:

- Work towards strengthening/ensuring greater consistency in the current identification and assessment approaches going forward, particularly for children and young people with complex /multiple needs (including ASD/ ASC).
- Work to improve the system to ensure parents/carers have better accessible, accurate and up to date information about services and processes regarding SEND as soon as issues are identified.
- Improve early intervention and the support for parents with/expected babies or have very young children where there appears to be higher chances of them having SEND.
- Improve take up of a pre-school place for all children with SEND to enable them and maximise the take up of the free early education offer.
- Support the development of professionals across the sector to equip them with the skills they need to meet a range of complex/multiple needs.
- Review current funding mechanisms to ensure funding reflects the high level of SEND in Southwark's nurseries and enables early intensive intervention.
- Develop a more proactive approach to identifying those children/young people who fall through the net – including those young people in the youth justice system.

7.4 Priority 4 – Working with mainstream schools

7.4.1 Feedback

- Consensus view that this should refer to all settings and to include all early years settings (childminders seen as important but not usually involved).
- Need to define inclusion, for instance to also include racial literacy.
- Recognition that some schools doing well but others hampered by the physical environment but key issue is the culture of the school and the approach of the senior team in schools.

- Be more explicit about training – child development, neurodevelopment, what's atypical behaviour, language/speech conditions, racial literacy etc. Also working/effectively communicating with parents or more challenging families.
- Important to remember those children receiving SEND support, but who do not have an EHCP plan.

7.4.2 What parent/carers told us

- The feeling that getting an EHCP was a fight and process not clear, could it be more straightforward.
- EHCPs very long and difficult to get the right things on it.
- EHCPs very education and academic focused, other important aspects of child life e.g. health less obvious.
- Some parents described good multi agency input into plans in particularly in primary school and nursery but generally little experience of the process and plan being multi agency or joined up.
- Be aware of stigma of being on a plan, child aware they are on a different pathway than.
- More space in schools for subjects that are not subject to assessment and are more creative/ therapeutic or vocational.
- Training of all staff working in the school who have contact with children.

7.4.3 Recommendation

It is suggested that this priority be retitled to reflect all settings and references early years.

Working in all settings

We want to develop greater confidence skills and competencies in all settings from early years to leaving school so that we can consistently meet the needs of children and young people with SEND

We will:

- Increase the levels of support and training through outreach services, advice and consultancy services, and sharing of best practice for all settings with a focus on improving understanding of expected behaviours at different stages of child development.
- Ensure that we take a broad approach to early years and for example involve childminders and other providers
- Positively engage with mainstream settings on what it means to be fully **inclusive** so that we celebrate best practice and sharing existing expertise.
- Look at ways to improve staff recruitment and retention and for example will develop enhanced initial and teacher training and ongoing face-to-face and e-learning CPD offer for teachers, SENDCOs, heads, and governors on SEND and to include all front line staff who work with children and young people.

- Support staff in all settings to facilitate better communication between parents and schools to get best plans.
- Monitor the makeup of those children/young people who are being excluded or have attendance issues to ensure there is no disproportionate representation for example from those from BME backgrounds or who have specific conditions.
- Develop flexible training and opportunities so that staff in settings are able to access learning e.g twilight training and more experienced schools with SEND helping other schools.

7.5 Priority 5 – Pathways to adulthood for young people 16-25 with SEND

7.5.1 Feedback

- There was overall less comment on this priority possibly due to the range of stakeholders involved and it was possible to give confident information on the development of pathways.
- There were some views that it is important to reference physical health more/healthy lifestyles and wider life choices, e.g. access to leisure/hobbies, particularly in recognition of those YP with very complex needs.
- Considered important to reference those in the Youth Justice system.

7.5.2 What parent/carers told us

- More available information on future opportunities and processes as aware child is on different pathway.
- Decisions about placements being made very late, parents not clear what is happening at a time when they need certainty about the next stage.
- Unclear what happens, processes or where to go for support when young person is approaching 25, seems to be less focus as they get older and no longer a child.

7.5.3 Recommendation

The title should remain the same with some amendments and additions to the actions.

We want to develop pathways for young people with SEND moving into adulthood that enable them to lead more independent and fulfilling lives.

We will:

- Develop clear multi-agency pathways for young people with SEND including those in the youth justice system and for those with complex multiple needs. This will give them meaningful opportunities including into education, vocational or work settings.
- Develop more options for quality post-19 provision by working with secondary mainstream and special schools and local providers.
- Reduce the number of young people who remain in education without clear outcomes for independence.
- Better realise the range of available opportunities (e.g. supported internships, apprenticeships, and training).

- Increase the number of young people with SEND who are successfully supported into meaningful work and/ or independent living and realising their full potential.

8 Challenges

All involved in the consultation raised challenges; many of which reflect real/perceived service shortfalls and concerns about 'how' change can happen. These are listed below and highlight both the extent and depth of the challenges ahead and the need to explore these and address them in delivery plans.

- The 'how' this is to be achieved is complex and is difficult to measure and will need considerable effort and an understanding of the evidence base for developments.
- A range of service pressures/gaps were cited e.g. CAMHs (long waits), lack of specialist autism input for secondary schools (focus considered more on early years and primary) and no SENCO for early year settings.
- Need to think how this links with the broader preventative approach with children in need (early intervention initiatives, early years health supports etc) and other specific groups e.g. those in the youth justice system (especially as they leave the youth justice system at 18).
- Need to be much clear what would be useful information and how effectively it reaches all families.
- Commitment for EHCPs is variable and needs addressing with a tendency for them to be unduly education focussed, this was cited by most parents consulted.
- Funding not following the child - issue of child having funding in early years settings and then gap as funding not transferred when goes to school, could the funding process be better streamlined?
- Lost initiatives – there appear to be a number of specific initiatives (e.g. early years/health at point of 'diagnosis') that are no longer activated.
- Some concerns about how academies can be proactively involved in developing services and responding to those with SEND.
- A 'can do' culture in schools is seen as important but not always evident.
- Equity of SEND pupils in primary schools – seems disproportionate as only 4 dedicated SEND resource centres attached to schools (also facing funding threat) and 15 primary schools have all the SEND children - is that equitable? What happens to others when they have reached their 'quota'.
- Processes are seen by all as cumbersome with unclear roles/responsibilities. Schools particularly consider that too often they are left trying to resolve the situation for the child/young person/family but can feel 'out of the loop' and unsupported.

9 How will we know we are making a difference?

- We will publish how feedback from the local area is influencing services on our local offer.
- Our strategy will develop and be informed by the voice of those who use the system.
- Children and young people with complex and multiple needs (including ASC) will have access to services that meet their needs locally.

- Educational settings and staff can demonstrate they have a good understanding of a range of complex needs and how they can be met.
- There is a consistent approach to identifying and assessing the needs of all of our children and **young people** with SEND.
- The right funding mechanisms are in place and support exists to provide the highest quality provision for children with SEND aged 0-5 years.
- An increase in capacity of mainstream schools to support a wider range of SEND.
- An increase in the proportion of children with newly issued EHC plans placed and **retained** in mainstream schools.
- An increase in sustainability of mainstream placements for children and young people from BME backgrounds.
- A decrease in the number of children and young people from BME backgrounds who are excluded/suspended from mainstream schools.
- An increase in parent confidence that their children's needs can be met locally, within a mainstream school.
- We will have a more financially sustainable service with fewer young people needing educating out of area.
- Young people and their parent/carers have a greater and informed understanding of the pathways and options available to them.
- Evidence that there is an increase in the number of young people taking up a broader range of opportunities for meaningful learning, vocational, employment **or other activities that enhance their wellbeing**.
- Young adults are expressing higher levels of satisfaction and confidence in undertaking life choices.

10 Conclusion

This consultation feedback report has captured and summarised views and comments from a range of stakeholders. These have led to recommendations for changes to the consultation strategy which it is anticipated could form the basis of the final SEND strategy.

It is always difficult to determine what constitutes a good response to a consultation process. Although numbers overall are not high, particularly from parent/carers and young people, nevertheless there can be confidence that there was appropriate considered input from all those individual professionals and organisation involved in the SEND process. There is an undoubted commitment with partners to improve Southwark's approach and delivery of SEND services. Although it is disappointing that it was not possible, due to time and organisational constraints, to get a strong sense of the range of children/young people's views, some are included, and it is reassuring that parents/carers in particular and many professionals had a good insight into their needs and aspirations.

Inevitably consultation on a strategy raised questions of how it can be implemented. It is hoped that the general themes, challenges and considerations about how it will know things are improving that have been highlighted will assist in developing realistic implementation plans that will a difference over the next 3 years.

Appendix 1

Valuing the parent/carer views – feedback summary

1 Comments on themes

Engagement and working together with parent/carers

- Encouragement and respect to enable parents to support their child – ‘not sympathy.’ ‘taken by the hand to start, and then enabling by giving resources for parents to do things themselves’.
- Parents need time to come to terms with a diagnosis and to begin to navigate the system deal with professionals and possibly particularly for parents less familiar/confident with the education and care system.
- Listen to parents - ‘It can feel like parents are a burden, we want too much, as though you are not an active participant in your child’s life’.
- Professionals see ‘the tip of the iceberg but parents have to manage the whole underneath and everything else’.

Services for children with ASD and other developmental conditions

- ASD is important but absolute need to understand/support other conditions e.g PICA which child may have in addition and which have considerable impact on daily living and support needs for child at school and in the family home.
- Need to make sure all a child’s needs are recognised and supported, not focusing on just one condition.
- Experience of having difficulty getting early diagnosis and support for girls with autistic traits as presents differently.

Early identification and early support

- Really important – GPs need to be more alert. “I had to find my own way”.
- Parents are not aware where to go, need to spread the word and give more information.
- Feeling parents have to sort everything.
- Need to recognise the needs of the quieter child who isn’t demanding, doesn’t mean they don’t need help, make sure doesn’t go unnoticed. ‘If its not visible, its not recognised’.
- Never felt taken seriously with concerns, pushed aside, not listened to as a parent, or recognising the experience the parent has.

SEND support and inclusion in mainstream settings

- Need to be alert to discrimination in both special and mainstream schools about identifying as autistic/disabled.
- Be aware of stigma, feeling they have failed, are different, their pathway will be different but child aware of this and the usual pathway.
- EHCPs – long, can it be made more straightforward? Education and academic focused, other important aspects of child life e.g. health less obvious, little experience of being multi agency or joined up, but does give opportunity to have conversation about child.

- 'Getting the plan was a fight and the right things on it and not regularly reviewed'.

Pathways to adulthood for young people 16-25 with SEND

- Information on future opportunities and processes.
- 'Pathway not clear and not much happened after year 9 review and adult services present'.
- 'I'm worried about the future, I know he will probably be ok, but he is on a different pathway than others'.
- Decisions about placements being made very late, parents not clear what happening, communication confused, 'we need certainty about next stage'.
- Unclear what happens, processes or where to go for support when approaching 25, seems to be less focus as they get older, no longer a child.

2 Comments on family experience

What has worked well in terms of looking for information, advice and support for your child/young person and working with agencies?

- Good support/sign posting from advisor at Sunshine House.
- School fantastic during lock down (daily calls etc) and then responsive to pulling things together post covid when backlogs in services etc Also positive about way school managing continuity as child moved classes and experience of school providing a transitional person from primary to secondary school to support transition.
- Key worker/link for EHCP.
- Get a massive amount of support from each other as parents, don't feel isolated, not alone, have experience in common. Those of us who have lived it, support others.
- Early years support positive.
- Some described good multi agency input into plans in primary school and nursery.
- 'it was a huge relief to be finally listened to and for the simple steps to be taken by the school to support my son but it took a lot of determination'.

What has been more challenging?

- Finding right primary school for my child (child identified as having complex needs at 2 and a half) – 'worst year of my life' – 'its scary ' complex processes, lots of reports and getting information about schools and visiting them to get a real sense of whether could cope with range of complex needs.
- Feeling of being left to get on with it, parents have to force the pace, always trying to solve issues, where is the support for parents to maintain energy?
- Hurdle of getting an assessment, and then not sure what happens.
- Waiting for CAMHS service – 2 years +.
- More difficult during Covid, we couldn't get the supports we were having, appointments cancelled and now a backlog.
- Difficult at first getting the EHCP and getting everybody involved, "felt like a crazy person trying to find out as much as possible".

- Really anxious about transition (child now 10 with complex and challenging behaviours) – fewer special schools – will they understand and respond to my child's needs (confidence and reality?) 'Right choice right school'.
- Wanting to get a sense of what lies ahead as my child grows up.
- Fought for diagnosis and felt when had diagnosis would get support, but this is not the case. Issues of getting clarity and agreement about the diagnosis, you prepare child that things may be different, but then if don't get clear diagnosis where do you go.
- Transitions – they keep you hanging, you can't plan or build up your young person's hopes about a placement.
- Making children's services accessible for disabled parents.
- Less involvement as a parent in secondary school, can assume things are happening and plans being worked too, but sometimes it isn't.

What qualities/good practice should any approach around inclusive support with families be promoting?

- Communication - positive experience of primary special school, kept parent informed of everything, even small changes - 'Parents and teachers working together to make things happen'.
- Enabling – supporting not sympathising (not being criticised/blamed).
- Teachers (in special and mainstream) having more training around the range of complex needs as often children have more than one condition.
- Having a single person/point to go to if need support for child/young person and also where to get support for oneself.
- A relational approach – we know your world.
- Recognition of all that is going on in the family life and all the different appointments that the family needs to go to, hence not discharging if family fail to keep an appointment.

What else is important to improving a family's experience?

- Little things can go a long way - better awareness that simple solutions can make a huge difference e.g extra care support hours for child during schools holidays has a disproportionate positive impact on giving parents the time to catch up on tasks in the home. "They don't understand how much these hours mean to me, it is lifesaving".
- Support for parents and having access to others who have similar experiences early on in the process.
- Central Information Hub specifically relating to SEND- not being passed from pillar to post.
- Process put in place for timely diagnosis of girls with autistic traits.
- Not to multiply the challenges the child already has.
- Equal access to clubs, short breaks holiday activities and the use of and access to personal budgets across the 0-25 age groups.

Appendix 2

What do children and young people think?

What do you enjoy the most about being at school?

- Several young people said they enjoyed being with friends.
- Others also said they enjoyed physical activities like going into the gym, PE and football and Lunch times.
- Others described particular subjects they enjoyed like ICT, art and maths.
- Work and learning.

What are the things you don't enjoy as much or find hard?

- Work or being in class – 'sometimes I can't be bothered to do work'.
- Some said particular subjects they didn't enjoy or found hard, such as English, art.
- Several of the young people described difficulties with people around them or with their peers - 'When people keep going on and on', 'people keep looking at me'.

What helps you to feel supported at school and learn well?

- Several young people said they weren't sure what helps.
- Being in a quiet room.
- Teachers and LSAs.
- Learning things.
- Football as it calms me down.
- Walks around the park.

What do you enjoy doing outside of school?

- Chill at home.
- Football, boxing.
- Playing outside, meeting up with my friends.
- Playing X-box and video computer games.
- Music.

How do you get to know about these things you can do?

- Not sure.
- On line, or other media such as television.
- Several young people said they found out from talking with friends - my friends call/text me.
- I learn about them.
- My dad.

What kinds of supports are most important to help you as you grow older and become an adult?

- Not sure.
- Myself.

- My mum and my family and cat.
- Football.
- 'keep out of trouble'.
- Not sure what is ahead, some stress at becoming independent, but also looking forward to getting a job and getting money.

Appendix 3

Proposed framework for revised Southwark Council SEND Strategy 2022-25

Our vision is to improve life chances for our residents.

For our children and young people with SEND this means we want to:

- Improve and further develop our continuum of provision for all children and young people of all ages.
- Have a stronger commitment to early intervention, prevention, assessment, planning and support through working with partner agencies and the voluntary and community sector.
- Make sure that our early years' settings, mainstream and special schools, as well as post- 16 settings, are more effective and inclusive in ensuring children and young people with SEND make good progress in their learning, personal and social development.
- Enable all our children and young people to transfer successfully to the next stage of their education, the world of employment, to live as independently wherever possible or for those with the most complex needs have quality experiences that enhance their everyday life.
- Reduce the disproportionality of children and young people from BME background assessed as needing and receiving SEND support.

Our statement of intent

We want to better engage and work together with every child/young people with SEND and all other agencies involved in supporting them to ensure that the wellbeing of the child or young person is central to the way that we work together.

We will:

- Make sure that children and young people with SEND and their families are included in all decisions about their support.
- Provide high quality, accessible, information, advice and guidance in a range of formats to support children, young people and their families at key transition points.
- Develop new and flexible ways of engaging children, young people and their families and carers in the co-production and commissioning of services.
- Create bespoke pathways as young people develop towards adulthood that recognises that they need support to make their own choice.
- Improve awareness with parents and partners to understand and take into account when assessing and supporting children/young people and their families the impact of Adverse Childhood Experiences (ACEs); including the impact of racial discrimination on peoples everyday lives and mental health issues.

- Enhance and improve family wellbeing by improving the short breaks and extra-curricular activities/holiday activities offer for children and young people with SEND and the use of and access to personal budgets for all.

Priority 1. We want to improve provision and support across the age range for children and young people who have complex/multiple needs; including those with ASC (Autistic Spectrum Condition)

We will:

- Continue to develop a wide range of services closer to home and community.
- Improve early years provision and transition to specialist primary school provision to reduce exclusions.
- Continue to increase capacity in our special primary and special schools for our children and young people with the most complex/ multiple needs.
- Work with all new/ expanding schools and providers to ensure friendly and appropriate learning opportunities for those with complex/multiple needs (including ASC).
- Increase the provision in our mainstream secondary schools for young people with complex/multiple needs (including ASC).
- Work more closely with young people and their families to match provision to their needs and aspirations.
- Provide parents with more choice and create new/strengthen existing, high quality educational pathways for complex/ multiple needs. (moved from priority 3).
- Continue to return proactively to their communities those children and young people in out of borough provision.
- Support the needs of those young people complex/with multiple needs (including ASC) who are in or at risk of entering the youth justice system to improve their chances of living in the community and reducing their offending behaviour.

Priority 2. We want to provide timelier high-quality provision for young children and young people with complex/multiple needs and their families throughout their life journey.

We will:

- Work towards strengthening/ensuring greater consistency in the current identification and assessment approaches going forward, particularly for children and young people with complex /multiple needs (including ASC).
- Work to improve the system to ensure parents/carers have better accessible, accurate and up to date information about services and processes regarding SEND as soon as issues are identified.
- Improve early intervention and the support for parents with/expected babies or have very young children where there appears to be higher chances of them having SEND.
- Improve take up of a pre-school place for all children with SEND to enable them and maximise the take up of the free early education offer.

- Support the development of professionals across the sector to equip them with the skills they need to meet a range of complex/multiple needs
- Review current funding mechanisms to ensure funding reflects the high level of SEND in Southwark's nurseries and enables early intensive intervention.
- Develop a more proactive approach to identifying those children/young people who fallen through the net – including those young people in the youth justice system.

Priority 3. Working in all settings

We want to develop greater confidence skills and competencies in all settings from early years to leaving school to so that we can consistently meet the needs of children and young people with SEND

We will:

- Increase the levels of support and training through outreach services, advice and consultancy services, and sharing of best practice for all settings with a focus on improving understanding of expected behaviours at different stages of child development.
- Ensure that we take a broad approach to early years and for example involve childminders and other providers
- Positively engage with mainstream settings on what it means to be fully inclusive so that we celebrate best practice and sharing existing expertise.
- Look at ways to improve staff recruitment and retention and for examples will develop enhanced initial and teacher training and ongoing face-to-face and e-learning CPD offer for teachers, SENDCOs, heads, and governors on SEND and to include all front-line staff who work with children and young people.
- Support staff in all settings to facilitate better communication between parents and schools to get best plans.
- Monitor the make-up of those children/young people who are being excluded or have attendance issues to ensure there is no disproportionate representation for example from those from BME backgrounds or who have specific conditions.
- Develop flexible training and opportunities so that staff in settings are able to access learning e.g. twilight training and more experienced schools with SEND helping other schools.

Priority 4. We want to develop pathways for young people with SEND moving into adulthood that enable them to lead more independent and fulfilling lives.

We will:

- Develop clear multi-agency pathways for young people with SEND including those in the youth justice system and for those with complex multiple needs. This will give them meaningful opportunities including into education, vocational or work settings.
- Develop more options for quality post-19 provision by working with secondary mainstream and special schools and local providers.
- Reduce the number of young people who remain in education without clear outcomes for independence.

- Better realise the range of available opportunities (e.g. supported internships, apprenticeships, and training).
- Increase the number of young people with SEND who are successfully supported into meaningful work and/or independent living and realising their full potential.

How will we know we are making a difference?

(N.B. these have been revised from the consultation document and the document to assist identify areas which are more likely to be evidenced)

- An increase in capacity of mainstream schools to support a wider range of SEND.
- An increase in the proportion of children with newly issued EHC plans placed and retained in mainstream settings.
- An increase in sustainability of mainstream placements for children and young people from BME backgrounds.
- A decrease in the number of children and young people from BME backgrounds who are excluded/suspended from mainstream schools.
- An increase in parent confidence that their children's needs can be met locally, within a mainstream setting.
- A reduction in young people with complex/multiple needs being educated out of area and that more are having their needs appropriately met in the community.
- Young people and their parent/carers have a greater and informed understanding of the pathways and options available to them.
- Evidence that there is an increase in the number of young people taking up a broader range of opportunities for meaningful learning, vocational, employment or other activities that enhance their wellbeing.
- Young adults are expressing higher levels of satisfaction and confidence in undertaking life choices.