

London Region, National Network of Parent Carer Forums SEND Reform Consultation Written Response, May 2026

Feedback from parent carers and PCFs across London

The following response is based on regional engagement including:

- 8 SEND Reform Online Workshops with feedback from more than 200 parent carers
- 4 Community of Practice sessions with London Parent Carer Forums
- London Region SEND Reform Survey
- Feedback from PCFs from engagement activity within their Local Area
- Whole system engagement via LIA and London Councils and Local Area SEND Reform Planning

The Universal Offer

Training: Parent carers welcome plans to ensure that all school staff receive training in SEND and inclusion. They are concerned about the quality and content of the training, how it's effectiveness will be measured and if and how it will be refreshed.

Inclusion Bases: Many children and young people need a quiet, safe physical space in school in which to regulate if overwhelmed and access individual or small group interventions that support their wellbeing and learning. Parent carers generally felt that Inclusion Bases could improve the mainstream offer for some children and young people with SEND while also expressing the following concerns:

- Increased inequity in the mainstream offer (what if my child's school or college doesn't have an inclusion Base?)
- Risk that inclusion Bases could become 'exclusion' spaces that segregate 'challenging' children and young people.
- How appropriate staffing in Bases will be achieved given schools' already stretched finances and no extra funding to support this?
- How will schools ensure full access to quality first teaching across the curriculum within these bases, especially in secondary?

"The idea of inclusion in mainstream is admirable. And the potential for early support instead of relying on official diagnosis."

The Targeted Offer

Individual Support Plans: Most of the parent carers that we consulted with were unaware that children and young people that need support in addition to the Ordinarily Available Offer should already have a plan as part of Assess, Plan, Do, Review. The obligation for education settings to document and review the needs and provision for those on the SEN Support Register already exists in statutory guidance (SEND Code of Practice 2015). That most parent carers did not know about this is an indicator that this does not consistently happen in practice and/or plans are not being co-produced with parent carers.

While parent carers welcome the change from statutory guidance to legal duty as a move in the right direction, they do not feel confident that this will automatically translate to access to support for their child or young person. A legal duty to create an ISP when a child is identified as having SEND will not in as of itself guarantee early, accurate identification of needs or that the ISP will be well written and the provision in it will actually be delivered. Parent carers also have concerns about the potential conflict of interest for education settings. When identifying and acknowledging a need automatically confers a legal and financial obligation there is an inherent disincentive for cash strapped schools and overworked teachers to be curious and proactive about children's needs. The lack of external oversight, accountability and quality control around ISPs was one of the most frequently repeated concerns that we heard from parent carers in relation to the proposed SEND Reforms.

"Still a lack of tangible accountability."

The Targeted Plus Offer

Experts at Hand: Parent carers in London generally agree with the principal that faster, easier access to specialists and expertise would improve outcomes for children and young people with SEND. Parent carers are however concerned that there are not sufficient qualified or experienced practitioners available to deliver this service in reality. There is also concern, despite the ambition, that need will outstrip available resource and there will continue to be rationing and gatekeeping of services and preventable escalation of children's and young people's needs.

"Won't local areas be competing to recruit from the same limited workforce?"

While there has been excellent practice in some local areas, generally parent carers and Parent Carer Forums feel that their expertise in SEND is being overlooked and undervalued in the planning of the Experts at Hand offer. We asked parent carers if they wanted to be delivery partners in the Experts at Hand offer and most do, although some acknowledge that they would not have capacity to do this in addition to their caring responsibilities. For those that are willing and able to contribute, 85% think that parent carers should be involved in

developing and delivering training to schools, families and practitioners in training. Some parent carers would value being supported to train as a practitioner themselves and stressed the importance of lived experience in workforce development and design. We asked parent carers what support they would need in order to be involved. Childcare/care support, training and being paid for their time were consistently referenced. Parent carers would also need the option to work flexibly and remotely and to feel that they were equal and respected members of the experts at hand community.

“Training and being paid. I would love to be involved.”

“Parents need to be properly compensated for their time and not taken advantage of.”

The Specialist Offer

EHCPs: There was initially relief that EHCPs were being retained (following media speculation that they might not be), however parent carers feel that the proposed changes so fundamentally undermine the purpose and principal of Plans that they are EHCPs in name only. Most parent carers that we consulted with felt that the individualised provision that they highly valued would not be possible under the revised model and had grave concerns about lack of expertise and conflict of interest if responsibility for co-developing and delivering the provision specified in an EHCP (or ISP) were to sit with education settings.

We welcome the proposed ‘fast track’ EHCP assessments for children in the Early Years. We would recommend that this option is available at all ages and stages, especially where; there is a risk of placement breakdown, a child or young person is in mental health crisis or a disability is acquired due to injury or illness.

Reviewing an EHCP: Proposed changes from annual reviews to phase transfer reviews for most age groups underestimate the importance of the statutory annual review process in convening services and practitioners around the child, young person and family and ensuring co-ordinated, holistic care. There was also concern about the timing of EHCP reviews/eligibility reassessments and how this might undermine effective support for transitions (moving to secondary school and post 16 destinations in particular).

Annual reviews too often are purely bureaucratic processes that are not child/young person centred. The SEND Code of Practice could be improved and clearer guidance provided around supporting children and young people to be active participants in their review and ensuring that review meetings are accessible and purposeful. Parent carers agree that more frequent reviews are necessary for EYFS and Post 16 cohorts.

Specialist Provision Packages: Many parent carers do not feel that the proposed Specialist Provision Package model reflects the reality of being or supporting a child or young person with complex needs. The model does not take account of how the intersection of needs, family context and environment for a child or young person influence the type of care and

support that is needed and the value of the personalisation enabled via the current EHCP framework. Either the scope of provision and funding would have to be so broad that SPPs would be in-effective as commissioning tools *or* provision would be expected to ‘fit’ the package and would not be a true reflection of an individual child or young person’s needs. Parent carers know through painful lived experience that unmet needs escalate, as do the challenges and costs of meeting those needs. The parent carers that we consulted with did not feel that Specialist Provision Packages would enable Local Areas to commission placements more effectively, ensure sufficiency and value for money or improve outcomes for children and young people with SEND.

SEN 2 Data: Improved child level data would be more effective in helping Local Areas to plan, commission and achieve better sufficiency and value for money with their SEND budgets. National, digitised EHCP and ISP templates would allow direct comparison of commissioning and provision for children and young people with similar needs locally, regionally and nationally. Our regional PCF network participated in workshops commissioned by LIIA considering how to improve regional commissioning of placements for children and young people with SEND. The principal barrier identified by all stakeholders was the inadequacy of primary needs data in accurately quantifying a child or young person’s needs and the type of provision likely to be required to meet them, both now and in the future.

Specialist Bases in Mainstream Schools: None of the parent carers that we consulted with were in favour of specialist placements within mainstream schools. Some parents were neutral about the proposals (parent carers with a child or young person with a moderate learning disability most commonly) however most did not agree that mainstream schools could offer a suitable and safe environment for most children with complex needs. Instead they wanted to see more specialist school placements in their local area and a meaningful offer other than a typical mainstream environment for children and young people with sensory processing differences, sensory impairment and mental health needs.

Development of National Inclusion Standards and Expert Advisory Team

Parent Carer Forums have consistently challenged the lack of a representative parent carer voice on the Expert Advisory Group. We asked parent carers to what extent parent carer representation would affect their confidence in the development of National Inclusion Standards and Specialist Provision Packages. On average parent carers reported a 90% increase in confidence in the resulting Standards and Packages if parent carer representatives were part of the expert advisory group that develops them.

“Parents/carers are essential to providing insight of the challenges their children face & the support required.”

“Making decisions about our needs and what support we will get without any parents involvement is ridiculous and will lead to decisions based on popularity and cost saving, not true needs.”

“‘Experts’ don’t live our lives and bring up our children on zero sleep. We do. How can you ask people who don’t experience what we do to make recommendations that effect every inch of OUR lives.”

SEND Code of Practice 2015 (SCOP) Areas of Need vs Areas of Development

There were mixed views about this with some parent carers feeling strongly that the current areas of need should not be changed, some parent carers feeling that the proposed areas of development were an improvement and some parent carers who were unsure. Almost all parent carers that we consulted with did not agree with Mental Health being omitted from areas of need/development and the importance of mental health support was one of the strongest recurring themes that we heard.

“Mental health underpins everything in life. If you have poor mental health, you aren’t capable of working on other development areas.”

In discussions with system partners we have found that there is confusion around why children and young people with the same headline diagnosis (e.g. ADHD) have needs and provision listed under different Areas of Need. For us this highlighted the need for better support and training, particularly for education partners to understand how the same condition or developmental difference can vary significantly in its presentation for individual children. The Areas of Needs exist to ensure that support is tailored to the individual child/young person and is needs led, not diagnosis driven. Any changes should be co-produced with children, young people and parent carers.

There was also concern around the potential loss of interaction in the broad areas of need/development. How a child interacts is key, is separate from how they communicate and can pose significant barriers to learning, social development and wellbeing.

Changes to legal rights and duties

None of the parent carers we consulted with were in favour of changes to legal rights for children and young people with SEND and most were emphatically opposed. This includes changes to tribunal powers, an amended threshold to access an EHCP needs assessment, the legal duty for Local Authorities to develop the content and ensure delivery of provision in an EHCP and the use of predetermined Specialist Provision Packages. Parent Carers and Forums are particularly concerned that proposed changes to tribunal powers (to name a placement in Section I of a child or young person’s EHCP) could lead to a ‘revolving door’ of appeals and lengthy delays to access support.

Increased duties for schools had some support, however do not go far enough and still allow schools to 'mark their own homework' in respect identification of needs and the resulting financial exposure and legal accountability in producing Individual Support Plans.

Accountability is key in any proposed changes to rights and duties. It is unrealistic to expect parent carers to put their trust in a new system until willingness and ability to hold to account under the current system have been demonstrated.

The lived experience of school life

The current reality is that mainstream schools are unsafe environments for too many children with SEND; emotionally unsafe and full of overwhelming sensory experiences. The principle of "Maslow before Bloom" needs to guide how our education system progresses towards genuine inclusivity.

The current workload of teachers and school staff does not realistically allow them the time they need to build relationships and effectively support all children with SEND. Parent carers are aware of the pressures that schools are under and this undermines their confidence in the ability of mainstream settings to meet their child's needs. There would need to be a substantial increase in revenue funding for schools and colleges to enable them to employ the staff they need (teaching assistants in particular) to make the ambition of these reforms a reality.

One parent carer community has suggested that the creation of a SEND family liaison role in all schools would help to support SENCOs and teachers to build partnerships with parents. There also needs to be a significant cultural shift towards viewing parents as valued partners. As a minimum, all school staff should receive dedicated training in working in partnership with parents and this training should be co-developed and co-delivered with parent carers.

Dispute resolution: There is considerable anxiety that resolving disputes about ISP/EHCP content and delivery of provision via a school complaints process will critically undermine partnership working between families and schools.

"Parent carers [in X London Borough] overwhelmingly felt that disputes cannot safely be resolved solely through school complaints procedures... There was significant lack of confidence that internal school systems alone could fairly resolve disputes, particularly where: schools are under financial pressure, staff lack SEND expertise, relationships have already broken down, children's needs are disputed and attendance pressures conflict with wellbeing needs."

It must also be noted that there are many schools who are doing a great job in supporting our children with SEND. This would suggest that accountability measures and cultures that need to change, rather than legislation and policy - if some can do it why not all?

Schools Community Trusts: Parent carers are cautiously optimistic about the opportunities for schools to work together to improve support for children with SEND in their locality through a Community Trust model. Multi-disciplinary 'clusters' including parent carer forum representation could be an effective model to hold schools and services to account, share resources and expertise and drive up standards. Most stakeholders have expressed concern about the difficulties of working in partnership with large Multi Academy Trusts and the role that central government and the DfE must play in holding MATs to account on partnership working and inclusion.

The Role of the School Governor: Many of the parent carers in our regional PCF network are active members of their communities and have previously held or currently hold roles as school governors. They felt that that expectations of governors to hold school leaders to account regarding quality of ISPs and provision for children with SEND were unrealistic.

The reality of implementing new legislation in strained systems

We must pause to consider the implications of introducing major legislative change to a system that is in crisis. The process of engaging with this consultation and preparing Local Area SEND reform plans has highlighted how ill equipped the SEND system is to implement major change, not because we lack commitment or skills, but because as a partnership (schools, parent carers, PCFs, LAs, Health commissioners and Providers) we are exhausted from years of trying to operate day to day in a system that isn't working. We know that our collective efforts are needed to drive the culture change that is necessary to ensure that children and young people with SEND can thrive. We must prioritise carefully how we deploy the time and energy of system partners. Parents carers want reforms to focus on:

- Genuinely inclusive mainstream education
- Needs identified and met early
- Faster, easier access to support and expertise
- Meaningful accountability when services fall short
- Being welcome, valued, equal co-production partners

The scale of the challenge and the cultural shift that is needed should not be underestimated and will require the best efforts of all system partners pulling in the same direction. All of these priorities are achievable without changes to legislation and the sequencing of change is important. Mainstream education setting must become genuinely inclusive environments and the baseline understanding of all staff must significantly improve before we can reasonably expect schools to take responsibility for supporting more complex needs e.g. developing the content of EHCPs or hosting specialist inclusion bases.

As a regional PCF network we have worked with hundreds of schools as part of the PINS, Autism and Schools and other local projects and understand the challenges and commitment needed to embed strategic partnership with parent carers in education settings. The timeline to achieve this has been underestimated in the reform proposals, five years is a more realistic expectation. Current plans would see a shift of legal duties before the mainstream sector have been able to fully develop and embed their inclusion strategies.

The learning from the implementation of the 2014 reforms is that major legislative change consumes vast resource in terms of funding, energy and focus -all of which are badly needed to support our children and young people right now. Many parent carers feel strongly that it is not the system that needs changing but the way in which it is implemented. There are concerns that, while the funding committed by central government is welcome that it may be inadequate to support transformation and should instead be deployed to support the current system to deliver improved outcomes for children and young people.

8 years after the Children and Families Act 2014 was passed case law precedent was still needed to clarify how the Act should be implemented ([R \(L, M, and P\) v Devon County Council](#)). It's our expectation that Local Authorities, Schools and other statutory bodies will again spend years testing the boundaries of new legislation and families will still have to bring legal challenge to establish case law precedent and hold those bodies to account.

"If they followed the law as it is now it would work. This is all about saving money"

Information, Advice and Support

We asked parent carers how they would prefer to access help to understand the new SEND system, to ensure that their child or young person was getting the right support or to resolve a dispute. Most parent carers (over 70%) preferred to access support via their local SENDIAS Service, second preference was a locally commissioned independent mediation service and third preference was the Local Authority. Some parent carers felt that the local offer website and Family Hubs could do a better job than they currently do of providing useful information about SEND. Some parent carers also indicated that their local PCF was a preferred place to access information and support.

Parental confidence and trust

Parental confidence and trust is low. The conflicting messages and lack of genuine consultation on some aspects of the proposed reforms have eroded them further. Some parent carers are hopeful about the ambition of the reforms, but most still doubt that they will materialise in reality or that education settings, health services and local authorities will be held to account to ensure they do.

"I think it's a done deal already. Our children are seen as a burden they don't want to pay for"

“I hope it does work, if done properly and time taken, involving all key partners and co-production with parents and carers. Depends if they take on board what is suggested, which they probably won't”

Working in Partnership with Families

Co-production: Co-production needs to become more than just a tick box exercise which too often involves performative processes and no meaningful influence on how services are designed and resources utilised. We need a standardised definition, clear expectations, realistic timelines, adequate resourcing and meaningful accountability to achieve genuine partnership with those most affected by how services are designed and delivered. Children, young people and their families and Parent Carer Forums must be respected and equal partners in both the planning of support for individual children/young people and strategic partners in decision making about local, regional and national systems that affect families with SEND. Updates to the SEND Code of Practice must include clearer expectations around strategic co-production and mandate that a parent carer's expertise in their own child (or a young person themselves) has equal weight in decision making with professional views.

“co-production must not rely on unpaid labour from exhausted families.”

Balance of Children / Young People's and Parent Carer Voices: It is important that the views of parent carers and children and young people are balanced and that services take account both of what is important **to** children and young people and what is important **for** them.

There needs to be more investment in supporting and enabling children and young people to share their views and experiences and accountability to ensure that this influences decision making. This offer needs to be available to **all** children and young people including; those without EHCPs, children and young people that do not typically communicate via speech, those with learning disabilities and children and young people that are not in school.

Parent carers Forums understand all too well the weight of responsibility that comes with being a representative voice and advocate for your community. This isn't a burden that children and young people should be expected to carry (although the opportunity to represent others should be available and supported if that is a child or young person's choice).

“Parent carers scream from the rooftops and nothing changes, when children and young people whisper, the system listens”

The role of Parent Carer Forums: Parent Carer Forums hold an important and sometimes uncomfortable role in the SEND system. We walk a very fine line of solution focussed challenge and representation without individual advocacy. We need to ensure that the PCF network continues to be and crucially is *perceived* to be the independent and representative voice that it is.

“We need to make sure that the Parent Carer Forum isn't limited on what they can say based on what the LA and Government want to hear though. It has to be honest, unfiltered and unbiased.”

In London we have a committed, passionate, diverse network of Forums and representatives. There is still more to do to ensure that the voices of all parent carers are heard in our region. In order to preserve and build on the diversity we enjoy in London we must avoid over-professionalising our PCF network. We must ensure that regional and national structures can support and enable individual Forums to flourish as representative voices of their local parent carer communities and valued strategic partners in their Local Areas and beyond.

The role of Best Start Family Hubs in SEND Reforms

Experiences of Best Start Family Hubs vary for parent carers and PCFs in London. While some areas have excellent practice and a maturing Family Hub offer developed in partnership with their Parent Carer Forum, some areas have not yet progressed significantly beyond the previous Children's Centre 0-5 years model. The funding envelope to support development of the Family Hub offer varies significantly across London and will impact scope and equity of access to SEND services between Local Areas.

Some parent carers are concerned that SEND support can become diluted within a universal Family Hub model and expressed a preference for a targeted, specialist SEND Specialist Hub in each area, ensuring dedicated expertise, clearer pathways, and more meaningful support. Families want a space that recognises their lived reality, where support is not an add-on but is purpose-built, visible, and consistently delivered and they can connect with families having similar experiences.

All parent carers must be supported in their journey to acknowledge, identify, accept and support their child or young person's condition or difference. A Family Hub model that relies *only* on dedicated services and facilities for families with SEND could miss opportunities to support CYP with emerging needs or families that experience greater barriers to accessing support (e.g. cultural stigma around SEND). There needs to be a mix of dedicated provision for families with SEND and support embedded in the universal Family Hub offer.

Independent/Non Maintained Special Schools

There is general agreement across system partners that the rampant profiteering of private equity companies in the INMSS sector must be stopped. The lived experience of parent carers is sometimes that an INMSS placement appears to have a strong offer, but does not always deliver the quality of education and support promised and LAs have limited ability to hold to account.

We also hear from parent carers and commissioners that some high cost placements do constitute good value for money, deliver excellent outcomes for children and young people and allow access to a unique or rare offer for children and young people with less commonly occurring needs and conditions. This is a nuanced issue and requires a nuanced response.

Parent carers also have concerns that a 'heavy handed' approach to spiralling INMSS fees could result in a mass exodus from the sector, abrupt closure of settings and very vulnerable children being without a suitable placement. We have heard of the devastating impact on children, young people and families when independent special schools have closed unexpectedly because of inadequate standards of care. Legislation to hold the INMSS sector to account should also consider the resilience of the rest of the SEND system to absorb the shock of unplanned withdrawal of specialist services and how risks will be mitigated (e.g. compulsory purchase orders, emergency absorption into established MATs)

The independent school sector should not be overlooked in this conversation. It is providing a unique role for children and young people who need a less overwhelming sensory environment, smaller class sizes and the offer of a mainstream style education. The SEND reforms should consider how the best of this offer can be replicated in the maintained sector with equity of access and at reasonable cost.

What's Missing?

Children not in School: One of the strongest messages that we have heard through this consultation period is that the needs of vulnerable and growing group of children and young people who are unable to attend school regularly or who are NEET have been completely overlooked in the proposed SEND reforms. This includes children and young people experiencing EBSNA, those on reduced timetables and/or accessing alternative provision, those who are out of schools because of a lack of a suitable places, children and young people with medical needs that prevent them being in school and those receiving Elective Home Education (and in many case this is not a preference for families but a desperate attempt to protect their child's mental health and shield the family from prosecution for non-attendance)

Mental Health: Another key message we have heard from parent carers is about the lack of consideration in this consultation for mental health conditions and how they affect access to learning and general development for children and young people. These include school and systems related trauma, complex PTSD, autistic burnout, eating disorders, clinical depression and obsessive compulsive disorders (OCD)

Needs and conditions other than Autism and ADHD: Parent carers feel the proposed reforms are very neurodivergence focussed and that the impact on children and young

people with less commonly occurring and/or highly complex needs has not been properly considered.

Early Years, Post 16 and Preparation for Adulthood: While the SEND Reform Consultation is attached to a Schools White Paper and therefore focussed on statutory school aged children, parent carers feel strongly that children and young people at EYFS and Post 16 are not adequately considered in this consultation and that Preparation for Adulthood at all ages and stages does not feature prominently enough.

Teaching Assistants/Learning Support Assistants: Parent carers and wider system partners have been shocked by the omission of TAs/LSAs in the proposed SEND reforms. These are the staff who deliver care and support on a day to day basis and their expertise, kindness and capacity are very often what makes the difference between a child that thrives and a child falls through the cracks. These practitioners are highly valued by children, young people and parent carers but consistently overlooked and undervalued by the system both in pay and conditions and recognition and respect.

Ability to for everyone to participate: Participation in this consultation required a baseline understanding of our democratic processes and existing legal and statutory framework for SEND that does not exist for many parent carers. The consultation questions have been written in such a way that parent carers have to understand the proposals in detail in order to meaningfully respond. In addition, the consultation and resources are only available in English language.

Parent carers have felt that many questions about how the proposed reforms would work in practice were either unanswered or responses were unclear. The combined result of these barriers to participation is that, despite the best efforts of our regional parent carer forum network the voices of some parent carers and communities will not be heard in this consultation process.

Conclusion

The ambition of genuinely inclusive mainstream education and access to the specialist education, health and community services each child or young person needs is the right one. The cultural shift and investment needed to achieve this is considerable and will not be successful without all system partners pulling together towards the same objective. We strongly recommend delaying the process of legislative change until inclusive practice is well established and the risks and benefits can be more accurately evaluated. Proceeding with changes to the SEND legal framework that do not have the support of parent carers and all stakeholders risks distraction from the core task and division when we most need to work together to transform the experiences and outcomes of our precious children and young people.