



National Network of Parent Carer Forums

'Our Strength Is Our Shared Experience'

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for families with disabled children

Strengthening Parent Carer Participation

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Markers of good practice in building Parent Carer Participation:

Working effectively with parent carers

Definition: A partnership process where parent carers are valued members of a team shaping and delivering services for families of children and young people with special educational needs and/or disabilities. 'Effective parent participation happens when parents have conversations with and work alongside professionals in order to design, develop and improve services.'¹

Markers of good practice

Minimum

1. Parent carers' engagement is valued, planned, and resourced.
2. Pan disability – all conditions, spectrums, additional needs and/or disabilities
3. Parent carer leadership – proactive not just consultation responsive.
4. Parent carer participation is evident throughout planning, delivery and monitoring stages.
5. Clarity for parents and providers about function of parent forums (mission statement etc).
6. Clearly described roles for Parent Representatives.
7. Two-way feedback mechanisms to main parent carer group and wider parent carer community.

In development

1. Authentic co-ownership of work and partnerships, and co-presenting of user/provider experiences.
2. Parent carer forums are well linked to other local groups and participate in regional networks.
3. Transparent written forum governance.
4. 'Reward, Recognition and Remuneration' policy to aid sustainability.
5. Ongoing recruitment and training opportunities of new parent carers.

We recognise that this is a complex, sometimes tense arena for parents, practitioners and managers. Those involved need skilled leadership and encouragement to mark progress and build trust. Local Authorities that performed well in the delivery of Short Breaks reported that having strong parent carer forum involved throughout the process was a significant factor for success.

Outcomes: Families report better outcomes and experiences for the disabled child or young person, siblings and other family members when these groups are involved in shaping those services or reforms. There is evidence that effective Parent Participation results in better fit between families' needs and service provision, higher satisfaction with service delivery, reduced service costs as long term benefits emerge, better value for money decisions and less conflict between providers and those dependent upon services.²

Current SEND reforms, like extending the 'personalisation agenda' require a cultural shift alongside informed investment and support: like Parent Participation. Local histories and relationships have shaped a wide range of experiences and arrangements in local parent carer forums, and the

¹ Complete 'How to Guide on Parent Participation' is available from Contact a Family and NNPCF websites.

² Full TDC report about delivery of Short Breaks available on CAF website – summary report to be found on www.nnpkf.org.uk



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emphasis is to build on these foundations to extend good practise, and achieve better outcomes for disabled children, young people and their families.

Mechanism: Meeting the challenges of engaging with a range of parent carers whose families' have a range of experiences, and accessing parents who are available, informed, skilled and committed to problem solving is demanding. We strongly affirm that the solution lies in investment in pan disability Parent Carer Forums rather than just individual parents. Local Parent Carer Forums who form constructive partnerships with local managers and commissioners are usually those that have good quality support, effective communication resources, network with a wide range of parents and groups, and have transparent governance.

Sustainability: parental expertise is a scarce resource and requires skilled support. A key tool to encourage wider participation, and flow-through of parent carers is a clear governance and a transparent written policy for fair and consistent 'Reward, Recognition and Remuneration' policy for parent carer engagement in decision-making, service planning and delivery, and ongoing monitoring.

The minimum requirement is for quick and easy system to repay parent carers any out of pocket expenses incurred. A good policy would include clear descriptions of graded tasks and responsibilities and corresponding rates of remuneration for expertise, time and commitment. The remuneration of parent carers should be commensurate with other advisors working on the SEND programmes. It will also enable parent carers who wish to contribute their expertise to do so in a range of ways with consideration for their primary role as parent carers.³

We wish you every success in working with colleagues and parent carer forums to collectively make a difference for families of parent carers, and in shaping services to effectively meet needs of disabled children and young people, and their families.

Carrie Britton	Co Chair NNPCF, and member for South East
Anna Gill	Co chair NNPCF
Sue North	Director of Operations, Strengthening Parent Carer Participation (CAF)

***For more information please visit our website: www.nnpcf.org.uk
To contact us please email for the attention of the co- chairs: info@nnpcf.org.uk***

For further advice and assistance regarding parent carer participation and effective involvement, please contact Sue North at: Contact a Family 209 City Road, London EC1V 1JN Tel 020 7608 8778 / 07738896474

³ The National Network for Parent Carer Forums (NNPCF) and Parent Participation Strategic Partner (Contact a Family) is preparing guidelines and other resources to assist Pathfinders, local Authorities, local forums and others. These will shortly be available at www.nnpcf.org.uk and www.caf.org.uk



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Summary of Feedback from questionnaire sent to Parent Carer Forums

Special Educational Needs – Indicative Code of Practice Consultation Summary

Overview

Having the opportunity to discuss the “*Indicative Draft: The (0-25) Special Educational Needs Code of Practice – March 2013*” (COP) with the Department of Education (The Department) is something that has been welcomed by the NNPCF. The Event on 8th July at The Department will be used to help inform and contribute to what the NNPCF expects will be a more complete document that goes out to full public consultation in the autumn.

Prior to the Event, the NNPCF sent out a consultation request through the regional network for feedback from Parent Carer Forums (PCFs) about their initial reaction to the COP. The intention of the consultation was to obtain feedback that will encourage discussion and also to identify key areas of concern. All PCFs were asked to:

- Express their concerns about the Code of Practice.
- Describe any solutions they might like to offer.
- Specifically comment on their involvement with the Local Offer.
- Provide any examples of participation within their own Local Authority.
- Add any additional comments they might like to make.

The questionnaire provided no specific guidance and intentionally did not ask for feedback from any section of the COP other than the specific Local Offer questions. As a result the comments that have been received are diverse and range from general observations to specific wording.

The NNPCF recognise the short timescales provided for arranging feedback and were pleased with the level and diversity of the responses. Regardless of the timescales feedback was received from:

- 27 sources that cover over 30% of the groups nationally and included
 - Individual Parent Carers.
 - Parent Carers Forums in groups.
 - Steering groups.
 - Regional groups.
- The responses were received from all 9 regions in the network. All 9 regions will be represented at the Event on 8th July.
- 96 parent carers were responsible for preparing the responses.
- Over 550 parent carers contributed nationally to the responses.



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The table below provides a summary of the level of involvement each of the responding groups reported they have in their own Local Authorities:

Respondent	Participation Level				
	Information	Consultation	Participation	Co-Production	Other
Bolton		✓			
Bournemouth	✓		✓		
Brighton & Hove				✓	
Calderdale	✓	✓	✓		
Central Bedfordshire				✓	
Cheshire West and Chester			✓		
Devon	✓	✓	✓	✓	
East Midlands Regional Forums	✓	✓	✓	✓	
East Sussex					✓
Gateshead			✓		
Hammersmith & Fulham	✓	✓			
Hampshire					✓
Hertfordshire			✓		
Hull	✓	✓	✓		
Lancashire	✓	✓	✓	✓	
Lewisham	✓		✓	✓	
North Somerset	✓	✓	✓		
Poole				✓	
Portsmouth	✓	✓	✓		
Rutland	✓	✓	✓	✓	✓
Sheffield					✓
Shropshire		✓			
South West Regional Forums	✓	✓	✓	✓	
Telford	✓	✓	✓		
Waltham Forest					✓
Wandsworth		✓			
Wokingham					✓

Some forums were able to provide specific detail as to their involvement which was:

- ✓ Our parent forum has an excellent working relationship to the borough social services, SEN and Transition teams which we would describe as working in co-production to solve issues in these areas. With regard to the bigger picture with key leads for this work in our borough we would only be able to say we are at an information stage. (Waltham Forest)
- ✓ Some Consultation and hopefully Co-Production (Bournemouth)
- ✓ Promoting Events (Rutland)
- ✓ Only in very early stages for consultation and participation. (Telford)

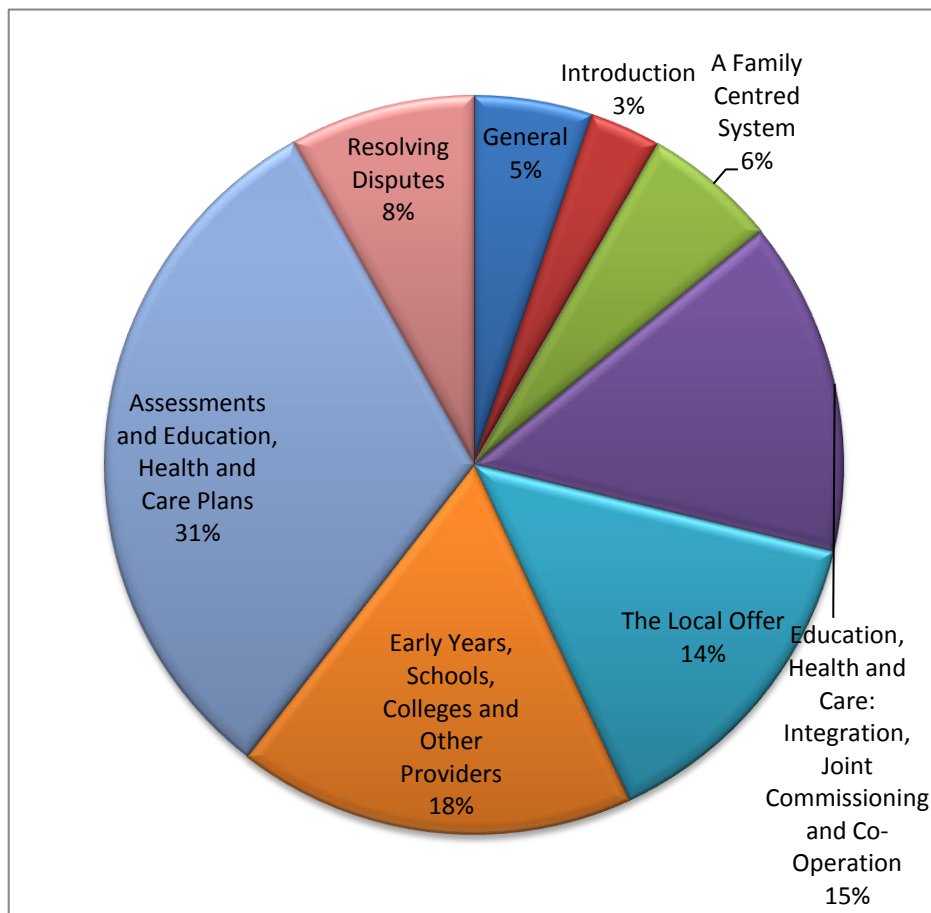
It should be noted that not all of the responses were returned in the requested format, however it has still been possible to discern the relevant information from what was returned and from the NNPCF regional representatives.

Responses

Of the feedback that was received we have been able to analyse them as follows:

- 580 concerns were raised
- 126 solutions were offered
- Over 80% of forums reported they were clear what the local offer should provide.
- Over 90% reported that they were involved, expected or are planned to be involved in the development of the local offer.
- All of the forums who responded using the feedback forms provided were able to give a positive and practical example of where they have made a difference in their area.

NNPCF have done a broad analysis of the **concerns** raised and this is shown in the graph below.





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CONCERNS RAISED DURING THE INDICATIVE CODE OF PRACTICE CONSULTATION

Each of the concerns raised were allocated one of 8 sections. Sections 1 -7 were as described in the COP and a final section "General" was allocated where a concern may not have fitted into a specific section in the COP.

Breakdown of Concerns

As well as the graph we have provided a numerical breakdown of the concerns:

	Description	Count	Percentage
0	General	30	5.17%
1	Introduction	18	3.10%
2	A Family Centred System	34	5.86%
3	Education, Health and Care: Integration, Joint Commissioning and Co-Operation	85	14.66%
4	The Local Offer	83	14.31%
5	Early Years, Schools, Colleges and Other Providers	101	17.41%
6	Assessments and Education, Health and Care Plans	182	31.38%
7	Resolving Disputes	47	8.10%
	Total	580	100.00%

It is clear that Parent Carers have identified the following as their headline sections of concern:

- Assessments and Education and Health Care Plan
- Early Years, Schools, Colleges and Other Providers
- Education, Health and Care: Integration, Joint Commissioning and Co-Operation.
- Local Offer

Each of these subjects is on the agenda for specific discussion on 8th July.

Summary of Concerns

Overall there appears to be an overwhelming response that the COP should:

- Provide CLEAR guidance that reflects the implemented bill. Any ambiguity MUST be removed and the inclusion of the strong directives like SHOULD, MUST, DUTY etc are imperative.
- Be clear about the roles and responsibilities of each of those who have a DUTY to deliver. There must be no opportunity for "get out" clauses or "wriggle room" as these clauses are often used by Local Authorities and others during any given complaints or legal process.



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- Deliver clarity about the involvement of all relevant stakeholders in the design, implementation, delivery, monitoring and review processes with due regard given to the involvement of PCFs.
- Ensure that it provides Parent Carers with appropriate assurance that they will get what their children "Need" in a timely and effective manner.
- Describe the content of the Local Offer, ensuring that services available are clearly defined and understandable.
- Ensure that any other legislation that may affect or be affected by the Children and Families Bill is clear within the COP and referenced appropriately.

Summary

NNPCF are pleased with the comments provided by the respondents especially in the areas of the involvement in the Local Offer and Parent Participation.

It was interesting that although NNPCF provided a proforma to complete, a number of forums chose to go beyond the high level appraisal that was expected and went into much more detail. As well as being welcomed it also reflects the energy put into this consultation and the importance parents attribute to this.

In general the feedback from the consultation about concerns is consistent in its message – CLARITY! It is also pleasing to show that many forums are happy to offer solutions to the concerns that are identified.

It is clear that Parent Carers are becoming increasingly involved in service review and design, as demonstrated in the participation table (above) but there is a potential for parent carers to continue to mistrust the processes at present; this needs to be overcome.

NNPCF have contributed outside of this consultation to providing a statement for Chapter 2 of the COP, describing the role of PCFs. It is hoped that by including a message about Parent Carer involvement that this may go some way to addressing some deep seated worries.

Overall NNPCF feel that this has been a positive consultation which will inform immediate discussions and provide a background for more intensive scrutiny of the COP in the autumn.

Associated Documents

- *NNPCF Code of Practice Consultation Letter to Forums*
- *NNPCF Code of Practice Feedback (Word Form)*
- *NNPCF Code of Practice Consultation Consolidated Feedback*
- *NNPCF Code of Practice Consultation Concerns Consolidation (Excel Spreadsheet)*



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Feedback from discussion groups on 8th July 2013

SEN Code of Practice, NNPCF consultation event 8th July Flipchart and notes collation

Green Group - Discussion

Q. Parental support and engagement

General Points

- Parents Carer Forums (PCF's) place within the new reforms needs to be strengthened and more akin to the statutory requirement for Parent Partnerships services
- There is still general confusion about role and remit of Parent Partnership and PCF
- Capacity remains an issue for forums.
- Strategic place of PCFs needs to be acknowledged and embedded into planning
- In some areas there is pressure on forums to move to an independent model and secure external funding. However, this development itself has capacity implications on the forum and may not be suitable to all.
- There is anxiety about the future of the support offered to PCF's and whether the grant will continue after 2015. This impact on long term security and sustainability plans.

Remuneration

- Remuneration issues needs to be resolved as there is no consistency across the country.
- Without proper remuneration there is a lack of equity and parity between parents.
- Even if individual parents do not feel able to take any remuneration (because of benefit complications) payment could be made to the forum towards running costs etc.

School and Colleges

- Section 2.1 & 2.2 in the new code need to be strengthened, at the moment the language is too woolly and not specific enough. Particular concern was raised regarding school and college understanding of parent participation and willingness to engage with parents at both an individual and collective level.



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- Following on from this, the independence of schools and lack of accountability to any overarching body was seen as an impediment to the pursuit of parent's involvement, at all levels.
- The new OFSTED inspection framework was mentioned as a solution to the above problem – However there was some concern raised about the definition used in the OFSTED framework as 'disabled children' is too narrow and should be revised as SEND.
- Workforce development at all levels needs to change in order for parent participation to be embedded.

Key good practice issues

- Time of meetings/sharing information/ open honest communications.
- When cultural change occurs, it changes relationship with partners and stop parents having to battle.
- Commitment to involving parents, an acknowledgement of the power relationship.
- Willingness of statutory partners to adapt their behaviour and mode of operations as opposed to expecting parents to adapt to theirs.

Red Group - Discussion

Q. How can we make the code more accessible and easy to understand?

Structure and layout of the code

- Colour code the code (according to age)
- Order the code in terms of the life or journey of child – this will be much clearer and has a logic too it that would be understand by all (it does not matter if some information that applies across all ages is repeated as in practice the code is not read like a book, but will be dipped into for specific information)
- Also the aim that the code should be shortened was itself questioned, as it was felt that as a general rule parents and professionals will only need to access a particular section that relates to the issue they are dealing with. Therefore, as long as the sections are easy to navigate, the size of the document as a whole should not be problematic
- Some of the current headings are not helpful. For example what is 'Family Centred Help?'
- Language –Have a glossary and always use clear language
- The accessibility of the code could be improved by use of pictures, diagrams (to indicate process/time frames etc) and breaking the text up



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- Case examples with clear indications of what the process is... for example the case example might be ... What can I expect if my child has been given a diagnosis of...

Language and definition.

- *'Best Endeavours'* – this phrase prompted some discussion, and was felt could be strengthened. The issue raised was whose definition of best endeavours would be paramount?
- *'Have regard'* – Again this phrase was identified as being too weak and felt could be strengthened.
- *Academies* – It needs to be explicitly stated that all Academies are covered by the code
- *Tribunals* – There needs to be transparency regarding the outcomes of tribunals, there is much anecdotal evidence that often L/A use the process as a delaying technique.
- *Re-assessments* – Currently if a re-assessment is requested the L/A can choose which areas to re-assess, thus only undertaking a partial re-assessment and perhaps skewing the outcome. It was felt that a re-assessment should be a full assessment.
- *School Action / School Action Plus* - Clarity is needed with regard to pupils who formally were on SA or SA+. The code needs to be much more explicit with regard to the support, outcomes and expectations for those children.

Sue Mennear notes on LOCAL OFFER

- Too schools focused – what about children who are not well enough to be in school?
- Not just a list of schools-Needs to be a list of everything and aspirational
- Website – very few are choosing to print theirs so how do we make sure it is accessible to those who are not computer literate people and those for whom English is a second language
- We had conversation about forums doing Drop in information sessions e.g. one forum had different speakers at each one e.g. educational psychologists and Parent Partnership there. Parents are saying they need drop-ins to access this information.
- It was recognized that in large areas quite challenging and also discussed whether this was appropriate role for forums who are already stretched.
- Parents are carers, more and more is being placed on us – exhausted – need to concentrate on key things.
- Had a discussion about forum role in making LO parent friendly and making sure it is fit for purpose. Some forums are given feedback on services e.g. trip adviser element can you do that to a GP surgery or cinema (probably)



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- Had someone who did FIS, PPs, forums – whoever knew whatsoever it wasn't good, connexions want very good either – they are using local offer as opportunity to put all the info together and then tender it out to have someone keep it up to date and a working document – they think this will result in much better service for parents negotiating the maze.
- Funding forum and /or PPS to run local offer – this might be option for some forums but not all. There was a discussion around the different roles e.g. FIS will find it for you if you can't find it. Forum will identify what is not working, gaps, parents will do this too using personal budgets where they can't find services they need.
- Personal budgets will widen the offer as parents will identify new ways of doing things, might stimulate the market – will develop the market, where you see the gaps service might fill them - you don't know what you don't know.
- Not static all our responsibility can't just be la or parents or professionals. It is a joint endeavour to keep it as a living document.
- Schools need to be engaged in the local offer, what each school would provide and what resource base they are offering – what is additional and different to what is offered by others.
- Some parents were saying schools in their areas are nearly all academies now and are having real trouble getting them to engage. Some are turning pupils away because they do not want to spend on them (they want to use allocated funding just to run and achieve – it is not ring-fenced so nothing to stop them doing this. Also they are accountable to the Government not LA – Ofsted supposed to have role in making sure they meet these requirements but parents round table didn't think they would do this (take on this role- have other priorities) AND parents can't wait till inspection anyway. The parents asked how schools were going to be held to account to make sure they do provide services to disabled children and provide for their needs.
- High statementing authorities ARE going to be using the legislation to reduce number of plans/ statements this will mean mainstream schools are going to need to be provided for in mainstream, schools will need to be providing for their needs via local offer. Threshold will be less. Worrying this won't be around children's needs – will be around money.
- EHP is not going to be anything like the number of statements. In one local authority it was estimated there would be 17 percent plans compared to statements talking money not children's needs.
- Accountability needs to be built into the local offer and code, how will you tell parents how to get redress if their needs are not being met. Assume we cannot change the law so that academies are accountable to Las on this? It's the la who is responsible for the



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education of children. Not the school. This change of emphasis isn't reflected. How much teeth is Ofsted going to have? Only the DFE can hold the academies to account. Lack of money at schools means some schools are choosing not to accept disabled children and are spending the money on just running.

- The wording around working with forums need to be strengthened – how do we encourage Las and health that this is the right approach that this will save you money make services better etc. Got to find ways of encouraging LAS and Health to work with parent and voluntary sector and young people
- Needs to be clear in pps and parent forum – where is the overlap and who has responsibility for what. PPS are training staff in health and social care – the code mentions a strategic role. Is this correct or does this need to be taken out?? One parent strongly felt the wording about pps should be change the bullet as it says they have a strategic role and she felt this was forums not PPS. Others were not so sure.
- Local authority will have to host or choose to host Local Offer on their websites – there were some concerns about LA websites not being easy to navigate or that parents would not ever look there. Some LAS are saying the local offer has to go on the corporate website (rather than being contracted out) and there is a worry parents are not going to look at it
- Language is important here in developing local offer - oneparent was making point that language used is important to show parents are a formal part of the process. And that Las must be using them.
- Some felt it was important to have something in the code about an expectation that Las and health and schools would work in partnership with their forum. The schools bit are WAY too vague. Suggests it "might be a good idea" rather than putting a strong emphasis on how important it is that they do.
- Also important to highlight that LAS should support forums – either in kind of with resources so they can reimburse and pay expense and sometimes pay parents for their input. Should point out many forums are run on a voluntary basis as many LAS don't realize this – also something about remembering they are parents, mostly volunteers too so to consider this when working with them e.g. have meetings during school hours and not in holidays.
- Developing a policy to pay the forum for its work – when it is coproduction it is a lot of work alongside paid professional. They can then use this to pay parents or to run, etc. Coproduction should be paid work we felt.
- There were some concerns that the LA is so stretched that they are likely to water down the Local offer only put what they can afford so won't be aspirational as they can't afford to put in to meet need – so there is a conflict there.



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- We can't let Las use the local offer as a tool to cut services – really needs to be added to and looked at as a planning tool,
- Suggestions that pathways diagrams /customer journey 0-25 are included – things you might be considering at different stages, or a way of being guided through to meet your needs at your stage of journey and in your situation with child with his/her needs
- Manchester or Trafford –has nice set up with Local Offer said one parent.

Sue Mennear notes on CODE OF PRACTICE

- **How can we make it more accessible and easy to understand?**
- At the moment it's a bit local authorities orientated.
- Written with education as main focus too, includes health but health doesn't come out very clearly who is responsible, not sure health would be able to relate to it and know what is expected of them.
- Fairly parent friendly – but it is more switched on parents who would be finding it more useful. Is it more for them than others? What can we do to make sure other parent can access it?
- What does local offer mean> It's not that obvious. Not a good label. Forums are representing people who are very switched on and know where to go. What about an Easy peasy guide too.
- Some disagreed and said would be watering it down. Others thought it was important.
- Did have a parents' version of the code. But you don't want to water down the code. The guide was so good you didn't have to go into the code very much. We want that again
- Another person wasn't so sure. Cost is everything. What we ask for costs – is having another booklet important. Maybe part of the website, code of practice and like the one. Resource – who is able to pdfs are online – DFE are saying they could do an online one. Public Health England Improving Lives. Easy peasy guide. Bringing in Social care and health at the same time.
- Anyway we can get some extra resource to do it.
- All agreed the Local Offer had to be labelled and promoted in a way that people understood what it is.
- The duty is on the la to relay it to people in a meaningful way. E.g. have people who would interpret it and communicate it, help people with it.
- One person pointed out it must be really accessible as it need this to be understood by some young people under 25 and parents who haven't got English as secondary language AND you must have signalling in it in different languages to say what it is and where to get more info in your language.



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- It is too long. Can we have several version of same thing – not dumbed down version just an Easy peasy version where you can read more in the full version if you need to.
- Is this code more aimed at parents, easier language – overall we think it is better than the last one. More parent friendly
- Definitions – must and should – going to clarify this. THIS IS SO IMPORTANT we understand and have this explained in there to avoid wrangling.
- People have no idea what local offer e.g. one LA said they already have a local offer but it is an Aiming High one.
- A lot easier to read than the other one- young people's agenda and parents who won't find written stuff easy.
- PPS have key role to play. In helping parents access it particularly if they are being trained in Health and Social Care. Does this mean forums are more about strategic rather than individual which can be left to PPS.
- Depends on relationship. Not always
- Forums are not going to be doing explaining for parents on an individual basis/ or should not be.
- Consultations – parents can say during the consultation what they don't understand and what bits don't work with them; young people need to be involved in this. WE need to test it out.
- Health not feeling part of it.
- Never going to know it all.
- **Draft too specific or not specific enough or just right?**
- Hard to give an answer- would be easy to say not specific enough but legislation is being made so the general approach is nearly there but when you get down to specifics you need to see the same thing.
- When they were introducing the bill back in March a lot of the stuff the DfE didn't know – things changed between pre-legislative scrutiny and now (think what they have produced is good considering so many unknowns and some changes). Hard to be specific – particularly as the pathfinders were still trialling things and finding out what is best – this came from DfE rep but people agreed difficult to do them both at same time.
- Pathfinders are not as far along – is there a risk that the code won't be complete because the pathfinders won't have found the answer. She didn't think that would happen as a lot of the pathfinders have got further along as a result of accelerated learning groups which are helping with this. Personal budgets, local offer. EHC plans etc.. Meeting weekly to really move things on. Risk was recognised and they have taken action. Feeling confident that by time goes through the lords committee but done a lot of work in this period to sort that out. It's a real challenge to do it while you are drafting.



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- Duty on health to provide provision in EHC plans – this needs to be made REALLY CLEAR.

Green Group Exercise 1

- Code needs to be more strategic – PCFs need to be part of the strategy. Capture how we will capture strategic vision.
- Have the right vision = deliver better outcomes
- Clarity of how we can capitalise on this opportunity to affect the outcomes
- Accessibility – clearer use of colours - SENCOs etc. they need to really understand it – will enable parents to understand
- Lack of accountability for schools/SENCOs etc.
- Local offer shop – use forums to signpost – schools need to know where parent can get help
- Don't want to lose accountability
- Not acceptable that SENCOs don't know COP
- More training for SENCOs
- Document currently overwhelming for most parents – very complex – will need support to understand
- SEN toolkit – exists but SENCOs don't know about it
- Move away from combative culture – ensure joint working together from the beginning
- Assessment process with funder = no independent tribunal
- Remove assessment from funder = less/no tribunal
- How to get access to Social and Health support – not enough engagement
- What happens if Health and Social care don't commission
- Strategic bit in code on how to make the code work in practice and how PCFs need to be part of it
- Practical examples – of how the code works/should work for children with Health/Social and educational needs
- Not just about school provision
- 4 principal examples – Rotherham – of who to work together – charter principles of communication for all children 45 parents disseminating this
- Practical examples of what good PCFs are doing and why it works – in the CoP
- Payment – parents not exploited

Gold Group Exercise 2

- Needs to have all the information in it for individual families and strategic



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- Fetter coordination. CAF forms similar to EHCP – no joined up working on CAF so needs to be different for EHCP
- Needs to be clear what needs to be in it
- More specifics
- Difficult to move across authorities – needs to be transferable
- Multiple assessments still likely – so more intelligent planning of how this happens
- More explicit that who makes decision about next steps
- Clarity about who is responsible for deciding what happened – accountability
- Needs clear joint commissioning strategy
- What's not working element of PCP needs to be dealt with and agreed by all before moving forwards to either EHCP or alternatives
- We're working on where the child in not, what is possible – needs to be more specific about plans need to be aspiration and plans might be necessary to achieve more than OK/mediocre
- If no plan how do we be clear about how aspirations and better outcomes are going to be achieved
- All children need a plan regardless of if they fit EHCP criteria and needs regular review
- All plans, EHCP or not, much be person centred
- Who is responsible for collating/analysing all information on assessments because assessment are happening constantly, especially if Heath related issues
- Key worker having some authority
- Greater clarity on role of key worker
- Difficulties of mobility if different roles of key workers
- Question – what is the role of the medical directors? Not clear at the moment
- How will school funding effect assessments
- LA having monitoring role about how school funding is being used otherwise will fall to parents – accountability for school funding spending
- Appropriate professionals with relevant skills in assessment and monitoring and planning – not just education
- Multi agency planning/assessing really hard due to staffing levels more professions doesn't = better
- Quality report/assessments- what does good look like?
- Reports need to be quality assured
- Could key worker oversee quality and appropriateness of content?
- Where's the recourse for poor/wrong reports – performance management for staff
- More clarity on how health assessments are to be brought into planning assessments



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Strengthening Parent Carer Participation

- Clarity of outcomes – what is possible
- Role of therapists
- Parent feedback of accuracy/quality of information – Assessment shouldn't take place until parents are happy information being considered is right and of good quality
- LA ability to intervene if school quality not good
- Advocates for parents who can't identify the issue themselves – key worker/PCFs?
- Accountability/transparency of and for poor assessment – redress
- Who will advocate/clear signpost of where to go if unhappy – preferably independent
- PCP training delivered before but professions still not doing it
- Get culture of PCP all the time right – will save time and money
- If PCP done well then the plan will be right then time to solve problems won't be needed
- Greater clarity on need for PCP
- Clear – to the avoidance of all doubt that working in PCF way ESSENTIAL
- Article 19 – must involve family and young person, doesn't specify the HOW
- Clause – more detail needed on what article 19 needed
- Query status of single plan – needs to be a must
- Needs to be clear definite guidance that one plan much to be produced and must be meaningful
- Plan must address what isn't working
- More clarity in COP on what CCGs should/must do
- COP needs to give more guidance on ensuring outcomes are written and understood in plans

Gold Group LOCAL OFFER

- SE7 pathfinder – several versions down the line
- None of the areas have a local offer yet
- Concern – that larger groups of children with an EHC plan – how do we support them?
- EHC plan - how do we support them?
- Trafford – is an online directory
- All look very family information service
- There's no TEMPLATE – LAs are struggling to picture what it should look like
- Concern – some area still haven't got the Short Breaks right
- Question; who do you need to get round the table at the start?
- Is it being support at a high strategic level?
- Pathfinders – if we had looked at the local offer first it would have helped us
- Challenge – the amount of definitions and eligibility that needs to go in to it



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Strengthening Parent Carer Participation

- SE7 started by scoping with parents – ‘what do parents and families need?’
- Question – should it include what is available for parent carers? E.g. ES and key working?
- Yes - if parents can cope they will be better equipped to look after their family

Cheryl/Karen

- Stockport – started a ‘community offer’
- It includes services all families
- Is it clear in the code? – no it’s enormous, not family friendly
- Is the market there/funding available to deliver the local offer?
- How will this happen when there are so many cuts

SOLUTIONS

- Coproduction approach – with PCF not individual parents – the collective voice
- Ensuring the information is clear and accessible
- Needs to be clear throughout that PCFs need to design review the local offer
- PCF can support with demonstration needs and ‘what works’
- Is the accountability clear in the local offer? Who is measuring whether the local offer meets families’ needs?
- Is it an annual review of services?
- SE7 have developed pathways – would this help with measuring the impact?
- PCFs need to be a MUST in the code
- Needs to be a whole families approach
- No one likes the term ‘local offer’ not clear what it is? What it does?

Red Group Single Category

- How will support/progress be measured given that the plan is focused upon outcomes
- The accountability within the plan needs to be clear – clarity around progress and it needs to be monitored
- What happens to the school if EHC children do not make process or SGI category
- Some pathfinders have put plans in place for single category ‘children’ (Cornwall and Lewisham) so there is something to be accountable for
- Want to see accountability and measurement of those children who do not meet the EHC threshold – through a structured plan
- Nothing in the code about IEPs – need to be included
- The code should include examples of how a child’s progress is monitored



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- Monitoring progress is key – a consistent best practice way needs to be included in the code
- There needs to be a consequence if outcomes/progress are not met
- Children below the threshold – how are we identifying them, ensuring that we meet their needs?
- How are we ensuring early preventative work with those children?
- How are we supporting those families where parents cannot advocate on behalf of their own child?
- Single category – needs to be person centred
- Needs to link to the local offer? What is the schools local offer?
- AfA programme looks at a wider group of children
- There is a danger that the approach could be too broad and if then wouldn't meet the need of SEND children
- SEN needs to be a system of ensuring outcomes and accountability to be measured and demonstrated
- Ofsted – schools that are good and outstanding would appear on Ofsted radar in terms of SEN children. How do we flag this as a concern?
- That's why parents need some sort of plan to protect them and their child and gives them a point of reference to raise concerns/concerns with the school
- Nothing in the code to say that 'sometimes' behaviour difficulties may mask SEN – needs to be clearer in the code
- How do we identify SEN? Does that mean that children without a diagnostic label do not receive support? It reads like there are other 'get out' definitions/reasons for poor performance e.g. attendance, poor teaching
- Attendance should not be a prerequisite for receiving support, some children will not be able to attend school 5 days a week

Category Definitions

- Use of word 'sensory' does not include 'SPD' sensory processing disorder – needs to be clear what this covers to protect ALL children. Need to add a link to an authoritative link and reminder that this will not be exhaustive – give an example e.g. 'this child has SPD.....' this is covered under the term 'sensory'
- SHOULD and MUSTS – need to say all educational settings MUST identify children with SEN
- BEST endeavours (awful phrase) by whose definition?

Single Category



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'Without impacting on the needs of children'

- Who decides this? This ends up being broken down in to its one or the other. Which comes first? The needs of the child or those of the other Children?
- The phrase 'best endeavours' needs defining
- Add a good example in to the code – needs to be more that 'we have tried this'
- Could include developing some ancillary guidance to accompany the code 'record of endeavours will be transparent and open for discussion of involvement with parents' – giving discretion but ensuring due diligence
- It feels like the DDA at the moment. There are so many 'get out' clauses
- Should there be a 'limiting judgement' whereby Ofsted can enforce/downgrade schools of SEN children aren't achieving?
- Alternative would be to have a robust system of monitoring and enforcement
- Could you add a statistical measure of SEN children's progress within Ofsted measure???
- There's a perception that with school action/school action plus being taken away that there will be a gap
- We need to communicate this well to families

Red Group Local Offer

- Need to say what it is, not just that is isn't a directory
- How do needs inform the local offer and how does assessment of individual child's need slink to accessing the local offer?
- How do you keep it up to date?
- How do you make it not just a dire story?
- Leeds – used 'underground map' approach, bust 'stations' covered large chunks
- How does local offer cover schools w.r.t kids who would have been on school action and school action plus, need to clarify
- Suggest each school specified their offer
- State how competencies/specifics of services are e.g. 'wheelchairs series could be manual,' = electrical
- Need to see how many people are using a services, this needs to be part of monitoring
- Need to do away with the thresholds/eligibility criteria, parents should decide what they need
- Objective – children need to be part of community
- Needs led local offer
- Document needs to be intuitive
- Define minimum standard which can be achievable



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Strengthening Parent Carer Participation

- Local offer – should include universal services everyone child comes in to contact with
- If right for child – should be able to access other areas 'local offer'
- This should follow principles of person centred approach
- How do you link budgets to ensure child's need is met? E.g. a piece of equipment could meet education, health and social need
- If a P.B. holder 'bump' a local offer service but three others access service via local offer, how is that paid for, how do you divvy up the payment is made?
- How do you go beyond service listing to give enough information for parents to make a choice, e.g. quality, what precisely is offered, how many people access services etc. needs/experience of the users?
- Local offer needs to be tested by range of users
- Clear guidance – enforceable
- Where does Ofsted fit in process, and other regulator and health watch?

Blue Group – Making the Code clearer

- Key messages should be highlighted at the beginning
- Having a means to find relevant section – search option on the internet
- Paper copy – clear sections – key words like early years transition
- Numbers within the sections to aid finding the right section - people are still having to use the family guide - too much jargon - it needs to be person centred
- The SHOULD and MUST needs to be clearer and the penalties if a LA doesn't comply
- TOP LINE – needs to say exactly what you can expect
- BEST ENDEAVOURS needs to be made clearer
- ACCOUNTABILITY needs to be clearer

Practical Steps

- Put it out to young people to see what they think
- Young person friendly version
- Need to the support in place to ensure that children and young people can participate
- Range/Options of where you receive support
- Consistent level of support/information/service from PPS across all LAs
- PPS need to be funded directly from the departments/need to be seen as being independent from the LA
- Is the draft specific/not specific or just right?
- PP needs to be specific and EXPLICIT
- PCFs are ESSENTIAL



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- The code needs to say 'this is how you need to work with your PCFs'
- The SHOULDs must be carried out and guidance about which laws that refers to (numbered code to which law)
- Open to interpretation at the movement – too top level
- This has to be a USEABLE documents – need to broaden it out
- Include detail/case studies
- Needs to be clear/simple and jargon free
- Doesn't matter how long the document is
- Be clear about 'who decides'

Blue Group EHC Plans

- Beyond 'annual' review – need to review how LA is being delivered
- Define what is meant by 'complex needs'
- Is it complex needs in education or health or social care
- What happens if cognitively able but health needs
- Lead on each plan should be based on child's needs e.g. if child has major medical needs – health = lead
- Who is key worker/navigator = key for moderate need kids
- EHC plan should be needs led – not reflected in draft code
- Plan should be set of outcomes (how much ££) and how do we get there
- Code needs to be clear that eg LA needs to say how needs and outcomes will be met
- How will outcomes be measured – be clear
- Be clear how plan will be person centred
- Make clear EHC plan is live docent with appropriate content W.F.T age, progress etc.
- Be clear heath and social care targets have same status as education targets
- How do the way budgets work in reality work with a genuine person centre plan – so budgets not just about a diagnosis
- If not quality for EHC plan clarity about who is responsible for assessing and meeting need
- How do you have consistent eligibility criteria across LA areas around country
- How does this link with ensuring transport
- Code needs to be clear about criteria about who qualifies for plan
- May need wide range of therapies e.g. to access education e.g. physiotherapy
- Default for parents – our child will need plan – doesn't always have to cost – EHC plan is not about a budget – could just be a plan – creative to meet needs and setting out what will be done



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- 'Family' page is crucial
- Make clear plan is portable – may live in one area but plan delivered by neighbouring authority
- Clear heading in EHC plan – TRANSPORT
- Link with carers rights – link to plan – plan should enable carers rights etc. to work
- Define links to other areas, e.g. carers support, Munroe etc safeguarding and existing frame works
- Set out who is responsible for EHC plan – top tiered and individual
- Workforce development
- Be clearer about where children's services end and adult services end
- Post 16 what happens about e.g. housing
- Clarity about transition and what will be in place post plan
- How is EHC plan and needs assessment link to DLA/PIP entitlements/assessments
- What about kids 15/16 - statement ended will they qualify for EHC plan – how do you get one – be clear

Blue Group Local Offer

- Some started some haven't - how will everyone get up to speed – set some timescales
- Get learning's from Pathfinders – make sure we don't repeat the learning and waste time – invite pathfinder leads to local meetings
- People don't know what it means to them
- Worried it will be un-wieldy
- Difficulty over definition – Hartlepool Tube map
- More clarity of what it is not - just what it isn't
- Who is it for?
- What are they meant to get out of it?
- Local offer should guide you through all things disability/SEN once diagnosis is made or from early problems
- We need to identify what are the gaps in services through building local offer
- Leicester city – example of automated assessment i.e. enter young person's age and difficulties and local offer identifies support available
- Local offer not framed in delivering outcomes – where are the outcomes for young people who are not eligible for EHCP
- Local offer need to link to personal budget
- Clarity over eligibility for EHCP = therefore no clarity over who local offer is aimed at



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- How can we get schools to buy in to local offer accountability on schools to put information into local offer
- Local offer must be outcomes focused
- Who will monitor and assess what is in local offer?
- Needs to be broader accountability than just parents complaining (Ofsted/Health)
- Recourse if not delivered (listed but not available)
- Where is the accountability for what is written in if being delivered
- Local joint commissioning needs to review that what they are delivering what is needed and fills gaps
- Needs to be dynamic process that delivers what is needed – intelligent commission done in partnership with families and all
- Locked in to monitoring assessment and accountability
- Parents need support to navigate local offer – or can it be more intuitive?
- Fear/worry that it is being developed as a directory
- Directory is needed to know what there is
- Who is accountable for quality of school local offer
- Young people need to be involved – what are the frameworks for this to happen?
- No duty to get social care to engage on the local offer and join discussion to make it joint discussion to write local offer
- No fighting – early intervention – good outcomes – good local offer
- Needs to be an intelligent dynamic process
- Needs to be clear who is it for – parents, young people, professionals
- How do we manage potential redundancy if information is constantly changing
- Isn't just the core offer by another name
- Needs to be kept current – accountability for keeping it current – duty on joint commissioning??
- No benchmark of what good looks like



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Strengthening Parent Carer Participation

List of specific questions raised at SEN Code of Practice, NNPCF consultation event 8th July

Questions

- I think it is really important that the section on additional needs is as strong as possible and focuses on outcomes for the child (as the EHC's will) otherwise all parents will clamber for the 'safety' of the EHC plans believing it is the only way to guarantee the support they need
- Is the legislation moving us towards a more segregated schooling system, moving away from inclusion?
- How will the local offer be regulated?
- What happens to children 16+ who have lost their statements?
- Local authority is legally responsible for providing all children with an education, but individual schools (especially academies) don't have to provide for a particular child, they can just decline to admit it or provide for it. This mismatch inevitably means some children don't get provided for. How to solve?
- Personal budgets - what happens if the LA say they have no funds to give the support that parents feel is required?
- The 9 million that will be given to non pathfinders, will forums be told how much each LA will get?
- What happens if the LA doesn't support parent forums after DfE funding stops?
- Are forums expected to set themselves up as a company to carry on this work?
- How do we engage with Health?
- How will children who are now on school action or school action plus be supported under new plans?
- SEN and Disability tribunal should be a single point of appeal - covering education, health and social care
- Where is the evidence that scrapping school action/school action plus will provide a better outcome for the 84% of children supported from school funding?
- Why are universities not included?
- Will local offer be statutory? LAs could have a legal duty to provide what's set out in local offer
- How is it all going to link together with confidence - EHC, Local offer, budgets



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- Can the DfE please look carefully at the key concerns of ALLFIE and IPS EA - the legislation and COP is lacking
- Can you encourage LAs and Health to support forums? Point out they have very little or no paid support, run on mostly voluntary input, encourage partnership agreements, resourcing
- Can you strengthen the opus on schools to work with forums?
- Can you strengthen wording around parents needing to be centered to process of assessment and delivery of services for their child – describe this for partners
- Too 'education-y' title
- Children are being turned away by academies – how can we ensure they are not and local offer applies and has 'teeth' where this happens for no good reason apart from LA want to use more money on generic stuff