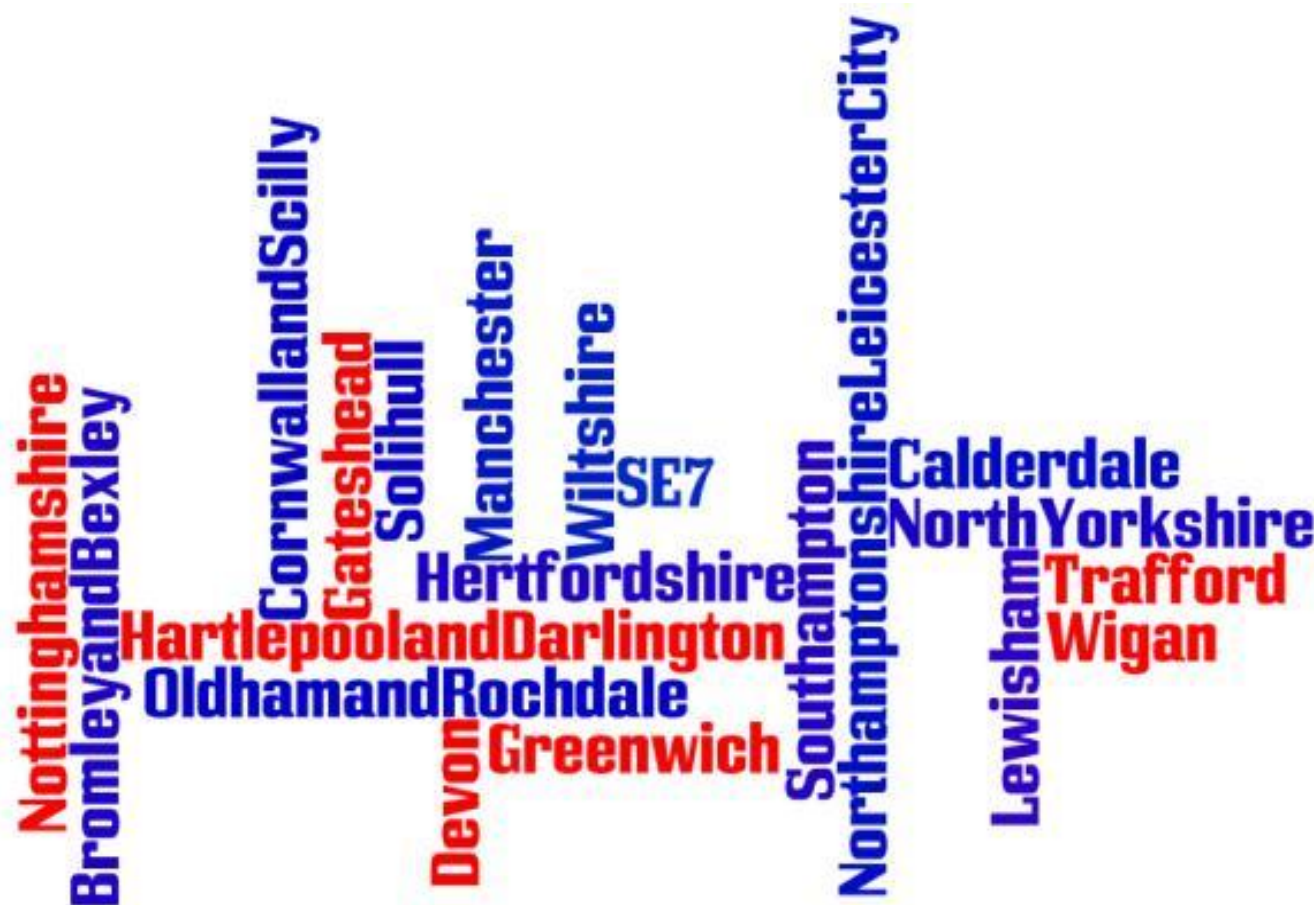


# SEND Pathfinder Information Pack



Version 3, December 2013 – Engagement and participation of children, young people, parents and carers

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## Introduction

### **Background & Context**

The pathfinder programme has been running for over 2 years. There is a growing body of learning that the new approaches pathfinders are trialling are making a real difference to the lives of children, young people and families, but that putting these reforms in place takes time, energy and determination.

**Subject to Parliamentary approval of provisions in the Children and Families Bill, all areas will need to implement the SEND reforms from September 2014.** The experience of the pathfinders has shown that the workforce development and culture change needed to implement the reforms takes time. Services and professionals across education, health and care for children and adults need to work together closely, putting families and young people at the centre of commissioning, assessment and planning. Every area will therefore want to begin considering the steps they need to take to implement the reforms successfully.

There have been clear messages that local areas would value practical advice and support in preparing for implementation. There is now a pathfinder champion in every region providing a mixture of information, advice and support to all non-pathfinder areas. **The information packs support the work of the regional champions by demonstrating learning from across the whole programme.** Further information and case studies, together with details of the pathfinder champions, are available at [www.sendpathfinder.co.uk](http://www.sendpathfinder.co.uk)

### **Information Pack Format & Structure**

**This third version has been updated to reflect the draft SEN Code of Practice, draft regulations and the proposals for transitional arrangements which were published in October 2013. In addition a small number of case studies have been added or updated, which is reflected in the contents page.**

The information pack is designed to draw together key emerging principles and case study learning from the pathfinder programme to support non-pathfinder areas to prepare to implement the SEND reforms themselves. This pack is created for everyone involved in making the reforms work – amongst others, children, young people and families, parent carer forums, local authority children's and adult services, the health service, early years settings, schools, post 16 institutions and VCS providers.

This information pack covers the following six overarching themes of pathfinder testing:

- Coordinated assessment and EHC planning

- Personal Budgets
- Local Offer
- Preparing for adulthood
- Engagement and participation of children, young people, parents and carers
- Joint Commissioning

Please note these packs are supported by a glossary which can be found at the end of each pack.

### **Future Versions**

The pathfinder champion programme will run until March 2015. Pathfinders are now scaling up their new approaches to whole areas, working across the 0-25 age range and with the full range of providers. This will provide further vital learning that will be incorporated into future packs.

Information packs will be updated and published periodically over the coming months and feedback will inform development of future packs. **This pack will receive a substantial update in February 2014, with the inclusion of new case studies and materials to further support implementation of the SEN reforms.**

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### Introduction *(Last updated December 2013)*

This information pack includes an overview of the ‘engagement and participation of children, young people, and parent carers’ Pathfinder theme, including links to relevant documentation and resources, such as the draft SEN regulations and Code of Practice (CoP). This is supported by on-going learning from Pathfinders and a report that outlines the learning from parent carer forums in Pathfinder areas<sup>i</sup>. This information pack is version 3, which builds upon the introductory packs issued in June and September 2013. This is a working document and the latest version can be found on the SEND Pathfinder website: [www.sendpathfinder.co.uk](http://www.sendpathfinder.co.uk). More detailed information will be included in future Pathfinder information packs.

At the outset of the programme, a specific requirement on those local authorities and partners who applied to become Pathfinders was that parent carers, children and young people should be both active and equal partners within any Pathfinder. This requirement relates to all parents, children and young people being enabled and empowered to have clear and active participation in the development of all Pathfinder thematic areas, such as the 0-25 coordinated assessment process and EHC plan and the local offer, as an equal partner and strategic voice in the SEND reforms. This requirement continues to be at the forefront of the reforms and has been carried forward to be included within the draft SEN regulations and CoP. Given a key aim for the new system is for ‘children, and young people to be at the heart of the system,’<sup>ii</sup> children, young people and those who understand and support them the most should be supported and encouraged to participate in its design. This does not underestimate the importance of professionals but affirms the requirement for a co-produced approach.



“Because I am a parent, I don’t have to report to a manager. I can share my problems and other people’s problems with every one... The outcome of this is that people at strategic level hear about what needs to change. Sometimes these messages don’t get to the top, and because I’m a parent I can make sure they do” – **Cath Stone, Manchester Parents for Change (Parent Carer Forum)**



As stated by Edward Timpson MP Parliamentary Under Secretary of State for Children and Families during his speech at the joint Contact a Family and National Network of Parent Carer Forums held on the 5<sup>th</sup> of November:

*‘We’re reforming the system to put you and your needs at the heart of everything we do. Now, you’ve doubtless heard this before. But the commitment, this time, is unequivocal. It’s there in black and white in the Children and Families Bill, which is currently going through the House of*

*Lords led by clause 19 that says that local authorities “must have regard to the views, wishes and feelings of the child or young person and their parents. And it’s there underpinning the new Code of Practice...”<sup>iii</sup>*

**Much Pathfinder progress has been made in this area and there continues to be a heavy focus on the participation of parent carers across the pathfinder community. Increasingly participation of children and young people in preparing for the reforms is becoming more evident, which has in part been encouraged by the work at a national level of groups such as [EPIC](#)<sup>iv</sup> and [VIPER](#)<sup>v</sup>. As Pathfinders continue to work towards implementing and sustaining the core areas of the reforms, emphasis continues to be placed on the importance of doing this in partnership with parent carers, children and young people. It is important that this approach continues to be viewed as a core thread throughout all Pathfinder work and very much at the heart of the reform programme.**

When we discuss the engagement and participation of parent carers and children and young people with SEND, there are four very specific areas this includes. It is important that local areas embrace all of these, and not one at the exclusion of others. These are:

**1. *Engagement of individual children and young people***

Working in a person centred approach enables children and young people with special educational needs and disabilities to have an active part in their own assessment, planning and service delivery.

**2. *Engagement of individual parent carers and families***

Working with and enabling a meaningful participation of parent carers and families in relation to the assessment, planning and delivery of services for their own individual child and young person with special educational needs and disabilities

**3. *Strategic participation of parent carers***

Parent carer participation in co-production of strategic planning, decision making, commissioning and service evaluation is important. It is essential that Parent Carer Forums are involved in co-producing plans and implementation of the reforms. Over the last five years, the Department for Education (and previously DCSF) has

supported and funded the development of parent carer forums in every region across England. Representatives from the National Network of Parent Carer Forums (NNPCF) and Contact a Family (CaF) work strategically with Department for Education (DfE) and Department of Health (DH) to strengthen and develop Parent Carer Participation and ensure that parent carers become effective partners in strategic planning, decision making and evaluation.. The Forums are also members of the NNPCF and provide the opportunity for feedback at regional and national levels.

#### 4. **Strategic participation of disabled children and young people**

In some areas, there are representative groups of children and young people with special educational needs and disabilities who are enabled to be involved in strategic decision making. Local authorities will need to ensure that there is effective participation by children and young people at the strategic level. In some areas this is already happening. EPIC – a national group of disabled children and young people are currently working with the DfE and DH to model and embed this approach.

**What do the Children and Families Bill, indicative regulations and Code of Practice say? (Last updated December 2013)**

Bill and Supporting Documents			
<a href="#"><u>Children and Families Bill (referenced throughout part 3)<sup>vi</sup></u></a>	<a href="#"><u>Draft SEN Regulations (referenced throughout)<sup>vii</sup></u></a>	<a href="#"><u>Draft SEN Code of Practice (referenced throughout)<sup>viii</sup></u></a>	<a href="#"><u>Consultation on transition to Education, Health and Care plans and the local offer<sup>ix</sup></u></a>

Between the 4<sup>th</sup> October and 9<sup>th</sup> December 2013 there was a national consultation on the draft SEN Code of Practice, draft Regulations and the proposals for transitional arrangements. The DfE stated that:

*‘We will take account of any changes that may be made as result of Parliament’s consideration of the Bill and the responses to consultation in developing versions of the Code of Practice and Regulations, including transitional arrangements. These will then be placed before Parliament for approval in the spring to come into force from September 2014 at the same time as the provisions in the Bill. The results of the consultation and the Department’s response will be published on the Department for Education e-consultation website in spring 2014.’<sup>x</sup>*



Engagement and participation of children, young people, parent carers is a consistent theme across the reforms. Progress within this area will continue to be informed by Pathfinder learning and updated over the life of the programme. Evidence from Pathfinders has supported the development a number of principles, these principles underpin the new system and set out ways of working that Pathfinders, the Strategic Reform Partner and delivery partners including the [National Network of Parent Carer Forums<sup>xi</sup>](#) and [Contact a Family delivery partner<sup>xii</sup>](#), have found key to preparing for implementation of the reforms.

A number of these principles can be found in section 2.2 of the draft SEN CoP; the key headings for this section are included below:

- Involving children, parents and young people in decision making
- Identifying children and young people's needs
- Greater choice and control for parents and young people over their support
- Collaboration between education, health and social care services to provide support
- High quality provision to meet the needs of children and young people with SEN
- Supporting successful preparation for adulthood

The draft SEN CoP focuses on the establishment of a family centred system:

***Within section 3.1, 'A family centred system', of the CoP, it notes that 'Local authorities must ensure that parents and young people are involved in discussions and decisions about every aspect of SEN, planning outcomes and making provision to meet those outcomes and in:***

- *Planning and reviewing the local offer;*
- *Reviewing special educational and social care provision;*
- *Drawing up individual EHC plans, and in reviews and reassessments.*

*Local authorities should work in partnership with health professionals, educational settings (including early years), and other agencies to promote aspiration for children and young people with SEN and to promote positive engagement with children and young people with SEN and their parents. Early years providers, schools and colleges should fully engage parents and/or young people with SEN when drawing up policies that affect them. They must also take steps to ensure that parents and/or young people are actively supported in contributing to assessments, planning and reviewing EHC plans. Schools should ensure that where practical pupils with SEN are represented on class and school forums. Colleges should ensure that students with SEN are similarly represented.*

*Enabling parents to share their knowledge about their child and engage in positive discussion helps to give them confidence that their views and contributions are valued and will be acted upon. At times, parents, teachers and others may have differing expectations of how a child's needs are best met. Sometimes these discussions can be challenging but it is in the child's best interests for a positive dialogue*



*between parents, teachers and others to be maintained, to work through points of difference and agree outcomes.*

*It is very important to engage directly with children and young people to discuss their needs, and plan how they can achieve the best outcomes. This should be integral to all planning for children and young people with SEN throughout their lives. The Children and Families Bill gives significant rights directly to young people once they reach 16. When a young person is over 16, local authorities and other agencies should normally engage directly with the young person, ensuring that as part of the planning process, they identify the relevant people who should be involved, and how to involve them.*

*Parents are often the main carers for young people with SEN, and their views and opinions are important and valid during assessment, planning and reviewing’.*

**Section 3.2, ‘Involving children, young people and parents in decision making’, of the draft SEN CoP notes:** *‘Planning should start with the individual and take account of their wishes and aspirations, the outcomes they seek and the support they need to achieve them. It should enable parents, children and young people to have more control over decisions about their support.*

*Effective planning should help parents, children and young people express their needs, wishes and goals and should:*

- *focus on the child or young person as an individual, not their SEN label;*
- *be easy for children, young people and their parents to understand and use clear ordinary language and images, rather than professional jargon;*
- *highlight the child or young person's strengths and capacities;*
- *enable the child or young person, and those who know them best, to say what they have done, what they are interested in and what outcomes they are seeking in the future;*
- *tailor support to the needs of the individual;*
- *organise assessments to minimise demands on families; and*
- *bring together relevant professionals to discuss and agree together the overall approach.*

*This approach is often referred to as ‘person-centred planning’. Using this approach within a family context, educational settings, professionals and local authorities can ensure that parents, children and young people are genuinely involved in all aspects of planning and decision making. Drawing up a one-page profile of the child or young person can help to ensure that those working with them and their parents have an accessible summary of the information about them, ensuring that EHC plans are developed with the child, young person and parents and reflect aspirational and achievable outcomes.*

*Local authorities must work with young people with SEN directly in preparing and reviewing the local offer, reviewing and planning SEN provision and in the joint commissioning of services. They must ensure that there are arrangements in place to do this effectively, and seek the views directly of young people. This must include the support young people need and want to help them prepare for adulthood. Most young people want their parents, and other family members, to remain involved in their care, and so local authorities should expect also to seek the views of their parents in the majority of cases’.*

**As noted in section 3.4, ‘Parent carer forums’, of the draft SEN CoP:**

**Effective parent participation happens when parents are enabled to work alongside professionals to ensure that:**

- *the engagement and participation of parent carers in the local authority is valued, planned and resourced;*
- *the parent carer forum offers proactive and on-going leadership in parent carer participation;*
- *the participation of parent carers is evident at all stages in the planning, delivery and monitoring of services;*
- *the contribution of parents is recognised, for example, through public recognition, reward and remuneration;*
- *there are clearly described roles for parent carer representatives; and*
- *plans are in place for on-going recruitment and training of parent carer representatives.*

**The importance of participation of parent carers, children and young people continues to be reinforced throughout the draft CoP, for example within section 5.4 ‘Preparing and reviewing the local offer’.**

#### **In Focus – Learning from Pathfinder work including a number of Case Studies (Last updated December 2013)**

All Pathfinders were asked to test and explore how the participation and engagement of parent carers, children and young people could inform and drive the development of all aspects of their Pathfinder programme. Much work has taken place across the country which is documented on local Pathfinder and parent carer forum websites. In addition, a breadth of evidence and good practice is available on a number of voluntary sector organisation’s websites including [Contact a Family](#), [National Network of Parent Carer Forum \(NNPCF\)](#), [EPIC](#) and [VIPER](#) . A brief description of some of these organisations can be found below:

- Contact a Family is a national charity that supports the families of disabled children whatever their condition or disability. Over the last ten years, Contact a Family have supported the development of the parent carer participation agenda and the development of local parent carer forums across England.
- The National Network of Parent Carer Forums (NNPCF) is a parent carer led organisation, whose membership is made up of all of the Parent Carer Forums who are eligible to receive a parent participation grant from the Department for Education. In January 2013, NNPCF and Contact a Family jointly produced a report outlining learning from parent carer forums in Pathfinder areas<sup>xiii</sup>.
- EPIC are a group of 16 disabled young people from across the country who are supported by the Council for Disabled Children to advise the Department for Education on changes to the special educational needs and disabilities (SEND) system.
- VIPER is a three year project, funded by the Big Lottery to research disabled children and young people's participation in decision-making about local services with the aim of improving services used by disabled children and young people in England.

**Part 1** of this document provides detail and examples on '**Parent Carer Co-production, Participation and Consultation**', whilst **Part 2** covers '**Children and Young People Engagement**'. The 'engagement and participation of children, young people, parent carers' theme is at the centre of Pathfinder testing and is the driver behind the other Pathfinder testing themes.

#### ***What have been the key lessons learned to date?***

- It is important that all local authorities involve their local Parent Carer Forums and other local parent carer groups in co-producing, planning and implementing the reforms. Feedback from pathfinders who have successfully coproduced with parent carers is that shifting both parent carer and professional's perspectives to ensure parent carer and children and young people are involved in the development of new approaches and service planning takes a lot of time and commitment. However, is crucial to enable them to develop targeted communications to quickly build awareness of the reforms, widen representation and inspire active membership and adds clear value and focuses professionals on what is important and what really makes a difference.



**A quote from Dr Carrie Britton, SE7 Parent Carer Participation Adviser and Former Co-Chair of the NNPCF:** “This is a cultural change; this is a shift of the hearts and mind. Once people have engaged with it and see that it takes a bit longer but you do actually chew over the issues and come to resolutions that are shared ... it is worth it.”



- Working together properly requires all parties to listen to each other, consider each other's views and respect them.
- It is important to recognise the realities of life for parent carers of children with special education needs and disabilities, especially when setting meeting times, providing frequent communications and providing quick turnaround of expenses and recognition payments.
- Co-production is a dynamic, group process and involves parent carer forums from the start and at every stage.
- It is important to get it right from the start - the development of a 'co-production' framework and principles helps to ensure a consistent approach is established and sustained from the outset.
- Improved outcomes are achieved when parent carers, children and young people co-produce work with practitioners.
- The strategic participation and co-production of parent carers is essential, particularly in relation to commissioning and evaluation of services.
- The positive impact of parents and children and young people having the opportunity to meet each other and increase their confidence to contribute to discussions and be seen as equal partner should not be underestimated.
- The use of targeted focus groups for both parent carers and children and young people has been invaluable in helping professionals learn from those whom the reforms will be affecting on a daily basis. A good example of this can be seen in the Brighton and Hove, Hove Park School case study which can be found on page 29 of this pack.
- It is important to provide training for parent carers and staff about the meaning and benefits of co-production.
- Young people often have the answer about how best to support them, just ask.
- Developing co-produced solutions can reduce potential conflict.
- Regular, honest and open communication is essential to support the development of trust.
- Person centred tools are effective to engage with the child and young person to ensure that their views are fully understood.

### Summary of case studies (Last updated December 2013)

The Mott MacDonald Pathfinder Support Team intends to publish further versions of these SEND Pathfinder Information Packs. As these packs grow in size to reflect the continued progress, the summary table below should help readers to find content relevant to them.

Case Study	Area of Focus	Key Points	Page
<b>Part 1 – Parent Carer Co-production, Participation and Consultation</b>			
<b>South East 7 (SE7) Consortium</b>  <i>Last updated June 2013 (Version 1)</i>	This provides an oversight of the frameworks developed in partnership with parent carers in SE7 and how this has driven Pathfinder testing.	<u>Why is this approach being showcased?</u> The SE7 Consortium has developed a number of regional frameworks which are implemented locally to accommodate local circumstances. All of these frameworks have been developed in partnership with parent carers.  <u>Points of interest</u> <ul style="list-style-type: none"> <li>SE7 SEND Pathfinder Commitment to parent carers.</li> <li>Definition of ‘co-production’ and how this differs from participation and consultation.</li> <li>Link to the SE7 report, ‘Co-production with parent carers: the SE7 experience’.</li> </ul>	<a href="#">15</a>
<b>Contact a Family, NNPCF and Pathfinder Champions case study (Updated)</b>  <i>Last updated December 2013 (version 3)</i>	An overview of a video on co-production	<u>Why is this approach being showcased?</u> The video, introduced by Edward Timpson, the Minister responsible for SEN and Disability within the Department for Education, provides an overview of how parent carer forums, families, young people, local authorities, health commissioners and wider partners have worked closely together to develop outcome-focused, person-centred support for children and young people with SEN and disabilities.  <u>Points of interest</u> <ul style="list-style-type: none"> <li>The impact and benefits of co-production: <a href="http://www.youtube.com/watch?v=Ze-gFplpKFw">http://www.youtube.com/watch?v=Ze-gFplpKFw</a></li> <li>Showcases approaches in three Pathfinders (Leicester City, SE7 and Wiltshire).</li> <li>Provides details on a recently held Co-production: tools, tips and outcomes workshop which includes a selection of useful materials and resources related to co-production and participation.</li> </ul> <i>(New)</i>	<a href="#">20</a>

Case Study	Area of Focus	Key Points	
<b>Brighton &amp; Hove</b> <i>(Updated)</i>  <i>Last updated  December 2013  (version 3)</i>	Overview of an approach by Brighton and Hove's 'improving the confidence of parent carers' work stream.	<p><u>Why is this approach being showcased?</u></p> <p>In order to identify ways to improve provision for children and young people, Brighton &amp; Hove developed a questionnaire for parents and educational setting staff to assess current views, in partnership with VCS organisation <i>Amaze</i>.</p> <p><u>Points of interest</u></p> <ul style="list-style-type: none"> <li>• An approach to seeking feedback from parent carers and educational settings.</li> <li>• Creative activities, such as the creation of SEN parent groups to work more closely with school staff, opportunities for joint training for both parents and staff to learn together.</li> <li>• Mini case study of Hove Park School, where students created audio visual presentations in order to inform Individual Education Plans (IEPs) and teachers' lesson planning.</li> <li>• Details some of the key outcomes for one of the young people taking part in this project including the development of 10 golden rules focused on the key things they feel are the most important for parent carers and staff in educational settings working with children and young people with SEN. <i>(New)</i></li> </ul>	<a href="#">23</a>

<p><b>Snapshots</b></p> <p><i>Last updated September 2013 (version 2)</i></p>	<p>Excerpts at how partnership working is making a difference in other Pathfinder areas.</p>	<p><u>Points of interest</u></p> <ul style="list-style-type: none"> <li>• Bromley's Parent Carer Forum involvement in Bromley's Pathfinder work, including the role of Bromley's Parent Participation Officer acting as a conduit between the Local Authority and the Parent Carer Forum.</li> </ul> <p>Calderdale working in partnership with families, including the positive outcomes achieved by basing the Pathfinder Project Manager within the Calderdale Parent Carers Forum.</p>	<p><a href="#"><u>29</u></a></p>
<p><b>Part 2 – Children and Young People Engagement</b></p>			
<p><b>VIPER research project</b> <i>(New)</i></p>	<p>Three year project aimed at exploring the most effective ways of enabling the participation of disabled children and young people in the development and delivery of services in England.</p>	<p><u>Points of interest:</u></p> <ul style="list-style-type: none"> <li>• VIPER has 16 young researchers aged between 15-24 from across England, all of whom are young disabled people.</li> <li>• This case study details the key findings of the project to date including what is working well and some of the key challenges still to overcome.</li> <li>• Details key recommendations and learnings to take forward.</li> </ul>	<p><a href="#"><u>30</u></a></p>



<b>London Borough of Bromley</b>  <i>Last updated September 2013 (version 2)</i>	Overview of the 'Pupil Voice' research project, which sought how to embed the voice of the young person in the new coordinated assessment process and EHC plan.	<u>Why is this approach being showcased?</u> This is an example of how school staff listened and understood the views of pupils with complex special educational needs in preparation for their EHC plan meeting and how the pupil voice was incorporated within the EHC plan itself.  <u>Points of interest</u> <ul style="list-style-type: none"> <li>• Overview of the Accessible, Collaborative and Evidence-based (ACE) Model.</li> <li>• Duties that a key worker must be able to fulfil outside of the EHC plan meeting.</li> </ul>	<a href="#">34</a>
Case Study	Area of Focus	Key Points	Page
<b>Darlington</b>  <i>Last updated September 2013 (version 2)</i>	Summary of work with Darlington Association on Disability, a local user-led organisation committed to increasing choice and control for disabled people.	<u>Why is this approach being showcased?</u> This is an example of how the reforms were used as the impetus to enable children and young people to participate fully in decisions that affected their lives and to give them ownership of their Education Health and Care (EHC) plan.  <u>Points of interest</u> <ul style="list-style-type: none"> <li>• Examples of children and young people informing developments, including the inclusion of a young person on the 'Key working in Partnership' steering group.</li> </ul>	<a href="#">37</a>

<b>Gateshead</b>  <i>Last updated September 2013 (version 2)</i>	A summary of working with young people with SEND to discover their views of the current statement process and how they could be more involved in the new coordinated assessment process and EHC plan.	<p><u>Why is this approach being showcased?</u></p> <p>This inclusive approach to working with young people to understand their views for the development of new approaches and service planning adds clear value and focuses professionals on what is important and what really makes a difference.</p> <p><u>Points of interest</u></p> <ul style="list-style-type: none"> <li>• Examples of engaging with young people to hear their views, including creating a DVD, hosting breakfast events with Gateshead's Young Council and producing termly 'What's on' guides</li> <li>• A video of Gateshead's approach can be found via the following link:  <a href="http://www.youtube.com/watch?v=jJKoSjYxjO8">http://www.youtube.com/watch?v=jJKoSjYxjO8</a> </li> </ul>	<a href="#">40</a>
<b>Links to other related Pathfinder Information Packs</b>			
<p>The 'engagement and participation of children, young people, and parent carers' theme is at the centre of Pathfinder testing and is the driver behind the other Pathfinder themes:</p> <p><a href="#">0 – 25 Coordinated Assessment Process and Education, Health and Care (EHC) Plan Version 3, December 2013</a></p> <p><a href="#">Joint Commissioning Version 3, December 2013</a></p> <p><a href="#">Personal Budgets, Version 3, December 2013</a></p> <p><a href="#">Preparing for Adulthood, Version 2, December 2013</a></p> <p><a href="#">Local Offer, Version 3, December 2013</a></p>			

### **Part 1 - Parent Carer Co-production, Participation and Consultation (Last updated December 2013)**

The participation and engagement of Parent Carers has informed and shaped Pathfinder developments both at a **strategic** and **individual** level. The case studies below highlight how some of the Pathfinders and VCS partners have explored this aspect and the associated learning.

#### **SE7 Pathfinder Case Study (Last updated June 2013)**

*Much of the content of this case study is derived from the SE7 report '[Co-production with parent carers: the SE7 experience](#)'<sup>xiv</sup> which was developed by Dr Carrie Britton: SE7 Parent Carer Participation Adviser, supported by Mott MacDonald.*

SE7 is a partnership of 7 Local Authorities, their NHS partners, Parent Carer Forums and Voluntary and Community Sector (VCS) partners. An SE7 Steering Group comprises key representatives from each of these partners including elected parent carer representatives. In addition there is an SE7 Parent Carer sub-group which has two representatives from the seven parent carer forums.

Each SE7 area has local arrangements for involving children and young people. For instance the East Sussex Young Inspectors undertook research on what supports young people to be included. To ensure that young people's voices were heard in their regional work SE7 worked with KIDS<sup>xv</sup> to undertake a substantial regional consultation and also to set up the SE7 Young People's Engagement Group. This group has made a film about their hopes and aspirations for the SEND reforms in SE7 and they are now working on two major tasks - to develop an SE7 children and young people's participation charter and to develop with SE7's Local Offer group the preparation for adulthood section of their Local Offer Framework. SE7 has also agreed a [Children and Young People's Participation Framework](#)<sup>xvi</sup> which sits alongside their [Parent Carer Participation Framework](#)<sup>xvii</sup>. Both of these documents can be found on SE7's website.

Within the [SE7 Pathfinder Assessment and Planning Framework](#) it states “**parent carer participation is welcoming parent carers to the strategic decision making process as full partners from the start**”<sup>xviii</sup>.

Further to this, **Contact a Family** and the **National Network of Parent Carer Forums (NNPCF)** with the **South East 7 (SE7)**, **Wiltshire** and **Leicester City** Pathfinder Champions have produced a video on 'co-production' called 'Working Together – our experience of co-production', this can be viewed via the following link: <http://www.youtube.com/watch?v=Ze-gFplpKFw>. Further information can be found in the case study on page 21.

Figure 1 SE7 SEND Pathfinder  
Commitment

Further examples  
of co-production  
materials produced  
by SE7 can be  
found via the  
following link:  
[http://www.se7pa  
thfinder.co.uk/se7  
-useful-links/co-  
production-  
resources](http://www.se7pathfinder.co.uk/se7-useful-links/co-production-resources)

## SE7 SEND Pathfinder Commitment

We promise to all parent carers  
participating in the pathfinder that:

“ We will ensure that you  
and your child are valued  
and treated with respect by everyone  
in the pathfinder.

We will understand your concerns  
and work with you to make things  
better for you and your family.

You and your family will be at the  
centre of the process and there will  
be equality of opportunity to all  
families.

We will recognise your child is a whole  
person. Agencies and practitioners  
will cooperate with each other.

As a pathfinder we won't be  
constrained by what is not possible  
today and will work with you  
creatively to agree and achieve  
outcomes and priorities for you and  
your family.

We will be honest and open with  
you and know that you will be the  
same with us. We will learn together  
with each other and together we will  
develop new and better ways of  
working.

As we work together on the  
Pathfinder parent carers will be  
involved in all of our work including  
decision making at all levels.

We will respect and honour your right  
to use the current legal framework  
at any time during the pathfinder  
and we will assist you to do this. ”

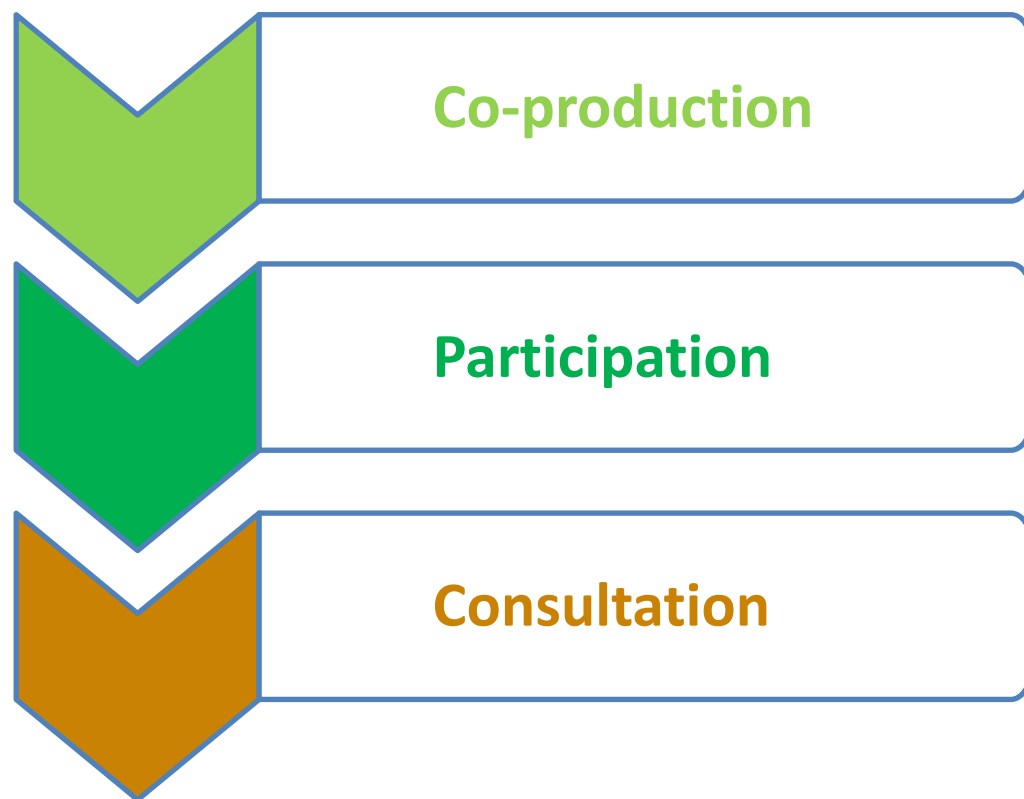


Figure 2 SE7 types of engagement with parent carers <sup>xix</sup>

“Previously I felt very isolated, however through the parent carer forum and the work they are doing I feel like the joined up voice of parents is the way forward.” – SE7 Parent Carer

SE7 produced the following definitions as part of their report into co-production with parent carers in SE7.

**Co-production is:**

“when **all team members together agree outcomes, coproduce recommendations, plans, actions and materials as a collective**. It is an approach which builds upon meaningful participation and assumes effective consultation and information sharing. In its essence, co-production is a dynamic group process and happens in the room when there is equal value for each participant’s contribution and when there is a meaningful proportion of participants who are service users (in this case parent carers) present”.

**Participation is:**

“when **parent carers are involved in meetings to express their views and experiences and take part in the debate**. A range of approaches could be used (citizen’s juries, deliberative mapping, attending decision making meetings). It is 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”.

**Consultation is:**

“**asking parent carers about their response to pre-set questions, strategies or services**. The respondents themselves are not involved with any further stage of the process. A range of approaches might be involved (surveys, public meetings, graffiti boards, Vox Box).”

### Pathfinder background/context

Towards the end of the first 18 months of the SEND Pathfinder programme the SE7 Parent Carer sub group **completed a questionnaire** and also met to **take stock of the progress made to date**; this included an assessment by all attendees against the commitments set out at the beginning of the programme in the [SE7 Parent Carer Participation Statement](#)<sup>xx</sup> A fuller summary of the learning from this can be found within SE7 report '[Co-production with parent carers: the SE7 experience](#)'.<sup>xxi</sup>

The following includes **flavour of feedback** from across the SE7 Pathfinder partnerships on individual's experience of parent carer participation during the first phase of the Pathfinder.



SE7 Parent Carer Forum members



**"Parent carers have been instrumental** in shaping the Education, Health and Care (EHC) plan thus far... Pathfinder parents have given positive feedback to us about their involvement in developing an EHC plan for their child and the quality of the plan." – **Manager**

**"The involvement of parent carers** in the Pathfinder work streams and in co-production of the new pathway we are trialling **has been very successful**. It has brought **the views and perspectives of parent carers' right into the heart of all the planning discussions** and has **challenged existing ways of thinking and talking**. This presents us with real opportunities of **transforming the relationship between the Local Authority and parent carers** and a **change of culture** towards one that sees parents as vital partners in this work." – **Manager**

**"More transparency and honesty** all round. **Less jargon**. More time invested in **relationships** and seeing this as vital, **not an 'add on'**. A shift towards **co-production, not just consultation and participation**." – **Manager**

**"Before SE7, I thought I worked with parents well and understood participation. I have learned so much from the co-production approach. I would never go back to how I did things before: this is about trust and really putting child and family at the heart of what we are doing."** – **Practitioner**



## Key Learning Points<sup>xxii</sup>

A summary of the key learning points for SE7 during the Pathfinder work to date.

- Co-production is a **dynamic, group process** and **involves parent carer forums** from the **start**, and at **every stage**
  - **Agreement of the underpinning framework** and delivery tools is essential from the outset
- Leadership **commitment** is needed throughout the process
- **Training** to underpin the cultural shift needs to provide practical examples, good practice guidelines, and safe rehearsal for dealing with difference. Furthermore, to **widen representation** and inspire active membership of parent carer forums, training resources and support need to be provided
- **Regular meetings** between peers are needed. Local Authority (LA) leads together with parent carer forums gain a wider perspective and develop a shared learning
- **Regular, honest and open communication** is essential to support the development of the trust
- **Consistency in co-production approaches** and valuing all contributions is needed in all meetings
- The **realities of life for parent carers of disabled children should be recognised** when setting meetings times, regular communication and turning around of expenses and recognition payments
- Using **plain language** as far as possible – cut out the jargon and the bureaucratic language



## Contact a Family, NNPCF and Pathfinder Champions Co-production Video Case Study *(Last updated December 2013)*

### **Background/Overview**

**Contact a Family** and the **National Network of Parent Carer Forums** (NNPCF) with the **South East 7 (SE7)**, **Wiltshire** and **Leicester City** Pathfinder Champions have produced a video on 'co-production'. The video, introduced by Edward Timpson, the Minister responsible for SEN and Disability within the Department for Education, provides an overview of how parent carer forums, families, young people, local authorities, health commissioners and wider partners have worked closely together to develop outcome-focused, person-centred support for children and young people with SEN and disabilities. In Pathfinder areas, this culture change has occurred at a strategic level, and the benefits of working in this way being realised.

**Video Link:** <http://www.youtube.com/watch?v=Ze-gFplpKFW>

### **Aims and Outcomes**

The video has been **developed to support local areas** as they plan to transform their services for children and young people with SEND. It is based on the experiences of those Pathfinder partnerships who have contributed to this video. The video seeks to **share the learning of Pathfinder areas**, highlighting the importance of working in co-production with parent carers and young people.

This demonstrates:

- Why co-production works
- How it has worked
- The impact it has had
- The benefits of co-production
- Why those who have worked in this way would not go back.



***What is the key learning to share with others?***

- The confidence to lead Co-production requires a **cultural shift**, but has proved **effective in improving relationships** between families and a range of professionals.
- Long term perspectives are important
- Invest in relationships
- Need to build resilience and family skills
- Co-production **builds trust** between both parties.
- Working together properly requires all parties to **listen** to each other, consider each other's views and **respect** them.
- **Training** for parents and practitioners has helped them to be equal partners.
- **Early investment in time** to coproduce work, strategically and operationally, with parents, lays **strong groundwork** for more effective and person-centered provision and reduces conflict.
- Having parent carers **involved in** making strategic decisions for their child and the service means that services remain **focused on delivering the desired outcomes for children, young people and families**.



**A quote from Leicester City's Pathfinder Lead:**

"There is no going back now, with families in the room everything changes, the plan, the process and the services we are shaping for Leicester. It makes you feel a bit more aspirational because there's still a lot to improve".

**A quote from Ruby Lalor - SE7 Young People's Engagement Group:**

"This is proof that I have been listened to by being in front of all of you today."



### ***‘Co-production: tools, tips and outcomes’ workshops (New)***

SE7 together with Contact a Family, the National Network of Parent Carer Forums and Dr, Carrie Britton hosted two action learning events on co-production in October and November 2013. These events were aimed at groups from local areas (including practitioners, commissioners from both councils and health and local parent carer forum reps). So far two very successful workshops have been held in London and Sheffield. Feedback from these events includes the following comments:



“It has given me ideas on how to engage parents. To ‘challenge’ and ask questions of our Local Offer group and to be more confident as I have more knowledge” ... “It’s been great spending more time with the person who came from the LA. Made me think out of the box more. Learning more about people we work with” ... “Better understanding and tools to start to embed this into SEN work and beyond”



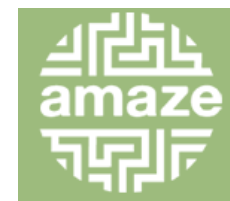
A number of useful documents were shared during these events including the following **(please refer to the Appendix to view these documents):**

- Amaze’s Top 10 Tips for mutually effective partnership working document.
- Write up of ‘Learning from Pathfinder Parent Carer Forums’ event held on the 8<sup>th</sup> of February 2013.
- Leicester City ‘Co-production: Why it works and top tips for parent representatives’ document.
- National Academy for Parenting Practitioners ‘Good practice in working with parents of disabled children’ document.
- NNPCF ‘Markers of good practice in building Parent Carer Participation’ document.
- NHS England ‘Transforming Participation in Health and Care’ presentation.
- Wiltshire Parental Representative Agreement Form.
- Wiltshire Ten Top Tips for Co-production.

#### **Coproduction: Tools, Tips & SEND Reforms – three new workshops for 2014**

Three new workshops are being held in 2014 for non-pathfinder authorities and parent carers. These will be held in London on the 7<sup>th</sup> March 2014, in Birmingham on the 13<sup>th</sup> of March 2014 and in Newcastle on the 20<sup>th</sup> of March 2014. **For more details or to book your place, please contact; Tracy Mander SE7 and SEN & Disability Project Officer email: [tracy.mander@eastsussex.gov.uk](mailto:tracy.mander@eastsussex.gov.uk) or on 01273482967 providing details of any access or dietary requirements.**

## Brighton and Hove Case Study (Last updated December 2013)



### Pathfinder background/context

Brighton and Hove is a South coast unitary authority and is part of the largest SEND Pathfinder consortium, SE7.

SE7 is committed to engaging with children and young people across the consortium, as well as within each Local Authority (LA) area.

### What they did – to improve the confidence of parent carers

Brighton and Hove's 'improving the confidence of parent carers' work stream is led by Amaze's Parent Participation Officer, who is also a parent carer herself and is a member of the LA's Pathfinder team for one day a week.

This parent chaired the 'Working with Parents' Pathfinder group which included head teachers, LA staff and parents as a subgroup of the Pathfinder local change board.

Version 3, December 2013

### Section A – Engagement and involvement

1. When additional support requirements for a student are identified, you involve the parents.	Strongly Disagree	1	2	3	4	5	Strongly Agree
2. In addressing a student's needs, you involve their parents in setting the targets and action plan for the student's Individual Education Plan (IEP).	Strongly Disagree	1	2	3	4	5	Strongly Agree
3. You involve the student and their parents in meetings when the student is discussed.	Strongly Disagree	1	2	3	4	5	Strongly Agree
4. Your school makes students' parents feel welcome whenever they visit.	Strongly Disagree	1	2	3	4	5	Strongly Agree

Figure 3: Example section of Brighton & Hove's educational setting staff questionnaire

This group sought to identify **ways to improve provision** for children and young people, particularly within Brighton & Hove's educational settings. A Local Authority and parental review was undertaken. To support this, Brighton & Hove (including Amaze), supported by Mott MacDonald, **developed a questionnaire for parents and educational setting staff to assess current views** of provision, to help **identify improvements**. The following diagram provides a step-by-step overview of Brighton and Hove's on-going approach to seeking feedback from parent carers and educational settings over the life of the SEND Pathfinder work.

### Step 1 - conducting the questionnaire

- A **short baseline survey** was created with **consistent scoring** and **ranking of answers** for all staff and parents of children with SEN at each of the schools who took part in the survey.
- Evidence gathered about the **current level of parents' confidence** in their child's school. Staff were also asked to complete the survey from their perspective.
- **Seven schools participated** - four primary schools, one with a specialist unit, one junior, one secondary mainstream academy and a special secondary school.
- **Unbiased analysis of the feedback** from both the parents and staff from each school was compiled.

### Step 2 - collating and acting upon the results

- A meeting took place with the SENCOs and senior staff to **consider the results** and how the settings might best improve the confidence of parents further and improve provision.
- Brighton & Hove then worked with each educational setting to **develop an action plan** in response to the survey results. This action plan was **co-produced with parents and staff**, giving them the opportunity to prioritise areas of activity and develop the best ways the educational settings could improve support for their children.
- A common **theme** emerging in all settings was that **parents did not have the opportunity to meet other parents of children with SEN**. Creating these opportunities has led parents to form **new friendships** and provide support for each other. It has also enabled parents to **meet with the SENCO in an informal setting**.
- Staff have also been **able to devise training programmes** for parents tailored to their needs and **make small changes** in ways of working, which have **made a huge difference for families**.

### Step 3 (to be completed next)

- The **initial survey is to be repeated** one year after the first one to **compare with the results of the first survey**, assess improvements made and continue to highlight areas for improvement.



“Building a closer relationship with parents is proving very rewarding as it is crucial we work as a team to support their child's needs.” - **School Staff member**



***What is the key learning to share with others?***

- Although the numbers of surveys returned were not huge, this compared favourably to national response rates for surveys. The results were useful and enabled the identification of **common themes emerging** from the responses gathered.
- One of the common themes identified from the parents of children in years 5 & 6 was the anxiety they felt over the **transition of their children to secondary school**. Many of the parents felt that the schools supported their children very well in the months prior to the move to secondary school and during the school day they were able to manage their anxieties when in the company of their friends. However, when the child or young person was at home the true extent of their often hidden feelings became apparent to their parents who felt equally anxious about the change.
- **All the schools who took part** reported that they **found the exercise useful**. A number of creative new activities have emerged, such as the creation of SEN parent groups to work more closely with school staff, opportunities for **joint training for both parents and staff** to learn together.
- Working much more closely with parents **challenged some schools to rethink how they welcomed parents into the school**.
- One school felt **more confident to ask parents for their opinions** when writing new SEND policies and for their input when planning the curriculum for their children.
- One common theme all the parents identified was the positive impact of having **the opportunity to meet other parents in a similar position** to them. Giving the parents the opportunity to meet others helped to address the isolation that so many parents of children with SEND feel and also helped increase their confidence.
- Brighton and Hove are to learn from the process and **replicate this approach in more schools across the city to leave a legacy of partnership working** which will ultimately leave both parents and schools feeling more confident and lead to a better working relationship.



“Having my 7 year old son diagnosed with dyslexia was very daunting. I lacked the knowledge to know how to deal with things in the most positive and productive way which left me feeling isolated. Communication and support has been a key factor in building our confidence as a family. Meeting other parents in a similar situation (organised by Amaze and school A) has helped me both practically and emotionally. The communication at the school between my son, SENCO, class teacher and us has been brilliant. Everyone has been very open, honest and approachable. Both my son and I are well supported by the school and I feel confident about my son’s future.” – **Brighton & Hove Parent**



### ***Brighton & Hove mini-case study – Hove Park School (Updated)***

#### ***Background***

Hove Park School wanted to improve the following aspects of their engagement and participation with children, young people, parent carers:

- **Further information about the needs of individual students** is shared with staff
- **Offering students greater responsibility** for their own learning
- **Encouraging students to actively reflect** on what would make a difference to their progress

- Offering means for **students to help improve the quality of teaching and provision**
- **Ensure that individual staff are listened to** and **communicate extensively with parents**

To meet these objectives:

**The SENCo sought the support of Head teachers and SEN Governors to trial audio visual presentations** to inform Individual Education Plans (IEPs) and teachers’ lesson planning. This idea was also discussed with three students and their parents, with one parent agreeing to be actively involved in scripting and filming of the audio visual presentations.



The 3 **students planned the content and style of the film clips** with their parents’ support, in order to **structure and present their ideas** to give the maximum impact.

#### ***How has this made a difference?***

Following the development of these audio-visual presentations, each student produced a **45 second film clip** telling staff the things that make the most difference to their learning and giving their **five top tips**. These clips were then uploaded into the school’s IT system for **easy access to all staff**, including supply teachers.



- Brighton and Hove organised a **Pathfinder Pupil and Family Voice day** in November 2012, when **all 3 students talked about their experience of this trial and the positive impact it has made**. A **gradual improvement in their confidence** and the pride in their degree of influence were key outcomes of this activity.
- *(New)* One of the young people, involved in the Pathfinder, George, is now speaking at training events for professionals and parents. On the 22nd November George opened the Amaze yearly event and spoke to the Mayor, parents and professionals about his experience with the Pathfinder and how much using ICT has helped him with learning. ICT was made available to George as a result of his involvement with the Pathfinder. George is also part of the consultation focus group for the Local Offer, representing young people's voice.
- George's messages have been well received and he has written his own Powerpoint presentation. Within his presentation, he outlines the key changes that have occurred as a result of the project including the following:
  - 'My mum's regular contact with the deputy head and SENCo.
  - Parents talking to the school because they know me better than anyone.
  - Teachers checking my understanding of what we are working on.
  - Through the Pathfinder project, being given the use of a computer in the classroom and also in exams and tests.
  - The laptop enables me to get my thoughts down. Using pen and paper disturbs my train of thought and everything stops.
  - Learning Objectives written out for me in a language I can understand.
  - I now have options.



- Learning styles and choices about my education, using methods which aren't actually working for me, are not selected for me by others any more'.



**Colleagues in Education, Health and Social Care have feedback positively on the approach. These are some of their comments:**

"Listening to George was the most useful part of the training".

"George's talk was inspirational and made us think".

"Listening to George made it real and we need to learn to listen to young people as well as colleagues".



### ***Lessons Learnt***

**George often says how much being part of the Pathfinder project has helped him. He is now more confident and has made great progress in school. From his experience, George has developed the following 10 Golden rules for both parent carers and staff in educational settings supporting children and young people with SEN:**

1. 'Listen to the students.
2. Understand how each student learns.
3. Cut and break work up into understandable snippets.
4. Guidelines – provide very precise information about what is required, e.g., boxes on a page to write in.
5. Alter and experiment with different methods/ideas (learning through games on computer for example)
6. Be attentive and proactive to the students' needs.
7. Give learning objectives in a language the student can understand.
8. Provide structure and good behaviour management in the classroom.
9. Use clearer explanations to describe a point - say what you mean.
10. Patience, Patience, Patience: Never give up on a student, WE WILL GET THERE'.

### ***Overall learnings:***

- **Young people often have the answer** about how best to support them.
- The need to **listen and discover student's individual learning styles.**
- **Film clips linked into the school's IT system offer easy and effective access** to all staff and were received positively.

- **Listening to young people and their parents is crucial** to draw up meaningful and effective outcomes.
- **A small change can make a big difference.**
- **It pays off to be creative and innovative.**
- **Flexibility is crucial to provide better support** for children and young people.
- **Opening up communication between school and parent** leads to better understanding, clarity, and transparency.

**Snapshots: A glance at how it's working across the country** (Last updated September 2013)

***Bromley – Bromley Parent Voice and parent carer strategic involvement in Pathfinder work***

Bromley Parent Voice (Bromley's Parent Carer Forum) has been intrinsically involved in Bromley's Pathfinder work:

"The role of [Bromley's] **Parent Participation Officer has been central to the engagement of parent carers** in the Pathfinder project and the implementation of the SEN reforms in the London Borough of Bromley. This role has acted as a conduit between the Local Authority and the Parent Carer Forum and provided parental representation at a strategic level."

Further, the deep strategic and operational level co-production and evaluation of Pathfinder work has led to the following outcomes:

"**Parent participation at a strategic level has enabled co-production through the involvement of the parent carer forum from the start**, and at every stage. Regular meetings between LA leads and parent carer representatives enable a **wider perspective, shared learning and information**. Involving parent carers results in **better outcomes** and experiences for the disabled child or young person and other family members when these groups are involved in shaping the reforms.

"There is evidence that effective Parent Participation resulted in a **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."

**Bromley Parent Voice & Bromley's Parent Participation Officer, Kay Moore**

### **Calderdale - moving to work in partnership with families of disabled children**

Prior to Calderdale becoming a SEND Pathfinder, parent representatives sat on all strategic working groups and Calderdale Parent Carer Forum was represented on the Disabled Children's Strategy Board. In becoming a SEND Pathfinder, a decision was taken to build on this and **base the project manager within Calderdale Parent Carers Forum.**

Basing the project manager within Calderdale Parent Carers forum has allowed **more effective engagement and partnership working with families.** The **project manager is accessible to families** and works with colleagues from within Calderdale. They **identify issues and service successes and feed this into the service developments.** This has informed the development of new systems and processes.

On a daily basis, **Calderdale have been able to respond quickly to any parental concerns as the project manager** is very accessible to families and the practitioners supporting them. Calderdale has also been testing the approach of parents supporting other parents to advocate and champion the importance of partnership working to services. This has involved arranging opportunities for meetings between parents and practitioners informally.



**Calderdale Parent:** "I no longer feel isolated and have made friends with other families and professionals"



### **Part 2 - Children and Young People engagement focused learning (Last updated December 2013)**

The participation of children and young people has informed Pathfinder developments at both individual and strategic level. The case studies below highlight how some of the Pathfinders have explored this aspect and the associated learning.

#### **The VIPER project (New)**

VIPER stands for Voice, Inclusion, Participation, Empowerment, Research. VIPER is a three year project exploring the most effective ways of enabling the participation of disabled children and young people in the development and delivery of services in England. VIPER's project partners include NCB Research Centre, Alliance for Inclusive Education (Allfie), the Council for Disabled Children (CDC) and the Children's Society.



### ***Young researcher's participation***

Young researchers are a central part of VIPER's research project plan. The Vipers have regular meetings during which they learn research skills and give advice around upcoming issues in the research. Currently VIPER has 16 young researchers aged between 15-24 from across England. All the young researchers are young disabled people.

The following information within this case study provides a summary of VIPER's 'Hear Us Out' report which contains a number of research findings and recommendations aimed at bringing about change for young disabled children to improve their lives and empower them to make decisions about their future. The full version of this report can be accessed via the following link:

<http://vipercouncilfordisabledchildren.org.uk/media/7834/hear-us-out.pdf>

### ***Aims of the project:***

The aims of the project are:

- To map how young disabled people are involved in strategic and operational decisions by services
- To understand the barriers, impacts and benefits of young disabled people's participation
- To understand what works for young disabled people's participation
- To produce resources to help professionals support young disabled people's participation

### ***Research Methods:***

The research evidence was collected using a variety of methods:

- A literature review of theory, policy and research literature
- A survey of organisations, agencies, services and projects which involve disabled children and young people in decision making
- Qualitative research in 8 organisations and services across health, education and social care settings in the statutory and voluntary sector in England.

### ***VIPER's Findings...***

- There are many groups of disabled young people who are still being excluded from decision making due to their impairments and a perception they are too hard to work with.
- Funding cuts are having an impact on practice – uncertain future, curtailing of activities, closing of projects.
- Impact frequently anecdotal and therefore easily lost with staff change. Limited evaluation of practice and outcomes.
- Lack of opportunities for disabled young people in mainstream services.

What is working?	What are the challenges?
<ul style="list-style-type: none"><li>• <b>Maximising inclusive practices (social model)</b></li><li>• <b>Embedding participation (not working in silos)</b></li><li>• <b>Empowering young disabled decision makers</b></li><li>• <b>Lots of different approaches to participation</b></li><li>• <b>Encouraging participation</b></li><li>• <b>Evidencing impact</b></li></ul>	<ul style="list-style-type: none"><li>• <b>Definitions of disability</b></li><li>• <b>Self-image of the young people</b></li><li>• <b>Time</b></li><li>• <b>Thinking about wide experience and service level oppose to day-to-day</b></li></ul>

VIPER's recommendations and future objectives focus on the following 4 areas:

#### **1. Lack of understanding:**

- Everyone should have a clear understanding of what disabled young people's participation means.
- All disabled young people should have opportunities to participate in all decisions about their lives, including individual and strategic level decisions. Their participation should influence decisions and bring about change.

#### **2. Inclusion:**

- All young disabled people should have the opportunity to participate in decisions about the services they use, including mainstream services and opportunities. This should include young disabled people who have communication needs, older (18 – 25) and younger (under 12) disabled young people.
- All young disabled people and non-disabled young people should have opportunities participate in decision making together.

### 3. Accessibility:

- Services should meet young disabled people's access needs including disability and age-appropriate support to participate in decision making.

### 4. Feedback and Impact

- Disabled young people should be involved in strategic decisions about services, for example deciding what services to commission.
- Disabled young people should have the opportunity to provide proper feedback about the difference their participation has made.

#### ***Learnings:***

- Social model, can do approach gets better results for all involved
- Everyone buying into engagement with young people it can't just be 1 person's responsibility
- Communicating with young disabled people and their families in accessible ways is key. No acronyms, technical terms and more what it will mean to them in reality.
- Young people need to be involved in the planning around decisions including their views about the materials being used to collect their views.
- Young people need to be respected and their views acknowledged as different from their parents.
- Space and time need to be given so young disabled people
- People like to be involved in lots of different ways
- It is possible to talk about technical things as long as you do it in an interesting and relevant format



London Borough of Bromley Pathfinder  
Case Study (Last updated September 2013)



**Pathfinder background/context**

The London Borough (LB) of Bromley is geographically the largest of the London Boroughs. It has **approximately 1966 children and young people with Statements of SEN**, which represent 2.6% of the population of the borough.

In March 2013 the 'Pupil Voice' research project began, the aim of the work was to further understand how staff in educational settings could ensure that the voice of the young person was embedded in the new coordinated assessment process and EHC plan.

***What they did – Pupil voice research***

In March 2013, research took place within 3 educational settings in Bromley to explore:-

- a) How school staff listened and understood the views of pupils with complex special educational needs (SEN) in preparation for their Education, Health and Care Plan (EHC plan) Meeting
- b) How the pupil voice was incorporated within the EHC plan itself.

It was anticipated that the research findings would lead to further adaptations to the EHC plan and enhance understanding regarding the overall process of assessment and review for pupils with complex needs. Semi-structured interviews were used to work with 5 young people to gain their views and the findings were analysed to identify the following common themes:

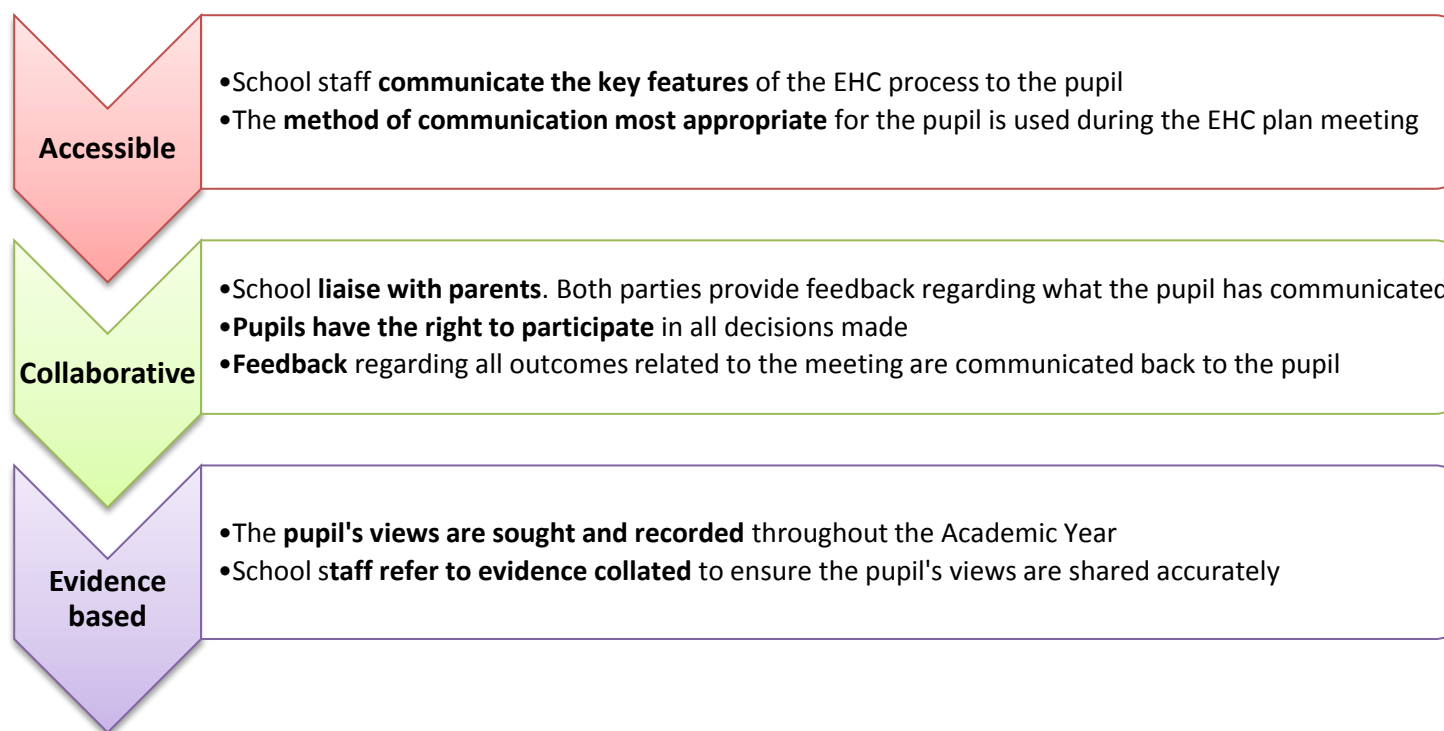


Figure 4: The Accessible, Collaborative and Evidence Based (ACE) Model

***What was the learning from Bromley 'Pupil Voice' research:-***

- Participating schools believe that to get an accurate picture of pupils' views, **evidence must be gathered throughout the academic year** along with the development of **a school culture which encourages all pupils to share their views**.
- The **school's interpretations of pupils' views need to be quantified with the views of parents and outside agencies**. This will reduce the chance of adults stating what they perceive the pupils' views to be which contradicts the actual pupils' views.
- **School staff should use accessible approaches which can be repeated over time** to identify the views of pupils with complex needs.

- An approach needs to be developed to **understanding pupils' views about their health and care** as well as education.
- **Applying the Assessment for Learning (AfL) principles with pupils with complex needs can help to focus on outcomes**, which in turn supports the on-going development of the EHC plan.
- The **key worker must be able to fulfil the following duties** which will take place outside of the EHC plan meeting:-
  - Develop an understanding of the roles, responsibilities and guiding principles of education, health and care professionals.
  - Liaise with key parties to resolve the unresolved issues or decisions which occur outside the meeting.
  - Develop rapport with the pupil prior to the meeting, to ensure their presence does not inhibit the pupil from sharing their views.
  - Fulfil an advocacy role to ensure the pupil's voice is heard.
- **Professionals, parent carers will benefit from information prior to the person-centred SEN review meeting detailing the purpose and structure.** This should further reduce misunderstandings or conflict within the meeting.

### Quotes



**A quote from Lesley - SENCO at a Bromley school:** "I think that's why it's really important to have the pupil fill in their views before the meeting because then everybody can see what they've said and what their wishes are, so it's then very difficult for an adult to hijack the meeting and go off on a different direction..' 'We look at multi-agency input where we can, they don't come at the moment but if they came that would be great and that's really important that we're all working on the same thing, we all understand the same thing, we all know what the priorities are."

**A quote from Lauren – a pupil involved in the research project:** "They've got opportunities throughout the year to have a say, so they have the worry box, the school council, the listening ear, those sorts of things, there's a child who we often quote who says 'we don't need the worry box because we speak to you every day'. There is a lot of air time in our class."



## Darlington Pathfinder Case Study (Last updated September 2013)

### Pathfinder background/context

As a Pathfinder, Darlington made a commitment to ensure that disabled children and young people and those with special educational needs were involved in its development.

One of the guiding principles for the work was that the participation and engagement activities in developing the new coordinated assessment process and EHC plan needed to be meaningful. To achieve this, Darlington Pathfinder worked with a number of organisations within education, health and social care, and externally. One of its key partners has been [Darlington Association on Disability \(DAD\)](#)<sup>xxiii</sup>, which is a local user-led organisation, committed to increasing choice and control for disabled people, including disabled children and young people and those with special educational needs.

### What they did - Consultation and Co-production

Part of DAD's remit is to ensure that children, young people and families are fully engaged in the development of the Darlington Pathfinder strand. These include a young leaders group, which supports members to influence locally and nationally, and a project enabling disabled children to share their experiences and voice their views in relation to play and leisure services.



#### Breaking Through Barriers

Prior to the Pathfinder, project participation in decision making, particularly in relation to education, health and social care, was **not consistent**. Children and young people were **not meaningful** in the statement and education review processes, although there were pockets of good practice. In some schools and colleges there was **no decision making mechanism around health** for disabled children and young people.

Darlington Pathfinder wanted to ensure that the work of the pathfinder was **shaped and directed** by disabled children and young people and those with SEN. They also wanted to ensure that any pathways, documents and policies which developed out of the Pathfinder **enabled children and young people to participate fully in decisions that affected their lives and they had ownership** of the emerging Education Health and Care (EHC) Plan.



## Examples of Children and Young People informing developments

Disabled children and young people and those with SEN, have been involved in **developing and piloting a new EHC plan**. The Pathfinder has piloted several versions of the EHC plan; feedback from children and young people has informed successive versions.

**Person centred tools** are used to engage with the child and young person to ensure that their views are fully explored and included. This has included:

- Preparing a power point presentation.
- Creating a poster.
- Meeting at a place where the child feels comfortable.
- Gathering ideas through crafts or play.

Young Leaders groups supported by the Pathfinder Support Officer have shared their views on the Local Offer and the versions of the EHC plan, which has **informed their development**.

The young person is **invited to the Making Sense meeting** along with their family, at which the draft EHC plan is discussed.

- They present their views and fully participate in discussions.
- They attend the meeting for short or longer periods of time
- They choose how they want to be involved



A young person sits on the 'Key working in Partnership' steering group; this group is **developing the key working model** in Darlington.

All families in Darlington are offered a keyworker to support the development of their EHC plan. The **young person can have a separate keyworker / Participation worker**. For example: a young boy of 11 did not want a keyworker associated with his school. His mother chose a colleague to act as her keyworker; the boy had a Participation worker to support him to think about what he wanted to include in his EHC plan

***What is the key learning to share with others?***

- Early attempts were made to engage young people in the Pathfinder steering group. This did not work, partly because the group met during the day but primarily because **the meetings were not structured in a way to enable meaningful engagement by young people.**
- **Feedback from children and young people** who have received an EHC plan indicates **that they feel more included in the process of developing their EHC plan.** There is evidence that children and young people now feel that they ‘own’ their EHC plan.
- **Some practitioners were uncomfortable with the style and layout of the EHC plans** and protracted negotiations took place, with the outcome that individual concerns were addressed without removing any aspect of the full and

meaningful involvement by the young person in their EHC plan.

- **Using person centred approaches has meant refocusing the document towards outcomes rather than on outputs.** Some practitioners are unfamiliar with an outcomes approach so training has been commissioned to support practitioners to write an EHC plan.
- **The EHC plans now directly correlate to the needs and aspirations expressed by the child.** For example, a young man aged 11 years old during his Making Sense (previously Review) Meeting expressed a view about transport to school which contradicted that of his parents. He wanted to travel to his new secondary school using his wheelchair, accompanied by friends and not to travel – as planned – by taxi. At the meeting a compromise was reached whereby his parent would receive a direct payment for travel to and from school to cover those days where the use of his wheelchair would be difficult due to the weather. The young person would be primarily able to travel to school with his friends and feel part of the group, which was his main priority.



**Following a Making Sense meeting at which an 8 year old boy had attended and shared his views at the start of the meeting the Speech and Language Therapist (SALT) commented:** “It really changed the feeling of the meeting having ‘Jamie’ at the meeting, it reminds you why you are here and that it is about ‘Jamie’.



**Gateshead Pathfinder Case Study (Last updated September 2013)**

**Pathfinder background/ context**

Gateshead's Pathfinder Engagement Group commissioned the authority's Children's Rights Officer and Disabled Children's Involvement Worker to work with young people with SEND to discover their views of the current statement process and how they could be more involved in the new coordinated assessment process and EHC plan. Please find a video of this approach via the following link:

<http://www.youtube.com/watch?v=jJKoSjYxi08>



Version 3, December 2013

**What they did**

Gateshead has consulted with Children & Young People (CYP) with SEND in order to understand their **views of both the current statement process** and how they could become **more involved in developing the new coordinated assessment process and EHC plan**.

The School Council at The Cedars Academy, a special school in Gateshead, was approached for their view by Children's Rights Officer and Disabled Children's Involvement Worker. The following was agreed:



- **A DVD would be one good way for people to hear directly the views and aspirations** of Children and Young People with SEND.
- The Cedars Academy worked with an animation company to create a DVD called 'Thanks for Listening' which has a mixture of interviews and animations using the technique 'stop motion' animation. The pupils devised a storyboard and were given equipment and instructions to make the stop motion animation.
- With the support of a professional to help with editing, **the pupils developed the DVD** themselves and also signed this off once complete.
- They were **all happy with the way that ideas had been communicated** in the DVD and felt that it reflected their views clearly. The DVD was presented to parent carers and professionals at Gateshead's Parent Conference by the young people who had made the film along with their Head Teacher. The DVD has also been shown at team meetings for staff who work with CYP with SEND to raise their awareness of the young people's views.



Wider consultation with CYP has also taken place at **Power Breakfast events organised by Gateshead's Youth Council**. These were focused around specific themes, for example, the Local Offer. As a result of this wider consultation, Gateshead is now producing a termly 'What's On' guide for CYP which is distributed through schools and available online.

***What is the key learning to share with others?***

- During the existing statement process, the views of the CYP were sought but this was not the main focus of the process.
- During the new process, CYP's views are collected by Gateshead's Person Centred Planner, who visits the family at home and wherever possible, the **young person now plays an active part**.
- The **form to support staff in capturing the views of CYP needed to be re-designed to make it more accessible**. There are now two forms, one for CYP who communicate verbally and another one for those who use symbols to communicate.
- **The views, goals and aspirations of the child or young person are now clearly presented in a specific section of the EHC plan**, which is much more accessible.



**A quote from Pat Bolton, Chair, Parents In Power (Gateshead's Parent Carer Forum) talking about the DVD:** "It was moving and honest and we must remember what these young people told us throughout all of the work of the Pathfinder"

**A quote from Delegate at tranSEND Conference:** "Interesting and thought provoking DVD by The Cedars"

**A quote from a student at Cedars Academy:** "Listen to us and make sure every student gets the respect they deserve. Makes sure we all get chances in life to achieve their goals and ambition".





What are the challenges for Pathfinders to address over the coming months? *(Last updated September 2013)*

- **Effective and real co-production, participation and engagement** of parent carers, children and young people **requires a cultural shift** and an **investment of time** by all involved. However, the outcomes are much improved with this way of working and it has proved effective in improving relationships between families and a range of professionals.
- **Some professionals are initially unfamiliar with the new ways of working** which underpin the new coordinated assessment process and EHC plan, such as the more person centred or outcome driven approach. An investment of time and resource is required to ensure the right training to support those individuals involved.
- **Training and meeting opportunities are required for parent carers** to help improve confidence and enables them to co-produce and participate fully.

These challenges are well worth overcoming, as **Sharon Smith, Chair of the Hampshire Parent Carer Network**, highlights:



“The Pathfinder work in Hampshire has offered parent carers a **new opportunity to work at a strategic level with practitioners** in the Local Authority and Health in order to **develop and improve services and working practices**... Parents have been able to provide valuable input and feedback from the beginning of the process, and we hope that our input will mean that the resulting **Pathfinder trials and outputs will benefit families and provide much better outcomes than had we not been involved, or merely consulted at the final stages.**

It has been a **challenging time, requiring a high level of commitment from both parents and practitioners**, and often the planning and discussion stages have taken longer due to parent involvement. However, we strongly believe **it has been worth the commitment and the time** we have all taken to build and develop close working relationships. The trust and positive constructive relationships we have built are now being carried into other non-Pathfinder initiatives. I am confident that although it has taken a long time for us to get here, it has been worth the effort, and **I do not see us returning to a time where parents are merely asked their opinion after decisions have already been made.**”

**Sharon Smith, Chair of the Hampshire Parent Carer Network**



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<sup>i</sup> 'Findings from Parent Carer Forums in pathfinder areas' (Contact a Family & NNPCF report) -

[http://www.cafamily.org.uk/media/656431/pathfinder\\_parent\\_carer\\_forum\\_report\\_final\\_low\\_res\\_2.pdf](http://www.cafamily.org.uk/media/656431/pathfinder_parent_carer_forum_report_final_low_res_2.pdf)

<sup>ii</sup> Indicative Draft: The (0-25) SEN Code of Practice(section 1.1)

<http://media.education.gov.uk/assets/files/pdf/s/sen%20code%20of%20practice%20indicative%20draft%20for%20committee.pdf>

<sup>iii</sup> Quote from Edward Timpson from speech at the joint Contact a Family and National Network of Parent Carer Forums on the 5<sup>th</sup> of November 2013.

<sup>iv</sup> EPIC are a group of 16 disabled young people from across the country who are supported by the Council for Disabled Children to advise the Department for Education on changes to the special educational needs and disabilities (SEND) system. Their website can be accessed here: <http://www.councilfordisabledchildren.org.uk/epic>

<sup>v</sup> VIPER is a three year project, funded by the Big Lottery to research disabled children and young people's participation in decision-making about local services with the aim of improving services used by disabled children and young people in England. The website can be accessed here: <http://www.councilfordisabledchildren.org.uk/viper>

<sup>vi</sup> Children and Families Bill (as amended in public committee), <http://www.publications.parliament.uk/pa/bills/cbill/2012-2013/0168/2013168.pdf>

<sup>vii</sup> Draft (0-25) SEN Regulations.

Link: <https://www.gov.uk/government/consultations/special-educational-needs-sen-code-of-practice-and-regulations>

<sup>viii</sup> Draft(0-25) Special Educational Needs Code of Practice

[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/251839/Draft\\_SEN\\_Code\\_of\\_Practice\\_-\\_statutory\\_guidance.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/251839/Draft_SEN_Code_of_Practice_-_statutory_guidance.pdf)

<sup>ix</sup> Consultation on transition to Education, Health and Care plans and the local offer:

[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/251879/SEN\\_-\\_Transitional\\_arrangements\\_document.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/251879/SEN_-_Transitional_arrangements_document.pdf)

<sup>x</sup> Consultation on DRAFT 0-25 Special Educational Needs (SEN) Code of Practice, Draft Regulations and Transitional Arrangements, Section 4.1 -

[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/251832/SEN\\_consultation\\_document.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/251832/SEN_consultation_document.pdf)

<sup>xi</sup> The National Network of Parent Carer Forums (NNPCF) is a parent carer led organisation, whose membership is made up of all of the Parent Carer Forums who are eligible to receive a parent participation grant from the Department for Education. <http://www.nnpf.org.uk/>

<sup>xii</sup> Contact a Family is a national charity that supports the families of disabled children whatever their condition or disability. Over the last ten years, Contact a Family have supported the development of the parent carer participation agenda and the development of local parent carer forums across England. <http://www.cafamily.org.uk/>

<sup>xiii</sup> 'Findings from Parent Carer Forums in pathfinder areas' (Contact a Family & NNPCF report) -

[http://www.cafamily.org.uk/media/656431/pathfinder\\_parent\\_carer\\_forum\\_report\\_final\\_low\\_res\\_2.pdf](http://www.cafamily.org.uk/media/656431/pathfinder_parent_carer_forum_report_final_low_res_2.pdf)

<sup>xiv</sup> Co-production with parent carers: the SE7 experience <http://se7pathfinder.files.wordpress.com/2013/11/se7-coproduction-final-april-2013.pdf>

<sup>xv</sup> KIDS is a leading disabled children's charity that has been in existence for over 40 years working to enable disabled children and young people and their families to enjoy their lives. <http://www.kids.org.uk/about-us>

<sup>xvi</sup> SE7 Children and Young People Regional Participation Framework <http://se7pathfinder.files.wordpress.com/2013/11/se7-cyp-participation-framework.pdf>

<sup>xvii</sup> SE7 Parent Carer Participation Statement [http://se7pathfinder.files.wordpress.com/2013/11/se7\\_send\\_regional\\_parent\\_carer\\_participation\\_statement.pdf](http://se7pathfinder.files.wordpress.com/2013/11/se7_send_regional_parent_carer_participation_statement.pdf)

<sup>xviii</sup> SE7 SEND Pathfinder Assessment and Planning framework <http://se7pathfinder.files.wordpress.com/2013/12/se7-framework-for-assessment-and-planning-jan-2012.pdf>

<sup>xix</sup> Co-production with parent carers: the SE7 experience <http://se7pathfinder.files.wordpress.com/2013/11/se7-coproduction-final-april-2013.pdf>

<sup>xx</sup> SE7 Parent Carer Participation Statement [http://se7pathfinder.files.wordpress.com/2013/11/se7\\_send\\_regional\\_parent\\_carer\\_participation\\_statement.pdf](http://se7pathfinder.files.wordpress.com/2013/11/se7_send_regional_parent_carer_participation_statement.pdf)

<sup>xxi</sup> Co-production with parent carers: the SE7 experience <http://se7pathfinder.files.wordpress.com/2013/11/se7-coproduction-final-april-2013.pdf>

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<sup>xxii</sup> Co-production with parent carers: the SE7 experience <http://se7pathfinder.files.wordpress.com/2013/11/se7-coproduction-final-april-2013.pdf>  
<sup>xxiii</sup> Darlington Association of Disability website link <http://www.darlingtondisability.org/>

# Glossary

Term	Meaning
CoP	Code of Practice
CCG	Clinical Commissioning Group
CYP	Children and Young People
DH/DoH	Department of Health
EHC plan	Education, Health, and Care plan
ES	Early Support
FE	Further Education
FIS	Family Information Service
FSD	Family Services Directory
ISP	Independent Specialist Provider
Joint Commissioning	Commissioning arrangements that are coordinated or integrated across agencies or groups
JSNA	Joint Strategic Needs Assessment
LA	Local Authority
LDA	Learning Difficulty Assessment
NEET	Not in Education, Employment or Training
Personal Budgets Accelerated Testing Group	A group of the SEND Pathfinders asked to produce a set of case studies on work with families who have received SEN Personal Budgets.
PfA	Preparing for adulthood (both the theme and DfE SEND Delivery Partner - <a href="http://www.preparingforadulthood.org.uk/">http://www.preparingforadulthood.org.uk/</a> )
SE7	South East 7 – a consortium of 7 local areas in the South East of England, acting as a SEND Pathfinder.
SEN	Special Educational Needs
SENCo	SEN Coordinator (based in educational settings)
SEND	Special Educational Needs and Disability
VCS	Voluntary and Community Sector

# RESOURCES

In addition to the resources outlined in notes at the end of each section, below are links to additional resources linked to the SEND Pathfinder Programme.

**SEND Pathfinder Support Team (Mott MacDonald)** – [www.sendpathfinder.co.uk](http://www.sendpathfinder.co.uk)

**Department for Education (DfE) SEND Delivery Partners:**

There are seven Delivery Partners focusing on the following key issues:

- **The Bond consortium:** child mental health - [http://www.youngminds.org.uk/training\\_services/bond](http://www.youngminds.org.uk/training_services/bond)
- **The Early Language Consortium:** early language development - <http://eldp.talkingpoint.org.uk/>
- **The ES Trust with the National Children's Bureau:** early support and key working - <http://ncb.org.uk/early-support>
- **Contact a Family and the National Network of Parent Carer Forums (NNPCF):** parent participation - <http://www.nnpf.org.uk/> & <http://www.cafamily.org.uk/>
- **The National Parent Partnership Network:** supporting Parent Partnership Services - <http://www.parentpartnership.org.uk/>
- **The National Development Team for Inclusion the Council for Disabled Children and Helen Sanderson Associates (Preparing for Adulthood):** preparing for adulthood - <http://preparingforadulthood.org.uk/>
- **The IMPACT consortium:** short breaks delivery - <http://www.shortbreaksnetwork.org.uk/policyandpractice/impact>

**Achievement for All**, a school improvement approach that was piloted in ten local authorities from 2009 - 2011, is also being rolled out nationally - <http://www.afa3as.org.uk/>

**Additional DfE-funded SEND Organisations referenced in these packs:**

**Council for Disabled Children (CDC):** The Council for Disabled Children (CDC) is the umbrella body for the disabled children's sector in England, with links to other UK nations, bringing together the diverse range of organisations that work with and for disabled children to support the development and implementation of policy and practice. CDC has developed some useful resource sheets on SEN and Disability Policy which can be found on their website via the following link <http://www.councilfordisabledchildren.org.uk/resources/cdcs-resources> (please refer to top right hand side of web page).

**In Control:** In Control is a DfE SEND Grant Holder, is a charity supporting organisations implement personalisation. They are one of the organisations supporting the SEN Personal Budgets Accelerated Testing Group - <http://www.in-control.org.uk/>

***The Communication Trust:*** The Communication Trust is a coalition of nearly 50 VCS organisations with expertise in speech, language and communication and has resources to help local authorities develop their local offers -

[https://www.thecommunicationtrust.org.uk/media/154158/resources\\_to\\_support\\_the\\_local\\_offer\\_final\\_version\\_september\\_2013.doc](https://www.thecommunicationtrust.org.uk/media/154158/resources_to_support_the_local_offer_final_version_september_2013.doc)