

SEND Pathfinder Information Pack



Version 4, April 2014 – Engagement and participation of parents carers, children and young people

A word cloud of UK regions and cities, with text oriented vertically and horizontally. The words are in blue and red. The regions and cities included are: Nottinghamshire, Bromley and Bexley, Cornwall and Scilly, Gateshead, Solihull, Manchester, Wiltshire, SE7, Hertfordshire, Devon, Oldham and Rochdale, Greenwich, Southampton, Northamptonshire, Leicester City, Calderdale, North Yorkshire, Trafford, Wigan, and Lewisham.

Nottinghamshire
Bromley and Bexley
Cornwall and Scilly
Gateshead
Solihull
Manchester
Wiltshire
SE7
Hertfordshire
Devon
Oldham and Rochdale
Greenwich
Southampton
Northamptonshire
Leicester City
Calderdale
North Yorkshire
Trafford
Wigan
Lewisham

INTRODUCTION

Background & Context

The pathfinder programme has been running for over 2.5 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.

All areas will need to implement the SEND reforms from September 2014 as outlined within the Children and Families Act (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. A pathfinder champion will be available 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.** On 8 April 2014, Edward Timpson (Parliamentary Under-Secretary of State for Children and Families) and Dr Dan Poulter (Parliamentary Under-Secretary of State at the Department of Health) [wrote to local authority and health leaders](#) with further information on transition arrangements in relation to the reforms. The Department for Education and Department of Health also recently published an updated [implementation pack](#) which outlines the vision for the reforms and contains useful information for strategic leaders. Further information and case studies, together with details of the pathfinder champions, are available at www.sendpathfinder.co.uk.

Information Pack Format & Structure

This fourth version has been updated to reflect the Children and Families Act (2014), draft SEN Code of Practice, draft regulations and the proposals for transitional arrangements which were published in October 2013. It is designed to draw together useful resources and case study learning from the pathfinder programme to support non-pathfinder areas to prepare to implement the SEND reforms themselves. **This month it has been updated to provide top tips for implementation based on a combination of key learning from Pathfinders areas, delivery partners and other VCS organisations including examples of how to use them and associated resources and case studies.**

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 and resource list 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. **Resources and examples from other sources are welcomed and can be incorporated into later versions of the information pack** contact pathfinder@mottmac.com to share your approach and any associated resources.

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Engagement and participation of parent carers, children and young people

Introduction (Last updated April 2014)

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 Special Educational Needs (SEN) regulations and SEN Code of Practice (CoP). This is supported by on-going learning from Pathfinders and other stakeholders including reports and guides that outline the learning from parent carer forums in Pathfinder areasⁱ. This is **version 4**, which **builds upon learning from previous introductory packs** as well as developing more of an illustration of **'How' authorities have carried out these changes**. This is a working document and the latest version can be found on the [SEND Pathfinder website](#)ⁱⁱ. More detailed information will be included in future pathfinder information packs.

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**. 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/ young people should all be **active and equal partners** within any Pathfinder. This requirement relates to all parent carers, children/ 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 draft SEN CoP. Given a **key aim for the new system is for children, and young people to be at the heart of the system**, 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 of a co-produced approach to both individual and strategic decision making.**

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 organisations' websites** including [Contact a Family \(CaF\)](#)ⁱⁱⁱ, [National Network of Parent Carer Forum \(NNPCF\)](#)^{iv}, [EPIC](#)^v and [VIPER](#)^{vi}. A brief description of some of these organisations can be found below:

- **CaF is a national charity that supports the families of disabled children whatever their condition or disability.** Over the last ten years, CaF have supported the development of the parent carer participation agenda and the development of local parent carer forums across England. CaF has written a 'How to guide to parent carer participation' to support parent carer forums, commissioners and managers to develop parent carer participation which can be **downloaded in separate sections on their [resources page by clicking here](#)**^{vii}. In addition to this, CaF

will be publishing an updated version of this guide which will provide detailed information around Parent Carer participation including a **step by step guide** to setting up a sustainable Parent Carer Forum and working together with professionals to improve local services. **This updated guide will be made available on the [Contact a Family website](#)^{viii} in early May 2014.**

- **The NNPCF is a parent carer led organisation**, whose membership is made up of all of the Parent Carer Forums that are eligible to receive a parent participation grant from the Department for Education (DfE). In January 2013, NNPCF and CaF jointly produced a report outlining learning from parent carer forums in Pathfinder areas^{ix}.
- **EPIC is a group of 16 disabled young people from across the country** that 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/ young people's participation in decision-making about local services**, with the aim of improving services used by disabled children/ young people in England. VIPER is currently developing targeted resources to support the participation of disabled children/ young people in decision making within the SEND Pathfinders and wider SEND reforms. It is expected that this will be available by the release of the next information pack.



“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 CaF and NNPCF held on the 5th of November 2013:

‘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 (enacted 13th March 2014), 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...”^x

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, the participation of children/ 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^{xi}](#) and [VIPER^{xii}](#).**

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/ 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.**

'The value of the participation of both parent carers and children/ young people is now widely recognised in the Children and Families Bill (enacted 13th March 2014)

which incorporates this as something local authorities and their partners must promote and support. The Health and Social Care Act (2013) also acts as another level by embedding public and patient involvement at all levels within the NHS'.^{xiii}

What do the Children and Families Act 2014, draft regulations and draft Code of Practice say? (Last updated April 2014)

Act and Supporting Documents				
Children and Families Act 2014 (referenced throughout part 3)^{xiv}	Draft SEN Regulations (referenced throughout)^{xv}	Updated draft SEN Code of Practice (referenced throughout)^{xvi}	Consultation on transition to Education, Health and Care plans and the local offer^{xvii}	Implementing a new 0 to 25 special needs system: LAs and partners. Further Government advice for local authorities and health partners^{xviii}

Between the 4th October and 9th December 2013 there was a national consultation on the draft SEN regulations, CoP, and the proposals for transitional arrangements. The DfE stated:

'We will take account of any changes that may be made as a result of Parliament's consideration of the Bill (enacted 13th March 2014) 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 (enacted March 2014). The results of the consultation and the Department's response will be published on the Department for Education e-consultation website in spring 2014.'^{xxix}

As part of this formal consultation, over a six week period the Council for Disabled Children (CDC) carried out and commissioned 19 focus groups with disabled young people across England on the draft Code of Practice. CDC spoke with a wide range of young people aged 5-25 years. The young people who took part in the focus groups talked to CDC about a range of issues, including: decision making; EHC plans; the Local Offer, transition to adulthood and access to information. Following this a report was written that brings together young people's views from those discussions. [This report can be viewed by clicking here](#)^{xx}.

In April 2014 the DfE and DH published ['Implementing a new 0 to 25 special needs system: LAs and partners. Further Government advice for local authorities and health partners.'](#)^{xxi} This is non-statutory advice to help Local Authorities and their Health partners understand their role in implementing the reforms to the special educational

needs and disability system. Extracts from this document are included within this information pack and referenced accordingly.

This non-statutory guidance ['Implementing a new 0 to 25 special needs system'](#)^{xxii}, specifically notes the following in relation to timescales for local implementation:

- 'April 2014 – September 2015: local authorities involve partners and parents in planning for implementation and delivery of the reformed system.'

In addition to this, further information on involving children, young people and parent carers can be found on page 21 and 22 of the [implementation pack](#)^{xxiii}.

The engagement and participation of children, young people and 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 NNPCF and CaF delivery partner 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^{xxiv}; the key headings for this section are included below:

- Involving children, parents and young people in decision making
- Identifying children/ 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/ young people with SEN
- Supporting successful preparation for adulthood

The draft SEN CoP^{xxv} 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; and*
- *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/ young people with SEN and to

promote positive engagement with children/ 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/ young people to discuss their needs, and plan how they can achieve the best outcomes. This should be integral to all planning for children/ young people with SEN throughout their lives. The Children and Families Bill (enacted 13th March 2014) 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/ young people to have more control over decisions about their support.*

Effective planning should help parents, children/ 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/ 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 ongoing recruitment and training of parent carer representatives*

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



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 worthwhile”.



Individual vs. Strategic Participation (Last updated December 2013)

When we discuss the engagement and participation of parent carers and families and children/ 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:**

1. Individual participation of parent carers and families of children/ young people with SEND	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.
2. Individual participation of children/ young people with SEND	Working in a person centred approach to enable children/ young people with special educational needs and disabilities to actively contribute in their own assessment, planning and service delivery.
3. Strategic participation of parent carers and families of children/ young people with SEND	Ensuring 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 NNPCF and CaF work strategically with the 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 children/ young people with SEND	In some areas, there are representative groups of children/ 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/ young people at the strategic level. In some areas this is already happening. EPIC and VIPER are both currently working with the DfE and DH to model and embed this approach.

Top Tips for Implementation: Learning from Pathfinders (New)

Since September 2011 Pathfinders have been working together with their partners, parent carers and children/ young people to co-produce the new system. These approaches have evolved in light of their collective and individual experiences and the emerging legislation, which is also supplemented by learning from a number of non-pathfinder areas that are also preparing for the implementation of the SEN reforms. **This section**

provides top tips for implementation based on a combination of key learning from Pathfinders areas to date and research and learning from [CaF^{xxvii}](#), the [NNPCF^{xxviii}](#), [EPIC^{xxix}](#) and [VIPER^{xxx}](#), examples of how to use these and associated resources.

Please note that resources and examples from other sources are welcomed and can be incorporated into later versions of the information pack contact pathfinder@mottmac.com to share your approach and any associated resources.

This section has been split into the following three sections:

- **Part 1: Participation of Parent Carers and Children/ young people:** includes overarching tips that should be undertaken regardless of whether participation is strategic or individual.
- **Part 2: Individual Participation of Parent Carers and Children/ young people:** includes tips that should be considered when planning individual participation of Parent Carers and Children/ young people.
- **Part 3: Strategic Participation of Parent Carers and Children/ young people:** includes tips that should be considered when planning strategic participation of Parent Carers and Children/ young people.

Whilst there are a number of similarities between the participation of children/ young people and parent carers both at an individual and at a strategic level, it is important to note that **there are also a number of key differences that should be carefully considered**. In order to reflect these similarities and differences within the table on the following page, ideas and examples of how to implement learning that is similar for both groups have been merged under the heading 'Parents and Carers and Children/ young people' and, where different, have been grouped under the appropriate heading of either 'Parent and Carers' or 'Children/ young people'.

Summary of Top Tips (please note these are not in sequential order)

Please click on the links below for further information and resources:

- [Top Tip 1: Embedding sustainable participation and co-production principles and processes takes time and energy](#)
- [Top Tip 2: It is important to 'take stock' before taking action](#)
- [Top Tip 3: Co-produce a mutual agreement to support individual and strategic participation](#)
- [Top Tip 4: Invest in sustainable engagement processes e.g. guidelines, toolkits and training to develop professionals' and parent carers' skills around individual and strategic participation](#)

- [Top Tip 5: Parent carers and children/ young people need continuity and a single point of contact](#)
- [Top Tip 6: Parent carers and children/ young people need greater choice and control over the support for their child or young person](#)
- [Top Tip 7: Children, Young People and Parent Carers need appropriate support at different stages of a child or young person's development](#)
- [Top Tip 8: It is important to establish clear and transparent strategy and governance arrangements for strategic participation](#)
- [Top Tip 9: It is important to recognise and reward parent carers and children/ young people for their contributions](#)
- [Top Tip 10: Shifting PC, CYP and professional's perspectives takes a time and commitment. However, this is crucial to enable them to develop targeted communications to quickly build awareness of the reforms and widen representation](#)

Part 1: Participation of Parent Carers and Children/ young people (New)

<i>Top Tip 1: Embedding sustainable participation and co-production principles and processes takes time and energy</i>	
<i>Ideas and examples of how to use and/or embed this learning</i>	<i>Examples/ Resources</i>
<p><u>Parents and Carers and Children/ young people:</u></p> <ul style="list-style-type: none"> • Ensure genuine co-production of work from the start, at every stage, across all partners including parents carers, children/ young people so that changes work for all involved and there is a consistent and agreed direction of travel. <ul style="list-style-type: none"> - Take time to understand how participation and co-production works in practice, both at an individual and strategic level. • It is important to consider how to approach this within the context of your locality. • Ensure parent carers, children/ young people and partner agencies have time to build relationships, develop trust and establish sustainable and mutual ways of working together. 	<p><u>Case Studies:</u></p> <ul style="list-style-type: none"> • <u>Stockport Case Study</u> – provides detail around how the parent carer forum and the local authority and its partners have worked together and taken time to embed co-production practices. <p><u>Resources:</u></p> <ul style="list-style-type: none"> • <u>NNPCF, Contact a Family & Pathfinder Champions Co-production Video^{xxxi}</u> – provides an overview of pathfinder champion experiences of co-production, and the benefits this has had for both professionals and parent carers. • <u>Contact a Family 'Key ingredients for successful parent carer participation' Snapshot</u> – summary of CaF's key elements needed for successful parent carer participation.

	<ul style="list-style-type: none"> • Contact a Family's 'How to guide to parent carer participation' can be downloaded in separate sections on their resources page by clicking here^{xxxii}. CaF will be publishing an updated version of this guide which will be made available on the Contact a Family website^{xxxiii} in early May 2014.
Top Tip 2: It is important to 'take stock' before taking action	
Ideas and examples of how to use and/or embed this learning	Examples/ Resources
<p><u>Parent Carers and Children/ young people:</u></p> <ul style="list-style-type: none"> • Before starting this process, review your current position including workforce skills, processes and existing parent carer or children and young person groups that can be drawn upon. <ul style="list-style-type: none"> - Identify existing expertise and skills already within the workforce that can be drawn upon to facilitate participation at an individual/strategic level. - Identify gaps in expertise and skills within your workforce with the aim of investing in the development of sustainable engagement processes to address these. - There is DfE funding for a parent carer forum to be set up in every local area. Funding for parent carer forums was increased to £15,000 per forum in 2014-15 to recognise the increased demands placed on them to help implement the reforms. It is therefore expected that this will be the first point of contact when wanting to involve the views of parent carers in reviewing service delivery. CaF^{xxxiv} is the DfE's delivery partner for parent carer participation and can be contacted for further information and advice on which groups hold the funding and how to work with them. - It is important to consider the ways in which children/ young people are supported to participate. The forums and mechanisms 	<p><u>Case Studies:</u></p> <ul style="list-style-type: none"> • Brighton and Hove Snapshot – details the approach to consulting with parent carers on an ongoing basis to gather feedback around ways to improve provision for children/ young people. • Darlington Case Study – provides detail around Darlington's approach to enabling Children/ young people to inform developments at both an individual and strategic level. <p><u>Resources:</u></p> <ul style="list-style-type: none"> • SE7 Pathfinder 'Co-production with parent carers: the SE7 experience'^{xxxv} - gives an overview of SE7's approach to co-production whereby parent carers were initially brought together to discuss ideas around how they could work together with the LAs, which were later reflected upon to co-produce the SE7 Parent Carer Pathfinder Commitment. • Please also refer to the Bromley Case Study on page 34 in Version 3 of the Engagement and Participation Information Pack.

<p>used are often different from those for parent carers (but not always), for example in the form of focus groups as opposed to a dedicated young persons' forums.</p> <ul style="list-style-type: none"> • Both parties have equal responsibility in making contact, for welcoming any approach and for being open to explore how a relationship can be developed. • Identify a person to lead this work who will be responsible for acting as the lead coordinator between the parent carer/ CYP group, local authority and partners. • Co-produce an action plan across the partnership that sets out key steps towards embedding sustainable participation. 	
<p>Top Tip 3: Co-produce a mutual agreement to support individual and strategic participation</p>	
<p>Ideas and examples of how to use and/or embed this learning</p>	<p>Examples/ Resources</p>
<p><u>Parent carers and Children/ young people:</u></p> <ul style="list-style-type: none"> • Co-produce a mutual agreement/ commitment across the partnership. This should include details around how the partnership will work including local authority and parent carer responsibilities plus details about the remuneration policy. • When drawing up this agreement demands on parent carers/ children/ young people should be accounted for especially, for example, when detailing protocols around setting meeting times, sharing information, considering confidentiality and providing quick turnaround of expenses and recognition payments. 	<p><u>Parent Carers:</u></p> <ul style="list-style-type: none"> • <u>SE7 Regional Parent Carer Participation Statement^{xxxvi}</u> - details SE7's parent carer agreement including responsibilities, recruitment, support and training and payment arrangements. • Brighton and Hove Council and Amaze Parent Participation Charter [Refer to Appendix 1] - details Brighton and Hove's parent carer agreement. • Wiltshire Pathfinder Parent Agreement [Refer to Appendix 2] - These three documents are examples of agreements between parent carers and their local authority. <p><u>Children/ young people:</u></p> <ul style="list-style-type: none"> • <u>SE7 Snapshot</u> – summary of work with SE7's Young Person's Engagement Group and link to <u>SE7's children/ young people's Participation Framework^{xxxvii}</u>.

	<ul style="list-style-type: none"> • SE7 'Thoughts on Involving Children and Young People'^{xxxviii} – contains a collation from ideas arising from a number of SE7 Pathfinder events and from SE7's experience of working with the SE7 Young People's Engagement. • SE7's Young People's Engagement Group Participation Charter^{xxxix} – details SE7's young person's agreement. • SE7 'Children and Young People sharing their views on participation' film (made in partnership with SE7 Children and Young People from SE7 and KIDS^{xl})
Top Tip 4: Invest in sustainable engagement processes e.g. guidelines, toolkits and training to develop professionals' and parent carers' skills around individual and strategic participation	
Ideas and examples of how to use and/or embed this learning	Examples/ Resources
<p><u>Parents and Carers:</u></p> <ul style="list-style-type: none"> • Provide joint training for managers, practitioners and parent carers to help develop a shared sense of values and practices to encourage closer working and problem solving. • Ensure regular training is in place so learning is continuously embedded and refreshed. <p><u>Children/ young people:</u></p> <ul style="list-style-type: none"> • Provide training for managers and practitioners to help staff understand disabled young people's right to participate. • Ensure staff who support young people with SEND's participation have training in the social model of SEND and inclusive participation methods. • Ensure consideration is given to how person centred tools can be used effectively to engage with the child/young person to ensure they can express themselves and that their views are fully understood and listened to. Disabled children/ young people do not 	<p><u>Parent Carers:</u></p> <ul style="list-style-type: none"> • Contact a Family's 'Learning and Events' webpage^{xli} contains information around training opportunities, resources and links to approved trainers. • Contact a Family's 'Top Tips to help you work with professionals and feel in control'^{xlii} – provides tips for parent carers working with professionals. • Resource document containing combined good practice tips and guidance from the NNPCF, Contact a Family and 2013/14 Pathfinder Champion areas [Refer to Appendix 3]. <p><u>Children/ young people:</u></p> <ul style="list-style-type: none"> • VIPER 'About Me' Guide^{xliii} – a useful tool for planning participation, evaluation and exit strategies for young people. VIPER has also linked to some additional useful partner resources.

always realise they have a say and therefore need to be supported in doing so. It is the local authority's responsibility to ensure that those who are seeking the views of children/ young people provide accessible information and develop engagement tools or techniques that are **relevant to children/ young people's age and SEND Type**.

- Establish **clear accountability** about how and where children's/ young people's input will be used and **honesty about what is likely to change as a result**.
- **Ensure consideration is given to the difference between engaging with a child or young person with their parent or carer present and without them present.** In most cases parents and carers are able to communicate more effectively with their child or young person and consequently the outcomes of these communications can be quite different from those between professionals and young people.

- **VIPER's 'Guide to Participation in Decision Making' [Refer to Appendix 4]** – provides guidance and practical tips for effective participation of disabled children and young people.
- [Participation Works 'Evaluating Participation Work' Toolkit^{xliv}](#) – provides useful information on participation techniques for children/ young people and a compilation of sample forms and activities that can be adapted for use.
- [Participation Works 'How to involve children and young people with communication impairments in decision-making'^{xliv}](#) – provides information and ideas about how you can enable children and young people with communication impairments to be involved in decision making.
- [Participation Works 'How to support disabled and non-disabled children and young people to work together in inclusive groups'^{xlvi}](#) – aimed at helping workers who want to ensure that the groups they are working with are inclusive by providing support and advice.
- **Participation Works 'How to Support Inclusive Groups in schools and Other Educational Settings' [Refer to Appendix 5]** - provides guidelines and practical suggestions on how to support the on-going work of schools and other educational settings, seeking to achieve inclusive participation for children and young people in schools.
- **Hertfordshire Children/ young people Engagement Workshop - Example Agenda [Refer to Appendix 6]** – example work plan and agenda for Preparing for Adulthood consultation workshop with children/ young people including example questions.

Part 2: Individual Participation of Parent Carers and Children/ young people (New)

Top Tip 5: Parent carers and children/ young people need continuity and a single point of contact	
Ideas and examples of how to use and/or embed this learning	Examples/ Resources
<p><u>Parents and Carers and Children/ young people:</u></p> <ul style="list-style-type: none"> • Provide continuity and a single point of contact for parent carers, children/ young people in relation to the assessment, planning and delivery of services for the child or young person. • This person should establish how the parent carer, child or young person wishes to be communicated with and the best times for this and have regular contact with them to provide information, links to services and coordination of support across education, health and social care. • Whatever the specific function or role that supports the process or the background and experience of the person fulfilling it, they should not be expected to be specialists in all areas, e.g. across education, health and social care, but they do need to be able to have access to the right specialist support and information at the right time. It is important that this person carries out as many aspects of the role as possible to ensure continuity for the parent carer and child or young person. 	<p><u>Parent Carers and Children/ Young People:</u></p> <ul style="list-style-type: none"> • For examples of how parent carers and children/young people have been involved in provision and outcomes planning please refer to Version 4 of the Coordinated Assessment and Plan and Personal Budgets Information Pack and Version 3 of the Preparing for Adulthood Information Pack.
Top Tip 6: Parent carers and children/ young people need greater choice and control over the support for their child or young person	
Ideas and examples of how to use and/or embed this learning	Examples/ Resources
<p><u>Parent Carers:</u></p> <ul style="list-style-type: none"> • Decisions around EHC plans, the provision to achieve outcomes and the support for a child or young person should be discussed and made in partnership between the professional and parent carer. An environment where all partners work through points of difference 	<p><u>Parent Carers and Children/ Young People:</u></p> <ul style="list-style-type: none"> • For examples of how parent carers and children/ young people have been involved in provision and outcomes planning please refer to Version 4 of the Coordinated Assessment and Plan and Personal Budgets Information Pack

and agree aspirational and achievable outcomes is required.

- **Professionals should provide clear feedback** around how and when the parent carer's views and wishes will be acted upon.
- Professionals providing advice and support to parent carers should always **offer the widest choice of options, ensuring that these are based on available services and support.** The types and level of services and support appropriate and available to individual children/ young people is likely to vary based on need, preference and local provision.
- When discussing options, **professionals should discuss the full implications** of those options so parent carers can make an **informed decision**, knowing all of the facts.

Children/ young people:

- **Engage directly with children/ young people** to discuss their needs, and plan how they can be supported to achieve the best outcomes. This should be integral to all planning for children/ young people with SEN throughout their lives.
- Professionals should **provide clear feedback** on how the child or young person's views and wishes will be acted upon.
- **If the child is under 16, the child and parent carer must be involved in planning.** When a young person reaches the age of 16, as outlined within the Children and Families Act 2014, the local authority is required to **engage with the young person directly** (please note there are a number of exceptions to this). In this case, identification of and direct contact with this young person should be made. It is important to remember that **in most cases the young person and parent carer are both still likely to be involved in discussions.**
- 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/ young

Pack and Version 3 of the Preparing for Adulthood Information Pack.

- SE7 Pathfinder Assessment and Planning Framework^{xlvii} – states “parent carer participation is welcoming parent carers to the strategic decision making process as full partners from the start”

<p>people to have more control over decisions about their support.</p> <ul style="list-style-type: none"> • A ‘person-centred planning’ approach should be used to ensure children/ 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. 	
<p>Top Tip 7: <i>Children, Young People and Parent Carers need appropriate support at different stages of a child or young person’s development</i></p>	
<p><i>Ideas and examples of how to use and/or embed this learning</i></p>	<p><i>Examples/ Resources</i></p>
<p><u>Parents and Carers and Children/ Young People:</u></p> <ul style="list-style-type: none"> • Ensure those working with the parent carer understand the family and child or young person in the context of their life, to recognise and understand the impact of any transitions they may be going through. • Ensure professionals recognise the role of parents and carers in supporting children at points of transition and understand the need for reassurance, advice and support that parents and carers may express at these points, for example, needs will be different for early support and support in preparation for adulthood. • Provide clear, accessible information and advice via the local offer and designated professionals committed to working closely with these families to support key transitions between these stages of development. These professionals’ expertise and experience should be matched, where possible, with the stage of development the child is at. 	<p><u>Parent Carers and Children/ Young People:</u></p> <ul style="list-style-type: none"> • Please refer to <u>Version 4 of the Coordinated Assessment and Plan Information Pack</u> which includes example 0-25 pathways illustrating how the EHC plan, along with the associated outcomes, needs, support and services should change over time as the child or young person develops.

Part 3: Strategic Participation of Parent Carers and Children/ young people (New)

Top Tip 8: It is important to establish clear and transparent strategy and governance arrangements for strategic participation	
Ideas and examples of how to use and/or embed this learning	Examples/ Resources
<p><u>Parent Carers:</u></p> <p>Contact a Family has provided some practical steps that parent carers and practitioners should take when developing strategic participation:</p> <ul style="list-style-type: none"> • ‘Work in partnership with the DfE funded parent carer participation forum. • Write a clear consultation/ participation/ co-production strategy with clear minimum standards of good practice jointly with parent carers and incorporate into the annual Children and Young People’s Plan’. • Parental /carer representation should be considered to be a normal part of decision-making and parent carer forums should always be invited to be represented on boards, committees, working groups, work streams. • A task group of parent carers and practitioners could be established to develop and review a central source of information for parents and professionals. • A permanent task group of parent carers and practitioners could be set up to coordinate all consultations in the area and to feed the results to strategic working groups’. <p><u>Children/ young people:</u></p> <ul style="list-style-type: none"> • Strategically involve children/ young people from the start to enable to impact and shape services and policy decision. • Support and empower children/ young people to take part in strategic participation and feel comfortable in making a contribution. 	<p><u>Parent Carers:</u></p> <ul style="list-style-type: none"> • Calderdale Case Study; Bromley Snapshot - provide detail around how parent carers have been involved in pathfinder work at a strategic level. <p><u>Children/ young people:</u></p> <ul style="list-style-type: none"> • VIPER Project Snapshot – gives a summary of VIPER’s research findings for effective participation of children/ young people.

<ul style="list-style-type: none"> • Ensure you use a full spectrum of children/ young people in terms of both age and type of SEND. • Create sustainable local participation structures for young people with SEND to take part in decision-making about services. • Ensure services promote young people with SEND's participation and demonstrate how they have involved disabled young people in their planning and design. 	
<p><i>Top Tip 9: It is important to recognise and reward parent carers and children/ young people for their contributions</i></p>	
<p><i>Ideas and examples of how to use and/or embed this learning</i></p>	<p><i>Examples/ Resources</i></p>
<p><u>Parent Carers and Children/ young people:</u></p> <ul style="list-style-type: none"> • Account and budget for the costs of maintaining effective parent carer, children/ young people participation in the annual children's service budgets and ensure there are mechanisms in place for this to be reviewed annually to meet extra costs as participation develops. • Pay/reimburse expenses for parent carers, children/ young people for their involvement in strategic decision making. By offering payment for involvement in the process and having an agreement in place demonstrates commitment on both sides and ensures that forums are part of the process. • It is important to recognise that not all parent carers, children/ young people want to be paid for their involvement. • An overall strategy should be agreed between the local authority and local parent carers, children/ young people forum or group, which treats all parent carers, children/ young people equally. 	<p><u>Parent Carers:</u></p> <ul style="list-style-type: none"> • <u>SE7 Regional Parent Carer Participation Statement^{xlvi}</u> - details SE7's parent carer agreement including responsibilities, recruitment, support and training and payment arrangements.

Top Tip 10: Shifting PC, CYP and professional's perspectives takes a time and commitment. However, this is crucial to enable them to develop targeted communications to quickly build awareness of the reforms and widen representation

Ideas and examples of how to use and/or embed this learning	Examples/ Resources
<p><u>Parent Carers and Children/ young people:</u></p> <ul style="list-style-type: none"> • Where possible involve your local parent carers, children/ young people forums or groups in co-producing, planning and implementing the reforms rather than selecting individual parents to participate in consultation to ensure balanced feedback. • Work with your local parent carers, children/ young people forums and representative groups to ensure new members are being attracted and existing members are maintained. This will ensure improvements in services are reflective of the needs of parent carers with children/ young people with <u>all</u> disabilities and also to ensure the workload commitments are shared and therefore sustainable. • This can be done through a number of different ways including setting up dedicated websites, social media, holding family, parent carer, children or young people events and activities and developing promotional materials for use within local media. 	<p><u>Parent Carers:</u></p> <ul style="list-style-type: none"> • Gloucestershire Parent Carer Case Study (sourced from <i>Contact a Family</i>) – example of how a parent carer forum increased its representation. • Leicester City Snapshot - provides an overview of the ongoing work between Leicester City Council and the Parent Carer Forum. • Contact a Family's 'How to guide to parent carer participation' can be downloaded in separate sections on their resources page by clicking here^{xlix}. CaF will be publishing an updated version of this guide which will be made available on the Contact a Family website^l in early May 2014. • Contact a Family 'Health checklist'^{li} - a useful resource for parent groups to help take stock and review the state of the group.

In Focus: Parent Carer Co-production, Participation and Consultation Case Studies (Updated April 2014)

The participation and engagement of Parents and 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 non-pathfinders have explored this aspect and the associated learning.

Stockport Non-Pathfinder Case Study – Co-production with Parent Carers on the 0-25 Programme (New)

Background/ Context:

Stockport is a **non-pathfinder** local authority in the **North West of England**. Stockport's Parent Carer Forum '**Parents in Partnership Stockport**' (**PIPS**) is a parent led group for parents and carers who have children or young people in Stockport with disabilities or additional needs. They work with parents, carers and local organisations in Stockport (statutory, voluntary, private and independent) to **assess, develop, maintain and improve what their children and young people receive**.



Although not a pathfinder, Stockport is currently rolling out the second phase of their 0-25 transformation programme in preparation for the SEND reforms. This programme includes a number of **dedicated work streams** which are listed within **figure 1**. PIPS have had **proactive involvement** in the transformational programme **from the very beginning** and have **worked in co-production with both professionals and providers** to ensure the system meets the needs of local children, young people and their families. **Stockport Council has also recently provided additional funding to PIPs to continue to contribute and help shape this programme.**

The project leads have responsibility for ensuring that the relevant stakeholders for their area of work are engaged (e.g. health colleagues, PIPS, Stockport Advocacy, Early Years Settings and Schools, Providers etc.). A key component in the success of this has been the dynamic relationship that has developed between this group, the Head of SEN and dedicated project and logistics managers.

Figure 1: Stockport's Workstreams

Stockport's Workstreams:

1. CAF/ TAC/ EHC One Common Process
2. Education Design Schools and LA
3. Vocational and Employment Pathways
4. Aspirational Early Years Offer
5. Personal Budgets
6. Travel Assistance Policy
7. Local and Community Offers
8. Health and Care Pathways

Key Actions:

- Each of Stockport's workstreams (see **figure 1 on page 22**) **includes 2 parent carer representatives**. Parents are chosen to represent workstreams based on their previous experience and related knowledge to the area.
- Figure 2 to the right illustrates how PIPS gathers the views and feeds them back into the programme.
- As part of the transformation programme, Stockport has established a **design authority group**, which has the ultimate responsibility of approving the full service blueprint to cover 0-25 services. This group **includes both parent carer representatives and professionals**.
- PIPS works closely with the local authority to ensure materials going out to parent carers contain the right content.
- **PIPS has engaged new members through a number of different activities within the local community** including holding curry nights, coffee mornings and parent groups at the local ball park. This has ensured a good number of parent carers continue to represent the forum. Further to this, PIPS has set up a **closed Facebook group** providing the opportunity for parent carers to provide feedback and discuss their views in confidence.
- PIPs has also **used play sessions to get feedback and input from over 130 families** around the previous system within Stockport, which has been used to inform the new transformation programme.

Two parent representatives have been trained to participate in and contribute to directorate meetings. These parent representatives then report back to parent carers on each of the workstreams.

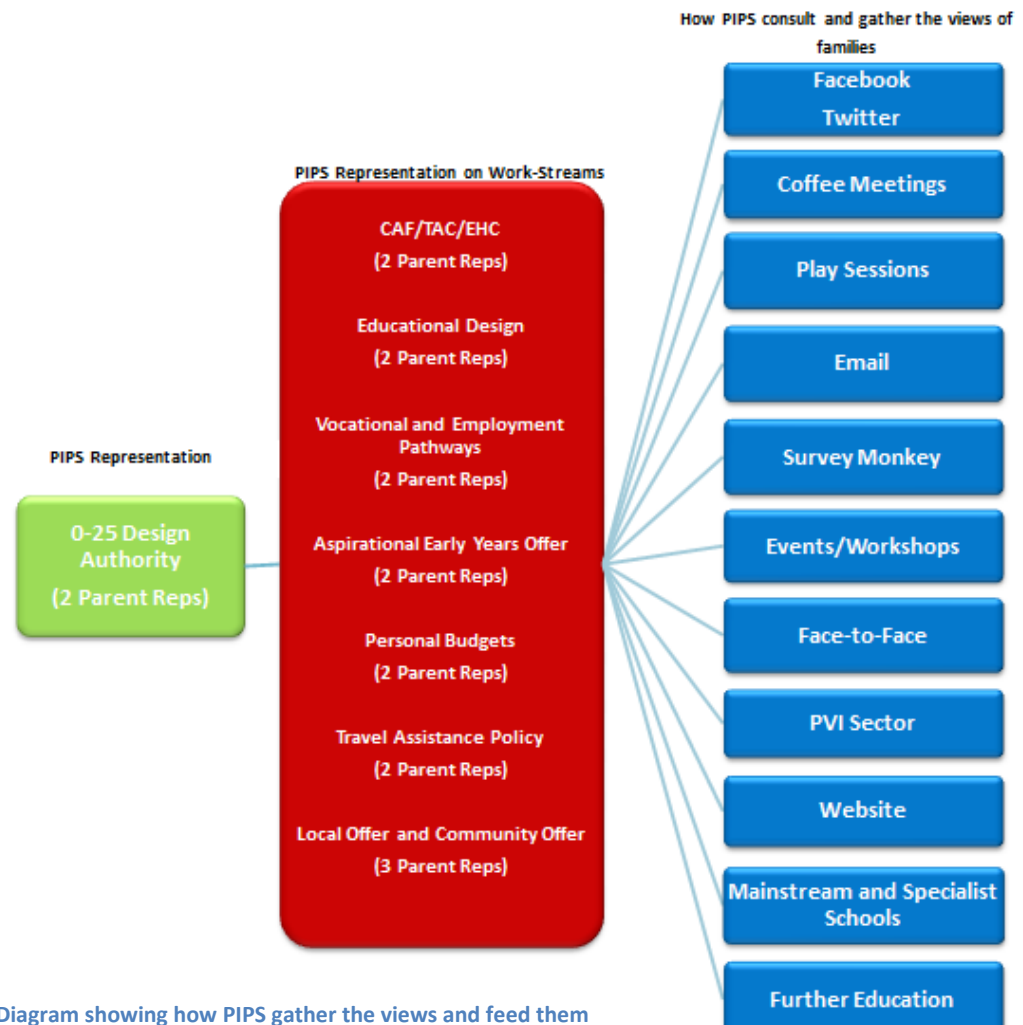


Figure 2: Diagram showing how PIPS gather the views and feed them back into the programme

Lessons Learned:



“Co-production is about working together to find new ways of working. It is about hearts and minds and embedding the process in design, development and delivery” ...“It is important to take a step back and understand what it actually means to co-produce and how you know when you have successfully done so. It is not about having lots of meetings with lots of different people, it is about the outcome of those meetings and the benefits it brings to ensuring parents carers, children/ young people are at the heart of what you do”.

Sherann Hillman Stockport PIPS



- **Don't rush into things**, co-production takes time. Start by holding workshops to explain the nature of co-production and focus on what the gains will be. **Everyone needs to put the effort in to build better relationships and trust** and understand what their role is in developing and sustaining this new way of working.
- **Use joint parent carer and professional training** to challenge legacy working.
- **Ensure commitment of staff at all levels.**
- **Ensure parent carer representatives sit on each workstream and are included in all meetings.**
- **Don't make decisions** and progress work outside of meetings **without buy-in from all partners.**
- It is important to **contextualise co-production** and think of ways to work together **within the existing boundaries**, for example, everyone can't always be sitting round a table, but there are other ways co-production can take place. It is important to **establish the ways in which people can communicate and work together from the beginning.**

Contact a Family's Key Ingredients to Successful Parent Carer Participation (New)

Contact a Family notes that there are four essential ingredients to successful parent participation. Each of these ingredients builds on the other:



1. **Good information (one way communication):** parent carers need timely, clear, accessible and relevant information to access the right services and support for their child/ young person. As part of this, it is important for parent carers and children/ young people to be involved in the shaping and development of the local offer to ensure it meets their needs.
2. **Honest consultation (two way communication):** this could, for example, include getting parent carers feedback to inform the development and improvement of services and communicating the outcome of this consultation back to them along with a detailed explanation of the reasoning for the outcome.
3. **Effective participation (involvement in decision making):** Participation is when parents become involved in the decision making process. For example, a number of local authorities have parent carers on their workstreams, ensuring they are involved in making decisions around service design, planning and commissioning.
4. **Working together to co-produce solutions (working together collectively):** Co-production tends to evolve from participation and is the process of working together as a collective to shape, improve and design services. For co-production to happen, professionals and parent carers need to trust and respect each other and have an equal footing in decision making.

Calderdale Case Study (Last updated April 2014)

Background/Context

Calderdale Parents and Carers (CPC) was set up approximately 10 years ago as a forum, and over time has developed into a charitable organisation that delivers services as well as forum work. CPC has over 400 members, and membership is continually growing. One of CPC's key strengths is the fact that it is long established and is therefore seen, by statutory colleagues, as a key player in the engagement and participation of parent carers. It is one of the three strategic partners leading in the Calderdale Pathfinder, along with the LA and CCG, all of which share good working relationships. It was this long developed relationship that enabled a joint application to be made for the Calderdale Pathfinder.

CPC reviews this charity/forum relationship on an ongoing basis to ensure both are best served and conflicts are minimised. Over the past years CPC's successes in engaging parents have been due to the fact that they continually look at ways to increase membership and encourage parent

carers to be involved. They also look to review the forum and parent representatives periodically to ensure new parents get involved and are happy with how things are working. CPC is currently reviewing not only the forum structure, but parent representative training and induction, remuneration and agreements to ensure they continue to be fit for purpose.

Pathfinder Project Manager and Pathfinder Champion Project Officer employed by CPC

- Prior to Calderdale becoming a SEND Pathfinder, **parent representatives sat on all strategic working groups and CPC** 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 CPC.
- Basing the project manager within CPC has **allowed more effective engagement and partnership working with families**. The project manager has been **accessible to families and works with colleagues from within Calderdale**. The project manager identifies 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 has been able to **respond quickly to any parental concerns** as the project manager has been 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 informal meetings between parents and practitioners.
- Calderdale Parents and Carers now also has **funding to employ a strategic engagement officer to capture families' voices to inform decision making**.

Engaging Parent Carers

Strategic Engagement:

CPC has many different vehicles to enable parents to feel engaged and have their say. These include regular events both within their premises and throughout Calderdale. CPC has also recently developed a specific family room, where it can hold meetings, coffee mornings and other activities. This room also now houses a toy library and offers an

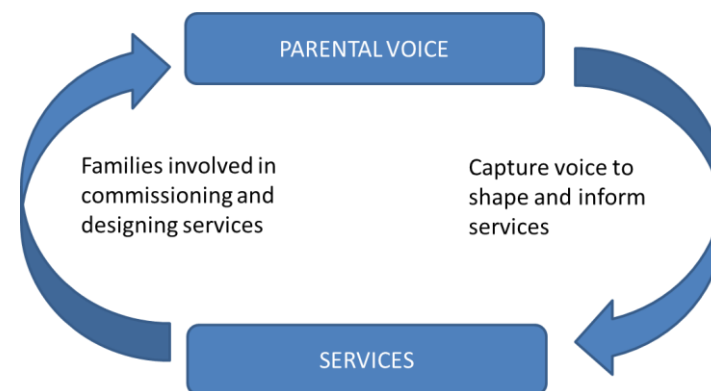


Figure 3 Parental voice shaping and informing services

inviting space where parents and children can try out toys before borrowing them. All parents are encouraged to have their views heard in a number of ways including:

- Contract between CPC and Calderdale LA and CCG to involve families in the development of services.
- Conducting an annual CPC survey which will be used to provide a holistic picture of family needs to help to identify outcomes that are important to families, inform joint commissioning arrangements and feed into commissioning decisions.
- Working with services to run consultation events and questionnaire surveys for a specific objective, for example, when redesigning or commissioning services. Examples of activity include informing the re-commissioning of CAMHS services and wheelchair services, and consultation activity on council budget proposals, which resulted in reductions in savings to the short breaks budget.
- CPC Chief Executive Member sits on the Disabled Children and Young People Strategy Board.
- The strategic planning framework for Calderdale and draft disabled children's strategy show Calderdale's commitment to working with families.
- Parent representation on various work streams and task and finish groups including Pathfinder working groups. These include groups developing the local offer, core offer, personal budgets, participation and engagement, and joint commissioning. CPC aim to increase parent representation on all groups very soon. Calderdale has also facilitated consultation activity around the SEN reforms including the Draft Code of Practice.
- The Participation Officer attends coffee mornings (both CPC's own and others) and family information sessions and works with other colleagues to identify issues. These include 'toast and post' sessions, where parents can 'post' their opinions/views about a specific topic or a general view on CPC's family board in the family room.
- 'Voice boxes' where parent carers can post views confidentially will be in various venues across Calderdale. Contents will be reviewed and inform pro- active consultations.
- An itinerary of information sessions, where colleagues from the LA, CCG or other VCS organisations are invited to meet with parent/carers to inform about changes, services or discuss issues.
- A weekly e-bulletin, Facebook and Twitter are also used to keep members informed.
- CPC is the lead partner in the Inclusive Calderdale magazine, together with the local authority and CCG - a magazine specifically aimed at Parent Carers in Calderdale.

Individual Engagement – involving families in planning their own support:

Calderdale has involved families in planning their own support through a number of different ways including:

- training parent planners supported families to develop plans;
- helping families think creatively about the support they need and the outcomes they want to achieve;
- building relationships between families, providing inspiration and challenging traditional ideas;
- developing links between early years services and CPC to promote resilience and build contacts with other families from the start;
- working with Early Years and Portage staff to develop a person centred plan that links to the EHC plan and focusses on outcomes and supporting families to lead ordinary lives.

A summary of some of the work Calderdale LA and CPC have undertaken can be found below:

The initial development of single plans in Calderdale was undertaken by volunteer families, Parent Planners (trained in person centred planning), and representatives from services, working in partnership together. Parents worked to develop their plans in 'peer groups' based on their child's age. They were supported by the Parent Planners, and by practitioners and commissioners with whom parents were able to discuss family needs. Group working enabled families to support each other through the process, and share ideas and experiences. If they preferred, parents were also offered the choice of working directly with a Parent Planner in a 1:1 setting.

This work has helped to develop the Calderdale's EHC plan format and process. EHC plans have also been undertaken by colleagues in Early Years and transition services. The Parent Planners have also undertaken specific work with groups of young people at transition stage at three 11-18 schools. Person centred thinking training was delivered to all groups to engage them in thinking about their transitions into adulthood and how they could work towards reaching their outcomes. Colleagues from Calderdale MBC have been involved in a number of information sharing sessions held at CPC and within local special schools including sessions on transition to adulthood, future education opportunities and the impact of reforms.

Calderdale is committed to helping parents to feel empowered to enable them to be ready for EHC plans. Much of the work undertaken has been aimed at developing parent carer resilience and to help them to consider aspirational outcomes for children and young people with SEND. As part of this, Calderdale offers the Insider's Guide course which is seen as one of the first steps of this journey. This course is jointly delivered by a trained professionals and trained parent, promoting joint working. CPC is currently developing follow on training for parent carers to look at person centred

approaches. The aim is to help parent carers prepare for outcome planning for their children and to be more confident about being involved in the EHC Plan process.



Parent's Experience of the Coordinated Assessment and Plan Process in Calderdale -

'I am the parent to my ten year old son who is on the autistic spectrum. He attends special school and has significant needs with communication, imagination and cognition. My involvement with the single plan process has had a positive effect on my life and that of my son.

The opportunity to meet and network with other parents, carers and professionals was an excellent way of getting advice and ideas for social activities, expanding my expectations for my son, learning how to network within my own community and believing that things were achievable. Working through the plan process gave me the knowledge and the confidence to believe that things I had previously thought impossible because of lack of support, were possible if the planning was right.

There are a number of positive effects which resulted from the single plan. Before my involvement, my son had very limited out of school activity which gave him little opportunity to socialise and form friendships. Through the single plan process I looked at different activities and opportunities which my son would enjoy and looked at finding the most appropriate support to enable this to happen. For us this was gaining a direct payment for my son to develop some independence from me and learn how to access things with someone new. My son joined a local cubs group and has continued his involvement two years later. He is soon to move up to scouts.

The single plan process helped me reflect upon my local community. I had recently moved and was conscious of feeling isolated especially as my son did not attend the local school and his autism meant it was very difficult for him to form friendships. I developed the confidence and met another local mum who encouraged me to join with the local school out of hours activities, such as school discos. This worked well as my son had just started to have inclusion one afternoon at his local school. This helped us to have a greater presence within the community and stopped me and my son feeling like a stranger where we lived.

Within the home there were some positive ideas too. My son has always found it difficult to sleep in his own bed. After talking to other parents and carers I decided to offer him pocket money to sleep in his bed at night. This worked really well as it gave him a positive reward system and

me a better night's sleep. It doesn't work every night but it is big improvement and my son has learnt a new important skill of sleeping in his own bed.

Working through the single plan process certainly helped me to look at things holistically for my son. It encouraged me to start with the ideas about what my son would like to do then rather than think his disability was a barrier which would prevent him from achieving, to look at things in a real way with real support to make things happen. It has certainly been a very valuable process for us. Having the parent support to guide us through the process was very helpful and we now have a plan on paper that shows my sons strengths and things he needs to work on. It shows his goals and things he would like to achieve in the future. It is something I can share with others and that we can all add too in the future as strengths, weaknesses, goals and achievements change as my son gets older. Overall it has been a very valuable experience and has definitely had a huge benefit to both me and my son'.

”

Gloucestershire Non Pathfinder Case Study (New – sourced from Contact a Family)

Background/Context

Gloucestershire is a large, mainly rural county. The forum is **supported by a part-time parent carer coordinator who reports to the forum's steering group of parent carers**, funded by the local authority and hosted by 'Carers Gloucestershire'. The forum has developed by **encouraging and supporting parents to form into local support groups** (geographical and special interest). Support groups then nominate a parent carer **to represent them on the forum steering group**. The forum wanted to be able to represent the views of a greater number and **wider range of parents, including ethnic minority group and families living in remote rural areas**.

This case study provides insight into how Gloucestershire Parent Carers and Parent Carer Council worked together to increase awareness and broaden representation across the community. [The full case study can be viewed by clicking hereⁱⁱⁱ](#).



Leicester City Pathfinder Case Study (New)

Strategic Parent Carer Involvement

Leicester City has provided an overview of the ongoing work between Leicester City Council and the Parent Carer Forum:

- **At least one parent carer attends each meeting** to represent the Parent Carer Forum which is involved directly in the development of each of the current workstreams (Personal Budgets, Preparing for Adulthood, Coordinated Assessment and Plan and the Local Offer), plus the Steering group.
- In addition to this, other parent carers with particular experience in the workstream areas are on the **email circulation and attend or feedback comments to whoever is attending.**
- The **Parent Carer Forum is then updated monthly** by the attendees together with supporting information from Voluntary Action Leicester (Parent Partnership and Local Offer Compilation) on the latest developments from the meetings as well as **information and updates from the National Network, Mott MacDonald and other partners.** This ensures that a **broad range of parent carers' views are heard** and there is an opportunity for those who do not have the ability to attend all events to feed into these views and keep up to date with developments.
- The Parent Carer Forum has also held **focus groups on particular topics** as they came up and met with the Local Offer Workstream lead, together with Young Person representatives from the Big Mouth Forum, to help **develop the feedback/questionnaire forms for the Local Offer site.**

Please refer to Appendix 7 for Leicester City 'Co-production: Why it works and top tips for parent representatives' document

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

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/ 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. [Please click here to view this video^{liii}.](#)



Bromley Pathfinder Snapshot (Last updated April 2014)

Strategic Parent Carer Involvement

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.

Benefits and Challenges (Updated)

1. Agreement about underpinning framework and delivery tools at outset is important.
2. Commitment of leadership needed throughout process is essential
3. Training to provide practical examples, good practice guidelines and safe rehearsal for dealing with difference and to underpin cultural shift.
4. Regular meetings between LA leads and parent carer forum to gain wider perspective, share learning and information.
5. Resources, support and training for parent carer forum to widen representation skills and active membership.
6. Regular, honest and open communication supports the development of the trust which is so vital
7. Regular and consistent meetings using consistent co-production approach and valuing all contributions
8. Recognition of the realities of life for parent carers of disabled children including setting meetings at convenient times, regular communication and swift turnaround of expenses and recognition payments.
9. Using plain language as far as possible – cut out the jargon and the bureaucratic language.
10. Involving parent carers results in better outcomes for children, young people and their families

Brighton and Hove Pathfinder Snapshot (Last updated December 2013)

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 4 Brighton and Hove Questionnaire

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 ways to improve provision for children/ young people**. This questionnaire is being used to seek feedback from parent carers and educational settings on an ongoing basis over the life of the SEND Pathfinder work. The full case study on the Brighton and Hove's approach can be found on **page 23** of the archived [Engagement and participation of parent carers, children and young people \(Version 3\) information pack](#).

In Focus: Children and Young Person Engagement, Participation and Consultation Case Studies (Updated April 2014)

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



VIPER Project Snapshot (Last updated December 2013)

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/ 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 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**. 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^{liv}](#), 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**. Recommendations from this report have been summarised below. The full case study can be found on **page 30** of the archived [Engagement and participation of parent carers, children and young people \(Version 3\) information pack](#).

Key Learnings:

- 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.
- 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 to participate in decision making together**.
- **Services should meet young disabled people's access needs including disability and age-appropriate support to participate in decision making**.
- 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 get proper feedback about the difference their participation has made**.
- **Everyone needs to buy into engagement with young people** it can't just be one person's responsibility.
- Communicating with young disabled people and their families **in accessible ways** is key. No acronyms, technical terms and more on 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.
- It is possible to talk about technical things as long as you do it in an **interesting and relevant format**.

Further to this, VIPER recently received funding from the Department for Education to carry out research on the effective participation of disabled children and young people including how to engage this group, how to facilitate and/ or address accessibility issues and how to evidence the outcomes and impact of participation activities. This research involved the VIPER young researchers to ensure the resources developed maintain a young person-centred approach. Based on this research, VIPER has produced a **‘Guide to Participation in Decision Making’ [refer to Appendix 4]** which provides guidance and practical tips for effective participation of disabled children and young people and focuses on the following topics:

1. Recruiting disabled young people
2. Meeting young people’s access needs
3. Running the activity or a group
4. Feedback and rewards
5. Keeping disabled
6. VIPER 15 stages to successful participation
7. Who are VIPER



Darlington Pathfinder Case Study (Last updated September 2013)

Pathfinder background/context

As a Pathfinder, Darlington made a commitment to ensure that disabled children/ 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 \(DAD\)^{iv}](#), which is a **local user-led**

organisation, committed to increasing choice and control for disabled people, including disabled children/ 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.

Prior to the Pathfinder, project participation in decision making, particularly in relation to education, health and social care, was **not consistent**. Children/ 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/ young people.



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



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’.



Examples of Children/ 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/ 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/ 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.

SE7 Pathfinder Snapshot (Last Updated July 2013)

Each SE7 area has local arrangements for involving children/ 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^{lvi} 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. [This film can be viewed by clicking here^{lvii}](#). They are now working on two major tasks - to develop an SE7 children/ 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/ young people's Participation Framework^{lviii}](#).**

ⁱ '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, Contact a Family's 'How to guide to parent carer participation' [http://www.cafamily.org.uk/what-we-do/parent-carer-participation/resources-\(general\)/](http://www.cafamily.org.uk/what-we-do/parent-carer-participation/resources-(general)/) and VIPER research <http://www.councilfordisabledchildren.org.uk/viper>

ⁱⁱ SEND Pathfinder website available at www.sendpathfinder.co.uk

ⁱⁱⁱ Contact a Family, national charity that supports the families of disabled children whatever their condition or disability <http://www.cafamily.org.uk/what-we-do/parent-carer-participation/>

^{iv} 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. www.nnpfc.org.uk/

^v 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>

^{vi} 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>

^{vii} Contact a Family's 'How to guide to parent carer participation', available at [http://www.cafamily.org.uk/what-we-do/parent-carer-participation/resources-\(general\)/](http://www.cafamily.org.uk/what-we-do/parent-carer-participation/resources-(general)/)

^{viii} Contact a Family website available at <http://www.cafamily.org.uk/>

^{ix} '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

^x Quote from Edward Timpson from speech at the joint Contact a Family and National Network of Parent Carer Forums on the 5th of November 2013.

^{xi} EPIC website available at <http://www.councilfordisabledchildren.org.uk/EPIC>

^{xii} VIPER website available at <http://www.councilfordisabledchildren.org.uk/VIPER>

^{xiii} Contact a Family updated 'Parent Carer Guide' (due to be released early May 2014 on the Contact a Family website <http://www.cafamily.org.uk/>)

^{xiv} Children and Families Act 2014 <http://www.legislation.gov.uk/ukpga/2014/6/contents/enacted>

^{xv} Draft SEN Regulations Link: <https://www.gov.uk/government/consultations/special-educational-needs-sen-code-of-practice-and-regulations>

^{xvi} Updated draft(0-25) Special Educational Needs Code of Practice <https://www.education.gov.uk/consultations/downloadableDocs/SEN%20Code%20of%20Practice1.pdf>

^{xvii} 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

^{xviii} Implementing the 0 to 25 special needs system: advice for local authorities and health partners, April 2014.

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/301779/Implementing_a_new_0_to_25_special_needs_system_LAs_and_partners_-_April_2014_v2.pdf

^{xix} Consultation on DRAFT 0-25 Special Educational Needs (SEN) Code of Practice, regulations and Transitional Arrangements, Section 4.1 -

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/251832/SEN_consultation_document.pdf

^{xx} Council for Disabled Children's Draft 0-25 special educational needs (SEN) Code of Practice: disabled young people's views

http://www.councilfordisabledchildren.org.uk/media/528850/draft-0-25-special-educational-needs-sen-draft-code-of-practice-participation_young-peoples-views.pdf?_sm_au=iMV54nFbLW0HK6jM

^{xxi} Implementing the 0 to 25 special needs system: advice for local authorities and health partners, April 2014.

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/301779/Implementing_a_new_0_to_25_special_needs_system_LAs_and_partners_-_April_2014_v2.pdf

^{xxii} Implementing the 0 to 25 special needs system: advice for local authorities and health partners, April 2014.

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/301779/Implementing_a_new_0_to_25_special_needs_system_LAs_and_partners_-_April_2014_v2.pdf

^{xxiii} Implementing the 0 to 25 special needs system: advice for local authorities and health partners, April 2014.

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/301779/Implementing_a_new_0_to_25_special_needs_system_LAs_and_partners_-_April_2014_v2.pdf

xxiv Draft Special Educational Needs (SEN) Code of Practice: for 0 to 25 years

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/251839/Draft_SEN_Code_of_Practice_-_statutory_guidance.pdf

^{xxv} Draft Special Educational Needs (SEN) Code of Practice: for 0 to 25 years

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/251839/Draft_SEN_Code_of_Practice_-_statutory_guidance.pdf

xxvi Draft Special Educational Needs (SEN) Code of Practice: for 0 to 25 years

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/251839/Draft_SEN_Code_of_Practice_-_statutory_guidance.pdf

xxvii Contact a Family website available at <http://www.cafamily.org.uk/>

xxviii National Network of Parent Carer Forums website <http://www.nnpcf.org.uk/>

xxix EPIC website <http://www.councilfordisabledchildren.org.uk/epic>

^{xxx} VIPER website <http://viper.councilfordisabledchildren.org.uk/>

xxxii Contact a Family, NNPCF and Pathfinder Champions Co-production 'Working Together' Video <https://www.youtube.com/watch?v=Ze-gFplpKFw>

xxxix Contact a Family's 'How to guide to parent carer participation', available at [http://www.cafamily.org.uk/what-we-do/parent-carer-participation/resources-\(general\)/](http://www.cafamily.org.uk/what-we-do/parent-carer-participation/resources-(general)/)

xxxiii Contact a Family website available at <http://www.cafamily.org.uk/>

xxxiv Contact a Family website available at <http://www.cafamily.org.uk/>

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

SE7 Parent Carer Participation Statement http://se7pathfinder.files.wordpress.com/2013/11/se7_send_regional_parent_carer_participation_statement.pdf

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

xxxviii SE7's Thoughts on Involving Children and Young People <http://se7pathfinder.files.wordpress.com/2014/03/thoughts-on-involving-children-and-young-peoples-copy.pdf>

SE7's Young People's Engagement Group Participation Charter <http://se7pathfinder.files.wordpress.com/2014/03/draft-se7-young-peoples-charter-march-2014-copy.pdf>

^{xl} 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>

^{xli} Contact a Family's learning and events webpage <http://www.cafamily.org.uk/what-we-do/parent-carer-participation/learning-and-events-for-forums/>

xlii Contact a Family's 'Top Tips to help you work with professionals and feel in control' http://www.cafamily.org.uk/media/679153/carers_family_and_friends_helping_you_work_with_professionals_and_feel_in_control_top_tips.pdf

^{xliii} VIPER 'About Me' Guide <http://viper.councilfordisabledchildren.org.uk/resources/resources-from-this-project/> sm au =iHVNQVgtWTvfqwFH

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- ^{xliv} Participation Works ‘Evaluating Participation Work’ Toolkit http://www.participationworks.org.uk/files/webfm/files/resources/k-items/participationworks/diy_evaluation_toolkit/diy_evaluation_toolkit.pdf?sm_au=iHVNQVqtWTvfqwFH
- ^{xlvi} Participation Works ‘How to involve children and young people with communication impairments in decision-making’ <http://www.participationworks.org.uk/resources/how-to-involve-children-and-young-people-with-communication-impairments-in-decision-making>
- ^{xlvi} Participation Works ‘How to support disabled and non-disabled children and young people to work together in inclusive groups’ <http://www.participationworks.org.uk/resources/how-to-support-disabled-and-non-disabled-children-and-young-people-to-work-together-in-inc>
- ^{xlvi} SE7 SEND Pathfinder Assessment and Planning framework <http://se7pathfinder.files.wordpress.com/2013/12/se7-framework-for-assessment-and-planning-jan-2012.pdf>
- ^{xlvi} SE7 Parent Carer Participation Statement http://se7pathfinder.files.wordpress.com/2013/11/se7_send_regional_parent_carer_participation_statement.pdf
- ^{xlvi} Contact a Family’s ‘How to guide to parent carer participation’, available at [http://www.cafamily.org.uk/what-we-do/parent-carer-participation/resources-\(general\)/](http://www.cafamily.org.uk/what-we-do/parent-carer-participation/resources-(general)/)
- ⁱ Contact a Family website available at <http://www.cafamily.org.uk/>
- ^{li} Contact a Family ‘Health Checklist’ http://www.cafamily.org.uk/media/746890/goup_development_information_master_jan_2014_pdf.pdf
- ^{lii} Gloucestershire Non-Pathfinder Case Study (*sourced from Contact a Family*) http://www.cafamily.org.uk/media/689379/parent_carer_participation_case_study_gloucestershire_representing_a_diverse_range_of_parent_experience.pdf
- ^{liii} Contact a Family, NNPCF and Pathfinder Champions Co-production ‘Working Together’ Video <https://www.youtube.com/watch?v=Ze-gFplpKFw>
- ^{liii} VIPER Hear Us Out Report http://vipercouncilfordisabledchildren.org.uk/media/7834/hear-us-out.pdf?sm_au=iMV54nFbLW0HK6jM
- ^{liii} Darlington Association of Disability website link <http://www.darlingtondisability.org/>
- ^{liii} 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>
- ^{liii} ‘SE7 Children and Young People sharing their views on participation’ film <http://www.youtube.com/watch?v=atck5kEixGI&feature=youtu.be>
- ^{liii} SE7 Children and Young People Regional Participation Framework <http://se7pathfinder.files.wordpress.com/2013/11/se7-cyp-participation-framework.pdf>

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 - http://www.preparingforadulthood.org.uk/)
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 within the information packs, below are links to additional resources linked to the SEND Pathfinder Programme.

Support offer available to local authorities and their partners in 2014-15 to help prepare for implementation of the SEND reforms: On 8 April 2014, Edward Timpson (Parliamentary Under-Secretary of State for Children and Families) and Dr Dan Poulter (Parliamentary Under-Secretary of State at the Department of Health) [wrote to local authority and health leaders](#) with further information on transition arrangements in relation to the reforms. The Department for Education and Department of Health also recently published an updated [implementation pack](#) which outlines the vision for the reforms and contains useful information for strategic leaders.

Strategic Reform Partner - 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 a number of useful resources which can be found on their website via the following link <http://www.councilfordisabledchildren.org.uk/resources/cdcs-resources>

SEND Pathfinder Support Team (Mott MacDonald) – Further information and case studies, together with details of the pathfinder champions, are available at www.sendpathfinder.co.uk

Department for Education (DfE) SEND Delivery Partners:

There are seven Delivery Partners focusing on the following areas:

- **The Bond consortium:** child mental health - 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:

VIPER: 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>

EPIC: 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>

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 - <https://www.thecommunicationtrust.org.uk>

The Dyslexia SPLD Trust: The Dyslexia-SpLD-Trust is a collaboration of voluntary and community organisations with funding from the Department for Education to provide reliable information to parents, teachers, schools and the wider sector. It acts as the important communication channel between government, leading dyslexia organisations, parents, schools, colleges, teachers and the sector- <http://www.thedyslexia-spldtrust.org.uk/>