

Co-production with parent carers: the SE7 experience

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What is SE7?

SE7 is a collective of seven local authorities in the South East of England who have a history of joint working and have agreed to work together to test the Special Educational Needs and Disability reforms¹ as a single Pathfinder. Working together with 4 PCT clusters, the seven local authority areas include Brighton and Hove, East Sussex, Kent, Hampshire, Medway, Surrey and West Sussex as seen below.

The SE7 Regional Steering Group comprises key representatives from each local authority area, education, social care and health leads, the strategic health authority, national and local representatives from the community and voluntary sector and

elected parent carer representatives. There are a number of regional sub groups that feed directly into this group. The SE7 Parent Carer sub group is one of these and involves two representatives from each of the seven parent carer forums in SE7 and the parent carer adviser. This group has met every six weeks to regularly share ideas, work plans, challenges and solutions from working across the SE7 workstreams, and from the wider experience of families during this period of national and local change. It has also served as a focus of peer support and building good practice for forums and outreach to pathfinder families. In order to build wider regional awareness of the progress and direction of the Pathfinder work, alternate meetings have included other parent carer forums from the regional group of the National Network for Parent Carer Forums (NNPCF).

Figure 1
Map showing SE7 areas



¹ 'Support and Aspiration: A new approach to special education needs and disability' Green Paper

What is co-production?

Co-production is one approach within Participation and in SE7 'Parent Carer Participation is welcoming parent carers to the strategic decision making process as full partners from the start'². 'Co-production is about trust', (parent carer³) and builds upon transparency, open communication and equal value being given to each participant's contribution. Co-production happens when all team members together agree outcomes, co-produce recommendations, plans, actions and materials as a collective. It is an approach which builds upon meaningful participation and assumes effective consultation and information sharing. In its essence, co-production is a dynamic group process and happens in the room when there is equal value for each participant's contribution and when there is a meaningful proportion of participants who are service users (in this case parent carers) present. Parent carers are not there just to illustrate the experiences of services users but rather to take responsibility to help shape future experiences and be an active part of delivering the solutions.

See the glossary for definition of consultation, participation and range of different tools that could be used.



All participants seek to understand different viewpoints and use a solution focused approach to agree 'fit for purpose' outcomes, and collectively action plan to achieve these. Co-production means doing things differently. It shifts perspectives, and meaningfully puts the child and family central to collective effort.

Co-production is a learning process which:

- Develops over time and is a complex option;
- Blends a range of expertise and perspectives and involves difference;
- Is driven by a solution-focused approach from all participants.

And requires:

- Strong leadership, patience and joint commitment;
- Communication that is transparent and open;
- Relationships that are equitable and respectful to help the team overcome complex challenges.

² Cited in the SE7 SEND Pathfinder Assessment and Planning Framework

³ Lara Roberts, Co Chair of West Sussex Parents Forum

What we did in SE7

1. Reach consensus agreement about practicalities

Personal willingness to work collaboratively is a starting point, and commitment of leaders is essential. In SE7 we developed agreements and standards at the outset so that there was a consistency in regional work. Building upon the initial September 2011 briefing statement for Pathfinders⁴, the SE7 SEND Parent Carer Participation Framework was agreed in November 2011 and established a consistent set of mutual commitments and expectations. The framework outlined a two way set of responsibilities between SE7 and parent carer forums. For example the forums agreed to ensure they improved their outreach to other parent carer groups and the wider community of families of children and young people with additional needs, while SE7 made a commitment to operate in the following way:

- Meetings will be held at convenient times to allow parent carers to participate.
- Meetings will have clear terms of reference.

- Meetings will have clear agendas which are distributed with the appropriate papers in sufficient time for parent carers to be able to read and digest them.
- Papers will be written in plain English.
- Abbreviations and jargon will be avoided or, if necessarily included, they will be explained.
- Notes of meetings will be clear with action points and agreements identified. They will be distributed as soon as possible after the meeting.
- Parent carers will abide by confidentiality agreements in the same way as staff members are required to do.
- Appointments to posts specifically for the Pathfinder will involve parent carers in the full appointment process including short listing and interviews. Parent carers will be full and equal members of the appointment panels.
- Expenses will be reimbursed according to the relevant policy – regional or local.
- Recompense for their contribution will be made to parent carers according to the regional statement or local policy as appropriate.

As part of this agreement, and recognising the input from parent carer representatives from the forums, SE7 established a regional ‘Reward and Remuneration’⁵ policy that paid travel and child care costs incurred by parent carers and paid a set amount for their time and contribution to regional activities. It always remained the responsibility of individual parent carers to check with the Department for Work and Pensions (DWP), the tax office and other advisers about whether any payment might impact their existing benefits or tax position. Local areas developed local policies for representatives taking part in local pathfinder activities.

⁴ ‘Markers for Good Practice in Participation’ This document formed part of the initial briefing for pathfinder leads at the Department of Education in September 2011 by the National Network for Parent Carer Forums

⁵ SE7 Parent Carer Participation Statement

2. Agree SE7 Pathfinder Commitment

Parent carers and the Regional Steering Group together agreed the [SE7 Pathfinder Commitment](#) for families taking part in Pathfinder activity. These aspirational promises have underpinned all regional work, and influenced local delivery.

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

- We will ensure that you and your child are valued and treated with respect by everyone in the pathfinder.
- We will understand your concerns and work with you to make things better for you and your family.
- You and your family will be at the centre of the process and there will be equality of opportunity to all families.
- We will recognise your child is a whole person. Agencies and practitioners will cooperate with each other.
- As a pathfinder we won't be constrained by what is not possible today and will work with you creatively to agree and achieve outcomes and priorities for you and your family.
- We will be honest and open with you and know that you will be the same with us. We will learn together with each other and together we will develop new and better ways of working.

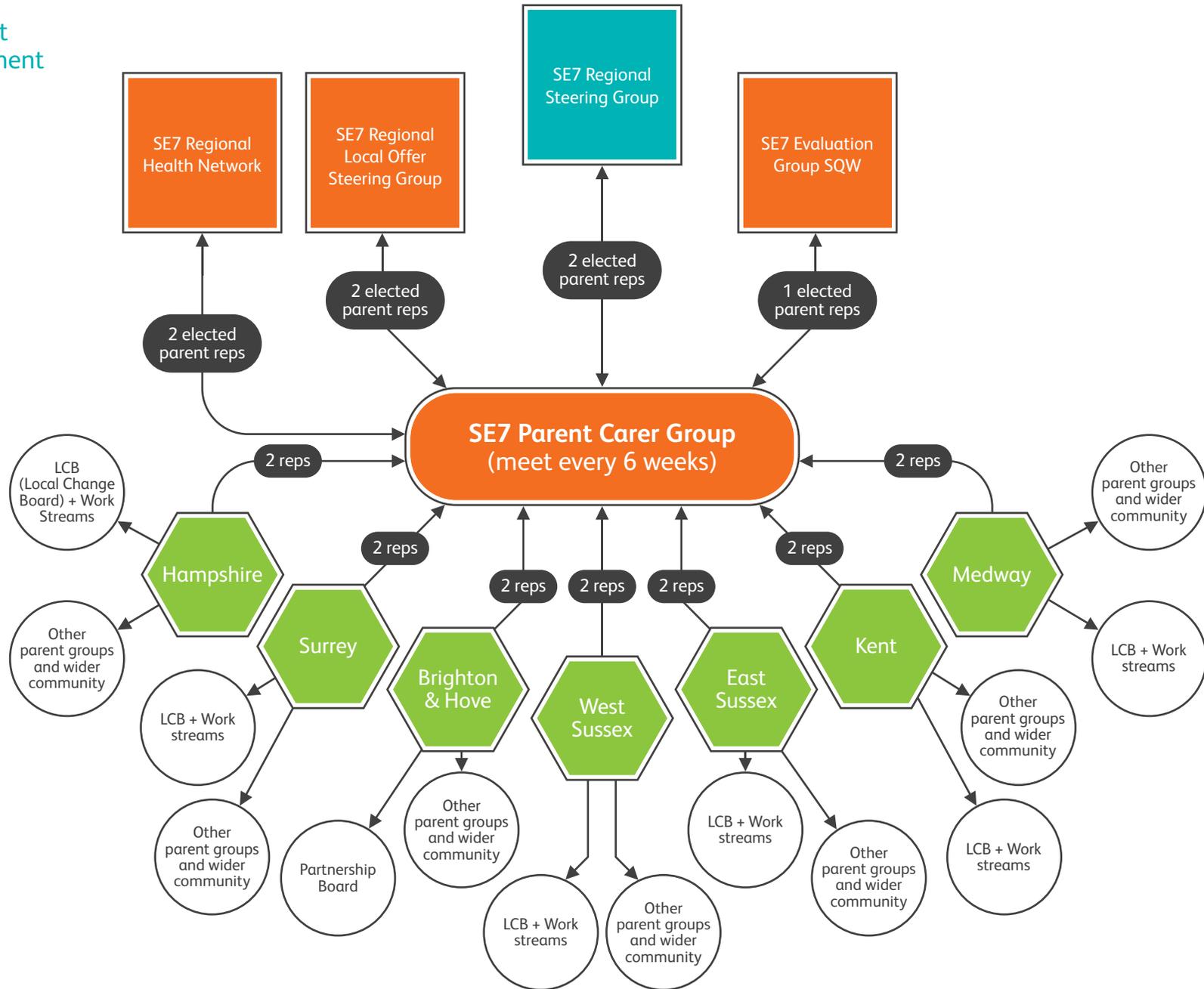
- As we work together on the Pathfinder parent carers will be involved in all of our work including decision making at all levels.
- We will respect and honour your right to use the current legal framework at any time during the pathfinder and we will assist you to do this.'

3. Resource parent carer participation

In order to deliver the co-production model it was necessary to resource co-production from the Pathfinder budget. This meant resourcing the payment policy for parent carer engagement, recruitment of a specialist participation adviser, and accessing delivery partner support from Contact a Family (CAF) through the 'Strengthening Parent Carer Participation' programme. The main support was through free training for forum members (four day training courses offered). Three local parent carer forums and authorities have accessed free CAF Associate input from a pool of specialist advisers.

Mott MacDonald has also provided valuable human and technological support (eg Skype equipment) at meetings, research and administration support for forums undertaking surveys, and for the evaluation of the co-production survey and focus group.

Map of parent carer involvement



What have we achieved so far

1. Modelled co-production within all SE7 events, workstreams and wider dissemination events

This has been a learning process for everyone and all regional workshops involved 4-7 people from each area; two of whom were parents from the forums. Therefore, there was an active and diverse dynamic of hearing from a range of parents and managers who had a variety of views and experiences, not just those people worked with locally. All regional meetings used a co-production approach and included a range of managers, commissioners, parent carers and CVS colleagues.

The SE7 Regional Steering Group has two parent carer members. There are five subgroups that report to the Steering Group: Health, Looked after Children, Local Offer, Regional Evaluation and the Parent Carers Group. The regional workstreams were the Regional Local Offer Framework, the Assessment and Planning Framework, Choice and Control (Personal budgets) Framework. In addition other regional workshops e.g. Keyworking and Family Resilience, Joint Commissioning and Personal Transport Budgets deployed a co-production approach so that each topic lead by a local authority included a parent's

view of the issue, the process and outcomes reached. We have also led two South East Region conferences with each topic being co-presented by a parent and practitioner. Similarly, parent and practitioner duos have represented SE7 at national events at Department of Education, and at the Mott MacDonald Pathfinder events.

2. Evaluation of outcomes from development stage

In December 2012, we conducted a focus group day with parent carer representatives from the forums, and a short survey with the regional steering group and other managers who had been involved in the regional working. The comments below come from these processes. A third evaluation was carried out using the same questions with parent carer forum members from 24 of the 31 Pathfinder areas⁶.

a) Building trust and constructive relationships – moving away from adversarial relationships

- 'The involvement of parent carers in the Pathfinder workstreams and in co-production of the new pathway we are trialling has been very successful. It has brought the views and perspectives of parent carers' right into the heart of all the planning discussions and has challenged existing ways of thinking and talking. This presents us with real opportunities of transforming the relationship between the Local Authority and parent carers and a change of

culture towards one that sees parents as vital partners in this work'

- 'More transparency and honesty all round. Less jargon. More time invested in relationships and seeing this as vital not an 'add on'. A shift towards co-production not just consultation and participation'
- 'Beforehand I felt like Parent Partnership and the Parent Carer Forum were against each other but now I feel like we are much more of a team'
- 'I think that working together on a regular basis has helped understanding from all perspectives. The result of that is a far less confrontational approach when discussing new ways of working'
- 'Improved trust and knowledge'.

b) A mutual learning process – helped with mutual understanding so that we learnt to do things differently

- 'Parental confidence has increased'
- 'Some members of the LA found it hard to adjust to the presence of parent carers at all the meetings and have been challenged about the way they present information – but real progress has been made. Occasionally parent carers who are new to their representative role have struggled with how to manage this alongside their ongoing personal concerns as parents but

⁶ Findings from Parent Carer Forums in the Pathfinder areas' Justin Simon (December 2012) on behalf of Contact a Family and the NNPCF

again this has been a learning process. I see both these issues as two sides of the same coin – learning how to work together in partnership. It would be unrealistic to expect this to be perfect from the outset but real learning and development is taking place and the partnership is maturing rapidly’

- ‘Provided a challenge and valuable insight into what does and doesn’t work for parents and families of children with SEND’
- ‘Seeing real changes in relationships with professionals who are now approaching things differently. I understand now too why some things can’t be done’
- ‘Better understanding for managers on the impact of services and where the gaps are’.

c) Improvement in processes, documents, information or services which become more family focused

- ‘Led to the development of a more family centred approach’
- ‘Parent carers have been instrumental in shaping the Education, Health and Care Plan (EHCP) thus far... Pathfinder parents have given positive feedback to us about their involvement in developing an EHCP for their child and the quality of the plan’
- ‘Having parents on our steering group has helped enormously. We have amended the

format and tone of many of our documents for our personal budgets pilot, to make them more parent-friendly’.

d) Personal development: of parent carers as representatives.

At the focus day parents said they had benefitted in a number of ways personally from taking part. They said:

- ‘There has been so much intense activity in such a small time. This has helped me to see what works well and what hasn’t worked well. Overall I have found the whole experience extremely rewarding and satisfying’.
- ‘Previously I felt very isolated, however through the parent carer forum and the work they are doing I feel like the joined up voice of parents is the way forward’.

of practitioners, managers and commissioners

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

The regional work was underpinned by the payment policy and all SE7 parent carer forums agreed that this had worked very well and expenses were

often paid within two weeks. Parents said that the efficiency of this process helped them commit to extra meetings at short notice because they knew their contributions were valued during the meeting, and their expenses would be reimbursed promptly. In some areas their experience of local practice was variable and sometimes problematic.

3. Outcomes sought from implementation stage

Meaningful shared ownership of the outputs and outcomes

Achieving meaningful shared ownership of the outputs and outcomes will depend upon the intentions of those engaged. At a time of austerity and cuts, Simon Burrall, Director of Involve, describes the changing relationship between local government and citizens in general. He writes: ‘On one level, the cuts are likely to force local government to engage more with affected individuals and communities. The best will use this opportunity to build a real level of shared ownership over the difficult decisions that are made; the worst will ask citizens to participate in order to legitimize decisions already taken, thus further eroding citizens’ trust in government...’

...Whether or not this has resulted in citizens gaining more power over decisions that shape their lives is as much down to the culture of individual institutions as it is the reforms themselves’. A key question therefore is to how culture changes in order to promote more meaningful citizen participation⁷.

⁷ Simon Burrall quoted on page 36 Participation: trends, facts and figures (2011) NCVO

Richness, depth and creativity underpinning transparent decision making processes.

‘Everybody who participates in something does not take something away, so that others cannot have it. The opposite is true: by sharing, by our participating in things, we enrich them: they do not become smaller, but larger.’⁸

Better family experience and confidence in service delivery

Better value for money

Better outcomes for children and young people

What are the key learning points?

- Co-production is a dynamic group process and involves parent carer forums from the start, and at every stage
- Agreement about underpinning framework and delivery tools at outset is essential
- Commitment of leadership needed throughout process
- Training to provide practical examples, good practice guidelines, safe rehearsal for dealing with difference and to underpin cultural shift
- Regular meetings between peers – LA leads together, and parent carer forums together to gain wider perspective, share learning and information
- Resources, support and training for parent carer forums to widen representation skills and active membership
- Regular, honest and open communication supports the development of the trust which is so essential
- Regular and consistent meetings using consistent co-production approach and valuing all contributions
- 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
- Using plain language as far as possible – cut out the jargon and the bureaucratic language

⁸ GadamerHG The Hermeneutics of suspicion. In Shapiro G, Sica K ‘Hemeneutics’ (1984) Amherst, Massachusetts, Univesity of Massachusetts Press

Glossary of terms

Definitions about consultation and participation

Over the past fifty years there is a growing body of research and community development work about the wider impacts of participation across communities⁹ in the UK. Participation and active citizenship builds upon the provision of timely, clear and user-friendly information, meaningful consultation and transparency about decision-making. During the Aiming High programme working in partnership with parent carers, children and young people with additional needs proved an effective methodology to improve outcomes: both for the family members and service providers. Families reported better outcomes and experiences for the disabled child or young person, siblings and other family members when these groups were involved in shaping those services or reforms.

There was evidence that effective Parent Participation resulted in a better fit between families' needs and service provision, higher satisfaction with service delivery, reduced service costs as long term benefits emerge, better value for money decisions and less conflict between providers and those dependent upon services.¹⁰

In relation to parent carers:

Consultation is:

asking parent carers about their response to preset questions, strategies or services. The respondents themselves are not involved with any further stage of the process. A range of approaches might be involved (surveys, public meetings, graffiti boards, vox box).

Participation is:

when parent carers are involved in meetings to express their views and experiences and take part in the debate. A range of approaches could be used (citizens juries, deliberative mapping, attending decision making meetings). It is a partnership process where parent carers are valued members of a team shaping and delivering services for families of children and young people with special educational needs and/or disabilities. Effective parent participation happens when parents have conversations with and work alongside professionals in order to design, develop and improve services.

Co-production is:

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

⁹ For example the seminal work of S Arnstein, (1969) 'The Ladder of Participation', Journal of American Institute of Planners 35, (2), 216-224. Also R A Hart 'The Challenge of Partnership in Child Protection. The Spectrum of Partnership'. See also R A Hart (1992) 'Children's participation From Tokenism to citizenship', UNICEF Innocenti Essays No. 4. Also 'Building a Culture of Participation: involving children and young people in policy, service planning, delivery and evaluation'. P Kirby, C Lanyon, K Cronin & R Sinclair (2005) Dept for Education and Skills/NCB.

¹⁰ Full TDC report about delivery of Short Breaks available on CAF website – summary report to be found on www.nnpfc.org.uk

About SE7 forums

Parent Carer Forums are the pan disability forums in receipt of the participation grant (£10,000 for participation work only) which is administered on behalf of the Department of Education by Contact a Family under the 'Strengthening Parent Carer Participation Programme'. There was no increase in this grant for forums involved in the Pathfinders areas despite the considerable increase in work and participation activities. There is an expectation¹¹ that the forums will be actively developing an effective steering group of at least 5 active members.

It is important to recognise that in SE7 the seven parent carer forums demonstrate the full range development of forums typical across England. One of the success factors for Pathfinders may be whether the forums, who will be at different stages of development, have been able to evidence progress. The range includes forums that have only just newly formed and those who have become established, and those who are long established and thriving.

Figure 2.
Progression of families' engagement with reform

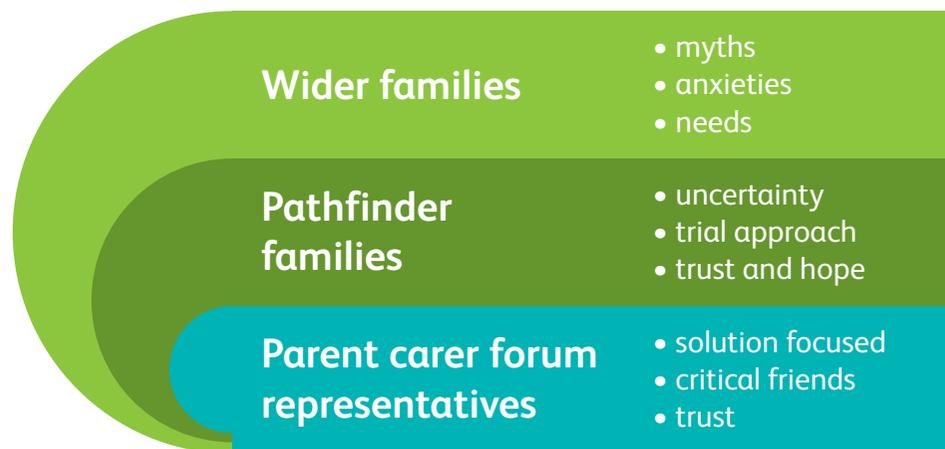


Figure 3.
Progression of staff groups' engagement



¹¹ See 'Markers for good practice in Parent Carer Participation' NNPCF Sept 2011

References

- 1 'Support and Aspiration: A new approach to special education needs and disability' Green Paper
- 2 Cited in the SE7 SEND Pathfinder Assessment and Planning Framework
- 3 Lara Roberts, Co Chair of West Sussex Parents Forum
- 4 'Markers for Good Practice in Participation' This document formed part of the initial briefing for pathfinder leads at the Department of Education in September 2011 by the National Network for Parent Carer Forums
- 5 SE7 Parent Carer Participation Statement
- 6 Findings from Parent Carer Forums in the Pathfinder areas' Justin Simon (December 2012) on behalf of Contact a Family and the NNPCF
- 7 Simon Burrell quoted on page 36 Participation: trends, facts and figures (2011) NCVO
- 8 GadamerHG The Hermeneutics of suspicion. In Shapiro G, Sica K 'Hemeneutics' (1984) Amherst, Massachusetts, Univesity of Massachusetts Press
- 9 For example the seminal work of S Arnstein, (1969) 'The Ladder of Participation', Journal of American Institute of Planners 35, (2), 216-224. Also R A Hart 'The Challenge of Partnership in Child Protection. The Spectrum of Partnership'. See also R A Hart (1992) 'Children's participation From Tokenism to citizenship', UNICEF Innocenti Essays No. 4. Also 'Building a Culture of Participation: involving children and young people in policy, service planning, delivery and evaluation'. P Kirby, C Lanyon, K Cronin & R Sinclair (2005) Dept for Education and Skills/ NCB.
- 10 Full TDC report about delivery of Short Breaks available on CAF website – summary report to be found on www.nnpcf.org.uk

For further information

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SE7 will be developing training regarding co-production - if you would like further advice or information please contact:

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Websites

National Network of Parent Carer Forums

www.nnpfc.org.uk

SE7 Pathfinder

www.se7pathfinder.co.uk

National Pathfinder

www.sendpathfinder.co.uk