



How Parent Participation and Parent Carer Forums leads to better outcomes for disabled children, young people and their families

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1 Introduction

This paper sets out the current development of parent forums, and the existing support for parent carer participation. It outlines how the development of parent carer participation supports the Government's aims to move towards a 'big society', and helps local areas to meet their statutory duties to involve and consult with parents and carers of disabled children. It also considers the outcomes that have already been evidenced by effective parent participation. It is based on the following four principles;

1. That user involvement should be central to policy making, and the design and delivery of services at a local, regional and national level.
2. That parent carer participation is acknowledged as mutually beneficial to service planners and service users.
3. That parent carer participation needs support both financially and developmentally, at a national, regional and local level.
4. That local authorities will continue to consult with and involve parent carers in service development and delivery.

1 Background

The Aiming High for Disabled Children agenda committed to the development of parent carer forums in every area, following evidence that found that where parents were "active agents" rather than "passive recipients" this could lead to lower levels of stress for families and better outcomes for both parents and children. This included increased feelings of control for parents over their child's wellbeing, better use of services, and increased parental understanding of how services work were positive outcomes of active parent participation, which often led to better working relationships with professionals. It also recognised that given some parents of disabled children may have substantial caring responsibilities, they may need additional support to express their views at a local level and be actively involved in participation activity.

This led to the commitment of £5,000,000 over the last comprehensive spending review period to support the development or enhancement of parent carer forums and parent carer participation in every local area in England. TDC has supported and facilitated parent participation, with the majority of local areas now having an established parent carer forum or a clear parent participation strategy that enables parents and carers of disabled children to actively engage in strategic decision making, planning, commissioning and service evaluation.

From September 2008 to the present, local areas have been supported to strengthen or develop parent carer forums and parent carer participation. Significant support has been provided to develop the forums and ensure that local areas are meaningfully engaged and working in partnership with their local forum or network.

2 How parent carer participation contributes to the 'big society'

Building the big society is not just a question of the state handing over the reins of power and hoping that people will grab them. We've got to actively help and encourage people to play their part. The rule of this government should be this: If it unleashes community engagement – we should do it. If you've got an idea to make life better, if you want to improve your local area, don't just think about it – tell us what you want to do and we will try and give you the tools to make this happen.

David Cameron¹

Parent carer forums are an excellent example of where the leading force for progress is based on the society and user groups who receive services, working together to identify and solve problems locally.

The big society states an intent to put more power and opportunity into people's hands, devolving power down to neighbourhoods, making government more accountable. The development of local parent carer forums has had a significant impact in holding local government and local health commissioners to account over decisions about service provision, eligibility, commissioning and evaluation. The development of the National Network of Parent Carer Forums (NNPCF) will also enable the local and regional groups to have a voice and inform central Government of issues that are being faced by local and regional forums, to help inform policy.

The development of parent carer forums and parent carer participation supports the three main tenets of the big society;

- Social action.
- Public service reform.
- Community empowerment.

Often, and for many individuals for the first time, parents and carers of disabled children and young people have been provided with the support they require, practically and emotionally, to become involved in public service reform. Practical barriers such as transport, childcare, and language have been overcome by a small financial investment to local areas and as a result, we have some extremely active forums working in partnership with local areas.

¹ David Cameron Speech 31.03.10

2.1 Volunteering

The financial contribution to support the development of parent carer forums has been small on a local level, and whilst some areas have been able to employ participation workers, the majority have not. What needs to be recognised is that even when a participation worker is employed, or has dedicated hours to support parent carer forums, the involvement of all of the parents and carers in the forum is voluntary. Many parents volunteer for up to 14 hours a week, whilst a few active parents can spend up to 35 or more hours per week volunteering to attend meetings, support other parents or undertake the administrative duties that accompany the forum. Being an active member of a parent carer forum enables parents to be a part of the big society, and to volunteer their time and energy, but often in ways that are conducive to their caring responsibilities.

Forums report that parents volunteering their time can have raised self esteem and develop other skills and experience.

One of the Forums is led by a chair who works virtually full time on a voluntary basis to canvass for parent feedback, attend service strategy meetings with the LA and all five PCTs to feed parents views into service delivery decisions. She arranges training and development for other parents to enable them to feel empowered to do the same.

Through this volunteering role, the chair is developing business and meeting skills, line management and negotiation skills. She is also hoping that she and some of the other parents will be able to become trainers themselves so that they can generate an income for themselves through delivering learning to other parents and professionals.

Engaging what has traditionally been a hard to reach group of parents and a group, who by their very nature often have complex and demanding caring responsibilities, has been challenging. However as parents have seen that their commitment and volunteering has led to positive outcomes, they have been willing to continue to volunteer their valuable time. There has been a cost to enable this level of volunteering, which has included the need for local areas and forums to support basic transport costs, childcare costs, (traditionally significantly more expensive to provide childcare for disabled children than non disabled children), interpreting and venue costs. Forums have also had to negotiate some of the complexities of caring for disabled children with their volunteering, and arrange events and meetings to support this. These costs are variable depending on the geographical nature of the local area, the diversity of the local community and the particular needs of those parents involved.

2.2 Developing opportunities for parents to return to work

Many parent carer forums have enabled parents to consider the opportunity to return to work. The skills and confidence that parents gain through volunteering can often help to build confidence, develop skills, and provide experience for parents who may have previously been denied these opportunities. For some parents, this has led to them considering how they could potentially commit to working. This has resulted in some parents being successful in applying for paid employment. Many forums report the very positive outcomes of parents' involvement, and the development of forums in this area, as evidenced below.

One of the Forums have been commissioned by the local authority to manage a short break provision.. The forum was able to recruit a parent carer as a paid co-ordinator of the service. This also promoted close working with the joint commissioning manager from the local area to offered training and support to develop the role and provision.

A local charity run by parents of disabled children have developed a model to train and develop parents of disabled children to become paid disability awareness trainers.

Parents are paid to deliver training to service providers and professionals and work towards achieving an award which will give them a recognised qualification in adult learning.

One Forum now supports three paid roles, all of which are carried out by parents of children with disabilities or additional needs who began their involvement with as volunteers. The core activities are supported by an admin / development role of 10 hours per week and the website is allocated a further three hours for updating and enhancement.

Of the three parents who work across these areas, one was previously unemployed and two had left employment due to the difficulties of balancing their work responsibilities with their roles as carers. The roles offer maximum flexibility for its employees, supporting parents in working around the needs of their families in any way possible. In addition to this the employees work as a team to provide support and cover for each other and to ensure that the required outputs are delivered. The paid roles are also given essential support from the volunteers on the Parent Carer Forum committee and by the parent representatives (also volunteers). The combination of volunteers and a paid co-ordination team has proved to be a very successful and effective approach that delivers good value for money.

In one Forum the Chair has developed so many work related skills through her volunteer role that she felt confident enough to apply for a project officer job in her local authority. Prior to getting involved in parent participation she had said she would never had had the confidence or skills to demonstrate that she might be the best person for the job.

She was shortlisted for interview on the basis of her volunteer experience but unfortunately was not successful in her application, however the feedback she received was positive and she is not deterred and hopes to apply for other jobs in the future.

In another area, 12 parents will be trained to become trainers employed by the local authority. these parent trainers will deliver a course created by the parent forum. The parents will be paid to deliver the course to family workers across the Local Authority, and each time the course is delivered the Parent Carer Council receives income.

The PCC employs three parent staff members; pays parents to be advisers to the local authority and creates opportunities for volunteering to develop skills leading to paid work. One parent is being paid by the local authority to work with the Family Information Service to produce an information booklet for families.

As parents of disabled children are three times less likely to be in paid employment, and families caring for disabled children are more likely to live in poverty, this is a particularly positive outcome.

2.3 Duty to Involve / National Service Framework

Parent carer forums support local authorities to ensure they are meeting their statutory duties to involve.

Ensuring that local authorities support and engage with parent carer forums enables them to evidence that they are embedding a culture of engagement and empowerment in line with their duty to involve.

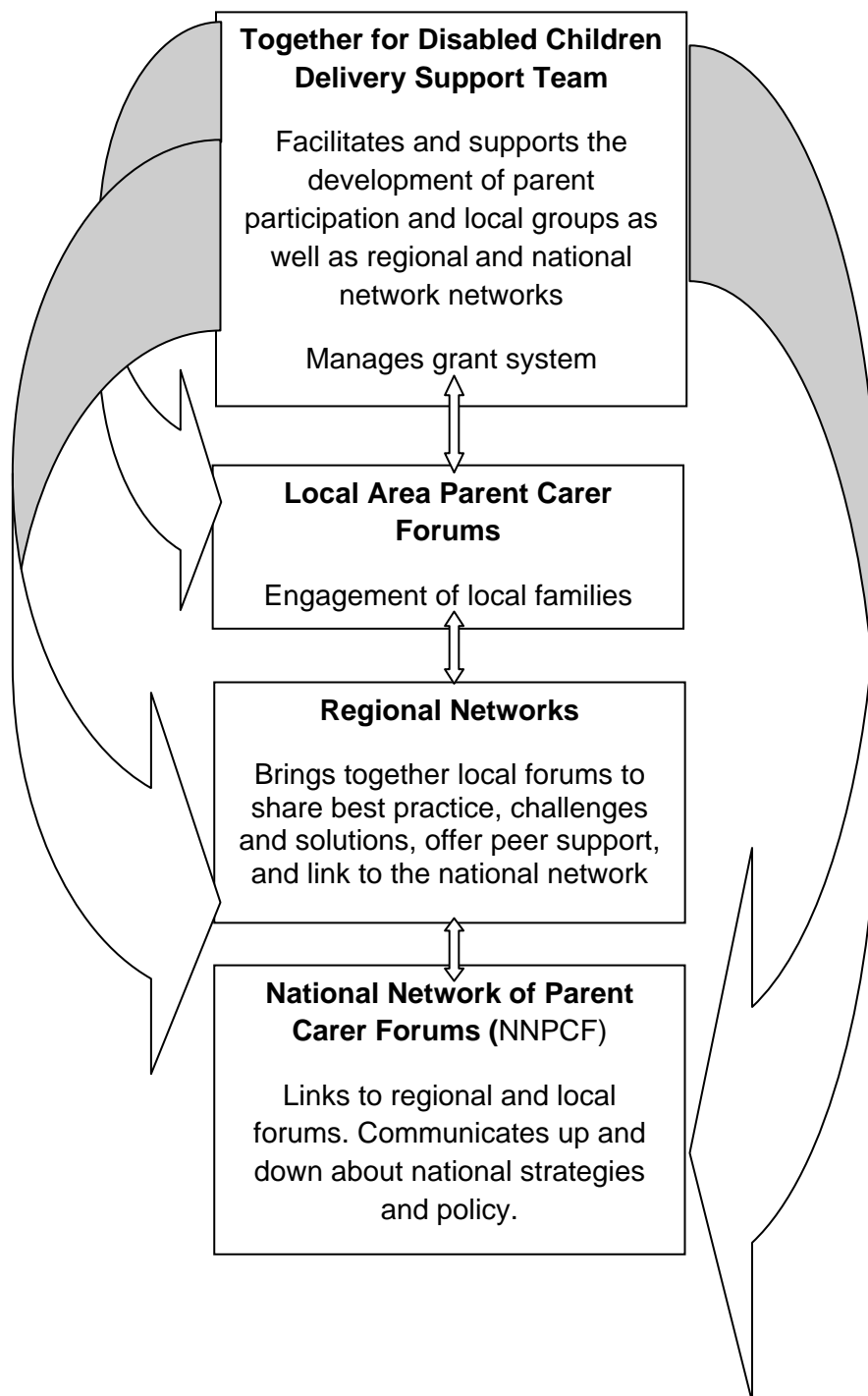
Standard 8 of the English National Service Framework for Children requires local authorities, primary care trusts (PCTs) and other NHS Trusts to ensure disabled children and their parents are routinely involved and supported in making informed decisions, that there is an ongoing user involvement programme for disabled children and young people in line with the wider patient and public involvement programmes and that facilities, equipment and skilled workers are available to enable children who communicate differently to others to participate in assessment and decision-making processes.

Many parent carer forums have significantly supported local areas as they have developed their Aiming High for Disabled Children plans and have been involved in a number of areas in significant decisions around health and social care provision.

In one are, the Parent Carer Forum hosted their own health consultation regarding the replacement of paediatricians in their area. From that, the parent carer council compiled a report which was submitted to the paediatric review.

3 Current models of parent carer participation and support structures.

The current structure supporting parent carer participation consists of Together for Disabled Children supporting the direct development, or strengthening of local parent carer forums ; co-ordinating regional networks to enable links and networking on a regional level; the pilot of the National Network of Parent Carer Forums, linking to regional and local forums and offering participation and involvement on a national level.



3.1 Local area parent carer forums

It is possible to describe local parent carer participation as taking place within three broad models.

i) Steering group/parent carer representatives (around 65%)

A steering group of parent carers, who between them can and should represent a range of disabilities/carer-experiences, meet regularly to share knowledge and agree on issues to prioritise. This is then fed into strategic, decision-making boards, through parent representation at a strategic level building on joint partnership working. These may be specific disabled children / Aiming High groups, and in some areas, some parents and carers have been invited to be part of their local area children's trust boards. In addition, there are opportunities for other parents to raise issues through forum meetings and consultations.

ii) Parent carer meetings with managers/parent representatives (around 25%)

Regular meetings are held, usually monthly or termly, where parents raise their concerns with services. Children's services managers are then invited to attend specific meetings to respond to and take on board parent concerns. Sometimes parents who attend these meetings are also parent representatives on strategic decision making boards.

iii) Parent carer conference/task groups (around 10%)

Parent carers are invited to attend a conference, usually once or twice a year, to agree issues they want prioritised. From this, small task groups of professionals and parents are formed to work on the prioritised issue. The task group meets regularly for a limited period of time, to reach a more detailed understanding of the issue and look for practical solutions. Their conclusions are fed back to the next parents' conference, as well as feeding in to the strategic decision makers.

All of these groups will have their own arrangements for organising local parent carer participation, but there are common themes and approaches:

- a) Consultation with parent carers about local priorities and issues.
- b) Contribution to service development with the local authority.
- c) Involvement with other forums.
- d) Involvement with the PCT in some cases.
- e) Engagement with local councillors and MPs in some cases.
- f) Raising the profile of issues pertaining to disabled children and young people.
- g) Working with other parent-led voluntary groups.
- h) Informing parent carers about their opportunity to participate and the outcomes of this work.
- i) Training parent carers to build confidence and develop skills to enable them to participate, and manage the parent carer forum.

3.2 Regional networks

The regional networks are in the process of forming and could ultimately serve as the way in which local area forums can feed into and draw on the activities and resources of the national network, specifically:

- Providing opportunities for peer support, sharing practice, challenges and solutions.
- Providing regional representatives for the NNPCF.
- Providing opportunities for peer support, joint training, supporting and maintaining levels of motivation.
- Serving as a more local network for receiving and cascading information; agreeing the work plan and priorities for the NNPCF in the future.

3.3 National Network of Parent Carer Forums

The National Network of Parent Carer Forums is a national group made up of nine regional representatives, and the previous Ministerial Implementation Group Parent Representative. The Network's aim is to act as a conduit for ensuring regional and local forums access, consult and participate with regional and national developments. Members of the group will also represent parent carer forums on national working and steering groups. A communication strategy outlining how this will be achieved is currently in draft form, and the nine representatives have already attending regional networks outlining this process.

In future, the NNPCF will ensure that local area forums remain networked within their regions and are linking to national developments. The NNPCF could provide opportunities for statutory bodies to communicate with the widest possible informed audience, as well as cascading information and advice on best practice through the networks. The priorities for the National Network for 2010-2011 are:

- To establish a process for appointing the regional representatives on the National Network at the end of the pilot year.
- Communication: with parents and parent forums, between parent carer forums and with government and statutory bodies.
- To share experience and successes.
- To be ambassadors for parent carer participation.
- To establish key relationships and partnerships to support parents having a voice to influence and effect change at a national level.
- To ensure parent carers can participate with one voice at a national level.
- To contribute to sustainability discussions and participate in the exit strategy that will be developed post TDC.

3.4 Other resources

- TDC grant for parent forums from 2008-2011
- TDC website on-line resources e.g. How to Guide and examples of material developed by parent carer forums.
- E-bulletin sharing updates from forums and top tips.
- Case studies of innovative practice.
- Various tool-kits.
- Parent carer participation grant of £10k available to 152 local areas.

3.5 Ensuring the engagement and turnover of a wide range of active parent carers

Due to the very nature of being parents and carers of disabled children, pressures on members of forums can be great. One of the greatest dangers for volunteers is burnout, so parent carer forums need to establish cultures of sharing workloads and ensuring an ongoing throughput of active parent carer representatives. Whilst initially establishing forums and engaging a broad membership has been a challenge for local areas, they are being supported to consider this important element which is essential to ensuring the continued sustainability of parents forums, ensuring they remain vibrant, and that they are representative of a wide range of parent carers, and not just a small regular group.

3.6 Engaging with black and minority ethnic communities

Parent carer forums need to ensure that they are representative of their local communities, and for many local areas, this brings an added layer of complexity, as they strive to ensure that they are engaging, and encouraging the active participation of hard to reach, including black and minority ethnic, groups. For local areas who have diverse populations, work is already underway to address this, and for 2010-11, three pilot projects are being undertaken with three areas across the country to consider which approaches are particularly successful, and why. The additional barriers that black and minority ethnic parent carers face can prevent them from becoming active participants, and it is particularly important to support local forums to ensure that they are considering the needs of their entire communities, and putting systems in place to ensure that all parent carers are represented. There are undoubtedly considerable additional financial commitments that have to be considered (e.g. interpreters, appropriate venues) to ensure that this occurs.

5. Outcomes of parent carer participation

“Being part of a parent forum and having central commitment has changed the dynamic in favour of parent carers and meaningful parent participation”

Parent – London Parent Carer Forum

Parent participation has influenced the choice and quality of the short break services we buy, by making sure we ask the right questions in applications and interviews, and influencing processes such as the entitlement framework, so I consider the local authority to have better value services as a result of an ongoing process of parent participation.

Commissioning Officer

For local areas, the idea of meaningful parent carer participation and becoming partners in policy and decision making has not been without challenge. However, all local areas have made progress in ensuring parents are consulted and involved and in many instances not only for the developments around Aiming High for Disabled Children but also across children's services.

Parent carer participation has added value by helping to design services which are appropriate and provide better outcomes for children and their families. Some local areas have provided evidence that decisions about service provision and delivery have been directly affected and influenced by parent carer participation.

It is unquestionable that parent carer participation has led to improved outcomes for disabled children and young people and their parents and carers, and also for local authorities and primary care trusts. However, empirical evidence to support this is difficult to determine so early into such a radical programme of transformation, and when services are still evolving.

Qualitative data gives clear examples of where outcomes of parent carer participation has led to improved service provision, changes in traditional decision making, prevention of duplication and has ultimately saved money.

The examples below provide evidence of the positive outcomes of parent carer participation.

5.1 Parent carer participation influencing commissioning to ensure appropriate services are delivered

Parents from one Forum were part of the commissioning process of short breaks. A synopsis for each bid was written in a user friendly format and parent evaluation and scoring document was developed giving parent information around who the project was for (age, group, disability etc) how many children could access the project and how the projects would plan for sustainability after funding. The evaluation form included a space for additional comments so parents could suggest ways to improve the service from their point of view.

Scores were then weighted by the procurement team and those services where parents suggested changes to make services more accessible were asked to come to interview.

A great example of this is the bid for swimming: parents had been requesting more swimming but did not feel that the swimming bid would be suitable for their children. Parents said that they wouldn't have used the service at the time suggested and would like more exclusive fun sessions for families to spend time together.

Following interview, parents' suggestions were taken to the provider and changes were made to be brought back to parents. This resulted in happy parents feeling they had a real influence in their service and provided Trafford with a successful service being accessed by lots of children.

This provided fit for purpose services not services that would have been commissioned and not used, therefore a waste of money. It improved universal services to ensure they were inclusive and accessible taking into account a wide range of disabilities and impairments. Parents were making decisions in partnership, and this improved their previous perceptions of the local authority.

Another Forum brought parents of disabled children together to have their say about what they wanted in their community for their children. Seeing that the planned development of the sea front did not make any provision for disabled children or adults. The Forum engaged with their local authority and asked them if they could have some input to what was being planned. The local authority agreed and the development plans now include three changing spaces along the seafront, a ramp to the beach that extends right into the sea to enable wheelchair users to go into the water and a beach bungalow that houses beach buggies for disabled children to use on the sand.

Parents just wanted their families to be able to use the great natural resource that was key to their community. The local authority listened and accepted it improved access and enjoyment for many of its residents and visitors by doing just a few small things.

One Forum were involved in deciding the area should support the implementation of the Playbuilder initiative in their area. The main programme funding was enhanced with short breaks funding following consultation with families that indicated a need for increased outdoor play opportunities for children with disabilities or additional needs. The short breaks capital funding would enable the development of three play areas throughout the county that specifically catered for children and young people with disabilities or additional needs. The initial consultation had identified the basic need but the Parent Carer Forum survey identified that there were four main priorities for families when providing inclusive play areas;

- An even, level and hygienic floor surface.*
- An enclosed play area.*
- Size and ability appropriate equipment rather than age appropriate equipment.*
- Toilets with changing facilities close by.*

The outcome of sharing this information with the Playbuilder team was a fundamental change in how the scheme was implemented for the three sites identified for funding from the short breaks project;

- The tender brief was changed to include the need for reference to documents such as 'Design for Play Guidance', 'Inclusion by Design', 'Playing Outdoors' as well as the results from the PACC survey.*
- The scoring system for the tender evaluation process was changed so that greater detail and a wider range of features would be needed to secure all the points associated with design for inclusion and accessibility.*
- A parent carer was invited to sit on the tender panel.*
- A consultation play event is being held to collect parent carers views on the concepts submitted as part of the tender process.*
- It has been agreed that rubberised surfaces can be incorporated into designs – this was identified as the preferred surface by families in the Parent Forum survey.*
- It was agreed that some areas can be enclosed within the wider design.*
- The disabled toilets near to one of the sites will now be refurbished instead of demolished, removing the need for a ten minute walk to the alternative disabled*

toilets.

- *Concepts should now include careful consideration of the equipment included in the play areas so that they are size and ability appropriate rather than the standard approach of requiring equipment to be age appropriate.*

The result of this parent participation is that the short breaks funding committed to the Playbuilder initiative will secure real and meaningful gains for the community of families with children with disabilities or additional needs in their local area. For the Council it will deliver value for money that otherwise would not have been achieved.

In one authority, the parents forum had been actively involved in deciding how the area's capital spend should be utilised and had drawn up a plan which involved the purchase of two adapted camper vans for use by families. However, the strategic partnership and senior managers did not agree to this element of the spend proposal, with concerns about the ongoing revenue costs. Despite various reports outlining the potential cost benefits, the decision was not repealed. Finally a meeting was held between the assistant director, lead member and the chair of the parents forum, who was not a parent who would themselves benefit from the service. They were, however able to debate the issue and represent the views of the parents and children in relation to the provision. As a direct consequence of the meeting, the decision was repealed and the area was able to proceed with their plans.

One Parent Carer Forum reported that the forum in met with leisure representatives in May about special swim and activity sessions during the holidays. The leisure services informed the forum they had organised a permanent swimming session every Sunday for one hour for 50 pence per child / young person with parent / carer free of charge, at two local leisure centres. The group were thrilled at this result in universal accessible provision for their families

5.2 Engaging effectively with local authorities and PCTs to ensure change

One Forum took a 'bottom up' approach from the start. The key strategy used has been the Skill Building courses. These were undertaken in various children's centres across the area. The courses have been run at various times throughout the day to meet the needs of all parents. The Skill Building courses have developed an informed enthusiastic network of parents interested in further training, strategy development and plans for the futures of their children and of other families. Following the Skill Building courses - to date there have been thirteen - the parents have developed their Local Parents Forum which meets monthly. From the Forum and the website, which again is monitored and updated by parents, lots of different training and events have happened. The parents decide and lead on which events they want to be in conjunction with professionals. They feed into the local authority on a weekly basis what the hot topic on the website is, and facilitate and support a range of parent participation activity.

One Parents Forum have worked successfully with their local area, and have now been invited for a representative to be a member of their Children's Trust, thus ensuring the parents forum will have influence around all service provision for children and young people.

One Forum newsletter was read by the Senior Matron at the children's services at the Royal Hospital, who replied to all of the comments and queries that were raised, and necessary adjustment to the service were made. The forum had invited them to attend their meeting, but now no longer needed to do so.

One Parent Carer Council has 47 active work streams that they participate with, and have an efficient feedback mechanism. They keep abreast of what service providers are doing. They have found cases however such as the Independent Travel Trainers, where it seems the authority's different departments are unclear about developments in other service areas, and parent representatives have been able to advise in relation to this and prevent duplication, thus saving money. There are 30 active parents within the Parent Carer Council membership and a network of over 1,800 families who are regularly communicated with.

5.3 Emotional well being of parent carers

Caring can have a major impact on carers' health and wellbeing, and carers are significantly more likely to be in poor health - both physical and emotional - than people without caring responsibilities.² Parent carer forums report that a positive outcome of being part of a forum is the added emotional support and sharing opportunities that are provided, which enhances the emotional well being of carers. As this enables parent carers to continue to effectively care for their children, this is a significant outcome of being a member of a parent carer forum.

5.4 How parent carer participation can support disabled children and young people's participation

The investment in the development of parent carer forums has been a key driver in the significant increase in the numbers of parent and carers actively participating. A further positive outcome is the involvement and participation of disabled children and young people, as they see their own parents and carers becoming actively involved.

It is of note that the empowerment of parents and carers, established through their active involvement in parent carer participation can lead to disabled children and young people believing that they too can have some control and involvement in the decisions that affect them.

² Carers UK 2010

In one area, the parents forum successfully gained a grant from their local authority, established their disabled youth forum. This has been successful for several years, and is now funded through the local authority's base budget. Young people who are part of this group have been actively involved in helping determine the local authority's Aiming High plans, and sit on their own short break panel.

In one area, the Disabled Children and Young People's Forum was developed alongside the parents forum with the support of the local authority and PCT. Several parents only became aware of the Young People's Forum through the parents forum, and there are now several families whose children are part of the Forum whilst the parents are active participants of the parents forum. The chair of the parents forum, stated that his commitment to the parents forum mirrors his son's commitment to the Young Peoples Forum, and in turn his son's engagement encourages him to actively participate in the parents forum. In addition, there is a significantly positive outcome for a young person who prior to this attended no social groups and had few friends.

6. Costs of running a Parent Carer Forum

6.1 *Costs of running a parent carer forum*

Parent carer forums have used the DfE grant to pay for a range of costs to include:

- Meetings of forum steering groups, focus groups and public meetings which all parents can attend.
- Training to forum members to skill them in running the forum and being parent representatives.
- Communicating with parents via newsletters, flyers and websites to tell parents about how they can get involved and what has been achieved so far.
- Paying for admin costs such as stationery, photocopying, mailings, telephone bills.
- Covering the cost of parents' travel and childcare costs.
- Supporting parents to access learning and development to enable them to effectively work within and lead the forum.
- Reach out to a wider range of parents through events and targeted work with BME communities.

It has been estimated that the annual running cost of a forum can range from £8,000 to £14,000, with variables such as geographic nature of location (greater travel costs) population, and language support (see appendix 2 for details).

7. Challenges in assessing the true cost and benefit of parent carer participation

It is widely acknowledged that it is challenging to assess the true cost or benefits of participation, and the same is true for parent carer participation. Many of the

important deliverables that participation seeks to produce, such as active citizenship, and capacity building are hard to measure and even harder to satisfactorily compare to the time and money required to deliver them. Participatory products are often intangible and beyond economic analysis. There are no obvious methodologies for undertaking economic assessments of the cost and benefit of participation,³ and the complexity of participatory processes means their outcomes can never be reduced to a simple monetary calculation alone.

The desired outcomes of parent carer participation have been evidenced through the examples and progress made in local areas. The development of parent carer participation is still in its infancy and robust analysis of any financial direct benefit to local areas would be premature.

One of the aims of effective parent carer participation is the development of services that are appropriate and required by families, reducing duplication and the provision of unnecessary or unwanted services. By its very nature, participation prevents these things from occurring, making it difficult to determine financial benefits.

8. Value of parent carer participation in current climate

The commitment to participation by the Government remains high, with the meaningful engagement of parents in local and national service delivery being key to the big society objectives.

Engaging stakeholders in significant but potentially controversial issues could be a core part of supporting the Government's agenda of openness and transparency. Local areas have been encouraged and supported to work in partnership with parent carer forums for the last three years, with much success. However, the imperative around doing so is higher than ever as local areas will be making extremely difficult decisions in the coming year about service provision.

It is important that parent carer forums and parent carer participation continues as a priority to maximise the significant investment over the last three years.

Parent carers of disabled children are probably the least likely to be represented in other fora locally because parent carers do not have the time to invest in groups like LINK or General Carers Forums in the hope that our voice might be heard over all the others. These groups tend to be quite bureaucratic, whereas parent forums get to the point and give us the right to participate when and where it matters.

Parent Carer – London Parents Forum

9. Additional benefits of parent carer participation / good short break provision

There is emerging evidence that the provision of good quality, fit for purpose short breaks prevents the need for disabled children and young people to require more intensive service provision, including on occasions, preventing the need for disabled

³ The true costs of public participation Nov 2005, Involve

children to become looked after on a full time basis. Good quality short breaks are best demonstrated where there has been effective participation from parent carers, as evidenced in the above case studies to ensure that services are fit for purpose, and truly meet the needs of disabled children, young people and their families.

A study undertaken by TDC indicates

- Short break services appear to have prevented children entering the looked after system and thus potentially saved money for the LA.
- All participating local areas state that they are focussing on early identification and support as a means of preventing children and young people from requiring emergency and long term looked after placements.
- All local areas have developed a wide range of holiday provision recognising it as the peak time for increased requests for children to be at risk of becoming 'Looked After' or for emergency placements.
- Short breaks have reduced the need for costly out of borough placements. In staying closer to home, children are potentially enabled to have improved engagement in their own communities and reduced transition issues.
- Targeted support via the Common Assessment Framework has had the added value of improving multi-disciplinary working relationships.
- Local Authorities involved see short breaks as part of their preventative strategy.

In one Local Authority the costs savings in preventing just a few children from entering the looked after system exceeds the total short break revenue grant for the whole year.

10. Conclusion

Parent Carer Forums have contributed to the transformation of the way in which services for disabled children and young people are developed, delivered and evaluated. The many and significant improved outcomes for children and young people and their families are clearly evidenced. Better and closer partnership working in Local Authorities has reduced the often traditional combative relationships that parent carers have had with their Local Authorities, reducing stress, pressure and time for all involved. However, the continued development, and close partnership working with Parent Carer Forums is reliant on the continuation of support, resource, and commitment from Local Areas to their local community of Parent Carers. Aiming High has enabled a new agenda to begin. It is therefore vital that all parties continue to work together and not re trench into silos as was evident at the onset of the programme.