

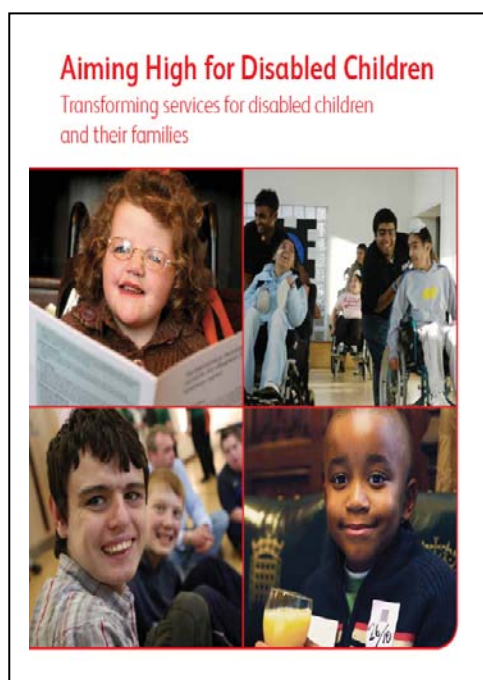


Towards a more ordinary life....

A report on the progress of parent carer participation and the development of short breaks: 2008 – 2011

SUMMARY OF FINAL PROGRAMME REPORT

Introduction



This is a summary of the final programme report on two components of Aiming High for Disabled Children, *Increasing Parent Carer Participation* and *Development of Short Breaks*, providing key highlights and outcomes.

The full report, produced by Together for Disabled Children (TDC), tells the story of the transformation. Beginning with parent carers, it details the growth of forums and the increase in the number of parents involved. It tracks the development of regional and national structures that will strengthen the voice of parents and enable them to actively participate in shaping policy planning and services in the future.

In the second section, it tells the story of the growth in volume and range of short breaks services. It discusses the way that services have been developed for children with the most severe impairments who often previously received the least help, and explores the way that authorities are responding to the concept of personalisation.

It also tells of the growth in commissioning from the voluntary sector and the role of that sector in creating innovative responses to need. Throughout the report, there are concise examples that are there to inspire and encourage the reader to follow up if more information is needed.

Supporting the development of parent carer participation

Parent Participation has significantly developed. Defined as the involvement of parent carers in all aspects of service planning, monitoring, evaluation and decision making across health and social care.

1. Almost all local areas now have an established parent carer forum, or process for ensuring parent carers work with their local authority and health partners in making decisions about services for disabled children.



Sheffield Parent Carer Forums Mgt Group

- 99% of local areas have seen an increase in the number of parent carers involved in participation
- 87% say local information for families of disabled children is better coordinated
- 97% of forums report improved joint working between parents and professionals
- The number of parent carers actively involved in strategic planning of services in their own localities has increased to 1,710 parent carers across 146 local authority areas, up from 465 in September 2008



2. A newly established National Network of Parent Carer Forums and regional Networks have created a credible collective and influencing voice for parents
3. Involvement in participation has increased the confidence of parents including those parents traditionally harder to reach; pilot projects have successfully provided examples of increased

participation from black and minority ethnic parent carers.

4. Children and young people are also taking a more active role in shaping services and the programme has been a catalyst for change in increasing children's participation



5. There are a wide range of identifiable positive outcomes for disabled children and young people and parent carers as a result of their active participation in decision making, planning services and monitoring and evaluating service delivery including evidence of better planned, more sustainable and cost effective services for disabled children and young people.

Supporting the development of short breaks

The short break programme was the area with the greatest investment from the Aiming High Programme. Every local area was tasked to find the disabled children and young people living in their areas, and to improve and increase the short break services available for them, ensuring a wide range, and high quality of services that provided a positive life experience for children and young people whilst also providing a break for parent carers.

There have been significant increases in the provision of short breaks for disabled children and young people, and increased numbers of disabled children and young people now accessing these.



Bradford

- ❖ Over 105,000 more disabled children are now receiving short breaks – an increase of 184% since 2008
- ❖ Over 73,000 more children with the severest level of needs are now receiving short breaks – an increase of over 200%
- ❖ The proportion of disabled children receiving short breaks as a percentage of the total child population – has increased from 0.48% to 1.36%

An additional 193,000 nights and an additional eight million daytime short break hours (a total increase of 135%) are now being provided each year (total increase across all daytime short breaks service models).

Progress



- A range of alternate way of devising and providing short breaks leads to increased value for money
- Spending on short breaks has increased nationally by £251 million, a growth of 71% since 2007/2008
- Health sector contribution has increased, with a 47% growth in spending from Primary Care Trusts
- Personalisation of short breaks is being seen in service development, with a **demonstrable commitment to active participation** of disabled children and their families. 20,000 children are receiving a direct payment as part of their short breaks package (an increase of 83%) and almost

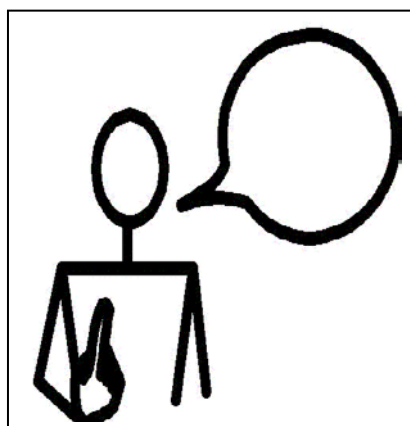
3,000 families are in receipt of some form of individual budget (an increase of 184%)

Effective partnerships



- ❖ Collaborative approaches and more effective relationships between local authorities and the **health sector and voluntary and community sector organisations** have been key to the **transformation of commissioning practice** and the development of the local authority’s role as market manager
- ❖ The voluntary and community sector has played a **key role in shaping service development**, delivering innovative models of service provision, supporting development of a diverse workforce and working to support parents/carers and young people to have a more influential voice in how short breaks are commissioned and delivered

Positive outcomes of development of short breaks

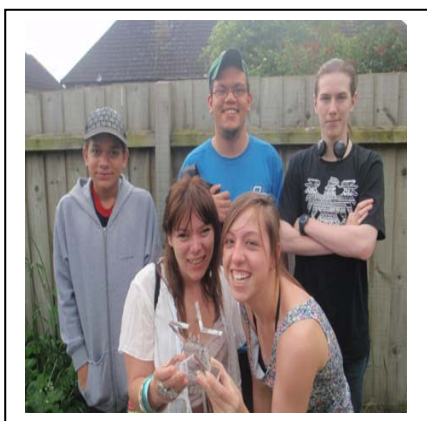


A range of positive outcomes resulting from the developments and improved delivery of short breaks has been evidenced across the country. These include:

- Local authorities are seeing **less need for social care interventions**, a **decrease in costly out-of-area placements** and a **fall in the number of**

disabled children entering the looked after system

- Disabled children and young people are experiencing **increased choices**, wider social networks and are growing in **confidence and independence**
- Children and young people are taking a **more active role in shaping services** and the programme has been a catalyst for change in increasing children's participation
- More '**ordinary life**' **models of provision in universal settings** have developed - giving **excellent value for money** as they are easier to access and give high user satisfaction
- Parents are experiencing **more choice and control of family life**, developing supportive peer relationships and have raised their expectations and aspirations of what their children may achieve



Factors contributing to successful transformation

Having reviewed those areas with the most successful short break transformation programmes, a range of common factors have been identified that have contributed to their success. These include:

1. **Passionate commitment**
From managers, workers, partners, parents carers
2. **Collaboration**



- a. Partnership with parent carers is vital
 - b. With Health / Voluntary Sector / Internal partners
- 3. Innovation**

Creative thinking and willingness to try new models and approaches
 - 4. Leading from the front**

Senior Management and lead member support for the programme from all partner agencies
 - 5. Strengthening the structures**

Ensuring processes are in place to enable service delivery to improve and increase
 - 6. Focusing on fairness**

Ensuring there is equity and that a wide range of disabled children and their families access services, whilst ensuring those with the greatest need have those needs met.
 - 7. Knowing the numbers**

Understanding who and where disabled children and their families are in the local area, and how they can be engaged and involved.

Next steps and recommendations for securing lasting change in parent carer participation and development of short breaks



- ❖ Continued support to strengthen parent carer participation
- ❖ Continue with data collection and analysis to underpin effective commissioning and evaluation - demonstrating the outcomes and impact of parent carer participation and service development is essential



- ❖ Consider development of local offers and open access frameworks - improving access and widening the range of breaks available has been a cost-effective strategy
- ❖ Review the reach of short break services – access has increased but there are more children who would benefit from short breaks that are not yet receiving them
- ❖ Invest time and energy in the development of partnerships across sectors, particularly with the health sector, voluntary and community sector organisations and universal children’s services - effective working relationships are fundamental to achieving better outcomes
- ❖ Continue to develop universal provision and enable more disabled children to access the same opportunities available to their peers
- ❖ Target children with the severest level of need – parent carers of children with the most complex of needs may not always seek out early support
- ❖ Develop personalisation approaches and make more widely available to all families - personalised strategies have enabled parents and children to have increase choices and more control over their own lives
- ❖ Responsibility for service improvement should be owned by the sector
- ❖ Commitment and continued investment at national and local level
- ❖ Disseminate learning and factors of success



Conclusion

There has been a remarkable transformation across services for disabled children and their families over the course of the past three years. More parents are involved in local service planning and they have a greater say in how decisions are made. They are developing a collective voice in shaping policies at a national and local level and this is enabling them to have a greater level of control over their own and their children's lives.

Short breaks services have increased significantly, with a greater range available, more choice and easier access. Disabled children and young people are having more of a say in how services are commissioned and the programme has been a catalyst for increasing their participation. Disabled children are enjoying more opportunities to engage in ordinary activities and are increasing their social networks, as well as increasing in confidence and skills.

Positive outcomes are being seen for services too, and they include fewer children needing emergency social care interventions, less reliance on costly out-of-area placements and fewer disabled children becoming looked after.

The full programme report gives a wealth of information about the journey of transformation and a vast range of examples of where things are working well. This is only the beginning. In many ways, achieving the changes, notwithstanding the challenges involved to do this, has been the easier task. The toughest one is to embed change and make it last. It seems fitting that a parent carer of a disabled child should have the last word in this report:

“Now, we have services that we actually want, they cost less and she is so much happier – and she is learning more and growing in confidence. It would be madness to stop this. Whose purposes will that serve? No, there is no going back.”



Acknowledgments

Many people have worked tirelessly for many years to improve services for disabled children and young people and their families. They recognised that there were inequalities in opportunity that were severely disadvantaging a group of children and preventing them achieving their full potential.

Without their passionate commitment this programme of transformation would not have been possible and this report could not have been written. Together for Disabled Children would like to acknowledge all those who have contributed to developments and to the collection of knowledge that was needed to bring about transformation and is reported here.

In particular we want to acknowledge the contribution of:

Disabled children and young people

Parent carers of disabled children and young people

Professionals and managers of Local Authority and Primary Care Trusts

Voluntary and community sector organisations, including:

Council for Disabled Children

Contact a Family

Shared Care Network

Action for Children

Aspire

Barnardos

Children's Society

The Children's Trust

Children England

Cool2Care

Kids

Mencap

National Autistic Society

National Deaf Children's Society

Scope

Sense

Whizz Kidz

National Children's Bureau

We would also like to make a special mention of all the numerous talented and professional individuals who worked on the TDC programme in various roles, such as strategic leads, local programme and parent participation advisors, regional assistants, programme support officers and administrators. It was a privilege and joy to work on this programme with such a vibrant and wholly committed team.

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