



Is the Voice of the Child Having an Impact on the Development of Short Breaks for Disabled Children?

A small-scale survey that explores whether the 'Aiming High for Disabled Children: Short Breaks Programme' has enabled effective participation of disabled children and young people to take place.

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Abstract

The difficulties of engaging effectively with disabled children and young people and therefore enabling them to participate in service design and development, has been recognised for many years. Although children's participation generally has increased, disabled children and young people, particularly those with complex needs or communication impairments, have long been excluded from participation activities due to a lack of understanding, training and resources (Franklin and Sloper 2009)¹. Aiming High for Disabled Children (AHDC) (2007) provided the resources, financial and directional, to allow meaningful participation for disabled children and young people and during October and November 2010 'Together for Disabled Children' set out to explore whether the AHDC Short Break Programme has been the much needed catalyst to enable the 'voice' of the disabled child to be heard and so influence the design and development of short breaks.

This report reflects on the outcomes from the survey that took place and verifies the overwhelming evidence to suggest that the Aiming High Short Breaks Programme has led to a significant increase in the numbers of disabled children and young people involved in participation in their areas. It has been a 'catalyst for change' and allowed, sometimes for the first time, groups of disabled children to come together and be supported, by well-trained staff, to begin to shape and influence the type of services that they need to support them to have 'fun' and live 'normal' lives. Although, there are still some gaps, often at a strategic level in the commissioning process, service providers are generally more confident about working alongside disabled children and young people and allowing them to play a major role in the way their services are developed.

The intrinsic difficulties highlighted by Franklin & Sloper (2007) and Martin (2009)² of enabling disabled children and young people with communication impairments to participate are still apparent, but they have been lessened to some extent by the additional funding that has been made available. AHDC has provided the resources to develop training for staff across all levels of service provision and it is hoped that the staff that are now skilled and practiced in supporting participation will be able to embed this in future practice. The report also highlights some difficulties in enabling participation with children from black and minority ethnic backgrounds and whilst we can evidence some very good practice taking place some areas felt they needed more time and resources to ensure their service development truly reflected the needs of these groups of children.

Participation offers disabled children and young people opportunities to build their skills and influence decision making. When the time and resources are dedicated towards allowing this to happen the outcomes, as shown in the case studies, are

¹ Franklin, A. & Sloper, P. (2007). Supporting the Participation of Disabled Children and Young People in Decision Making. University of York, Social Policy Research Unit.

² Martin, K. (2009). Making Ourselves Heard: Exploring Disabled Children's Participation. London: National Children's Bureau.

nearly always positive, leading to more accurate and focused information on need and hence more cost effective commissioning. Most importantly participation allows disabled children to gain a 'voice' and make choices about the services they receive.

Acknowledgements

Many thanks go to all the 14 local areas that responded to the questionnaires within the agreed timescales and provided such comprehensive and valuable information.

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I. Introduction

This report presents findings from a small-scale survey exploring the extent to which disabled children and young people have been involved in the development of the Aiming High Short Breaks Programme³. By focussing specifically on practice relating to the participation of disabled children and young people in service development and analysing it in the context of the Short Breaks Programme we have been able to substantiate and build on existing research (Franklin & Sloper, 2007) and projects (Martin, 2009) in this field.

The involvement of children and young people in decision-making has been embedded in government policy for a number of years. Aiming High: A Ten-Year Strategy for Positive Activities⁴ states:

'It is clear from the evidence considered by the Review and consultation with young people, that giving them genuine influence is a crucial first step to increasing participation in activities and access to wider public services.'

This movement towards involving young people in decision making and service design was strengthened further in 2007 by the publication of "Aiming High for Disabled Children: Better Support for Families" (AHDC) which stated that a short breaks service should be:

'based on a needs assessment of the local disabled child population taking into account the voice of disabled children, young people and their families ..'

The expectation being that:

'all local authorities, primary care trusts, and schools engage parents and disabled children and young people in the design and delivery of services appropriate to their needs.'

Despite these policy statements and the rights enshrined in the UN Convention on the Rights of Persons with Disabilities (UNCRPD) and the Disability Discrimination Act (2005) it would appear that opportunities for disabled children and young people to participate are often fraught with barriers and challenges (Martin, 2009).

³ HM Treasury and DCSF (2007) Aiming High for Disabled Children: Better Support for Families

⁴ HM Treasury and DfES (2007) Aiming High for Young People: A Ten-Year Strategy for Positive Activities

Although this survey uncovers and discusses some of these challenges it also evidences how AHDC has been the impetus from which local areas have been able to break down some of the organisational and attitudinal barriers that had historically prevented them from achieving the successful participation of disabled children and young people. It will suggest that the Short Breaks Transformation Programme has enabled the successful involvement and participation of disabled children and young people in many areas in the development of services and also provided a range of valuable outcomes for local areas as well as the children and young people themselves.

Finally, through the dissemination of interesting and innovative examples of practice we provide recommendations that will support local areas to sustain disabled children and young people's participation beyond the life of the programme.

2. Key Findings

- 1 The AHDC programme has been a 'catalyst for change' and provided a 'focus' for the participation of disabled children and young people
- 2 As a result of the Aiming High Short Breaks Programme 100% of the sample identified an increase in the numbers of disabled children and young people involved in participation in their areas
- 3 100% of the respondents to the questionnaire said that 'the voice of the child' had influenced their short breaks strategy
- 4 As a direct result of disabled children and young people's participation, a wider range of universal services, sporting and leisure activities, have been commissioned
- 5 The Aiming High Short Breaks Programme has led to a large increase (66%) in the number of disabled children and young people being involved in commissioning
- 6 Involving disabled children and young people in the commissioning process has led to more useable and therefore cost effective services
- 7 Feedback to disabled children and young people about their involvement in the development of services requires further consideration
- 8 It is evident that the majority of local areas recognise that it is important to use a range of methods to consult with children of different ages and with different levels of disability
- 9 The experience of involving children and young people as part of the Short Breaks Programme is evidenced as being overwhelming positive despite the inherent challenges

However:

- 10 40% of the randomly selected sample had not previously enabled disabled children and young people to participate in service development
- 11 Practical implications relating to the additional time needed and the skills and capacity of staff were highlighted as a factor leading to inactivity
- 12 Local areas continue to report difficulties in engaging effectively with disabled children and young people from black and minority ethnic groups

3. Methodology

The methodology for this survey was undertaken in two distinct stages.

Stage 1 – The Questionnaire – Section One

Our aim was to present a reflection of the impact of the voice of the child on the development of short breaks across all regions. We therefore used a 12% randomised sample (20 local areas) from across the country. These 20 areas were sent a semi-structured questionnaire (Appendix 1) to complete together with a covering e-mail explaining the purpose of the research (Appendix 2). The purpose of using semi-structured questionnaires was to provide a mix of qualitative and quantitative data. The questionnaire was designed to relate specifically to the Short Breaks Programme and was divided into four distinct sections in line with each of the Full Service Offer Objectives: planning, commissioning, evaluation and sustainability.

The local areas that took part in this stage of the research have not been identified to allow the evaluation to reflect their responses honestly and openly.

Stage 2 – Interesting and Innovative Practice – Section Two

In order to present a range of examples of innovative and interesting practice from across the three regions we sought to identify six to eight case studies. Local Programme Advisers from TDC and TfC as well as Parent Participation Advisers were asked to identify any local areas that they felt could provide examples of participation that would reflect the positive impact on short break development.

Some advisors worked with the local areas to provide detailed case studies and others gave contact details of areas that they knew were involving disabled children and young people well. We then contacted these areas to carry out short interviews about their participation work. We have ensured that each local area has validated all of these case studies before being included in this report.

From these case studies we have been able to analyse a number of common themes and hence provide some recommendations for achieving effective outcomes in the future. These are discussed in detail in the section below – So what does work well?⁵

⁵ The full case studies and reports are not contained within this report but are available as downloads from the TDC website or directly from the associated links.

4. Section One - How Has Participation With Disabled Children and Young People Influenced the Development of Short Breaks?

Findings from the Questionnaires

14 local areas (a 70% response rate) from across six regions of the country returned completed questionnaires within an agreed timescale. East of England (2), West Midlands (1), South East (4), London (2), South West (1), North West (4). One of the respondents was a pathfinder authority.

The following is a summary of the detailed information provided in the questionnaires.

4.1 Planning, Implementation and Impact on Strategy

4.1.1 The starting point

Whilst over 60% of respondents had methods in place for enabling disabled children and young people to participate in some form of service development prior to the AHDC programme this was totally new activity for 40% of the respondents.

- participation already took place through a number of different channels, including: youth parliaments, youth councils, student/school councils and a bi-annual special congress. In one case children and young people were already represented on the Children and Young People Partnership Board
- a full-time participation officer for disabled children and young people was employed in one of the local areas. A number of voluntary organisation advocacy initiatives were also mentioned

Local areas gathered views in many different ways but nearly all in face-to-face events or meetings. In some cases a series of consultation events or workshops was held to help inform the strategy for AHDC.

- one local area reported having regular focus group meetings. Another employed a consultant specifically to engage with children, young people and their parent/carers. Several local areas worked with voluntary sector organisations
- some local areas incorporated consultation into fun/activity days. One said that they had commissioned a voluntary sector organisation to undertake the initial consultation and provide a methodology for future work by the in-house team in

the future. Two local areas reported having made specific provision to consult with non-verbal children and young people

The number of young people consulted ranged from 6 to 50+. Only one local area reported consulting with fewer than 10 children. All the others consulted with more than 16 young people. Two areas reported 40-50 young people having attended consultation events.

4.1.2 Evidence of a wide range of children and young people?

Although the large majority of respondents believed that the children involved in participation were representative of their local area child population, 35% were either unsure how representative their sample was or felt it was not representative.

There were a number of reasons for this. Some felt that it was easier to consult with certain groups e.g. children and young people with physical/complex health who have good communication skills. Another reported that it was difficult to enable participation to take place with children and young people who access mainstream education.

Efforts were made to reach out to some black and minority ethnic and religious groups such as travellers or orthodox jews. Respondents realised that this often needed different approaches and sometimes the use of third party groups such as Gypsy Traveller Projects to encourage engagement.

4.1.3 Supporting the early development of participation

We are able to evidence that a range of people, in-house teams, consultants, and voluntary agency personnel were involved in the early stages of participation.

- in order to allow participation to take place with children and young people who do not use speech, one local area commissioned trained and experienced staff who not only had experience of direct work with this group of young people but also had the skills to develop the confidence of children and young people to represent or support others within their peer group
- in another local area workers who knew them well and understood how they expressed like and dislike supported children and young people with pre-intentional communication

In many cases special schools and their staff were involved in the consultations and wide ranges of communication aids were used.

- a number of local areas created information in accessible formats (using Widgit/ Boardmaker /Communicate In Print software, Photography and video) to ensure children and young people understood what was being asked of them

- facial expression stickers were sometimes created, so that children and young people could give their views about activities
- art and craft activities were used as ways for children and young people to express their views. One local area held an art competition asking children to draw what they liked doing and what was important to them and from that got a number of ideas, including from quite young children

4.1.4 Some difficulties were encountered

The majority of local areas encountered some difficulties in developing and enhancing participation. Whilst it was recognised that it was important to use a range of methods to consult with children of different ages and with different levels of disability the practical implications relating to the additional time needed and the skills and capacity of staff were highlighted. The importance of those consulting having good information about the ways that individual children and young people communicate was a significant factor.

- one local area felt that whilst people who work closely with individual children and young people may have that knowledge, it was not always recorded in detail. The amount of time needed for someone who does not already know the child/young person to build the trust and gain an understanding of the views of children and young people with the most severe and profound needs was another difficulty that was also mentioned

Engaging with children with reduced levels of communication and younger children were the most problematic.

- one local area found that those engaged to do the consultations were insufficiently well trained:

'The level of training for those who did ask children and young people were not sufficient to clearly communicate with the children and young people we tried to engage initially. This led to very predictable answers to questions asked.'

- respondents mentioned practical difficulties; organisational aspects, parental consent, consulting with non-verbal communication due to time constraints and funding as having been the greatest difficulties

4.14.5 Impact of participation on the development of strategy

All the respondents felt that 'the voice of the child' had influenced their short breaks strategy to some extent and many gave examples of the positive impact of the children and young people's input.

'The children and young people's opinions were key to shaping the programme.'

'They asked for information be more child friendly - we have subsequently developed Widgit communication booklets for the programme and a young person's section of [the council's] website

'It did influence the developments strongly.'

'I believe the message from children and young people was very clear. Their views enabled us to prioritise our commissioning programme to meet these needs.'

'Their voice in part led to ensuring that all children and young people identified as disabled under the DDA criteria could access short breaks and that they received support and activities.'

As a result Short Breaks offered as a result of the children and young people's input to planning were more diverse providing a much wider range of sporting and leisure activities than had previously been on offer.

4.2 Commissioning

4.2.1 How disabled children and young people were involved

Children and young people were involved in commissioning short breaks in two thirds (66%) of the local areas responding and for the large majority this was the first time they had been involved.

- in one area disabled young people commissioned a designer to produce a transition workbook and in another area participation led to a 'Playbuilder' design consultation. All felt that the children and young people's involvement had been positive and had been influential or very influential

In a number of local areas children and young people have been involved in commissioning panels. Easy read versions of each bid were asked for from providers in one instance and children and young people's feedback was given up to 25% weighting in the selection processes.

Other ways that children and young people were involved included: doing a 'test run' on services in order to give feedback on accessibility, general atmosphere, staff and level of support needed to use the service and disabled Young Advisors independently evaluating outcomes of a summer scheme on behalf of commissioners.

Where the local areas did not involve children and young people in commissioning a number of reasons were cited. These included not having the skills to facilitate work with children, child-unfriendly formal processes and the amount of time available.

4.2.2 Difficulties encountered

Although the involvement of children and young people was very positive it was not without difficulty. Problems noted were logistics, the mismatch between the essentially bureaucratic process of tendering and the participatory approaches used with children and young people. A number of local areas noted that 'real-time' participation is time-consuming and requires a great deal of preparation. In this connection, several mentioned time-constraints. One local area honestly reported that they had not really considered involving children and young people in commissioning.

As previously mentioned communication with the most profoundly disabled groups and young children was a clear barrier.

One local area had no intention of involving disabled children and young people at this level.

“The focus of the strategic team was on consultation within the process rather than decision-making.”

4.2.3 Impact of children and young people’s involvement in commissioning

Many local areas told us about the very positive impact of children and young people contributing in the commissioning process. Some examples include:

‘Making the [short breaks] activity more inclusive of all age ranges particularly those young people who were older and did not want to play on the outdoor equipment.’

‘Providers have a better insight into what children and young people want from short breaks. They are also much clearer about what children and young people want from their short break carers.’

‘In the beginning we were starting to set up community-based short breaks and tried to offer ‘challenging and adventurous’ activities like surfing, high ropes etc. In this service children and young people were involved right from the start and they were able to direct the kind of activities that they wanted to undertake. Instead of the proposed activities they wanted to do far more “realistic” activities like cooking or gardening. This has been set up and it has been possible to find sustainable funding sources for these very cost efficient activities that also have a very practical meaning for the young people. By allowing the young people to direct us we are able to offer more activities that receive much support from the community.’

'Children and young people said they were worried about their safety out and about on their own. A 'Safe Card' was developed in response, which children or young people can use to explain their problem and get support.'

'Disabled children and young people had had their voices heard, listened to and responded to and had gained an understanding of how their views can make a difference to what is provided or to who is recruited or commissioned.'

'In 2008, a small group of disabled children and young people carried out an audit of the new venue of [local area's] Integrated Children and Young People's Development Service. They took photos, video and notes about how accessible the building was for disabled children and young people and made recommendations about how the building needed to change to make it as accessible and inviting as possible. The young people's views were collated into a report that they then presented to the service manager and architects. Many changes were made to the building as a result of the feedback from the group, which would not have been done originally, including a buzzer at the start of the ramp (rather than just at the door) for anyone who needed support to get up the ramp.'

'Services have altered times, delivery of the provision and parents have started to realise in some of the provision that what they want for their child is not always what their child wants.'

Involvement in the commissioning process has led to self-directed support being developed in some local areas and it was felt that the participation work was good preparation for the young people, helping them to become more positively assertive about their needs and wishes.

One local area reported that the most cost efficient services are now those services where young people have been involved.

4.3 Evaluation and Feedback

4.3.1 Gathering evidence and feedback

In most cases contracts with service providers require them to provide feedback – both qualitative and quantitative and this data forms part of the monitoring process. This section of the questionnaire asked the local areas to provide information about how disabled children and young people had been involved in gathering information about the services they attended.

Most service providers used questionnaires, often using Widgits and symbols to gather information about their services. Two respondents described evaluation activities that children and young people took part in. In one case the voluntary

organisation that had carried out the consultation were also involved in the evaluation.

Formative evaluation was used in one instance with young people deciding at the end of an activity session what they would like to do the following week.

Taster sessions were used in another local area with a provider was initially funded for a 6-month period and then reviewed on the basis of feedback from young people.

4.3.2 Evidence of effectiveness of feedback

The effectiveness of feedback was evidenced in a number of ways. One service used observation of the children and young people as a crosscheck on questionnaire data. Another looked at how the basic materials had been adapted and individualised to show that all children and young people have been included in the feedback process. Comparison of statements made at the beginning of the service with statements made throughout and at the end of the service were also used.

In most cases the views of the children and young people were correlated with feedback from providers and the experience of commissioners.

The majority of local areas tried to communicate the effectiveness of their participation back to the children and young people. This was done through newsletters, events and personalised letters as well as through the changes to services brought about as a result of consultation.

A minority of services felt that this remained an area for development.

4.4 Sustainability

4.4.1 Longer-term benefits of participation of disabled children and young people

Every respondent (100%) saw value in having involved children and young people in the development of their short break services. Ranges of benefits were highlighted:

'The services that were commissioned were contracted on the basis that they are what the children wanted and needed and not based solely on what the Local Authority thought was needed.'

'The most important factor is its impact on culture change within our organisation / service where this is no longer viewed as an 'add on luxury' but integral to good practice and partnership working.'

'Prior to AHDC we did not consult with disabled children and young people. The programme has given us the impetus to start the process.'

'As a result of the short breaks programme booklets using Widgit were created for the children and young people to get a better idea of what was included in the activities before they made their choice as to which activity they would like to take part in.'

'When taster sessions have resulted in successful funding bids, children and young people can be shown a really clear example of the process of how their views have been listened to and taken seriously and have led to the provision of a new service or activity for them.'

'There are now three young people with disabilities on the Youth Council who represent a mix of disabilities and can give a true representation for young people with disabilities that feeds in to the council and out to other children in school councils.'

'Services are more thoughtful about involving parents as a result (of the work with children and young people).'

4.4.2 The reality of sustainability

When asked about the longer term impact of their participation work with disabled children and young people only a minority of respondents were very confident about its ability to continue. 75% of the respondents cited uncertainty about financial resources available to disabled children services as a key factor. Half of the respondents (50%) believed that would need support to ensure that participation of children and young people is sustained.

Although some spoke about how the Aiming High for Disabled Children programme had made the participation of disabled children and young people a reality, and cited examples of how this had led to it being embedded in professional practice, enabling whole-system modernisation, a greater number were only partly confident of the longer-term outlook.

One outcome of the programme that is likely to be sustained is the development of strategic partnerships between service providers as they have become more aware of the importance of engaging with one another as a way of developing their workforce therefore sustaining their services.

4.5 Success Stories

All of the respondents (100%), whatever their starting points, had success stories they wanted to share. Their experience of involving children and young people was overwhelming positive despite the inherent challenges.

Developments that services were most proud of are evidenced in the following quotes:

'Showing that it is possible to include even the most profoundly disabled children and that they have views that are relevant and useful.'

'Cultural change, where we have supported the voices of some of our most vulnerable children to be heard.'

'Move away from foster care and overnights - more about fun - biggest message.'

'The face-to-face involvement in the interview stage of the Tender Process.'

'Considering the wishes and feelings of children in the development of short breaks that provide profoundly disabled children with the fun and enjoyable activities needed by all children.'

'Being able to challenge universal services as a result of direct consultation.'

'Changed thinking and provision.'

'A surf event that was organised in close cooperation with young people who were helping with the risk assessments, the advertising and the running of the session.'

Conclusions

This research has evidenced that participation offers disabled children and young people opportunities to build their skills, influence decisions and gain a 'voice'. It provides them with opportunities to get involved within their communities and gain confidence to express their feelings openly. Participation can provide more accurate, honest and focused information and this helps commissioners shape the services provided by statutory and voluntary sector organisations to meet the needs of disabled children and young people in their areas.

The AHDC Short Breaks Programme has clearly been an impetus for change and it is evident that the 'voice' of disabled children and young people has, in the main, had a positive impact not only on the development of short breaks but also on the transformation of services for disabled children.

Section 5 includes some examples received from a number of local authorities, of interesting and innovative practice in relation to children and young people's participation that further illustrate the concluding points of this study.

5. Section Two - So What Does Work Well? Examples of Interesting and Innovative Practice

We invited local areas to submit examples of interesting and innovative practice that showed how successful participation with disabled children and young people could and has been influencing the development of the short breaks programme.

As a direct result of the AHDC funding several areas have been able to set up forums or groups that have successfully given disabled children and young people a 'voice'.

Leicester City Council

The Big Mouth Forum

Leicester City Council wanted to give disabled children and young people the opportunity to tell service providers, professionals and society what is working and what is not working across Leicester City for them. Since the 'Big Mouth Forum' was established in 2008 the number of disabled children and young people involved has increased from 7 to 50. They have all had an extremely positive role in improving practice, strategy and AHDC local services.

The Forum have delivered presentations at regional and national conferences and have been able to support other local areas set up their own Forums. They were runners up for the Most Innovative Youth Led Project in April 2010.

The outcomes for the children and young people have been numerous. As a group they have all become very good friends who are able to discuss and support each other's issues. They have also obtained representation on the Young People's Council and been involved in the development work of the Youth Hub.

One of the key successes of the Forum is that the children and young people have responsibility and know the Forum is 'theirs'. They are all equally encouraged to participate and their efforts rewarded. In essence the Forum is an understanding, committed, enthusiastic and passionate group who are not only looking to improve services for themselves, but for disabled children and young people in general.

There is every expectation that the Forum will continue to grow and develop beyond March 2011.

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Durham County Council

Durham's 'eXtreme' Participation Group

Children and young people in Durham are supported, via an organisation called 'Investing in Children', to participate in a number of different groups to engage with adult decision-makers to highlight problems or gaps in services and agree how these should be resolved. One of these groups is called the 'eXtreme' group and is made up of disabled children and young people from across Co. Durham. In their own words; *"we meet to discuss the advantages and disadvantages of being a young person with a disability. We aim to improve services so that other young people don't have to experience the difficulties we have sometimes experienced. We support each other as a group; we listen to other people's opinions; we grow ourselves, in confidence and work to challenge policies, services and people's perceptions."*

'eXtreme' has been involved in a number of projects including:

- helping to shape the type of short break services they would like to see commissioned. The group met with the lead commissioner and discussed what activities they wanted to do and with whom. As a result an imaginative range of activities were provided that met the needs of many Disabled Children & Young People
- giving feedback on the activities they took part in and as a result changes were made to the programme of events
- commenting on the service of local transport companies. Disabled young people were involved as 'mystery shoppers' to evaluate the accessibility of transport in the area and highlight any issues. This resulted in young people delivering training to the transport companies and being involved in the information the Local Authority produces
- helping to develop the Children's Network Directory by visiting and researching good places to go which are accessible for all children and young people

In addition the Group put forward an application to become Young Ambassador's for the European Year for Combating Poverty and Social Exclusion and were successful in being chosen to represent Durham County Council. As a result the young people enjoyed a three day trip to Brussels supported by The Commissioning Manager and an IiC Project Worker. This included attending the EU commissioners, "Construire ensemble une societe pour tous Un cirque contre l'exclusion" event that focussed on exclusion and poverty in Europe. The group also attended various projects around the capital including the Flemish Youth Council. On their return the young people were interviewed for the BBC and spoke at a conference which ended the year of activities.

The outcomes are that disabled children and young people in Co. Durham have a

say in the services they access and as a result the Local Authority has been able to deliver services that are cost effective and good quality. As young people, they have grown and have much more confidence from the process they have been involved in. Some of the young people are now following various career paths, including the West End stage! The group has fun, while effecting real change.

It works because there is a clear strategy for developing, publicising and sustaining dialogue with all children and young people who wish to be involved. Responsibility for children and young people's participation is accepted collectively, across the organisation, and members of the organisation hold each other accountable for this. Durham County Council as an organisation is committed to making opportunities accessible to children and young people with diverse life, cultural, family, educational and other experiences. Treating children and young people with respect and honesty, and their contribution is acknowledged as important. The children and young people have access to the agenda, and are able to initiate dialogue on issues identified by them and that Key decision-makers make themselves available to talk and listen to children and young people.

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These newly heard voices have been impacting on the development of short breaks in very positive ways across the country. The following from the London Borough of Hounslow is an excellent example of disabled children being directly involved in decision-making.

London Borough of Hounslow

Aiming High Young People's Panel

In Hounslow the Decisions R Us Youth Panel has been set up to distribute £30,000 from the Aiming High Grant to disabled children and young people aged 5 – 18 who are looking for help with a short break or activity.

This panel has two main aims:

- 1 to enable disabled children and young people to participate fully in the whole decision-making process on activities and projects that they would like to do
- 2 to encourage and allow them to plan, develop and deliver activities for themselves and other disabled children and young people aged 5 – 18

Bids for up to £500 can be applied for to spend on new activities, a short break away from parents and carers or equipment. The Panel is made up of young people who understand what it is to have special needs and they come together once a month to consider the applications.

A participation worker supports the children and young people to become actively responsible for commissioning, monitoring and evaluation of the award scheme. Assistance is given to children and young people who may have difficulty applying.

Children and young people can apply on their own or together with a friend or a group of friends. The bid should improve the life opportunities and weight is given to ideas that promote access to community services and activities.

Two examples of successful bids include a 15 year old boy who bid for £150 to go on an activity adventure with people his own age and two 9 year old girls with visual impairments who enjoyed a week of horse grooming and riding at a local stable.

Children and young people who are given money by the panel are asked to feedback about their experiences – and have used a range of media to do this.

Contact details for further information:

Phil Hopkins, AHDC lead, Joanna Dawson, Short Break Project Lead, Service Coordinator Children with a Disability, Social Work Team for Children with a Disability, Pavillon CG, Civic Centre, Lampton Road, Hounslow, Middx, TW3 4DN.
Tel: 020 8583 6482. E-mail Phil.Hopkins@hounslow.gov.uk,
joanna.dawson@hounslow.gov.uk

As the results from the questionnaire have indicated, Aiming High for Disabled Children has enabled disabled children and young people to become more fully involved in the commissioning process. The London Borough of Redbridge has provided an interesting example of this.

London Borough of Redbridge

Give us a Break – Redbridge’s Young Commissioners

The active participation of children and young people has been a key feature of the development of short breaks in Redbridge. Participation has included creating a commissioning panel of children and young people in parallel with the (adult) commissioning group. The young commissioners have provided input to the providers’ forum, evaluated tenders and provided evaluation of the services they have received.

As part of the Redbridge tendering process providers were requested to submit a separate, child-friendly version of the tender. This version was evaluated and scored by a dedicated children and young people’s commissioning panel, which gave feedback to the overall commissioning group. The children and young people’s scores made up 10% of the overall score. The requirement for a child-friendly version of the tender documents has been very revealing. Some bidders clearly had difficulty producing something meaningful and as a consequence the children and young people’s panel rejected these.

The panel also gave approval to bids for short breaks that offered activities that would give them new challenges and experiences. Their preferences were orientated to adventure type activities – sailing, climbing, abseiling etc. and doing things that other young people do, for example through befriending projects. They rejected some of the more tried and tested models of ‘safer’ short break provision because they wanted something different.

The involvement of the children and young people in this way has been very influential. Some of the outcomes of their evaluation of bids came as a surprise to the adult commissioning panel and has improved their understanding of the children and young people’s wishes and aspirations. As a consequence money was spent on services that the children and young people really wanted.

It worked because children and young people:

- were given a genuine role in the process
- experienced the effect of their participation in the commissioning process

They were shown respect and active participation and self-determination have been

modelled to the children and young people, their parents and to professionals.

A DVD has been produced highlighting the outcomes of the successful commissioning and evaluation from the children and young people has fed into the last round of commissioning. The participation of children and young people is now embedded in the commissioning process.

Contact details for further information: Amanda Ridgewell, AHDC Strategy Manager, Station Road Centre, Station Road, Barking Side, IG6 1NB. Tel: 020 8708 7524. E-mail Amanda.Ridgewell@redbridge.gov.uk

But not all areas have taken the same approach.

Knowsley Metropolitan Borough Council

Knowsley's Young Inspectors Programme

Knowsley takes a considered approach to disabled children and young people's participation and in response to Aiming High for Disabled Children (AHDC) they did not want to just simply establish a Children and Young People's Disability Forum. Alternatively they decided to work with universal services and use their established engagement systems to consistently engage and listen to the views of disabled children and young people.

A test for the DCFS Engagement & Participation Team was to review current activities to challenge disabilism and support meaningful, inclusive participation. The Children and Young People's Forum, known as S.P.A.R.K (Shout Participation And Rights in Knowsley) was established as the authoritative and credible voice of all children and young people in Knowsley (aged 0-25). The focus of S.P.A.R.K is to primarily increase the scope of engagement and decision making for children and young people in the borough, including representing the views of those at risk and vulnerable groups. It is led by a diverse membership of young volunteers from a wide range of services and young people's networks in Knowsley. Young people identified the need for S.P.A.R.K to be all-encompassing and helped to develop resources that ensure meetings are not only inclusive but also interactive; using:

- Wigit Symbol Software
- Inclusive Communication Resources
- LDD Toolkit
- large print/symbol/brail minutes and agendas
- fun & inclusive warm-ups/ice-breakers/workshops

As one of only 8 Local Authorities selected to be the first to pilot the Youth4U Young

Inspectors Programme in England, Knowsley had an opportunity for disabled children and young people to be at the heart of service inspection and to actively participate in mixed ability settings.

Youth4U Young Inspectors is a two year programme co-ordinated nationally by NCB as part of the Look Listen Change Consortium (LLCC). The purpose is to increase the number and quality of opportunities for marginalised young people to influence services and engage their peers in influencing local policies and services across a wide range of issues including; locality, health, neighbourhood renewal, transport and community service.

As Knowsley Young Inspectors, disabled children and young people take part in a training programme which is designed to not only give the young people skills to inspect and evaluate services but also provides a range of transferable social skills including; working as part of a group, working towards goals and problem solving. As part of the reporting process, all inspections carried out by Young Inspectors are fed back to S.P.A.R.K who respond and can challenge any areas highlighted in the Inspection Reports. As Young Inspectors our disabled young people independently identify services to inspect and draw up conclusions and recommendations from their findings. Through their involvement on the programme disabled children and young people have the opportunity to gain an ASDAN Award of Personal Effectiveness Qualification, equivalent to a GCSE.

Two examples of inspections undertaken and the techniques used by Knowsley Young Inspectors:

Transport

Young Inspectors 'mystery shopped' boroughwide buses/bus routes – this included carrying out journeys from their home to a facility or an activity they or other young people access, such as shopping centres, leisure centres and hospital/doctors surgery. As part of the mystery shopping exercise Young Inspectors recorded how accessible the buses were, attitude of drivers, how long the journey took, how much it cost, whether the transport was reliable and rated their overall experience.

Kirkby Family Centre

Young Inspectors contacted the Family Centre and were invited to undertake an unannounced inspection. They used observation and interviews with young people using the centre as part of the inspection process, and asked the young people what their feelings were about the building, the facilities, staff, accessibility and overall experience. Young Inspectors researched the activities provided and rated how inclusive they were.

Once Young Inspectors complete an inspection they produce a report that includes strengths, areas of development, and recommendations. This is presented back to the inspected service and S.P.A.R.K who feedback to the Knowsley Children and

Families Board. Through this systematic approach information highlighted is used to inform service improvement plans and commissioning. The work of the Young Inspectors will be used to inform work being undertaken as a small project jointly with adult and children within Transition in the Borough, working with Mersey Travel with regard to developing young people's skills for independent travel and training of staff on buses.

A key feature of the training Knowsley Young Inspectors enjoy is that it is delivered by Knowsley Young Advisors as Peer Trainers. Young Advisors are local young people aged between 16 - 21, who guide community leaders and decision makers on how to engage young people in community life, decision making and empowerment. Young Advisors bring their expertise and experience in delivering fun, interactive sessions to diverse groups of young people. They encourage, motivate and support all levels of participation that help to build confidence and skills, beyond inspection. This has given an extra dimension to the training programme that has been recognised by NCB as an exemplar of innovative engagement. Knowsley's approach to develop bespoke training and tools that meet the individual needs of marginalised young people led to an invitation to help in the re-design of the Youth4u Young Inspectors training materials, which are distributed to all authorities and organisations running the programme.

Knowsley's 'LINKed-Up' is a children and young people's Local Involvement Network (LINK) which provides an opportunity for children and young people to voice their own views, issues and concerns about their health and wellbeing. LINKed-Up is the only children and young people's Local Improvement Network in the Country. We recognise that children and young people have different issues and concerns regarding their health and evidence from previous consultation has shown that adult issues tend to dominate, and the issues of children and young people are not given the same opportunity to be heard.

With this in mind Knowsley Young Advisors led two inclusive and interactive consultation days, 'Lets Talk Health' and 'Lets Talk Health 2', to gather the views and ideas of young people and determine what their health priorities are. The workshops were fully inclusive to support participation from children and young people with disability and to gain a sharper understanding of their needs. From the ideas and contributions from young people LINKed-Up has been able to inform a needs led approach to improve services and commission differently.

This year LINKed-Up won two awards at the NHS Inspiration North West Annual Awards. The idea of one young wheelchair user for 'wheelchair lane' access to health and social care buildings won the 'Inspiration on the Front Line' award. The colourful, smooth surface pathways would give easier access to disabled service users and is an idea which will be adopted in the design of all future NHS Knowsley buildings wherever possible. The group also had an idea for an interactive staff training DVD, which won the 'Inspiration in Communication' award. The DVD has

been produced with young people to be distributed to frontline Health and Wellbeing staff. It will be delivered by Young Advisors as a training tool to discuss how to improve children and young people's service experience.

The work of S.P.A.R.K, LINKed-Up and the Young Inspectors Programme demonstrates a commitment to the active involvement of disabled children and young people. The inclusive engagement practices adopted across all fora and consultation activities has led to acknowledgement from regional and national bodies of Knowsley's progressive universalism and focus to involve disabled children and young people in meaningful and inclusive ways.

Contact details for further information:

Patricia Jackson, DCFS Engagement & Participation Team Manager, Huyton Hey Road, Huyton, L35 5YH. Tel: 0151 443 5745. E-mail patricia.jackson@knowsley.gov.uk

And in some areas existing groups of disabled children and young people have been involved in the evaluation of short break services:

London Borough of Barking and Dagenham

The Disabled Children and Young People's Development Forum

The Barking and Dagenham Progress Project is a voluntary sector partnership initiated in 1998 to support and involve disabled young people to give their opinions and express themselves about the services they receive.

They were commissioned earlier this year to evaluate Short Break services in the Borough and produce a consultation report for the Local Authority. The report 'New Innovations for working with Disabled Children and Young People' not only provides a valuable evaluation on the feedback received about short break services but also evidences the need for adequate structures to be put in place if consultation and participation with disabled children and young people is to be meaningful. The findings from the report are being used to help plan and improve the current provision of short break activities as well as give advice for service providers on what evaluation tools are most effective when working with disabled children and young people.

Contact details for further information and a copy of the report: Carron Beckwith, Participation Officer, Barking and Dagenham Progress Project, Kingsley Hall, Parsloes Avenue, Dagenham, Essex, RM9 5NB. Tel: (020) 8592 2020. E-mail c.beckwithpp@btconnect.com

A key part of the Aiming High Short Breaks Programme has been the development of Universal Service Provision. The questionnaires provided evidence that the participation of disabled children and young people has had an impact on the development of universal services. The first example considers a research report from Luton and the second, from Southend, highlights the importance of supporting the development of the workforce if universal services are going to be able to meet the needs of disabled children and young people.

Luton Borough Council

Luton Leisure Report – are disabled children and young people included in leisure activities in Luton?

Luton Borough Council sought to research the extent to which disabled children are included in universal leisure activities across the borough.

Luton commissioned the charity Out & About to conduct this research on their behalf and produce a report that has been used to inform the current Aiming High for Disabled Children programme in Luton. They fully included disabled children and young people at every stage of this research, involving the children and young people in the design, interviewing and evaluation stages of this work. This has been of immense interest to disabled children and young people, their families and anyone who shares the view that they are entitled to the same leisure opportunities as non-disabled children. It highlighted the barriers to access and provides potential solutions from the perspective of the leisure provider.

A copy of the full report is available from the Out and About website:
<http://www.oaa.co.uk/>

Southend-on Sea Borough Council

Expanding Universal Services

Southend Borough Council encourages inclusion by supporting universal services in developing their work with disabled children and young people.

Workers' negative perceptions and irrational fears have sometimes acted as a barrier to inclusion, so extensive training has been offered to the workforce to address this. This has led to evidence that workers' confidence and understanding has now increased significantly.

Aiming High for Disabled Children has funded several Connexions projects and as a result disabled children and young people have been able to participate in a range of service developments including:

- peer mentoring - a group of young people from the youth council were trained and then employed to mentor disabled young people. The disabled young people are now able to play a full role in planning services and campaigns. This has proved so successful and popular that additional funding has been given to increase the project
- the young people from the above project (with their peer mentors) are undertaking an access audit of leisure resources, including a photographic directory. This enables others who have little or no language to specify what interests them and have a greater choice about their own leisure activities
- one-to-one workers have been employed so that young disabled people are supported to choose and access groups, clubs and activities that interest them. The aim is that the young person is supported to integrate fully and that the confidence of the resource staff gradually increases

It is felt that this has worked well because high quality training was commissioned that was carefully planned to allay people's anxieties and give them practical strategies.

The outcomes have been positive and feedback from all projects indicate a very high level of satisfaction from the young people involved, Connexions now work in a completely new way with disabled young people and their individual needs and aspirations are considered and individually addressed. The cohort of workers trained to support disabled young people has increased and this has led to greater confidence from families and enhanced safeguarding standards.

Contact details for further information: Laura Clarke, AHDC Commissioning Officer, Lighthouse CDC Snakes Lane, Southend, Essex, SS2 6XT. Tel: 07789723508. E-mail: lauraclarke@southend.gov.uk

There are also interesting and innovative examples of how successful participation can lead to influence on wider children services.

Swindon Borough Council

Chatterboxes

Chatterboxes (Swindon's participation group funded by Aiming High for Disabled Children) was established to ensure that disabled children and young people are actively involved and consulted with, in all services that affect them. In March 2010,

the group was approached by the Local Safeguarding Children Board (LSCB) to gather information on the level of disabled children and young people's understanding of safeguarding.

12 young disabled people from Chatterboxes, aged between 9 and 19 years, were involved in a project that ran for six consecutive sessions. Three issues were addressed; safeguarding, bullying and disability hate crime.

Various methods were used to enable the children and young people to participate – including, art workshops, interactive group games, discussions and identifying picture and work games. The group was well supported by highly trained staff.

The project demonstrated that although the group had a basic understanding of emotional and physical abuse and all had experienced this to some level, there was little understanding or reference to sexual abuse or neglect. Young people with a learning disability demonstrated a greater risk of being a target from coercive or persuasive forms of abuse.

This has highlighted the need to strengthen service providers' access to specific disability child protection training to ensure all staff working in the short break services are proactive in dealing with safeguarding issues and can fulfil their duty of care. It has also reinforced the need to address disabled children and young people's awareness and understanding of neglect and sexual abuse and follow up sessions are currently taking place.

As a direct result of this project the Local Safeguarding Children Board (LSCB) management group have asked the LSCB disabled sub-group to address some of the key points highlighted.

Contact details for further information: Rebecca Taylor, Participation Officer, Disabled Children Team – Aiming High, Swindon Borough Council. Tel: 01793 464088. E-mail: RMTaylor@swindon.gov.uk

Appendices

Appendix 1

The Questionnaire.

<http://www.togetherfdc.org/SupportDocuments/Questionnaire08.10.10Final.xls>
(spreadsheet, 183kb)

Appendix 2

Covering e-mail sent to local areas.

Dear,

We are contacting you to ask for your help with a small-scale survey we are carrying out to look at the outcome of children and young people's participation in the development and commissioning of short breaks.

There has been tremendous progress in the development of short breaks over the last two years and we know that in many local areas the participation of children and young people has been an integral part of that development. DfE has now asked us to capture some more detailed information about local practice and the benefits of participation in order to inform further discussion with Ministers.

We have prepared this short questionnaire (attached) to capture information from a randomised sample of LAs about children's/young people's involvement in various aspects of the short breaks programme. We would be very grateful if you would be willing to help with this. We think it is really important to highlight the work that has been done and to do everything we can to influence spending decisions regarding the future of short breaks.

If you can help, please complete this by **Friday 22 October 2010** and return it to Kate Whetton, Regional Assistant at kate.whetton@togetherfdc.co.uk, 07738893659. Alternatively if you would prefer to provide your answers to the survey over the phone, please let Kate know and she will arrange for one of us to contact you.

We hope you will be able to take part but would appreciate you letting us know as soon as possible if this will not be possible. Please do not hesitate to contact us with any queries you may have.

Very best wishes,

Susan Hayward and Mary Kuhn.

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