contact a family
for families with disabled children

Strengthening Parent Carer Participation
‘Short Breaks services, the journey so far…’

• Welcome to this Contact a Family Webinar

• If there is a technical hitch, please do bear with us

• Those of you joining by pc, laptop, tablet or smart phone should now be able to see this introduction slide
Timing & Questions

• As there are so many attendees, it is not practical for verbal questions to be taken, therefore you will all remain ‘muted’ throughout.

• If at any point you have questions, please use the question icon on your GoToWebinar tool bar on your screen.

• This will allow you to type your question in to the text box and submit this to the Webinar administrator.

• I will select as many relevant questions to answer as time allows, if similar questions are received I will condense these where possible.
Q&A Session

• Further relevant questions, not covered in the time allowed, will be answered and posted on the Contact a Family website along with the recording of this Webinar, details of which will be circulated next week.

• At the end of the Webinar a short questionnaire will launch, please take the time to complete this as this will assist with future online training events.
‘A person (P) has a disability if:

a) P has a physical or mental impairment, and
b) the impairment has a substantial and long-term adverse effect on P’s ability to carry out normal day-to-day activities.’

This includes physical disabilities, sensory impairments, mental health conditions, learning disabilities, and long-term medical conditions.

Equality Act 2010
A child or young person has special educational needs if he or she has a learning difficulty or disability which calls for special educational provision to be made for him or her.

A child of compulsory school age or a young person has a learning difficulty or disability if he or she

a) has a significantly greater difficulty in learning than the majority of others of the same age, or

b) has a disability which prevents or hinders him or her from making use of facilities of a kind generally provided for others of the same age in mainstream schools or mainstream post-16 institutions.’

Children and Families Act 2014
‘…a child shall be taken to be in need if—

a) he is unlikely to achieve or maintain, or to have the opportunity of achieving or maintaining, a reasonable standard of health or development without the provision for him of services by a local authority under this Part;

b) his health or development is likely to be significantly impaired, or further impaired, without the provision for him of such services; or

c) he is disabled,’

Children Act 1989
‘Short Breaks Services’

‘Short Breaks’ are services that provide parent carers of disabled children with a break from their caring responsibilities.

‘Short Breaks’ also help disabled children to enjoy different experiences, develop new skills and assist them to achieve their ambitions in life.

‘Short Breaks’ can be provided by councils (local authorities), health services or private, voluntary and community sector organisations.
An Act to make further provision with respect to the welfare of chronically sick and disabled persons; and for connected services.

‘Provision of welfare services’

‘An Act to make further provision with respect to the welfare of chronically sick and disabled persons; and for connected services.’

Chronically Sick and Disabled Persons Act 1970
‘Provision for disabled children’

‘Every local authority shall provide services designed

a) to minimise the effect on disabled children within their area of their disabilities; and

b) to give such children the opportunity to lead lives which are as normal as possible; and

c) to assist individuals who provide care for such children to continue to do so, or to do so more effectively, by giving them breaks from caring.

Children Act 1989; Children and Young Persons Act 2008
‘Support with caring…’

‘All parents need a break from caring sometimes…but around one-third of parents with disabled children wait over a year for a short break service…families with very young children, children with complex needs, “challenging” behaviour and Autistic Spectrum Disorders, as well as those from minority ethnic communities, are less likely to have short breaks.’

Improving the Life Chances of Disabled People 2005
‘...the one thing that can help life be bearable and keep you going.’
‘Aiming high for disabled children’

‘Aiming High’ launched in 2007 as a transformation programme with four specific areas of development:

- Short Breaks
- Disabled Children’s Access to Childcare (DCATCH)
- Transition Support Programme
- Parent Forums

Aiming High for Disabled Children
'Families with disabled children often face particularly high levels of stress which may result in family breakdown. For parents and siblings of disabled children, short breaks reduce stress, allow a rest from caring, provide time to carry out tasks and activities that other parents take for granted and allow more time with other children.'

Aiming High for Disabled Children
‘I needed a break from caring, just to recharge my own batteries’

‘make our lives easier’

‘breathing space to recharge’

‘enable us to go on holiday’
‘Short breaks can also have a positive impact on disabled children, as they help to tackle social isolation, provide access to leisure activities, friendship networks and promote development.’

Aiming High for Disabled Children
‘...experience life outside the family home!’

‘...confidence to try different activities.’

‘...able to freely express himself’

‘very happy and full of confidence’
‘Short Breaks’ Regulations

Breaks for Carers of Disabled Children Regulations 2011

- Duty to Make Provision
- Types of Services which must be Provided
- Short Breaks Services Statement

Breaks for Carers of Disabled Children Regulations 2011
‘Duty to make provision’

‘a local authority must have regard to the needs of those carers…who would be unable to continue to provide care unless breaks from caring were given to them…who would be able to provide care for their disabled child more effectively if breaks from caring were given to them to allow them to:

• undertake education, training or any regular leisure activity,

• meet the needs of other children in the family more effectively, or

• carry out day to day tasks which they must perform in order to run their household.’

*Breaks for Carers of Disabled Children Regulations 2011*
‘Types of services…’

‘A local authority must provide, so far as is reasonably practicable, a range of services which is sufficient to assist carers to continue to provide care or to do so more effectively.’

• day-time care and or elsewhere,
• overnight care in the homes of disabled children or elsewhere,
• educational or leisure activities for disabled children outside their homes, and
• services available to assist carers in the evenings, at weekends and during the school holidays.

Breaks for Carers of Disabled Children Regulations 2011
‘A local authority must...prepare a statement for carers in their area setting out details of the range of services provided; any criteria by which eligibility for those services will be assessed; and how the range of services is designed to meet the needs of carers in their area.

• publish their short breaks services statement
• keep their short breaks services statement under review
• where appropriate, revise the statement.

In preparing and revising their statement, the local authority must have regard to the views of carers in their area.’
Parent Carer Participation

‘The Act places the views, wishes and aspirations of children, parents and young people at the heart of the system and requires a culture change in the ways in which professionals work with families and with each other.’
What is the impact?
Children, Young People & Families

perpetuation of ‘myths’

families at ‘crisis’ point

new diagnoses

higher thresholds for support

stigma of social care

‘asset’ : ‘deficit’

knowing what’s available

keeping informed

understanding ‘rights’

perception of ‘failure’
Parent Carer Forums

- information overload
- knowledge of case law
- own lives to lead
- succession planning
- poor relationships
- low membership
- parents are burnt out
- internal struggles
- awareness of resources
- participation ‘bedding in’
- internal struggles
Local Authorities & Health Services

- participation not appreciated
- redundancies & restructures
- workforce development
- ‘influence’ : ‘understanding’
- reduced finances
- increased pressures
- understanding of ‘responsibilities’
- potential for unlawful practice
- political priorities & policies
- less sector support
How can forums get involved?

Parent Carer Forum Handbook

- Getting Started
- Working as a Team
- Communications
- Working in Partnership
- Improving Services
‘…must have regard to…’

- the views, wishes and feelings of the child and his or her parent, or the young person...
- the importance of the child and his or her parent, or the young person, participating as fully as possible...
- the importance of the child and his or her parent, or the young person, being provided with the information and support necessary to enable participation...
- the need to support the child and his or her parent, or the young person...to achieve the best possible educational and other outcomes.’

Children and Families Act 2014; SEND Code of Practice
Short Breaks Partnership
Short Breaks Partnership: Joint Bulletin (Q1)

Contact a Family, Case Study: ‘How the views of parent carers are informing short break provision in Hampshire’

Council for Disabled Children, Case Study: ‘How the views of disabled children are informing commissioning at Enfield Council’

Action for Children, Case Study: ‘The importance of personalising short break provision’

KIDS, Case Study: ‘The value of short break provision in preparing young people for adulthood’
Useful resources…

Short Breaks Services Statements: Commitment and Transparency

Raised Expectations: Parental Experiences of Short Breaks

No Going Back! Parents' Expectations of Short Breaks

Short Breaks Tracking Interim Report

Calling for Clarity: Eligibility Criteria for Short Breaks

The Social and Economic Value of Short Breaks

Challenging Cuts to Short Break Services

Council for Disabled Children: 'Resources'

Contact a Family: 'Improving Short Breaks Services'
We are very interested in hearing from areas where they may be facing particular challenges in relation to Short Breaks services and local authority children with disability social care teams.

We are particularly keen to promote positive examples of participation and coproduction, but are appreciative in recognising that many areas are facing challenges at this time.

You can get in touch by emailing ben.palmer@cafamily.org.uk.
Thank you for attending with us today

A short questionnaire will launch at the end of this webinar

Please take the time to complete this as it will help us plan future online training events including other topics you would like to see.

The recording of this Webinar, presentation and questions will be on the parent participation Resources page of Contact a Family’s website next week – an email confirming this will be sent to you once this is available.