

## Talking points

The NNPCF is a membership organisation and our mission states that “we aim to empower our members to ensure that their voice is heard at a local, regional and national level.”

Working with our membership we have identified a number of key “talking points” - these are topics and themes that are the most important to our membership and the ones that have been prioritised by the NNPCF.

Based on feedback from our membership and from other partners and stakeholders, the “talking point” summarise:

- The lived experience of our members about each topic,
- What is working and what is not working, and
- What we would like to see changed.

The talking points have been created using a range of feedback which includes:

- Surveys (including the SEND surveys)
- Feedback from our annual conferences
- The topics raised at regional meetings
- Themes and topics raised by our membership on social media
- Face to face conversations with our membership

## Short breaks

### Background

Short breaks services offer both a valuable lifeline for families, and give disabled children and young people opportunities to enjoy different experiences, make friends and realise their aspirations in life.

There is strong evidence that providing short breaks results in positive outcomes for children, young people and their families and statutory authorities:

- disabled children and young people experience increased choices, wider social networks and are growing in confidence and independence

- Parents experience more choice and control of family life, develop supportive peer relationships, and their expectations and aspirations of what their children may achieve are raised
- local authorities see 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.<sup>1</sup>

The Children and Families Act 2014, the Special Educational Needs and Disability (SEND) Code of Practice<sup>2</sup> and supporting regulations place duties on local authorities and health services to fully participate and co-produce services with children and young people with SEND and their families.

These place duties on local authorities and health services to change the way in which they provide services for children and young people with SEND and their families including the Local Offer and **Short Breaks**.

**Local Offer:** *'Local authorities in England are required to set out in their Local Offer information about provision they expect to be available across education, health and social care for children and young people in their area who have SEN or are disabled, including those who do not have Education, Health and Care (EHC) plans. Local authorities must consult locally on what provision the Local Offer should contain.'*

### **Breaks for Carers of Disabled Children Regulations 2011**

Short Breaks can provide opportunities for disabled children and young people to have enjoyable experiences away from their primary carers, contributing to their social inclusion and personal and social development. They also provide the parents and carers of disabled children and young people with a necessary and valuable break from their caring responsibilities.<sup>3</sup>

Short Breaks can include day, evening, overnight, weekend or holiday activities. They can take place in the child or young person's own home, in the home of an approved carer, a residential or community setting. Short breaks range from

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<sup>1</sup> [https://contact.org.uk/media/1210596/short\\_breaks\\_toolkit.pdf](https://contact.org.uk/media/1210596/short_breaks_toolkit.pdf)

<sup>2</sup> <https://www.gov.uk/government/publications/send-code-of-practice-0-to-25>

<sup>3</sup> <http://www.legislation.gov.uk/ukxi/2011/707/contents/made>

supporting disabled children to access a break within a universal setting, to providing specialist services at a local level.

The eligibility to apply for Short Breaks will vary across Local Authorities. Under in the Children Act 1989 all disabled children are children in need.<sup>4</sup> Typically, disabled children and young people who meet the remit of the Disabled Children’s Team are eligible for Short Breaks. These are disabled children and young people aged birth-18 where the disability *has a substantial and long-term adverse effect on the child/young person’s ability to carry out normal day-to-day activities*.<sup>5</sup>

Support can also be provided to families where the need may be greater due to individual family circumstances and not necessarily due to the severity of the child or young person’s disability. Examples of this include where there is more than one disabled child or young person in the family impacting on the parent’s ability to cope, or where additional support is required to safeguard a child.

Families that do not meet the threshold for services from the Disabled Children’s Team may be provided with general information and contact details for universal and targeted services which are available through the **Local Offer**.

### The Short breaks services statement

Since October 2011, a local authority must prepare a statement for carers in their area (a “short breaks services statement”) setting out details of—

- the range of services provided
- any criteria by which eligibility for those services will be assessed
- how the range of services is designed to meet the needs of carers in their area

The local authority must publish their short breaks services statement, including by placing a copy of the statement on their website.

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<sup>4</sup> <http://www.legislation.gov.uk/ukpga/1989/41/contents>

<sup>5</sup> <https://www.gov.uk/guidance/equality-act-2010-guidance>

The local authority must keep their short breaks services statement under review and, where appropriate, revise the statement. In preparing and revising their statement, the local authority must have regard to the views of parent carers in their area. **This is an important role for PCFs.**

### Health responsibilities

The primary responsibility for meeting the health needs of disabled children rests with Clinical Commissioning Groups (CCGs).<sup>6</sup> The primary duty on CCGs is to commission services 'to such extent as it considers necessary to meet the reasonable requirements of the persons for whom it has responsibility'.<sup>7</sup> This implies a duty to assess disabled children to see if it is necessary to meet their reasonable requirements for short breaks.

All specialist health provision for disabled children must also be clearly set out in the Local Offer.

There are important co-operation duties on local authorities and CCGs including a requirement for joint commissioning arrangements to be in place in every area.<sup>8</sup>

### The role of Parent Carer Forums

The NNPCF believe that disabled children and their families should have the same opportunities as their peers. Parent Carer forums have reported the following key issues:

#### **Financial pressures on local authorities mean that short breaks services are under threat**

Many forums report that pressures on funding are causing local authorities to take short term decisions that impact the outcomes and life chances of children and young people with SEND. For example, forums report that the thresholds for receiving social care are being raised depriving many families of the early help they need; this creates further pressures on resources.

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<sup>6</sup> <http://www.legislation.gov.uk/ukpga/2012/7/contents/enacted>

<sup>7</sup> Section 3 of the National Health Service Act 2006 (as amended).

<sup>8</sup> Section 26 of the Children and Families Act 2014

According to the Disabled Children Partnership, disabled children are missing out on £1.2 million of support from authorities. This is preventing disabled children living their best lives.<sup>9</sup> They say that only 10% of parents of a disabled child believe that social care services in their area are fit for purpose and 90% of families say they have to fight to get the services their disabled child needs.

**Local areas do not have a good understanding of the services they need to provide and outcome based commissioning.**

PCFs are reporting that education health and social care services are not working together effectively at a strategic level. This is supported by evidence from local area inspections by Ofsted and CQC where many of the Written Statements of Action issued reference poor joint working and joint commissioning as a concern.

*'Area leaders have a weak understanding of the needs and lived experience of children, young people with SEND and their families. Joint commissioning is weak and arrangements for jointly planning and providing services are ineffective.'*<sup>10</sup>

Amanda Spielman, Her Majesty's Chief Inspector

### **Concerns about the level of coproduction**

Forums have a mixed experience of co-production. Too many say that their views and experiences are neither heard nor valued. Short breaks work best when they are co-produced and tailed to the individual family. Families should not be given a rigid menu of what is on offer rather Local Authorities should be willing to enter into a dialogue and deliver person-centred services that families actually need. What looks like respite for one family will look very different for another.

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<sup>9</sup> <https://disabledchildrenpartnership.org.uk/>

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[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/859422/Annual\\_Report\\_of\\_Her\\_Majesty\\_s\\_Chief\\_Inspector\\_of\\_Education\\_Children\\_s\\_Services\\_and\\_Skills\\_201819.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/859422/Annual_Report_of_Her_Majesty_s_Chief_Inspector_of_Education_Children_s_Services_and_Skills_201819.pdf)

## Outcomes Based Commissioning (OBC)

**Outcomes based commissioning** is an approach that is increasingly being adopted by Local Authorities and Clinical Commissioning Groups (CCGs), wherein services, families and young people come together to develop a series of commissioning arrangements that are underpinned by the measurement of progress towards a set of shared outcomes.<sup>11</sup>

### Coproduction is a key part of this process

The NNPCF have worked with our membership to identify examples of innovative and effective solutions developed in coproduction which has led to transformative changes and better outcomes for children and young people with SEND and their families.<sup>12</sup>

Parent Carer Forums should continue to raise awareness of short breaks, highlight their value and work with statutory authorities towards further coproduction of services.

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<sup>11</sup> <https://councilfordisabledchildren.org.uk/sites/default/files/uploads/OBC%20briefing%20Final.pdf>

<sup>12</sup> <http://www.nnpcf.org.uk/about-the-nnpcf/nnpcf-key-documents/wow-moments/>  
[https://contact.org.uk/media/1210596/short\\_breaks\\_toolkit.pdf](https://contact.org.uk/media/1210596/short_breaks_toolkit.pdf)

## Appendix: The Legal Context

Looking after children with complex disabilities can be demanding for parents and carers and the local authority can be a vital source of support. A Short Break gives parents and carers a much needed break from caring and it also gives disabled children and young people the chance to have fun and to make friends, something that a typically developing child can take for granted.

The Children Act 1989 requires Local Authorities to provide services designed to give breaks for carers of disabled children. The Breaks for Carers of Disabled Children Regulations came into force on 1<sup>st</sup> April 2011, requiring each Local Authority to provide

*'so far as is reasonably practicable, a range of services designed to meet the needs of families with disabled children in their area which is sufficient to assist carers to continue to provide care, or to do so more effectively'.*

Local authorities are required to publish a Statement informing families about the Short Breaks services available to them. The Children and Families Act 2014 also places a duty on the Council to produce a 'Local Offer' providing information on support and services including the provision of **Short Breaks**.

Every local authority must provide services designed to minimize the effect on disabled children within their area of their disabilities; and to give such children the opportunity to lead lives which are as normal as possible; and 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.

Section 25 of the Children and Families Act 2014 places a duty on local authorities that should ensure integration between educational provision and training provision, health and social care provision, where this would promote wellbeing and improve the quality of provision for disabled young people and those with SEN.

The Care Act 2014 requires local authorities to ensure co-operation between children's and adults' services to promote the integration of care and support with health services, so that young adults are not left without care and support as they make the transition from children's to adult social care. Local authorities must ensure the availability of preventative services for adults, a diverse range of high quality local care and support services and information and advice on how adults can access this universal support.

Local authorities and clinical commissioning groups (CCGs) must make joint commissioning arrangements for education, health and care provision (including Short Breaks) for children and young people with SEN or disabilities (Section 26 of the Act).

Joint commissioning should be informed by a clear assessment of local needs. Health and Wellbeing Boards are required to develop Joint Strategic Needs Assessments and Joint Health and Wellbeing Strategies, to support prevention, identification, assessment and early intervention and a joined-up approach. Under section 75 of the National Health Service Act 2006, local authorities and CCGs can pool resources and delegate certain NHS and local authority health-related functions to the other partner(s) if it would lead to an improvement in the way those functions are exercised.

There are important co-operation duties on local authorities and CCGs, including:

- **Children Act 2004 section 10**, which requires local authorities and health bodies to co-operate to safeguard and promote the welfare of children in their area
- **NHS Act 2006 section 82**, which requires NHS bodies and local authorities to co-operate to advance the health and welfare of their populations
- **Children and Families Act 2014**, which imposes a range of duties in relation to co-operation including a requirement for joint commissioning arrangements to be in place in every area (section 26).

Under the Public Sector Equality Duty (Equality Act 2010), public bodies (including CCGs, local authorities, maintained schools, maintained nursery schools, academies and free schools) must have regard to the need to eliminate discrimination, promote equality of opportunity and foster good relations between disabled and non-disabled children and young people when carrying out their functions.

In addition to the *general* principles within the Children and Families Act, the SEND Code of Practice outlines *specific* principles to underpin policy and practice. This incorporates the participation of children and young people and their families in decision-making, early identification and early intervention for support needs and a greater choice and control over support. They also cover responsibilities for education, health and social care services to work collaboratively in the provision of high quality services with a focus on inclusive practice, better access to learning and successful preparation for adulthood.