

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

This is the latest version of this Talking Point which has been further developed to include Social Care.

Social Care Needs of disabled children and young people and those with SEN, including Short breaks

Everyone needs some kind of support for their social care needs. For many children and young people that support is provided by friends, family, and local groups. But at times it may be necessary for particular support to be provided through social care services delivered or commissioned by local authorities.

Under the Children Act 1989 disabled children are regarded as ‘**children in need**’. However, identifying the social care needs of disabled children and young people does not necessarily require an assessment by a social worker. In many cases needs can be met through universal services or early help without the need for a formal assessment, provided there is a good understanding of those needs and families have access to clear information about what support is available and how to get it. This information should be available on the Local Offer.

In some cases there will be a need for a more formal assessment. All disabled children have a right to an assessment under **section 17 of the Children Act 1989**. The form of the assessment
Version 3.

May 2021

is not set out in either the Act or regulations and therefore the assessments are governed by statutory guidance, currently Working Together to Safeguard Children (2018).¹

Safeguarding – Children at Risk

Professionals working with a disabled child must be aware of any circumstance which raises safeguarding concerns. Working Together to Safeguard Children (2018) and Safeguarding Disabled Children: Practice Guidance (2009)² gives advice on what to do if this is the case.

Developing an understanding of social care needs

The key to supporting the child, young person and their family is having a clear understanding of their social care needs and what they require by way of support. This could be information, advice or practical support.

Engaging children, young people and parents is the starting point for establishing social care needs. Education, health and care needs assessments should focus on enabling the child or young person to achieve specific outcomes including social outcomes such as developing independence, friendships and community access.

Education, health and care needs assessments – providing advice on social Care

When a local authority decides it may be necessary for special educational provision to be made for a child or young person through an EHC plan it must carry out an assessment of their special educational needs, and related health and care needs. The local authority must seek social care advice as part of that assessment.

When, following an EHC needs assessment, an EHC plan is issued it must contain details of the child or young person's social care needs which are related to the learning difficulties and disabilities which result in them having special educational needs. The plan must specify any social care provision which must be made, for a child or young person under 18, under section 2 of the Chronically Sick and Disabled Person's Act 1970.

It may also include social care provision reasonably required by the learning difficulties or disabilities which result in the child or young person having special educational needs which is not to be made under section 2 of the Chronically Sick and Disabled Person's Act 1970,

¹ <https://www.gov.uk/government/publications/working-together-to-safeguard-children--2>

² https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/190544/00374-2009DOM-EN.pdf

including any adult social care provision made under the Care Act 2014 to meet the needs of young people over 18.

Local authorities can choose to specify other social care provision reasonably required by the child or young person, which is not linked to their learning difficulties or disabilities. This will enable them to include social care provision in child in need or child protection plans.

Short Breaks

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.

There is strong evidence that providing short breaks results in positive outcomes:

- 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.³

The Children and Families Act 2014, the Special Educational Needs and Disability (SEND) Code of Practice⁴ 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**.

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.⁵

³ https://contact.org.uk/media/1210596/short_breaks_toolkit.pdf

⁴ <https://www.gov.uk/government/publications/send-code-of-practice-0-to-25>

⁵ <http://www.legislation.gov.uk/ukxi/2011/707/contents/made>

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

Forums report that the eligibility criteria to apply for Short Breaks vary across Local Authorities. 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*.⁶

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.

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.

⁶ <https://www.gov.uk/guidance/equality-act-2010-guidance>

Health responsibilities

The primary responsibility for meeting the health needs of disabled children rests with Clinical Commissioning Groups (CCGs).⁷ 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’.⁸ 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.⁹

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.

Independent Review of Children’s Social Care

The NNPCF believe that disabled children, young people and their families should have the same opportunities as their peers.

In January 2021, the government announced a review into children’s social care.¹⁰ The NNPCF have been working with the review team to ensure the voice of parent carer forums is heard and that the review understands and considers the unique challenges faced by our families.

The NNPCF have raised five issues for the Review to consider:

1. **“Support not safeguarding”** – Much of the social care system is focussed on safeguarding and the approaches and systems are too often based on this model. Children and Young People with SEND and their families need support from the social care system and the bias towards safeguarding means that families often slip through the net and other families are reluctant to engage with social care.
2. **Social Care Input into EHCPs is variable** – PCFs report that social care input into EHCPs remains patchy or the quality of advice is poor.

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

⁸ Section 3 of the National Health Service Act 2006 (as amended).

⁹ Section 26 of the Children and Families Act 2014

¹⁰ Independent review of children’s social care – GOV.UK (www.gov.uk)

3. **Consistency and criteria** – PCFs report there is a postcode lottery for social care services. Some areas recognise children with SEND as children in need, most do not; many areas have different (and high) thresholds for services.
4. **Availability of services** – many social care services that families would benefit from are simply not available to too many. Thresholds and cuts mean that respite care, residential care and short breaks are in short supply. The NNPCF are calling for Children's social care to be prioritised and funded properly.
5. **Prioritisation with the NHS integrated care systems** – we must ensure that children's social care is included in plans being developed by the new integrated care systems.

The Case for Change for Children Social Care has recently been published.¹¹ 'The Children's Social Care Review – "The Case for Change"' online learning session recording is available to view.¹²

The Impact of Covid

The challenges already faced by children and young people with SEND and their parents/carers who support them have been exacerbated by the Covid 19 Pandemic.

PCFs reported reduced or no access to support. In a survey undertaken by the London Region during the third lockdown only 7% of parents/carers who responded reported accessing short breaks as normal.

Ofsted noted that Short Break provision has seen a similar pattern of reduced attendance from children with SEND. Their report highlighted that even where short break services have reopened, not all children and young people were using them to the extent that they were before the pandemic. Ofsted cite barriers to attendance at short break provision including providers reducing capacity, as well as anxiety from parents, carers and children and young people.

This means that for many children and young people with SEND they not been accessing enrichment and support, as well as education leading to additional pressures on families due to the lack of respite.¹³

¹¹ <https://childrensocialcare.independent-review.uk/wp-content/uploads/2021/06/case-for-change.pdf>

¹² <https://www.youtube.com/watch?v=p9GsKXLtUZE>

¹³

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/943488/COVID-19_series_briefing_on_special_educational_needs_and_disabilities_provision_November_2020.pdf

Most respite offers were not available to families; some families were in receipt of Direct Payments or Personal Budget although they were unable to use those funds in the traditional ways. Some forums worked constructively with their Local Authorities to provide for more flexible use of these monies. e.g. allow payment for Personal Assistant to relieve pressure by shopping for family. Or use of Direct Payments to buy tech equipment or subscription to online media.

The third report undertaken by the Disabled Children's Partnership on the impact of the coronavirus pandemic on their families revealed that, despite the easing of lockdown restrictions, a high proportion of disabled children and their families are still experiencing severe levels of social isolation.¹⁴

The NNPCF would like to see the national recovery policies to include Short Breaks to address the high levels of family 'burn out' and social isolation.

Coproduction is a key part of this process

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.

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

¹⁴ <https://disabledchildrenpartnership.org.uk/no-end-in-sight/>

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 1st 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.