Welcome to the final edition of the Short Breaks Partnership bulletin

Welcome to the fourth and final of our scheduled quarterly Short Breaks Partnership Bulletins, brought to you by Action for Children, Council for Disabled Children, Contact a Family and KIDS. This edition’s theme is short breaks for children with complex needs.

Inside you’ll find our regular legal guidance from leading Barrister Steve Broach, a range of good practice case studies from around the country and a report on how Contact a Family’s health project is bringing parent voices into NHS England’s national decision-making structures affecting children with complex needs.

In preparing this edition one issue that has concerned the Partnership is the quality of training available to providers of short breaks services. It is very important to have effective, child-centred training, accountability and governance in place to ensure that children and young people’s health needs are met safely and competently by any person providing short break support. This also helps ensure children with complex health needs have the same opportunities to be actively involved in all their communities have to offer.

The key documents to support your organisation to develop robust systems and process and help you decide what training is right for you are: RCN 2012, Managing children with health care needs: delegation of clinical procedures, training, accountability and governance issues and Dignity and Inclusion published by the Council for Disabled Children.

These publications will help you to quality assure staff and carers undertaking the administration of medication or invasive clinical procedures as prescribed by a registered nurse or qualified medical. They also help inform young people, families, staff and carers of what they need to do to feel competent and confident to do so. For more insight take a look at the Action for Children case study on page 9.

We hope you enjoy this our final Bulletin and have found these resources useful in your own work. If you’d like to give us feedback, and for further news on the future of the Short Breaks Partnership please see page 5.

On behalf of the Partnership,

Gethyn Williams
Director of Development and Engagement at Contact a Family
What the Short Breaks Partnership is providing

The Short Breaks Partnership is a consortium of four organisations: Contact a Family; Council for Disabled Children; Action for Children; and Kids. The partnership offers a range of information, resources and support to parent carer forums, children and young people, commissioners and short breaks providers.
By now you’ve hopefully seen that in March the Partnership launched a series of resources for Parent Carer Forums, Short Breaks providers, Commissioners and young people to help them better access and plan short breaks provision. Building these resources has been our core work this year, so we hope you find them useful. If you missed them you can access them here:

**For Parent Carer Forums**

Led by Contact a Family, these resources include:
- A series of bitesize factsheets for quick reference;
- A Toolkit for Parent Carer Forums wanting to work with the local authority on short breaks.

**For providers of Short Breaks Services**

Led by Action for Children, these resources include:
- Guidance for Short Breaks Providers;

**For young people and those working with them**

Led by KIDS, these resources include a series of films demonstrating the value and range of short breaks provision.

**For commissioners of short breaks services**

Led by the Council for Disabled Children these resources include:
- Guidance for commissioners;
- All 4 editions of the Short Breaks Partnership Bulletin;
- Legacy materials from the Short Break Network.

**E-learning for all audiences**
Providers, Commissioners and Parent Carer Forums wishing to access e-learning resources should visit [http://elearning.kids.org.uk/](http://elearning.kids.org.uk/) create a free account and access the modules under Free Modules/Short Breaks Partnership Modules.
Health Decision Making
By Contact a Family

In 2015 Contact A Family secured funding from the Department For Education to further develop strategic parent carer participation in health decision making. There had been consistent feedback from local parent carer forums that this was an area of challenge and that there was limited health involvement in the implementation of the SEND reforms in many areas.

The project aimed to:
• Develop the working relationship between parent carer forums and local health decision makers;
• Raise the understanding of local and national health decision makers about their role in delivering the SEND Reforms and the principle of participation that underpins the Reforms.

The project core work included identifying 9 pilot forums across England, which had a range of experiences and structures and who would receive additional support to develop their relationship with local health decision makers. The health pilot forums were:
• Parents in Power – Gateshead;
• North East Lincolnshire Parent Participation Forum;
• Epic Leeds;
• Bolton Parent Carer Consortium;
• Birmingham Parent Carer Forum;
• South Gloucester Parent Carer Forum;
• Leicestershire Family Voice & Leicester City Parent Carer Forum;
• East Sussex Parent Carer Forum;
• West Sussex Parent Carer Forum.

The project manager worked with the pilot forums to explore their experience of working with health decision makers locally and the level of local health engagement in the implementation of the SEND reforms. The main challenges identified were:
• The need to develop a shared understanding of participation and coproduction;
• Identifying who does what and when in the health commissioning process;
• Understanding health duties in relation to SEND;
• Children and Young People with SEND as a strategic priority.

The need for strong leadership both locally and nationally to champion SEND and parent carer participation

“Participation needs to be built into the system, we should be co-producing not just fire fighting.”

Discussions with the pilot forums informed the development of a one day workshop to address some of these issues and to work with Forum to develop an action plan to strengthen local engagement with health decision makers. This included developing clear
messages about what the Forum could offer to their local CCG’s, identifying priority issues and evidencing their case. The workshops were delivered by Contact A Family Associates and were extremely well received by in all pilot areas.

At the same time as the health workshop were being developed the CAF Health Manager also worked with NHS England’s newly formed Children with Complex Needs Implementation Board, to develop national messaging promoting the key role of CCG’s in the SEND reforms and the need to develop strategic partnerships with parent carer forums. This work culminated in the recent SEND Together national conference attended by Forums and representatives from CCG’s.

While the project formally ends on the 31st March, the work started will continue, building on the learning and awareness and delivering a partnership approach to the commissioning and delivery of health services.

**Update on the future of the Short Break Partnership**

As you may already know, the Short Breaks Partnership has was a one-year initiative designed to help young people and all partners involved in the delivery of short breaks to and go further in their provision of what many parents describe as a ‘lifeline’ for their children and families.

By joining forces we have been able to take a holistic approach to improving short breaks services. Our aim has been to produce a range of resources for all involved to pick up and use. In doing so we’ve worked with a great number of Parent Carer Forums, service providers, commissioners and young people. The resources are now freely available and you can access them via the links on page 3.

The resources are designed to help support co-production between commissioners, practitioners and service users - going beyond ‘participation’ or ‘engagement’. When adopting this way of working together from the start – in planning, developing, implementing or reviewing a service – real cultural change can be achieved and an enormous difference made to the quality of provision.

We therefore encourage all partners to seek out and use them. We’d also love to hear your feedback. Please use the contact points at the bottom of page 10.

This work would not have been possible without the grant and wider support of the Department for Education and their commitment to improving good practice in short breaks. Our grant comes to an end on March 31st after which the Partnership will disband, but the resources developed will continue to live on our individual websites.

Our sincere thanks to all those that have engaged and supported our work this year, including representatives of the Short Breaks Network and the National Network of Parent Carer Forums (NNPCF). We will continue to monitor developments in short breaks and consider any new joint initiatives when and if further resources become available.
The final article in this series on key legal issues in the provision of short breaks concerns short breaks for children with complex needs. In particular the focus is on the duties owed by the NHS to facilitate short breaks for this group of children.

The overriding obligation on local authorities and NHS bodies, particularly Clinical Commissioning Groups (CCGs), is to work together to ensure children’s needs are considered and addressed. This duty is expressed in a number of places throughout the statutory scheme – for example:

- Children Act 2004 section 10, which requires local authorities and health bodies to cooperate 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 cooperation including a requirement for joint commissioning arrangements to be in place in every area (section 26).

It is particularly important that CCGs play a full part in the commissioning and development of short break services in their area, as there will be some children with needs of such complexity that they fall outside the scope of the duties owed by local authorities. This is shown by the important case of *R (T, D and B) v Haringey LBC* [2005] EWHC 2235 (Admin), concerning a three year old child with a tracheostomy. The issue was whether either the local authority or the NHS body had a duty to provide child D with additional short break care. The Judge held that on the facts of that case the care required fell outside of the scope of the duties in the Children Act 1989 (para 68). A local authority cannot act as ‘substitute or additional NHS for children’ (also para 68). Therefore high levels of medical care (including nursing care) for children will be the responsibility of CCGs, not local authorities.

The key duty on CCGs is found in section 3 of the NHS Act 2006, as amended by the Health and Social Care Act 2012. This requires each CCG to arrange for the provision of a wide range of services ‘to such extent as it considers necessary to meet the reasonable requirements of the persons for whom it has responsibility’.

This duty is drafted in very broad terms and does not create any specific right to health services for a particular person. This is one of the reasons why the imposition of duties on NHS bodies under the Children and Families Act 2014 is so important. New advice for CCGs, health professionals and local authorities was published by central government in February 2016. In particular, under the Children and Families Act where a disabled child with complex needs has an Education, Health and Care Plan, the CCG must ‘arrange the

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1 NHS England has commissioning responsibility for some very specialist health services which disabled children may need, for example ‘tier 4’ CAMHS (Child and Adolescent Mental Health Services).

2 Department for Education / Department of Health, 0 to 25 SEND code of practice: a guide for health professionals, Advice for clinical commissioning groups, health professionals and local authorities, February 2016.
specified health care provision for the child or young person’, see section 42(3). Education, Health and Care Plans are however reserved for children with significant special educational needs.

CCGs must also work with local authorities to contribute to the ‘Local Offer’ of services available, but there is no right to any particular level or type of services under the Local Offer. Paragraph 12 schedule 2 to the SEN and Disability Regulations 2014 mandates that every Local Offer must include ‘Health care provision for children and young people with special educational needs or a disability that is additional to or different from that which is available to all children and young people in the area...’ It is important to note that paragraph 12 specifically requires the Local Offer to include arrangements for making universal services accessible to children and young people with special educational needs and disabled children and young people, which may reduce the need for specialist short breaks.

Key guidance: The National Framework

The guidance which applies to all children with complex needs is the National Framework for Children and Young People’s Continuing Care, which has recently been reissued (February 2016). The National Framework is for children whose needs are ‘so complex, that they cannot be met by the services which are routinely available from GP practices, hospitals or in the community’ (para 2). Although the National Framework is said merely to provide ‘advice’ to CCGs, it sets out a detailed process by which eligibility for ‘continuing care’ should be determined. Any CCG which departs significantly from the National Framework may therefore have to justify this if challenged in court.

The National Framework sets out a three stage process:
• Assessment, led by a nominated children and young people’s health assessor and leading to a recommendation as to whether the child has continuing care needs
• Decision making, by a multi-agency forum or panel considering the recommendation and deciding whether or not the child has continuing care needs. The aim should be for a decision to be given to the child or young person and their family within 6 weeks (para 50).
• Development of a package of care. The National Framework states that ‘Commissioners will decide how the continuing care will be provided, what proportion and level of resource is required to deliver it and how much needs to be specially commissioned’.

Importantly, the National Framework states that ‘Unless there is a good reason for this not to happen, continuing care should be part of a wider package of care, agreed and delivered by collaboration between health, education and social care’. This is plainly correct, albeit that the social care input must not require the local authority to act as a ‘substitute NHS’. The National Framework recognises this by reference to the Haringey judgment, see para 26 and Annex C.

Guidance as to which children may have continuing care needs is provided in a ‘decision support tool’. The National Framework states (para 148) that ‘A child is likely to have continuing care needs if assessed as having a severe or priority level of need in at least
one domain of care, or a high level of need in three domains of care’. Importantly one of the domains is ‘behaviour’. As a consequence the National Framework states (para 28) that ‘Assessment of a child’s needs should consider the extent to which a child with a learning disability, or autism may have a continuing care need due to challenging behaviour’.

There is undoubtedly an expectation under the National Framework that children assessed as eligible for continuing care will receive a bespoke package of support, which may include short breaks. The National Framework states (para 95) that ‘The package of care must be shaped by the child or young person’s support needs, rather than by what is offered by providers’.

In deciding what level of services, including short breaks, are required by a child with complex needs, the CCG must take into account:

- The NHS Mandate for 2016-17, which states that vulnerable children ‘should receive high quality, integrated services that meet their health needs’. The current NHS Mandate (2015-16) states that ‘One area where there is a particular need for improvement, working in partnership across different services, is in supporting children and young people with special educational needs or disabilities’.
- The NHS Constitution, which contains a number of statements of ‘rights’, including that ‘You have the right to receive care and treatment that is appropriate to you, meets your needs and reflects your preferences’ and ‘You have the right to expect your NHS to assess the health requirements of your community and to commission and put in place the services to meet those needs as considered necessary’.

In all decisions made in relation to children’s health needs time will be of the essence. As the Working Together to Safeguard Children guidance says in relation to children’s social care needs, ‘For children who need additional help, every day matters’ (para 10, p7). The response to children’s assessed health needs must therefore always be made in a reasonable time. Where children are eligible for continuing care, the National Framework states that arrangements to deliver the package of care should be in place ‘as soon as possible’.

As set out in the previous bulletin, children with complex health needs will generally be entitled to a personal budget, and can receive a direct payment. There is however no right to direct payments in health – it will be up to the CCG in each case to decide whether the child’s needs should be met that way if it is what the family want, subject to the usual public law requirements of fair, rational and reasonable decision making.

Steve Broach is a barrister at Monckton Chambers who specialises in the law affecting disabled children and their families. Steve can be contacted at sbroach@monckton.com. This article is intended for general information and should not be relied on as legal advice. Case-specific advice should be sought in any particular case.
Supporting young people with complex needs in a residential short breaks service

Xanthe is a 15 year old young lady who has been using Action for Children's residential short break service in Hertfordshire called the Pines for 5 years. She has a small team of skilled, confident and competent staff who provide meticulous and consistent support with all aspect of Xanthes care and support.

With the help of the staff at the Pines Xanthe has overcome a lot her complex needs in her day to day life and is able to enjoy her time at the centre with help and personalised support from staff and her peers. Xanthe enjoys her short breaks alongside young people she knows from school and absolutely loves the social side of her break, she loves the hustle and bustle of a busy residential short break home environment, especially dinner time where people catch up and socialise.

To read the full story go to http://www.councilfordisabledchildren.org.uk/sbncasestudy13

Encompassing the need for health support in universal settings and continuing care

The framework for children and young people’s Continuing Care, along with recent legislation, has created a new integrated approach to the provision of services for children with SEND. However, there have been many difficulties for families where their child’s needs encompass health and social care. This case study shows how West Sussex County Council have addressed some of these issues in their area successfully by working with the West Sussex Parent Carer Forum in the decision making process. These results of these changes is that the majority of families have made a good transition to the new arrangements and have made a truly significant difference to the lives of children and families.

To read the full story go to http://www.councilfordisabledchildren.org.uk/sbncasestudy14
Personalised approach to supporting children with complex needs

D was unable to access a mainstream nursery so he now attends a KIDS nursery in the West Midlands. This allows Child D the opportunity to play and interact in a calm, accessible, sensitive environment with responsive practitioners who understand how to best meet his needs.

As Child D has complex medical needs the diagnosis has affected all areas of his development; specifically within his physical development and his communication. D was unable to sit unsupported and had little control over core movements and limbs. D communicates through basic eye contact which is understood by the key practitioners that work with him on a weekly basis. Child D therefore is reliant on practitioners to meet his entire educational, medical and care needs whilst attending KIDS.

To read the full story go to http://www.councilfordisabledchildren.org.uk/sbncasestudy15

Commissioning to support children with complex needs

Luton Borough Councils’ Contract Shared Care Service is a short break provision for children and young people (0-18) with complex health needs provided under the Foster Care Regulations 2002. Contract Carers are employed by the council to provide care in their own homes which have been fully adapted for children with complex needs. Supported by a small team of dedicated social workers and a short breaks nurse, the service sits within Section 75 pooled budget arrangements between the local authority and Luton Clinical Commissioning Group whereby each partner agrees to work together to consider budgets, align activities to deliver agreed aims and outcomes while retaining complete accountability and responsibility for their own resources.

To read the full story go to http://www.councilfordisabledchildren.org.uk/sbncasestudy16

Tell us About Your Good Practice Examples

The Short Breaks Partnership is interested in hearing from you if you have been involved in developing short breaks services, particularly if this has involved unique and innovative features, has demonstrated inclusive practice or has had a focus on personalised approaches. If you feel that you are able share examples of good practice in these, or other areas please contact us using the details below.

Parent Carer Forums: ben.palmer@cafamily.org.uk
Children and young people: lynn.horsfield@KIDS.org.uk
Commissioners: shortbreaks@ncb.org.uk
Short Breaks providers: erica.whitfield@actionforchildren.org.uk
About the consortium

The Short Breaks Partnership is a consortium made up of Contact a Family, the Council for Disabled Children, Action for Children and KIDS. As part of the National Prospectus Grants programme, we have received funding from the Department for Education to develop guidance on the importance of Short Breaks services for Parent Carer Forums, Children and Young People, Local Authorities and Commissioners and Short Breaks Providers.

About the Short Breaks Partnership bulletin

The Short Breaks Partnership Bulletin is a quarterly round-up of all the essential policy, practice and news on short breaks. The bulletin is a special feature in the CDC Digest which is published in July, September, December and March.

You can download recent issues of CDC Digest from their website.

If you would like to be added to the list to receive this bulletin please email shortbreaks@ncb.org.uk with ‘Subscribe to Short Breaks Bulletin’in the subject line.

Get in contact

If you have any questions or would like more information about the Short Break Partnership please contact us at shortbreaks@ncb.org.uk.

If you are a parent or carer and would like information or advice about your own child’s access to short breaks please call Contact a Family on the Freephone helpline 0808 808 3555 (available 09:30-17:00, Monday to Friday), by email: helpline@cafamily.org.uk, or by visiting www.cafamily.org.uk.

Alternatively you can follow us on Twitter @SBPartnerships and receive up to date news and announcements.