

Parent Carer Participation

JOINT BULLETIN

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WEDNESDAY 9 MARCH 2016 No. 28

NEWS

Department for Education Confirms Grant Funding for Parent Carer Forums

The NNPCF Steering Group and Contact a Family were delighted to hear the news that the Department for Education have confirmed grant funding for parent carer forums at the same level for next year and pledged to continue this funding for 2017/18 too. This is a practical demonstration of the value that is placed on the strategic involvement of parent carers through parent carer forums. We are hugely proud of the recognition this brings for parent carer participation and is a direct result of all the hard work you do and many many hours of volunteer time that you have given and continue to give to achieve this level of value and credibility at a national level. We are currently working with the Department for Education to confirm the grant application process and we will update you as soon as application forms are available. If you have any queries about grant funding do please get in touch with your Parent Participation Advisor.

SEND Ministerial Meeting Update

On Monday 7th December 2016 parent representatives from NNPCF, local forums, Council For Disabled Children and Special Needs Jungle met with the Minister of State for Children and Families Edward Timpson and Director for Children, Families & Communities at the Department of Health, Flora Goldhill, at the Department for Education. Its purpose was to help the minister take stock of progress in implementing SEND reforms by hearing directly from parents. The meeting provided an opportunity for parents to share their experiences directly with the Minister and a senior official from the Department for Health.



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To see a full list of all our newsletters please [click here](#).

Key areas discussed included; Accountability, EHC Plans, Transition to Adulthood, SEND Support, Health and Social Care and the Local Offer. Parents shared what is working in their area, their concerns and put forward suggestions for how good practice can be shared and built upon. The Minister reiterated how it is essential that arrangements for children and young people with SEND support families effectively, rather than families having to 'fit in'. He advised that it is still early days and that changing culture, attitudes and structures will take time. However he believes that it is clear that people working with families want the reforms to work and they need to be empowered to do so.

The Minister reassured parents that the DfE want to keep listening and will do that in a number of ways. He said that the DfE are gaining a richer understanding of what works and need to ensure this learning is shared effectively. He advised that the DfE want to hear direct experiences so that the views of children, young people and parents are the main drivers behind their work. The NNPCF Steering Group will be meeting with Edward Timpson on 15th March 2016. The Steering Group will also be meeting with Parliamentary Under Secretary of State for Public Health - Jane Ellison at the Department of Health on 16th March 2016.

South Glos Parents and Carers, Thank the Stars that make it all Possible - Parent Carers

South Gloucester Parents and Carers held an end of year "star-studded" event to thank their volunteers and to celebrate their achievements during the year. Members of the forum were given the red carpet treatment as they collected their awards and others stars included [cardboard cut-outs of] George Clooney and Brad Pitt. Leonie Pollinger who organised the event co-presented our *Building Active Members* webinar where she outlined how the forum support, recruit and invest in their active members. To view the webinar and associated materials visit the [Parent Participation Resources Page](#).



New Year's Honour for Parent Carer Forum Member



In recognition of her outstanding and dedicated work over the last seven years with the parent carer forum [Warrington Parents and Carers](#), Gail Hall has been awarded a British Empire Medal in the Queen's New Year's Honours list. Speaking of her award, Gail acknowledges that she could not have achieved it without the support of her fellow forum colleagues who share her passion for making a difference to the lives of disabled children and young people in Warrington. We'd like to congratulate Gail on this magnificent accolade, which is a real indication of [the brilliant work that all parent carer forums do](#).

Need Associate Support? This is how Contact a Family can help

The associates offer an independent view and appraisal of the issues. Associates are able to work with the forum and their partners to resolve issues and to plan a way forward. Once an associate referral has been completed, the associate is assigned on a skills match basis. Contact a Family will make an assessment based on the information available on the presenting issues and see which associate's skills are the best fit for the case. The first step is for the associate to contact all of the key people involved to gain a full understanding of the difficulties. Once they have done this they will work with the forum to resolve the issues. This may involve the forum committing to a few meetings. The associate may also meet the local authority or other partners. This may involve the forum committing to a few meetings. The associate may also meet the local authority or other partners. If your forum needs associate support please contact your [parent participation advisor](#).

A record– breaking Parent Carer Forum Conference!

Last year's annual conference of Parent Carer Forums was the biggest to date. Bringing together representatives from nearly 90 forums, it took place on 8th October at the Camden Centre in London and included:

- Keynote speaker Ann Gross from the Department for Education
- Sharing from forums across England about successes and managing challenges
- Networking opportunities
- Contact a Family Health & Short Break Projects
- The NNPCF AGM



165 parent carer forum representatives attended, representing 87 parent carer forums. The full breakdown of delegates was as follows:

Parent Carer Forum members	165
Number of Forums represented	87
NNPCF delegates	10
Contact a Family delegates and staff	24
DfE officials	2
TOTAL Attendees	201

Overall feedback from the conference was very positive parent carers talked strongly about the value they find in coming together in a supportive environment with so many of their peers. They also recognised the symbolic value of a large national event in focusing attention on their movement, taking stock of progress, highlighting collective issues and celebrating achievement.

In measuring the impact, an overwhelming majority of attendees agreed or strongly agreed that as a result of the conference:

- They know where to go to get more help and assistance on parent participation and grants;
- They feel better able to ensure that parent voices are heard on issues that matter to them;
- They feel more confident in managing situations in relation to parent participation and forums.

Specific feedback included:

Networking and collective action

"Being new I have been able to meet other forums, networking and listening to their experiences"

"Every forum is having challenges, but together it is something we can change"

"I felt valued as a pcf and have met some people who I didn't know, but will be contacting in the future"

"Feel I have more focus, understanding and enthusiasm to continue my role within forum"

"Great networking opportunity and has increased my confidence knowing we are not alone"

"The world is run by the people who turn up"

Taking stock

"Encouraged so many parents are fighting. Discouraged at how little the DfE understands about SEN issues and how they really affect children and young people. Overwhelmed by the amount of work we are expected to do."

"Still feels like personalities in LA are most important factor in co-production as opposed to having a robust system in place"

"Great to have someone from DfE. Perhaps don't clash with Tory conference next year? Excellent chat to Patrick post meeting. Great for him to stay".

The [playlist for videos](#) from the Conference are available to [view here](#).

Thank you again to all Forums who were able to take part or feed in. Let's go even bigger in 2016!

How Ofsted and the CQC will Inspect Special Educational Needs Provision

Charlie Henry, Ofsted lead on special educational needs, explains what the processes for inspecting special educational needs will be.

When does the process of inspection begin and end? In one sense, that's an easy question to answer. It begins when the Ofsted inspector turns up, laptop in hand, and ends when the inspection report or outcome letter is published. On the other hand, publication is the beginning of the process. In highlighting key strengths and in identifying problems, the inspection report acts as catalyst for change, and change for the better. That applies across all remits which we inspect: schools, early years, social care, and further education and skills. But I'd argue that this concept of publication as a starting point will particularly be the case when we publish the first of a new kind of inspection outcome letter in summer 2016. It will be concerned with some of the most vulnerable people in our society: children and young people with special educational needs up to the age of 25.

Whole local area

From May 2016, Ofsted and the Care Quality Commission will inspect local areas to see how they are fulfilling their responsibilities to children and young people who really do need, and are often dependent upon, local public services. These are the services they receive from their nurseries, schools and colleges and from the specialist therapists and other professionals in educational, health and social care services. These inspections are about how the whole local area meets the needs of some of the most vulnerable children and young people. But we will not just want to see that these services are being delivered well. Inspectors will want to see evidence that children and young people are progressing, whether to their next stage of education or employment. The new inspection is not just about holding local areas to account; crucially it's also about helping the area to develop and improve. I want to stress this key part of our inspection outcome letter – which will be jointly written with the Care Quality Commission. We will highlight key strengths of local areas. It is my hope and indeed my expectation that local areas' key strengths will be seriously considered by other local areas.

Potential

So, what will we actually do from May next year? Special educational needs is, of course, a wide spectrum. We are talking about young children with profound learning or physical disabilities on the one hand, and those with, for example, Asperger's or social, emotional and mental health issues on the other. It's a wide range but the aim of special education is the same: to make the young person fulfil their potential, and lead as independent a life as is possible. Inspectors will look at the wide range of children and young people, and consider the services they use. In most cases this will include a school or college of some type. Inspection teams will usually consist of an SEND specialist HMI from Ofsted, a Children's services inspector from the Care Quality Commission and a specially recruited and trained SEND Ofsted inspector from another local authority. And I want to stress that these inspections will not just be about the local authority. While I recognise that local authorities have a key leadership role for their area, they cannot implement the special educational needs reforms on their own.

We will tell the Director of Children's Services and the Chief Executive of the clinical commissioning group two working days before the inspection starts. Once they have got going, the inspection team will meet the important managers and leaders from the area's education, health and social care services. They will also visit early years settings, schools and further education providers. On these visits inspectors will not be inspecting the nursery, school or college themselves since these are covered other inspections. They will be exploring how the whole local area fulfils its responsibilities and how providers contribute towards them, to ensure disabled children and young people and those who have special educational needs are identified and that their needs are met and their outcomes improve.

Contract

We will assess how well schools and colleges are fulfilling the responsibilities of the education and health care plans – a kind of contract between the child or young person who has special educational needs, and the public service. But it's not just about those young people who have the new education, health and care plans; it's as important that we look at those who receive additional support but whose needs are not severe enough to require one of these plans.

Our inspections will be thorough, and last five days. We will talk to school leaders and managers of the services the children and young people use. So, for example, we may ask about the effectiveness of reading support for pupils who have particular problems, or the success of specialist support for deaf children. Inspectors will also ask health service managers how they are meeting the needs of children and young people who use their services. And, of course, we will talk to children and young people with special educational needs, and to their parents too. They are at the heart of this process.

Sobering truths

There will be some sobering truths to be told in the next few years, I am sure. These will always be grounded in evidence; what inspectors have seen and have found out about the services for some of the most vulnerable people in the country. I do not expect there to be an overnight transformation in the fortunes of children and young people who have special educational needs. But I am optimistic that this new way of inspection will help to bring about a cultural change whereby children and young people with special educational needs really do get the services they need to be as independent as they can.

Charlie Henry retired from his role as the Ofsted Lead on Special Educational Needs earlier this year. The Ofsted Consultation closed on 4th January 2016. For more information please [click here](#). To read the full article please visit the [Community Care](#) website.

NEW Resources to Promote Good Practice in Producing Quality EHC Plans

Parent carers from forums helped in the delivery of EHCP plan workshops across the country organised by Mott McDonald to support local areas in producing quality Education, Health and Care Plans. Parent carers gave presentations about how they were working with their LA to ensure quality in assessments and plans. Parents also talked about how LA and Health colleagues and parent carers and young people can work together to agree meaningful and aspirations education and life outcomes for disabled children and young people. One of the aims of the sessions was for participants to be able to disseminate the learning to train and share good practice with other colleagues. Forums who wish to do this can find the [resource pack and presentations here](#).

Somerset Parent Carer Forum and Shane from the Unstoppables Young People's Forum

In Bath, the Somerset Parent Carer Forum co-presented with Sarah Hayes (SEN Caseworker Manager, Somerset County Council) and Shane Dangar from the Unstoppables Young People's forum who explained how disabled young people are involved in decision making in Somerset and his role as a Young People's champion.



Picture: Shane Dangar, Young People's Champion (The Unstoppables Young People's Forum), Tina Emery from Somerset Parent Carer Forum and Sarah Hayes (SEN Caseworker Manager, Somerset County Council) presenting at the Bath workshop.

WORKING WITH THE DEPARTMENT FOR EDUCATION

Department for Education SEND Survey

A massive thank you to everyone who was able to respond to the December SEND Survey. We were delighted to have 104 forums complete the survey which means that there is really meaningful data reflecting what parent carers are experiencing.

We know the survey takes a lot of your time and the turnaround is often quite short but we want to let you know that the information you contribute is compared to the feedback from Local Authorities and helps inform what support and resources are needed to enable local areas to be fully implementing the changes. There is now a summary report available [here](#) if you would like to see what the national picture looks like.

Many of you reported that you had met with your LA partners to either complete the survey or review your answers this time which is really positive to hear and we hope to be able to give you more notice in future to enable this to happen.





Hopefully many of you are aware that there is a team of SEND Advisors working across England to provide support and guidance to Local Areas on how to deliver and implement the changes expected by the reforms.

The team is led by André Imich and currently comprises 5 members covering all 152 local areas in England. They find the information from many sources, including the LA survey, parent carers forums, Contact a Family, the Council for Disabled Children, really helpful in getting a good overview of progress and helping them target their time most effectively. The SEND advisors are particularly keen to see the development of the cultural changes that the reforms hope to deliver, and do emphasise the value of co-production, so the feedback from parent carer forums is very useful in helping to gauge this.

Share your challenges and successes with us and the DfE

Contact a Family and the NNPCF Steering Group are always keen to ensure that your experiences, challenges and successes are being heard and recognised at the senior levels in the DfE.

One way to do this is to share information with your regional NNPCF representative at regional meetings. We also have a feedback form, if you want us to particularly feedback your individual experiences to the Department, who can then consider this within their support to local areas. You can [find the feedback forms here](#) (see feedback form below).

 National Network of Parent Carer Forums Our Strength Is Our Shared Experience		 contact a family for families with disabled children Strengthening Parent Carer Participation		 National Network of Parent Carer Forums Our Strength Is Our Shared Experience		 contact a family for families with disabled children Strengthening Parent Carer Participation	
CHALLENGES				SUCCESSES			
Summary of challenges in local areas in relation to the implementation of the Special Educational Needs and Disability (SEND) reforms.				Summary of successes in local areas in relation to the implementation of the Special Educational Needs and Disability (SEND) reforms.			
Parent Carer Forums have had the opportunity to feed in their views about their local area's readiness for implementing the SEND reforms to the Department for Education, but we know from the range of information forums often share that this picture often changes rapidly.				Parent Carer Forums have had the opportunity to feed in their views about their local area's readiness for implementing the SEND reforms to the Department for Education, but we know from the range of information forums often share that this picture often changes rapidly.			
We have agreed with the Department to offer all forums the opportunity to send us - at any time - information about the challenges and successes they are experiencing when working and co-producing with their local partners to deliver the SEND reforms. This information will then be fed directly to the Department for Education.				We have agreed with the Department that we will offer all forums the opportunity to send us at any time information about the challenges and successes they are experiencing when working and co-producing with their local partners to deliver the SEND reforms. This information will then be fed directly to the Department for Education.			
Name of Forum				Name of Forum			
Region				Region			
Name and contact details of individual				Name and contact details of individual			
How many members of the forum have been involved in deciding to share this information				How many members of the forum have been involved in deciding to share this information			
Please describe the particular challenges you are experiencing				Please describe the particular successes you have experienced			
Please describe what the forum have already done to try to redress this				What were the key contributing factors to success?			
Please describe what solutions you feel would assist in resolving these challenges				What learning has there been for your forum, and partners in achieving this success?			

News from the NNPCF Steering Group



National Network of Parent Carer Forums
'Our Strength Is Our Shared Experience'

We would like to thank you all for your efforts for and support to the functioning of our Network in 2015, you have responded so well to our requests for help, opinions and contributions to aid the Steering Groups strategic thinking.



We were especially pleased to receive your responses to the questions that we asked you about future priorities for your SG. This is simply an overview and represents a wide range of views, which are sometimes contradictory to each other, you don't all think the same! However, as you will see you have given us some key overall messages:

- You would like your Regional Rep to be more visible in your region.
- Stronger communications and greater understanding of the outputs and outcomes of the Steering Group.
- Clarity of role between your Regional Rep and the Contact a Family Advisers.

Burning Issues

At the National Conference in October, we asked you to tell us about your "Burning Issues" the things that were of greatest concern to you at that moment. We have spent some time collating and considering your responses. Our written report is currently being edited and will be shared on the website at the end of March. This also gave us a clear steer as to what you would like us to prioritise at national level.

We spent some time at our last meeting considering how best to adapt our ways of working to meet your needs. As you know, at the time of writing we have not had confirmation of funding for the coming year and therefore we cannot be definitive about what we will do, but would like to share our thinking with you. We are going to start by developing more structure within the Steering Group and develop some Lead roles within the team which will have an emphasis on Communications, Finance, Data Collection (collecting information about our activities) and the Development of Participation at national level. We are also considering how we use the time available to ensure that the focus of the Regional Representative role can be strengthened to spend more time with you, our members. We hope that you will soon see a difference in our communications with you and with our other partners, our aim is for you to feel much more connected to your Steering Group.

If we make these changes we will have less capacity to attend the huge range of meetings that we are asked to participate in, it is our intention to separate the role of Steering Group Member/Regional Rep from the role of Parent Carer Representative, to attend these meetings. This is where we will need your help. We currently have a small team of National Parent Carer Representatives, we are keen to strengthen this, both in terms of numbers and by developing a more structured approach to supporting the team. If you are not already a member of the team but are interested in joining us, please contact Sarah Gallimore at info@nnpcf.org.uk for an application form.

We have set a date to meet with our colleagues at Contact a Family to begin to address your concerns about the perceived confusion between our respective roles, and how we can make best use of the resources that are available to us both, to ensure that the impact of Parent Carer Participation and Co-production is maximised. All this, is of course, dependant on funding. We are confident that we have been able to show that having a national structured way for us all to come together has been beneficial to the development of services at local, regional and national levels and are therefore optimistic that funding will be forthcoming!

- [Karen Wooddissee](#), East of England NNPCF Steering Group representative

Update on the NNPCF's Consultation with Parent Carer Forums

The NNPCF ran a consultation from Thursday 8th October - Friday 20th November 2015. All 151 local Parent Carer Forums were invited to be a part of the consultation on the NNPCF. The consultation has come out of local Parent Carer Forums raising questions with their regional representatives on how they would like to see the NNPCF operate and it's role in relation to the regional networks and local Parent Carer Forums. A total of 84 Parent Carer Forums responded to the consultation through different approaches, some were individual local parent carer responses and some were from regional network meeting discussions.

Three questions were asked:

- What do you see as the relationship between your forum and other forums in your region?
- How do you see the relationship between your region and the NNPCF?
- What is your forum expectation of the NNPCF SG?

Some of the initial intelligence arising from the consultation have been listed below:

- Forums felt that being part of a wider picture was important to them.
- Sharing good practice and experience within the region was a positive experience for them.
- Communication was a large part of your response with reference to many aspects such as, 'you said we did'- exploring the cycle on how local parent carer forums had fed information to regional networks, how it was acted upon and what was the impact from this information.
- In relation to their Steering Group Regional Representatives - forums wanted their Regional representatives to have more of a presence in the region.
- Clearer understanding of what the roles of Contact a Family are, and what the NNPCF does and it's boundaries.

A full report on the consultation will be brought to the Steering Group after the Easter Break. The Steering Group will be exploring a number of solutions to take forward, in response to some of the questions and issues that the local Parent Carer Forums have raised.

- [Lara Roberts](#), South East NNPCF Steering Group representative.

Health Project - Update from Sarah Thomas, Health Manager

The project is progressing well and by year end we will develop a comprehensive package of support for Forums, that will help them to develop their partnership with local health decision makers and support the implementation of the SEND reforms. This will be supported by the other main area of work, which is to promote the NNPCF and the value of parent carer participation to local, regional and national health decision makers.



It has become clear as the project progresses, that there is much to do in terms of creating an environment where parent carer participation is embedded in health decision making at all levels, but the project aims to start to create an environment where this can happen. To do this there will need to be work and commitment from all parties involved and a willingness to consider new way of working and to be open to listening to what we each have to say.

Currently a support package for forums is being trialled by the pilot Forums. This has been based on the feedback from the pilot Forums about the key challenges they are facing in terms of developing their partnership with health colleagues. The support package includes:

- Information being provided to the Forum about the local health structure, key contacts and an analysis of the local key strategic documents in terms of children and young people with SEND
- An introduction to Health Commissioning, nationally, regionally and locally
- Key duties for health in terms of children and young people with SEND
- Support for Forum in action planning and developing key messages around Health

The work with Forums is being supported by myself and colleagues from the NNPCF Steering Group, working at a national level to raise the profile of Forums and to secure that clear national message from Health leaders to CCG's in particular, about the need to work with Forums. Our work with the Children with Complex Needs Implementation Board is progressing and we are providing input to a communications plan and guidance from NHS England around the SEND reforms and participation.

Health Checks for People with Learning Disabilities

Towards the end of 2015 we wrote to all Forums asking you to promote GP health checks for individuals with learning disabilities. This included a template letter that parent carers could use to contact their GP's to request that their child was registered as having a Learning Disability. We know that some parents had difficulties in using the template, with their GP's being unclear about what was expected of them. To clarify the situation this request is part of the work being done by NHS England to improve health outcomes for those with learning disabilities and is promoting good practice in terms of the clear identification of people with learning disabilities in all healthcare record systems. The General Medical Services contract Quality and Outcomes Framework - guidance 2015/16 includes Indicator LD003 'The contractor establishes and maintains a register of patients with learning disabilities' and provides the following rationale;

"This register indicator includes people of any age with a learning disability. This is because without a complete register of people with learning disabilities, practices may not be aware of the reasonable adjustments that may be needed for a child or young person with learning disabilities and their family, and of the help and support that may be useful to them." Further information can be found at <https://www.england.nhs.uk/learningdisabilities/improving-health/>. Please promote this opportunity to your members and ask them to encourage their local GP Surgery to collect this important data, and support the improvement of health outcomes for individuals with learning disabilities.

CAMHS Transformation Plans

Following a national campaign last year resulting in the Government response document 'Your Future in Mind' being published, all CCG's were required to produce a CAMHS Transformation plan for their local area that delivers system wide improvements as well additional funding being made available for some specific work areas.

Transformation plans are expected to be completed within the year 2015/16 with an expectation that most will be approved by NHS England by 16th October. Guidance produced by NHS England states that:

"We understand that every local area is different. What is included in the Local Transformation Plan should be decided at local level in collaboration with children, young people and those who care for them as well as providers, commissioners and other key partners including local Healthwatch."

It also states that transformation plans should; **"cover the whole spectrum of services for children and young people's mental health and wellbeing from prevention to interventions, for existing or emerging mental health problems including;**

- In patient care and transitions between services;

Address the full spectrum of need including children and young people who have particular vulnerability to mental health problems for e.g. those with learning disabilities (LDs), looked after children and care leavers, those at risk or in contact with the Youth Justice System, or who have been sexually abused and/or exploited;

Set out the steps towards agreeing a clear role for schools and colleges locally including providing locations for delivering accessible services."

Further information is available on the following links:

- [Local Transformation Plans CYP Mental Health and Wellbeing - Guidance](#)
- [Improving Mental Health Services for Young People](#)

We would like to hear from any Forums that have been involved in developing their local CAMHS Transformation plans – please contact sarah.thomas@cafamilly.org.uk if you have are willing to share your experience.

New Care Model and Vanguard Report

The Vanguard sites are exploring a new model of care built on partnerships and integration, which will inform NHS England's planning for the next 5 years. There are 50 sites nationally each leading on one of the following areas:

- Integrated primary and acute care systems
- Multispecialty community providers
- Enhanced health in care homes
- Urgent and emergency care
- Acute care collaboration

More information can be found [here](#). The first report on the work of the Vanguard sites has just been published. [This report](#) has a focus on empowering patients and communities and has some key messages that might be used to support the work of Forums. You can also [watch a video](#) by the Director for New Care Models Programme, Sam Jones.



National Health Event - 14th March 2016

We are delighted to confirm that Contact a Family, the NNPCF and NHS England are jointly hosting a national conference for forum members and CCG representatives. The event will take place on 14th March 2016 at the [Congress Centre](#) in the centre of London.

This is a great opportunity to bring forum and CCG representatives together and to start building a relationship that is crucial for the successful implementation of the SEND reforms, the culmination of this year's health project led by Sarah Thomas.

We have the support of key speakers from both NHS England and the Department of Health for the event and are excited about the profile that this will give to both forums and the importance of strategic parent carer participation—both key principles of the reforms.

Spaces are very limited so unfortunately we are unable to invite all forums. Priority will be given to those who are part of the Health Project and the CCGs they work with, with regional networks will be asked to nominate additional local areas from which forums and CCG representatives will be invited to take up the remaining places.

If you have any questions about this event please contact me at sarah.thomas@cafamily.org.uk or your NNPCF regional representative.

Launching #ShortBreaksMatter

On 22 February Contact a Family launched 'Short Breaks Matter', a month of features and conversations about short breaks services to help families who might be missing out on this vital support service.

Over the course of Short Breaks Matter, we'll be talking about ways to access short breaks services, what to do if you've been denied a short break and how to challenge cuts to short breaks in your local area. Later in the month we'll be sharing some important research published by our SENDirect team, and we'll also explain how you can influence short break services by getting involved in a parent carer forum.

We want to hear from families about their experiences of short breaks services, so we'll be asking people to get involved in conversations on our Facebook page.

If you'd like to keep up to date with Short Breaks Matter, you can do so by joining our Facebook community here: www.facebook.com/contactafamily/. For more information on Short Breaks Matter Launch please [click here](#) or follow [#ShortBreaksMatter](#) on twitter.

Short Breaks Partnership

In late March look out for new resources from the Short Breaks Partnership, (Contact a Family with support and guidance from the NNPCF, Council for Disabled Children, Action for Children and KIDS), designed to help Parent Carers and Forums better understand and take action on local short breaks provision.



Short Breaks Partnership



Bulletin: 'Short Breaks and Personal Budgets'

The Short Breaks Partnership is a consortium of Action for Children, Contact a Family, the Council for Disabled Children and KIDS. We aim to provide information, advice and guidance; support for legal and policy topics; good practice case studies; and resources through our Short Breaks bulletin and associated guidance.

An essential principle necessary for the success of the Special Educational Needs and Disability (SEND) reforms is respect. Where the individual *'views, wishes and feelings'* of children, young people and their families are fully recognized and valued, support and outcomes are meaningfully personalised to *'aspirations'*. Choice and control is a significant aspect of this, not least in relation to personal budgets.

'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.' (Edward Timpson)

The [SEND Code of Practice](#) states that: *'Young people and parents of children who have EHC plans have the right to request a personal budget, which may contain elements of education, social care and health funding.'* However, there are aspects that local authorities will need to take into consideration when making decisions about personal budgets, on an individual and collective basis.

What is important for children, young people and families, is that information relating to personal budgets is readily available, in a format that is genuinely accessible and with sufficient detail to support informed decision-making. Local authorities should *'develop and agree a formal approach to making fair and equitable allocations of funding and should set out a local policy for personal budgets.'* (SEND Code of Practice (Section 3.38))

Local authorities should also publish information on the range of services across education, health and social care that currently lend themselves to the use of personal budgets; the mechanisms of control for funding available to parents and young people; and clear and simple statements of eligibility criteria and the decision-making processes that underpin them.

In the latest edition of the Short Breaks Partnership bulletin, we are covering the topic of 'Short Breaks and Personal Budgets'. We consider the legislation around personal budgets, how they can enable access to short breaks services and how they can help children and young people to achieve their *'aspirations'* in life.

To read the latest Short Breaks Partnership bulletin click here: [Short Breaks Partnership \(Q3\)](#). We are really keen to hear from you if you have any feedback or suggestions for this bulletin.

Below are links to case studies and articles that you may find useful:

- Contact a Family Case Study - [Increased Choice and Control](#)
- KIDS Case Study - [Short Breaks and Personal Budgets](#)
- CDC Case Study - [Commissioning to Support Personal Budgets](#)
- Action for Children Case Study - [Made to Measure](#)
- Steve Broach - [The Legal Landscape for Short Breaks and Personal Budgets](#)



You can get in touch by emailing ben.palmer@cafamily.org.uk, on Twitter [@SBPartnership](#), using the hashtag [#shortbreaksservices](#) or visit www.cafamily.org.uk/pcp/shortbreaks for more information.

Parents Say Toolkit - Information Pack

NHS England has been working with YoungMinds to improve the participation of parents and carers in mental health services for children and young people (CYP). As well as helping parents and carers understand the mental health issues faced by CYP and the services and support that is available, evidence shows that where families are fully engaged in treatment, outcomes improve for CYP.

The Parents Say toolkit comprises videos based on comments and feedback from some of the 900-plus parents signed up to Parents Say about their experiences of CAMHS, plus downloadable guides for commissioners and 14 case studies.

Using the Toolkit

If you are a parent or carer looking for tailored resources which will help you to influence and develop parent participation in your own service, please click directly through to our Parent Toolkits. The parents who reviewed the modules in their early draft requested these tailored versions of the resources be created. They can be used to champion parent involvement across local services.

Sharing the Toolkit

We want the Toolkit to reach as many parents and professionals as possible so that parents will be better informed by services, be able to give views, and get simpler explanations of the care their child will receive. If you use Facebook or Twitter, please help us to publicise the launch as much as possible.

For more information please visit the following links:

- <http://www.youngminds.org.uk/psaytoolkit>
- http://www.youngminds.org.uk/for_parents/parents_improving_services

Webinars for Parent Carer Forums

Recordings of our recently run webinars are available to view anytime on our [Resources Page](#). These include:

- [Making your case](#)
- [Roles and responsibilities of the chair, secretary and other forum committee members](#)
- [SEND consultation: parent carer forums \(delivered by Ofsted\)](#)
- [Building active members](#)
- [Role of the treasurer](#)
- [Short Breaks Services, the journey so far...](#)
- [Reach out a little further](#)

Look out for future invitations for webinars, including Using Social Media Responsibly.

Sleep – it's a serious issue

A child that doesn't sleep well affects the whole family. Exhaustion kicks in, you can't think clearly and brothers and sisters are also affected. Many parents say they feel caught in a vicious cycle struggling to cope, and it's no surprise when you look at the research - 86 per cent of children with additional needs have issues with sleep. So if you're experiencing difficulties, you're not alone. There are many reasons disabled children have difficulties with sleep, and there are different strategies and approaches to helping children sleep you can try.

Our guide [Helping your child sleep](#) has been written by experts in the field, together with parents. It has practical information and support for parents - you can check how much sleep a child needs at each age, learn about the sleep cycle and common causes of sleep disturbance.

It also includes information on:



- why sleep can be a problem
- how to make your child's bedroom a relaxing place
- creating a bedtime routine
- how to deal with crying to avoid bedtime
- what is Melatonin and how it may help, plus much more.

Call [our freephone helpline](#) for your free copy, or download it from [our resource library](#). All our guides are free for parents.

Also in this series:



[Understanding your child's behaviour](#) - suggestions about some of the ways your child can be helped
[Potty/Toilet training](#) - practical tips and advice on how to approach this issue.
[Feeding and eating](#) - some of the reasons behind difficulties disabled children may have with eating and where to go to get help.

Transition from Children's to Adults' services for Young People using Health or Social Care Services

NICE have published new guidance on the transition to adult services. This guideline covers the period before, during and after a young person moves from children's to adults' services. It aims to help young people and their carers have a better experience of transition by improving the way it's planned and carried out. It covers both health and social care. The Care Quality Commission uses NICE guidelines as evidence to inform the inspection process. For a copy of this or for more information [please click here](#).

Got a teenager? We have FREE guides for parents

We all remember the turmoil of teenage years, and being the parent of a disabled young person can bring particular challenges. Not least the thorny subject of sex and relationships. There is a tendency to think that disabled people, including those with severe disabilities, do not have sexual feelings, sexual needs and sexual capabilities. But they do. Parents sometimes feel uncomfortable about this. They may feel concerned about this for a number of reasons.

Family

contact a family
the national helpline

Growing up, sex and relationships

A guide to support parents of young disabled people



About this guide

This guide looks at how being disabled might impact on issues around sex and relationships. We use the term disabled children to include children who are affected by any type of impairment, special educational need, health or genetic condition or developmental delay. It offers guidance on what parents can do to support their child as they grow into young adults and start to form intimate relationships. There are thousands of different causes of impairments and the range of difficulties a child may have will depend very much on the diagnosis, how their condition is managed and what support and help is available.

Throughout this guide we use terms such as 'talk to' and 'discuss'. Not all children are able to communicate verbally, and you will know best how to explain some of these ideas to your child. We also have an information leaflet for young people, written for disabled young people in or approaching their teenage years. Parents may wish to read some of the information with a younger child or a child with learning disabilities. Or you may want to obtain some of the resources listed in this guide which explain the process of puberty and growing up in simple words and pictures.

Growing up, sex and relationships

Introduction

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Introduction

Parents are key in teaching their children about sex and relationships, helping them cope with the emotional and physical aspects of growing up and preparing them for the challenges and responsibilities that sexual maturity brings. Parents of all young people face a range of issues around sex and relationships. Disabled young people are sexual beings like everyone else and have the same rights and needs for good sex education and sexual health care, and the same opportunities for socialising and sexual expression as their non-disabled peers. Parents of disabled children and young people have a special role in providing support and guidance to enable their children to embrace the challenges of adolescence and grow into informed and confident adults.



example in music videos and advertisements. Compared with ten years ago, they have unprecedented access to digital technology like smart phones and tablets, with better internet access at home and outdoors. Last year 62 per cent of 12-15 year-olds accessed the internet from a smartphone or other hand held device¹.

¹ For Adults Only! Usage access to online porn, AVOD, March 2014

Freephone helpline 0800 808 3555 helpline@cafamilly.org.uk

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Parent guide

Our [Growing up, sex and relationships parent guide](#) has been written specially to support parents of disabled children around this tricky subject. We have tips on developing your child's self-esteem and keeping them safe, encouraging friendships, and how to talk to your child about puberty and the changes that are happening to them. The guide also covers safe sex and contraception, and what to expect of sex and relationships education in school. Packed with useful resources, including for parents of learning disabled teenagers, we hope you will find this guide helpful as your child grows up to adulthood.

Information leaflet for disabled young people

We also have a [Growing up, sex and relationships information leaflet for young people](#), written for disabled young people in or those approaching their teenage years. Parents may wish to read some of the information with a younger child or a child with learning disabilities.

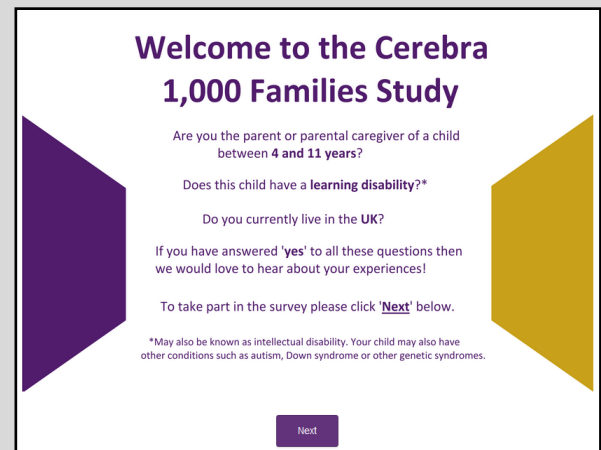
Download or order our resources

Both resources are free to parents who call our freephone helpline on 0808 808 3555, and free to download from [our resource library](#). Professionals can buy copies of all our guides from [our resource library](#). If you are a parent and would like to receive a FREE guide please call the Contact a Family Helpline on 808 3555 or email helpline@cafamilly.org.uk.

The Cerebra Family Research Group

Are you the parent or parental caregiver of a child aged 4-11 years that has a learning disability? If so, please take part in our new 'Cerebra 1000 Families study.' Your child might have other conditions - such as Autism, or any one of a number of genetic syndromes. As long as your child also has a learning disability, we would be very keen to hear from you.

The Cerebra Family Research Group, at the University of Warwick, in collaboration with the research charity Cerebra, wishes to explore the experiences of families who live with a child with a learning disability in the UK. We want to make this the largest study ever of families of children with learning disability in the UK. This research will further our understanding of what it is like to raise a child with a learning disability in the UK and will help shape future support for families and children.



Sleep Support For Parents of Children with Autism

Tired parents in Gloucestershire, Worcestershire and Herefordshire are about to receive help thanks to an innovative sleep project taking place across the regions. The Children's Sleep Charity have been funded by the NHS to pilot sleep workshops aimed specifically at children with autism and their families.

It is estimated that around 40% of children will suffer with sleep issues at some point during their childhood with this figure rising to 86% for children with additional needs. It is well documented that sleep deprivation can cause a wide range of difficulties for both parent and child including lowering of the immune system, behavioural issues and under achievement in education.

Vicki Dawson is the Founder of the Children's Sleep Charity, a charity she set up to help sleep deprived parents to get a better night's sleep. Vicki says, "The charity supports all families to get a better night's sleep. We have however been inundated with requests for support from families of children with autism and are keen to explore ways that we can support them more effectively. This pilot project has provided us with the opportunity to consult with families in order to develop a package of support to meet their needs."

Marie Simmons is mum to Kristan who is six years old and on the Autistic Spectrum, he also has sensory processing difficulties. She received support from The Children's Sleep Charity after suffering years of sleep deprivation she says, "Kristan was up for most of the night. I decided to get help and hoped there was a light at the end of what felt a very dark tunnel. I approached The Children's Sleep Charity and they supported me to make changes to his bedtime routine. They also supported me through implementing the new programme, especially when I wanted to give up! After a few weeks Kristan started to sleep through the night, his behavior improved in the day time and evenings are no longer spent running up and down the stairs. Our lives have changed so much now we can relax at night and get some sleep."



To find out more about the service and to book a place please contact info@thechildrenssleepcharity.org.uk or visit: www.thechildrenssleepcharity.org.uk

Disability Matters: Call for Evidence

Disability Matters, which was coproduced with NNPCF, is proud to partner with the Royal College of Paediatrics and Child Health (RCPCH) to promote the importance of inclusion and access for all disabled children and young people aged 0 - 25 years. We are collecting evidence and case-studies from young disabled people, parent carers and those who work or volunteer with disabled people to highlight the many positive ways that people are:

- working pro-actively with disabled children and young people and their families
- enabling inclusion
- making services accessible

As a pan-disability programme we are interested in examples that relate to all disabilities, including intellectual/learning disabilities, physical disabilities, complex needs and visual or hearing impairments. We will compile the responses to this survey in a report that will be available in the early summer of 2016. Please share your views with us by completing this survey <https://www.surveymonkey.com/r/Disabilitymatters>. An introduction to Disability Matters and the Call for Evidence can also be downloaded as an [easy read overview](#). The call for evidence closes on **Friday 11th March, 2016**. For more information on Disability Matters [please click here](#).

Learning Disabilities Mortality Review (LeDeR) Programme

About the Programme

The new [Learning Disabilities Mortality Review \(LeDeR\) Programme](#) was recently announced by NHS England and HQIP. This follows on from the work of the Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD) which found that up to a third of the deaths of people with learning disabilities reviewed were from causes of death amenable to good quality healthcare. A key part of the new Programme, which will be rolled out across England from January 2016 onwards, will be a focus on local reviews of deaths of people with learning disabilities to drive service improvement. They are establishing a multiagency Programme Review Panel to support the work and would like to invite health and social care professionals, independent care providers (including advocates) and family members to join this.

About the role

The role of the multiagency Programme Review Panel will be to scrutinize completed reports of deaths that are subject to priority themed review and add additional insights or comments as appropriate. In 2016, deaths subject to Priority Themed Review will be those of people from Black and Minority Ethnic (BME) communities and young people aged 18-24. They are seeking professionals and family members with personal and/or professional experience, of the issues faced by young people with learning disabilities and those from Black and Minority Ethnic Communities. Most of the work will be 'virtual' using an online web-based platform, but there will be a training/update day each year in the North and South of the UK, starting at the end of January 2016. A Review Panel of people with learning disabilities will run parallel with the multiagency Review Panel and will also be instrumental in advising on specific issues relating to these themes.

If you are interested in the opportunity or have any questions, please contact us with:

- your name and contact details (address, email address, phone number plus preferred times and type of contact) and tell us about your relevant experience and why you are interested.

Please get in touch **ASAP** if you wish to be considered. Please contact Patty Ramirez patty.ramirez@bristol.ac.uk for further information. If you know of any people with learning disabilities, other family members, health and social care professionals or advocates who may be interested.

Court of Appeal rules that bedroom tax discriminates against disabled children

The decision by the Court of Appeal ruled that the bedroom tax discriminates against disabled children who need overnight care.

Spare room for carers of disabled children

Susan and Paul Rutherford, of Pembrokeshire, challenged cuts to their housing benefit made because they were treated as having a spare bedroom. This room was essential because it is used by carers to look after their severely disabled grandson overnight. While the housing benefit rules allow for an extra bedroom for an overnight carer if needed by an adult, they do not allow for an extra room if an overnight carer looks after a disabled child. The Court Of Appeal has now found that this unlawfully discriminates against disabled children who need overnight care.

Families would reach breaking point without overnight carers

Una Summerson, Head of Policy at Contact a Family says: "We know from calls to [our helpline](#) that this is not an isolated case. Some children have high care needs through the night and an overnight carer enables their parents to get a vital night's sleep. Without the help of overnight care workers some families would reach breaking point and may consider residential care, at a substantial extra cost to taxpayers. We are delighted that the Court of Appeal has found the current rules to be unlawful. Contact a Family hopes that the Department of Work and Pensions will now act quickly to amend the housing benefit rules rather than challenge this ruling in the Supreme Court."

Our campaign against unfair bedroom tax

We have been campaigning to ensure all disabled children are exempt from unfair bedroom tax rules. The housing benefit rules had previously been changed to take into account where a child's disability means they are unable to share a bedroom with their brother or sister. However, families who need an extra room for an overnight carer or to store equipment still face cuts in their housing benefit. Una Summerson added: "Many families have seen a reduction in their housing benefit since the bedroom tax was introduced. 'Spare' rooms are anything but for families with disabled children - they are often essential in caring for a disabled child. As well as families needing a room for overnight carers, extra rooms are important spaces to store lifesaving equipment or vital supplies which are delivered in bulk, or as a safe or quiet room for children."

Families should not be penalised

As part of our [Counting the Costs campaign](#), we're calling for the size criteria rule to be amended to allow for the costs of an extra bedroom where this is required as a result of a [disabled child's condition](#). Our [Counting the Costs research](#) shows that nearly one in ten families with disabled children are still affected by bedroom tax or similar rules in the private rented sector. 38 per cent are experiencing a cut to their housing benefit of more than £25 a week. The research also shows that the vast majority (80 per cent) of families with disabled children who applied for discretionary housing payments had been turned down. Families who need an additional room due to reasons connected to their child's disability should not be penalised for this fact. They should receive help with the costs of that additional room as a right and not have to rely on a discretionary form of support.

Other families who are having their housing benefit reduced because they have an extra bedroom for an overnight carer for their child should [contact our helpline](#) for further advice. This applies not only to those tenants in social housing affected by the bedroom tax but also to private tenants whose housing benefit is being capped under local housing allowance rules.



NNPCF Social Media — Twitter and Facebook.

We hope that you are already linked up to our Facebook pages and Twitter. We have been sending out daily jargon busters in relation to the reforms and examples of the work of forums to share some of the excellent activity that is happening all over England. If you are not already linked with us join us:

Need Advice?

If you, or any parent carers in your forum want individual advice about how the SEND reforms might affect them, or have any questions or queries about their service provision or support, then please tell them to contact the Contact a Family [free helpline](tel:08088083555) from 09:30 - 17:00 Monday to Friday.



Call: 0808 808 3555

Email: helpline@cafamily.org.uk

Website: www.cafamily.org.uk

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