

ISSUE 8

SPRING / SUMMER 2018 • FREE

WELCOME

...to Issue 8 of our newsletter, which also marks ten years of parent participation in NE Lincs. We still get asked asked: *"What is Parent Participation anyway, and why is it important?"*



Parent carers can help pinpoint problems frequently experienced by families with disabled children. This knowledge is useful to professionals to help them improve how services are delivered, so they better fit families' needs. With successful parent participation, parents and professionals work together, recognising each other's expert knowledge, so informed decisions are made which make best use of people's time and money.

We all know that cuts continue to be made to services and money is tight for those that survive, that is why it is vitally important that local parent carers get involved with the crucial decisions being made so that, what money there is, is spent wisely to best benefit disabled children and their families.

Supported by the National Network of Parent Carer Forums, North East Lincolnshire Parent Participation Forum (NELPPF) is the local opportunity for parent carers to have their voices heard and help influence local decisions that may affect their families. For parent carers, by parent carers.

Any feedback you can give us helps make the collective NELPPF voice more accurate and we welcome any enquiries into becoming a NELPPF committee member, with your contribution being as much or as little time you can give.

Contact NELPPF for further information on 07583 474892 or email nelppf@gmail.com and via our Facebook and Twitter pages.

A day in the life of Clare Linfitt

Hi, I am Clare Linfitt. I was a school SENCo for 20 years in this country and in Spain and a Special Educational Needs and Disabilities consultant helping other local authorities and schools to improve their SEN practices up and down the UK.

Currently I am the Special Educational Needs Services Manager for our local area. I live in Cleethorpes with my two sons.

My day usually starts by dropping my boys off at school and heading to the Civic Offices in Cleethorpes. On a good morning nobody has forgotten their bag, PE kit, homework, phone etc. and we are all calm.

On a regular day someone's shirt is too itchy, their trousers are too baggy, they don't like the cereal because the packet design has changed, the bathroom floor is covered in water and towels and the cat has been sick in the hall! Yes my morning is much like 99% of homes at 8am during the week.

Once at work I check my calendar for the day. I have Specific Literacy and number recognition Differences (SpLD) and the technology available really helps me get organised. My outlook diary is colour coded in blocks as I am better able to remember patterns of activity as a picture of my day rather than individual times and dates. I use voice recognition technology and spell check is my constant companion.



It took a long time – nearly 30 years, before I'd ask for help with the things I found challenging. I now feel it's not a weakness to openly say 'I find this difficult'. Most people are happy to be supportive and if things take longer, are done differently or if I stumble over words, numbers and acronyms - it matters not a jot as long as the outcome is good and my contribution is valid. I encourage all children and young people with SEND to say openly that they need help if they do. Trying to cover up an additional need is completely exhausting and you end up in more of a muddle.

Every Tuesday I chair the SEN advisory group panel (SENAG) that make recommendations regarding Education, Health and Care Plans. The first thing we look at is what the child or young person says they would like their future to look like, what is important to them and what their parents/carers would like to happen to help them achieve good outcomes. Some children and young people need a lot of planned support and finance through an Education Health and Care Plan (EHCP) for them to make progress, others need a really good 'My Plan' that everyone agrees on and sticks to.

Continues inside...

Clare Linfitt article continued...

Some days I meet with parents and colleagues from NELPPF and SENDIASS. Collectively we try to ensure through our termly SEND Parental Engagement and Participation action plan that children and young people with SEND and their families are at the heart of everything we do and that that we listen to what they say they need. Often things go well for families, good news stories brighten everyone's day. Sometimes there are changes that need to be made.

SEND services work best when families are able to tell us straight away when things are not working for them. Finding ways to help families of children with SEND engage with us and talk openly at the first point of issue is always a priority.

2014 - 2018 has been a busy time for SEND changes but I am very proud to say NE Lincolnshire has transferred all statements to EHCPs four days ahead of the government timescales.

We still have so much to do to ensure the SEND reforms are fully embedded in our local area and we are always looking for parents/carers to talk to us and work in co-production. Any ideas or thoughts about Special Educational Needs in North East Lincolnshire please contact SEN@nelincs.gov.uk.

If you would like to know more about 'My Plan', we are holding two parent/carer 'My Plan' workshop sessions at the Town Hall in Grimsby on Thursday, 7th June or Wednesday, 20th June 2018 from 10am - 12pm. Please contact susan.jones@nelincs.gov.uk to book your FREE place.

Carers' Needs Assessments

Looking after someone can be rewarding and enjoyable, but sometimes it can be demanding and stressful. It is important to make sure you get support before you feel unable to cope, so that you can look after yourself and manage your caring role.



Carers are entitled to seek support and advice locally if the person they care for lives in North East Lincolnshire.

For example, Mr Smith is a Carer living in Essex, caring for his mother who lives in North East Lincolnshire. To access support, Mr Smith needs to identify himself as a Carer in North East Lincolnshire, not to any local authority in Essex.

A Carers' needs assessment is your opportunity to identify your goals and to talk about the specific things that could be helpful or make life easier for you

A Carers' Needs Assessment will consider the impact of your caring responsibilities on you, your current and future needs for support, and what you want to achieve in your daily life.

The Care Act 2014 states that Carers who appear to have any level of need for support must be offered an assessment. The Children and Families Act sets out similar provision for Young Carers and Parent Carers.

It doesn't matter how much care you provide or what your financial situation is, as long as you are providing care, you can request an assessment.



If you want to find out more about Carers' Needs Assessments call the Carers' Support Service on 01472 242277. Phone lines are open Monday to Friday 8am to 7pm and Saturday and Sunday 10am to 2pm. Alternatively, if you are an adult caring for an adult you can call the Single Point of Access on 01472 256256. Lines are open 24 hours a day.

Parents looking after a child with additional needs can call The Family Information Service which is open Monday to Thursday 8:30am to 5pm and Friday 8:30am to 4:30pm.

Young Carers looking after a family member can call the Young Carers Team on 01472 326294 (option 3 then option 2)

Training and workshops at the Carers' Support Service

Free First Aid Training for Carers

DAY ONE

Dealing with an emergency Unconsciousness Choking Bleeding **Burns Recovery Position** April and July - FULL

DAY TWO Heart attack Stroke

Head Injuries

Hypothermia

Diabetic emergency



Course content may be subject to change

Call 01472 242277 to book a place Sprains, strains and broken bones

> The Carers' Support Service 1 Town Hall Square, Grimsby

IMPORTANT CHANGES TO END TRIBUNALS



As from 3rd April 2018, SEND tribunals will have some new powers.

A SEND tribunal can now look at health and social care concerns too...

If you have concerns about the education sections of an Education, Health and Care (EHC) Plan or about a local authority decision to not issue an EHC Plan, you can go to the tribunal and ask for these concerns to be addressed. For these cases, you will now also be able to ask the tribunal to look at the health and social care sections of the EHC Plan as long as the local authority decision happened on or after 3rd April 2018 or the plan was issued or amended on or after 3rd April 2018.

You still need an education complaint to go to tribunal...

A health or social care complaint without a special educational concern does not enable you to use the SEND tribunal which must be "triggered" by a special educational concern. More information on what is included in a special educational concern, and how to appeal, is set out on the www.gov.uk website.

This gives families a "one stop shop" (or single route of redress) where they can seek to remedy concerns about an EHC Plan...

Previously, the tribunal had no powers over the health and social care aspects of a plan. Now, all elements of a plan can be reviewed in one place as long as there is an education concern.

The tribunal can only make "non-binding" recommendations about health and social care provision in EHC Plans...

The judgements that the SEND tribunal makes about health and social care elements of an EHC Plan are "non-binding" i.e. the law does not require health and social care commissioners to follow the judgements.

Nevertheless, the local authority and health care commissioners are expected to follow them and because they are recommendations from a specialist tribunal, they cannot be rejected lightly.

The health or social care commissioner must write to the family and the local authority within five weeks to tell them if they are going to follow the recommendations or not. If they are then they need to explain the actions they are going to take. However, if they decide not to follow the tribunal judgement, they must explain why they are not following the tribunal's recommendations. In these instances, you can still take your case to the relevant ombudsman (www.lgo.org.uk for social care or www.ombudsman.org.uk for health) or to Judicial Review as before.

This is a two-year national trial...

The government are trialling this new process for two years. At the end of the period, they will assess how well it has worked and make a decision on what happens next. An agency called 'IFF Research' will be contacting parents and young people who have been through the trial to find out about their experiences. They will be gathering evidence to help the government make this decision.

October 4th & 11th, 10am to 1pm - SPACES

Calling all Dads...



My partner does most of the appointments and has made friends with other special needs mums... I feel like I'm on the outside.

> As strong as I may seem on the outside, I'm scared as hell on the inside for what the future holds.

We dads tend to bottle things up and pretend everything is fine. My mates don't understand. It can be lonely sometimes.

JOIN OUR NEW "DADS GROUP"... ...FOR A FREE BREAKFAST!

Would you be interested in a support group for dads, stepdads, granddads and other male carers?



We want your ideas guys so come for a free big breakfast at Brewers Fayre in Cleethorpes on Sunday 3rd June 10am for a first meeting - book your place by 25th May via the **NELPPF Facebook** page, text/call on **07583 474892** or email **help@nelppf.co.uk**.

(First come first serve. Conditions apply.)

If you can't make it but still fancy the idea of a "dads only group" and want to be kept in the loop about future dates etc, let us know using the same contact details. **Please leave full name and contact number.**

> I nearly didn't go because I don't see myself as a carer but thank goodness I did, I've learned so much.

I definitely feel less depressed since I started the group, my family has noticed the difference.

It was refreshing just to be around other blokes who understood where I'm coming from an not feeling like I'm being judged.

North East Lincolnshire Access Pathway for Additional Needs - Written by Anita Havercroft, NELC

Supporting children with communication and interaction, cognition and learning, and social, emotional and mental health

Some of our parents told us that they were dissatisfied with the service provided to them, when they felt their child was experiencing difficulties with communication, learning and mental health. Families told us it was not clear where to go for support, which left children bouncing around a system looking for the right door to open, to get the right support for their child.

We listened to parents views and recognised that we needed to improve the journey for children and young people experiencing these difficulties, so a joint scrutiny panel working group was created, and a wide range of organisations delivering services to children formed a partnership, both with the aim of reviewing the situation and sharing their findings to propose and develop solutions.

The partnership is made up of staff in services across the NEL and with links to parents and parent forums/groups. The partnership includes North East Lincolnshire Council (NELC), North East Lincolnshire Clinical Commissioning Group (NELCCG), North East Lincolnshire Parents Participation Forum (NELPPF), GP's, North East Lincolnshire Clinical Commissioning Group Community Reps, Child and Adult Mental Health Services (CAMHS), Paediatrics & Speech and Language Services, Barnardo's, Lincolnshire Partnership Foundation Trust (LPFT) and North Lincolnshire and Goole NHS Foundation Trust (NLAG).



The joint scrutiny panel working group presented their findings to Cabinet in March 2018 along with 7 recommendations, and the partnership have worked to create a pathway to change the way children access services, and provide families dealing with these complex issues the support they need to manage their everyday lives and address where appropriate the recommendations made by scrutiny.

LAUNCH OF THE PATHWAY AND THE PROCESS

The Access Pathway is launching at the end of April 18 and will be taking referrals via the Families First Access Point (FFAP). These referrals will be reviewed by FFAP and if they meet the criteria will be sent directly to be heard at the regular multi agency panel.

However...

The model of support for our children, young people and families in North East Lincolnshire is prevention and early intervention and there is a significant amount of support and activity freely available for all children to support their development (universal services), much of which can be readily accessed by families themselves. Professionals working alongside your children such as health visitors, family hubs staff and schools staff are all good first points of contact to share concerns and consider options to improve individual children's development.

Where it is believed that a child may have multiple or complex needs, an Early Help Assessment form (EHA) should be completed clearly outlining the worries, concerns and strengths - professionals working with children will record the information known by themselves and the family, and send this to FFAP. FFAP will check other electronic system's that hold information on social care, health and education to gather any relevant recorded information which will provide a fuller and clearer picture of individuals needs before forwarding all of this information through to the Access Pathway Panel.

The Access Pathway panel includes several multi-disciplinary professionals, with specialist knowledge and skills, who will review complex cases and coordinate intervention plans and ensure that the child and family have access to the right support, as soon as possible.

As well as the coordination of services, we recognise it's essential to provide specialist support and activity to give families the strategies, knowledge and confidence to manage their children needs long term, and to build resilience within their own family network. *These services will not just be available to those families with a diagnosis; and will be developed as part of the local offer to be used for families who experience a wide range of issues.*

We recognise that some children will need to access Paediatricians to gain a formal diagnosis; however this will not be a pre-requisite for access to support. These children will remain on the Access Pathway and branch off for specialist assessments or services, with the outcomes of those guiding the ongoing support package which is offered to the family.

In doing this we will reduce waiting times and waiting lists in specialist provision, reduce the need for unnecessary and costly assessment and most importantly it will provide children and families with the right support at the right time.

FEEDBACK AND COMPLAINTS

When any new service starts operating, it is normal to make some early adjustments and improvements based on feedback so there will be a process to collect feedback from stakeholders, including parents. The pathway journey for families will include clear information about where and how families can raise questions and concerns, and in order to build good communication and relationships, we will encourage families to use this system. However the formal complaints procedure will also be available and more information on both these processes will follow, as they are still being finalised due to the various partner organisations involved.

SUPPORTING COMMUNITY RESILIENCE

We are also looking at encouraging and supporting the development of parent led peer support activity, developing resilience in communities and drawing in specialist advice and support when needed. Examples are activities such as play therapy, speech and language support and occupational therapy support which could be delivered out in localities and within parent support groups.

Members of the partnership development group are happy to come and speak to parents who wish to have a full overview of the pathway and how it can support the needs of children and families in NEL. In the first instance, please contact Sarah Impey.

Sarah.impey@nelincs.gov.uk



www.nelppf.co.uk North East Lincolnshire Parent Participation Forum (NELPPF) is one of over 150 voluntary parent-led parent forums across the UK, helping parent carers have a voice in how local services are shaped, find the information they need and meet other parents in similar situations.

www.barnardos.org.uk/nelsendiass

Find out how Barnardo's SEND Information and Advice Service (SENDIASS) can help you.

www.nelincs.gov.uk/children-and-families/send-and-local-offer

Advice, support and information about all things SEND, for your child / young person from 0-25years. Signposts to all education, health and social care provision in NE Lincolnshire and more.

www.nelincs.gov.uk/children-and-families/family-hubs

Keep up-to-date with Family Hubs' (formerly Children's Centres) activity timetables here, including training opportunities, coffee mornings, play sessions and more. Highlights: 'Young Carers Project' Thursdays 3-5pm, Immingham Hub; 'Parents Supporting Parents' group Thursdays 12-2pm, Riverside Hub.

www.nelincs-downs-syndrome.co.uk

North East Lincolnshire Down's Syndrome Family Support Group is a voluntary parent-led charity for families living in the North East Lincolnshire area and are affiliated to the national Down's Syndrome Association.

www.lincsinspire.com/enterprise/HealthandWellbeing_DisabilitySports

Keep up-to-date with Grimsby, Cleethorpes and Nunsthorpe Leisure Centre activities and services for the disabled, which includes a Sunday 2-4pm swimming session, perfect for school aged children.

www.bridgemcfarland.co.uk

For all you local legal needs from our esteemed sponsor!

www.carerssupportcentre.com

The Carers Centre, Town Hall Square, Grimsby – offering support, counselling, advocacy, specialist advice (e.g. benefits) and holistic therapies for carers.

NATIONAL

www.ipsea.org.uk

"Independent Parental Special Education Advice" (IPSEA) is a national charity that offers free and independent legally based information, advice and support to help get the right education for children and young people with all kinds of SEND.

www.sossen.org.uk

SOS!SEN is a national charity aiming to empower parents and carers of children with SEN to tackle successfully themselves the difficulties they face when battling for their children's rights.

www.cafamily.org.uk

Contact (formerly Contact A Family) is a national charity for families with disabled children, providing information, advice and support.

www.ambitiousaboutautism.org.uk/when-will-we-learn-campaign

A national campaign to stop the illegal exclusions of autistic school pupils.

www.childnet.com/parents-and-carers Internet safety guides for SEND parents

www.cerebra.org.uk/help-and-information/guides-for-parents/dla-guide

www.tiredout.org.uk/sleeptips

www.scope.org.uk/support/disabled-people/benefits/check

If you have any useful links you think are worth sharing, or know any local SEND friendly resources, groups etc not advertised in this issue, let us know using the "Tell The Editors" contact details on the front of this newsletter.

NELPPF & SENDIASS PARENT CARERS' DROP-IN DATES FOR 2018

Pop over to Riverside Children's Centre for a cuppa and a chat on the last Friday of every month between 10am and midday. Meet other parent carers and benefit from free impartial advice about all things S.E.N.D. at the same time!

North East Lincolnshire Parent Participation Forum



Friday 25th May 2018 Friday 29th June 2018 Friday 27th July 2018* Friday 31st August 2018* Friday 28th September 2018 Friday 26th October 2018* Friday 30th November 2018



*Children welcome in school holidays. Baby changing facilities and wheelchair access toilets available.

Riverside Children's Centre, Central Parade, Grimsby DN34 9AT

Ofsted & the CQC are doing Local Area Inspections of ALL services related to Special Educational Needs & Disabilities (SEND).

They will seek feedback from parents via a Webinar.

"What the **** is a webinar?"

A webinar is a bit like a live meeting or workshop, but on your computer, laptop, tablet, or phone. So no need to leave the house!



It is super-simple, anonymous and you have the ability to contribute (type in) questions or comments, or just listen.



You will need to sign up to take part but your name and email address will ONLY be used to send you the link to the webinar. The date & time and any other basic instructions you need will be sent in an email.



Click on the email link at least five minutes before the start time and follow the simple instructions. The Ofsted webinar should last no more than around 40 minutes.

> The Ofsted webinar date will be set once the Inspection Week has been announced.

Disclaimer.