SEND Newsletter of children and young people with special needs and/or disabilities in North East Lincolnshire

For parents, carers and families

ISSUE 9 NEW YEAR 2019 FREE

WELCOME

...to Issue 9 of our newsletter which we're dubbing "The Inspiration Edition - New Year, New NEL"!

2018 saw some great achievements captured in this newsletter - and some seriously eye-opening lapses in the world of SEND. For those who weren't aware, a "Local Area SEND Inspection" was carried out by Ofsted and the CQC 2nd-6th July 2018 to assess how effective local SEND services were at (a) identifying children and young people's SEND, (b) meeting the needs of children and young people who have SEND and (c) improving outcomes for children and young people who have SEND. To see the inspector's official report, follow the links on the Council's Local Offer page www.nelincs.gov.uk/children-and-

families/send-and-local-offer/.

We've been promised that 2019 is going to be a year of concerted effort, culture change and forward thinking to radically turn things around for those SEND families who have yet to access the support they so desperately need... and of course to ensure what's going well STAYS going well. But for now, let's ring in the New Year by celebrating local success stories to inspire us all. And as usual, if there's anything you'd like to see covered in future editions, or you're interested in volunteering with NELPPF. Let us know.



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

NELPPF Coordinator Awarded OBE Karen Hoe "humbled and embarrassed" by honour



Karen started volunteering soon after her son's main diagnosis and during the pregnancy with her second child, learning as much about the SEND world as possible while on maternity leave from a retail management job which she subsequently left to pursue SEND related ventures full-time. As well as NELPPF she also works for Contact (formerly Contact A Family), Sky Badger, recently appointed "Changing Places" development officer and is a freelance SEND consultant.

"This is going to sound so clichéd but I never have and never will do what I do for awards or recognition, I just want to do what I'm passionate about and that is improving outcomes for parent carers and their families by ensuring our voices and views and experiences are heard locally regionally and nationally."

Congratulations Karen, you may be embarrassed by the attention but you do deserve it.

Karen Hoe, NELPPF coordinator for the past six years, was awarded with an OBE for services to children with SEND in the Queens Honours List 2018. Karen, who has an adult son with severe and complex disabilities, received her award from Prince William at Buckingham Palace in what she described as a petrifying experience.

"I could barely remember how to walk or even breathe I was so terrified. But every single person involved from the welcoming staff to the prince himself did everything they could to put you at ease, show you what to do or crack a joke to help calm you down."

The prince even disclosed how he finds his own parenting experiences challenging, so the esteem with which he holds Parent Carers he said was 'phenomenal and I don't know how you all do it.'



Working with families to improve the 'Access Pathway' for North East Lincolnshire

We asked Lauren King, Strategic Lead for Access Pathway Development, what it's all about and how YOU can help!

What exactly is the Access Pathway?

The Access Pathway is a single route for those children and young people who have very complex needs across Communication and Interaction, Cognition and Learning and Social Emotional and Mental Health Difficulties. The pathway was set up last year to ensure parents/carers and young people only have to tell their story once and this is captured through the Early Help Assessment form.

The Early Help Assessment (EHA) form helps to evidence what has been previously tried, what has worked and things that worry or concern you / your child and the service you are working closely with. The EHA should be completed by a professional that best knows you, your child and family.

The EHA form is then sent on to the Families First Access Point (FFAP) for triage to get the right help, at the right point. The FFAP worker will review the EHA. At this point there are three routes for further help.

- Signpost to a single service e.g. 'Young Minds Matter'
- 2) Direct to support that is available in the community through the Family Hubs, or
- 3) Referral to the Access Pathway Panel.

What is the Access Pathway Panel?

The Access Pathway Panel is a group with a wide range of specialist skills and knowledge in Communication and Interaction, Social, Emotional Wellbeing, Mental Health, Special Educational Needs, Cognition and Learning, Disabilities and Early Learning.

The panel will meet with the professional who helped complete the EHA with the parent/carer to review this information, alongside electronic records across health, education and social care. The group make joint recommendations on how best to coordinate support to improve outcomes for the child and their family.

This process will follow one of the following routes:

- 1) Signpost to a single service e.g. 'Young Minds Matter'
- 2) Direct to support that is available in the community through the Family Hubs
- Gather further evidence e.g. from organised support in place within the school environment, or
- Onward referral to a specialist service for diagnosis.

Why and how do you need families to help improve the Access Pathway?

We still need feedback from families who use the services and people working in the services about how we can keep improving the process and tackle any frustrations people encounter.

For example, from initial feedback, parents and professionals have told us that they haven't been kept informed. From the New Year all professionals, parents and carers will receive written notification when the EHA has been received and then further written updates along their journey.

We want to carry out an **independent review** of the pathway and we have invited Healthwatch (an independent organisation working on behalf of people who use health and care services) to do this important piece of work that will include workshops and focus groups for children, young people, parents and carers who will be able to share their thoughts and experiences.

While the CCG and Council are supporting the review, our only input and/or presence will be organising the practical details such as helping to get the rooms ready. This means these events will be solely for families to share their feelings and experiences with an independent ear.

The workshops will take place over the next few months and we expect the review to be completed by the end of March 2019. The feedback from this review will be invaluable as we continue to work hard to improve the service and experience for the families using it.

Great! What are the workshop dates?

Workshop 1 – will give parents/carers the opportunity to share their thoughts and feelings about identifying issues and how they initially received support:

Tuesday 15th January 2019 – 9.30am to 12.30pm – Scartho Community Centre

Workshop 2 – will allow parent/carers the opportunity to share their opinions and views about the Early Help process to the Access Pathway Panel. How they found it? And who helped them through the process? Wednesday 6th February 2019 – 12.30pm to 14.30pm – Grimsby Town Hall

Workshop 3 – will allow parents/carers the opportunity to share their thoughts and opinions on how they found the Access Pathway from the decision made to post pathway support:

Tuesday 5th March 2019 – 10am to 12.30pm – Grimsby Town Hall

Workshop 4 – will be interactive for your child to have their say about the help and support they have received and what professionals can do better:

Wednesday 27th March 2019 – 6pm to 8pm – Riverside Children's Centre

There will then be two feedback sessions available for you to attend and find out what the findings were and what we plan to do with that information:

Tuesday 30th April 2019 – 9.30am to 11.30am – feedback session – Grimsby Town Hall

Wednesday 1st May 2019 – 12.30pm to 2.30pm – feedback session – Riverside Children's Centre

Two questions that seem to be come up a lot... (1) Do I need to go down the Access Pathway route for 'Young Minds Matter', including specialist CAMHS? and (2) Can I self-refer to the Access Pathway?

Good questions!

(1) No, if your child has a need that can be met via a single service e.g. Young Minds Matter, a direct referral to that service should be made and you do not need to go via the Access Pathway. The professional you speak with should have access to relevant referral forms. And (2), re self-referral, we would advise you where possible to identify a professional that best knows you, your child and your family, so that as much information as possible can be captured in your Early Help Assessment for the Access Pathway. EHAs sent to the Families First Access Point (FFAP) with limited information will result in a delay in reaching panel, whilst other services / agencies involved with your child and family are contacted to submit supporting information. This supporting / additional information is important as it will show what has been tried before, what has worked and not worked and highlight any concerns from supporting services. This information will be considered by the Access Panel to ensure a package of support is recommended appropriate to your child's needs.

If you have any general questions about the workshops, please contact Healthwatch on 01472 361459 or simply book* a free place at www.eventbrite.co.uk - search for "Access Pathway".

*BOOKINGS ARE HELPFUL BUT NOT ESSENTIAL. It is to give the organisers an idea of numbers in order to set the rooms up accordingly. So if you can, please do.





"Building Change" with Fortis Therapy and Training

When working with children with SEN or social anxieties, art and play therapy can be incredibly engaging. Using toy bricks such as Lego to build and create structures, scenes, and objects enables the children to express their feelings whilst developing social interaction skills. This is why we are delighted to be bringing Building Change: Lego-based therapy to Fortis Therapy and Training in 2019.



What is Building Change?

This Lego-based therapy helps to improve social skills in children aged 5 to 16 years, especially those with autism spectrum disorders. In small groups of up to six children, and with the help of a fully- accredited child therapist, those taking part will work together to build models, switching between the roles of 'supplier', 'engineer' and 'builder' throughout the one-hour session. Should a social difficulty arise, the therapist will encourage the children to solve the problem and find an alternative strategy. Children can also express their creativity by building models from their imagination without instruction.

Building Change allows young people to practice problem solving, working in collaboration, communication, listening, sharing, and taking turns in a friendly, fun environment.

For more information, please give Fortis Therapy and Training a call on 01472 241794 or email enquiries@fortistherapy.co.uk.

"We have a team of seven specialist advisory service colleagues that work with children with complex needs in schools across our area. In the last academic year, after working with over 500 youngsters, the team has helped a whopping 87% of them to improve in their work."

Sharon Gest, Deputy Manager, Special Advisory Service

An Interview With... Mike Burton

From rock bottom to the heady heights of The Pride of Britain Awards, meet the man behind 'The Orchard' Special School

The Orchard Special School is an educational setting that provides a bespoke and totally unique curriculum to students aged 11-16yrs with social emotional and mental health (SEMH) needs who have been unable to cope in any other setting and exhausted every other avenue. Just a few short years ago, it was known as DKM, an Alternative Provision, providing a safe place for disengaged young people to go, but little in the way of education. Now with pupils achieving well and voluntarily turning in homework each week, everyone from the Local Authority to stunned Ofsted inspectors are begging to know what their secret is. We had to go and ask the extraordinary man who made this happen, Principal Mike Burton, about how he's managed turned things around so dramatically... and so quickly.

The morning I turn up bleary eyed at The Orchard to meet him, he's in a cracking festive jumper, has been in early to help prep the Christmas dinners happening that day (which he also helps to serve) prior to which he has also been to the gym. "If I don't go at 5am every day, I'd not fit it in as I'm on the go until late at night writing lesson plans." Fitness is incredibly important to Mike, as it is the positive mental attitude he learned through the discipline of exercise that turned his own life around as a teenager. At 16 years old, still unable to read or write after an unsettled childhood left him totally disengaged with life, a traumatic event made him realise he needed to turn his life around. He went back to college to gain his basic qualifications, secured a position in a local gym and found he enjoyed helping people achieve their fitness goals which were often wrapped up in self esteem. Watching people grow in mental strength alongside their physical strength and seeing how it impacted on all areas of their life inspired him so much so he decided to train as a teacher, despite his lingering issues with literacy - fast forward some years and he has become a SEMH consultant, an inspirational speaker, charity owner (Inspire-TCI, standing for "Inspire The Champion Inside"), a National Diversity Awards winner for 'Positive Role Model' and was also shortlisted to the last four for The Pride of Britain Awards 'Fundraiser of the Year' 2018.

Mike isn't shy about the recognition which he welcomes greatly, but not out of ego; it's largely for the doors it can and has opened for his charitable causes, not to mention his students. "After doing a successful twelve week inspire program for the DKM kids, Pete (MacLeod, former director and founder of DKM) asked me to help formally develop the educational side of his provision not as a consultant but as permanent staff. We quickly found though that

nobody wanted to help. Every door was closed to us. We just needed a helping hand to get some ideas with things like how policies should be worded. One school said we could look at theirs but it would cost us four grand. We were stunned." Eventually through grit and determination (and a solid goal in sight) Mike came up with all the statutory paperwork required including a curriculum written from absolute scratch that suits their learners perfectly. "There's no point trying to use an off the shelf curriculum that has failed them time and time again, if it didn't work for them in other schools, it's not going to work for them here."

And it is working. Students are enjoying learning like never before and there's even talk about introducing a GCSE offer in the future for those who are able to access it. So what on earth are The Orchard staff doing to make this a reality? "Every member of staff here is passionate. Passion in this environment is far far more important than qualifications. The kids and their parents know 100% that we will not give up on them, that they are valued, listened to and their personal circumstances are always taken into account. Parents can literally contact Pete 24/7 on his mobile (it is actually now Pete's full time job, 'parent liaison & safeguarding') which is absolutely key to ensuring you get the best from your students - build up a solid trusting relationship with them and it's half the battle won." However it's not always easy and it can be heartbreaking when a student who's grown so much has a setback at home which leaves them back at square one. "That's the hardest part for me, seeing all that work undone. But we're always here to pick up the pieces and start

So what next? A string of Orchards rolled out nationwide? "To be honest it did cross my mind but we decided quickly not to do that, it would dilute our focus too much." As one Ofsted inspector put it: 'If you take Mike and Pete out of The Orchard, it isn't The Orchard anymore.' I leave the interview as Mike takes another quick call this time from a parent whose child is staying for Christmas lunch and he arranges for him to be dropped home afterwards. Is it normal practice to be a taxi service as well as a school? "We do whatever it takes to enable the kids to be here. I say yes to everything which gets me in trouble sometimes but I can't help it, I just want to help everyone!" And I totally believe it.

www.orchardhumber.co.uk www.supportinglocalchampions.co.uk

By Sarah Harrison





LOCAL

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 FIRST ½ of 2019

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 January 2019 Friday 22nd February 2019* Friday 29th March 2019 Friday 26th April 2019 Friday 31st May 2019* Friday 28th June 2019



*Children welcome on these dates in school holidays. Activities provided, plus enclosed outdoor play area (weather permitting). Baby changing facilities and wheelchair access toilets available.

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

"Our new apprentice support worker Ryan Smith has a real passion to help other people with disabilities which will enable him to succeed within his new career. With guidance from Employability Services -Supported Employment, Ryan overcame hurdles associated with his Asperger's Syndrome to land his dream job and we couldn't be more proud."

> Norma Yarborough, Supported **Employment Team Leader**





A friendly, relaxed group providing guidance friendship and practical solutions

FOR DETAILS

Last Monday of the month. Alternate times. STARTS MONDAY24th SEPTEMBER. 11am

At the Carers' Support Service 1 Town Hall Square, Grimsby, DN31 1HY 01472 242277

GRIMSBY TOWN CENTRE. ON ALL LOCAL BUS ROUTES

For parents who have children with additional needs

"In September the Lincolnshire Cerebral Palsy Society re-launched in style with help from the fantastic Rumble Band and Bridge McFarland Solicitors. The event was able to raise over £3,500 for local girl Leonie's SDR Surgery."

Rosalia O'Reilly, Bridge McFarland **Solicitors**