

Making a Difference...



contact *For families
with disabled children*

Our Voice sponsored by the Department of Education via Contact

Welcome... to our Spring Newsletter

Over the past six months we've continued working hard with the Local Authority and Health Services to make sure that the views of parents/carers and families with children and young people with additional needs and disabilities are fully represented.

In addition, our third annual 'Meet the SEND Heads' conference took place in February and was a big success. Parents and carers got an exceptional opportunity to hear directly from the Heads of Services responsible for SEND and from the new Council Leader, Nesil Caliskan, about her plans for SEND funding. These are vital conversations as funding becomes ever tighter. We



Some of the Our Voice Management Committee (from left to right) Fazilla Amide, Rupali Bhullar, Niki Michael, Seema Islam, Jackie Pummell, Liz Willis, Khilna Gudhka and Natalie Sherman.

all need to work together to make the most of limited resources and hope that the LA will not cut SEND funding

further. Continue to get in touch and talk to us, so we can make sure your views are heard.

COMMUNITY STAR AWARD

Fond farewell

This issue's award goes to Janet Leach, Enfield's Head of Joint Service for Disabled Children, who is retiring in June, after 42 years at Enfield Local Authority.

Janet has consistently been a champion of children with Special Needs and Disabilities within Enfield and in 2016 Our Voice were delighted

that the importance of her work was recognised and she was awarded an MBE.

Fazilla Amide, Chair of Our Voice says, 'It's down to Janet's passion, commitment and energy to parents/carers and their families that has kept us going. We as a Forum would not be as involved with professionals, locally influencing and persuading services, if it were not for her dedication to the cause. Whilst it doesn't always feel like it to parents/carers at the sharp end of cuts or challenges with services, Janet has made a big difference to the lives of many of our families across Enfield.'

We hope her legacy will be a lasting one and wish her well for her retirement.



OUR VOICE UPDATE

Our Voice held its third Parents' Conference, organised fun days and is working with the Local Authority to ensure services in Enfield meet the needs of disabled children and their families. For example, working on the post 16 agenda, we've been working to support the LA to get more of our young people into employment. See page 4-5.

Parents' conference

Our 'Meet the SEND Heads' conference held on 5-6th February 2019 was attended by over 80 parents, LA professionals and educational representatives including School Heads, SEN Governors and SENCOs.

The first day started with a welcome from Our Voice Chair, Fazilla Amide, and Anne Stoker, Director of Children and Family Services and Principal Social Worker.

This was followed by updates on new developments from the Heads of all the Departments responsible for SEND Services including the Joint Service for Disabled Children, Integrated Learning Disabilities Service, Education, Health, Educational Psychology and Emotional Well-being Service, Child and Adolescent Mental Health Service and Transport. There was a lively Q&A panel session with the Heads of Services and parents/

carers had 1:1 appointments with professionals from different services to discuss individual concerns.

Workshops covering the 'Local Offer', Positive Behaviour Support, Speech and Language and Moving on were well received

On the Second day, we welcomed the Leader of Enfield Council, Councillor Nesil Caliskan, who outlined her plans for SEND funding and heard from parents about their experiences and concerns, particularly around the length of time it takes to get services, an Education, Health and Care Plan or getting out of borough provision.

Feedback from the two days included 'It is always great to have the opportunity to meet heads of departments and the transparency is good. It gives me a better understanding of what's going to change to make a long term plan.'



'I feel I've come away with the information I wanted and getting the help I have searched for, for months. Thank you.'

'Excellent event - so useful to hear first-hand about the wider funding issues for the LA. It can only help future co-production.'

Our Voice are very grateful to the Angle House Foundation who provided us with funding to facilitate the two-day conference.



Seasonal fun

More than 80 children, parents and carers joined in the festive fun at our Christmas party. Arts and crafts, an interactive animal show, bouncy castle, games and a surprise visit from Santa, who handed out party bags to children, made it an enjoyable family afternoon. Thanks to Free Cakes for Kids, All About Anna's Animals, Movers and Shakers, Katie's Kastles and the Our Voice team for organising and running the event.



Family fun

Our monthly fun days have continued to be enjoyed by new families as well as our regular ones. Members tell us how much they value our fun days as providing a great opportunity for the whole family to spend time together in a fun and inclusive safe space and to meet with other families and the Our Voice team.

Families particularly enjoy our larger events that have a wide variety of

activities on offer. So, for the remainder of 2019, we'll be putting on a smaller number of events but providing fantastic entertainment plus food and drink.

Join our Spring Party, **Sunday 24th March 2019**, from 2-4pm and our Summer Party, **Sunday 23rd June 2019**, 2.30-4.30pm, both at Russet House School, Autumn Close, Enfield EN1 4JA.



Working together: Dyslexia project

As a parents' forum, our primary purpose is to work with the Local Authority to support the interests of our families.

We are immensely proud of the success of our recent Dyslexia project, which involved working tirelessly with a wide team from different disciplines from Schools to Educational Psychologists, providing expertise, as it finally gives clarity

and consistency on all Specific Learning Difficulties (SpLD) including Dyslexia.

Prompted by major concerns from parents and carers at our first annual conference, who felt the service was poorly or inconsistently supported, Our Voice set up a working party to look at what guidance could be provided, and this soon extended to cover all Specific Learning Difficulties.

The result is that 'Specific Learning Difficulties Information and Guidance for Schools and Parents' has recently been produced and is available on the Enfield Local Offer at new.enfield.gov.uk/services/children-and-education/local-offer

Guidance in brief

- ▶ Focus on identification rather than formal diagnosis.
- ▶ Importance of ensuring children / young people are properly supported irrespective of formal diagnosis.
- ▶ Specialist support and advice e.g. EPS routes are explained, but cost constraints will affect availability.
- ▶ Explanation of the access arrangements for exams.
- ▶ A new pathway has been put in place on a trial basis for the diagnosis of DCD (which must involve a paediatrician) via the Occupational Therapy team.

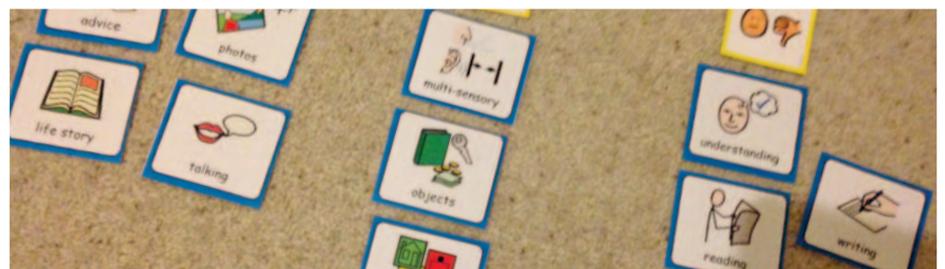
It covers SpLD including Dyslexia, Dyscalculia, Developmental Coordination Disorder (DCD), Dyspraxia and Developmental Language Disorder (DL).



Speech and language session

Feedback from last year's OV Parents' Conference and a follow-up survey demonstrated that our parents want to learn more about Enfield's Speech and Language Services.

So, we teamed up with the School Age Speech and Language team to host an informative session. As well as



discussing individual concerns, parents explored the use of talking mats, which are used as part of a tool kit to

help children with communication difficulties express their wishes, views and aspirations.

NEWS FROM THE JOINT SERVICE FOR DISABLED CHILDREN



Janet Leach, Head of the Joint Service for Disabled Children (JSDC) updates us on what's been happening in the borough.

We continue to work with parent forums Our Voice and ENAS to improve and develop services for children and young people with SEND. They provide invaluable insight and expertise into the lives of children with disabilities and their families and we're proud of the work we are progressing together.

Supported internships

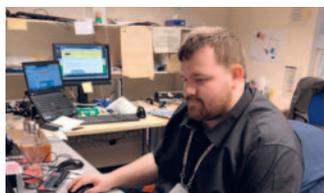
The Supported Internship programme, run by West Lea School for Enfield Council, supports young disabled people aged 19–25 to get into employment by spending time with an employer and learning workplace skills.

At the end of the programme's first year, nine young people aged 19+ were successful in getting paid employment and there are currently 25 young people aged 19–25 on this year's scheme.

For its part, The Council has seven internship opportunities within Housing, Libraries, Joint Service for Disabled Children, Education Psychology Service and Housing and Regeneration Teams.

About our interns

Interning in Council Housing, Philemon restocks printers and copiers and scans housing documents. He does this with a smile and has very neat handwriting and excellent attention to detail. *'I feel very happy when I take the lift and I'm on time. I'm pleased to work with nice people, it's helping me with my life and to get a job,'* says Philemon.



Harry has impressive IT skills and is working as a Project Assistant with the Housing Development and Renewal Team. He says, *'I'm enjoying working with the team and feel I am mixing quite well. I hope I can continue to work here after my internship.'*

Lucy works with The Joint Service for Disabled Children, assisting with making resources such as Makaton cards to help us communicate with children and young people. *'Doing this internship helps to raise awareness with employers so that people with disabilities can show their true capabilities throughout life,'* she says.



George works independently with the Communal Services team covering the Turkey Street Ward. He's completed a comprehensive induction and continues to gain valuable work experience and industry knowledge.

For information about supported internships go to the Local Offer new.enfield.gov.uk/services/children-and-education/local-offer, contact Kika Charalambous on 020 8887 1160 or at kcharalambous@westleaschool.co.uk.

As Team Assistant, Ebony is supporting both CAMHS and the EPS in the busy day to day running of the office; a vital role, hugely valued by everyone.



Stay healthy

Health Drop-ins for young people aged 18+ with a learning disability and who struggle with visiting the GP are run twice a month without needing an appointment. The sessions at Community House, Edmonton N9 0PZ on the second Tuesday of every month and at Radiomathon in Turkey Street, EN1 4NW on the last Friday of each month, run from 9.30–12noon. They offer advice and information about health, diet, fitness, do weight and blood pressure checks and a Community Nurse can help with general health queries.

Anyone with a learning disability, from the age of 14, should be invited to an annual health check by their GP.



Sleep well

Currently being piloted for parents of children and young people in Enfield's special schools and at Cheviots, the Sleep Service offers information, guidance and support to improve and manage sleep for children with SEND.

Feedback from workshops is being analysed and discussed by the Sleep Project Board, to decide the best way to offer the Sleep Service once the pilot ends this summer.



How it helped me

My name is Rupali Bhullar, I'm a member of Our Voice and have a daughter, Gia, with special needs who goes to Waverley School.

I was struggling with Gia's interrupted sleep pattern and it was disturbing the whole family, so I turned to Enfield Council's Sleep support programme for

help. Sleep difficulties are common in children with SEN.

I highly recommend the programme. It helped me make lifestyle changes that helped my whole family to get a better night's sleep.

Different tips and strategies will be more effective for different families but I kept a diary to analyse poor sleep patterns, then worked on breaking them. I used bright lights in the morning to help wake her up and no lights at night to make her feel sleepy. Making these changes helped to improve her sleep. We still have bad days where she won't sleep, but at least we get some good nights where she sleeps through. It has helped the whole family especially her older sister who was getting disturbed throughout the night.



More inclusive

North Middlesex University Hospital NHS Trust and Healthwatch Enfield piloted an initiative to improve the experience of disabled patients who visit the hospital.

Open2All is an innovative project seeking to improve access for disabled patients and the way staff respond to their needs.

Healthwatch Enfield, with the support of Enfield Disability Action (EDA) and Enfield Vision, is placing disabled people from local communities alongside reception staff at North Mid to provide mentoring, coaching and support on access considerations for those who are blind and visually impaired, deaf, have physical disability, Learning Disabilities or autism. 'Feedback from staff was positive



with many having 'light bulb' moments when being presented with situations from a totally new perspective,' says Fazilla Amide, Community Engagement Manager at Healthwatch Enfield.



Alternative therapy

Sarah Jepson Jones updates us on how her daughter, Gabriella, who asphyxiated at birth and has brain damage and cerebral palsy, benefitted from Hyperbaric Oxygen Treatment (HBOT).



What is it?

It's a non-invasive treatment where you go into a pressure chamber to breathe in highly enriched oxygen which supports healing. It's not officially recognised in the UK for supporting brain damage and neurological conditions, but in the US it's beginning to be used to support recovery from a stroke. It's used widely in the UK for conditions, including multiple sclerosis, carbon monoxide poisoning, radiation injury and skin graft healing.

Our experience

Gabriella and I sat in the chamber and she was given a mask, which looks very like a plastic spaceman's helmet, to go over her head and this was connected to the oxygen supply. It took around 90 mins and as a parent you don't notice anything, apart from maybe your ears popping, as you don't receive extra

oxygen. I took things to keep Gabriella entertained as you can't leave the chamber until the session is complete. However, the team is wonderful and keeps an eye on you and can bring the pressure back down in an emergency.

Did it help?

The science behind it is that increased oxygen levels speed up the body's natural healing process.

Whilst brain cells that have died cannot be regrown, within brain trauma there is typically also inflammation and swelling around the damage. The improved healing process and increased oxygen may help reduce this surrounding damage and bring about improved function in these cells.

We felt it helped Gabriella to gain more from some of her physical therapy and it definitely boosted her immune system as chest infections were far less frequent.

Our HBOT sessions were at Multiple Sclerosis Action in Walthamstow and you pay a small fee which helps towards the running of the service. Primarily it's for MS sufferers, but children with neurological conditions can use the chamber. To start with an initial course of 20 sessions in close succession is recommended followed by regular top ups. For more information about the centre go to msntc.org.uk.



Big difference

My AFK (formerly Action for Kids) is a charity supporting children and young people with disabilities and learning difficulties in Haringey and the local area. Its work includes providing specialist mobility equipment and preparing students for life after school.

My AFK (my-afk.org) helped four year old Georgiana, who has a rare genetic condition that affects her motor skills and muscle tone, making it harder for her to maintain positions and coordinate

her body. Her family applied to my AFK for a specialist trike, so she could go on bike rides with her family and friends.

'The fun and health benefits have been life changing,' says Georgiana's mum. 'Being able to attach the trike onto the back of my bike has been and continues to be fabulous. Today Georgiana biked to our local park with her three friends that called for her (with my supervision) and for the first time I felt she was fully included despite her disabilities.'

Wheely good

For Our Voice member Seema Islam, finding activities which her autistic son with learning disabilities could take part in and the whole family could enjoy was challenging. But a visit by Cycle Enfield to her son's school changed this.

'I purchased a second-hand trailer bike for Samir and booked on to a Family Cycle Skills session, run by Cycle Enfield. The sessions are free to local residents of all abilities and the instructor tailored the session to difficulties we, as a family, might experience on public roads. So although he didn't teach my autistic son, he taught me how to ride safely and confidently with a large trailer attached to my bike. He also taught my other two children cycle skills, so we can go out as a family enjoying an activity that's fun for everyone.'

Eva, nine years old at the time, says, 'I felt nervous before the lessons but the instructor was easy to understand and patient with me.' My son Arman who was 16 years old at the time, says 'The instructor helped me to understand what drivers may do on the roads and how to keep myself safe from accidents and visible to drivers.'

For information on sessions go to cycleenfield.co.uk.



Appetite for change

Sunday evenings for Jamie Ashton at Zebras Charity means visiting Tesco at Southbury Road, Enfield to collect surplus in date food for its FareShare project.

One box of food goes to a family who Zebras Charity has supported for over a year. The food we've been delivering to her and her disabled son each

week has been a lifeline. Not only is it helping her and her son, some weeks there has been enough food for her to pass on to her Granddaughter, who also has a son with a pre-diagnosis of Autism. Her Granddaughter was affected by the delay to Universal Credit being awarded and the additional food support helped her during this hard time.

The food collections aim to alleviate the effects of poverty and reduce the amount of food waste from large supermarkets. If you know anyone who may benefit from our support with food donations, refer them to us at zebrascacharity@outlook.com or go to zebrasccharity.org.uk for information.



WHAT'S ON?

Get out and about this Spring and visit these shows and events

All aboard

London Transport Museum have produced a visual story to prepare children with SEN on what to expect when they visit. View it online <https://bit.ly/2Ee8kGo> or email learningmailbox@ltmuseum.co.uk for a printed copy.

The museum has 90 minute Explorer mornings and evenings where families can enjoy the Museum at a quieter time, free from the general public and with many

of the gallery sounds turned off. Explore the trains and buses, have fun in the All Aboard Playzone and get hands on at the object handling table to find out about ticket machines and smaller parts of the collection. Sensory Explorer Bags specially developed for children and young people with additional needs are available.

The next sessions are 13 April 2019, 8.30 until 10.00; 1 June 2019, 18.15 until 19.45 and 27 July 2019, 8.30 until 10.00. Under 18's and carers go



free, and adults are charged standard museum rate. Places are limited, call **020 7379 6344** to book in advance.



Easter fun

Have fun at the farm and take part in an Easter Egg Hunt at Lee Valley Park Farm, 6-22 April 2019. Meet the new spring arrivals in the farmyard, take part in fun

activities with the Easter Bunny, take a tractor ride to the dairy farm or have fun in the indoor and outdoor play areas. Tickets £10, carers and under two's free, call **01992 892781** or visit lvfarms.co.uk.

Animal tales

Chickenshed's Tales from the Shed team present a brand new show about extraordinary big cats, appreciating your differences and learning to love

the skin you're in. *The Tigon and the Liger* has three performances a day from 13-18 April 2019 and is for age 3-7 years. Tickets £7, call **020 8292 9222** or visit chickenshed.org.uk for information.



Easter panto

Rapunzel at the Dugdale Theatre, 3-22 April 2019 is packed with songs, dance, comedy and of course audience participation. It's a magical retelling of the classic fairy tale of a young girl with

flowing tresses locked away in the tower by the evil witch. Will the Prince rescue his heroine? Will Mary Cherry, the castle cook, bake the cake in time? Tickets £14.50, concessions, £13 and a family ticket £50. Call **020 8807 6680** or visit dugdalecentre.co.uk.

Easter adventure

Join the hunt for dragon eggs on a legendary quest this Easter Holiday at Kenwood House, Hampstead. Crack the clues as you and your family follow the trail through the grounds. Adventurers who track down the dragon egg will get a certificate and a sticker to prove it, and a chocolate treat. From 19-22 April 2019, it costs just £1 per child and there's no need to book. For more information english-heritage.org.uk.



Contact

The Contact free phone helpline offers help and support to the families of disabled children. The confidential service can be contacted on **0808 808 3555** or at helpline@contact.org.uk. The service is staffed by experienced advisers and is intended as a one-stop-shop for parents and family members. For more information visit contact.org.uk

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