

Our Voice



Our Voice Newsletter

Issue 14
Spring 2013

Trust for London
Action, safety and equality



Welcome to the Spring edition of the Our Voice newsletter. As parents of children with special needs or disabilities, we are all aware how important it is to be informed. We have to know what services are available and we have to know how we can help one another.

This edition of the newsletter gives useful information about children's groups and services run through the council – such as the sleep service or the disabled facilities at leisure centres. We've also included some of the activities Our Voice is focusing on to help improve these services. For most parents in our position, these services are a life-saver. Without them, we would struggle to give our children (or ourselves) any quality of life.

In this issue of the newsletter we feature the story of a mother who sent her child, who has Down's Syndrome, to camp with the Beavers. If anyone has had similar positive experiences with other groups, don't keep it to yourself! Let us know!

.As a parent-led organisation, Our Voice is a forum where we can organise self-help-sessions, coffee mornings & network meetings, so we can share experiences, knowing that we are not alone in feeling the way we do. We can also offer one another support and guidance.

So we want to get more involved with our local schools and communities. Representatives of Our Voice are happy to talk at school social mornings or to have public discussions with parents and SENCOs. We would love to come into schools and encourage greater disability-awareness. We can organise events for groups of pupils. We feel that it is vital to participate as much as possible in schools and local activities. Only then, can we get the best for our children.

So if you would like to get more involved, or would like us to come to your child's school, or you are a Special Educational Needs co-ordinator and want to know how we can help, do get in touch.

Carol Mustafa

Our Voice Development Coordinator



What's new

Improving the Enfield Council Website...

Many parents have complained about the Enfield council website. When we put your views to the council, we were asked to provide more evidence. Hence we emailed a number of you who have provided us with your email address, to give us your views. As a test of the site, we also asked people to see if they could find a particular pamphlet about school transport, which the council had made available on-line.

Around 10 per cent of the people we contacted got back to us. Most of them pointed out that the website had many problems: it's difficult and time-consuming to find information and the site isn't laid out in a logical way. And many users pointed out that they would never have known that the pamphlet was available if we hadn't told them about it.

On the plus side the 'search facility' seems to work fairly well and much of the information is available in different languages.

Our findings were presented to Enfield's Communication team. To be fair to them, they were

continued over

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Please pass this newsletter on to others - parents and service providers - who might find it useful. You can contact us for additional copies by email or phone.

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aware of many of the points and had started to address some of them. The council has held meetings with the Special Educational Needs (SEN) and the Joint Services teams to improve the situation. So watch this space for updates on how the website is being improved and, if you have any further comments to make, please email Carol Mustafa and we'll include your views in future feedback to the council.

Disability awareness training for children

When the Our Voice parent forum was asked to provide disability awareness training for children aged between 6 and 13 we were delighted. We were approached by a Mum who wanted the children at her son's club to have a greater awareness of disabilities and the Edmonton Scouts team were extremely supportive in ensuring this happened.

The workshop lasted for 1 hour 15 minutes. There was a quick 'ice-breaker' designed to get everyone in the mood, and then it was down to work! As well as group work identifying different disabilities there were communication games, and plenty of facts and figures. The final game was called 'the communication jumble,' and gave the children the chance to consider how people with autism and learning disabilities constantly struggle to communicate.

During the final part of the session children were given a 'My pledge to disabled children and people' template to complete and sign. This involved completing one statement that started 'I promise that I will...' And then doing the same to a second statement starting 'I promise that I will never....' The final statement to complete was 'today I have learnt that...' The objective of the pledges was to consolidate learning from the session, and to take home with them.

The evening flew by, and very quickly it was time for the children to go home with pledges in hand. We certainly felt that the session had been enjoyable, and team leader Donna Willard described it as '*a fantastic workshop. It has had an amazing impact on all of our Beavers.*'

Any schools and clubs that would like to consider running this training for their children should direct enquiries to K.linke@sky.com

Kate Linke

Kian Goes Camping

Last year Resim Clear took the brave step of letting her eight year old son Kian, who has Down's Syndrome, attend a camp with the Beavers. As she explains, it was a great experience, not just for Kian, but for the whole family.

'Kian, camping, without us', these were words we never thought we would use in the same sentence. Kian had never spent the night away from us, so it was only natural that we were very nervous about letting him go camping with his Beavers group. Deep down we knew he would probably be fine and that he'd have a good time but what about us, how would we cope!



Kian has Down Syndrome and Autism, he can say a small handful of words but mainly communicates using Makaton and gestures. Kian goes to West Lea School and we wanted him to start an evening activity to develop his social skills. It took a long time to find somewhere that would actually take him but finally, towards the end of 2011, we found a place that was happy to have him. Kian joined the 10th Edmonton Beaver Scout Colony. As most parents will know, the Beavers is the junior part of the scout movement – intended for boys and girls between six and eight. We were very excited but anxious at the same time.

Kian took some time to settle in, his Beaver leaders were patient and let Kian do things at his own pace. Activities were adapted to suit his needs and he was included in everything.

Then to my horror, we got a letter about camping!! Who would have thought that such a small word would stir up so much emotion and make a fully grown person cry so much!



Kian at play at the Beavers camp

Despite reassurance from the Beaver leaders, I was still undecided about sending him. So we decided to ask Kian what he thought. My husband asked if he wanted to go camping and play with his Beaver friends. Kian answered 'Yes' – well of course he would've said yes, he had heard the word 'play' in the sentence! When we made the decision to let him go, I actually started to feel faint.

The Beaver leaders planned every detail of the trip before going. His Beaver leader was going to provide one-to-one support on the Saturday and Cheviots Children Centre would provide a further eight hours on the Sunday. They looked after all of his feeding, toileting and dressing needs and even had a stair gate for his room at night. We

would be kept updated throughout the weekend and could call to check on Kian whenever we wanted.

On the day of the trip Kian got very excited when we arrived at the Beaver hut and he saw all his friends. For the first time ever, it was his sister and brother waving him off on an adventure and he was deliriously happy as the bus drove off and we waved him goodbye. I, however, felt my world was about to end.

Two hours later, his Beaver leader sent us a text to say they had arrived safely and attached a picture of Kian, smiling with his friends: he was happy and he was having fun.

Kian worked alongside his Beaver friends and helped build the camp area which he proudly showed us at the end of camp. With the encouragement of the leaders and his friends, he happily participated in most of the activities. In the evening, he loved sitting around the campfire with his torch.

It was a wonderful experience and Kian loved every moment of his adventure. Camping has helped Kian develop friendships within his Beavers group and his new-found confidence and independence is wonderful to watch.

Yes, we had been anxious about sending him but our worries were needless because not only was Kian cared for, but we too were looked after very well.

Kian talks about camping all the time and would love to go again. We will, of course, be just as nervous about sending him again, but the experience and the joy he felt are worth the tears. And we will always be incredibly grateful to the leaders at the 10th Edmonton Beaver Scout Colony who made it possible for Kian to have such a wonderful time.



Enfield District Scouts

What's happening in the borough



Janet Leach is Head of the Joint Service for Disabled Children, which helps co-ordinate social care, education, health services and voluntary agencies in Enfield. She gives an update on new developments.

Short Breaks!

The Joint Service for Disabled Children will soon be launching 'Breakaway', a magazine that explains what short breaks are available for Enfield's disabled children and young people, and how they can access these. The magazine will be produced twice a year, and will work alongside the Joint Service's new website (coming soon!) to give families the information they need. Email caroline.fanning@enfield.gov.uk to ensure you receive your copy.

Better Breaks

Don't forget that there is an organisation called the 'Short Breaks Network' which has lots of useful information on its website (www.shortbreaksnetwork.org.uk) and produces an online newsletter called 'Better Breaks'. The organisation has close links to Enfield. I chair the organisation and Fazilla Amide - the Co-Chair of Our Voice – is a trustee.

Cheviots – Outstanding Ofsted inspection

Cheviots Children's Centre is the 'hub' of our Joint Service for Disabled Children. Children's Centres

provide a range of support and activities for pre-school children and their families. At the end of last year the Centre had its first Ofsted inspection resulting in an 'Outstanding' overall judgement for its work with under 5s and their families.

The Ofsted report states: 'Exceptionally experienced staff have excellent levels of knowledge and skills and can call on an extensive range of specialists to provide highly effective support for children's multiple and complex needs.'

A parent quoted in the report says: 'I can't fault this centre; staff are fantastic and know my child extremely well.'

Inspectors note that the centre ... 'has done much to champion the cause of disabled children in the community through outreach work in schools and other children's centres as well as some activities being open to all children.'



Clare Redrupp, centre worker manager at Cheviots, with the Ofsted report

Cheviots Refurbishment – better facilities

In November 2012, Cheviots Children's Centre re-opened its doors after a much-needed refurbishment. We now have additional specialist changing and toilet areas with wider doors for wheelchair users, ceiling track hoists, extended play rooms, improved access throughout the building and outdoor play rooms. The centre has been extensively redecorated. Children, parents and staff are all delighted with the improvements.

Need a good nights sleep?

We are currently working to establish an effective 'Sleep Service' in Enfield for disabled young people

from 0 to 17 years. This is in response to requests from parents, whose children can't or won't sleep. Through our Children's Centres we have been running workshops, one-to-one clinics and training sessions for parents. I'm delighted to tell you that our trained sleep practitioners will be running a further pilot project and we will work with families and professionals to develop different ways to overcome difficulties. We look at how this programme might continue in the long term. Fazilla Amide –co-chair of Our Voice - is our parent Sleep Practitioner.

For further information about the Sleep Service, contact Cheviots on 0208 363 4047.

Wheels for All Service!

On Wednesday 27 March we are launching our Wheels for All service at Waverley school, in the Enfield Highway area. We have purchased a range of specialist bikes for families to use at weekends and we would like to improve the path in Durants Park – opposite Waverley - to make it more accessible. We'll be issuing further details on how to use the service nearer the date.

Progress on our Capital Investment Programme.

We are still working with parents, young people and colleagues to ensure we spend our allocation of capital funding – which comes from the Government – on improving local leisure facilities, so all families can enjoy and benefit from what is available in Enfield.

Currently we are investing in several Leisure Centres – ensuring that there are suitable changing facilities. Three leisure centres - Albany, Southgate & Edmonton - are having an H Frame Hoist (please remember to take your shower slings with you!) and a height adjustable changing bed added to their existing accessible toilet and shower rooms. Albany is now complete, Southgate is in progress and Edmonton will follow later this year.

Fusion, which manages the leisure centres on behalf of Enfield, say children are welcome to use these toilet and changing facilities even if they are not using the leisure centre.

Centre for Excellence and Outcomes

The high quality of our work has been recognised

by the Centre for Excellence and Outcomes. Anyone wanting to learn more should go to www.c4eo.org.uk - click on the disability tab and scroll down the page to Promising Practice – 'Development of Inclusive Youth Provision Enfield'.

Moving On

By the time you read this newsletter we will have held our annual Moving On event – 25 January 2013. This is for parent/ carers and professionals to find out what is available for disabled young people in Enfield when they reach adulthood. The event incorporates a series of presentations, workshops and interactive sessions. Watch out for feedback in the next edition of Our Voice.

Champion Childminders



Here is a photograph of our Champion Childminders – receiving their 'Champion' certificates. The childminders attended additional training so they can support and mentor all our Enfield childminders - helping to develop their confidence in caring for all children and young people with disabilities.

For more information about childcare in Enfield contact Enfield's Family Information Service on 0800 694 1066 – this free telephone line is open Monday to Friday from 8.45am to 12pm and from 1pm to 4.15pm. Alternatively visit the website www.enfield.gov.uk/if

How the new funding changes affect your child

Dr Ahmad Ramjhun, Enfield's Head of Special Needs and Inclusion, explains what the new measures mean for you.

In April 2013, the Government will change the way that local authorities fund young people with exceptional needs. Obviously many parents are worried, but most parents will see relatively little difference.

The Government is introducing the changes for a number of reasons. It feels that the current system is not clear enough. It would like agencies, particularly health and education, to work more closely together to provide for children's needs. It would also like families to be given a 'personal budget' so they can decide how the money is spent on their children, and would like more private companies involved in the provision of care for people with special educational needs. It wants councils to take responsibility for children, not just up to the age of 19 (as is currently the case), but up to the age of 25, so that there is more help for disabled people entering the workplace. The Government believes that the new funding scheme will help this process.

The current system in which children with serious learning issues are given a 'statement' of special education needs (SEN) will be scrapped. Instead the statement will be replaced by an 'education, health and care plan' for children with 'High Need'. However in practice this won't make much difference. Parents will still be able to go to a tribunal if they feel that they are being treated unfairly or if the council is failing to give them the educational help to which they are entitled.

The Government is changing the way that the money is distributed. Although this is complicated for the organisations involved, parents shouldn't be affected.

Currently all schools are given a basic amount of money to spend on its pupils each year. This is currently approximately £4,000 per pupil. The Local Authority (in this case Enfield) will also give schools an additional £6,000 for each pupil with High Need. So if a school has 1,000 pupils, it will get basic funding of £4 million. If, for example, 20 of

these pupils have 'High Need', the local authority will have to give another £120,000. In some cases, the pupils may have very serious problems, which will be extremely costly for the school. In these circumstances, an additional 'top up' will be provided by the local authority to cover this.

The council has very elaborate guidance on what happens if fewer than expected children turn up to a particular school or if children leave half way through the year. Parents do not need to worry about this. The fact is, if children need help it should be provided and paid for by their school and the council.

Enfield has a number of language units and inclusive resource bases - for example it has bases for autism and behavioural problems, which are attached to mainstream schools. These are known as Additionally Resourced Provision or ARP. The local authority will now buy a number of places at these centres at a cost of £10,000 per place per year. In some cases, children attending these will need additional support (top up payments). This money will again be provided by the council. This all sounds very complicated, but the changes shouldn't make any difference to parents or children.

Similarly, Enfield will buy a number of places at special schools in advance, at a cost of £10,000 per year per place. Again, any top up payments will be made by Enfield.

The funding arrangements for academies and colleges will also be similar – they have the same responsibilities as other schools when it comes to children and young people with high needs. There will be similar funding arrangements in early years settings – ie nursery schools. The one major difference is that there will be new statutory protection for people aged 16-25 in Further Education and there will be a stronger focus on preparing for adulthood.

These changes shouldn't make any difference to local people. Enfield Council has worked hard to ensure that none of the schools in the borough lose out and that budgets are protected as far as possible. And most children shouldn't be affected. The local authority and its schools will remain responsible for meeting the needs of children who are currently statemented. However it will be clearer how the schools are funded and where any top-up money is coming from.

Enfield Parent Partnership Service

The Enfield Partnership (EPS) offers help to parents of children with disabilities or special needs. It offers free, impartial and confidential advice, support and information about your rights and responsibilities for the education of your child. It also offers advice on what help children are entitled to. It is a statutory service; every local authority in England has a Parent Partnership Service.

The EPS offers telephone advice and face-to-face meetings. It can help parents prepare for meetings, so they can get the most out of them. It will support parents at school meetings or at annual statement reviews, and will help parents write letters and can offer advice on such subjects as the school system and exclusions from school. It can also put parents in touch with other local and national organisations.

To contact Enfield Parent Partnership Service phone 020 8373 2700 or email mary.mannion@enfieldparents.org.uk. The website, which is currently being updated, is www.enfieldparents.org.uk. The service is based at Enfield Parents & Children [EPC], The Ark, Marsh House, 500 Montagu Road, Edmonton, N9 0UR.

SENCO Partnership conference

Last October, around 70 SENCOs (schools Special Educational Needs Co-ordinators) attended a presentation held by Our Voice and Enfield Parents and Children at Enfield's annual SENCO conference. Kate Linke and Linda Pryor spoke and led discussions on multi-agency working.

Kate Linke said: 'We viewed this as a fantastic opportunity to show professionals how parents and carers view the role of the SENCO.' Additional points covered included effective communication techniques and meeting planning.

One of the highlights was a tongue-in-cheek role play of how not to organise a meeting with a parent. As well as raising a few laughs, this provoked lively discussion around best practice for working with parents.

SENCOs who would like to know more about Our Voice, should contact k.linke@sky.com

Celebrate best practice within Enfield!

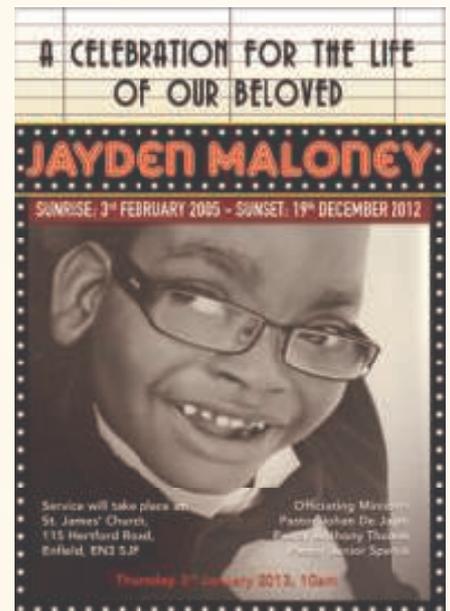
Our Voice would like to recognise businesses, shops, cafes, restaurants and services within Enfield that do 'that bit more' to make our children feel welcome! So, please let us know if you've been given top quality service.

Kate Linke is nominating Café Rouge in Southgate. 'Waiting staff always say hello to Noah and never object to any of his repetitive behaviours and noises. We think they're great,' she says. So if you think someone deserves to be singled out, contact Kate on k.linke@sky.com and let us know

Jayden Maloney

We'd like to take the opportunity to remember Jayden Maloney who passed away on 19 December. The seven-year-old boy, who had multiple disabilities and attended Waverley School, was well known to many of the parents involved in Our Voice. Large crowds

attended the funeral, which was an amazing and fitting celebration of his life. Speakers paid tribute to his infectious smile and his love of games. Leaving a huge impression in the hearts of everyone who knew him, he will be sadly missed.



contact a family
for families with disabled children

The **contact a family** freephone helpline is offering help to the families of disabled children. The confidential service can be contacted by phone **0808 808 3555** or on helpline@cafamily.org.uk. The service is staffed by experienced advisers and is intended as a one-stop-shop for parents and family members. The service has two advice lines - one for general enquiries and one for SEN enquiries. More information is available on www.cafamily.org.uk

Sleep Workshops

Due to popular demand, Our Voice will be running more sleep workshops. These are open to parents in Enfield. The workshops are intended for the large number of parents who simply can't get their children into a reasonable sleep pattern.

The workshops were a huge success. For example, one family had their child still sleeping in their bed every night. After a few weeks, their child was falling asleep in their own bed, with the parent giving re-assurance by sitting in a comfy chair by their bed (not in it.) They are then able to go and sleep in their own bed! (That said, the child still sometimes creeps out in the middle of the night and sneaks into the parent's bed! But hey, small steps of improvement should eventually see the child staying in their own bed all night long!)

Three dates are lined up. Participants will be expected to attend the first session. The following two follow-up sessions are for participants who feel the need for further discussion and support.

The workshops will be held at the Edmonton Children's Centre, 23 South Mall, Edmonton N9 OTS. The sessions will be held at the following times:

Tuesday 7th May – 10am – 2pm

Tuesday 4th June – 10am – 12 noon

Tuesday 2nd July – 10am – 12 noon

Spaces are limited & very popular, so book now by telephoning Megan Steven on 0208 363 4047 or email her on megan.steven@enfield.gov.uk.



As parents we all love the idea of photographs of our kids. But this is not always easy with disabled children. My son is now 12 years old, and has never posed for a photograph. So we've had to go for a more natural style.

I'm learning that taking photos of children with disabilities is enormously rewarding and here is one of my son, Noah. If you would like me to photograph your child, I'd be delighted. Call me on 07921360636 or email k.linke@sky.com

www.ourvoiceenfield.org.uk

