

Our Voice



Our Voice Newsletter

Issue 8, Winter/Spring 2010

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Welcome

Welcome to the winter/spring issue of the **Our Voice** newsletter, the parent-led organisation seeking to improve services for children with disabilities in Enfield.

Now that spring is almost here it's a great time to encourage your child to take up sport or another out-of-school leisure activity. Whatever their ability, sports and leisure can help children gain confidence and social skills as well as have fun and get fit. This issue looks at some of the opportunities for children with disabilities available in Enfield. If you've had a good (or bad) experience of your child taking part in sport or another activity locally do get in touch to let us know so that we can pass on information to others.

I'd like to say a huge thank you to Julia Paylor and Orla Keeley for their tremendous work in getting the **Our Voice parent forum** up and running. I took on the role of Our Voice Development Coordinator just before Christmas and am delighted to be taking things forward as we plan events and campaigns to take us into the spring and beyond. I do hope you can join us at our meetings - please see the back page for details.

Carol Mustafa

Our Voice Development Coordinator

If you are interested in joining Our Voice please contact me on 07503 161248 or email carol@ourvoiceenfield.org.uk. I look forward to hearing from you

Introducing our new Development Coordinator

Carol Mustafa gives an insight into her son Hassan's early life and what inspired her to become the new Our Voice Development Coordinator.

"My family consists of my husband Mus, my son Hassan who is 15 years old and my daughter Yasmin who is 8. Hassan has severe physical difficulties as well as profound learning and medical needs. He is a fulltime wheelchair user and has attended Waverley School since nursery age. He's also a very sociable young man who really enjoys school and being around people.

In the early stages of pregnancy I was told that Hassan had a very severe condition called an occipital encephalocoele as well as a cleft lip and

palate. It was devastating news as I was told he would be severely disabled and may not live beyond a few minutes or hours. I decided to continue with my pregnancy as I wanted to give my baby a chance. When he was born Hassan was very unwell and could not breathe for himself. Once stable he was transferred to Great Ormond Street Hospital. I did not know then that this would be where I would spend most of the rest of Hassan's childhood, where he would have to undergo many operations and where we would meet nurses and doctors that can only be described as amazing.

We were allowed to bring Hassan home for a weekend before he had major brain surgery. It was thought he would not survive and it was a weekend I will never forget. Unfortunately he suffered hydrocephalus as a result of the operation and the brain condition and needed a shunt to

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Carol Mustafa ■ Telephone: 07503 161248 ■ Email carol@ourvoiceenfield.org.uk

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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keep him alive. He also needed plastic surgery to repair his cleft lip and palate, and reconstruct his nose. From then on Hassan had surgery nearly every year of his early life for different conditions that developed. It has been very very stressful at times and even now the medical conditions are still present and ongoing.



But amazingly, Hassan has managed to keep smiling through all of this. And if he can still smile then so can I. Hassan has

a lot of interaction with close family members who have supported me and my husband through difficult times and he loves to socialise and take part in leisure activities with his uncle Antony.

Having Hassan has been a journey that has made me who I am today. I have met many wonderful people that I would otherwise never have met, and I have had experiences that have made me look at life in a totally different way and helped me realise that every day is very precious.

The care and support we received at Great Ormond Street inspired me to work as a volunteer on their parent's telephone support network. We support parents whose child is admitted to the neonatal or paediatric intensive care units. I do this work from home under the direction of the intensive care sisters.

My background is in education and health - I've worked for the district nursing team at St Michael's hospital in Enfield and also at Chase Farm Hospital in midwifery. For over ten years I worked in special and mainstream schools supporting children with physical disabilities, autism and learning difficulties. I have undertaken level three studies at Enfield College in Nursing and Health. Then at Middlesex University I studied nursing, early childhood studies and social sciences.

I have lived in Enfield for most of my life. For me, one of the best things about the Borough is that you can be in town very quickly yet also have easy access to nearby countryside. Some of my favourite

places are the fruit and vegetable farm on Hadley Road and Whitewebbs. Although there are lots of green spaces in Enfield, one thing that I would like to see improve is the equipment in parks and play areas for children in wheelchairs. I'd also love to see more sensory equipment for children with disabilities. And I would like to see better housing services for disabled children.

I have been part of the **Our Voice** forum for over a year and have found it to be an excellent source of information and support. If only it had been around when Hassan was younger! I decided to apply for the role of Development Coordinator as I wanted to do something different that involved working directly with people and children with disabilities. I also felt that my background, skills and life experiences would help to take the **Our Voice** parent forum forward.

There are exciting times ahead for **Our Voice**. We will continue to hold Our Voice Disability Network meetings for parents supported by the Joint Service at Cheviots, finding out what's working well and what's not. We will arrange for speakers and professionals from different services to attend our meetings and talk to parents to ensure people receive what they are entitled to. **Our Voice** will also run training courses for parents on assertiveness, building confidence and public speaking. We want to continue to expand and plan to hold an information day supported by the Joint Service, to show how parents can become involved in the **Our Voice** parent forum. I hope to meet many of you at our meetings and events - new faces are very welcome! Find out more on the back page of this newsletter. Our website at www.ourvoiceenfield.org.uk will be updated shortly, with new facilities added for parents and of course we will continue to keep you informed on a regular basis via this newsletter.

Apart from my voluntary work my life is very much focused on my family and ensuring that Hassan receives the best possible support. My hopes for my children's future are that Hassan will continue at Waverley School after the age of 16, and for him to be as happy as he can, taking each day as it comes. I hope Yasmin can pursue her talent in dance and performing arts, and to continue to extend her knowledge and life experiences and do things that make her smile. What better role model than her brother Hassan?"

What's new

Need additional support at home?

Leapfrog Nursery School has been supplying help at home for a small number of young children. We are now planning to take on some more families! Leapfrog's support workers have a real interest and commitment to working with disabled children and their families, and all are fully police checked. Whether enabling children to attend activities such as Brownies, Cubs, after-school clubs, providing babysitting or additional support at home, we are ready to take on the challenge!

We work with parents who receive Direct Payments

Here's what parents have said:



'Maria loves the time she spends with her carer. It gives her the independence to be away from us in a safe and fun environment. It also allowed Maria to go to see her very first film at the cinema! We are grateful that the stress of recruiting and CRB

checking carers has been taken away from us and put into the very capable and trustworthy hands of Leapfrog and hope to continue with this arrangement long term into the future.'

Niki Michael

'As a family we really need help. Direct payments is one of the only avenues open to us but is not always easy, particularly in trying to recruit someone and then manage the paperwork and accounts. Since using Leapfrog to source carers/helpers and their assistance with some of the financial administration we have been able to fully utilise direct payments. We have used a number of people so far to support our family needs, who have all been competent and professional. We are really happy to continue using direct payments in this way as it is much easier for us and been of great benefit to our family.' **Steve Kelly**

For more information please call Lesley Vincent on 020 8360 0088.

News from the Joint Service

Janet Leach, Head of the Joint Service for Disabled Children in Enfield gives an update on service developments.



I would first like to say how delighted I am to be working with Carol, the new Our Voice Development Coordinator. Carol brings a great deal of experience and knowledge to her role, most importantly as mum to Hassan and Yasmin. I must also take this opportunity to publicly thank Julia Paylor and Orla Keeley for their commitment and energy in working to develop the Our Voice Parent Forum. Their efforts have ensured that the Joint Service has a genuine partnership with parents so together we can work to improve the lives of disabled children and their families in Enfield.

Regarding the Joint Service I am pleased to tell you that we have printed our new information outlining the range of short breaks and services for disabled children and their families in Enfield. We have produced four leaflets, as agreed with parents through all our various parent groups - Our Voice, Parent2Parent and Capag. Each leaflet relates to a different age group, one for children aged 0 to 4 years, one for 5 to 11 years, one for 12 to 15 years and one relating to young people aged 16 to 17 years.

The leaflets explain who we are, how you can contact us, who is eligible for support, what assessment may be needed, what to do if you are not receiving any help, what to do if you feel you need more support and how you can meet other parents and professionals and be involved in helping to shape and improve services and short breaks.

We will distribute these leaflets through both mainstream and special schools. They will also be available in public buildings such as surgeries, clinics and libraries. If you do not receive one please contact Cheviots Children's Centre on the number given below and we will ensure you are sent a copy. They will also be available online and in other languages as needed.

Many of you will have heard about Aiming High, the Government's transformation programme

which aims to provide greater opportunities for disabled children and their families, ensuring they have the same life chances as any other family. Over the past three years we have been working in partnership with parents, children and young people to develop, increase and improve all of our services. Through the additional funding that has been made available to Local Authorities we have done the following:

- Increased holiday play and leisure activities. In July and August 2008 just over 300 sessions of holiday play schemes and leisure activities were offered. Last summer we were able to provide 339 sessions. These figures do not include the sessions offered and not taken up. Children and young people enjoyed themselves through a range of activities provided by Capag, Dazu, the Play Development Team and Cheviots.
- Increased after school provision. During the period October 2008 to December 2008 we offered 320 after school and weekend activities. During the same period in 2009 we offered 432 sessions. Again this does not include the sessions offered and not taken up.
- More families are now having direct payments - in 2007 we had 24 families receiving a direct payment; this rose to 33 families in 2008 and rose further to 54 families in 2009.
- More children and young people are enjoying a range of overnight short breaks including adventure holidays. In the period April 2009 to March 2010 26 young people enjoyed 44 weeks of 'actventure' holidays. During this period in 2007 to 2008 (prior to receiving any additional funding) 15 young people enjoyed 31 holidays.
- More under 5s are enjoying themselves at both specialist and inclusive parent/child groups in our Children's Centres. Currently 33 families attend, an increase on the 22 children who attended 3 years ago. 137 hours of supported group activities were provided between October and December 2009.
- We now run 8 Family Fun Days a year as well as Christmas parties whereas previously we ran 4 Fun Days a year. During this February's half term we have 24 families booked on to our Fun Day, and a total of 83 people - mums and dads, brothers and sisters and other close family members - enjoying a day out together.

In addition we have:

- Regular Our Voice/Disability Network meetings providing opportunities for parents to meet each other and meet professionals, so everyone can share advice and experience and learn together.
- Produced a range of information for parents and young people who are going through transition from Children's Services to Adult's Services, including the Parent/Carer Guide, the Young Person's Moving On Guide, an interactive Moving On game (which will soon be available in schools), and a Moving On Newsletter.
- Produced a Toolkit for Sports Clubs developed by our voluntary sector partners, Enfield Children and Young Persons Service and Tottenham Hotspur Football Foundation. This provides advice, guidance and information on how to ensure disabled children and young people can be confidently included in sport. There is some additional funding available to support local clubs, for example to purchase specific pieces of equipment.
- Following your advice raised the profile of young people in transition through a series of Moving On events and celebrations. These have been attended by senior managers and local Councillors highlighting the hopes and aspirations of our disabled young people and the need to support parents and carers through what can be a very difficult time.
- Continued to employ parent consultants Parent2Parent (P2P) who as part of Our Voice were on the interview panel to decide which organisations should be approved to deliver holiday play schemes and out of school activities. They will have a future role monitoring the quality of our short breaks, talking to you about what else needs to be done to make things better and working with us to approve other organisations to deliver more home sitting and home care services.
- Established an Aiming High Steering Group composed of parents and professionals who will report to the Children's Trust Board twice a year, thus ensuring collective accountability at the highest level.
- Worked with Our Voice parent forum to ensure greater representation on relevant groups and forums including the Special Educational Needs Steering Group, the

Disability Forum, the National Autistic Society (Enfield) Parents/Professionals Group.

- Established an inclusive Young Person's Consultation Panel who are working together to ensure we develop short breaks to meet their needs. They are involved in helping to develop inclusive and accessible play provision in the borough's local parks and outdoor play spaces.
- Invested in the following buildings to enhance the provision for disabled children - Memorial Hall, Oaktree School, Raglan Junior School and Raynham Children's Centre, through the provision of a sensory room, art facilities and outdoor play equipment including purchasing specialist bikes.

A couple of final points, some of you may be aware that the Government as part of its commitment to improving services for disabled children and their families introduced a national indicator to assess parent's satisfaction with services for disabled children. This includes satisfaction with health, education and social care services. Some of you completed a questionnaire about Enfield's services. The national average is a satisfaction rate of 59%. Enfield's satisfaction rate was 60%. The higher the score the better the services. Whilst our score is encouraging we know we need to do much better and so will be analysing the data with Our Voice and other parent groups and professionals to ensure we collectively address areas that need improving.

Through Our Voice we will continue to keep you informed of what we are doing and what you are telling us. We want to assure you that we do listen to your views and do our best to act on them. For example just before Christmas a small group of parents told me that the information they received from the staff at Cheviots about their children's play scheme day was simply not sufficient and didn't allow them to get 'a sense' of their child's day. Clare Redrupp, Centre Worker Manager at Cheviots is now addressing this issue and developing a more comprehensive form. So please do keep giving us the feedback no matter how small the issue - it all counts and helps us to improve! I look forward to meeting you at forthcoming Our Voice Disability Network meetings.

For more information about the Joint Service and our work or to know more about anything in this article please contact the Duty Social Worker at Cheviots Children's Centre on 020 8363 4047.

Did you know?

Sports training opportunities

Special Olympics is a worldwide voluntary organisation that offers sports training and competition opportunities for people with learning disabilities. Training sessions are intended to include skill and physical development and to be competitive and fun.

The North London group train in athletics at the Lee Valley Athletics Centre at Picketts Lock on Sunday mornings between 10 and 11.30am. Qualified coaches help individuals develop physically and participation helps increase confidence and improve social skills. In the last year the group have attended competitions in Eastbourne, Windsor, Portsmouth, Bournemouth, Leicester, St Albans and Hammersmith.

Membership is open from the age of 8 and there is no too old category. Members normally pay subs of £3 to help cover costs. New joiners will not have to pay the weekly subs until the end of March. When attending competitions athletes compete against people of similar standard.

For further information contact the Chair, SONL, Peter Palmer, 0208 364 6612.



Self-defence for you and your child

Learning a martial art is a fantastic way to boost fitness and self-esteem. The Ultimate Strike Martial Arts Academy is an inclusive martial arts academy. We teach disabled and able-bodied students from the age of 4 years. We also take part in the Special Malympex (Martial Arts Olympics) at the Stoke Mandeville Stadium, the birthplace of the Paralympics.

Sessions cost £2.50 for children and £3.50 for adults. Courses start 23 January 2010

Taekwondo, Tsui-Jitsu Shin Do Ryu, Cane Masters, Self-Defence, Wheelchair Self-Defence

Saturdays every 2 weeks 10am-12pm

At West Lea School, Haselbury Road, Edmonton, London N9 9TU

Contact: David Lee

Telephone 01992 878104 or 07731 562290

Taekwondo, Self-Defence, and Mixed Martial Arts

Saturdays 4pm-6pm

Alan Pullinger Centre, 1 John Bradshaw Road, Southgate, London N14 6BT

Contact: Stephen Lee

Telephone 01992 878104 or 07731 562290

Squash coaching for deaf young people

Free squash coaching sessions are offered for 8-19 year old young people or are deaf or hard of hearing during February half term. The sessions run from 10.30am - 12.30pm over 3 days on 15th, 16th and 17th February at Southgate Squash and Racketball Club, Waterfall Road N14. Places are limited so call or text 07904 300288 to reserve your place. Visit www.southgatesquashclub.co.uk for further details.

Athletics disability championships

Enfield and Haringey Athletics Club are holding a championship for people with disabilities on Thursday 11 March 2010 at Lee Valley Athletics Centre for people aged under 20 from any disability group. We have many years' experience with athletes with disabilities, and we want to widen participation of people with disabilities at all levels.

Championships will take place at the indoor facility at Lee Valley Athletics Centre, and will be held under UKA rules giving athletes the opportunity to compete at an event which is run in the same way as a mainstream Championship. It is ideal for those taking part in an event like this for the first time, but also will give athletes with aspirations an opportunity to take their athletics further.

We welcome people of all abilities, however we do ask for the benefit of those taking part that competitors are able to participate in the event they are entered in correctly. We will provide training sessions which your athletes can attend if required. We will also give full and clear instructions to the athletes on the day.

Events will include: running, hurdles, long jump, high jump and shot. Athletes can take part in a maximum of 2 events. The event is free to enter - please enter as soon as possible, as places in some events are limited. **Closing date for entries is strictly 22 February 2010.**

For more information or an entry form, please contact Yvonne Jacobs on 07906 885713 or email athletics.coaching@hotmail.co.uk

Police Cadets

Did you know that the Enfield Police Cadets meet every Wednesday at Lincoln Road, Great Cambridge Industrial Estate? Sessions are from 7-9.30pm and are for young people aged between 14 and 19.

Find out how the Cadets can offer you a world of adventure and new opportunities. It's an exciting way to make new friends, pick up valuable skills and have some fun. Cadets are involved in marshalling various local events such as the Enfield Pageant and the St George's Day Parade. They take part in various camps and competitions where they compete with Cadets from other boroughs. Subs are just £10 every half term which go towards the camps. Camps are heavily subsidised to make it easier for parents to afford.

To find out more about joining, contact the Cadet Leader, PC Sarah Gazzard on 07504 610874.

Saturday night youth club

Due to popular demand, the Dazū Youth Club now takes place every Saturday night (term time only). It's for all young people aged 11-18. Come and make new friends and take part in fun activities including arts and crafts, computer games, pool, sports and more.

Sessions are from 7-9.30pm and free of charge. The Youth Club takes place at the Alan Pullinger Centre, John Bradshaw Road, Southgate N14 6BT.

Soft drinks and bar snacks available. No booking required - just turn up. We would like to increase female club members and may put on a mini bus service for female members depending on interest. To register your interest or for any enquiries contact CJ or Lisa on 0208 373 2682 or 2718. We look forward to seeing you!



Gold star award

The nomination for the Gold star award this time comes from Brenda Stewart, parent of Ethan, who would like to thank staff at the Albany Children's Centre.

"My son Ethan has global development delay and has been attending Albany Children Centre in Bell Lane, Enfield from the age of 18 months. He has had to have quite intense physiotherapy and speech therapy. The girls at the nursery have been so supportive and worked really hard with him over and above the call of duty. They have also been so supportive of us as parents. When we have any worries they have always taken extra time to speak to us and reassure us.

I would like to nominate his keyworkers Sarah and Alex for the Gold Star Award as they have been an absolute godsend. I would also like to say a very big thank you to all the staff including the cook Anna. The managers have been very supportive in helping provide us with funding so Ethan is able to have one-to-one support on a daily basis. He has quite a severe weight problem and is on high calorie milk and needs extra calories in his food. Anna has provided wonderful home-cooked meals and lots of advice to us.

Ethan is now walking independently and has started saying some words and is improving every day. I wanted everyone to know how grateful I am to all the staff at the Centre."

If you would like to nominate an Enfield service, voluntary organisation or individual for a gold star award and special mention in our newsletter, please contact Our Voice.

Know your rights

Chris Barnett of Levenes Solicitors in Wood Green answers general questions about Special Educational Needs Law.

Q. "My child Danny has a statement and attends an out of borough maintained special school. If the school felt that he needed to change to another setting, what would be the process, and also vice versa (if we as parents felt that our child would be better suited to another school setting, what process would we need to follow)?"

A. Where a child has a Statement, the Statement must set out a suitable school

placement for the child. If the parents or school think that the school named is unsuitable, then they should seek an amendment to the Statement to name a different placement. The school would usually do this through the Annual Review process, although it can be done more urgently if that proves necessary. If the LEA amends the Statement to name another school, the child will be able to transfer to that new school.

If the LEA refuses to amend the Statement, then only the First-Tier Tribunal (formerly the Special Educational Needs and Disability Tribunal) can order them to do so. The parents would first need to obtain a right to appeal in order to bring the matter before the Tribunal.

Parents do not generally have a right to appeal against a refusal by the LEA to amend a Statement. However, they will have a right of appeal if they request that the child transfer to a different maintained special school, and the LEA refuse that. An appeal on this basis is a limited one and the Tribunal can only consider the issue of school placement: it cannot consider the other provision in the Statement, which has to remain the same.

If the parents are seeking a different type of school, or an independent school, or changes to the other Parts of the Statement, they would not be able to appeal a refusal by the LEA to amend the Statement. If the LEA amended the Statement in some respect - even if not in the way the parents wanted - that would give them a right of appeal.

Assuming the LEA did not amend the Statement at all, the usual route for parents would be to seek a re-assessment of the child's needs. If the LEA refuses that, then the parents would have a right to appeal to the Tribunal to get a re-assessment. Following a re-assessment, they would then have a further right to appeal and could seek the school that they want. While this route can take many months - and two Tribunal appeals - it may be the only way if the LEA refuses to make any change.

Levenes Solicitors can be contacted on 0800 118899/020 8881 7777 or email info@levenes.co.uk

Events

Our Voice/Enfield Disability Network meetings

Providing an opportunity for parents to network with professionals

For parents of children aged 0-4
16 March 2010 from 10am-12pm

For parents of children aged 5-11
23 March 2010 from 10am-12pm

For parents of children aged 12-15
24 March 2010 from 10am-12pm

Please contact Carol Mustafa on 07503 161248 or email: carol@ourvoiceenfield.org.uk to let us know if you are planning to join us.

Please note: Meetings will be held at Cheviots Children's Centre, 1 Cheviot Close, Enfield EN1 3UZ. Crèche places can be provided for your child but we need at least one week's notice please. Contact Megan Steven on 0208 363 4047 or at megan.steven@enfield.gov.uk

Information Day

What services are there in Enfield for my disabled child?

Our Voice supported by the Joint Service for Disabled Children is holding an Information Day on 17 March 2010 from 10am - 2pm at Forty Hall, Enfield.

Come and find out more about services and activities offered locally for disabled children and their families. This is also a great opportunity for you to help improve services in the future by getting involved and giving us your views and feedback.

Speakers from a range of relevant services will speak on the day.

Joint Service staff will be there to support parents/carers with children to enable you to view the information stalls.

free refreshments will be provided, throughout the day and a buffet lunch in the afternoon.

Learn to speak up! Free training workshops for parents

Would you like to sit on discussion-making panels in the Enfield community and have valuable input into how services are developed for disabled children?

Perhaps you lack the confidence to become more involved? Our Voice, supported by the Joint Service, is running two free half-day training sessions for parents on assertiveness training and developing confidence at public speaking. The skills you gain will equip you to sit on disability panels as well as benefiting you and your children in your everyday lives.

Being part of a panel is your chance to get involved and really make a difference. There are some exciting opportunities currently available to parents, including places on:

- the SEN steering group
- the multi-agency parent support steering group
- the Aiming High steering group.

Book now to take advantage of the free training.

The two sessions will be held on:

3rd March 2010 from 10am -1pm

10th March 2010 from 10am-1pm

Places are limited. A booking form must be completed in advance. To book your place please contact: Carol Mustafa, Development Coordinator, Our Voice Parent Forum, Enfield
Email: carol@ourvoiceenfield.org.uk or tel: 07503 161248.

Lunch will be provided. Travel costs will be reimbursed (eg petrol or public transport costs or taxis if you have no other means of getting to Cheviots).

Please note: Training sessions will be held at Cheviots Children's Centre, 1 Cheviot Close, Enfield EN1 3UZ. Crèche places can be provided for your child but we need at least one week's notice please. Contact Megan Steven on 0208 363 4047 or at megan.steven@enfield.gov.uk