

Our Voice



Our Voice Newsletter

Issue 2, Winter 2007



WELCOME

Welcome to the second edition of the Our Voice newsletter.

Our Voice is a parent-led organisation campaigning to improve services for children and young people with disabilities or special educational needs in the Borough of Enfield. We have representation on Enfield's Stakeholder Group for Disabled Children and the Disability Forum.

This time we feature parent Niki Michael's experience. If you'd like to share your story with readers we'd love to hear from you. Similarly if you'd like to promote your disability or special educational needs event through our newsletter please get in touch.

Our Voice meet regularly to share information and experiences of living in Enfield. Please see the 'Events' section at the end of this newsletter for details of our next meeting in January. You are very welcome to join us.

With all good wishes for the festive season and new year! **Julia Paylor**



Special thanks to:

Enfield Cheviot's Disability Service and Enfield Parents and Children for their support for Our Voice. Without the help from their staff many of you would not receive our newsletters or other information about us.

Your experience

Enfield Mum Niki Michael has two daughters; Maria aged three and Sophie aged one. Maria has cerebral palsy and while she is cognitively very bright, she has profound physical disabilities. Since the age of two Maria has attended her local nursery, Leapfrog, where she is part of a special needs group but joins in with mainstream activities, an arrangement that suits Maria and that Niki is very happy with, "She's a disabled child living in an able-bodied world", she says, "It's important to me to prepare her for this from an early age".

In line with this philosophy, Niki has applied to a local mainstream primary school for Maria and is now waiting to hear the outcome. The school is close to the family and the headteacher is very happy for Maria to attend. If she isn't accepted, Niki will consider appealing but this will add to her mountain of paperwork. One of her biggest



frustrations is the seemingly endless form-filling that needs to be tackled when you have a child with disabilities. "It's very stressful and unbelievably time consuming", she says. "At least English is my first language and I have access to the internet and am a determined person. I really worry for parents who don't know how the system works and who don't realise that things can take months, especially if you don't agree with the authorities." She is currently appealing against the levels of support and equipment given in Maria's Statement which she is convinced are not specific enough. As well as full time one-to-one support and access to regular speech and language therapy, she wants the Statement to include the equipment - supportive seat, standing frame and walker - that Maria relies upon. "At the moment these things are not quantified. It is frustrating and can feel as though I am begging for things my child has a right to".

About to move house, Niki has however decided to stay in Enfield, "It's a green borough with lots of open space and the schools here are very good" she says. There are also a number of excellent groups for parents of disabled children such as Cheviot's. Niki also recognises that Enfield does many things

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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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extremely well – she's delighted that communication aids are funded by the Borough as they are expensive and this is not the norm for many other boroughs in London. For non-verbal but very able children like Maria it is absolutely vital. She has received tremendous support from Enfield Communication Aids Service who she describes as having "huge knowledge and commitment". And the Early Support Keyworker Scheme that was trialled in Enfield offered her fantastic help in the early days coordinating the endless rounds of appointments.

In terms of advice, Niki has this to offer other parents starting to think about school admission: "Start early and explore every avenue. Use the internet, parent forums and the experiences of others. Charities often offer free confidential advice and even someone to come to your home to discuss your needs." She feels it is important to keep an open dialogue with the local special educational needs team and named officer as you are likely to be dealing with them for years to come. "Be persistent and keep focused," she adds, "Don't forget that your child is entitled by law to educational provision. And don't get bogged down with the argument that other children will lose out if you are granted X, Y or Z. New precedents can only make it better for others in future".

Niki has the same hopes for Maria as most other parents - that she will study at university, have a fulfilling job and live independently, "I haven't significantly altered the hopes I had for her before she was born and we discovered she had disabilities", she says. Right now the family's main aspiration is to ensure that Maria communicates well to enable her to make friends and socialise – vital skills for her future happiness.

What's new?

Speech and language services review – your views needed

On behalf of the Department for Children, Schools and Families and the Department of Health, John Bercow MP, is conducting a review of services for children and young people (aged 0-19) with speech, language and communication needs. It is the first major review in seven years.

John Bercow will be visiting speech, language and communication services across the country to learn what works, what the problems are and what people think should be done to facilitate effective early intervention. In addition to service providers he wants to hear from parents, children and young people themselves. His task is to write practical proposals for improved services that tackle the problems and boost the prospects of the children and young people who need our help.

To comment:

You can give your views by responding to the call for evidence at www.dcsf.gov.uk/consultations/ or you can email comments to John Bercow at Bercow.Review@dcsf.gsi.gov.uk The deadline is 18 January 2008. For more information see www.dcsf.gov.uk/bercowreview/index.shtml

Sport for all

Special Olympics is a worldwide body that provides training and sports competition for people aged 8 to 80 who have a learning disability. It offers opportunities for people with learning disabilities to develop their ability and compete in sport.

Special Olympics North London is looking for new members. Based in Enfield, the group specialises in athletics and trains on Sunday mornings at the new Lee Valley Stadium, Pickets Lock.

Training and competition help develop discipline, physical, social and communication skills and can lead to friendships and an opportunity to travel. Parents have the chance to meet other parents who have seen their own children develop with the help of sport.

To find out more please contact Peter, Chair of the Special Olympics North London Group on 0208 364 6612.

Promoting positive attitudes

Sadly most people go through life without having the confidence to talk openly with wheelchair users or voice output communication aid users about their disability and what it means in terms of their day to day life.

The Disability Equality Duty now requires schools to take a proactive approach to promoting disability equality and eliminating discrimination. More and more disabled children are being educated in mainstream school settings and many schools will now be organising awareness raising workshops for their children.

Hazelwood Infant School in Enfield is beginning to educate children with a wider range of needs and disabilities. A recent workshop there provided an excellent opportunity for children and staff to explore what disability means and gain the confidence to talk to disabled people.



Vicky Keeping, response worker from Scope began the workshop with a talk about disability and cerebral palsy followed by Toby Hewson,

Chief Executive of Just Different, talking about his day to day life. Toby uses a powered wheelchair and voice output communication aid. Louise Jones, a volunteer for Scope and also a powered wheelchair user, then gave a presentation about her life and experiences as a child in a mainstream school.

Pupils were encouraged to ask Toby and Louise absolutely anything. Questions ranged from 'Do you play football?', 'What is your favourite food?' and 'Do you like having cerebral palsy?' to 'Why are you so cheeky?' and 'Have you ever seen an owl?'.

Later Jeanne Willis, children's author and Scope supporter, joined the workshop to read from 'Susan Laughs', her book about a little girl who loves to do all the fun things that most little girls enjoy. It is not until the final page that the reader realises Susan uses a wheelchair.

The overriding message of the workshop was that disabled people like to do what everyone likes to do but sometimes they just do it a little differently.

The workshop inspired a range of emotions including admiration and inspiration. Headteacher, Peter Gordon, said, "Toby and Louise demonstrated that whatever your lot in life, determination, hard work, humility and a sense of humour will win through. We all learned that, whether they are able-bodied or disabled, people are still people who do the things that people do, want the things that people want and feel the things that people feel. It was a truly memorable visit." And pupil Evie, aged 5, said, "It was good to see that disabled people like to make jokes like us."

Our Voice would like every school in Enfield to organise a Disability Awareness workshop for their children and staff. There are many companies offering training and we would encourage parents to pass this newsletter to their headteacher or SENCO and suggest they organise a workshop. See contact details below.

Contact details

Vicky Keeping can be contacted via Scope's disability helpline on 0808 800 3333, www.scope.org.uk. Toby Hewson can be contacted at Just Different on 01243 778275 or www.justdifferent.org

Know your rights

Chris Barnett of Levenes Solicitors in Wood Green has agreed to answer general questions about Special Educational Needs Law in our 'know your rights' section.

Q: "My LEA has refused my request for an assessment for a Statement of Special Educational Needs for my four year old, who has autism. The LEA say it is because he does

not fit their criteria for assessments for Statements. I feel the Statement would provide security and clarity for us at a time of great change in my son's life. Can I appeal against the LEA's decision? What are my rights?"

A: "An LEA should agree to carry out an assessment if they consider that two criteria are fulfilled:

1. That the child has, or probably has, special educational needs; and
2. That an assessment is necessary, or probably necessary, for the LEA to determine the special educational provision that the child requires.

It is very likely that a child with autism will have some special educational needs, and if there is any dispute it is usually over point 2 above. LEAs should consider all of the evidence as to whether an assessment may be necessary for them to determine the special educational provision that a child requires. Usually, it is only necessary for the LEA to carry out an assessment if the child needs, or may need, provision beyond that which the school could make from within its own resources.

In any event, parents have a right to appeal to SENDIST against a refusal to carry out an assessment. They also have a right to approach their local Parent Partnership Service for impartial advice. The LEA should have set out their decision in writing, and should have explained in their letter the rights of appeal and the time limits for appealing. If you have not received a decision in writing, ask for it. In all cases, the deadline for bringing an appeal is 2 months from the date on which you receive the LEA's decision letter. More information on appealing is available on the website www.sendist.gov.uk or their telephone helpline 0870 241 2555."

Levenes Solicitors can be contacted on 0800 118899/020 8881 7777 Textphone: 020 8881 6764 or email: info@levenes.co.uk

Well done to Enfield's Early Years Development and Childcare Services...

...for securing London Development Agency (LDA) funding to help parents of disabled children back to work – the LDA have agreed to raise the age limit to qualify for funding. Previously it was for parents/carers with disabled children aged 0-5. The age limit has now been raised to 0-16 - good news for many parents. The funding will be available until November 2008 and will pay for any additional costs of childcare associated with a child's disability. For an information pack and further details of this scheme contact Megan Steven on 0208 363 4047 or e-mail Megan.Steven@enfield.gov.uk

Speak up – the voice of children and young people



'Me and my special brother Finley'
by Ciara aged 8

If you would like to submit a letter about your experiences of living in Enfield or a short story, poem or picture for Speak Up, please email julia.ourvoice@blueyonder.co.uk

Letter to Santa

If your child has a visual impairment encourage them to send a letter to Santa – a reply is guaranteed! Send your letter to Santa Claus, RNIB, PO Box 173, Peterborough PE2 6WS before 10 December. Include your child's name and address and choice of braille (grade 1 or 2), large print or audio cd. Or email Santa at santa@rnib.org.uk by midday on 21 December. It's free and guaranteed to raise a smile!



Events

Our Voice

The next meeting of Our Voice (our meeting!) will be on Thursday 17 January 2008 from 10-11.30am at Community House, 311 Fore Street, N9. Please contact Julia Paylor on 0208 292 0638 or email julia.ourvoice@blueyonder.co.uk by 9 January to let us know if you will be coming. We are a friendly group – come and tell us what services are working well and what needs to improve over tea/coffee and biscuits.

Our Voice is pleased to announce our first workshop for parents or carers of children with disabilities or special educational needs.

Special Educational Needs in schools sorting the myths from the truth

From 9.30am to 1.00pm on Thursday 7 February 2008, Community House, 311 Fore Street, N9

Delivered by Julia Wayment of the charity IPSEA (Independent Panel of Special Educational Needs Advisors) this workshop will cover a range of topics including how to get support for your child, the Statement process, what happens if you need to go down the SENDIST tribunal route, as well as information about the Disability Discrimination Act in relation to education.

To book a place (note that places are limited and will only be available to those who have pre-booked) please contact Our Voice on 0208 292 0638 or email: julia.ourvoice@blueyonder.co.uk. Sorry we cannot offer crèche facilities. We are pleased to confirm the event is free of charge.

Cheviot's meeting

The next Cheviot's Disability Network Meeting will be from 10am - 12pm on 7 February 2008. Contact Megan Steven for more information on 0208 363 4047 or e-mail Megan.Steven@enfield.gov.uk

Small ads

For Sale:

R82 small Yellow Pony: £350 (new £700) 07989 363898 – North London

Much loved! The Pony has a five-wheel construction specifically designed for indoor use. It is excellent for rehabilitating hip function, supporting the child so he or she can balance properly. The seat, body support and handle are all easy to adjust, and the angle can be regulated with a minimum of effort. <http://www.r82.com>



We welcome adverts from parents and carers free of charge. Contact julia.ourvoice@blueyonder.co.uk by 1 February 2008 to advertise in the Spring issue.

