

Our Voice



Our Voice Newsletter

Issue 1, Autumn 2007



WELCOME

Hello and a warm welcome to the first edition of the Our Voice newsletter.

Our Voice is a new parent led organisation aiming to improve services for children and young people with disabilities or special educational needs in the Borough of Enfield. We campaign for better local services and support for families. Our Voice has representation on Enfield's Stakeholder Group for Disabled Children and the Disability Forum. We are grateful to the Local Network Fund for Children and Young People via the Peabody Trust for funding our work.

Every few months this newsletter will bring you news, advice and tips to help you know about your rights and make the most of opportunities in Enfield. We will report on services that are working well as well as those that we feel are in need of improvement.

So we'd like to hear from you too! Please contact us and tell us about your experiences, both good and bad, of living with your children in Enfield. We are a friendly group who meet regularly to share information, experiences and report on activities. If you'd like to join us, please contact me. **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.

Every Disabled Child Matters

Every Disabled Child Matters (EDCM) is the national campaign to get rights and justice for every disabled child. EDCM wants all disabled children and their families to have the right to the services and support they need to live ordinary lives. It will challenge politicians and policy-makers to make good on the Government's commitment that every child matters.

EDCM supports and represents thousands of disabled children, young people and families.

What does EDCM want?

- Families with disabled children to have ordinary lives
- Disabled children to matter as much as all other children
- Disabled children and their families to be fully included in society
- All disabled children and their families to get the right services and support - no matter where they live

- Poverty amongst disabled children and their families to be cut by 50% by 2010 and eliminated by 2020
- An education system that meets the needs of each child and enables them to reach their full potential
- Disabled children and their families to shape the way that services are planned, commissioned and delivered

Enfield signs the EDCM charter

A total of 39 authorities have signed up to the EDCM's Local Authority Charter so far and Our Voice is encouraged that Enfield is one of them. This means that Enfield supports the aims of the EDCM campaign and we want to work with the Local Authority to help ensure that changes and improvements are a reality for families at a grass roots level. We will therefore be asking you directly to help the LA monitor progress by letting us know how local services for your children are developing over the coming months and years.

How can you help?

You can support this vital national campaign by signing up as an individual at www.edcm.org.uk. Locally, you can get in touch with Our Voice and let us know how services are working.

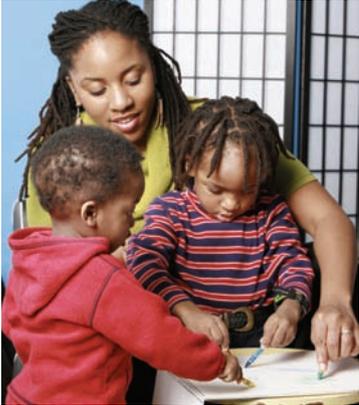
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Please pass this newsletter on to others - parents and service providers - who might find it useful. You can contact us for additional copies by email or phone.

If I could change one thing...

Every Disabled Child Matters (EDCM) is currently working on a new campaign called 'If I could change one thing...'. This will allow parents and children and young people to tell MPs, Government Ministers and key decision makers directly what they think needs to change. Over the summer EDCM collected the views of parents from all over the UK. Here's what parents from Enfield had to say:

"I would have information more readily available about benefits and funds, for example information about Disability Living Allowance, Direct Payments, the Family Fund and Carers' Allowance"



"I would improve respite care. I'm a single parent of a two and a half year old child with complex needs - I have been on the waiting list for six months for one night of respite - that is too long to wait"

"We want to be provided with full details of all the options available for our child's educational placement and not just the ones the Local Authority want parents to know about".

"It would be better if we didn't have to shout to be heard"

"I would have a world where we don't have to chase and re-chase services - where they ring us back or even ring us first and say 'How can we help?'"

Gold Star Awards

Our Voice aims to provide positive feedback to services and we have asked families to let us know what is working really well in Enfield. The following services got the thumbs up:

Parents found the **Pre-school Support Service** effective. The particular key workers involved with families are proactive, sensitive and helpful.

Enfield children thoroughly enjoyed the **Children and Parents Advisory Group (CAPAG)** and **Cheviots** play schemes over the summer period.

If you would like us to give a special mention to a local service that has made a difference to your child or family please contact Our Voice.



My child might have dyslexia - where next?

If you have concerns that your child might have dyslexia you might want to discuss this with the teacher and Special Educational Needs Coordinator (SENCO) at your school, and ask for a formal assessment of learning needs to be undertaken by a Local Education Authority Educational Psychologist.

What happens next may well be determined by the individual approach of the SENCO or school in relation to teaching children with dyslexia, the funds available in the school and the severity of the difficulties experienced by the child.

Many parents find themselves having to pay for assessments privately and they do not come cheap. Before going down that route you might want to contact the British Dyslexia Association helpline on 0118 966 8271 or visit www.bdadyslexia.org.uk.

Locally, you can contact Enfield District Dyslexic Association who are hoping to deliver a "practical solutions" workshop for parents that will provide a range of tips from supporting your child at home to what makes a school "dyslexia friendly". They can be contacted on 0208 366 4997 (answerphone) or e-mail jemftaylor@btopenworld.com to leave your details for the forthcoming events. The helpline number is 020 8886 7838.

Know your rights!

Should my child's Statement specify and quantify therapy visits and the number of support hours?

The Education Act makes clear that Statements have to be set out in a particular way. The SEN Code of Practice, which all LEAs must have regard to, says:

'A statement should specify clearly the provision necessary to meet the needs of the child' and 'Provision should normally be quantified (eg in terms of hours of provision)'.

The Statement sets out the special educational needs of your child and the special help your child will receive to support his or her education. Despite the Code of Practice a number of boroughs are reluctant to specify

and quantify provision because they know it will not be easy for them to reduce the provision at a later stage. Sometimes boroughs get round this by stating that a child should have access to a programme of therapy rather than specifying, for example, "direct access to a speech and language therapist on a fortnightly basis". Our Voice is not suggesting Enfield would act in such a manner but we would like to know if you are struggling to get educational needs specified or quantified in your child's Statement.

IPSEA

The Independent Panel of Special Educational Needs Advisors (IPSEA) is an organisation that helps by giving free, non means-tested, independent legal advice to parents to ensure their children get the education they are entitled to.

Briefly, IPSEA aims to:

- help ensure that all children with special educational needs receive the special educational provision to which they are legally entitled;
- help ensure that the views of parents and carers are taken fully into account when their children's needs are assessed and decisions are made about their special education provision;
- help to prevent or remedy discrimination by local authorities or schools against children on the grounds of their disability.

IPSEA has helped a number of parents in Enfield secure a Statement and/or an appropriate educational placement for their children. Call the IPSEA advice line on 0800 0184016 or see www.ipsea.org.uk for more information. The website contains some very useful model letters that you can use in different situations. Just a cautionary note - a number of parents have found that it is difficult to get through to the helpline but have stated that the help received was well worth the effort.

Enfield Parent Partnership Service [EPPS]

EPPS offers free, confidential independent, impartial information and advice to parents/carers whose children are facing difficulties at school.

EPPS helps support families and carers by:

- Supporting parents at school meetings, independent appeals and governors' hearings
- Guiding parents/carers through the Special Educational Needs and/or exclusions processes and legislation
- Helping parents/carers to write letters and with annual reviews
- Empowering parents/carers to feel confident to support their children in the education system

EPPS aims to influence policy making in the Local Authority in order to bring about positive change and acts in an advisory capacity to other agencies.

As a Parent Partnership Service they work with parents/carers whose children are facing difficulties at school to enable them to have positive learning experiences and to achieve their potential.

For EPPS call 020 8373 2700



Speech and language services to be reviewed

A major review into the provision of services for children and young people with speech, language and communications needs was launched in September by Children, Schools and Families Secretary of State Ed Balls and Health Secretary of State Alan Johnson.



The review, announced by the Prime Minister, will advise the Government on how the very best provision can be mirrored in all areas, so every young

person up to 19 with speech and language difficulties gets support as early as possible. It will also advise on how local services can work closer together so children get the support they need, when they need it.

Specific issues it will consider include:

- how to ensure speech and language therapy services meet local needs
- the recruitment and deployment of NHS speech and language therapists, particularly those specialising in working with children
- effective provision of assistive communication technology
- improving support and information for parents, children and young people.

The review will report by summer 2008 and the Government will formally respond in due course. For more information see www.dfes.gov.uk/pns

Well done to...

Enfield Communication Aids Service who held a successful fun afternoon for young children who use communication aids at Cedar House in August. Several children under the age of 6 attended the fun day and enjoyed talking, singing, and playing games with their Voice Output Communication Aids (VOCA). For many it was the first time they had met other VOCA users and the Communication Aids Service hope to hold another one in the Christmas holidays.

The Communication Aids Service is staffed by Speech and Language Therapists who support children using Voice Output Communication Aids (VOCA). The machines are expensive and we are fortunate that the Service in Enfield supplies communication aids on long-term loan to those who qualify. This is not the case in most other boroughs.

Speak Up!

The voice of children and young people

This poem (published in Rona Tutt's book 'Every Child Included' (Chapman, 2007) is by 8 year old Bethany Jagger. It is called 'Me and my friend Lucy'.



Lucy and me do a lot together.
And I know we'll be friends for ever.
We walk around the playground talking to each other.
Stay away from the football and my little brother.
We tell all our secrets with our other mates.
And every day we meet up at the school gates.
There's one thing I haven't mentioned, my friend Lucy cannot walk.
She's no different from you and me, even though Lucy cannot talk.
We have a lot of fun together, every single day.
Our school is called 'inclusive'. Lucy and me like it that way.

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

Enfield National Autistic Society (ENAS)

ENAS is a support network for families and children with autism and Asperger syndrome. It lobbies for better education, health and leisure services locally and interacts with other groups and national campaigns to improve the lives of families living with autism. It holds members' meetings at Cedar House or Russett House School once a month with speakers on various aspects of autism. Topics

include education, local services, therapies and diet. There are also informal Saturday morning get-togethers at a local soft-play area. For full details of the ENAS programme for 2007, or to join, email enfieldnas@tiscali.co.uk or call Miranda McAllister on 020 8882 9202 or Sophie Castell on 020 8886 3846.

Events

Cheviots Disability Network Meeting

The next Cheviots Disability Network Meeting will be from 10am to 12 noon on 1 November 2007. For more information contact Megan Steven on 0207 379 4047 or e-mail Megan.Steven@enfield.gov.uk.

Parent Participation Workshops

Following the success of the first round of parent workshops hosted by Contact a Family, the Every Disabled Child Matters (EDCM) campaign is pleased to announce further parent workshop dates in London on 15 October from 10.30am to 3pm at Wesley's Chapel Leysian Mission on City Road EC1 and 21 November from 6.30 to 9pm at the Contact A Family offices on City Road EC1.

The workshops will provide an update on the work of EDCM and information on how parents can support the campaign and use it to further their own involvement work. These events will be informative but relaxed and will look at practical issues that you might be facing in your participation work.

For further information please contact Liz Ranger, Parent Participation Manager on 020 7608 8784 or email liz.ranger@cafamily.org.uk.

These are free events, but Contact a Family ask for a £5 cheque returnable deposit to secure your booking. If you do decide to book it would be great to hear from you, as members of Our Voice will be attending the 21 November meeting.

New service for visually impaired children

Enfield Association for the Blind in partnership with the Joint Service for Children with Learning Difficulties and Disabilities (LDD) invites you to the launch of our new service aimed uniquely at visually impaired children and young people (from birth to 18 years), their parents and carers on Thursday, 4 October at 6.45 pm or Tuesday 9 October at 9.45 am at Cheviots Childrens' Centre.

Come and be a part of this new opportunity in Enfield for you to have your say in making things happen.

Contact Helen and Linda on 020 8429 7110 or 0208 367 7729 to find out more.

