

Our Voice



Our Voice Newsletter

Issue 7, Autumn 2009

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Welcome

Welcome to autumn's newsletter for **Our Voice**, the parent-led organisation seeking to improve services for children with disabilities in Enfield.

Summer might be a distant memory but we know the struggle over how to occupy children during the school holidays will come around again all too quickly. This issue takes a look at holiday **playschemes**, part of Enfield's core offer to parents of disabled children. We look back at the three main schemes that took place in Enfield over the summer, report on what you thought of them and look forward to how they might develop.

We'd like to thank Enfield's Joint Service for Disabled Children and Enfield Parent Partnership Service who are active in supporting our work. We'd also like to thank all the parents who have contributed to our meetings this year. Your input helps us to prioritise which service improvements we need to campaign for as well as to share knowledge about what is working well for you.

We'd also like to say a special thank you to those parents who are part of the research project on short breaks. The Every Disabled Child Matters Campaign team has asked **Our Voice** to carry out the research over two years and we are grateful to around 8 parents who are giving up their time every three months to input into it. The research is also being carried out in three other local authority areas. What you tell us is important in tracking whether short breaks services are improving or whether some of you continue to struggle over the next two years.

And finally, while we've enjoyed it enormously, both of us will soon be stepping down from our role as Development Coordinators for personal reasons. If you have the enthusiasm and commitment to take over (perhaps two of you might want to work together on this) please see the advert on the back page for more information. It's an exciting opportunity at this crucial time taking the **Our Voice** forum to the next stage of participation with professionals.

Julia Paylor and Orla Keeley

Happy kids equal happy parents

"It's the happiest she's been in a very long time," is how one parent summed up her daughter's experience at a playscheme run at Raglan School during the summer. A number of holiday playschemes come under short breaks services in Enfield. They offer high quality, safe, fun and stimulating activities giving parents the chance to work, rest or spend time with other children, safe in the knowledge that they are being well looked after.

The three main schemes for disabled children in Enfield are popular and not surprisingly both

children and parents want more of a good thing. We take a look at what's on offer and what you thought of it.

What's on offer?

There are currently two main providers of specialist playschemes in Enfield, Cheviots and CAPAG. The Play Development Team has run inclusive playschemes at Worcesters, Prince of Wales and Houndsfield Schools for a number of years. This year the Play Development Team and the Joint Service for Disabled Children ran a new and additional inclusive scheme at Raglan Primary School.

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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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The specialist schemes offer care and fun in a stimulating environment for children aged 4 to 17 inclusive, generally between the hours of 10am and 3pm. If your child is eligible, the minimum currently offered is two days per week during the majority of school holidays, although some families, depending on need, are offered more. Inclusive schemes offer a range of play activities mainly for primary age children.

Playschemes in Enfield

Cheviots

This scheme is funded and run by the Joint Service for Disabled Children and takes place at Cheviots Children's Centre and Waverley School. It aims to provide quality play and leisure opportunities for children and young people needing a high level of support, including those with medical needs.

CAPAG (Children and Parents Advisory Group)

CAPAG is commissioned and funded by the Joint Service to run playschemes at Durants, Oaktree and Russett House Special Schools. CAPAG aims to provide quality provision for a range of disabled children and young people with varying needs.

Raglan

This is a new playscheme following a successful pilot in 2008. The Joint Service for Disabled Children runs it in partnership with the Enfield Play Development Team. It provides inclusive provision for disabled and non-disabled children aged 8-14 at Raglan School.

The Joint Service for Disabled Children is aiming to provide up to 800 families with short breaks and services by April 2010

What's good about them?

To find out what you thought, Our Voice gave questionnaires to parents with children at each of the three main playschemes this summer. We received over 50 responses. In general you were very happy with the level of care and the range of activities on offer. Here's a summary of what you liked about the schemes:

- You love the fact that your children are safe and well looked after

- It's great that they are often in familiar territory with familiar faces
- Staff are kind, friendly, enthusiastic and involved
- It's a great opportunity for children to mix with other children during the holidays
- It's a break for you as parents too
- Many of the staff are familiar with your child's disabilities and needs
- At some schemes children are matched with another child which helps their social skills
- It's reliable, cheap and convenient
- It gives you time to play with your other children
- Favourite activities included bouncy castle, bikes, big toys, wet play, outdoor play, picnics, swings, soft play, computers, DVDs, football, swimming, painting, bowling, cooking and cinema, with computers being mentioned most often
- The range of activities is great and there is plenty on offer to stimulate and entertain
- Your children really want to attend
- Schemes offer outstanding levels of care
- The schemes are very well organised.

One mum whose daughter attended the scheme at Raglan said, "It was like I had a different daughter for the summer, she was happy to get up each morning and go to the playscheme...for me knowing she was having such a wonderful time made me enjoy my break so much more than in previous years. The activities and the staff were fantastic."

Other parents said, "My son cannot wait for the bus to take him to CAPAG" and, "I know that my child is in a safe environment and well looked after at Cheviots."

What would you like to improve?

Of course there is always room for improvement and many parents felt that they needed more flexibility around changing the days they'd been offered, as well as more notice of dates so that they could plan ahead more easily. Here's a snapshot of what you would like to see happen in the future:

- You'd like more notice of which days you've been allocated to enable you to plan them around work, siblings or booking something else
- You want siblings to be able to attend
- You'd like a short report (just a couple of sentences) from a playscheme worker on what your child has been up to that day - this is especially important for children with communication difficulties

- More outings and trips
- You'd like the length of the playscheme day to be the same as a school day
- Some sessions on Saturdays and Sundays would be very welcome
- You'd like your children to play some sports other than football
- More opportunities for kids to learn skills such as drumming, horse riding, tennis
- You'd like to have provision for children with profound medical needs to be able to attend more mainstream schemes
- In some cases in the mainstream provision, there were a number of outings on the same day (skating, Quasar etc) that meant a number of children with physical disabilities could not join in
- Overall, you want to be offered more days at holiday schemes.

How are things changing?

Janet Leach, Head of the Joint Service says, "We really want to involve parents and young people in developing playschemes. We want all our short breaks and services to get better and better. Parents have told us how they become frustrated and distressed waiting to find out if a short break or service will be offered, so we want to speed things up as well as offer more flexibility and choice, particularly for playscheme dates. We will continue to work with our partners in the Play and Sports Development Teams to offer greater choice of activities and to develop more inclusive provision at the same time as improving the quality of our specialist playschemes and short breaks. Following a lot of consultation and discussion with parents and young people, information about the Joint Service and short breaks is now ready to be printed and will be available after half term".

What you can do



If your child has a disability and you would like them to attend a playscheme, contact the Joint Service for Disabled Children at Cheviot's Children's Centre and ask to speak to the duty social worker. They will talk to you about eligibility and explain what assessment may be needed to ensure your child can be safely supported at a playscheme.

Playschemes come under the remit of short breaks. If you are offered a place, make sure you ask the social worker about the length of time you may have to wait as some parents have reported waiting several months before they hear.

And do please keep telling **Our Voice** about your experience of playschemes, both good and bad, so that we can keep track of how things are developing and campaign for more and better on your behalf.

What's new

Our Voice is your voice - parent forum update

We've had a busy summer. Here's a rundown of key developments over the past few months.

As you may be aware, under the Aiming High for Disabled Children agenda Our Voice was given additional funding to support our work up to spring 2010. In our summer newsletter we told you what parents (mostly of children in nurseries and in mainstream placements) had to say about services and support in Enfield. A report based on those consultations raises some specific ways that parents do not feel supported by SEN services and reveals that almost all parents have significant concerns about the speech and language support for their child. The report has been discussed with the Joint Service for Disabled Children and is now available to view on our website at www.ourvoiceenfield.org.uk

We are delighted that Our Voice representation on the SEN steering Group in Enfield has been agreed. We will let you know about changes that are introduced in schools as a result of our involvement in this key area through future editions of this newsletter.

Over the summer Orla Keeley (Our Voice Development Coordinator) took the opportunity to visit Enfield's special schools to introduce our work. She asked parents of children in special schools about their priorities and encouraged them to join the Our Voice forum. Her findings so far have echoed those of parents who have children in mainstream provision, particularly regarding a need for extra resourcing for speech and language therapy. They also reveal that parents of children in special schools are more likely to have concerns about suitable housing for their families. A report summarising the findings from the special school meetings will be delivered to the Joint Service for Disabled Children this autumn and will be on our website in early October.

We have negotiated our way on to the PCT's Child Development Steering Group and the Children's Trust. Dates have yet to be fixed but we would like to support volunteer parent representatives to sit on those meetings and to feed into them as well as back to the **Our Voice** forum.

We believe in working in partnership and have teamed up with Enfield's Disability network to run our Parent Forum meetings followed by Network meetings held on the same morning. We held our first one (for parents of under 5s) in June. Once our new Development Coordinators are in post we will run more of these. In the meantime other opportunities to network with parents will be provided by the Joint Service at Disability Network meetings in November (see back page for details).

And finally, we have been visiting our local MPs to introduce ourselves and to ensure they pass on information about us to parents who could benefit from being part of our Forum.

What's next?

We have an exciting few months ahead of us. We are going to develop our website as a one-stop information resource for parents of disabled children who live locally. As part of this we hope to develop an online chat forum for parents in Enfield, giving you an opportunity to talk to other parents about services, advice and support. We hope to launch it by summer 2010 and would be pleased to hear from you if you have any suggestions for topics to include on the website.

We will be providing training for those of you who would like to act as parent representatives. We will also be assessing the perceptions of parents from communities that do not find it easy to access services or where English is an additional language for them.

We will continue to hold Forum meetings, develop our structure and participate in consultations and research aimed at improving services for disabled children and their families. Finally, we will of course continue to report on changes and developments.

Help us have our say!

A number of parents volunteered to help **Our Voice** when we held meetings earlier in the year. We have not got back to you as it has taken some time to negotiate our way onto decision-making bodies within the service providers. However, we are now making progress and hopefully we will have representation on the SEN Steering Group, the PCT led Child Development Steering Group and

even the Children's Trust. We will soon be in touch if you said you might be interested in helping out by representing **Our Voice** at meetings.

If you have not already volunteered to be a parent representative and think you might have got what it takes please contact us by telephone or email. It involves attending two half-day training sessions (crèche provided) and a few hours of your time a month on a voluntary basis. In return, you will get first hand experience of negotiating with senior officers within the Local Authority and PCT as well as the satisfaction of helping our disabled children receive the best possible services and support. Plus it will all look good on your CV! We will provide training for at least six representatives who can attend meetings on behalf of **Our Voice**.

If you have volunteered help in other ways over the past six months, we'd like to know if you can still help us so expect to hear from our new Development Coordinators soon.

Healthy Lives, Brighter Futures

Where has all the money gone?

Under the government's "Healthy Lives, Brighter Futures" strategy Enfield Primary Care Trust (PCT) received an injection of in excess of £1m in 2009 and are due to receive a similar sum again in 2010. The Department of Health expected the PCT to spend this additional funding on palliative care and end-of-life services, short breaks and equipment such as wheelchairs. **Our Voice** has asked the PCT how this money has been spent. We have been told that £150,000 a year additional monies has been spent on disabled children's health services over the past two years. This is disappointing and implies that much of the £1m we had anticipated as being earmarked for our children's services has been used to soak up part of the £18m deficit instead.

The Every Disabled Child Matters Campaign has been urging Government to make PCTs more accountable for their expenditure on disabled children's services. **Our Voice** will provide updates in future newsletters about the PCT's plans. If you have not done so already please sign up to the Every Disabled Child Matters campaign via www.edcm.org.uk and scroll to the "get involved" section. Our Voice is fully committed to this national campaign.

Did you know?

Enfield girl gets her wheels



The charity Whizz-Kidz has given Maria Michael funding for a new powered wheelchair. Five-year-old Maria from Enfield has cerebral palsy and profound physical difficulties.

London Mayor Boris Johnson observed Maria being assessed for mobility equipment as part of the Making Mobility Happen partnership between charity Whizz-Kidz and Tower Hamlets Primary Care Trust. He said: "Whizz-Kidz is an excellent charity that makes a huge difference to the lives of many young disabled people."

Whizz-Kidz has changed the lives of over 7,500 disabled children since 1990. The charity supports young people to access the right mobility equipment, including powered wheelchairs. Whizz-

Kidz also delivers wheelchair skills-training and other life-skills to help young people with transition from childhood to adulthood.

The charity's therapists assess all children and young people referred to the service and prescribe mobility equipment that takes account of their educational, social and clinical needs, enabling them to lead independent, full and active lives.

Mum Niki Michael said, "Maria is really excited about getting her first powered wheelchair. It will mean she can independently chase her brother and sister around the house for the first time and allow her to access her school playground with all her friends, something she has been unable to do without assistance till now."

For more information visit www.whizz-kidz.org.uk

Do you need funding?

If you need funding to help with new computer equipment, a trike or other mobility equipment, speech and language therapy, conductive education or even a long-awaited holiday, then these charities may be able to help you. Each has their own area of what they will and will not fund so it is worth spending an hour or two going through the websites or giving the organisations a ring to find out if they can help you.

Potential funders

Children Today Charitable Trust

01244 335622, www.children-today.org.uk

Action for Kids

0208 347 8111, www.actionforkids.org

The Elifar Foundation

023 92267996, www.elifarfoundation.org.uk

CEREBRA

01267 244200, www.cerebra.org.uk

Caudwell Children

0845 3001348, www.caudwellchildren.com

David and Victoria Beckham's charity

Old School House, St James Road, Goffs Oak
Herts EN7 6TP

Lifeline 4 Kids

0207 794 1661, www.lifeline4kids.org

Dreams Come True

(for children who are seriously ill or with
life limiting conditions)

01730 815000, www.dctc.org.uk

The Family Fund

0845 130 4542, 01904 621115
www.familyfund.org.uk

Kids in Need

(for children who are seriously ill or with
life limiting conditions)

07949 429552, 07786 082076
www.essexinfo.net.kidsinneed

Variety Club of Great Britain

0207 286 4212, www.varietyclub.org.uk

Promise Dreams

01902 378 595, www.promisedreams.co.uk

In addition to the above, organisations such as MENCAP, the National Autistic Society, SCOPE and Contact a Family are worth contacting for information about other sources of funders and support. You could also write to your local branch of Lions Club, Round Table or Rotary Club. Good luck!

Gold star award

The nomination for the Gold star award this time comes from Jane Richards, parent of Marc Richards, who would like to thank Ian Reddington.

"I would like to nominate Ian Reddington who works as the Principal Sports Development Officer. Four boys who Ian works with represented Enfield and London at national disability athletic events. During the summer they were selected to attend England trials in Sheffield in September.

Thank you Ian for all your hard work to give our young people the chance to not only access athletics but for the high standard you are achieving with them.

Sometimes it's people like Ian who do not get the recognition they deserve. Well done Ian and all your athletes."

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 three-year-old son, Danny, has just been diagnosed with autism. He will be starting reception in September 2010 but we are not yet sure which school will be most appropriate for him and will be visiting several this autumn. Danny clearly already needs a lot of support in his playgroup. He sees a speech and language therapist for block input a few times a year and I'm sure he will need regular speech and language input in school. He is also under the OT service.

The LEA says it will not assess Danny for a Statement until he is in Reception so that staff can begin to work with him and get a feel for his needs. I believe his needs can be assessed now. I have heard of children who are not supported adequately during their Reception year because there is a delay in providing the one-to-one support they need. What are the benefits to Danny of delaying assessment for 12 months until he is in

Reception? If I decide to push for an assessment now, what should I do if the LEA continues to refuse to assess over the coming weeks and months?"

A. There is certainly nothing to prevent the LEA from carrying out an assessment now. In some cases it may well be appropriate for a child to start school first, and for provision short of a Statement to be made, to see if that is appropriate. However, where it is clear, or at least likely, that a child's needs will not be able to be met by a school from its own resources, an assessment can be requested before they attend school. Where a child needs support in class, as well as speech and language and occupational therapy, it would certainly seem likely that additional support will be required.

The assessment process can take 4-6 months (and can be extended considerably if an appeal to the First-Tier Tribunal - formerly SENDIST - is required), so waiting until a child starts school can mean that they miss out on provision at the start of term. Where parents consider that their child is likely to need support beyond what the school can provide then there is unlikely to be any benefit in delaying an assessment, and potentially considerable disruption to the start of his education. An LEA cannot refuse to consider a request simply because a child has not started school, and cannot refuse to assess on that basis. It can only refuse if an assessment is not necessary.

Where an LEA does refuse a request to assess a child, parents can appeal to the Tribunal. The LEA should set out their refusal in writing, and inform parents of their right to appeal. If you have a written decision, then you must appeal within two months of the decision. If you have no written decision, then you will need to ask the LEA for one. If they will not give you one, then the safest course would be to make a formal written request for an assessment. The LEA would then have to take a formal decision within six weeks as to whether to assess or not; if they fail to give a decision, in writing, in that time then you should seek legal advice. If their decision is to refuse to assess then you can bring your appeal to the Tribunal.

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

Speak up - the experience of children and young people

Enfield boys selected for England trials

Four boys who represented Enfield and London at national disability athletic events this summer in Watford and Blackpool have been selected to attend England trials in Sheffield in September.

The boys, three of whom are on the autistic spectrum and one who has learning disabilities, are all new to the national circuit. They broke national records and brought back a haul of gold and silver medals. Their results impressed members of the International Paralympic Committee so much they have been fast tracked to the national squad-training day.

Felix Kenhinde aged 17 ran a personal best of 11.8 in the 100m and 15-year-old Andre Parkinson ran 12.9, and 26.0 respectively in the 100m and 200m. Dalian Richmond and Jack Allsop impressed selectors in the throwing events, both throwing over 9 metres in the shot, with Jack breaking the national record in the under-17 category with a huge 9.87m throw.

Ian Reddington, Principal Sports Development Officer commented, "These four boys have been training in our after-school gifted and talented athletic club for 3 years now. They have shown much dedication and definitely have the ability to push on into the national squad. It's exciting times for the boys and their families."



Each year there are around four international events including the World or European Indoor Championships for athletes with a learning disability. The Enfield athletes who attend Durants and West Lea School could be joining up with athletes from Wales, Scotland and Ireland to compete in these events if they are successful at trials.

Thank you from the Parent2Parent Team

The Parent2Parent team (P2P) - who are all parents of children with additional needs and who were engaged by Enfield to consult parents about short breaks services - would like to thank all parents who gave up their time to come to meetings or complete questionnaires during the summer and autumn of 2008. We know details about the core offer have taken longer to get to families than we anticipated. However, the Joint Service for Disabled Children has assured P2P and Our Voice that information leaflets will be distributed shortly. P2P are now working to support the tendering process and commissioning of organisations that will provide short breaks in Enfield in the future.

Support from MPs

Our Voice recently met with Enfield MPs Andy Love and David Burrowes to ask them about what kinds of concerns parents of disabled children in Enfield raise with them. Both MPs said they get involved with a range of issues from parents needing transport for their disabled child to get to secondary school, to helping to progress unnecessary bureaucracy around the housing adaptations facilities grant.



Andy Love



David Burrowes

Both MPs cited issues relating to parents' experiences of SEN services in Enfield as being the biggest cause of stress for families supporting disabled children. Both also suggested that at least 80% of the issues causing the greatest concern to parents were those surrounding support in school or a dispute about the choice of school placement, and what was deemed appropriate by the LEA being at odds with parents' views.

"Usually by the time parents come to us they feel they have exhausted all other practical routes and need me to act as an advocate to move a case forward," said David Burrowes. Andy Love's experience has been similar, "Many of the parents come to me when their child is in mainstream school. Issues might have been brewing during nursery and reception but the parents have been told to wait to see how their child settles in school. Many of the parents have children on the autistic spectrum and feel their child is not being supported appropriately in school. I can help them by writing to local authority officers to ensure the child's case is progressed and their details do not get left at the bottom of a pile."

Events

Enfield Disability Network meetings

Pending the new **Our Voice** Development Coordinator(s) starting, Enfield Disability Network will continue to provide an opportunity for parents to network with professionals.

For parents of disabled children aged 6-11 10 November 2009 at 9.45-11.45am

Representatives of the Joint Service for Disabled Children will talk through the core offer for short breaks services.

For parents of children aged 12-15 17 November 2009 at 9.45-11.45am

Representatives of the Joint Service for Disabled Children will talk through the core offer for short breaks services.

For parents of pre-school children 24 November 2009 at 9.45-11.45

Linda Pryor of Enfield's Parent Partnership Service will start the meeting with a talk and question and answer session on the statement process and placements for pre-school children.

Contact: Megan Steven on 0208 363 4047 or at megan.steven@enfield.gov.uk to let us know if you are planning to join us.

Please note: All 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.

Special Educational Needs

25 November 2009 at 1-3pm

Confused about the special educational needs processes and what schools should be doing to support your child's education? Then come along to an informal talk and chat, given by the Enfield Parent Partnership Service (EPPS), to find out about the process and gain the information that you need. The Ark, Marsh House, Montagu Road, N9 0UR. To reserve your place please telephone EPPS on 020 8373 2700.

Early Years Parents' Workshops

Following requests from parents as a result of the Short Breaks Consultation, an Our Voice member is working on behalf of Sheila Gratton, Manager of the Early Intervention Support Service, (part of the Joint Service for Disabled Children), to set up a training programme aimed at parents with pre-school children who have a disability. The course, over four sessions, aims to help parents cope with their circumstances and give helpful hints and ideas on:

- how to obtain information
- how to access and to coordinate with professional agencies
- how to deal with their own emotions and
- how to look after themselves.

The first programme will run from **9:30-12:30 on the 2nd, 10th, 16th and 23rd of November** at Cheviots. If you are interested in attending, please email Fazilla Amide at f.amide@yahoo.co.uk by 23rd October.

Our Voice Parent Forum

Part Time Development Coordinator(s) £16 per hour

Do you have enthusiasm and commitment to take **Our Voice** to the next stage of its development as an active Forum for parents of disabled children? Then we want to hear from you.

Working an average of 12 hours a week - or two Development Coordinators working those hours on a job share basis - the role(s) can be carried out on a self-employed basis and might be suitable for those who receive Carers Allowance. This work might also suit parents who want to work the hours on a voluntary basis.

The posts are funded to 31 March 2010 in the first instance and the Development Coordinator(s) will need to secure funding from charitable trusts and/or the Local Authority beyond that date.

For more information contact Megan Steven at megan.steven@enfield.gov.uk by **16 October 2009**.