

Our Voice



Our Voice Newsletter

Issue 6, Summer 2009

Welcome

Welcome to the summer edition of the **Our Voice** newsletter. In this issue we take a look at the philosophy behind the Enfield-based **Chickenshed** theatre company and why they delight so many people with their workshops and performances. Whether your children are budding actors or prefer to watch, they'll enjoy a show at Chickenshed.

Many people shy away from using **direct payments**, believing they are a minefield of bureaucracy and not worth bothering with. But is this really the case? Read our guide and decide for yourself.

You'll remember that **Our Voice** was given funding earlier this year to formalise its position as the parent forum for parents of all disabled children living in Enfield. We're delighted to report that we've been overwhelmed with interest in the new forum and our membership has doubled in the last three months. We're also very pleased to welcome Orla Keeley as new Development Coordinator for **Our Voice**. There's more about **Our Voice** progress in **What's new** as well as news about how Enfield is improving short break services with the extra pathfinder funding it has received. Plus your chance to give the Every Disabled Child Matters Campaign (EDCM) feedback on what works for you.

A reminder that **Our Voice** is a parent-led organisation seeking to improve services for children and young people with disabilities or special needs in Enfield. **Julia Paylor**



Special thanks to:

The Disability Network Service of Enfield's Joint Service for Disabled Children, 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.

Chickenshed - everyone can thrive

Chickenshed is genuinely a theatre company for everyone. "Everything is for everybody and everyone can join in", Press Officer Susan Jamson sums up the deep-seated philosophy of all who work and perform for Chickenshed, which has its main theatre in Enfield.

Chickenshed began 35 years ago in Barnet, literally in a chicken shed, and moved to its Enfield

base on Chase Side, Southgate in 1994. Its unique methods mean that prior to a show, the cast is decided upon first and then the script adapted to fit the performers.



Performers may or may not have disabilities and come from many different walks of life. Literally everyone is welcome and this means that

when people come to watch a show there is almost always at least one performer that they can strongly identify with. There are 800 performers in total, taking part in shows and workshops around the UK and the theatre produces as good a performance as you would see anywhere.

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Julia Paylor ■ Telephone: 020 8292 0638 ■ Email: orlakeeley@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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The theatre company promote inclusion wherever they go but do not view their policy as 'doing good'. "People have lots to offer whoever they are and wherever they come from, we just help to harness their abilities," says Susan.

Shivaun, who is mum to three children, echoes this sentiment, "My three children have all enjoyed attending Chickenshed over the years. Many people are cautious around people with disabilities but this theatre ensures everyone, regardless of their needs, is ordinary to everyone who goes there."



Chickenshed runs children's and youth theatre workshops, education courses, community outreach projects and a network of satellite 'Sheds' across the country (and even

two in Russia). The workshops foster a nurturing environment where everyone has a voice and an input into the rehearsals and performances. They teach children respect for others and build their own self-esteem, but most importantly are great social experience and immensely enjoyable. As Joni, aged 9 enthuses, "My sister goes to Chickenshed too. It's great fun to do things together and this Christmas we will be in our first show. Although she has special needs she is treated just the same as anyone else and it's the highlight of our week."

Susan also has some personal experience of the benefits of the workshops as her daughter Emma, who has Down's Syndrome, attended one, "It taught her to listen. She's always had support workers with her at school and had got very used to them listening to instructions for her. At the workshop she was on her own and she really had to listen and participate for herself. She was part of a cast where everyone was important."

The workshops allow children and young people used to being on the receiving end of support a chance to support others, which can give them an immense confidence boost. For others it is just a great way to have fun. "You get to do shows, enjoy yourself and make friends with different people," says Declan, aged 11.

Chickenshed also run a fully inclusive BTEC course and foundation degree in partnership with Middlesex University. Admission is based on interviews rather than academic grades.

If you prefer to watch, the popular 'Tales from the shed' performance for under 7s has been running for several years. It is very much aimed at children - adults are not even allowed in without an accompanying child. So what can you expect from a show? "It's just brilliant, something to really lift your spirits", enthuses Susan. "The show is different each week so you'll never see the same performance twice."

Shows encompass a mixture of performance, puppets, mime, song and dance and are extremely colourful as well as being signed for young people who use British Sign Language. Each show has a theme which is often a topical one such as 'respect' or 'spring'. Children in the audience are encouraged to join in and be involved in the performance (although if they prefer not to, they don't have to). While there is a script, there is also a great deal of improvisation and because different children join in each time, every performance is unique.

There are performances on Friday and Saturday mornings from May through to 25 July.

Visit www.chickenshed.org.uk for more information on performance dates. To apply for your child to join an inclusive theatre project use the online application form, but be warned, at present there is a long waiting list.

What's new

New Development Coordinator

Hello everyone, I'm Orla, the new Development Coordinator for Our Voice. As a mother of a child with special needs, I am greatly aware of the many challenges we face. But I am also confident that if we, as parents, work together, some of these can be overcome.

I believe the parent forum is the ideal platform to share our views, ideas and experiences so we are all involved in improving the decision making process relating to our children.

I'm really looking forward to meeting you all very soon.

Best regards,
Orla Keeley
orlakeeley@ourvoiceenfield.org.uk



Aiming High for Disabled Children

Janet Leach, Head of Enfield's Joint Service for Disabled Children gives an update on the Aiming High programme in Enfield.

In brief:

Aiming High for Disabled Children: Better Support for Families was launched by the government in May 2007, and commits £430 million over three years (2008-11) to improve services for disabled children and their families.

The biggest single investment - £370 million - is being allocated to local authorities across England to transform short breaks provision.

Enfield is one of 21 pathfinder areas who have received significant funding to take forward best practice in short breaks over the next few years.

Many of you will be aware that Aiming High for Disabled Children is the Government's transformation programme for disabled children in England. The Government wants all families with disabled children to have the support they need to live 'ordinary family lives, as a matter of course'. Here in Enfield we completely support this aim.

So we need to:

- ensure our services are accessible and that you are involved in planning and developing them.
- focus on providing the services you want, ensuring you know how to get help and support, particularly at key times such as before your child starts school or during transition to adulthood.
- develop and provide more short breaks which families have described as their priority.

The Joint Service for Disabled Children (Cheviots Children's Centre and Service, the Early Intervention Support Team, including the Pre-School Support Service, Enfield NHS and the Voluntary Sector) is working together with parents and children to improve services, to give you the support your family needs.

What have we done over the past year?

Enfield is one of a small number of Local Authorities selected by the Government to lead the way in developing short breaks. Last year we received additional funding of £311,000, ahead of other areas. This is how we spent it:

- We employed parents of disabled children to talk to you about short breaks, to ask you how we should deliver short breaks and how we should provide you with information, advice and guidance
- You told us that holiday play schemes and after school groups are important to you so we provided significantly more children and young people with holiday play schemes and after school clubs.
- We worked with Facefront Theatre Company, Schools Out Club (SOCS) Crossroads Care and our Sports, Play Development and Extended Schools Teams to fund staff to support children enjoying drama and sports activities as well as providing transport to them
- We funded after-school groups in special schools
- We sponsored children having inclusive play schemes
- We provided more families with weekend activities and overnight breaks
- We provided more families with direct payments
- We ran pilot projects to test new ways of delivering short breaks including providing a small group of families with the opportunity to go on holiday together having some agreed support.
- We are producing new 'family friendly' information which will be available in the summer and will explain how you get advice and support, how you access short breaks and how we can work together to develop and improve services
- We updated and reprinted **Moving On**, our Parent/Carer guide to transition and produced a guide for young people. These guides and other information will be available in schools.
- We are working with our Parent Forum - Our Voice. Through this forum and the Disability Network we will meet with you and learn from you what we can do better.

Further development

This year we will receive 1.2 million pounds to further develop and provide more short breaks to more children and families. Our strategy to do this has been written in partnership with our parent consultants, who are all parents of disabled children. We will continue to concentrate on your priorities - holiday play schemes, out of school activities, home sitting and befriending, weekend activities and overnight short breaks

This summer we will run inclusive holiday play schemes at Raglan Junior School as well as at other venues. We are training all our staff to ensure they understand the needs of disabled children, so that they are skilled, trained and confident in supporting them. Cheviots will be running specialist holiday schemes as will CAPAG who we are funding to provide schemes at a number of venues throughout the borough.



We are also working with parents, young people and our colleagues in Adults' Services to improve transition for young people which we know can be a stressful

and challenging time for families.

Through meeting with you regularly and through this newsletter we will provide you with regular updates on our progress and keep you involved. We want to ensure we provide you with the right support at the right time so I look forward to seeing some of you on **9th June** at our first Our Voice/Disability Network meeting which will focus on the needs of families with pre-school children, 0 to 5 years.

Janet Leach

On behalf of the Joint Service for Disabled Children

For further information, advice or guidance please contact:

Sue Roberts, Manager at Cheviots Children's Centre/Disability Service on 020 8363 4047 or Sheila Gratton, Manager of the Early Years Intervention Service on 020 8350 5691.

To find out more about the government's **Aiming High for Disabled Children** programme go to www.everychildmatters.gov.uk/socialcare/ahdc

Our Voice is Your Voice - parent forum update

Under the Aiming High for Disabled Children agenda, Our Voice was given funding earlier this year to formalise its position as **the** parent forum for parents of disabled children living in Enfield. We're delighted to report that we have been overwhelmed with interest in the new forum and our membership has doubled in the last three months so that we now have close to 400 members. Throughout February and March this year we met with over 40 parents, mainly of pre-school children and those in mainstream provision, to explain how we will work with the local authority and to find out what services need to be improved in Enfield. We are now meeting parents of children in special schools during May, June and July.

Who can join us?

Our Voice is open to parents and carers of children with any kind of disability - physical, learning, communication, behavioural, sensory and rare conditions. Your child does not need to have a diagnosis. Membership is free and the only commitment we ask is for you to keep yourselves updated by receiving our termly newsletters. However, for those of you who are prepared to volunteer some support we particularly need your help to respond to consultations and act as representatives on decision-making bodies where we can really begin to make a difference. Our Voice works with existing groups and signposts parents to organisations that can help them. Although we are not able to take on individual issues we take forward common problems for particular groups of disabled children with the aim of improving services in the future.



How do we work?

We are in discussion with the Joint Service for Disabled Children about how **Our Voice** will have parent representatives on decision-making bodies. We will feed into all Disability Network meetings and keep parents updated with our progress.

What have you told us?

You praised a number of services and organisations including the Pre-School Support Service, CAPAG and Cheviot's play schemes, Enfield National Autistic Society and after school clubs, as well as counselling for parents. The London Development Agency funding for childcare for parents of disabled children to train, volunteer or get back into work was also praised and you told us that children had benefited from the Tiger Teams in mainstream schools.

We asked you to tell us what needs to improve: the biggest area of concern is **a perceived lack of support from SEN services**, particularly for those children going to mainstream school or where there is a disagreement about a special school placement. You are concerned about the way decisions are made within SEN services and the Panel process. You felt support from Special Educational Needs Coordinators is patchy in terms of empathy and knowledge of services. This is clearly a training issue and **Our Voice** would like to work with SEN services to deliver training in future.

Speech and Language Therapy input was raised as a concern by almost all parents of children in mainstream schools. We also met a number of parents whose reception-age children were not able to attend school full time - against the parents' wishes - because there was a disagreement between the school and the LA about how support should be provided and funded and by whom.

In terms of **health**, you felt that the quality of support varied and was often down to individuals. Some professionals follow up issues with parents efficiently, whilst others seem to need chasing and re-chasing, which is exhausting. You often only found out about alternatives to meeting your children's health needs, such as those offered by Great Ormond Street, via other parents. You had concerns about the bureaucracy surrounding the facilities grant for adapted housing and would like a parent to sit on the panel that issues grants. Finally, you felt you did not know about essential services and the waiting list was too long between an assessment and short break services kicking in.

What did we do with the information you gave us?

The concerns you raise were detailed in a report issued to the Joint Service for Disabled Children. You can view it at www.ourvoicenfield.org.uk or you can contact us for a copy. It is cheaper for us to email you but if you do not have access to a computer, we are happy to post you a copy.

We will report any progress in forthcoming issues of our newsletter. Our next priority is to ask for representation on decision-making bodies and we will approach you soon if you offered to do this.

What next?

During the summer our focus will shift to parents of children in special schools. We will report our findings to Enfield's Joint Service and will up-date parents in the Autumn Newsletter. Orla Keeley, our new Development Coordinator, has visited Waverley and West Lea schools in May and hopes to visit Russett House, Oaktree and Durants in June and July.

We want to work closer with black and minority ethnic communities in Enfield, including those who are newly arrived in the borough. If you have contacts within these communities or can facilitate a meeting please let us know. **Our Voice** can fund an interpreter and pay for the venue.

We have started discussions with the Joint Service for Disabled Children about how we can best influence services and keep parents informed without you needing to attend too many meetings. One new development we will be piloting over the coming months is to run our termly meetings as a joint **Our Voice/Disability Network** meeting - see Events on the back page for more information.

These meetings will be split by age group with a termly meeting for each group; pre-school 0-5, 5-11, 12-15 and transition. Each meeting will have a topic and discussion time. Our Voice will also meet with parents without professionals once a term directly before each Disability Network meeting.

We'll also continue our positive dialogue with service providers and formalise a structure for working with them. We have already made plenty of progress although, of course, the structure and process for providing information and influencing decisions will continue to evolve over time. We'll keep you informed of progress via our website, newsletters and meetings.

Did you know?

Direct payments - red tape or godsend?

"I tried it for two days - too much paperwork and red tape." Mum of 15-year-old boy in a special school.

Your views on short breaks

If you are receiving short breaks services in Enfield, or think your family need them but are not getting them, please help us by sharing your experiences. We are looking for parents of disabled children in Enfield to work with the Every Disabled Child Matters Campaign (EDCM) and Our Voice. We need your help to evaluate the impact of the government's programme to improve the provision of short breaks (formerly known as respite) for disabled children and their families. Short breaks might include after school and holiday play-schemes, help in the home, home sitting, befriending/buddying and overnight stays, carer support whilst on holidays as well as those provided by direct payments.

All we ask is that you come to a meeting in Enfield four times a year over the next couple of years. We can arrange crèche facilities or pay for child care and your transport costs will be refunded. We are also keen to hear from people with English as a second language

and can provide translators. In return for your time we provide an opportunity to network with other parents of disabled children and of course tea, coffee and cakes.

What you tell us will enable EDCM to track the impact of funding on your experience of short breaks. This information will be fed back to the government so they can see how the funding is making a difference to families and use our findings to campaign for sustained investment for short breaks from 2011.

To find out more, including details of the first Enfield Tracking meeting to be held on the morning of **23 June**, please contact Orla Keeley, Our Voice Development Coordinator at orlakeeley@ourvoiceenfield.org.uk or Julia Paylor on 0208 292 0638 by 16 June. Help us help EDCM help you!

Every Disabled Child Matters is the campaign to get rights and justice for disabled children and their families. To find out more visit www.edcm.org.uk

This view sums up the experience of many parents and goes some way to explaining why direct payments are still not being used by many people who are eligible for them.

The current number of families receiving a direct payment in Enfield during 2008/09 is only 38 - a relatively small number which perhaps highlights further that direct payments are not a popular choice for the service user.

But once you get around the red tape, direct payments can increase your choices about what kind of support you get, when you get it and give you greater control over your life. We take a look at what they are and how you get them.

What are direct payments?

Direct payments are cash payments made to individuals who have been assessed as needing services, in place of social care provision. They can be made to disabled people aged 16 or over, to people with parental responsibility for disabled children, and to carers aged 16 or over for carer services.

The aim of a direct payment is to give more flexibility in how services are provided. By giving individuals money in place of social care services it

gives people greater choice and control over their lives, so they are able to make decisions about how their care is delivered.

Who can receive them?

Direct payments can be made to any disabled person over the age of 16 or to people with parental responsibility for disabled children. If you opt to receive them regularly, in Enfield and most other boroughs a separate bank account must be opened unless it is a one-off payment, so that you can manage the direct payment money more easily.

To get direct payments a social care assessment is required to determine if you are in need of social care support to help look after your child. Social care professionals will also need to be satisfied that your child will be safe and happy if you get direct payments, so they need to be confident that you are able to make good decisions about what services you buy, in place of social care provision.

Parents often find it difficult to recruit carers (although relatives can be employed if they live at a different address) and need support with the forms associated with employing them. However, Enfield Disability Action provides advice about completing the paperwork.

"I had to push to get direct payments and I'm glad I did. I now feel I have control over my life, and have the flexibility over how and when I use my carer. Mum of 2.5 year old girl in special school.

What can they be used for?

You can use direct payments to pay for support services for your disabled child. However, social services must assess the types of services your child needs first.

Here are some examples of the kinds of things you can use direct payments for:

- to pay for a personal assistant to help your child go swimming or to the cinema
- to pay someone to help your child with washing, getting dressed or eating
- to pay for your child to spend a night with another family to give you a break
- to pay for someone to provide help in the home so you have more time to look after your child - this must be agreed with your social care professional.
- for some kinds of equipment - this must be discussed with your occupational therapist.

Enfield will soon be producing an easy guide to direct payments for parent and carers. If you would like to try direct payments, speak to Cheviots Children's Disability Service on 020 8363 4047. If you decide that they don't suit you, you can always go back to having services allocated to you.

Further information

www.specialkidsintheuk.org website has a useful short summary about direct payments and what they can be used for.

Scope's website www.scope.org.uk includes a longer 24 page factsheet entitled 'In the driving seat - direct payments for your child' written in an easy read format.

Gold star award

The nomination for the Gold star award this time comes from Natalie Keys who would like to thank those who work with her son Mathew.

"I would like to nominate Raglan Infant School for the exemplary way in which it provides for the educational needs of its children with SEN, particularly the SENCO Coordinator Mrs Davies and class teacher Mrs Coelho. They have nurtured and supported my son Mathew, who has exceptional special needs.

I would also like to nominate Marie Clifford (Teacher in charge), Lee (Speech therapist) and Leone from Houndsfield Speech and Language Unit. The work they do has been indispensable in helping my son to communicate.

Since these five professionals have taken an active interest, the difference in my child is phenomenal - I honestly can't believe he is the same child. Before he hardly spoke, now we can't get a word in edgeways.

I don't know how to express my gratitude for their unceasing efforts with my son. They go above and beyond what duty requires of them and I have found their support invaluable."

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 six year old daughter Muni is disabled with undiagnosed global developmental delay. She attends a mainstream primary school with 21 hours of one-to-one learning support assistance. We will be having our first annual review of her statement in two months time. I am concerned about two issues. Firstly, although the Statement provides for a review of Muni's needs by an Occupational Therapist (OT) at least once every half term, she has not seen an OT for over two terms. This is despite our concerns about her fine motor movements. Secondly, her Statement says that she should receive a programme of speech and language therapy under the guidance of a speech and language therapist. The therapist came in last term and talked through a programme with the LSA but this is not adequate for my daughter's needs. How can I get an OT to see my daughter? How can I ensure she is receiving the speech and language support she needs, considering there is agreement amongst the professionals that she is experiencing delay with her development in this area?

A. Where a child has a statement, the LEA has a legal obligation to ensure that the provision set out in Parts 3 and 4 of the statement is made. Assuming that your OT and Speech and Language Therapy (SLT) provision in Part 3 (and not in Part 6, in which case the LEA cannot be forced to provide it) that means that the LEA must take any steps necessary to get the provision put in place. If they ask someone else to do it, and that other person does not, then the LEA is required to make other arrangements.

However, it is important to check exactly what the statement says about what should be provided. If a statement is vague, and does not say clearly how much provision a child should get, or how often, then it may be difficult to show that the LEA are not meeting their legal duty. However, if the statement clearly says that Muni should have a review by an OT at least once per half term, then the LEA should be arranging those reviews. In failing to do so, the LEA is acting unlawfully, and you may wish to seek legal advice about enforcing the statement. Even if you do not, you can raise this with the LEA either before or at the Annual Review and insist that they ensure that the provision set out in the statement is made.

In relation to SLT, if the statement says that Muni should have a 'programme' under the guidance of a therapist, it may be that what the LEA is doing meets that requirement, so that they would be complying with their legal duty.

If so, then in order to obtain more provision you would need to seek changes to the statement. You should certainly raise the question of increased SLT input at the Annual Review and point to the professional agreement that is required. The LEA would however probably be entitled to refuse to amend the statement (and may also take a long time in making a decision at all after the Annual Review).

If they refuse, then the only way of pushing for an amended statement would be by requesting a statutory re-assessment of Muni's needs. The LEA would have to decide whether to re-assess (and you could appeal if they refuse). If they carried out an assessment, then at the end of that process you could appeal about the contents of the statement whether or not they issue a new statement.

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

Events

Future Our Voice/Disability Network Meetings

Future Our Voice meetings will be run as joint events with Enfield's Disability Network. We are piloting this new development to improve channels of communication with service providers and to influence decisions more effectively.

Under the new format parents will still have time together as a Forum - without professionals present - to share our experiences of services. Professionals will then join the meeting to provide relevant information and answer questions raised by individual parents and Our Voice representatives. It will be an opportunity for parents to talk informally with professionals and for parents and professionals to learn from each other. During the autumn term we will ensure we meet at least once with parents of children of key age groups including pre school, 5 -11, 12 -15 and transition age.

Our first joint Our Voice/Disability Network meeting will take place on **Tuesday 9 June from 9.30am to 12 noon** at Cheviots, 31 Cheviots Close, Enfield EN1 3UZ. All parents of pre-school children aged 0-5 with special needs are most welcome. The first half of the meeting will provide an opportunity to meet other parents, talk through services and explore common issues parents feel need to be addressed by professionals. At 10.45am we will be joined by representatives of the Joint Service and associated agencies.

Each meeting will have a theme. This time Janet Leach, Head of the Joint Service and Sheila Gratton, the Early Years Manager from the Joint Service will explain the Local Core Offer for Short Breaks Services for parents of children under five. A crèche will be provided.

Please let us know - via the contact details on this newsletter - if you can come along. We are a friendly group and you will be greeted with a warm welcome.

Registration

Our is a membership organisation. There is no fee to join. To receive three newsletters a year please telephone or email us to register. Please note that we no longer mail this newsletter to mainstream schools so it is important that you get in touch with us direct to register.