

Our Voice



Our Voice Newsletter

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Winter/Spring



Welcome

Welcome to the winter/spring 2011 issue of the **Our Voice** newsletter, the parent-led organisation seeking to improve services for children with disabilities in Enfield.

Times are already challenging and spending cuts are on the way. In this issue we summarise how changes to benefits might affect families with disabled children.

We have the usual news from the Joint Service for Disabled Children as well as hearing about how children enjoyed the specialist playschemes in Enfield last summer and we also find out all about a lively young people's question time event held recently.

How do young people feel about having a disabled brother or sister? We include extracts from Birsens' inspiring talk given at the Aiming High celebration event in November about how having a disabled sister is sometimes difficult but always life-enriching for her.

Life with a disabled child has its ups and downs and it can be difficult to know where to go for support. Our programme of six workshops for parents and carers will give you a wealth of information and tips to help you cope with your child's condition and enjoy parenthood more. Look out for more details on the back page.

Carol Mustafa

Our Voice Development Coordinator

What's new

Making ends meet

The government's white paper on Welfare Reform proposes the biggest changes to benefits since the Second World War. There are currently over 50 different benefits that can be claimed, depending on your circumstances. The Welfare Reform is designed to simplify the system as well as saving billions of pounds. These savings mean that there will be cuts to a number of benefits. So what will it mean for families caring for a disabled child? Here's a summary of some of the proposed changes.

Disability Living Allowance (DLA)

DLA is a tax-free benefit for disabled people, including children, who need somebody to help look after them. The government wants to make cuts of 20% by replacing Disability Living Allowance

with a new Personal Independence Payment (PIP) from April 2013. A new medical test would apply to all new and existing claims from 2013, and could result in a steep fall in the numbers of claimants. DLA is one of the biggest benefits paid in the UK and the government aims to save £1 billion. The proposals are part of a consultation process that ends on 14 February.

Consumer Price Index

From April 2011 the Consumer Price Index (CPI) will be used for the indexation of all benefits rather than the Retail Price Index. This is likely to result in benefits not keeping pace with cost of living rises as the CPI is historically much lower than RPI.

Universal Credit

From 2013 the 30 or so current work-related benefits will be merged into a single Universal Credit
continued on page two

Credit. The government has promised that, under the new system, people will always be better off in work than on benefits. There would be stricter rules for people losing their payments if they refused a job, with those who do so three times losing their benefits for three months.

Child Benefit

Child Benefit will be removed from families with a higher rate taxpayer from 2013. For everyone else it will be frozen for the next three years from April 2011.



Child Tax Credit

From April 2011, Child tax credits will be withdrawn for families earning more than £40,000 a year, rather than the current £50,000.

Child Trust Fund

Has been withdrawn completely at the start of 2011, parents were paid a voucher to invest for their children who could access the money at the age of 18.

Housing Benefit

New Housing Benefit caps will be £250 a week for a one bedroom property, £290 for two bedrooms, £340 for three and £400 for a four bedroom property. It will affect high cost areas such as London the most.

Extra funding for short breaks?

Providing short breaks for disabled children gives families much-needed help and can make the difference that allows them to keep going.

To help improve the way short breaks are provided, the Government has allocated £800 million over the next four years. The extra funding comes ahead of a complete overhaul of the special educational needs (SEN) system over the next few years.

Responses to the SEN Green Paper from parents, teachers, local authorities and others show that

- the SEN system is overly complex
- parents want to get better information on the services available
- better training is needed for school staff
- education, health and social care services need to work better together.

Ministers are keen to ensure the green paper takes account of everyone's concerns and delivers real changes with lasting benefits for children with SEN and disabilities and their families. The views gathered will inform the work on the green paper, which is soon to be published in February 2011.

Funding for short breaks has been protected in the Comprehensive Spending Review and will be included in the new Early Intervention Grant for local authorities. The funding includes additional money, recycled from savings to the Child Trust Fund.

However, local authorities are facing big cuts and the money that's been put aside for short breaks has not been ring-fenced, so councils may actually choose to spend that money elsewhere. Janet Leach, Head of Enfield's Joint Service assured us that, "Local and national research is clear about the cost effectiveness of short break services. Enfield's Joint Service will be working with Our Voice and with other parent and young person groups to consider how short breaks can continue to be delivered efficiently, making the best of their available resources and ensuring all eligible families receive the right level of support. For example it may be possible to reduce some of the transport costs thereby releasing funding for more playscheme sessions. The Joint Service wants to ensure that short breaks are allocated equitably and transparently and has no plans to reduce the number of short breaks. The Joint Service is committed to providing high quality services which meet the many different needs of the families living in Enfield."

Young people's consultation update

The boot is on the other foot!

In Autumn 2010 the Young People's Consultation Group (YPCG) held their own "Question time" Event at Oaktree School. The YPCG had a huge range of questions to put to those senior staff that make the decisions about services for Young People in Enfield.

We were very pleased to welcome Janet Leach (Head of the Joint Service), Yemi Akimfemwi (Youth Participation Lead), Stefan Cadek (Deputy Head of

the Youth Service), David Barnard (Deputy Head of the Youth Service) and Mick Lees (Police Inspector) to the event. The YPCG had clearly spent a lot of time and effort ensuring that their questions represented the views of all disabled young people in the borough.

Stefan Cadek spoke for all the panel when he said, **"...the young people had come up with some excellent questions and I was very impressed with their confidence in asking questions and also their ability to probe and ask follow ups. "**

David Barnard commented **"The importance of having the opportunity to hear first hand from young people about their hopes, concerns, aspirations and needs is crucial when it comes to understanding and delivering good services. The Question Time format was excellent, giving everyone a chance to be heard whilst remaining informal enough to be fun."**

Janet Leach stated that the YPCG are a **".....force to be reckoned with - which is exactly what we want - the voice of young people loud and clear!"**

Mick Lees stated **"The young people at the school asked some very sensible questions about crime that affects all their lives and I hope I was able to reassure them and helped to make them feel safer."**

The YPCG wrote the event up as follows:
We all really enjoyed having the opportunity to ask senior staff questions about their plans for our services in the future and how to keep safe in Enfield. Because senior staff came we felt we were really being listened to.



"The boot was firmly on the other foot" as we got to "grill" the police! Mick came across as very caring and clearly wanted to make us feel safer on the streets. We told him about our worries about knife crime, gangs and bullying and he listened and advised us on how we can

keep safe and out of trouble. He told us about the safer neighbourhood and transport officers and

how it is their job to help us feel safe on the streets of Enfield. He informed us of the CHPS scheme (community help points) and how these can be places of safety when we are in danger. We all feel he coped well "under interrogation" and he promised to come and see us again and talk to us in greater detail about these issues.

Janet Leach answered questions about the future of services in Enfield. She was very passionate! She was able to reassure us that our playschemes would remain open. She stated that we are not as rich as we were before so we must spend any money in the future very wisely and it is up to us to tell her exactly what we want. Despite difficult times ahead she will support the group to keep what is most important to us like the befriending groups. We will certainly be keeping an eye on future developments.

We asked Stefan, David and Yemi questions about things that worried us most when we think about coming to youth service activities, namely gangs, knife crime and safety.

They said that:
"..All youth workers have been trained to deal with bullying, conflict and bad behaviour. We also run activities which focus on bullying and look at different people's beliefs and encourage people to respect those who are different from you."

David talked about gangs and how we can keep away from joining them. We were disappointed that there was no befriending service at the moment in the youth service but we were promised that the youth and joint services would prioritise this in the future. The youth staff answered all our questions well and treated us with a lot of respect.

At the end of the interviews we felt a little safer, listened to and we are looking forward to a bright future.

YPCG intend to repeat the question time at a future date and invite MPs and Heads of Service watch this space.

Over the next six weeks the YPCG is writing a magazine article with a little help from our friends in the youth service. It will cover the issues that are important to us and what we would like to see changed. **Are there any young people aged 13-21 who want to have a say about services and activities in Enfield? Would you like to join our growing group in telling managers how it really is? Please contact Shaun at Cheviots Disability Service 0208 366 4203.**

PARENTS would you like to give us your views on what is important for disabled children? If so please come to one of our meetings.

Keone, Vijay, Connor, George, Jon, Chloe, Atlanta, Simon, Gary, Mark, Ben, Sena, Vinay, Zainab, Dalian, Belgu, Oliver, Shaun, Stephen of the YPCG.

Playschemes at Cheviots

Su Brown, the Centre Worker Manager at Cheviots tells us about how children enjoyed the specialist playschemes in Enfield last summer.

Cheviots is part of Enfield's Joint Service for Disabled Children and is one of the specialist playscheme providers that deliver short breaks to families of children with a wide variety of disabilities. Over the last year we have offered 150 children and young people holiday playschemes, and I am pleased to say that we currently have no families waiting to attend Cheviots playschemes.

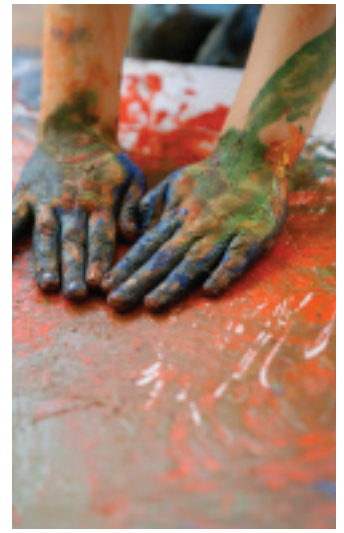
At Cheviots we always use the skills and experience of our staff to plan appropriate and fun activities. We ensure that we tailor the activities to the individual needs of each child/young person. During the summer playscheme the children/young people enjoyed getting involved with the activities on offer that linked to a specific theme. The 'Playdays' group which provides the playscheme for the 5 to 9 year olds, had the theme of 'On the beach'. The children enjoyed activities such as making collages of animals you find on the beach, water play and messy play using sand, jelly, puffed rice and much more!



The 'Holiday Club' group which provides playschemes for the 9 to 14 year olds had the theme of 'Around the world'. Each week the children/young people had fun enjoying cooking, music, and art, all linked to a particular country.

The 'Leisure Options' group which provides holiday activities for the 14 to 17 year olds enjoyed

the theme of 'Shops'. The young people set up different shops including a clothes shop, music shop, a travel agent and a café. They were very creative in producing the 'shop fronts', a cash point and items to sell in each shop which included musical instruments, t-shirt printing, passports and food.



Some of the great art work produced during the Summer playschemes was displayed during the Aiming High Celebration event that took place in November 2010.

We are always striving to improve our service so at every scheme we talk to everyone about what they have enjoyed and how we can make playschemes better. When we asked the children/young people if they think our playschemes are fun the response was overwhelmingly positive. We ensured that all young people's opinions were counted by helping them to have 'their say' through using symbols, signs, pictures and interpretation of facial and behavioural gestures.

Most parents said that their children enjoyed the playscheme. They told us their children enjoyed trips out, accessing the local community in a safe way, soft play, sensory room, messy play, cooking, bouncy castle, outdoor activities, painting and water play.

Some parents would however like to see the children visiting different places, with them contributing to costs, some parents would appreciate name badges for the staff and some parents would like the day to start earlier and end later.

Although most parents feel they are receiving a worthwhile break they would like more playscheme days. Some parents also told us about the need for overnight short breaks.

Our staff told us they enjoyed working on the playscheme. Most feel confident in their role and others said their confidence grew as they built relationships with the children/young people. The questionnaires illustrate that we seem to be getting 'a lot right'; we will of course with your help, work hard to continue to improve.

News from the Joint Service

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

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At the end of last year many of you will know that we held a celebration of the work done - so far - by Enfield's Joint Service for Disabled Children together with our many partners in delivering the **Aiming High for Disabled Children** three year transformation programme. It was held on 23rd and 24th November 2010 at the Dugdale Centre in Enfield.

There was a fantastic programme of events including performances by the children and young people from Waverley, Oaktree and West Lea Schools and an art exhibition from the students at Durants School, as well as presentations from parents and siblings of disabled children. There was also a market place with a whole host of services and information available.

Parents and colleagues heard how the Joint Service has developed over the past three years to deliver better services for disabled young people. Our relationship with parents of disabled children and with the young people themselves is the key to the improvements that have been achieved so far. We have listened to their views and ideas and together with all our partners including the Voluntary Sector, Adult's Services, Health and Special Educational Needs colleagues we have planned services to ensure that they more effectively meet the needs of our disabled children and young people and their families.

Successful partnerships with schools were also highlighted, notably our partnership with Raglan School. Together with our partners in the Play Development Team we have developed a new and fully inclusive holiday playscheme based at Raglan.

We welcomed politicians and many professionals to the event including Nick De Bois MP for Enfield

North, Leader of the Council Doug Taylor, the Lead Member for Children's Services, Councillor Orhan, our Chief Executive Rob Leake and Andrew Fraser, Director of our Schools and Children's Services. Parents and young people had the opportunity to meet and talk to all those present.

Whilst I acknowledge there is still lots to be done, the event was recognition of the significant improvements that can be achieved when parents, young people and professionals genuinely come together to improve services.

Here are some of the developments and improvements we have made so far:

Short breaks for disabled children young people and their families have been extended and increased and now include:

- Inclusive and specialist afterschool and weekend clubs; holiday playschemes, holiday leisure activities, home sitting, home care, befriending and a range of overnight breaks and more families now use direct payments to buy their short breaks.

Other service improvements include;

- Disabled young people represented on the Youth Parliament;
- Parents represented on the Aiming High, Special Educational Needs and Transition Steering Groups
- Improved transition pathways to adult services
- Improved Access to Childcare through the Disabled Children's Access to Childcare programme
- Improved and more accessible public information - the Joint Service Access Framework and information about short breaks and services is now on the Borough's website

Finally I would like to say a big thank you to all those parents, politicians and professionals who attended the event and contributed to making it such a success. Thanks also for your continued support and commitment to improving the lives of disabled children and their families here in Enfield. Collectively we really are working together to ensure that in Enfield 'disabled children are everybody's business'!

In the picture

The charity Scope's In the picture campaign raises awareness of the importance of stories featuring disabled characters. Here's our pick of some of the best books aimed at younger children:

The Sleepover by Irene Mooney Kid Premiership, 2007

First in a series of inclusive early years story books. The Sleepover tells the story of three best friends at school who are having their first sleepover. Join the girls as they imagine all the different ways they can climb the stairs and get into bed! One of the girls is a wheelchair user.

Moonbird by Joyce Dunbar Doubleday, 2006



A fairy tale about a young prince who is deaf and hears sounds in a different way. A Moonbird teaches him how to use his hands and eyes to communicate.

Jungle School (Banana Storybooks: Green) by Elizabeth Laird, Roz Davison Egmont Books, 2006

It's Jani's first day at school and she's nervous. Will the other monkeys be friendly? Will they stare at her? Jani uses a wheelchair and this makes her different. But, thanks to her cheekiness, she makes friends and has a very nice first day at school.



Best friends, a pop up book by illustrator Mark Chambers Tango Books, 2008

A story about two best friends who pretend to be pirates, mountain climbers, Olympic sprinters and more. They have a great time together. One of the children is a wheelchair user.



Looking after Louis by Lesley Ely Frances Lincoln, 2005



Louis is a new boy in school who really likes to play football but because he has autism he tends to run through the boys playing with his arms in the air - rather like a ballet dancer. The class learns that each individual has different needs and different ways to learn.

All of the above titles are available from www.amazon.co.uk

Did you know?

Enfield Advice Plus Partnership

Enfield Advice Plus Partnership (EAPP) helps people living in Enfield to access advice and information on housing, benefits, debt and community care. If you have a problem with getting the right adaptations for your home, if you are struggling to make ends meet or if you would just like to know what help is out there please contact us via the details below.

Here is an example of how we've helped parents:

A couple based in Edmonton had a daughter who is autistic. The daughter had been going to college, which was slightly further away than the local college, for two years. The daughter was comfortable there and had made a number of friends. The course was specially required to help her socially, as mentioned in her care plan. The council then decided that they would not fund the transport any longer. The parents got in contact with EAPP and we supported them by taking on the case, referring them to appropriate organisations and also getting a benefits check for the mother. In the end, the council decided to continue to fund the transport for the daughter and she was able to continue her college course.

If you think EAPP can help you call 020 8373 6330 or email eapp@e-d-a.org.uk

Newlife Foundation for Disabled Children

If you have a child with a disability, a long term health problem, learning difficulty or life limiting condition.

Our experienced nurses help thousands of families all over the UK, delivering genuine care, a listening ear, support, access to grants and information on:

- Conditions and treatments
- Equipment grants
- Referral services/signposting
- Rights and benefits

Or call if you just need to talk.

Grants

Newlife nurses are also the gateway to accessing our non-means tested equipment grants - mobility needs, pain relief, safety, communication, seating, special beds and more.

Free confidential helpline and email service: 0800 902 0095

Lines open Monday - Friday 9.30am-5pm and until 7pm on Wednesdays plus 24 hour ansaphone. Email: nurse@newlifecharity.co.uk Online live chat at newlifecharity.co.uk/live

Big Lottery Children's Play Programme

Janet Leach, Head of Enfield's Joint Service for Disabled Children with news about a successful lottery bid.



You may be aware that Enfield Children and Young Person's Service, the Play Development Service, the Joint Service for Disabled Children and our partners in Housing and Highways successfully bid for Big Lottery funding for the period February 2008 to January 2011.

This funding was used to provide transport to ensure children and young people with disabilities and additional needs could enjoy a range of leisure activities and holiday play schemes both in the borough and beyond.

A minimum of 600 unique children have benefited from the funding, most of them using the available transport on several occasions and for many of them it provided the transport for a series of activity sessions. We have really appreciated this funding so a big thank-you to the Big Lottery!

We will continue to work with all our partners to look at potential funding sources for transport and with Our Voice to identify ways in which we can bring our transport costs down.

Of course we want to provide young people with opportunities to develop their independence skills and where possible become independent travellers, so we are talking to young people and families about how we can support them to achieve this.

Speak up - your experiences

In this section we share some of your personal experiences of having a disabled child or sibling. Please get in touch if you have an experience you'd like to share. Here are some extracts from the talk that was given by Birsen Akkoyunoglu at the recent Aiming High Celebration Event. Birsen's sister Berfin is disabled.

"I have a younger sister who is disabled; she attends Waverly School. As her sister I'm very happy with the way she's treated and looked after there, she comes home jolly and looks like she's had an amazing day either face painting or going to the park. So I'd just like to say thank you for helping us and for brightening up my sister's life in many ways.

I don't remember a moment in my life when she wasn't there, I mean as I grew up my parents always helped me understand what was going on and why... Of course as a child I wondered what the reason was, what made her so unique, but never looked at her and wished I had a different sister because I'm SO happy my sister is the way she is, and I know that every other person in the same or a similar situation to me feels pretty much the same and it's impossible for me to imagine a life without her. So at a young age I got used to the idea of my sister not being as able as I am, long before I knew myself. Though you become more and more aware of what's changing around you your family and your brother or sister as time passes.

As all the people in the family grow older responsibilities gradually increase, I don't believe my parents should have more responsibilities than me I believe that we all should have it equal and when I think about my sister's future aloud wondering what happens to her after the age 19 and planning how I can help supply my family with support my parents both tell me it's not my responsibility and that this shouldn't be a part of my worries... but to me it sounds inhumane to think, 'Once I'm 18 I have my own life to get on with'. Because my sister and I are one and never will be any different.

Getting used to people around commenting in a harsh way or, for example, seeing a little 5-year-old stand and stare at my sister like she's something to be afraid of, hurt and still does but I guess we were the ones misunderstanding, maybe they're just looking at their beauty wondering why we don't shine as bright as them.

We moan about how hard life is for us but really who is it hard for... them or us? I think it takes a lot to be able to adapt to a life when you're expected to be independent. And I'm so proud of my sister for the development she's made to this day and of every single person with any sort of disability...I strongly believe that you all are so much cleverer and gifted than we or I am and ever will be."

Haircuts at home

Do you dread taking your child for a haircut?

If so, I can come and cut their hair in the comfort of your own home.

My name is Bina, I am a fully qualified hairdresser with experience of cutting hair of children with special needs.

Please contact me on 07957 709037 to arrange an appointment.

Events

Our Voice/Enfield Disability Network meetings

Providing an opportunity for parents to network with professionals

Wednesday 16 March at Bush Hill Park Children's Centre between 1- 3pm

For parents with children of all ages

Friday 25 March at Oaktree School between 1.30 - 3pm.

For parents with children of all ages

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

Please note: Crèche places can be provided for your child but we need at least one week's notice please. Contact Megan Steven on 0208 363 4047 or at megan.steven@enfield.gov.uk

Our Voice Workshops for parents

This programme of 6 workshops is specially designed for families with a child with additional needs. It will help you to:

- Understand national and local services for children and families
- Understand how to access information and what is available
- Feel confident about working with practitioners and making decisions about your child

- Have a greater awareness of the needs you and your family may experience

The workshops have been planned and written by parents who have direct experience of a having a child in the family with additional needs. We want these workshops to help you cope with your child's condition; to take pleasure in being with them and to enjoy parenthood, not just struggle with it.

Who are workshops for?

The workshops are aimed at parents/carers and the wider family of a child with additional needs of any age. It is envisaged that parent/carers attend as many of the 6 sessions as possible. We are offering a treat for those who attend all 6 workshops: a free therapy treatment (eg a massage) - details to be announced at the final session on 17th June.

The programme will be led by Fazilla Amide, an Enfield parent of a child with special needs and will be conducted on behalf of Our Voice.

The 6 workshops will be held at Cheviots from 12.15 - 2.30pm, every Friday afternoon from 6th May to the 17th June (excluding half term):

- Friday 6th May - Workshop 1 - Understanding this new world - explores how to obtain information, how to access support and to learn more about national and local services.
- Friday 13th and 20th May - Workshops 2 & 3 - Changing relationships - explores how to work in partnership with service providers to help build your confidence
- Friday 27th May & 10th June - Workshops 4 & 5 - Acknowledging your emotions - explores the issues around dealing with feelings and emotions, and looking after yourself.
- Friday 17th June - Workshop 6 - Understanding family relationships - considers the wider family and how to have quality time.

Note: A creche place can be provided if necessary. Places are limited so book now!

If you wish to confirm your attendance, book a creche place or have any queries, please telephone Carol Mustafa on 07503 161248 or email carol@ourvoiceenfield.org.uk by 29th April 2011