

# Our Voice



**Our Voice Newsletter**

Issue 5, Spring 2009

## Welcome

Welcome to the spring 2009 issue of the Our Voice newsletter. We're delighted to report that **Our Voice** has been given a grant to establish ourselves as a parent forum. Please join us by filling in our short questionnaire and letting us know how you'd like to be involved - it's our chance to really make a difference to the support and services for disabled children in Enfield. Read more about this in our **What's new** section.

Our main feature this time focuses on transition. We talk to two parents who have recent first-hand experience of supporting their children through a transitional period in their education. First, Liz Willis tells us about her very positive experiences of moving her son Finley from pre-school to a mainstream primary school in Enfield. For Liz, preparation was the key to her success. At the other end of the spectrum Jane Richards' son Marc is just finishing his statutory education and she talks about her feelings as he becomes an adult.

We also celebrate Sean Jean-Houston's sporting success in our **Speak Up** section and include our usual legal question and answer from solicitor Chris Barnett.

We welcome your experiences, views and comments. To contribute to future issues of this newsletter please do get in touch. **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.

## Changing times

Undergoing a period of transition to or from school can be stressful and challenging, as well as exciting. We talked to two parents about their quite different experiences.

"Start preparing as early as you possibly can", is Liz Willis's advice to parents of children about to start school. Her son Finley has started his second term



at St Georges, a mainstream primary school in Enfield. Their experience of transition has been excellent, but this is down to many hours of hard work and preparation on the part of both Liz and the school.

Since birth, Finley has had a very rare metabolic disorder which means his body does not absorb vitamin B12. It's so rare that there is only one other child in the country with the condition. It affects brain and eye development and means that Finley has learning difficulties and is registered severely sight impaired. Despite this, he is a very happy, sociable child known as a 'real charmer'. He uses his remaining sight extremely well.

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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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"It was a daunting prospect for us moving Finley from the safe, cosy environment of his pre-school into a large mainstream primary", says Liz. Finley went to Lesley Vincent's Leapfrog nursery attended by both mainstream and special needs children, spending three full days a week there. Initially with a small group of seven children with special needs, he was also integrated into the mainstream group of 20. "He just loved it there and received wonderful support", Liz enthuses. To prepare for the move to statutory education Liz spent time visiting every single school within her catchment area, as well as some that weren't. "In the end we opted for St Georges as that is where his older sister goes and I'd had a lot of contact with the SENCO beforehand. I'd given her a copy of his Statement and began to discuss him going there a whole year before he started school".

Liz feels that one of the reasons the move from pre-school to primary has gone so smoothly is that she applied for Finley to have a Statement of Special Educational Needs before he was three years of age. Liz went against the advice of the Local Authority who told her not to worry about a Statement until he was at school. Although she describes the process of obtaining the statement as "a battle", and, "one of the most stressful periods in my life", she feels it has paved the way for first-rate support for Finley. Support that comes from the school SENCO, Headteacher, Class teacher, Nursery Nurse and Learning Support Assistant (LSA) as well as regular specialist input from Joseph Clarke School, a special school for pupils with a visual impairment.

"I can't praise St Georges enough", says Liz. "Once we knew he had a place there, they really took the time to prepare. The term before he started, staff spent a whole morning at his nursery observing him and they offered us a day at school just for Finley to get used to the new environment - this was in addition to the day that all new children spent at the school in the summer". Small changes have proved a big success, such as the giant car sticker on the floor next to Finley's coat peg so that he can find it easily.

Finley's LSA and class teacher together with the nursery nurse also visited their home prior to him starting school. "Finley was excited about this, offering them cups of tea". At Liz's request, they also

had a preparatory meeting to discuss Finley's placement in June. This was attended by the class teacher, LSA, school nurse, Educational Psychologist, SENCO - everyone who was involved with Finley's education. "There must have been 12 people in the room", says Liz, "but it was so important to me that everyone was fully prepared."

The result? Finley loves his new school and is always up first in the morning, raring to get into his uniform.

Does Liz have any words of wisdom for other parents? "It's important to be open and honest with the school and to start preparing with them as soon as you get that place in March. Your child is entitled to having his needs met but try to understand that it may also be daunting for a school. It's vital to build good relationships early on to see you through those seven years at primary school".

And what about the future? "My motto is 'be prepared for anything'" says Liz, "I'm a realist and while Finley is doing well now we may need to keep an open mind, depending on what's best for him as he develops. My biggest hope is that he continues to have the same positive attitude to life he has now".

**Leaving school or disabled children's services and moving into adulthood can be a challenging time for young people and their parents. Jane Richards' son Marc is 17 and in the process of moving into adult services.**

"I really feel that it's me experiencing a transition far more than Marc. Although he's moving into adult services, because of his needs Marc will continue to have people supporting him and in many ways life won't feel significantly different to him. My role as his mum is changing however; I'm having to come to terms with taking a step back and becoming gradually less involved with Marc's life". It's obviously something Jane has very mixed emotions about. As she explains, "I'm a single mum and my life has been utterly focused on Marc for the past 17 years so it's going to be interesting to see how we both adapt to being more independent of each other".

Marc has been disabled since birth - he has a chromosome defect and is on the autistic spectrum. He also has learning difficulties, lower limb and

profound communication difficulties. Marc has attended no fewer than six different schools throughout his education so Jane has experienced 'transition' many times. He is currently educated by Durant's Special School and is focusing on learning life skills appropriate to his needs.



Jane's advice to other parents facing transition to adult services is, "Be prepared to go and find information and take things on yourself. In my experience you will not get things handed to you on a plate - go to meetings and support groups, ask questions, find out what you're entitled to - you have

to overcome any discomfort you might feel at doing this as there is no point in being a mouse". Jane sees her role very much as that of Marc's 'coordinator'. Every time she writes or emails a professional she copies in everyone who works with or supports Marc so that they are all "kept in the loop". It's a strategy that has worked well for her over the years.

A key milestone is the age 14 when a transition plan is drawn up for your child - this should draw together information from a range of professionals involved with your child such as health, education and social services with the aim of planning for their transition to adult life. The plan must also take into account the views of your child. Jane is full of praise for Marc's advocate Babette Bleach, Children's Rights Officer for Disabled Children and Young People, who has provided a voice for his views. "It's been fantastic to have a third party ensuring Marc's voice is heard. If your child has communication difficulties, using an advocate is something I would highly recommend. It's had much more impact than just me saying what I think he needs".

As he approaches 18, Jane feels very fortunate that Marc is leading the way in becoming an adult and teaching her how to let go. "It's obvious he wants to be more independent. For example, despite his communication difficulties, he is very motivated to travel on his own on public transport which amazes me". This has recently included a complicated bus journey which he managed successfully. There have been other signs of Marc's growing sense of independence - he loves looking at property magazines and has started pointing out flats he'd like to move into when they pass an Estate Agency.

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## Transition resources from age 14

### Connexions

The Connexions Service provides support for all young people from 13 to 19 years of age, but has a particular focus on supporting disadvantaged young people including those who are disabled and those with special educational needs but without a Statement. Specialist staff provide advice and guidance on transition planning for young people and parents and also attend year 9 review meetings. Contact Lesley Keegan in Enfield on 020 8366 9546 for more information.

### Preparing for adult life and transition

This guide aims to bring together some of the main issues that parents and young people need to think about during this time. Contact a Family's useful booklet can be downloaded from their website at [www.cafamily.org.uk/publications](http://www.cafamily.org.uk/publications)

**Transition: moving on well**, Department of Health and the Department for Schools, Children and Families, 19 March 2008

This good practice guide on effective transition from children's to adult services for young people with complex health needs is aimed at health and social care professionals but might also be of interest to parents. Download from [www.dh.gov.uk](http://www.dh.gov.uk)

### The Moving On transition handbook for parents and carers

This folder is given to all disabled young people and their families at their annual review at age 14 by Enfield schools. It's split into sections for different school years so you can dip into what is most relevant to your child. It's loose-leaf so updates are produced regularly. Google the title to download.

### Transition planning at the age of 14 (England and Wales)

There is a wealth of information on the National Autistic Society website at [www.nas.org.uk](http://www.nas.org.uk) Helpline 0845 070 4004.

Jane would encourage parents to attend the transition evenings and events that are held by the Borough. "Most events are offered to all parents and young people at transition stage and attended by service providers who welcome your questions. You can often find out information on a one-to-one basis. The evening events are changing to divide into age groups so that they are more age-appropriate".

She says, "There is still room for improvement in Enfield's transition support but I have certainly noticed significant changes in the 4 years since I went to Marc's transition planning meeting". One such improvement is the training set up by the Borough for parents like Jane to give social services staff an insight into what it's like to be a parent of a child with special needs. "One of the most valuable things we've got across is that not only are our children unique but each parent has a quite different perspective. We've sat there and cried while we've told our stories and it's really helped social workers appreciate what it's like for us".

## What's new

### Our Voice needs you - join our parent forum!

**Our Voice** is delighted to have been given a grant to support us in formalising our position as a parent forum in Enfield. The grant has been awarded as part of the government's **Aiming high for Disabled Children** programme. As a forum **Our Voice** will be more influential in shaping services for disabled children in Enfield. This is not just about taking part in consultations relating to services or proposed activities on offer - this is about getting involved in the way all services are designed and delivered from the start.

Until now we have been struggling to get our voice heard with a number of service providers. Now, with your support, we intend to negotiate seats on more decision-making bodies. We hope to influence change at a strategic level as well as the way our children experience services on a day to day basis.



We are very pleased that the Joint Service for Disabled Children, the Enfield Branch of National Autistic Society, CAPAG and Enfield's Parent Partnership Service all want to be involved in helping us work as a forum.

### What will Our Voice as a parent forum do?

- We will find out from you, as parents of disabled children, what services you think need to change for the better in Enfield. We will do this through coffee mornings, focus group sessions and questionnaires. To make it easy for you to inform us we will meet you at special schools as well as offer a variety of settings and times for those of you with pre-schoolers and children in mainstream education.
- We will negotiate a voice on decision making bodies within the services and our volunteer parent representatives (drawn from the forum itself) will tell services about our experiences.
- For those of you who have the time or want to participate actively in the forum we will provide training for you to represent the needs of all disabled children in the borough on various boards and groups.
- We will keep you up-to-date with service developments via our newsletters and meetings and the forum will provide an opportunity for parents of disabled children to meet locally and share information.
- We will provide opportunities for you to meet service providers, local councillors and other relevant key figures in the world of disabled children and families.
- We will provide workshops - for example on SEN law - to empower you as parents.

### What do we need from you?

With this newsletter or arriving separately in the post in the next few days, will be a questionnaire. As parents of disabled children we know you spend too much time filling in forms. However, please take two minutes to complete and return the questionnaire. Unless you have picked up this newsletter in a reception area, you will have received a freepost envelope to make it easy for you. There is also an added incentive of the chance to win £50 of Marks and Spencer vouchers for the first name pulled in a draw to be held on 24 February 2009.

If you do not receive the questionnaire until later in February or without a freepost envelope, please still take the time to send it in. It is so important that we have accurate details of the families in Enfield who have disabled children. Even if you are already on the **Our Voice** mailing list, again please take two minutes to complete the questionnaire as our database has only basic contact details. This forum and the questionnaire are not linked with other recent consultations, for example on short breaks. This new forum will be run by parents for parents.

By completing and returning the questionnaire you are registering for free membership of the **Our Voice parent forum**. You will automatically receive our regular newsletters.

As a member of the forum you can be as little or as much involved as you like. Many parents feel they have enough to do without taking part in attending meetings or answering consultations. They are happy just to receive our newsletters and occasional letters about consultations. Other parents prefer to be consulted with by telephone, letter or even focus groups. And others might wish to be more actively involved by undergoing training to sit on decision-making groups. Whatever you prefer, we would love to hear from you. There will be an opportunity on the questionnaire for you to choose your preferred level of involvement.

We look forward to receiving your completed questionnaires. We aim to have 400 parents registered with us - the **Our Voice parent forum** - by 31 March 2009. Please help us reach that target!

### Update on short breaks

Many Enfield parents took part in the recent consultation on short breaks led by Enfield's Joint Service for Disabled Children. Through focus groups, questionnaires and telephone interviews the Parent2Parent team (all parents of disabled children themselves) gathered useful information from parents of children of all ages in both mainstream and specialist settings. Parents told Parent2Parent that they would like more choice in terms of who provides the support, and more flexibility in when they can access the breaks. On the whole, parents thought the range of breaks on offer was appropriate but they wanted more of them. A number of parents of teenagers wanted befrienders or buddies to support their children, while parents of very young children felt help around the home was more important than having a carer for their child.

Parent2Parent will deliver a final report to the Joint Service in early February. In the meantime, the Joint Service has strengthened funding to CAPAG, Direct Payments, and Home-sitting services. The Service has also developed pilot inclusive playschemes and will be looking to build on those over the coming months.

## Did you know?

### The Family Fund survey

The Family Fund would like your help to understand the financial needs of families with disabled children. The Family Fund is conducting a survey of families and would like your input. Your help will allow them to ensure that they are meeting your needs and those of other families with disabled children. For information on how to complete the online survey visit [www.familyfund.org.uk](http://www.familyfund.org.uk) and click on "Get involved".

### Family Fund grants

The Family Fund gives grants that relate to the additional needs of a disabled child and help relieve the stress of everyday life. The Fund can help with the following and more:

- Specialist toys
- Family holidays so that everyone can enjoy time together
- Driving lessons to get children around and about
- Trampoline for a young person to let off steam
- Washing machines to help with extra washing needs.

However, the Fund cannot help where a statutory agency has a responsibility to provide or pay for the item needed. You can apply if you can answer yes to all of the following:

- You are the parent or carer of a severely disabled child aged 17 or under
- Your household's earned income before tax, excluding any overtime, is less than £23,000 per year OR your income is entirely from benefits
- You have less than £18,000 in savings
- You have permanent residency in the UK and have lived in the UK for six months.

Visit [www.familyfund.org.uk](http://www.familyfund.org.uk) to find out more about meeting the Family Fund definition of severe disability.

## How to request free nappies

If your child is over the age of three and their disability or known developmental delay means they need nappies, you can apply for nappies to be delivered to your home. This service is not means tested but is dependent on your child's needs. To apply, speak to your health visitor, school nurse or SENCO. For continence advice and further information, contact Sue Conroy, Enfield's Continence Advisor on 0208 344 3140 extension 3512.

## Gold star award

This very special Gold Star Award is in memory of Paul O'Byrne. Paul died on 16 November 2008 at the age of 51, following an 18 month courageous battle with cancer. Paul was the volunteer Chief Instructor for Halliwick Penguins swimming club in Southgate, North London and had been a member for 31 years. You would find him there most Saturday afternoons, providing specialist training to Halliwick volunteers, advice to parents, and of course, direct support to the children and young people themselves.

Halliwick Penguins cater for a wide range of disabled children, many of whom live in Enfield. We know the parents, children, volunteers and his devoted family will miss Paul so much.

Despite his struggle with cancer, Paul maintained his philosophy that "life is beautiful and life is for living" and that it is important to "seize the day". He supported hundreds of disabled children through his voluntary work and it was a real privilege to meet him.

Halliwick Penguins are coming to terms with their loss and are now reorganising themselves. They are, understandably, reluctant to take more children on to their waiting list just now but will in the future. If you are interested in volunteering with Halliwick - by undertaking training in specialist swimming tuition techniques - please contact them via [www.halliwick.org.uk](http://www.halliwick.org.uk)

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 four-year old, Jake, was diagnosed as being on the autistic spectrum a year ago. At that time I was advised by professionals from the LEA that it would be to his benefit to wait to apply for a statutory assessment of SEN once he was in mainstream school, when there would be a better understanding of his additional needs. However, I am now regretting delaying applying for the assessment.

Jake started reception in our local mainstream school in mid-September but when all the other children in his class started to stay for the afternoon, the school told me that there was nobody available to support him then. They also told me they thought he was too tired to stay all day as he was finding it difficult to focus on certain activities. We are now into January and he is the only child in reception who does not attend full-time. When I talked to the school, they said I should contact the LEA as the school feel they do not have the staff to accommodate Jake's needs or to support him one to one for most of the day. When I spoke with the LEA, I was told that the LEA do not have a statutory responsibility to provide a full-time school place for Jake until he turns five, in June 2009. Surely I should have the same rights as any other parent to choose whether my child attends school before the age of five? I'm not sure who is at fault - the school or the LEA. Please can you advise as I am at my wit's end."

**A:** With hindsight, it would certainly seem that the advice from the LEA to wait to apply for a statutory assessment until Jake had started school was less than helpful. It would be wrong to say that such advice could never be appropriate, though, and in some cases waiting is the right course.

## Speak Up - the voice of children and young people

Where a child is likely to have significant needs in school, though, it is best to start the process as soon as possible so that additional support can be put in place in time for their starting school.

Jake does not have to attend school until he is aged 5. If his parents wish for him to attend before then, however, it may be discriminatory for the LEA or school to refuse him a full-time place, if the reason for refusal relates to his disability (this is most obvious if a non-disabled child of the same age would be offered a full-time place). However, the Disability Discrimination Act (DDA) is complicated and it would be sensible to obtain legal advice on these issues before taking action against the LEA.

A claim against the school, in particular, may be difficult if the reason for their decision is that they cannot provide the support that Jake needs. Schools are not required to provide additional services such as Teaching Assistants under the DDA. In view of what the school is saying about being unable to provide the support that Jake needs, it may well be that, practically, there is little chance of succeeding in a discrimination claim here. There would, however, seem to be a strong case for applying for a statutory assessment now, if that has not already happened. In practice, that should be the next step. The assessment and statementing process does take time (usually a minimum of 6 months) to complete, but there would seem no reason to further delay in starting the process.

Unfortunately, getting provision in place is rarely a quick process. Until a statement is in place, it may be difficult to obtain any additional support in school in the interim and you should seek legal advice in relation to that.

Levenes Solicitors can be contacted on  
0800 118899/020 8881 7777  
or e-mail [info@levenes.co.uk](mailto:info@levenes.co.uk)

Sean Jean-Houston is 17 and was recently selected to attend the Great British Fast Track Power Programme for potential Paralympians at Loughborough.

Born prematurely, Sean had a severe bleed into his brain at one year old. The resulting haemoplegia has affected the right side of his body: he has around 75 per cent use of his right arm and his finger movements are also affected. It has also impacted on his development and learning abilities. Sean attends West Lea Special School in Enfield. He also has the lifelong condition haemophilia for which he needs drugs every other day.

His mum Kathy describes Sean as being a, "Quiet but very caring young man. Sean is not terribly confident, especially when faced with new people and places but athletics has really helped to boost his self-esteem." Sean's family has always been active and interested in sport. His younger brother is keen on football and Sean used to watch his matches with enthusiasm. So it was no surprise when Sean developed a keen interest in sport himself and, about a year ago, joined the Enfield Sport Development Athletic Academy where he now trains once a week after school.

Sean's training sessions include warming up, learning about safety, using gym apparatus and weights as well as running on the indoor and outdoor running tracks - his real strength is as a sprinter. One welcome side-effect of the training is that Sean has become significantly less frustrated. "He used to become frustrated and stressed when he faced something new or something he couldn't do immediately," says Kathy, "But now he has trained himself to stay cool. He doesn't get stressed about competing. He said to me recently 'I feel peaceful here mum. I can be myself'"



Sean was spotted at a Paralympic Talent Day in October and impressed the judges with his sprint trials. He's since been attending training weekends

at the Fast Track Power Programme in Loughborough where he is set to make it through to the final few selected for the London 2012 Paralympics. Disability Community Sports Coach Ian Reddington said, "Since joining the Academy Sean has really blossomed. His running and throwing have improved and he now has a fantastic opportunity to progress to the 2012 Paralympics."

Sean says, "I have enjoyed sport since I started doing it at school. My best things are running and throwing. I throw the shot put and javelin and I've also started long jump. My coach at Loughborough does different exercises with me and encourages me."

As Kathy says, "Sean has found an activity he really enjoys, where he can really be himself and compete at his level. He sees himself becoming famous through sport." And with these achievements already under his belt, there is no reason why he shouldn't. The last word goes to Sean, "Look out for me on TV soon!"

**Enfield Sports Development team run a range of inclusive activities engaging disabled children and young people. If you are interested in getting into sport and physical activity or to join their mailing list contact Ian Reddington at [ian.reddington@enfield.gov.uk](mailto:ian.reddington@enfield.gov.uk) or telephone 0208 351 2470.**

## Events

### Our Voice meeting

The next **Our Voice** meeting will be held on **Thursday 5 February 2009** from 9.45 to 11.45am at Community House, 311 Fore Street, N9.

We are a friendly group and parents find it useful to share experiences and ideas about how to tackle issues relating to service provision. This meeting will provide an opportunity for us to discuss how Our Voice might work as a parent forum as well as to find out what you feel are the priorities for service developments in Enfield.

Refreshments will be provided. Please let Julia Paylor know in advance by phone message or e-mail if you are coming so that we know how many to expect.

Note: parking is not easy at Community House so if you are coming by car please allow time to park in

the streets nearby or bring change for the pay and display machines on Fore Street.

If you receive this newsletter after 5 February and would like to attend future meetings or be added to our mailing list please contact Our Voice. If you are unable to attend on 5 February please note that there are opportunities to attend an evening meeting on 23 February as well as a morning meeting on 3 March. Again, please get in touch if you would like to come and we will give you details of the time and venue.

### Special Educational Needs - sorting the myths from the truth

From 9.30am to 12.45pm on Thursday 19 March 2009 at Community House, 311 Fore Street, N9.

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

To book a place (note that places are limited and will only be available to those who have pre-booked) please contact Our Voice on 0208 292 0638 or e-mail:

[julia.ourvoice@blueyonder.co.uk](mailto:julia.ourvoice@blueyonder.co.uk). Sorry, but we cannot offer crèche facilities. We are pleased to confirm the event is free of charge.

### Theatre production for parents



Stronger is a powerful and emotional drama and written and produced by award-winning theatre group 'Women and theatre'. This play was created following research into the real-life experiences of parents and families. Enfield has commissioned the theatre group to perform Stronger at Waverley School in ten not-to-be-missed performances. The production is suitable for parents/carers of disabled children and those who work with them.

Performances will take place twice daily from 23 - 27 February at Waverley School. To book, call 020 8805 1858 or email [info@waverley.enfield.sch.uk](mailto:info@waverley.enfield.sch.uk). Places are free but limited so early booking is advised.