

Our Voice



Our Voice Newsletter

Issue 4, Autumn 2008

Welcome

Welcome to the fourth edition of the Our Voice newsletter. This issue is longer than usual as we have a wealth of news and information to pass on, including exciting news about Enfield becoming one of just 21 local pathfinder areas in the country transforming short break services offered to children and their families.

But we begin this time with an article about Southgate School, which prides itself on being a true comprehensive and a successful example of inclusive policies in action. We meet three pupils who tell us what it's really like for them.

We're delighted to announce that Our Voice now has a website featuring the latest information about our meetings and events, useful contacts and links, as well as the opportunity to download previous issues of our newsletters. Find us at www.ourvoiceenfield.org.uk

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. Our next meeting is listed at the end of this issue. Join us and you will receive a warm welcome.

If you have an experience, news or information you'd like to share in a future edition of this newsletter, please 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.

Learning together

Southgate School is a large secondary school with 1600 pupils. Parents are impressed with the school's inclusive approach - 36 pupils have SEN Statements and many more have special needs. Ruth Chatto went to see the policy in action and to meet students Javed, Laura and Bronte.

"This school is fantastic," says Javed.

Javed communicates by means of a Delta-talker voice simulator which he operates with a head-pointer strapped by his right ear. The pointer picks out words on a screen attached to the front of his wheelchair and these are converted to almost human-sounding speech. He is reliant on his wheelchair and has help with all physical activities at school. "There is a superb Learning Support Department here," says Javed, who is at 18 halfway through his A-level course in media studies. "It really helps disabled people achieve."

And he's right. Southgate School's Special Educational Needs Co-ordinator (SENCO) Liz Gabrel heads a team of five specialist teachers and 25 support assistants dedicated to the students who need special help. "One of the reasons things have been so successful with Javed," says Liz, "is the

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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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commitment of Ellen North, the specialist teacher who has looked after him for the seven years he has been at the School."



Laura, Bronte & Javed

Ellen and Javed clearly have a great relationship which involves a lot of humour - Javed is quite a joker - together with a sense of mutual appreciation. It has not always been easy, however, but it's been very rewarding. We've all learned from the experience and Southgate School is certainly richer for Javed's presence."

"Yes, I agree," says Javed, quick as a flash.

Because of Javed's profound disabilities he says he finds socialising "a bit challenging" but, given his strength of character and mischievous sense of humour, not impossible. "Over the GCSE years I have made quite a few friends who know me well," he says. Other students are fascinated by his communication machine. "I show them how I use the head-pointer to press the different buttons. It's very comfortable to use but I have to remember where all the vocabulary is stored. I can input new words - I do this all the time - but it means I have to remember even more storage places."

Javed took eight GCSEs and was very pleased with his results, mostly A to Cs. During the exams, he had to dictate all his answers to staff who then transcribed them, a lengthy process that could take four hours for one exam. After A-levels Javed is not quite sure what he wants to do. "But I wish I could continue with learning - maybe a subject like philosophy."

Once the exams were over this summer the sixth form were taken on a trip to Alton Towers. This was

not a total success for Javed: "They said the park was disabled-friendly but in reality they did not have many rides that disabled people like me could go on." But after some teasing from Ellen who watched him screaming with delight, he admits, "Yes, I still loved the day."

Laura, 17, loved it too. "I go on the same trips as everyone else," she says. "I had a learning support teacher with me in the early years but this time I just went with my friend. We got soaked!"

Laura is lively and outgoing and has no problem making friends. "I love talking to people," she says. "One girl - she's a year below me - I started talking to her because I wanted to persuade her to come to choir. That's how we became friends".

Laura walks with aids and uses a wheelchair but has always been treated the same as all the other students at Southgate. She loves everything about the school ("except economics"), has never experienced bullying and her happy disposition makes her a very popular member of the school community. SENCO Liz says that Laura is someone who's always participated in school events: "She helps out at open evenings; she's always there with a smile. Everyone knows Laura.

"She comes to school by local authority mini-cab and staff see her every morning when she arrives and every evening. Sometimes we have to wait for transport and we are able to have longer conversations than we might otherwise have." At the moment these are about university choices. Laura wants to study maths and computer studies and is thinking about UCL or Queen Mary's. Liz tells her she won't get any special treatment when she applies: "You've got to get the grades, Laura!"

Laura's mum is very happy with Southgate School. "It's got lifts to all the floors and every classroom is wheelchair accessible. Laura talked to someone in a wheelchair when we first came to visit and decided it was the school for her. It's a lovely school. Everybody knows you and Laura's just one of the crowd."

Thirteen-year-old Bronte finds that having cerebral palsy makes keeping up in class difficult and struggles with the long school day. "I do get tired," she says. "I don't like the school being so big."

Bronte has a motorised wheelchair which is kept in the physiotherapy room and used when she is too tired to walk. The physiotherapy room is used by all the disabled students and others who are unable to participate in PE lessons. Bronte goes three times a week. "I do stretching exercises to make me strong," she says.

For Bronte DT, art and science are her favourite subjects - "I like all the practical subjects best" - and she already knows she wants to be an occupational therapist when she leaves school.

Headteacher Tony Wilde understands Bronte's difficulties but is passionate about including every child and helping them to achieve their full potential. "We are pleased to be known as a school that includes everybody. Our disabled children deserve the best," he says.

He is keen to stress that Southgate School is known as a school that is good for pupils with special needs but is also good for gifted and talented pupils. "That defines us quite nicely," he says. "We have 36 children with Statements of Special Educational Needs, many more with special needs but who are not statemented, about half a dozen children who use wheelchairs and then we have our high-flying Oxbridge candidates. And, of course, some of our disabled students are high-flying Oxbridge candidates too."

He adds: "There is another element: integration benefits the whole community. It's about living and learning together. I think all our students get a great deal from our inclusive policy."

Luisa from Year 10 clearly agrees. Asked how she feels about having students with additional needs in the school, she replies: "I think it's good because disabled students aren't singled out - they are just like everyone else. The school being adapted with ramps and things means that those students can get around by themselves, which I think is good. Having people with disabilities in school makes me feel lucky."

Liz Gabrel wholeheartedly endorses Luisa's comments: "As well as the dedication of individual teachers, there's a whole-school ethos. There is no question that under Tony Wilde we have a genuine spirit of inclusion which is embraced by students and staff alike. If you have a student with a

particular disability or need in your class then you can come and talk to me - I publish notes and give detailed guidance. It's very collaborative."

The last word goes to the Headteacher: "We are a real comprehensive. We cannot claim to be a comprehensive if we don't look after everybody, can we?"

Visit www.southgate.enfield.sch.uk for more information.

If you would like your school profiled in a future edition of Our Voice, please contact Julia Paylor, tel: 020 8292 0638, email: julia.ourvoice@blueyonder.co.uk

What's new

Consulting parents about short breaks

"He is not judged and meets lots of new friends away from school" - just one comment from a parent that sums up how valuable short breaks are for children with disabilities as well as their parents or carers.

What are short breaks?

Short breaks provide opportunities for children and young people with disabilities to spend time away from their parents/carers. They provide an essential opportunity for carers to recharge their batteries, and allow the children and young people to build new relationships, and experience different environments and activities. A short break may include day, evening, overnight or weekend activities and could take place at home, at an approved carer's home or in a residential or community setting.

Enfield is one of just 21 local areas that have been awarded 'Pathfinder' status to help them transform short break services for disabled children over the next three years.

In May 2007, the Government published a report called **Aiming high for disabled children: better support for families**, based on their review of services for disabled children. One of the

recommended actions from the report was to recognise the critical importance and significant benefits of short breaks to those children and young people and their families.

Now a total of £370 million is being invested in short break services across the country, with 21 Pathfinder areas being awarded monies earlier to develop innovative and effective ways to improve short break services, which local authorities can build on.

Enfield is unique among the Pathfinders in that it has engaged a team of 'parent consultants' to find out what parents really want in the way of short breaks. The team is called **Parent 2 Parent** and they not only bring a range of personal and professional expertise to the consultation work but more importantly all have disabled children themselves, a crucial factor in terms of both direct experience and empathy with other parents.



The Parent 2 Parent team

The consultation process will enable Enfield's Joint Service for Disabled Children to further develop its programme of short breaks and related services to meet the needs of local families.

The consultation process will:

- determine whether what Enfield hopes to deliver will meet the needs of children, young people and their families
- identify what is missing
- provide feedback on how the local authority should communicate information to families about the short breaks available.

Over the summer Parent 2 Parent consulted with 30 parents of disabled children in Enfield. In addition, in September, it co-organised a successful parent forum with Enfield's Joint Service at West Lodge Hotel. This event was attended by around 50 parents and 10 professionals.

Findings to date were fed back to the delegates by members of the Parent 2 Parent team and it will come as no surprise to find that parents were often feeling exhausted: "Just to find time to wash my face and brush my hair is an achievement". A number of parents had expressed feelings of isolation, that "everything has to be fought for" and that they had to be at breaking point to get services.

However, parents were appreciative of support when it is offered and were encouraged that Enfield is 'listening' to their concerns. There was also much praise for the CAPAG and Cheviots play schemes. Parents came up with the following priority areas to be developed:

- holiday/weekend/after-school activities
- buddying or befriending
- support in the home
- overnight short breaks
- support for siblings
- transport to activities.

Many parents were also keen that short breaks had a 'family focus' and did not just concentrate on the disabled child. They also stressed that choice and flexibility were important to them.

Similar conclusions were drawn by researcher Jessica Datta, recently engaged by the Council for Disabled Children to undertake research on the use of services by disabled children and families. Her findings echoed those of the Parent 2 Parent consultations being carried out on short breaks.

In addition to listening to the views of parents, the local authority has been keen to consult with disabled children and young people themselves, to find out what they want in terms of short breaks. During the summer holidays Enfield provided a number of inclusive taster days in mainstream settings for disabled children. A range of consultation tools were used to obtain children's views about the taster days. Babette Bleach, Children's Rights Officer for Disabled Children and Young People attended the parent forum in September and confirmed that the activities on offer at the taster days met with an enthusiastic response. The majority of children wanted more similar play activities in the future.



Parent 2 Parent will continue to consult parents over the coming months to ensure that all key groups of parents and carers have been engaged with. These are exciting times and it is tremendous that parents and service providers are united in a common objective: to make things better. Your views are essential to help build up as complete a picture as possible. If you have not yet had your say and would like to input into the consultation process please contact Julia Paylor at Our Voice and she will pass your details to the team.

Working together with SEN Services

Just before the summer holidays Niki Michael, Our Voice Chair and Julia Paylor, Our Voice Development Coordinator met with two senior members of staff at the London Borough of Enfield - Ahmad Ramjhun, Head of Special Needs, Inclusion and Transport and Lynn Brana, Service Manager for SEN and Transport. The brief was to discuss how we can work together on SEN and inclusion issues.

It was a positive meeting at which we agreed that Our Voice could provide parent representatives to input on some of the Local Authority training forums and/or to join one of the Local Authority's SEN working groups. This will ensure that the particular perspective of parents on SEN issues and concerns are well represented.

Top of the agenda for Our Voice is a need to involve parents in the design and delivery of disability awareness training to teachers and SENCOs across the Borough. Experience in other boroughs demonstrates that small SEN forums with a jointly agreed remit improve parental perceptions of service providers and enable council officers

to be better informed about what is going on at a grass roots level.

Our Voice will be finding out how parents are involved in shaping SEN services across the country, with a view to building on parent participation in Enfield. We will keep you updated in this newsletter.

Enfield parents tell us about service priorities

Our Voice visited Chesterfield School before the summer break to hear about parents' priorities for improving services for their children with additional needs.

A number of parents wanted transport to take their children to after-school activities. Given their children's needs, it is not viable to get there on public transport as this may involve travelling on two buses each way.

Many parents also asked for more short breaks, such as the schemes run by the organisation Crossroads which offers parents a break from their caring responsibilities.

We are hopeful both these issues will be addressed as a result of the wider consultation on short breaks and leisure opportunities for disabled children in Enfield.

Did you know?

Free cinema entry for carers

The Cinema Exhibitors' Association Card is a national card that entitles the holder to one free ticket for a person accompanying them to the cinema. To apply for the card, you will need to be in receipt of disability living allowance or attendance allowance. There is a one-off admin fee of £5.50 and the card is valid for 3 years. Find out more and download an application form from www.ceacard.co.uk



If you have information about services or resources that might be of interest to other parents please let Our Voice know so that we can include it in a future newsletter.

The Cerebra grant scheme

This year the Cerebra grant scheme has provided funding for special needs tricycles, trampolines, conductive education, car seats, buggies, computers, and swings amongst other things.

The Cerebra grant scheme is available to children aged sixteen and under with a diagnosed brain related condition. (If you are not sure whether your child's condition is covered, please call Cerebra). The item you are requesting funding for has to be of direct benefit to the child, related to their disability.

For more information contact Cerebra via Debbie Godsave on 0800 32 81 159.
DebbieG@Cerebra.org.uk

Gold Star Award

Our Gold Star Award this time goes to Clinical Psychologist Jo Attree, who works in Enfield for two teams: the Service for Children and Adolescents with Neurodevelopmental Disorders and the Child Development Team.

As part of her work in the Child Development Team Jo participates in a Social Communication Clinic which assesses children with autism. The work is carried out with paediatricians, psychiatrists, and speech and language therapists. Jo offers follow up sessions to families and works with them in groups or individually. She also offers clinical psychology input to children with complex needs and their families.

One mother of a 17 year old with complex needs summed up what Jo's help has done for her, "Things are so much clearer now and I don't know what I would have done without her".

Young people are referred to Jo by the Child Development Team based in Cedar House.

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 son, Jacob, is on the autistic spectrum and his current school does not have provision for children beyond age 11. I have found a special school four miles from my house that will suit his particular educational needs. Although another child funded by the LEA, Nita, already attends there, the LEA says the transport costs will be too expensive for us. The LEA says that they will have to provide a taxi with an escort for Jacob at a cost of £110 per day, so they have named another school in his amended statement.

I do not understand the costing. Nita lives just one mile away from us, and currently has LEA-provided transport with an escort. Like Jacob, she does not require the escort to be one to one. I think the two children could travel in the same taxi or bus together with one escort, with just ten minutes or so added to the length of the journey. An SEN specialist has suggested that the Local Authority should be putting in a nil cost for Jacob's transport given Nita is already going to the school on funded transport. Can the LEA rely on their suggested costing in this way to show that the cost of the school placement when transport is included is too expensive? Do you have any advice on the points I should raise as my Tribunal hearing is next month?

A: Where a parent expresses a preference for a particular school, there are only limited legal grounds on which the LEA can refuse to name the school in their child's statement. One of those grounds is that the cost of the parents' proposed placement would be too expensive compared to another suitable placement. Assuming that the LEA's proposed school is suitable, and that there is no other difference in costs between the LEA's school and the parents' proposed school, an additional transport

Speak Up - the voice of children and young people

cost of £110 per day (£20,000 per year) would almost certainly be a legitimate reason for the LEA not to name the parents' school.

In order to succeed in an appeal, you would therefore need to show either that the LEA's proposed school is not suitable, that the LEA's figure for the transport costs is incorrect, or that there are other costs at the LEA's proposed school that would balance out the total cost.

Decisions of the High Court have established that where the LEA already arranges a taxi and escort to take another pupil to the same school, the relevant cost is the additional cost (sometimes called the marginal cost) that would be incurred if Jacob also used it, not the total cost of the transport (nor the total cost divided by the number of children).

It may well be that, given the additional time involved, it may be slightly more expensive for the LEA to arrange transport and escort for both children, but the LEA cannot rely on the total cost of the transport. The figure that is relevant for the Tribunal should be the total cost once Jacob is involved minus the total cost if only Nita is travelling.

If even that figure is significant, then it may still be difficult to show that there is not an unreasonable additional cost. It is not possible to say how much additional cost would be unreasonable, as it will depend on the circumstances of each case. If there is no, or almost no, additional cost arising from Jacob accessing the existing transport and escort, then all other things being equal, the LEA should not be able to rely on cost as a reason for not naming your preferred school in his statement.

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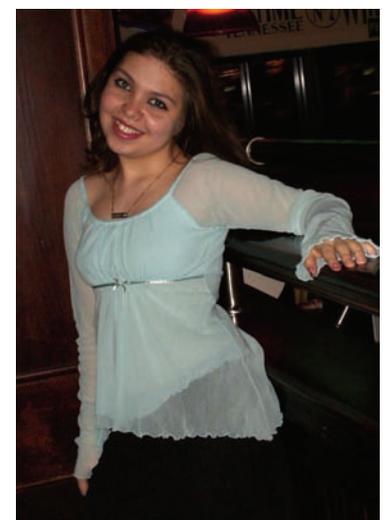
Sheida's story

My name is Sheida and this is my story.

It's a story of how I was left out in some of the activities in my school because of my disability. I am 18 years old and I have now finished my school education but while I was still in school there were times when I felt I was being discriminated against. I wasn't allowed to do PE because of my disability; I couldn't even get involved in the theory of PE. I found it quite hard to accept because I also studied in my country Iran where I went to school until I was 12.

PE was also a compulsory subject there but their attitude towards me was different. I was involved in the lessons, I was studying the theory just as others did and while everyone was doing their practical I was taught new skills such as being a referee. I was the referee for my school's tennis team and I was also taught how to coach a football team and learned all the small details needed for a match such as how the players line up and so on. So even though I have not done any specific sport in my life I know quite a lot about sports. Coming to this country and not being even engaged in anything to do with that lesson felt unacceptable. I think as a result of that I missed learning about my class mates as a whole team because PE is one of the subjects that you actually do as a form class and as a result of not being part of it I think my class mates never formed that special bond with me.

One of the other problems that I faced was that my regular ambulance calls from school made pupils act differently around me as if whatever they did would harm me. I think that was caused by their lack of knowledge about my problems - no one had told them that talking to me is not going to harm me. That made me lonely and I



Sheida

was isolated for most of my school years in England. I remember the day that I was leaving Iran my friends were in tears but when I left my high school in London I had no one to say goodbye to because I didn't have a close friend. I think schools should do more to get pupils with disabilities more engaged with others, they should use tactics to involve them with other students in lessons, so we should not suffer isolation as a result of our disability. After all, it is not our fault that we were born with a unique physical body.

Fundraising for Russet House

My name is Eloise-Sophie Lester and I am eleven. I have two brothers, Noah and Oliver aged 8 and 2. Noah is 8 and has autism which affects his language, his learning, his toilet ability and the way he takes in the world around him. Noah attends Russet House School in Enfield where all the pupils have autism. He has been there for three years and he has progressed and become more able than if he'd carried on at mainstream school. Russet House School is filled with dedicated willing staff wanting to do whatever they can to help the school and the children. One of the ways they do this is fundraising. So this is where my story starts.

A few summers ago me and my friends were mucking about in really silly dressing up clothes. My Mum dared us to go to the sweetshop and buy ice-cream in the silly clothes and we did! Along the way we came up with an idea of raising money in the clothes by asking the public for spare change. We even came up with a little chant..."We are raising money for charity so come join in the fun. The money goes to Russet House so fund fund fund!"



Eloise & Noah

I decided to write to Julie Foster, the wonderful Headteacher at Russet House and tell her about our idea. She replied to me a few days later telling me that she thought it was a lovely idea and invited me and my Mum to the next governor's meeting.

At the meeting, we discussed my idea and how it was related to the 24 hour walk they were planning for the adults. So we decided that between the hours 12 and 2 children would meet at the school in fancy dress and parade around Enfield, raising awareness with the public and also holding buckets for spare change. We raised over £3000 and it was a huge success!

To all children and young people in Enfield, if you would like to send in a piece for our Speak Up section please contact Our Voice. You might like to write about your experience as a disabled child or young person or send in a picture, poem or your ideas for improving services. You might be disabled yourself or be a sibling or friend. In short, if you have something to say, we want to hear from you!

Events

Our Voice meeting

The next Our Voice meeting will be held on Thursday 16 October 2008 from 9.45-11.15am 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. Pauline Malcolm from the Parent Partnership Service will talk about Special Educational Needs, particularly in relation to Statements, Individual Education Plans and Annual Reviews. We will also update you on the consultations in Enfield regarding short breaks for parents of disabled children. Refreshments provided. Please let Julia Paylor know if you will be coming.

If you receive this newsletter after 16 October and would like to attend future meetings or be added to our mailing list, please contact Our Voice.

