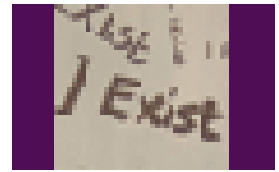


Spring Newsletter 2008

I EXIST!

'Because of high IQ, I am not eligible and do not fit into any category for support. They do not recognize my disability and send me away. Even if I was eligible, there is no ASD support (here) for people like me'

[ADULT WITH AUTISM]



The National Autistic Society (NAS)'s crucial campaign, *I Exist*, is a clear message from the many thousands of adults with autism who are isolated and ignored by society. Following the biggest ever survey of adults with autism, the NAS found that too many people with autistic spectrum disorders (ASDs) are unable to fulfil their true potential because of a lack of recognition of autism, a lack of understanding and a lack of suitable services.

The *I Exist* report demonstrates the gap between the support adults with autism need and what they actually receive, based on their own views and those of their families, as well as a national survey of local authorities and Primary Care Trusts.

I Exist aims to bring about changes that will transform lives. We need your help to achieve this! Please join us at the local launch of this vital campaign on **Thursday 15th May**. This event is about raising awareness but it is also a chance for people with ASDs and their families to meet and give their views to a wide range of professionals working in Lambeth.

I EXIST local launch event

When: Thursday 15 May, 5.30-7.30 pm

Where: LAMBETH COLLEGE, Clapham Centre, Clapham Common Southside, London SW4 9BL

Sorry, we are unable to provide childcare.

Buses: 35, 37, 88, 137, 155, 255, 322, 345, 437

Underground: Clapham Common (Northern line)

For more information, please ring **NAS Regional Officer Mel Carr** on: **020 7704 3809** or email:

mel.carr@nas.org.uk

NEW SECONDARY SCHOOL PROVISION FOR PUPILS WITH ASDS

If you have been through the process of transfer to secondary school for your child with autism and Asperger's Syndrome, you will know that there is no specialist autism secondary school in Lambeth. There is a limited service from Lark Hall Outreach Service to some mainstream pupils, but no specialist provision within any mainstream secondary schools. The choices in Lambeth currently are between support in mainstream, moderate learning difficulty or complex needs schools. Choices outside Lambeth are very limited and oversubscribed. To gain a place at an independent school generally involves a long struggle and sometimes tribunal (please let's hear from anyone with a different experience!).

On 2nd April 2008, a group of 8 LAG members and other parents met with Bob Ballard, Acting Principal Educational Psychologist at Lambeth CYPS. Ballard is working on the development of Lambeth's ASD Strategy, which includes the development of new secondary units for pupils with ASDs. Parents raised a number of concerns - for instance, whether parents' views would be considered in planning the new secondary units. Ballard set out the programme for consultation that aims to have plans in place by Summer 2009 (12 months

LAMBETH AUTISM GROUP is a voluntary organisation offering support, information, guidance & news about Autism in Lambeth

before 2 new units are due to open). The intention is to have parental representation in the planning process - any volunteers?

We discussed difficulties experienced by pupils with ASDs in mainstream secondary schools, like bullying, depression and a lack of understanding and appropriate support from teachers. We acknowledged the need for provision to meet a range of needs, not just for pupils able to access a mainstream curriculum. We heard that there are plans for Turney School to develop into autism-specific provision. Parents also raised problems in getting a mainstream school place for statemented children, with many schools refusing on the grounds that they can't meet a child's needs. Bob Ballard agreed on the need for secondary schools to improve on how they welcome and support pupils with ASDs.

GIVE LAMBETH CYPS YOUR VIEWS

If you have views about what kind of secondary provision is needed in Lambeth, Bob Ballard would like to hear from you and can be contacted at: bballard@lambeth.gov.uk

SE27 PARENT SUPPORT GROUP UPDATE

Calling all parents and carers with children with ASDs!

Since last September, a parent support group has been meeting in the West Norwood area. Although Isabelle can no longer be there every week, the group continues to meet at Little Starz and welcomes all parents of children with ASDs (including autism and Asperger Syndrome) and their children. In addition to the normal term-time sessions, we also organise holiday sessions. Please feel free to join us!

Children from the group are starting riding therapy at Vauxhall City Farm this term. We have high hopes for this activity, as riding therapy has been shown to benefit children with ASDs. We are very grateful to Vauxhall City Farm, Little Starz Children's Centre, Kingswood and Elm Wood schools for making this project possible. Please contact us if you would like your child to be put on the waiting list (**please see 'GET IN TOUCH' box**).

Finally, many thanks to all those parents who provided feedback for our sponsors, the Capital Community Foundation. Here are some of your inspiring comments:

Finally got to meet other parents going through or who have already gone through the same problems with diagnosis, getting help, statementing etc.'

"I understand my children better so

SE27 PARENT SUPPORT GROUP



When: 10-11.30am Fridays
(NB: term-time only)

Where: Little Starz Children's Centre, 18
Benton's Lane, off Gypsy Road,
London SE27 9UD

Trains: Gipsy Hill, West Norwood

Buses: 3,196,468,322,68

Free parking nearby

PLEASE NOTE: if you are bringing your children with you, please phone Little Starz in advance on 020 8761 9020

through the library and talking to other parents/carers I am able to be more tolerant of my children's quirks and behaviours.

'Increased my confidence in sharing my experiences with other parents. I am not alone... if we all work together we can achieve a lot more for our children.'

'My son has learnt to socialise and allow adults/children to interact with him.'

'I got to borrow materials, books DVDs etc which my son has enjoyed and I gained knowledge in order to help him.'

NEW RESOURCES LIBRARY SET-UP

The resources library will no longer be accessible at Little Starz. Instead, from May, library sessions will take place nearby at Kingswood and Elm Wood primary schools (term-time only):

Kingswood Primary School

Gipsy Road

London SE27 9RD

3rd Wednesday of the month

9.30-10.30 pm



Elm Wood Primary School

Carnac St

London SE27 9RR

1st Tuesday of the month

(from June) **3.30-4.30 pm**



Come and borrow a wide range of specialist books,
DVDs, toys and games



AUTISTIC PRIDE DAY June 18th

*Each year, June 18 has been marked as a celebration of the neurodiversity of people on the autism spectrum. The ear-marking of this day was an **Aspies For Freedom** (please visit www.aspiesforfreedom.com for more info) initiative to educate the public that the autism spectrum is not always a disability, and that there are advantages as well as disadvantages. It is unclear whether Aspies for Freedom will be organising anything this year. However, if you would like to take part in something locally to celebrate this day, please get in touch and share your ideas. It could be as simple as a bring- your-own picnic in the park. The important thing is for us all to take pride in autism and celebrate the diversity various neurological types express.*



Please see the 'GET IN TOUCH' box for our contact details.

GET IN TOUCH

Let us know what issues affect you and help us campaign for change!

Email: Lambethautismgroup@yahoo.co.uk



Or you can contact Mel Carr, South East Regional Officer at the NAS on: **020 7704 3809**

AUTISM AND LARGE HEADSIZE

The Institute of Cognitive Neuroscience, University College London is looking into possible links between increased head-size in autism and particular cognitive processing style (weak central coherence). They are interested in hearing from the parents of **high-functioning children aged 7-11 years old** with ASD who also have a large head circumference to take part in their research.

This research project is part of an ongoing programme of research at the Institute of Cognitive Neuroscience, University College London under Professor Uta Frith and Dr Sarah White. Macrocephaly is found in 20% of people with ASD but only 3% of the rest of the population. Weak central coherence is a

tendency to notice small details rather than the bigger picture or 'gist'. This style of processing may be an advantage when analytic skills are required and can also be found in some individuals without autism. This study aims further to investigate the relationship between macrocephaly and weak central coherence. We hope to confirm whether weak central coherence is only present in individuals with ASD who also have macrocephaly.



As children with ASD and macrocephaly are very hard to find, we would appreciate your help! Please could you measure your child's head size following these instructions: if your child's head size is greater than about 54cm, we would very much like to hear from you. We will also be seeing some children with smaller head sizes so please feel free to get in touch if your child's head size is less than 54cm.

If you are interested in taking part or would like further information, please contact **Gemma Morant** on **07942 041302** or email g.morant@ucl.ac.uk

Autism-friendly screenings

KIRIKU AND THE SORCERESS (U)

11am, Thursday 29 May



RITZY PICTURE HOUSE
Brixton Oval, SW2 1JG

Bookings 08708 505 703

Tickets for all screenings are £2.50 per person (No concessions or free carers' tickets)

For more info, contact **Alice Warren**

020 7326 2611 or alice.w@picturehouses.co.uk

SOS!SEN

SOS!SEN is an independent helpline for which offers free advice to parents of children with Special Educational Needs. In the words of one LAG member *'SOS!SEN provided amazing support for our autistic boy and his school provision, statementing, tribunal and post-tribunal times. It offered us guidance, understanding and knowledge, which enabled us to see a more positive and constructive way forward'*

Come and meet co-founder and former headteacher Marion Strudwick

When: Friday 16th May (10am -11.30am)

Where: Little Starz Children's Centre, 18 Benton's Lane, off Gipsy Road, London SE27

TREEHOUSE, SCHOOL GOVERNORS & AUTISM AWARENESS

School governing bodies are responsible for making sure that the school complies with the *Disability Discrimination Act 1995* (as amended by *the Disability Discrimination Act 2005*). The general duty on schools is to have due regard to the need to eliminate unlawful discrimination and to promote equality of opportunity in the area of disability.



However, there may well be additional responsibilities for school governors on the horizon. The government is currently consulting on the role of the school Special Educational Needs Coordinator (SENCO). The Department for Children, Schools and Families (DCSF) is keen to boost their influence by ensuring that they are qualified teachers, making them a member of the senior leadership team or, where that is not possible, designating a member of the senior team to champion the special needs cause. Draft regulations charge school governors with responsibility for making sure this happens.

School governors, usually volunteers, come from all walks of life and give up their free time to undertake their duties. Their role is likely to have an increasing emphasis on SEN and yet how many school governors will have previous knowledge and experience of Special Educational Needs, let alone autism?

Lambeth resident and parent of three children with autism, Linda Downie, lead parent for the *TreeHouse Constructive Campaigning Parent Support Project*, was therefore delighted to be invited to deliver autism awareness training for school governors in Lambeth, as part of the annual training programme for governors.

The session entitled '*Everything you wanted to know about autism but were afraid to ask*' was based around twelve key messages inspired by children with autism and their families. These messages (which formed the basis for the *TreeHouse Autism Calendar 2008*) provide an insight into strategies that teachers and other school staff can adopt to improve communication with children with autism. To download a copy of the calendar please visit the **TreeHouse** website www.treehouse.org.uk or alternatively phone the project team on 020 8815 5443.

NAS parent to parent line

0800 9 520 520

Freephone open 24 hours



The Parent to Parent Line is a free, confidential telephone support service offered by volunteer parents to other parents of an adult or child with an autistic spectrum disorder.

Call anytime and leave a message and contact number.

CREATIVE:SPACE EVENTS



Create is a dynamic charity that uses the creative arts to help transform the lives of disadvantaged and vulnerable people in society. It aims to give people of all ages access to the therapeutic, educational and social benefits of the creative arts.

creative:space events are unique, interactive music concerts organized specifically for disabled children and their families. Each event gives families the opportunity to hear and play live music, dance and create masks in a relaxed and friendly environment. Concerts are informal with seating around tables full of colouring activities.

The next three *creative:space* events are particularly suitable for children with communication, learning or sensory integration difficulties, and will take place at **Conway Hall, London WC1**, on **Sunday 8 June 2008** and **Sunday 7 December 2008**. The music will be performed by the exceptionally talented pianist, Derek Paravicini (who is blind and has severe learning difficulties) and the acclaimed new London Chamber Ensemble. There is lots of space for movement and percussion instruments are handed out during the event so that families can join in the music-making and have fun! The event will include:

- A 75-minute interactive concert
- A chance to join in the music-making
- Colouring activities for budding artists



For further information, please contact **Kate** on **020 7374 8485**

or email: kate@createarts.org.uk.

NB: creative:space events sell out quickly so we recommend booking early!

FOOTBALL UPDATE

Dulwich-based football organisation PELO has made a grant application to Children in Need with LAG's support to fund weekly football sessions and some holiday provision as well. The aim is to offer fun football training to 5 - 11 year olds with autism and Asperger's syndrome with activities differentiated according to children's abilities and needs. In our last newsletter, we reported that grant decisions are made by Children in Need at the end of March 2008. In fact, that was the closing date for applications; we should hear in August 2008.

