

South Manchester Down's Syndrome Support Group

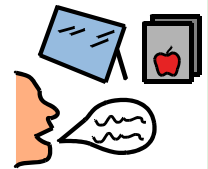
Fulfilling Potential

November 2010

phone: 07757 764 864, email: contact@dsmanchester.org.uk
Website: dsmanchester.org.uk

Group news

Chatterbox Club November 27 Heaton Moor Evangelical church, Green Lane, Heaton Moor SK4 3LH. Our monthly SALT sessions combined with play, a chance to meet other families, sing and sign and craft activities. **Teachers and TAs welcome** - the activities modelled in these sessions are suitable to be used in educational settings. **Even if your child is not enrolled for SALT sessions, your family is very welcome to come along for coffee, chat and sing and sign—just pop a donation in the box at the kitchen counter.**



Theme for November Houses and Homes - Building on the work we did last year. Please bring photo of your house or that of a family member or friend.



Swimming

The pool at the Seashell Trust is booked for our exclusive use on **Sunday November 21 from 2-3 pm and the common room from 3-4pm**, so we can have drinks and sandwiches afterwards (bring a packed tea!) To book places (ASAP please) at £5 per family, please contact Bernadette: Telephone: 07757 764 864, email: contact@dsmanchester.org.uk.

Family Christmas Party Saturday December 18 11:45am—2pm

Although still in the planning stage, we hope this year's party will include: a Christmas sensory session from Laura of Sensory Stars for the under 5's, Jabberjacks for the 5-10 year olds, Christmas crafts for teenagers, Circus skills to watch and do with Curious Eyebrows for everyone and Chrystal Chords Choir singing Christmas songs and Carols, as well as festive food and drinks. Of course Santa will also be visiting.



We will ask all families coming to bring wrapped gifts (value no more than £5 each) for each of their children for Santa.

To book places, at £5 per family, please contact Bernadette:

Telephone: 07757 764 864, email: contact@dsmanchester.org.uk.

SparkleBox is a great website for resources but it has been banned by some local authorities—here's some news from the DSA:

The owner of SparkleBox was imprisoned- is still IN prison. As a consequence - LAs banned the use of SparkleBox in schools although teachers were allowed of course to access it from their homes if they wished. However SparkleBox has now been bought by a new owner and therefore LAs are now allowing it to be accessed in school- Oxfordshire has given their OK. Even if a LA still bans it - which they shouldn't now it is under new ownership -people can still access it from home.

Training Opportunities

Proposed for Manchester 2011

Thursday January 27 9.30—2.30

The Inclusion of children with Down's syndrome—Expectations of Behaviour

By considering the learning profile of a child with Down syndrome and looking at areas of need this course will aim to understand and address areas where difficult behaviours may develop. It will look at expectations, appropriate behaviour, including self help skills and go on to outline strategies to encourage good behaviour.

To express interest, please contact Bernadette:

Telephone: 07757 764 864, email: contact@dsmanchester.org.uk.

What time is it? Teaching children with Down syndrome and other learning disabilities how to tell the time 9.30—3pm February 2011 to be confirmend

Learning to tell the time is a challenge for many children. The first step for all children is to have a feel for the passage of time, then later be able to tell the time and apply it to everyday life. Time is a very abstract concept and as such can present a major challenge to children with learning difficulties and disabilities. This workshop will equip participants with a structured programme of activities on how to teach the passage of time and then how, step by step, to teach a child how to tell the time. The full day workshop will include the use of a pack of resources and structured activities. This will be available to buy on the day for an additional cost of £5 for the CD of resources and £5 for the structured learning programme.

To express interest, please contact Bernadette:

Telephone: 07757 764 864, email: contact@dsmanchester.org.uk.

Downsed International www.downsed.org/en/gb/

Interactive web seminars and online courses—detailed information and guidance on all aspects of development and education for children and teenagers with Down syndrome. The courses of seminars share the structure and content of the accredited training provided at Down Syndrome Education Conferences. They describe practical, evidence-based interventions for children and young people with Down syndrome and explain the evidence. They offer in-depth information for parents, teachers, teaching assistants, educational/school psychologists, speech and language therapists/pathologists, and other health and education professionals. The speech and language course and sessions are specifically designed for speech and language professionals.

Free advice webinars – live group advice provided by expert practitioners focused on specific issues and areas of development for young people with Down syndrome. Participants can submit questions during the session and engage in discussions on a variety of practical topics across different age groups. Suitable for families, teachers, teaching assistants, educational/school psychologists, speech and language therapists/pathologists, other health and education professionals, and representatives of support groups. Each session lasts 1 hour, with a brief 5-10 minute presentation to introduce the topic, followed by a 50-55 minute interactive question and answer session. See <http://www.downsed.org/en/gb/online/>



Events/Activities/Groups

At Seashell Trust Stanley Road, Cheadle Hulme, Cheshire SK8 6RQ*

CADS swimming development team runs lessons for all ages and abilities. Both group sessions and one to one sessions are available and also parent and baby sessions in the hydro-therapy pool. Please contact Wendy McNeil 0161 610 0185
wendy.mcneil@seashelltrust.org.uk

CADS dance and drama session run by the Y dn't U dance group at the Seashell Trust. The cost of the sessions are £3.00 per child and they **run every Saturday in term time**. 10-11.30am Aged 4-11yrs and 11.45 -1.00pm ages 11+yrs. All abilities welcome. For more information please call 07960 279074 or 07966 559164

CADS Fitness Club Every Thursday during term time, £1.50 per session, £10 per term. 13-17 years 6-6.45pm, 18-25 years, 7-7.45pm. Contact Heather Potter on: 0161 610 0121 or email: heather.potter@seashelltrust.org.uk

November 20 Saturday club at the donkeys* –an open visiting time when children with additional needs are able to ride the donkeys with their brothers and sisters. Rides are booked in as you arrive between 10am and 1pm. It is also a chance to visit adoption donkeys, relax over a cup of tea/coffee, bring a picnic or have a snack and meet other parents, carers and supporters. Closes at 3.00 pm. At EST Donkey sanctuary Manchester, Green Fold Abbey Hey Manchester M18 8RJ,
www.elisabethsvendsentrust.org.uk/view/manchester Tel 0161 301 4051 for details.

Cheetham - New group for parents who have children with DS under 5 yrs old*, every 4th Monday at 10.30- 11.30. Its a meet up/play & learn group, at **Woodville children's Centre**, Shirley Rd, Cheetham M8 7NE. For more information, contact the Pre-school Special Needs Service on 0161 274 6377.

Bamboo* parent support group. Every Friday, 12.30—2.30, Burnage Children'e centre, Broadhill Rd. For parents of children with additional needs. For details, please call Nicki Mansfield (07815 675581), Sam Stout (07791 114179) or Sam Emblow (07948 961049).

***Please note: not run by the South Manchester Down Syndrome Support Group. For information only—we are not responsible for changes to date, time or venue. Please use the contact information supplied to confirm details and to ask any questions.**

Information

The Equality Act 2010 came into force from 1 October 2010

<http://www.equalityhumanrights.com/legal-and-policy/equality-act/>

We have a PowerPoint presentation from the DSA about **The Mental Capacity act and decision making** by Alison Picton from the social care institute for excellence. If you would like a copy, email contact@dsmanchester.org.uk

We also have a handout entitled: **"Know Your Rights"** - An outline of some key legal tools for challenging cuts to public services. It was presented to the DSA AGM by Gwendolen Morgan, Public Law & Human Rights Solicitor, Bindmans LLP. Again, if you would like a copy, email contact@dsmanchester.org.uk,

Carers UK has welcomed new rights to protect carers from discrimination.

On October 1 2010, millions of people caring unpaid for disabled people gained new rights under the Equality Act 2010 which will mean that they cannot be directly discriminated against or harassed because they are caring for someone who is disabled.

Imelda Redmond CBE, Chief Executive of Carers UK, said, "We often hear of situations where carers have been treated less favourably by employers, overlooked for promotion, or not allowed the flexibility they are legally entitled to in work. Around 3 million people currently juggle work with care and these rights could make a big difference. The employers that we work with through Employers for Carers are already supporting carers better in the workplace and have found real business benefits as a result - saving both money and keeping valuable staff - as well as improving carers' lives. She added, "Carers UK has fought for and won many rights for carers over the years, but this is a significant step forward that many carers have been waiting for. The new rights also protect carers where they are provided with a worse service than someone who isn't caring for a disabled person. It also includes protection where carers are discouraged or prevented from using a service because they are caring for a disabled person. Carers UK will be focussing on the Equality Act 2010 and carers new rights for Carers Rights Day 2010 on Friday 3 December. Organisations wanting to sign up to Carers Rights Day should go to:

<http://www.carersuk.org/Newsandcampaigns/CarersRightsDay>

Notes:

1. A briefing on the Equality Act 2010 is available from www.carersuk.org.
2. The public sector duties to promote equality come into force in April 2011.
3. The rights gained by the Equality Act in 2010 are based on a landmark case taken by Carers UK member, Sharon Coleman, who cares for her son who has a serious health condition.
4. Carers UK runs Carers Rights Day every year. This years theme is Know Your Rights and part of it will focus on carers new rights under the Equality Act 2010.

EDF's (**Equalities and Disability Forum**) produce great resources for anyone interested in current Equalities issues... <http://www.edf.org.uk/>

The Learning Disability Coalition's (of which DSA is a founding member) response to the Comprehensive Spending Review can be found in the Guardian at

<http://tiny.cc/x5gzm>

What the 2010 Spending Review means for children with disabilities and their families

EDCM has produced a guide for families and supporters on what the spending review means for children with disabilities

[http://www.ncb.org.uk/edcm/news/news_archive/2010_news_archive/](http://www.ncb.org.uk/edcm/news/news_archive/2010_news_archive/nov_2010/2_nov_10_-_spending_review.aspx)

[nov_2010/2_nov_10_-_spending_review.aspx](http://www.ncb.org.uk/edcm/news/news_archive/2010_news_archive/nov_2010/2_nov_10_-_spending_review.aspx) or try <http://snipurl.com/1em26b>

Supporting you as an older family carer - A booklet to support older family carers of people with learning disabilities to get the right support now and to plan for emergencies and the long term Free to download at:

[http://www.learningdisabilities.org.uk/publications/?](http://www.learningdisabilities.org.uk/publications/?esct1526505_entryid5=22354&esct1544701_entryid5=34978&p=2&char=S)

[esct1526505_entryid5=22354&esct1544701_entryid5=34978&p=2&char=S](http://www.learningdisabilities.org.uk/publications/?esct1526505_entryid5=22354&esct1544701_entryid5=34978&p=2&char=S)

or try <http://snipurl.com/1bq1uh>

NEW LEARNING DISABILITY WEBSITE POOLS EXPERTISE OF PARENTS AND PROFESSIONALS

www.Netbuddy.org.uk is a brand new website offering hundreds of simple, yet ingenious solutions to everyday issues encountered by parents, carers, teachers and therapists working with learning disability. PLEASE SHARE YOUR TIPS!

Sleep apnoea masquerading as dementia by Adult Down Syndrome Clinic

We have mentioned in our books as well as on posts on this Facebook page that sleep apnoea can cause many health problems. One of them is causing a person to have cognitive skill loss. This can appear to be a non-reversible dementia (such as Alzheimer Disease). We have evaluated and treated many patients with Down syndrome for sleep apnea who presented with a loss of skills. This is also being found in people without Down syndrome. The link below is to an interesting article in the New York Times.

<http://newoldage.blogs.nytimes.com/2010/10/06/when-sleep-apnea-masquerades-as-dementia/?emc=eta1%EF%BB%BF>

My Perspective 2011 Launches After the fantastic success of the first ever photographic competition for people with Down's syndrome, My Perspective, we are pleased to announce the details of the 2011 competition:

<http://www.downs-syndrome.org.uk/fundraising/news/738-my-perspective-2011-launches.html>

Diagnosis to Delivery - A Pregnant Mother's Guide To Down Syndrome - free ebook Although some info is US specific there is plenty of common sense info that would be relevant to any woman who is pregnant with a baby with Down's syndrome

<http://downsyndromepregnancy.org/resources-2/>

Children with Down Syndrome: Perspectives on Development and Behaviour

Presentation by Mary Pipan, MD Clinical Director, Trisomy 21 Program The Children's Hospital of Philadelphia Part of the American National Down Syndrome Society affiliate webinar series

www.ndss.org/images/stories/NDSSresources/pdfs/dsparentpresdelco91108%20read-only.pdf

Auditory Memory Exercises

One of the difficulties our children have is remembering words that are spoken long enough to process what is said. A common problem with young children is that they forget the first word in the sentence by the time you get to the last word. To improve on this situation, the auditory memory needs to be strengthened. The auditory memory helps us to "hold on" to words as they are spoken so that we can make sense out of what is said. Here are a couple examples of activities to use with young children to work on this skill. Use these ideas as a spring board and make up your own activities.

Activity 1: What's in the Box?

Materials Needed: A bag or box and a variety of objects.

Procedure: Start by showing your child two objects your child can label and identify them clearly. Put the two objects in the box in your child's view. Ask "what's in the box?" Wait a couple of seconds (literally, about 3) and then identify what you put in the box as you pull the items out. Your child should be able to name both items easily once familiar with the game. Be animated, playful and full of praise. When the game is understood and your child is successful with what's expected, play the game in the same way, but this time do not show the child the items going into the box. Instead, hide them and say "I am putting something into the box. Ready? It's a CAR and a BRUSH. What's in the box?" Only wait a few seconds and then show him. If he gets one, pause for only a few seconds and then give him the name of the other item. Keep playing with different combinations of objects until he is successful most of the time. This is hard work, so keep it fun and keep the pressure off. When he is getting both right 80% of the time, you can increase to three objects.

Activity 2: Laundromat

Materials Needed: Small items of clothing and a basket

Procedure: Make a washing machine out of a box or get a small basket that you label a 'laundry basket.' Lay the clothes out on the table saying and signing each one as you go. Only put out a few at a time. Say "my turn first" and "I'm going to put clothes in the washing machine. I'm going to put in the hat and socks." Then pick up the hat and socks and put them into the machine. Then say "your turn" and tell them that you are going to tell them what to put in the machine. "OK, ready? Socks...shirt". Wait three seconds and if there is no movement, repeat and you can physically prompt her/ him to put the item in the machine. Give plenty of praise. Keep practicing until successful and then increase the number of objects. Keep the session short because this is demanding work; 3 or 4 trials will probably be enough in one go.

Also explicitly teach how to remember items. Just as we remember phone numbers that are called out by saying the number over and over to ourselves until we get to a phone, I teach children how to do this kind of rehearsal. It is a very successful technique that we all use when we want to remember things. When I am doing the above activities with children I will take my turn and say the list of items I need to get (e.g., "sock....shirt....hat") and then I will repeat the list out loud as if to myself a few times before picking those items up. Basically, I am making the memory process observable by saying out loud what I would normally do in my head. © Ann Wheeler, DSC 2010

Resource guide to **oral-motor skill difficulties in children with Down syndrome** by Libby Kumin at: www.ndsccenter.org/resources/documents/speech/OralMotor.pdf

Helping Babies With Down Syndrome Develop Speech & Language by Libby Kumin - free to download at: <http://www.riverbendds.org/helpingbabies.pdf>

Four useful booklets about **early communication** produced by Down's Syndrome North East a few years ago Stage 1 - Getting Started Stage 2 - Before Words Stage 3 - Sounds & Words Stage 4 - Using Words

If you would like all or any of the booklets, please contact stuart.mills@downs-syndrome.org.uk

Cerebra's speech therapy scheme has reopened.

[Http://www.cerebra.org.UK/parent_support/support/speech_therapy](http://www.cerebra.org.UK/parent_support/support/speech_therapy)

To be eligible for the scheme, you must meet the following criteria:

Cerebra will only be accepting children aged 1 to 16 years old who have a neurological, brain-related condition. If they are school-age, the child must have an SEN Statement or be on School Action Plus in Wales and England, a Co-ordinated Support Plan in Scotland or be on Stage 4 or 5 in N. Ireland. The child must not have received direct individual or group speech therapy from a speech therapist in the last 6 months. To receive a Voucher, you will need to fill out an application form. You will need to send in a reference with your application. If your child is school age or attends pre-school, the reference must come from the school. Otherwise it should be from a professional who works with your child (health professional, social worker, Portage worker.) The letter needs to confirm your child's condition, recommend speech therapy and verify that your child has not had therapy from a speech therapist in the last 6 months. All references must be on headed paper.

If successful, the voucher is worth up to £500 of SLT. Cerebra will be using speech and language therapists who are members of the Association of Speech and Language Therapists in Independent Practice (ASLTIP). All ASLTIP therapists are certified members of the Royal College of Speech and Language Therapists and registered with the Health Professions Council. With the voucher, Cerebra will send you a list of ASLTIP therapists in your geographical area. You will need to contact a therapist who is able to help your child. **Symbol UK recommends that therapists working with our children have training in our children's very specific speech and language needs.** The therapist must invoice Cerebra direct for payment. If you have any questions please call Alex on 0800 328 1159 or e-mail alex@cerebra.org.uk.

DS-Autism Connection (USA) - 2nd Annual Conference - 8th Oct 2010 -

Powerpoint Presentations. DS-Autism Connection (USA) held their 2nd Annual Conference on Friday 8th Oct. Robin Zaborek (DS-Autism Connection's Coordinator) kindly emailed the DSA the following PowerPoint presentations from the Conference: Education And Intervention For Children With Down Syndrome And ASD - Deborah J. Fidler, PhD & Susan L. Hepburn, PhD; Down Syndrome And Autism - Susan Hepburn, PhD & Deborah Fidler, PhD; The Genetics Of Autism And Down Syndrome - Ellen Roy Elias, MD, FAAP; Behavioural Treatments For Sleep Problems In Individuals With DS-ASD - Tery Katz, PhD

Are you a parent or carer of a young person aged 14 – 25, with a learning difficulty or disability?

- **Worried about Transition?**
- **Thinking about what needs to change for your child?**
- **Need to share and solve problems with other parents carers?**
- **Need to get information?**

**Come to the The Westwood Street Centre,
Westwood Street, M14 4PH**

Dates for the rest of 2010:

(10am to 12.30pm)

Thursday 11th November **(Speaker from the National Getting a Life team - to talk about how Self Directed support works)**

Tuesday 16th November **(Speaker from Advicekit to talk about rights in work, benefits, housing, rights for carers)**

Thursday 25th November

Tuesday 30th November

Thursday 9th December

Tuesday 14th December **(Speaker from local authority to update us about changes to the Statementing process)**

Feel free to turn up to a session or for further information contact:

Ann Tarpey on 0161 8820890

anntarpey@talktalk.net

or Laura Upton on 0161 226 0843

laura.upton@manchester.gov.uk

Dates for your diary

CADS Saturday club	Saturdays
Seashell Swimming	Saturdays
Bamboo	Fridays
Saturday club at the donkeys	November 20
Swimming	November 21
Chatterbox Club	November 27
Christmas party	December 18
Inclusion and Behaviour	January 27

The views and items in this newsletter are not necessarily those of the South Manchester Down's Syndrome Support Group. Mention does not necessarily mean recommendation or support.



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