



South Manchester Down's Syndrome Support Group (SMDSSG) October 2010



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Group news



AGM Saturday October 23, 12.15-1.45 pm



If you are a parent/carer of a child with Down's syndrome and receive a monthly newsletter, you are a member of this support group.

Our AGM will be on October 23, 12.15 - 1.45 pm (after Chatterbox).

Please attend if you possibly can to contribute to **your** support group. The group is ticking along quite well and we remain fairly active. However this is due to the hard (voluntary) work of a small number of people. **There is a lot more we could do as a support group if we had the commitment of more people's time and energy.** If you would like to get involved by joining the committee, fundraising, organising an event or helping out, please come to the AGM. We are going through the process of becoming a charity in our own right. This will give us the opportunity to apply for a wider range of grants. A proposed agenda is attached. If you can't make the AGM but want to contribute your time, ideas, suggestions, or add items to the agenda, please contact Bernadette. Telephone: 07593 542 107, Email: contact@dsmanchester.org.uk. For catering, please let us know if you are coming

A sandwich lunch will be provided at 12.30 for those who attend for the AGM.

Chatterbox Club

October 23 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 October: "Multi-sensory Autumn" - We will be thinking about the language we use to describe the sights, sounds, smells and textures associated with Autumn.

Please bring an 'Autumn Find' - e.g. leaves, conker.

We now have 38 families attending Chatterbox and all groups are full. We will now be operating a waiting list and are looking into the possibility of employing a fourth therapist.

Upcoming Events

Fire Station visit. Quite a few families couldn't make our summer visit, so there's another on **Sunday October 10 2-3 pm**. Please book ASAP. You can come a second time if you want!

Run of the Mill indoor play centre

(Pear Mill Ind Est Stockport Rd West, Bredbury, Stockport SK6 2BP) is booked for our exclusive use **Thursday October 28 4.30-6 pm**. Cost £5 per family, including food. This cost is heavily subsidised so extra donations always welcome! To make organising easier, please let us know ASAP if you would like to book a place.



Swimming The pool at the Seashell Trust is booked for our exclusive use on **Sunday November 23 from 2-3 pm and the common room from 3-4pm**, so we can have drinks and sandwiches afterwards (bring a packed tea!)



To attend any of these events, please contact Bernadette: Telephone: 07593 542 107, email: contact@dsmanchester.org.uk. to book a place for your family.

Training Opportunities

Please pass information about training to your child's nursery or school. Organised by SMDSSG In Manchester: November 4: Using Numicon to teach numeracy at the Northern Tennis club Didsbury . See the enclosed booking form for full details. Please book ASAP as we need to ensure we have sufficient numbers of delegates before we can be sure of going ahead.

Downsided International www.downsided.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.

Events/Activities/Groups

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

October CADS event on Monday 25th and Tuesday 26th October 2010 at the Seashell Trust, Cheadle Hulme. The cost of the event will be £16.00 per child for two days of activities. The event will take place 10.00am - 3.00pm both days.

Please contact Gemma Castle on 0161 610 0122 or email gemma.castle@seashelltrust.org.uk to book a place.



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 or Rachel Chapman 0161 610 0159 rachel.chapman@seashelltrust.org.uk

CADS football Friday 10th September for 7 weeks until Friday 22nd October 2010 at St James' High School, Cheadle Hulme. The cost of the course is £17.50 per child. The sessions run from 6-7pm for children aged 5-11yrs and from 7-8pm for 12-16yrs. If you would like any further information please contact Gemma Castle on 0161 610 0122 or email gemma.castle@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

October 16 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 National Transition Support Team (NTST) have published a new leaflet '**Disability Equality: Fulfilling duties for young people in transition**'. This information leaflet, produced with support from Scope, focuses on what local authorities and their partners can do to ensure they are taking positive action to fulfil their duties to young people with disabilities under the Disability Discrimination Act (DDA) during the transition to adulthood. A supplementary appendices is also available. This guide will be updated once the Equality Act provisions are in place. Free to download at:

<http://www.transitionsupportprogramme.org.uk/resources/toolkits.aspx>

Passionate campaigners needed - Are you 8 -18? Enthusiastic about getting your voice heard? The Diana Award and the Office of the Children's Commissioner are proud to announce a collaboration to set up a Children and Young People Advisory Group. The group will advise Maggie Atkinson, Children's Commissioner and her office, on children and young people's views regarding all aspects of their work. So if you are an enthusiastic advocate eager to represent the voice of young people, apply for a position. Applications are open to all young people aged 8-18. Eighteen people from across England will be selected to sit on the board. The Group will meet with Maggie Atkinson four times a year to represent the voice of young people across the country. For more information or to send an application please email didi.yvonne@diana-award.org.uk by 14th September.

<http://diana-award.org.uk/news-events/passionate-campaigners-needed/>

Breastfeeding infants with down's syndrome

If you are interested in learning more, please contact Dr Roja Sooben - r.d.sooben@herts.ac.uk <<mailto:r.d.sooben@herts.ac.uk>>

Stuart Mills from the DSA has an article by Dennis McGuire entitled '**Promoting Mental Wellness In Teens And Adults With Down Syndrome**' (this paper was delivered at the World Down Syndrome Conference held at Dublin City University, August 2009 and the scan is from DS Ireland's latest newsletter). If you would like a copy, please email him at: stuart.mills@downs-syndrome.org.uk.

You Tube Channel for People who Have Siblings with Down Syndrome Brian Skoto and Sue Levine, co-authors of *Fasten Your Seatbelt: A Crash Course on Down Syndrome for Brothers and Sisters*, have created a new YouTube Channel exclusively for brothers and sisters who have siblings with Down syndrome. On this site, Skoto and Levine will be answering some of the toughest questions asked by brothers and sisters, which are featured in their new book. <http://www.youtube.com/user/downsyndromesibbook>

DS-UK@LISTSERV.DOWN-SYNDROME.NET

Mailbase for parents/carers of children who have Down's syndrome

Home Access Programme The main Home Access programme has been a runaway success. More than 250,000 families have already benefitted from Home Access Grants, which are now no longer available. The programme is now focused on providing packages to families with children who have profound disabilities or special educational needs. If you are a low-income family in receipt of certain benefits you could qualify for a Home Access package with Assistive Technology. Find out more at: <http://www.homeaccess.org.uk/>



Dates for your diary



CADS Saturday club	Saturdays
Seashell Swimming	Saturdays
Bamboo	Fridays
Fire Station visit	October 10
Saturday club at the donkeys	October 16
Chatterbox Club	October 23
AGM	October 23
Run of the Mill	October 28
Numicon Training	November 4
Chatterbox Club	November 27
Christmas party	December 18

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.

***South Manchester Down's
Syndrome Support Group October 2010***



Performance Anxiety

Did you ever have to give a presentation to your class when you were in school? Did you ever have to do this when you were not well prepared? Maybe not, but I am sure that you can imagine how you would feel if this were the case. Chances are you would feel anxious; some would feel that anxiety even if they were well prepared for the presentation. This is aptly called "performance anxiety". This kind of anxiety is very common for people with Down syndrome and I believe that it is important that teachers and parents alike be aware of this so that they can help prevent the anxiety affecting their school work. Why would someone with no self consciousness have performance anxiety?

Enjoying a dance to good music in the aisle of a movie theatre (I joined Allie once) or showing off on a stage is not the same thing. Performance anxiety stems from a fear of failure and often adversely impacts school work. Usually it shows itself when a child starts school and starts to experience difficulty with academic work. It makes a lot of sense when you consider that a child with an intellectual disability, by definition, has difficulty learning. When asked to do something that is hard (i.e., learning) then it is likely that a child might start trying to avoid a particular learning situation (e.g., math) or more seriously, any learning situation. The obvious ramifications of this are challenging behaviour and secondary impairment to learning. It is important to be aware of this situation so that children can be supported to be good learners (i.e., the best that they can be.)

Preventing Performance Anxiety

The best way to avoid this anxiety is to prevent it as much as possible (it is natural to experience anxiety at times.) There are a few simple ways to do this:

- Be a good model. We always want to show our children the best possible model so we always colour in the lines and pour our milk with no spills. Unfortunately, this is not realistic and can set too high of a goal for our children. We want to encourage colouring in the lines, and praise effort to colour in the lines, but I think it is helpful to model that life isn't perfect and how to handle mistakes. If a child learns these lessons then performance anxiety has no real basis to exist. If I learn to approach math with the understanding that sometimes I will make mistakes and how to obtain help, etc, then I am less likely to be too anxious to take the challenge. I think the problem is when our children see us as parents and teachers always turning out beautifully-coloured pages that they see the bar as too high. If, on the other hand, you "accidentally" colour a few strokes outside of the line in front of your child and model some response like "Rats! Nevermind" and carry on then your child is seeing that life isn't perfect and how they can respond in a similar situation. You are also modelling perseverance which is an invaluable tool.

- When first teaching a new skill, use errorless learning. Errorless learning is a process by which introduce a learning situation in such a way that your child can only succeed. For example, ask your child to show you the red car and point to it to help them find the right one. Basically, you are making sure that they arrive at the correct response in whatever way seems appropriate.

- When your child has been exposed to a new skill for a while, let them make mistakes. After you have presented a skill such as colour identification for a while, stop giving the correct answers. Ask for that red car and don't indicate the answer. If everything is always errorless then a child does not learn how to handle mistakes. The important thing here is how to cope with mistakes. Make sure that your response is light and matter-of-fact. If your child believes that you are disappointed or frustrated, then that puts an emotional price on failure and makes a child reluctant to want to try.

- Teach, don't test. Nothing supports performance anxiety like someone in your face staring at you with an expectant look after asking you a question. Remember how you felt when you ran into someone you recognized but you could not recall the name or where you knew them? Yikes, that's a horrible feeling. If you want to teach a skill, teach it. If you want to know if a child has acquired a skill (e.g., "where is that red car?") then by all means ask the question but don't make it appear as though it is a test. If they don't give the correct answer or pause too long, just give them the answer.

Although the article is obviously aimed at a US audience, there are some universally applicable observations contained therein:

The following is taken from Vol 7 Issue 5 of the 'Down Syndrome Of Central Texas' Newsletter (Nov 2009)

'The Three New "R's": Rigor, Relevancy, and Relationships Article submitted by Jana Palcer, Education Chair.

Reading, writing, and arithmetic are still alive and well in the mainstream education system, but an added emphasis is now put upon rigor, relevancy and relationships. For this article, ideas about rigor, relevancy and relationships, are adapted to what they could mean in the arena of "special" education. To some people, these concepts may be new, while to others, they may be old. Either way, this enlightened level of thinking provides parents a road map to guide their child toward the most optimistic and successful future possible.

Rigor, relevancy and relationships should be foundational components of your child's educational plan. In analyzing and evaluating the appropriateness of a child's Individualized Education Plan (IEP), these three things should be carefully identified, prominent, and clearly defined. If these elements are at the core of decision-making, framing, and implementation, there is great hope for solid student achievement and productive educational outcomes.

RIGOR

Rigor can be defined as a condition of the learning environment which stretches the individual learner to move beyond his/her current "comfort zone" and grow as an independent learner (Hibbard). Children with special needs require rigor in their educational planning, from the type of goals created to the ways in which those goals will be achieved. Standards and expectations should be high, academic content should be challenging, and final outcomes should project significant achievement. Do not ever let an Admission Review and Dismissal (ARD) Committee convince you otherwise. When your child's value or potential is underestimated, the IEP will not help your child to become the best that they can be. If your child has an IEP that primarily consists of Life Skills goals, your child is not likely to encounter a great amount of rigor in their learning. Life Skills do have value. For some children, a heavy focus on them might be the right approach, but many children with Down syndrome, Autism, Brain Injury, Cerebral Palsy, etc. are capable and have a deep need for a rigorous academic foundation. In this case, Life Skills should be more like the child's "appetizer" or "side dish" instead of the child's "main course." For example, if a second grade child is capable of reading or creating four word sentences, it would seem unfair if more time is spent helping this child blow their nose or put away toys. Unfortunately, these are real objectives listed on the IEP's of two extremely bright children within DSACT. If a child's expectations are to concentrate on and perform tasks that are far below their ability level and age range, then that is exactly where they will end up - far behind - and with a decreasing chance to ever catch up. Don't forget that the law says a child with special needs should be given access to the General Education curriculum, and appropriate resources/ support services should be put in place so that the undertaking of that curriculum is effective and productive. IEP's for children with special needs should be standards-based with the Texas Essential Knowledge and Skills (TEKS) as the underlying framework.

If the typically developing peer in your child's inclusion class is working on writing the alphabet, a child with disabilities should be also. If the typically developing peer is working on recognizing and ordering numbers, a child with disabilities should be also. Your child might be doing so with individualized accommodations or modifications, and the curriculum may be adapted to meet their specific needs and place in the process. Nonetheless, they should be engaging in parallel subjects and activities to those found in the General Education classroom.

RELEVANCE

Remember that certain things are important at certain ages and stages. Thoroughly analyze each goal and objective in your child's IEP. Is the skill something that helps them gain to greater useful academic or functional knowledge? Is this skill something they will actually utilize in their lives? Will they gain any of the necessary tools, concepts, and functions that will help them become independent and contributing members of society. For skills that seem to elude mastery year after year, determine the impact that skill will make. For example, at eight years old, if too much time is being spent on my child recognizing a "No Trespassing" sign, when I know my child is never left unattended, and would more likely need to understand a bathroom sign or a stop sign, I'll let the "No Trespassing" sign go for now and re-visit it if, and when, I feel it is relevant.

There is no formula for our children's IEP's, and that is the beauty of their educational plans. If something is not working, change it! If something is off target, take it away. If something lacks relevancy, don't let it swallow up your child's time and energy. There are enough other things in life that will do that. At some point, we must let our children live with their minor flaws or yet-to-be-mastered skills and move on to what is more relevant and vital for where they are today. Keep your eye on the ultimate prize, and they will be better for your careful discretion and foresight.

RELATIONSHIPS

To make the educational experience as successful as possible, a parent must also consider the importance of several key types of relationships: supportive peer relationships and supportive staff relationships. Our children are so often loved and adored by their typically developing peers, and they need the opportunity to bask in the beauty of all the goodness and kindness their peers tend to show. But as much as they need hugs and high fives, they also need the wonderful skills and characteristics that can be modelled for them by their typically developing peers, and they benefit greatly from the tutoring, assistance, and helping hand that their typically developing peers are ready to give.'