

# Journal

**Simon Beresford  
– An inspiration**

**Hearing Aid and Toilet  
Training Tips**

**Advice on  
Annual Reviews**

**Sibling Poetry**

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Nick Logan  
Professor Stuart Logan  
Dr Liz Marder  
Dr Philip Rees  
Cassie Smith  
Professor O. Connor Ward

## Getting Support

Help Line 0845 230 0372

Our Information Officers are available to answer calls Monday-Friday 10am-4pm. They can give advice about any aspect of living with Down's syndrome, from medical enquiries to support services to behavioural issues.

They work with our team of advisers to offer advice on any specialist areas.

## Resources

Our Information Department holds a wide selection of books, videos and other resources for consultation, which can be accessed Mon-Fri 10am-4pm.

Please telephone in advance to let the Information Team know you will be coming in, and to arrange a time to talk to a member of staff if you would like.

## Education

### • Education Advice

Bob Black is our Education Information Officer. He answers education related queries from parents and professionals and helps to develop DSA education resources.  
Tel: 0845 230 2172, Tues-Thurs 10am-4pm.  
E-mail: educate@downs-syndrome.org.uk

### • Education Advocacy

Jane McConnell is seconded from IPSEA to take calls on education law, statement appeals and Tribunal enquiries.

You can contact her through the DSA on 0845 230 0372

### Benefits Advisers

Our Welfare Benefits Adviser is available Monday-Friday 10am-4pm on 0845 230 0372.

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Langdon Down Centre  
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Teddington  
Middlesex TW11 9PS  
Tel: 0845 230 0372  
Fax: 0845 230 0373**

**E-mail: info@downs-syndrome.org.uk  
Website: www.downs-syndrome.org.uk**  
National Office hours are Monday-Friday 9am-5pm. Emergency numbers outside office hours are given by recorded message.

## Regional Offices

### WALES

Suite 1  
206 Whitchurch Road  
Heath  
Cardiff CF14 3NB

Tel/fax: 02920 522511  
Office hours Mon-Fri 9am-5pm

### NORTHERN IRELAND

Unit 2  
Marlborough House  
348 Lisburn Road  
Belfast BT9 6GH

Tel: 02890 665260  
Fax: 02890 667674  
Office hours Mon-Fri 9am-5pm

### SCOTLAND

is covered by its own association.  
For more information contact:  
Down's Syndrome Scotland  
158-160 Balgreen Road  
Edinburgh EH11 3AU

Tel: 0131 313 4225

### REPUBLIC OF IRELAND

is covered by its own association.  
For more information contact:  
Down's Syndrome Ireland  
Citylink Business Park  
Old Naas Road  
Dublin 12

Tel: 01 426 6500  
Fax: 01 426 6501  
Email: info@downsyndrome.ie  
Website: www.downsyndrome.ie

## Local Parent Support Groups

The DSA has details for hundreds of local parent support groups across the UK. For details of your nearest group, please contact head office.

If you are writing in, we would be grateful if you could send an SAE with your enquiry, to keep our postage costs down. **Thank you.**

the down syndrome  
educational trust  
<http://www.downsed.org>

The Down Syndrome  
Educational Trust  
Tel: 023 9285 5330  
enquiries@downsed.org  
www.downsed.org

**MENCAP**  
Understanding learning disability

Mencap  
Tel: 020 7454 0454  
info@mencap.org.uk  
www.mencap.org.uk

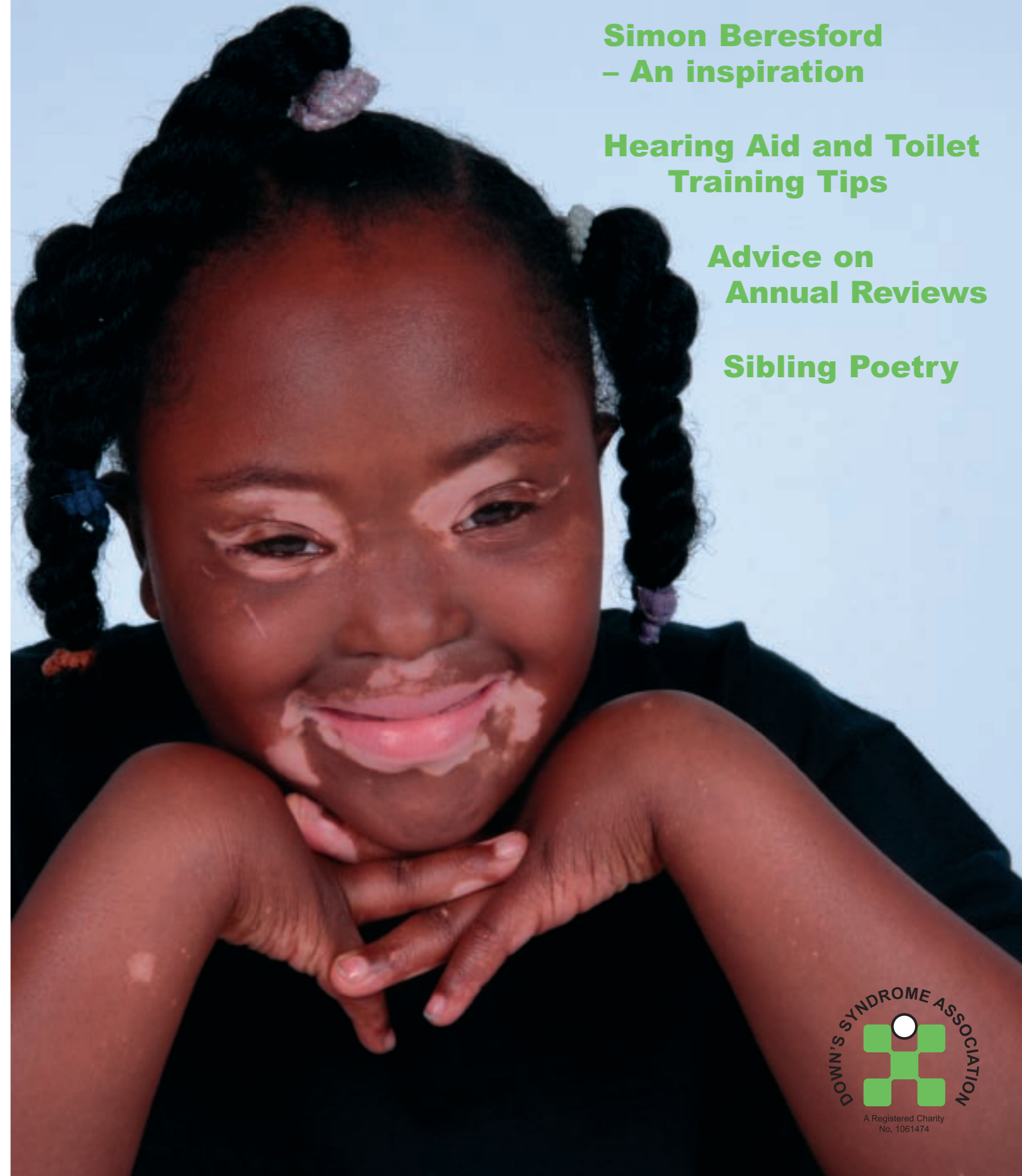


Down's Heart Group  
Tel: 0845 166 8061  
info@dhg.org.uk  
www.dhg.org.uk



Symbol UK  
Specialist Speech and  
Language Therapists  
Tel: 01795 844 440  
info@symboluk.co.uk  
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# Welcome

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Carol Boys

## Message from the Chief Executive

### Another year seems to have flown by and once again we are talking about our Christmas activities.

The Christmas Concert at the Langdon Down Centre is now a well established event which has been extended to two evening performances due to popular request. Most of the performers have Down's syndrome or some other form of learning disability and they come from all parts of the UK to take part. It's one of the benefits of having a working theatre on site and I can thoroughly recommend a visit if you are able to get to us. They will take place on 10th and 11th December. Please contact Alexa at the DSA to find out more about it and to book your tickets. Email [alexa.dizon@downs-syndrome.org.uk](mailto:alexa.dizon@downs-syndrome.org.uk).

The campaign against the cuts to social care packages is moving forward. At the DSA we have been working on written and visual materials to help people with Down's syndrome and their families to understand what is currently available to them. You can read more on page 6 and at [www.learningdisabilitycoalition.org.uk](http://www.learningdisabilitycoalition.org.uk).

I know as a parent of a young man with Down's syndrome just how difficult it can be to find your way through the maze of information and advice that is available to you. Like me you probably think that when your child is finally settled in school that the rest will just follow automatically. This is definitely not the case; it is really important to make sure that you are constantly reviewing the situation and the 14+ transition meeting is crucial for future planning. Families with younger children need to be active in the fight for better services now because it will be your children

that benefit from the work that we are doing. Information on Transition and Person Centred Planning will be available later in the year.

I would like to congratulate Dr Janet Carr who has received a lifetime achievement award from the Canadian Down Syndrome Research Foundation. The 'Josephine Mills Lifetime Achievement Award' was given to Janet in recognition of her work with people with Down's syndrome and their families around the world over the last forty years. Janet has been a behaviour advisor to the DSA for more years than I can remember and she has been a vital support to countless families.

The DSA is currently working on updating and modernising our website, making it more accessible and easier to navigate. We are really pleased with the new look and hope that you will be too. We also hope to receive some positive feedback when completed. The website is due to go live at the end of September so please keep an eye out at [www.downs-syndrome.org.uk](http://www.downs-syndrome.org.uk).

And lastly may I take this opportunity in advance of wishing you all a good Christmas and a happy new year.

Carol Boys, Chief Executive

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# Updated Inclusion

## in primary booklet



The DSA booklet *'Including Pupils with Down's syndrome: Primary'*, is probably the single most requested book in our comprehensive range of education information. It was originally written by Sandy Alton, the DSA's Teacher adviser in the 1990's, and has become the standard from which all other publications have emerged. Teachers across the UK have applauded its simplicity and its "Can Do" approach to inclusion. It has also been adopted and adapted by over 30 other countries worldwide and is downloaded from our website in over 150 countries.

The booklet has been comprehensively updated by the original author and sections added and amended to take into account the latest teaching strategies and approaches to learning. While it continues to cover all the essential information on the specific learning profile of children with

Down's syndrome it now acknowledges the huge increase in inclusion as well as the changing face of the classroom with its increased use of Phonics and the implementation of white boards and other policies and strategies that have come into play since the original booklet was published.

It further acknowledges the implementation of legislation such as the Special Educational Needs Disability Bill in 2001 and the Disability Discrimination Act 2005 which gives schools and authorities a positive duty to promote equality of opportunity for people with disabilities from 2006.

To name a few, the updated booklet has sections on:

- Thinking and reasoning
- Phonics
- Writing & spelling
- Classroom practice
- Adapting the curriculum

The booklet continues to offer the same ground breaking approach that the original had, namely never listing problems, difficulties or impairments without listing a range of strategies and approaches to help overcome or get round them.

The majority of Local authorities and professional teaching bodies use this publication as their benchmark for good practice and this is recognised in the new updated edition by its Co-badging and distribution by NASEN – the leading organisation in the UK which aims to promote the education, training, advancement and development of all those with special and additional support needs.

The DSA's booklet will be distributed to all NASEN members in September as well as being available through the National office and as a free download on the newly revamped DSA website – [www.downs-syndrome.org.uk](http://www.downs-syndrome.org.uk). Hard copies are available at £2.90 each plus P&P from the DSA on 0845 230 0372.

The more comprehensive, follow on publication *"The Education Support pack for schools"* is also still available in hard copy, on CD and from the DSA website.

# Benefits

## – employment and support allowance

*This is a new benefit due to come into effect from 27th October 08. It will replace the current Incapacity Benefit (IB) for new and repeat claims. Those already on Incapacity Benefit will remain on it.*

It is a major step forward in getting people back into employment. Currently on IB, the longer a person is on the benefit, the more money he or she receives.

Employment and Support Allowance (ESA) is a less generous benefit because it has no age related addition as IB has, however, there should be more opportunity for employment.

### Conditions of entitlement

To qualify for ESA a claimant must:

- a) be at least 16 years old
- b) have not reached pensionable age
- c) be resident in Great Britain
- d) satisfy one of the following conditions

- I. a contributions test
- II. a low income test
- III. be under age 20 (Most people with Down's syndrome will qualify under this condition – or under 25 in specified circumstances)

### Limited Capability for Work – The assessment phase

In addition to the above tests, ESA will be payable if the claimant is assessed as having 'limited capability for work'.

All claimants will enter a three month assessment phase during which they undergo a Work Capability Assessment (WCA) and undertake a work focused interview. The interview takes place after two months and the WCA takes place within three months. It is conducted by

a personal advisor at the jobcentre who will discuss work and training programmes.

During this phase, a basic allowance of £60.50 will be paid to over 25's and £47.95 for under 25's. Those entitled to means tested ESA will be entitled to extra premiums depending on their circumstances.

Claimants will be sent a questionnaire similar to the Incapacity Benefit (IB) form. Persons with Down's syndrome would probably be found to have limited capability for work and placed in the support group. If not, they would be referred for a medical examination, again much the same as IB, and placed in the work related activity group.

### The Support Group

Those placed in this group will not have any conditions related to work placed upon them. They will be paid an extra £29 per week.

### The Work Related Activity Group

If it is determined that the claimant has limited capability for work, but not limited capability for work related activity, they will be placed in this group. They receive an extra £24 per week. This group have to attend interviews to discuss employment chances.

As of yet we do not have the full details of the allowance and we will be undertaking training.

We will keep our members informed of developments as they happen.

# Simon Beresford...

## the story continues

*Following on from breaking the 6 hour barrier for running the London Marathon on April 13th 2008 Simon continues to push himself and inspire others too!*

Back in October 2007 Simon's story reached Germany and became the inspiration for the Nuremberg Marathon to get a group of people with Down's syndrome to take part. Cora Halder and Anita Kinle from Down's Syndrome Info Centre – Germany contacted us and we put them in touch with Simon.

So on Sunday 15th June Simon, his Uncle Charles Bevan and John Dawson lined up as guests of honour and started the Fürth Marathon. The roadsides were lined with people clapping and cheerleaders to spur everyone on. Simon had his own motorbike with camera man – just like an elite runner. The 26.2 miles went through fields, shopping arcades and cobbled streets before finally finishing in the town centre with a roaring crowd of smiling, teary faces as Simon was joined by cheerleaders and Team 21 to run across the finish line after 5 hours and 57 minutes – Simon's time would have been even faster but he had stopped to chat to supporters, policemen and even a priest!



Simon returned back to work on the Monday but a week later returned to Germany to receive a special award as part of DS Germany's jubilee celebrations – the Golden Chromosome Award.

The award was in recognition of Simon's achievements and the inspiration he has provided to Team 21 and many others.

### Adaptation from Anita's letter to Simon:

**Dear Simon,**

*Back in October of 2007, I heard about your sensational success at the London Marathon. The same day I had a dream: This dream was to get a group of adults with Down's syndrome interested in running, to form a team and train on a regular basis to improve their endurance and speed. We run the marathon together as a group in my hometown and other runners respect us and acknowledge our achievement.*

*Now 8 months later I realise this beautiful dream has come true – We have a team (Team 21), we have a team shirt and runners*

*who trained for 6 months with perseverance and great delight. We also have 20 volunteer runners committed as coaches.*

*Since we started training 6 months ago, there have been more than 70 media reports. The "Marathonis" have been featured on the radio 4 times and TV 8 times. There is a steady flow of donations to benefit the Down Syndrome Info Centre in Germany. Running clubs and other sports organisations support us. People take notice of our purpose, welcome us, embrace us and participate in our joy. And in my hometown, our 21 runners ran the marathon together.*

*Everyone in Fürth knows who the "Marathonis" are, and I have to thank you for that, dear Simon. Thank you that you were the first, that you proved it is possible and thank you that you participated in our first marathon.*

**From Anita**



For the full story in pictures visit this link and see Simons 26.2 miles of inspiration:  
<http://tiny.cc/wokMP>

### And finally:

The DSA nominated Simon Beresford for the Everyclick.com 'Britain's Most Inspiring Fundraiser'. Simon was honoured in exceptional company; he reached the final ten having been picked from 550 outstanding nominees. As a finalist the DSA received £500 from Everyclick.com along with a special edition home page on their website. In the last 14 months Simon Beresford has completed 4 marathons and raised over £20,000 for the DSA managing to fit his training schedule and various runs around his job as a Staff Trainer at Tamworth McDonalds.

We want to say an enormous 'Congratulations' to Simon for all his amazing achievements and dedication and an even bigger 'Thank You' for raising so much money for the DSA. He is an absolute inspiration to everyone.

# New Merchandise

## from the DSA

### Start a fashion trend! Order your DSA reusable bag today!

The DSA has just launched our very own reusable bags. The bags are black and white and feature the DSA logo. They are 38cm x 35cm x 16cm and have a rigid base which will meet all your shopping needs!

When not in use, the bag folds and securely fastens shut – making it easy to carry in your handbag, briefcase or car.



So order your bag today and help support the DSA. Bags cost £2.00 plus £1.00 p&p and will be available from the end of September. Call us on 0845 230 0372 to place your order.

### Shifting Perspectives Desk Top Diary for 2009



Richard Bailey has created our first ever desk top diary for the Down's Syndrome Association using over 30 inspirational photographs from the Shifting Perspectives collection.

Each diary is A5 (148 x 210mm) with a 2 weeks per view format, with plenty of space to fill in you and your families' appointments.

The diary is the perfect gift for family and friends and is reasonably priced at only £9.99 plus p&p.

An order form can be found on the inside back cover of the BFG Magazine Issue 8 or you can order it online at [www.downs-syndrome.org.uk](http://www.downs-syndrome.org.uk) or by calling 0845 230 0372 from October 2008.

Diaries will be available for dispatch by early October 2008.

### Learning Disability Coalition Update

First, a thank you: to all our members who returned the 'Tell It Like It Is' survey earlier this year, your responses have formed a hard-hitting and timely report from the Learning Disability Coalition (LDC).

Cuts to services and extra charges are having detrimental effects on people with learning disabilities and their families. The 'Tell It Like It Is' report draws together experiences of our members and others in the Coalition and is a key tool in the Coalition's campaign for an increase in public funding for people with learning disabilities.

The launch event at Parliament on 2nd July was well-attended – despite an unusually busy night in the Commons – with Parliamentary Under-Secretary Ivan Lewis and Lord Victor

Adebowale making inspirational speeches. Crucially, the DSA was represented by one of our members, who spoke movingly of the deterioration in his son's health after he was placed into supported living without adequate support.

Lord Adebowale likened the experiences of people with learning disabilities to a struggle for civil rights, while Ivan Lewis promised that the Government's report 'Valuing People Now' would focus on many of the difficulties faced by people with learning disabilities, and that he expected the paper to be published in October this year.

Other ministers and DSA Trustee Damon Hill expressed their support for the campaign. You can read the report at [www.learningdisabilitycoalition.org.uk](http://www.learningdisabilitycoalition.org.uk).

# DSA

## training update

### Ildi McIndoe, DSA Conference Officer

We had our last conference before the summer break on 3rd July at Green Park Training Centre in Aston Clinton Buckinghamshire. This was a joint conference which was in partnership with the Down's Syndrome Support Team from Buckinghamshire County Council. Heading this team is Julie Knight Acting Service Co-ordinator for the Communication and Interaction Team. This team of dedicated professionals support, advise and co-ordinate with schools and parents, carers, as well as children and young people with Down's syndrome to ensure that in Buckinghamshire, they receive the best possible start to their educational needs and continue to do so until they are ready to leave education. Some of the team have supported a specific child all the way through their school life – what an achievement for all concerned!

If all county councils adopted the same strategy and had specialist professionals supporting children with specific learning needs our children would have such a unique opportunity to succeed in their future careers.

We would like to take this opportunity to thank Julie and her team for the hard work in promoting this conference and their help on the day.

#### The Co-worker network

The Down's Syndrome Association and Symbol UK train and support local networks of co-workers, families

and speech and language therapists, to run speech and language groups that assist people who have Down's syndrome to develop all aspects of their communication skills.

We are now able to offer a three day co-worker training course in 2009, starting in February and continuing in March and April in Teddington, Greater London. We invite local partnerships and speech and language therapy departments to put forward pairs of co-workers and therapists to work with local people who have Down's syndrome and their families.

The training focuses on addressing the learning style and communication impairments associated with Down's syndrome so does not prepare co-workers to provide this kind of service to people with other diagnoses.

We are confident that co-workers supervised by specialist speech and language therapists who have attended our 'Effective Speech and Language Therapy for people with Down's syndrome' course, will provide effective, and otherwise unavailable speech and language therapy input.

Groups are supervised by speech and language therapists with specialist skills in working with people who have Down's syndrome. The speech and language therapists set individualised targets for each person who attends the groups, to ensure that their speech and language therapy needs are addressed in an

appropriate manner, as determined by a qualified and specialist speech and language therapist.

Speech and language therapy departments may wish to put forward pairs of therapists and assistants to augment existing provision.

Local networks of families, portage services, education support services, groups for young people with Down's syndrome, FE colleges and other provision for adults could approach local NHS speech and language therapy services and/or local independent speech and language therapists to provide supervision, and put forward one or more people to train as a co-worker.

#### Requirements for the Co-worker course include:

- Commitment to the principles of the project.
- Co-workers should have some relevant experience.
- Identified speech and language therapist who will work with the co-worker.
- Local network that will act as a point of contact for individuals/families who wish to join groups.

The 3-day co-worker training course will run on 5th February 2009, 26th March, and 7th May 2009 and costs £300 per place. Places are limited and applications should be submitted by November 7th to ensure that your

application is considered in the first round of allocating places. We will let you know whether your application has been accepted during December.

We have now completed our Learning Opportunity Programme for 2009,

details of some of the programmes are shown below, and we look forward to seeing you in the next few months.

If you would like more information about our 2009 training programme and co-worker training please contact

Ildi McIndoe on 0845 230 0372 or email [ildi.mcindoe@downs-syndrome.org.uk](mailto:ildi.mcindoe@downs-syndrome.org.uk).

For more information or to book a place on any of the conferences or courses below, please contact Lesley on 0845 230 0372 or email [Lesley.alabaf@downs-syndrome.org.uk](mailto:Lesley.alabaf@downs-syndrome.org.uk).

### Still to come in 2008-2009

#### EARLY YEARS

**Early Years (0-2 years)**

Leeds

Saturday 20 September 2008

**Family Weekend (under 2 years)**

Suffolk

Friday 14 - Sunday 16 November 2008

#### EDUCATION

**Early Years Education**

Sheffield

Thursday 2 October 2008

**Primary Education**

Warrington

Friday 3 October 2008

**Primary Education**

Norwich

Friday 10 October 2008

**Secondary Education**

Cheltenham

Friday 21 November 2008

**3-day NVQ Accredited Course**

Norwich

Friday 26 September,  
Friday 17 October,  
Friday 14 November 2008

**Secondary Education**

Norwich

Tuesday 3 March 2009

**Primary Education**

Taunton

Wednesday 25 March 2009

**Primary Education**

Hull

Thursday 26 March 2009

#### SPEECH & LANGUAGE

**Early Years Speech & Language (0-4 years)**

Gatwick

Thursday 16 October 2008

**School-age Speech & Language (5+ years)**

Gatwick

Friday 17 October 2008

**Eating and Drinking**

Birmingham

Thursday 19 March 2009

#### MISCELLANEOUS

**Looking Ahead**

Teddington (Greater London)

Saturday 18 October 2008

**3-day Co-worker Network Training**

Teddington (Greater London)

Thursday 5 February,  
Thursday 26 March,  
Thursday 7 May 2009

**3-day SWiS**

Teddington (Greater London)

Thursday 12 February,  
Thursday 12 March,  
Thursday 23 April

#### AGEING AND DEMENTIA

**Positive Ageing**

Reading

Friday 28 November 2008

**Dementia**

Norwich

Monday 2 March 2009

# Management of glue ear

*Patrick Sheehan, ENT consultant surgeon provides a summary of the NICE guidelines on the management of glue ear in children with Down's syndrome*

In February of this year NICE (The National Institute for Health and Clinical Excellence) published a guideline reference to the management of Glue Ear (Otitis Media with Effusion, OME) in children. Within this guideline NICE have a specific section on the management of glue ear in children with Down's syndrome.

These guidelines are intended to harmonize the services offered to children for the management of glue ear across the country. The guidelines represent the best practice advice based on the available clinical evidence in the medical literature

## So how were the guidelines derived?

The guidelines was developed by a cohort of individuals, the Guideline Development Group (GDG), representing ENT surgeons, audiologists, community pediatricians, GP's and representatives of the public who reviewed the medical evidence and drafted the recommendations. The recommendations were finalised after public consultation.

The group was assisted by researchers and health economists. The author of this article was selected to represent the interests of children with Down's syndrome both from a professional prospect, as a consultant Paediatric ENT surgeon, and also as a parent of a child with Down's syndrome. All the current literature on glue ear from medical journals were searched and analysed and based on the quality of the research were ranked according. The selected papers were discussed and, with the benefit of clinical experience from the professionals on the group, recommendations were drafted.

## What are the guidelines with respect to children with Down's syndrome?

It was clear that the current literature on management of glue ear in children with Down's syndrome was relatively poor quality and much of the evidence dates back to the 1980s

and 1990s. Indeed there were only three papers that fulfilled the criteria for consideration to formulate recommendations. However there was plenty of good research in relation to glue ear in typically developing children.

## What level of hearing loss?

Children with documented glue ear over three months with hearing levels of 25-30 dBHL (which represents a mild hearing loss) or worse should be assessed and their glue ear managed according to the guidelines.

## What is the advice for glue ear in children with Down's syndrome?

The GDG recognised that children with Down's syndrome were a special group that required special consideration. The glue ear problem starts at a younger age and has a protracted course. It also has significantly more impact on their speech and language development than in typically developing children.

It was unanimously agreed that children with Down's syndrome should be assessed by a specialist team of audiologist and hearing specialists with expertise in assessing and treating children with Down's syndrome.

After glue ear is identified, treatment should not be delayed unnecessarily but that a watchful period of three months was reasonable before active treatment was instituted. The active observation period is necessary because in a small proportion of children, the glue ear is not persistent and may improve. During the 3 month period of observation, active measures should be taken in educational and behavioral strategies to minimize the effects of the hearing loss including advice to parents/carers to speak louder when talking to children, reducing the ambient surrounding sound and getting direct eye contact with the child when speaking to him/her. In nursery or school, seating the child near to the teacher was important.

After three months, the child is re-examined and tested by the hearing assessment team. If the glue ear is still present, then active treatment should be instituted. In the younger age group the provision of hearing aids should be offered in the first instance. This advice took into consideration that the provision of grommets (ventilation tubes) was technically difficult in the very young child with Down's syndrome and the likelihood of early extrusion (rejection) of the grommet from the ear drums. In children that were not suitable for hearing aids for whatever reason then provision of grommets should be considered.

## What about Bone Anchored Hearing Aids (BAHA's)?

The GDG felt it was not able to prescribe a specific treatment option for any particular group of children as this was not within their remit however the provision of BAHA Softband<sup>™</sup> in the younger group and BAHA on the older age group should be considered in children who are not able to tolerate the conventional behind-the-ear hearing aids after trial of these aids.

The lack of good quality research prompted the GDG to recommend that further studies and national audits of treatment options of glue ear in children with Down's syndrome should be undertaken.

The NICE website (see below) has the recommendation in full, a quick reference guide and a summary of the guidelines for parents and carers. For printed copies of recommendations phone NICE publications on 0845 003 7783 or email publications@nice.org.uk and quote: N1461 (quick reference guide), N1462 (understanding NICE guidance). Also the quick reference guide can be downloaded from Mr. Sheehan's website listed below.

Mr. Patrick Sheehan FRCS (ORL)  
Consultant ENT surgeon

Member of the NICE Guideline Development Group  
The ENT and Hearing Clinic for people with Down syndrome  
Manchester Children's University Hospitals  
Manchester M9 7AA  
Tel: 0161 918 5039 E-mail: Patrick.Sheehan@cmmc.nhs.uk  
Web: www.manchesterentdoctor.co.uk

## NICE Recommendations on children with Down's syndrome

The care of children with Down's syndrome who are suspected of having OME (glue ear) should be undertaken by a multidisciplinary team with expertise in assessing and treating these children

Hearing aids should normally be offered to children with Down's syndrome and OME with hearing loss

Before ventilation tubes (grommets) are offered as an alternative to hearing aids for treating OME in children with Down's syndrome, the following factors should be considered

- severity of hearing loss
- the age of the child
- the practicality of ventilation tubes insertion
- the risks associated with ventilation tubes
- the likelihood of early extrusion of ventilation tubes



9 There is no way of predicting whether a person is more or less likely to make an egg or sperm with 24 chromosomes instead of the usual 23.

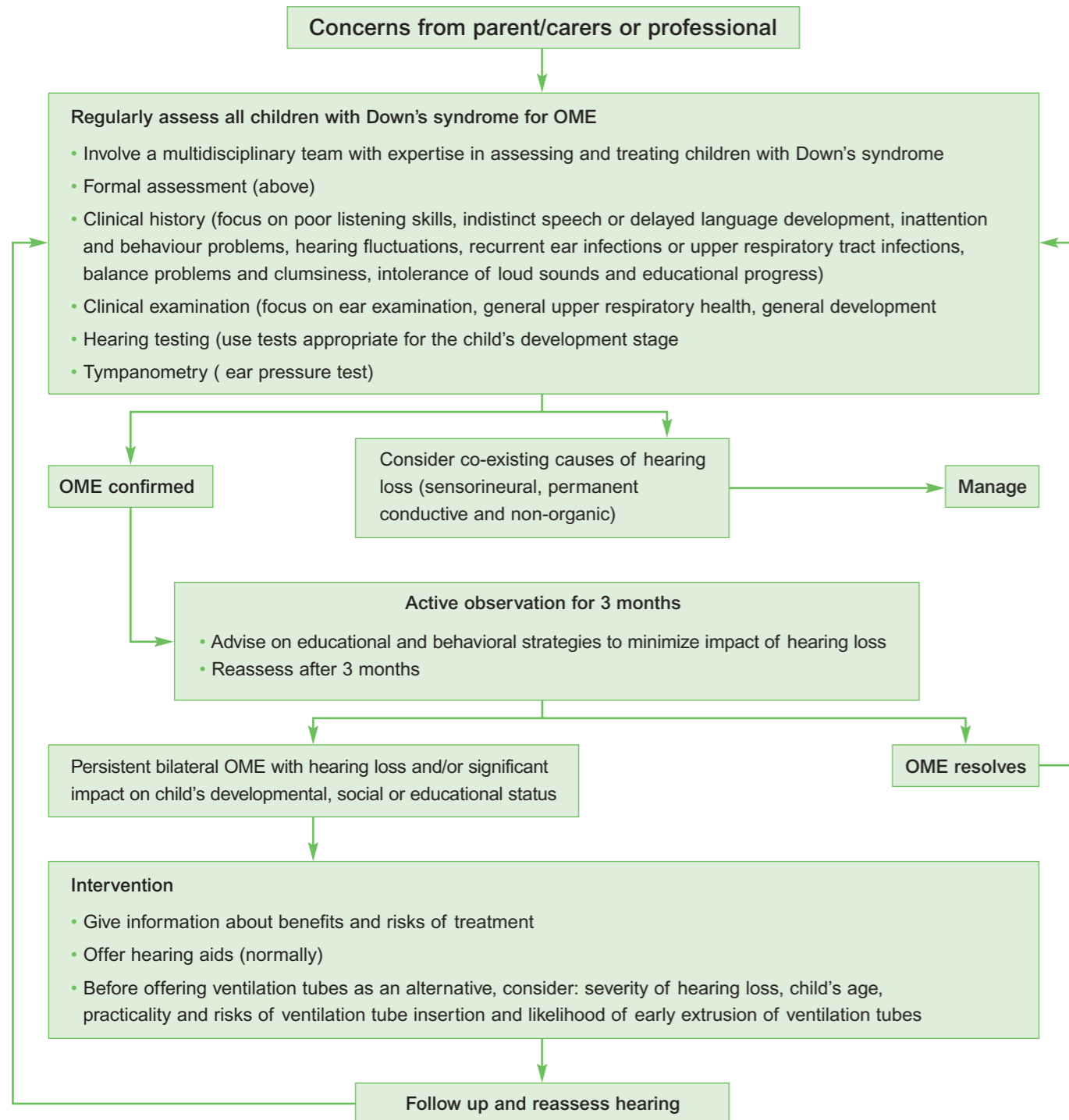


10 Although some health problems are more common in children with Down's syndrome, none of these problems are unique to people with Down's syndrome; they also appear in the rest of the population.

# Hearing Aid

advice

## Care pathway of children with Down's syndrome



Patrick Sheehan, ENT Consultant Surgeon gives advice and tips on hearing aids for children with Down's syndrome.



Since the 'Modernising Hearing Aid Service' was rolled out in 2001, the NHS provides digital hearing aids to all patients. These hearing aids are programmed according to hearing loss of each individual – it is therefore essential that an accurate hearing level is obtained before the hearing aid can be fitted. This may involve more than one visit to your Audiology department. Request an early morning appointment for testing from your Audiology department to suit the best time for your child. Remind them that your child has Down's syndrome so consideration to extra time for testing is given.

### Hearing aids are only useful if:

1. They make the right sound louder
2. They fit and work properly
3. They are worn regularly
4. There is something interesting to listen to

Hearing aids for children are smaller and usually can be requested in different colours with different mould colours.

### Making the most out of behind-the-ear hearing aids:

- Relax – if you are relaxed, your child will be more relaxed.
- Warm the ear mould in your hands before trying to insert them.
- Try to make putting the hearing aids in part of a dressing routine.
- At first try to relate the hearing aid fitting with something positive e.g. play time, especially using 'noise making' toys.
- Praise good behaviour and play singing games.
- When inserting the ear moulds try to get your child to occupy their hands with a toy (or food).
- Leave the hearing aids in for as long as possible and try to build on this time each day until the ultimate goal of all day use is achieved.
- Observe your child's response to sounds – especially loud sounds. If loud sounds do upset your child make an appointment back at the audiology department and explain your observations.
- If your child is old enough let him/her choose the hearing aid and ear mould colour.

- Have a special safe place to keep the hearing aids when they are not being worn and encourage your child to keep them there.

### Further advice and tips

- Don't laugh if your child removes the hearing aids – put the hearing aid straight back in with the phrase "Hearing aids stay on to listen".
- With young children a child support clip (see photo) available from PC Werth' and locking battery drawer may be suggested. Ask your audiologist about these.



- Don't get upset if you cannot insert the ear mould correctly every time. Just try later. ▶

# Toilet training



- Don't look for response immediately to sounds, let your child learn to hear and enjoy the listening experience.
- To keep hearing aids in place, try toupée tape available from Connevans<sup>2</sup>. Stick one side to the hearing aid and the other behind the ear. Hal-Hen pads (available from PC Werth<sup>1</sup>) or any double sided adhesive discs are excellent for boys or wide lacy hair bands for girls.



- If your child experiences feedback (whistling) try:
  - Turning volume down slightly but remember not all hearing aids have a volume control. If feedback is a persistent problem request a hearing aid with a volume control from your audiology department.
  - Make sure the ear mould is fitting well – there shouldn't be any gaps.

- Check the tube is not split, damaged or discoloured.
- Book an appointment to see your audiologist to check the ear canals for a build-up of wax. The audiologist or ENT doctors may try to remove the wax.
- If there is no sound from the aid – check the battery.



## Advice for those with BAHA Softband™

BAHA Softband™ ([www.cochlear.com](http://www.cochlear.com)) is a type of hearing aid that is provided to those children who cannot tolerate or are unable to wear a behind-the-ear hearing aid. These hearing aids provide sound amplification by a different method. If your child cannot wear a behind-the-ear hearing aid ask your Audiology department about the BAHA Softband™.

- To obtain maximum benefit from the BAHA Softband, the bands should be tight to apply a slight pressure to the hearing aid, but not too tight to leave marks on the head.
- Try putting the BAHA Softband™ on when brushing your child's hair.

- Leave the BAHA Softband™ on for as long as possible and try to build on this time each day until the ultimate of all day use is achieved.
- Softbands can be washed and replaced as necessary. Ask for a spare – bands are available in different colours and designs.

## Author

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## References

**1. PC Werth Ltd**  
Audiology House  
45 Nightingale Lane  
London SW12 8SP

Tel: 020 8772 2727  
E-mail [sales@pcwerth.co.uk](mailto:sales@pcwerth.co.uk)  
[www.pcwerth.co.uk](http://www.pcwerth.co.uk)

**2. Connevans**  
54 Albert Road North  
Reigate, Surrey RH2 9YR

Tel: 01737 247571  
Information website:  
[www.connevans.com](http://www.connevans.com)

Online shopping:  
[www.deafequipment.co.uk](http://www.deafequipment.co.uk)

*A child needs to cognitively understand the process of using the toilet before he/she can be toilet trained. If a child is cognitively delayed, he/she may be delayed in toilet training. This in no way means that he/she is NOT able to be toilet trained. The child will be toilet trained when he/she understands the process.*

Toilet training is an important step in your child's growing independence. It is a skill you will want to introduce patiently at the right time.

To check whether your child is ready for toilet training, ask the following questions:

### Does your child:

- Stay dry for 2 hours or more?
- Have bowel movements generally at the same time of day?
- Understand directions like "come here" or "where is your nose"?
- Move from one room to another without help?
- Sit in a chair and play quietly for up to 5 minutes at a time?
- Show periods of independence and pride in learning new skills?
- Copy adult behaviours?
- Feed him or herself?
- Have no viruses and urinary tract infections that may cause persistent wetting?
- Remain free from behaviour problems?
- Have no neurological damage that could prevent bladder or

### bladder control?

- Not taking medication that may have side effects on elimination?
- Show an awareness of having just urinated or had bowel movement by changing facial expression, making different sound, crossing legs, quietness, irritability, squirming, etc.

All the above skills are important – the most important prerequisite is the final one. Your child can't anticipate the need to urinate or defecate but somehow shows awareness after having done so.

Much of the success or failure of your child's toilet training is dependent on your readiness to spend a significant amount of time and energy for 2 weeks to a month. Start training when social disruptions are at a minimum. Distractions like the birth of a new baby, or if your child is sick can disrupt the process. If social disruptions occur so toilet training is unmanageable, stop and try again when your schedule is less hectic.

Before you begin training, collect data on when your child is wet and dry. Keep a record every half hour for 4 to 7 days during the child's wakeful hours. After pinpointing the times before your child is wet, you can plan

when you sit your child on the toilet. Consistency is very important, and you can plan to take your child to the toilet when family disruptions are at a minimum.

There are a couple of better things to consider about a potty chair. If the potty has sides or rails and the child's feet can touch the floor she/he will feel more secure. If you use a toilet insert for training on the toilet, provide a stool or box that will support the child's feet. Introduce the potty or potty chair to your child. Show him/her the toilet and the potty and talk about their uses. Set the potty up in the bathroom. Sooner or later she/he will sit on it. Let him/her get used to sitting on the potty with nappies on. ▶



When the child shows awareness, you can begin bowel training. There are several reasons for beginning with bowel movements first – the child has more time to anticipate a bowel movement than she/he has to urinate. Also, children move their bowels less often and more predictably, so you are more likely to succeed with training. When the child is likely to have a bowel movement, calmly encourage him/her to sit on the potty. If the child resists, do not argue. Wait and try again another time.

When the child is successful, praise him/her for being such a big boy or girl. Don't react too strongly or she/he may worry that not going on the potty is bad. Pay special attention to keeping your child dry and clean – when the child is kept dry, wetness becomes something the child finds unpleasant and wants to avoid.

While you are bowel training the child may urinate in the potty. Gradually she/he will connect the feeling of a full bladder, urination and wet pants. It takes time to learn this connection. The child will not immediately be able to act on the feeling of needing to urinate and waiting to get to the potty.

Place the child on the potty regularly. Don't leave the child on the chair for longer than 5-10 minutes. After a few weeks of occasional successes, put your child in training pants and plastic cover. Be prepared for accidents and clean up without a fuss. Keep your reminders positive – your goal is to encourage the child to be aware of

his/her need to urinate. Try timing your reminders when you think she/he may have a full bladder, or when it is time she/he often needs to go.

You may also let the child use the toilet from time to time so that she/he will be able to use toilets when you are away from home. Keep a stool or wooden box in front of the toilet so she/he has a place to rest his/her feet. Help him/her climb up and turn around.



### Some reminders

Before you begin training, decide what works you will use for urinating and defecating. Use words you will be comfortable with at home and in

public. You may consider using the sign for toilet (right hand index finger tapping on the palm of left hand – making a T).

During toilet training, do not flush the toilet until she/he has moved away from the toilet. Children may be frightened by the noise of the idea of being sucked away. Some children enjoy flushing the toilet themselves – use this as a reward when she/he has finished.

Dress child in loose fitting clothing. Use training pants and outer pants that she/he can pull up and down without help.

Your child will first learn to be toilet trained during the day. Nap time and night time training come later. Also, be prepared for temporary setbacks. A new baby, an illness, or moving may interfere with toilet training. Continue your routine in a positive and consistent pattern.

Reprinted with kind permission from Down Syndrome Association of Victoria.

Jo Yarnall of Charity P.R.O.U.D and mother of Hannah who has Down's syndrome has also put together some toileting tips from parents who have been through the process.

As Jo herself says – *“Remember every child is different and what works for one child might not work for another. There is no easy way so be patient. Don't expect a child to*

*have done it when they reach a certain age but do reward all progress no matter how small or insignificant it may seem.”*

I have summarised some tips from Jo's leaflets that parents have tried and tested.

- **Routine**

*“Put Sam on potty/toilet every 30 minutes (nursery did it every 10 minutes) and made sure he drank lots to increase the chance of going.”*

*“Made sure that school took him to the toilet with all the other boys so he could copy what they were doing, even if he didn't wee.”*

*“We used a cooking timer as it provided the regular, audible timing/warning needed to help Jack (and us) to get into a routine of the toilet. The timer, being small and easily carried, with only one type of ‘ping’, ensured a consistent signal was given, no matter where he was – at home, at school or out shopping. (Tip – don't use the same timer to cook with, otherwise you will end up in trouble!!!)”*

*“Lydia was toilet trained at school when she was 7. She had spare clothes at school and the thing that seemed to work was being pre-emptive and taking her at 9am, 12, 2 or 3pm and then after school.”*

*“Take them regularly to go to the toilet but not too frequently that they rebel.”*

- **Rewards**

*“We had a star chart. It was weeks before we got any stars at all, but once he got one, they started coming thick and fast.”*

*“Gave reward for having a wee on the potty/toilet – used stickers/grapes/raspberries.”*

- **Clothing**

*“Put cheap pants/knickers on under the nappies so your child knows they're wet. To start off with be really careful to check at least every hour so they don't get sore if they have had a wee, but it took George no time at all to start letting us know. Apparently because nappies are so absorbent, they are far too comfortable, and being very logical, our children can't see the point in bothering to wee anywhere else!”*

- **Sound Prompts**

*“We used to use a sound like “SSSSSS” every time she went and then when we put her onto the toilet and did the sound, eventually she started to do it.”*

- **Visual Prompts**

*“William was about 9 years old when he was toilet trained finally. We used to put a cotton ball in the toilet and asked him to pee on it which he found highly amusing so it used to make toilet times really fun and then he would want to go there. We also put some shampoo in the toilet once and he thought it was very amusing to pee and make bubbles in the toilet.”*  
*“We bought one of those dollies that could wee, so we had it sitting on the*

*potty going for a wee and did role playing. We feel that this made it much easier for her to understand and also it helped not to make it into a drama and we tried to make it as happy and light hearted as possible.”*

- **Patience**

*“Chloe was about 3 years old when we first started toilet training and she just didn't get it at all so we left it another year and started when she was about 4 years. It took about 18 months I would say in total before she was dry in the day (We still have pull ups at night – we are working on that)”*

*“You have to try and keep calm and don't get angry if you have lots of accidents.”*

*“Don't expect it to happen overnight and although it's hard be prepared for it to be a long process as it's really not worth rushing them as this is when accidents occur.”*

- **Talk to others**

*“It definitely helps to be able to speak to others that are going through the same thing or who have been through it as it gave us a light at the end of the tunnel.”*

*“It helped to talk to other parents to know that you are not on your own.”*

Information adapted and reprinted with kind permission from Jo Yarnall, Branch chair of P.R.O.U.D. in Walsall. Further resources are available from the DSA.

# Ask

## IPSEA

*Jane McConnell gives advice about Annual Reviews...*

**Q. My son has a Statement of SEN and we are coming up for an Annual Review. I have never really been clear about the purpose of the Annual Review and what is supposed to happen. Can you explain?**

**A.** Questions around the Annual Review (AR) process are one of the main topics parents ask about. Once a local authority (LA) has drawn up a statement they must review it within 12 months of the date the final statement was issued and thereafter within 12 months of the previous review. This is a legal requirement but often schools do not follow the process carefully or confuse parents by trying to merge an Annual Review meeting with an Individual Education Plan (IEP) meeting. The two compliment each other but are not the same. If they are to be held on the same day then I would suggest that you make it clear to the person chairing the meeting that you would like a distinction – possibly a break – between the two.

### Process and timetable

The LA is responsible for triggering the process. Within two weeks of the beginning of each term, they must write to head teachers with the names of all pupils whose statements will require reviewing that term.

The head teacher (or their delegate) must then request written advice from:

- the child's parents
- anyone specified by the LA
- anyone the head teacher considers appropriate.

Any amendment to a statement needs to be evidenced using this advice which must cover:

- the child's progress
- the application of the National Curriculum and/or substitutions for the National Curriculum
- whether the statement is still appropriate, or needs to be amended or dropped.

When parents are writing their comments they should use copies of their child's most recent school report, IEPs and results from any national tests or school tests to inform their views about their child's progress.

### Arranging a review meeting

The head teacher must also arrange a date for the Annual Review meeting and invite:

- the child's parents
- appropriate members of staff
- someone from the LA who looks after the statement
- anyone else the head or LA thinks appropriate.

### Before the meeting

At least two weeks before the meeting, the head teacher must circulate copies of any written advice they have received, inviting comments, to anyone who has not said that they will not be attending. Very often only teachers and parents will attend and the head will delegate his or her responsibility to the SENCO. If the head teacher agrees at the parents' request to write for advice from an independent professional who knows the

child, this person should automatically be invited to the review meeting.

Often schools fail to provide copies of advice received until a few days before an Annual Review meeting or even pass them to parents on the day. If you are "surprised" like this you are entitled to ask for the meeting to be delayed until the two week deadline has been met.

### At the meeting

The meeting should be focused on a child's statement and therefore it is important to take a copy with you. As well as considering the written advice and any new targets for the coming year, the annual review must consider any significant changes to the child's circumstances. The meeting may recommend changes to the statement if:

- there is significant new evidence not already covered by the statement
- significant needs recorded on the statement are no longer present
- different help is required to meet the child's changing needs and new targets
- the child should change school.

### After the meeting

No later than ten school days after the meeting, or at the end of that school term (whichever is earlier), the head teacher must send a report to the local authority and copies to parents and others involved in the review or to anyone else whom the LA or head teacher consider it appropriate that a copy be sent. The report summarises the meeting's conclusions and

includes recommendations.

If there is disagreement about recommendations the head teacher's report should reflect this. Parents should send their own views separately to the LA if they are unhappy with the way these are expressed in the report. If an independent professional has submitted advice which supports the parents' point of view, the parents could ask that they too write directly to the LA.

### Local authority reviews the statement

The local authority must send a copy of any decision to amend or cease to maintain a statement to the head teacher and child's parents within a week of making the decision. There is no time limit on the LA's consideration of the head teacher's report.

It is important to realise that even if the school and parents make an agreed recommendation to the LA to amend a statement they do not have to follow it. If they do not there is NO automatic right of appeal to SENDIST. At this point you will need to take some legally based advice quickly.

### Other types of review

#### Transition review for young person in year 5

Planning for transfer to secondary school should be part of the AR in year 5. The process for reviewing the statements of year 5 pupils is very similar to that of younger pupils (with for instance the same timetable and same issues to be considered) but obviously the additional focus is on secondary transfer. It should be possible at this Annual Review to

give clear recommendations as to the type of provision a child will require at the secondary stage so that parents can visit secondary schools and consider appropriate options within the same or similar timescales as other parents.

#### Transition review for young person in year 9

Again very similar process and timescales as previous reviews but in addition there must be:

- a focus on post 16 options
- advice sought from the Connexions adviser (or Career Wales adviser), and an invitation to the transition review
- a meeting, which a representative form Connexions must attend
- a transition plan drawn up by the Head teacher in consultation with Connexions covering post-16 options as well as Key Stage 4 support.

#### Annual reviews after year 9

In addition to the considerations made at annual reviews of younger pupils, these focus on the transition plan and decide whether any additions or amendments should be made.

#### Interim reviews

Local authorities may use their discretion to bring forward an annual review and a school or parent may ask for (but not require) an early review. The SEN Code and other government guidance suggest this might be appropriate in the following circumstances:

- a sudden deterioration of a child's health or development (although reassessment may be more appropriate)
- where a child is under five – the Code suggests more frequent informal reviews

- a change to their circumstances such as a new diagnosis or a crisis
- exclusion from school or where a child is at risk of permanent exclusion
- where there is a disagreement at a review meeting over a particular course of action, a review over a shorter period might resolve the dispute
- where there is doubt about the child's transfer to secondary education which cannot be resolved in Year 5, an interim review in the autumn term of year 6 is often required to ensure the statement is amended by the legal date – 15th February (the Code suggests this is rare but experience suggests otherwise).

### The law

#### Education Act 1996 Section 328(5) and (6)

Education (SEN) (England) Consolidation Regulations 2001 [SI 3455]

**Reg 20** – sets out the procedure for review of a statement for a child who attends school, other than a child in the tenth year of compulsory education.

**Reg 21** – sets out the procedure for review of a statement for a child who attends school who is in the tenth year (Year 9) of compulsory education.

**Reg 22** – sets out the procedure for review of a statement for a child who does not attend a school.

### The guidance

**SEN Code of Practice** – Chapter 9 deals with annual reviews in an understandable way.

**SEN Toolkit** – Section 9 also gives further detail.

# Radio diary

*Ten-year-old Charlotte Crees from East Yorkshire has Down's syndrome. Earlier this year she and her family made an audio diary for BBC Radio Humberside which was broadcast on their breakfast show. Here the breakfast show producer, Chris Arundel, explains how it came about.*

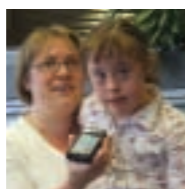
Before I got involved in this project I knew little about Down's syndrome. There was no-one with Down's syndrome in my family and none of my friends had children with the condition. Breakfast programmes on BBC local radio stations are usually a mix of local news and sport, weather forecasts and travel bulletins designed to set us up for the day ahead. But sometimes we do other things too. Last summer I was asked to come up with some ideas for breakfast stories that would make our listeners stop and think and it struck me that broadcasting the diary of a child with Down's syndrome at the start of the day could do just that. It would shed light on what it's like to be a person with Down's syndrome and could also potentially make some very compelling radio listening.

Where to start? Well the first thing I did was to call the press officer at the Down's Syndrome Association in London. Could she find a family in East Yorkshire or Northern Lincolnshire who might record an audio diary for us? It would take a lot of time, they wouldn't be paid (local radio budgets don't run to that) and it would be hard work. I wasn't optimistic. But a week later the DSA sent me an email explaining that two families were potentially interested.

We chose the Crees family who live near Hull. Veronica and Joseph Crees have a

ten-year-old daughter, Charlotte, who has Down's syndrome, and two younger children, Michael and Catherine. They would make recordings in the home, at Charlotte's school; wherever Charlotte went the recorder would follow.

But it's not as easy as it sounds. One of the first obstacles facing a would-be radio reporter is to learn what to record and how to record it. The mistake most of us make at first is to record too much material, most of which isn't relevant and can't be used.



Veronica Crees and Debbie Edwards, a teaching assistant at Charlotte's mainstream primary school, were invited

into the BBC building in Hull for some training. How to use the recorder, decide in advance what you need to record and then make sure you get it!

They departed with the recorder and instructions to email me if anything went wrong. Puzzlingly, I heard nothing. Then an email arrived explaining they had some recordings. Mrs. Crees returned the heavy recorder, its memory cards full of audio and I wondered what they might contain. Happily it was exactly the material we were looking for. They'd done a brilliant job. Charlotte getting ready to go swimming, in speech therapy at school struggling to express

herself, walking with dad, learning about road safety.

These recordings needed to be linked together, with Mr. and Mrs. Crees explaining to the listeners what was going on. We worked together on the scripts exchanging versions by email. Finally the whole family came into Radio Humberside to record the diaries.

This was the first time I met Charlotte. I found her to be full of enthusiasm, struggling to express herself and, like all children, kicking off when she was out of her comfort zone. Her diaries were broadcast during the week commencing July 14th and a feature was also placed on the BBC Humber website ([www.bbc.co.uk/humber](http://www.bbc.co.uk/humber)).

I think everybody has a story to tell and Charlotte's story is that people with Down's syndrome are primarily people who have lives and do things and that while bringing up a child with Down's syndrome can be very challenging at times it can also be rewarding and, yes, often fun.



I think Charlotte is a good ambassador for people with Down's syndrome and would like to

thank her and her family for working hard to make her diary a success.

# Down's syndrome in Europe

## Report about the situation of girls and women with Down syndrome in Europe

*This report was written by Cora Halder, Vice President of the European Down Syndrome Association (EDSA) for a conference on women with disabilities held on 16th-18th November 2007 in Madrid. It is based on information from different countries in Europe, as she asked the members of the EDSA to give their views and experiences on the topic.*

The first crucial point in which the situation of girls and women with Down Syndrome differs from that of women with other disabilities is the fact that, because of cognitive disabilities as well as difficulties with speech and communication, they are, generally, unable to assert their special situation and effectively speak up for themselves. This makes them even more vulnerable. This means that they will always be dependent on others to see and understand their needs, speak on their behalf and to represent them where necessary.

Only a few girls and women with Down syndrome have the means of making their voice heard, but – as women and, more importantly, as women with cognitive disabilities – they are often not taken seriously and, therefore, cannot make their own decisions or actively participate in community life.

It is seldom possible for women with Down syndrome to achieve generally accepted feminine characteristics or traits – neither in appearance, through a professional career, nor through assuming family responsibilities.

Because they do not match the model promoted by the media, women with Down Syndrome often have to deal with rude and hurtful comments about their figures, fashion, looks, hair, or weight, which makes it extremely difficult for them to develop a healthy self-esteem.

Most of these women work in sheltered workplaces, which is the lowest level in the employment hierarchy. The payment is often not more than a pocket-money, meaning that they will be financially dependent on other sources, such as their families or the State throughout the entirety of their lives.

Sheltered workplaces offer little job variation; the kind of activities is mainly mechanical, technical assembly line work. It is boring and uninspiring, and the work environment is often very loud. None of this meets the needs or preferences of those women, but they are forced to accept these working conditions because of the lack of viable alternatives.

In several European countries, women with Down syndrome, often more so

than their male counterparts, are not employed at all but spend all of their time in the family home or in institutions, without occupation and contact with others.

For women with Down syndrome, it is extremely difficult to find a partner as choices are few. Falling in love with someone out of reach is common, and having to deal with unacknowledged affections or learning to outgrow pain associated with these unfulfilled dreams are extremely difficult situations in the lives of women with Down syndrome.

Maintaining a partnership, though it may require external assistance, is not impossible for a woman with Down syndrome. Yet, it is still not widely accepted, nor is it considered a realistic objective. Many women with Down syndrome do not get the choices regarding their lifestyles or with whom they live by themselves. Rather, well-intentioned parents make decisions regarding what they believe is best for their daughter with little consideration for the resulting limitations upon the quality of life or the right to self-determination. ►

# The whole cheese!

For women with cognitive disabilities, the right to express their sexuality is even less accepted than it is for men with the same condition. Very often, these women are seen as sexless.

Out of fear, parents seek to protect their daughters from sexual abuse by keeping them home, but by doing so, these women have no opportunities for social interactions with other young people, are unable to develop a sexual identity, and are often prevented from leading a normal life.

For women with Down syndrome, the pressures not to become pregnant are extremely high. Even though it may be illegal to do so, many women with a cognitive disability are subject to sterilization without their consent or without being informed about the exact purpose of the surgical operation.

Society expects them not to have children. Nevertheless, women with Down syndrome yearn for children just like many other young women.

Even if the concerns surrounding the issue of a woman with Down syndrome becoming pregnant and having a child are valid, the decision

to deny a woman with Down syndrome the right to motherhood should not be made a priority. And as a mother, she should be entitled to the same support for childcare, just as other women or families encountering difficulties with the care and upbringing of their children receive.

However, developing a realistic understanding of pregnancy, child birth and child care and coming to terms with this (almost always) unrealistic dream of having a child is another of the many difficulties that women with Down syndrome must face. Again, their self-esteem and self-image suffer, because this again is an area in which they clearly experience their deficits that do not allow them the personal joy of motherhood, nor to prove their womanhood.

Girls and women with Down syndrome are often victims of sexual exploitation and abuse, more so than men with DS or even other women. Such violence is even more insufferable when one considers the inability of the victim with Down syndrome to defend herself or, because of poor communication skills, the inability to report the violent incident. The fact that a man who

rapes an intellectually disabled woman may receive a lesser degree of punishment is another intolerable violation of the basic human rights of these girls and women.



Girls and women with Down syndrome are entitled to sexuality as are other women. Sexual education from childhood onwards, awareness about sexual abuse, self-defence, training in independent living, opportunities to develop social interaction skills are important necessities and doing so with other young people is also necessary to enable this. Yet, these things are still neglected and not considered a natural part in the education of girls and women with Down syndrome.

**Cora Halder Vice president European Down Syndrome Association**



*Jim Cargin works for 'L'Arche', an association that looks after adults with a learning disability. He wrote this article about a man he cares for called Cathol who has Down's syndrome. His sister wanted to share it with us.....*

October 1980. I had been in Braerannoch, the L'Arche community in Inverness, for about a month. It was a Saturday and, for the first time, I had been asked to go down town with Cathol for a haircut.

Cathol didn't know me very well at that point, nor I him. That would come later. Back then, understandably, I was a bit nervous. The questioning looks we attracted on the streets of Inverness didn't help to set me at ease, either. They were new for me, but probably not for Cathol, who had Down's syndrome. Looks of pity, then steps of avoidance. I was glad when we eventually arrived at the barbers so that we could shut the door on these unfriendly streets for a while, at least.

On entering the barbers and finding no queue, Cathol immediately made a bee-line for the big chair facing the mirror. He'd obviously planned it this way – Cathol always prided himself on his appearance. Focusing his full attention on the mirror, he sat right up and began adjusting his jacket, tie and collar. I looked at him. He was taking a lot of care. The message couldn't have been clearer: 'I am Cathol of the clan Sutherland, and I am proud of who I am'. The barber, Mr. Gelli, just stood there, scissors and comb in his hand, patiently letting

Cathol make himself comfortable. The ceremony went on for some time. After looking and waiting for a good while, Mr. Gelli turned to me and said, 'This guy, he's the whole cheese, isn't he?'

It was a funny thing to say. But as soon as he said it, I realised he'd hit on a profound truth: Cathol really was the 'whole cheese'. Looking at him, you could see immediately what Mr. Gelli meant: Cathol was second to nobody. Not for a second. Every fibre of this highlander proclaimed loud and clear 'I am proud to be a Sutherland, I am proud of my life. I am immensely proud to be Cathol!'

But how came it that Mr. Gelli grasped what the people on the street had missed? For both saw exactly the same Cathol, still unmistakably a person with a disability.

Perhaps the answer lies in human prejudice, preventing us from seeing the full reality, out of fear; our insecurity does a very efficient job of screening off and sanitizing the world. Surely only prejudice makes it possible to see Cathol and immediately conclude, 'not all there,' as the saying goes. Mr. Gelli, on the other hand, also looked, so he also saw the same disability, but then he saw something more, a sudden flash of insight

revealed one of Cathol's great gifts – being the whole cheese, in other words, Cathol was very much all there. Fully present, in fact, in a way that many people without intellectual disabilities are often not!

In the eyes of many, blind to Cathol's real gifts, his disability would mark him as 'less'. Looks of pity followed by steps of avoidance. And so life can go on, undisturbed, and therefore tragically unenriched by Cathol's fantastic transcendence of his outward limitation.

For those who do stop just a second longer, whose hearts are not already slammed shut, Cathol holds out great hope, just by being himself. For being so fully himself, he reveals the core vocation of each one of us, which is surely this: to become most fully ourselves. For if he can, then why not you, or even me?

Whoever we are, and however limited our possibilities, however deep our disappointments, however long we have lived, Cathol's life shows that transcendence of limitations is a real possibility. Surely the answer is 'Yes' for us as well. Cathol and other masters of transcendence have much to teach us. If we can't learn from them, perhaps we should ask ourselves – 'What is stopping us?'



# Letting go

*Most of us are from time to time aware of our own mortality but perhaps more so when our son or daughter has a disability; for who will care for them after we are gone?*

My son Michael is now 28 and has Down's syndrome. For some years now I have been looking for a quality setting where he could enjoy semi-independent living which would enable him to experience life with a peer group doing activities young people would do as a matter of course.

My reasoning was twofold. By living away Michael would develop in many ways he could not do by staying at home (I would never expect his three siblings to be confined to life with Mum and Dad, so why Mike?). By making the transition now, I felt he would be able to adapt more easily and we as parents would hopefully be around for years to come to oversee his care and make sure it was of the best quality for his needs.

Secondly, by keeping Michael at home until we are infirm or we die I felt I would be doing him an enormous disservice as I would be leaving him to the mercies of whatever services were available. This, having experience of social care facilities over the years, has always been unthinkable. I simply could not bury my head in the sand and cross my fingers for his future after I'm gone.

Seven weeks ago I achieved my

goal and Mike moved into a lovely house which recently opened. The staff are young and vibrant, the residents are well suited and the house itself is beautifully converted with en-suites and even a Jacuzzi.

The transition has been amazingly easy and, most importantly, Mike is embracing it beyond our wildest dreams. He spends time with us each week but it seems a happier time as he has things going on in his "second home" so he is not reliant on us for all his entertainment.

For me as his primary carer, our time apart has given me the opportunity to do things denied for a long time and I am loving my new found freedom, secure in the knowledge that Mike is well cared for and happy but still very much part of our lives.

A weight has been lifted knowing that when we die (hopefully not for a long while yet) Mike will cope as it won't be the end of his world as he knows it, as he will have his own life just as his brother and sisters will, as it should be for all four.

In conclusion, to the professionals who always say parents/carers are the biggest obstacles in our youngster's lives, as we will not let

go, perhaps if QUALITY provision was made more easily accessible and carers weren't forced to run the gauntlet of the authorities whose mandate appears to be to make services as difficult to obtain as possible, more of us could contemplate a future for our offspring without us always there.

To other parents I would say forget about preconceptions of institutions – we have moved on – although sadly not enough – there are decent places out there but do your own research because, after all, who knows your son/daughter's needs best?

Don't give up, you can achieve a future for your child but only if you continue to fight for it. Whilst we accept poor services we will continue to get them. I have no experience other than what I have gained over the 28 years of bringing Michael up, so if I can achieve it, why can't you?

## Pat McDonald

*In the next issue, Pat will share with us how she went about finding a place and designing and writing Michael's care plan which was accepted without question by the local authority.*

# Sensory prompts and dementia

*This research is a follow up evaluation to the research that was published in the Journal – Issue 112, in 2006. It is written by Richard Johnson, Senior Occupational Therapist and Anne Elliott, Senior Specialist Speech and Language Therapist, both of the North Yorkshire and York Primary Care Trust.*

## Introduction

Over thirty people with learning disabilities with dementia have been referred to the learning disability service in Scarborough over the last five years. After reflecting on our clinical practice in the first year, we identified a need to re-focus our interventions. In assessments, the main problem area identified by carers was heightened stress and anxiety levels.

Low mood, restlessness and disturbed sleep are more common for individuals with Down's syndrome than for others with a learning disability and dementia (M.P.Cosgrove et al, 1999). We had also found that significant behavioural difficulties were encountered in encouraging the individual to move from one activity to another.

Traditionally, carers would be advised on the use of speech, symbols and photographs as a means of communicating. We found this to be mostly ineffective, particularly in the late stages of dementia. As a result we decided to introduce the use of all senses in communication and so encourage the use of smell, speech, touch and sight collectively to try to enhance communication. We named this approach Multi-sensory Prompts for Communication (MPC). Following our earlier report (R.Johnson, A.Elliott, 2006) which described the MPC approach within the Scarborough

area learning disability service, we decided it was time to evaluate the local service we provided in supporting this approach. This would enable us to develop the support we provide and to see if it could be improved in any way.

## Method

In order to evaluate the service we provide in relation to MPC, we devised a questionnaire which contained nineteen questions and additional space for comments. This was sent out in June 2007 to the carers of people with a learning disability who had dementia to whom we had introduced the MPC approach.

In order to reassure the carers that we personally would not know who had made individual comments, the questionnaires were sent out and posted back to an administrative staff member and were tracked by using identification numbers, not names of carers or clients. A reminder was sent to those who had not returned the questionnaires.

Of the twenty seven sent, twelve were returned. This report is, therefore, only based on the information provided by twelve carers and should therefore be treated with caution.

## Results

In order for us to be able to evaluate the service we provide, we felt that

it was important to collect some background information. The twelve questionnaires that were returned relate to five male and seven female clients. The MPC approach was initiated for ten of the clients in the early stage of dementia, one mid-stage and one in the later stage. The length of time that carers had been using the approach ranged from three months to five years. For eleven of the clients, the approach was implemented by their care team, whilst one client had just a sole carer. In eleven cases, the approach was used in the client's home and with one client it was used elsewhere. The MPC approach was also used in respite care for four of the clients.

We wanted to find out whether carers felt that they were being given enough training and support in the MPC approach and so a large part of the questionnaire was focused upon this. For eleven of the clients, carers reported that the approach was introduced at the right time and that they had had enough support from the learning disability service to implement the approach. All the care teams reported they had had the support of their own care team to implement this approach. Eleven carers felt that the training contained a sufficient level of information. The majority said that the training would be best carried out at six monthly intervals.

Carers also commented that they found the visits from the learning disability ►

# Current research

service useful. These included:

*'Staff developed better understanding of clients'*

*'Helps promote and maintain client's daily living'*

*'Support and advice is helpful when things are really difficult.'*

Although the purpose of the questionnaire was not to look at the effectiveness of the MPC approach, some of the comments from carers indicated that they felt that there

were positive changes in the clients' behaviour after introducing the approach, such as:

*'Helped her focus and jogged memory'*

*'Relaxed, not as stressed when moving from place to place especially in later stages'*

*'Helped re-focus her attention to time now rather than past'*

*'This made him less agitated and more settled and secure'*

*'Very simple approach and yet can make a great difference to carers and clients'*

It was also felt that as part of this local service evaluation we needed to know more about the ways in which carers were putting the MPC approach into practice. This information would be useful when further developing the training the service provides. Examples carers gave of the objects and smells for each activity were interesting and showed how they had taken on board the training and individualised the approach for their clients. Some of the examples are given in the table below.

| Activity                  | Visual Prompt            | Smell Prompt                | Tactile Prompt       | Verbal Prompt                             |
|---------------------------|--------------------------|-----------------------------|----------------------|---|
| Going to bed              | Teddy                    | Lavender bag                | Teddy                | We are going to bed                       |
| Bathtime/shower/wash      | Red towel & red flannel  | Lavender bath milk          | Red flannel          | Bathtime                                  |
| Toilet                    | Toilet roll              | Dettol spray                | Toilet roll          | It's time for the toilet                  |
| Going out in car          | Car keys                 | Air Freshener               | Car keys             | We are going out in the car               |
| Attending day centre      | Wheelchair, rucksack     | Aftershave                  | Wheelchair, Rucksack | Out in the bus                            |
| Painting garden ornaments | Paint brush              | White spirit                | Paint brush          | Client's name & garden ornaments          |
| Mealtime                  | Spoon & sign of dinner   | An orange                   | Spoon & an orange    | Client's name & dinner/tea/breakfast time |
| Swimming                  | Swimsuit & same swim bag | Shower gel (specific brand) | Swimsuit             | Client's name & swimming                  |

## Discussion

It is important to note that eleven of the twelve carers were members of care teams and so training is necessary for all staff in the team, in order for them to be able to implement the approach consistently. One of the comments was that the training could be improved with more examples of good practice so we have begun to collect ideas and take photographs of how carers are implementing the approach. Most of the carers commented that the approach was easy to implement and that they

were able to individualise the objects and smells for each client.

In the future, we would like to do some research on the MPC approach to investigate the effectiveness of the approach, which to date we have not done in any systematic way. Although we have been using this approach for five years and do believe it is effective, we only have anecdotal evidence for this. One possible way of researching this would be to conduct qualitative interviews with carers in localities where the MPC approach is not being used, then introduce the approach

for clients and then re-interview the carers after a specific time period to explore whether or not they feel the approach has had any effect.

## References

- R. Johnson and A. Elliott Down's Syndrome Association Journal Issue** 112 pp.21-22, Autumn 2006.
- M.P. Cosgrave, J. Tyrell, M. McCarron, M. Gill & B.A. Lawler Journal of Intellectual disability research**, Volume 43 Part 5 pp 393-399 October 1999.

## Effects of parental stress and immune function

We were specifically interested in finding out whether parents of children with developmental disabilities, including Down's syndrome, would be more stressed and produce less antibodies following vaccination than parents of typically developing children.

The results revealed that parents caring for children with developmental disabilities produced fewer antibodies following the pneumococcal and influenza vaccine compared to parents of typically developing children.

This finding is very novel and is the first to demonstrate such an effect in young parental caregivers. As such, we had

this paper accepted for publication in a very prestigious Journal 'Brain, Behavior and Immunity'.

This study showed that providing care to a child with a developmental disability can often be very stressful and, when it is, parents' immune systems can be affected in a way that could put them at risk of ill-health.

Currently these younger caregivers are not prioritized in annual vaccination programmes. However, our findings suggest that they should be.

Although our results help to raise awareness of the challenges faced by parents caring for a child with a

developmental disability, they also indicate that further study is needed in this area.

Our group is continuing this research and would be very interested in hearing from similar parents willing to complete some questionnaires. We are now interested in researching sleep quality and rates of infection.

**If you are interested in participating please contact Stephen Gallagher from the University of Birmingham, School of Sport and Exercise Sciences on 0121 4148747 or email [sxg598@bham.ac.uk](mailto:sxg598@bham.ac.uk).**

## Down's syndrome research at the Institute of Psychiatry/Maudsley Hospital in London

The Institute of Psychiatry currently has research projects involving individuals with Down's syndrome, their family members and carers.

The studies involve attending our research centre in London. All travel expenses will be refunded and participants will also be reimbursed for their time.

We would be delighted to hear from you if you are someone with Down's syndrome, or are a family member or carer of someone with Down's syndrome.

If you interested in learning more about these projects or in helping us with the research projects, please get

in touch with us. Nuria Vazquez and Giles Tan would be happy to talk to you about them.

**Please call Nuria or Giles on 020 7848 0984/0943 or email: [Nuria.Vazquez@iop.kcl.ac.uk](mailto:Nuria.Vazquez@iop.kcl.ac.uk) or [Giles.Tan@iop.kcl.ac.uk](mailto:Giles.Tan@iop.kcl.ac.uk).**

**Section of Brain Maturation, PO Box 50  
Division of Psychological Medicine & Psychiatry  
Institute of Psychiatry  
De Crespigny Park  
London, SE5 8AF  
Tel: 020 7848 0984/0943  
Fax: 020 7848 0650**

# Bulletin



## Early Support materials translated

The Early Support Background Information Booklets are now available in ten languages other than English. The languages are: Arabic, Bengali, Cantonese, Gujarati, North African French, Polish, Punjabi, Somali, Tamil and Urdu.

The material can be accessed from the website and you can download a written translation and/or listen to an audio version there – the audio versions are particularly important for families who don't read their own language.

New website pages about using Early Support with families who don't speak English

have also been developed to complement the publication of the translated materials. The following booklets have been translated: Introduction to the Background Information Booklets (ES21), People you may meet (ES20), Childcare (ES22), Financial help (ES23), Education (ES24), Health services (ES25), Social services (ES25A), Statutory assessment – Education (ES26)

The useful contacts and organisations have not been translated.

The new written and audio material will soon be available on DVD (one disc per language), which can be ordered from

DCSF Publications. English versions of the Background Information Booklets are already available in audio format on the website.

This material is now also available on a DVD disc (ref number ES58). Order a disc from the website, or by ringing DCSF Publications on 0845 602 2260.

**Early Support**  
Helping every child succeed

the UK and of course filming our DVD. We've performed a few times at various venues including Birmingham NEC.

The aim of our group is to have a good time and become pop superstars but along the way we want to show the world positive images of inclusion and show that people with and without disabilities can live and work in harmony.

Please check out our webpage, get in touch and buy our DVD at [www.mixitmusic.co.uk](http://www.mixitmusic.co.uk).

You can also read Charlotte's review in the *Down 2 Earth* magazine.



## Collis Curve Toothbrush

An innovative toothbrush is making an impact with Special Care Dentistry patients in the UK and Ireland. Dr George Collis, an American dentist has spent more than 20 years researching and perfecting his brush and it has already attracted a wide following in the USA and Australia.

The 'Collis Curve' has a unique design which means that it brushes all the tooth's surfaces simultaneously whilst gently massaging the gums and entering below the gum line to remove plaque more effectively than conventional brushes. In trials performed by the American Dental Association it removed up to 40% more plaque than a regular toothbrush and improved gingival health by up to 68%.

This also means that a simple backwards and forwards technique replaces the much more difficult scrub and roll and other brushing methods. This makes it particularly

suitable for those with a limited ability to brush their own teeth, or those who have to brush other people's teeth. Some conditions, like Down's syndrome and autism make the patient very resistant to lengthy cleaning sessions. Because the 'Collis Curve' immediately starts doing the job as soon as it is in the patient's mouth brushing time can be swift and the patient left undisturbed.

Dublin's central facilities for adult and child Special Care Dentistry are now working with the brush and it is being endorsed in the Irish outreach programme. In the UK a growing number of National Health Service Trusts are using it regularly. Through this and our website charities caring for Special Care Patients have also started to promote it, and these include the Leonard Cheshire Homes, the CdLS Foundation, BIBIC and Down's syndrome organisations.



The brush can be bought online at [www.colliscurve.co.uk](http://www.colliscurve.co.uk) or enquiries can be made via email at [colliscurveuk@aol.com](mailto:colliscurveuk@aol.com).

If you would like to discuss your requirements with us we are available on 01934 862415.



## MiXiT – the worlds first truly inclusive pop band



an industry standard approach to breaking into the pop world; Organising tours, filming DVD's and living the rock and roll lifestyle!

We're a bunch of mates who met through our involvement in inclusive theatre and through another inclusive group.

Some of us have known each other for years and we get on really well – usually.

MiXiT are a group made up of people with and without disabilities. We are attempting

The group has 10 members; Toria, Matt F, Paul, Matt M, Jayd, Craig, Emma, Charlotte, Lynsey and Natalie. 6 of whom have a learning disability, 4 with Down's syndrome. The group are also supported by a crew which includes people with and without disabilities.

We've just finished our new DVD. It was filmed in France and Germany and edited in England. We're really proud of it as we think it's well put together and full of good songs and hopefully is fun. It has our very first original song on it; Aspirations – which gives the DVD it's title too. We've also had a busy year as we've been on tour, in Germany and in



## Heavy Load – The Movie

When punk band Heavy Load agreed to take part in a documentary, they never thought it would change them for good. But this band, formed of people with and without learning disabilities, found their conflicting ambitions, coupled with the pressure-cooker of the filming process, nearly led to their meltdown.

You can follow their story in the forthcoming film 'Heavy Load' which comes to cinemas on October 3rd 2008. Watch out for drummer Michael who has Down's syndrome, who

decides he wants to leave the band, saying: "I want to become famous on my own, as a solo singer".

Visit [www.heavyloadthemovie.com](http://www.heavyloadthemovie.com) and [www.stayuplate.org](http://www.stayuplate.org) for more information on the film and the band's campaign to encourage support workers to give people with learning disabilities more control over their lives.

As the band themselves say, "We want to stay up late, we want to have some fun!"



# Down's syndrome

## North East



### BETT Exhibition 2009

2009 marks the 25th anniversary of BETT, and as this landmark approaches, it continues to cement its position as the world's leading technology in education event by remaining as topical and relevant as ever.

Over the past 25 years, hundreds of thousands of teachers, leaders, local authorities and decision makers have visited the show to gain a greater insight into the benefits that technology can offer. BETT has maintained its incredible success because of its constant innovation and evolution. Once again, BETT is set to address all the issues that are currently affecting those working to ensure people with Down's syndrome reach their full potential.

On stand SN58 Experia gives visitors a chance to try out their sensory equipment which this year has a fresh, new and fun approach. From sensory rooms and pools, soft play environments and outdoor sensory equipment to the very latest in sensory experiences – the Multisensory Interactive Learning Environment (MILE), visitors will have a chance to see, feel and experience

it all on their stand in the SEN Zone. BETT 2009 sees the launch of Experia's new software IRiS Room Director which allows many new possibilities in a sensory room.

Positioned as the world's largest technology in education show, BETT 2009 delivers many new opportunities to support inclusion and more efficient ways of accessing the curriculum. Exhibitors will be able to provide advice on promoting positive behaviour, along with numerous examples of resources designed to support the teaching of basic numeracy and literacy skills.

Teachers working with children who have Down's syndrome should take time to visit Scholastic on stand V6. Subscribers to their range of magazines including Nursery Education PLUS, Child Education PLUS, Junior Education PLUS and Literacy Time can now find an exclusive online area with free access to thousands of resources, making lesson planning much quicker and easier with a personal online folder to store favourite resources.

Throughout BETT 2009 Sweet Counter will



be on stand V32 showing its bright, colourful educational resources made from laminated card. All products are designed by an experienced teacher to display concepts in a practical, fun and child centred way.

Visitors to stand F30 can see Wordshark, a software program that combines the excitement of computer games with the serious task of learning to read and spell. It includes 50 different games and targets an age range of four to 15. The program's database consists of over 9,000 words, including word lists based on key stages one, two and three. With nearly 700 exhibitors sharing their breadth of experience, and nearly 100 seminars, visitors to BETT are ensured to leave inspired by new learning strategies, BETT 2009 will run over four days from 14 – 17 January, and will support creative teaching and learning by enabling practitioners to touch and test resources, debate ideas and continue their professional development.

Free online registration for BETT will be live from the beginning of September, visit [www.bettshow.com](http://www.bettshow.com) for more information.



### Couple's connection

**A new website to help your relationship for the better** One Plus One, the relationship charity has launched a new website for couples. The aim of the site is to provide a 'space' for individuals and couples to work on issues in their relationships, make resources and information readily available; and to provide opportunities for social networking.

*"It is well proven that when mum and dad are getting on, their children benefit from more*

*effective parenting and closer relationships with each parent. Our involvement in producing a special report, which highlighted some of the specific issues faced by parents of disabled children and the effects of this on their relationship, has encouraged us to make our resources available to all parents via the web."* says Penny Mansfield, director of One Plus One.

The site will combine resources, self-

assessment tools, weblogs and forums that can be tailored to personal circumstances and continually updated. It will provide research and practical experience directly into the hands of couples and parents, enabling them to work on their relationships for themselves.

The website is [www.coupleconnection.net](http://www.coupleconnection.net). Adapted from Contact a Family magazine – Connected, Summer 2008.

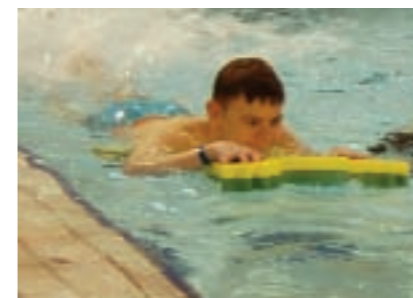
*Julia Pennock tells us about DSNE's fantastic sports events encouraging young people to work together and get fit!*



On Wednesday 23rd April 2008, we held a Swimming Gala at The Neptune pool in Middlesbrough. 43 children and young adults with Down's syndrome and other learning disabilities came along to swim, splash and generally have fun.



There were fun challenges including: The Crazy Frog – where swimmers swam widths on a frog-shaped float;



Treasure Island, in which competitors fished for objects with a net while completing a width of the pool and Cool dude, where a team of 6 swimmers took it in turns to swim across the pool with a piece of clothing and hand it to the dude – an adult at the other side – who then had to put on all the clothing and swim back once fully dressed!



Other race challenges included the 18 metre freestyle for 8-14 years, 18 or 25 optional metre freestyle for 14+ years, and a mixed relay.



We had the first gala last year but it was on a smaller scale compared to this year. We wanted to make it into a fun event but also cater for the serious swimmers who had the opportunity

to do lengths and compete in races at the end. The children learn about taking turns and teamwork and it all helps with their social development.

The event was organised with the help of Mick Sullivan from Middlesbrough Sports Development and Maggie Lawlor and staff from The Neptune pool. Supporting the event were Middlesbrough mayor Ray Mallon and Century Radio legends and ex-professional footballers Bernie Slaven and Micky Horswill. The trio presented the medals, certificates, and swimming bags to all the competitors.

Then on Wednesday 14th May 2008, we held an 'Athletics for All' day at Clairville Stadium in Middlesbrough. About 40 children and young adults laced up their trainers to take part.



The morning was spent participating in the track events: 60, 80 and 100 metre sprints and 60, 80 and 400 metre relays. After lunch it was time to head to the field to do the cricket ball throw, standing long jump, shot put, javelin, and long jump. ▶

# Reviews



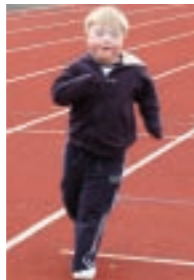
The event was organized with the help of Mick Sullivan and Paul Smith of Middlesbrough Sports Development.

All competitors were given a certificate for taking part and the 1st, 2nd and 3rd place winners of each event also received medals.

It was fantastic to see all the children competing and taking part. This was the first time we had attempted anything like this and we are over the moon with how it went.

It was a fun event and everyone got a medal for participating, but there was also a lot of competition, with some of the children winning more than one medal!

The day went really well and it's good for their fitness and co-ordination. It was a great success and we will definitely be doing it again.



Ray Malon, Micky Horswill and Bernie Slaven present the swimming certificates and medals.

## Book Review: *Living with Max. By Sandy Lewis.*

**Publisher:** Vermilion (29 May 2008)  
**EAN:** 9780091922085  
**Price:** £12.00



In *Living with Max*, Sandy takes us on a remarkable and inspiring journey, from Max's birth to his extraordinary film debut as one of the stars in the hit film *Notes on a Scandal*. With

unflinching honesty and humour she chronicles the highs and lows of bringing up Max. This is a wonderful, moving story of a mother's love. You can purchase this book at any good bookshop or go to [www.rbooks.co.uk](http://www.rbooks.co.uk). Sandy also writes a blog which you can read at [www.livingwithmax.blogspot.com](http://www.livingwithmax.blogspot.com).

A couple of parents' reviews on the book:

*"Living with Max is a very enjoyable, readable and well written book by his mother Sandy Lewis. It's about the life experiences of a very loving and strong family. I can really recommend this*

*book; I could almost be reading about myself, there are so many parallels.*

*It is a perfect read for parents of young children with DS, although some may find Sandy's experiences rather disturbing.*

*Our son Jonathan is about 4 years younger than Max. Thankfully we have never come across the prejudice, hostility and pure ignorance that this family have suffered, especially from professionals who should know better. I hope that time and education about DS is changing this.*

*I wish that I had read this book when Jonathan was a baby as it would have given me an idea of what to expect. The nightmare of choosing the right schooling, then fighting for it with the LEA, the stress of a Tribunal, all of the medical worries and the constant battle to get medical people to listen to us and treat our children as people with feelings.*

*It's also very reassuring that despite the fights, we can win, and get what is right for our children. This book is so encouraging.*

*We know Max from our Monday DS dance*

*and drama group. Jonathan is their latest recruit; he has been going for about 18 months. Max is a real credit to the group and a great role model. Max good luck with your next film, the sky is the limit for all our children, Max has proved it."*  
**Brenda Hall.**

*"I started this book at work, reading a few paragraphs, then pages at a time and before my shift was done (14hrs later) I am at page 146!!*

*It's a great read, I thoroughly enjoyed it. Shame there's no pictures other than the sleeve, but it's so nice to be able to relate to someone in a book or a film who has gone through all that we are going through with our son now and no doubt in the future. You'd look at Max now and think he has been one of the lucky ones – hardly affected, had loads of support, parents got loads of money etc. But it's not the case and Sandy's struggles mirror that of parents of a child with DS.*

*I will be giving this to our parents to read too just so they can understand things a bit better from another parents experiences."*  
**David Coles.**

## New Edition: *Surprise Package. By Steve and Liz Crowter.*

**Publisher:** DayOne Publications;  
 2nd edition (27 June 2008)  
**Price:** £7.00 inc P&P.

Recommended by Jo Yarnall:

*"As a new parent who had just had a baby with Down's syndrome, it was helpful and encouraging reading the*

*thoughts and experiences another family were going through.*

*It was compulsive reading as I read about the highs and lows of having a child with Down's syndrome and had a positive impact on my outlook on life after having a baby with Down's syndrome."*



Order online at [www.heidicrowter.com](http://www.heidicrowter.com) and click on My story.

# Our wonderful skin and blister



## Dear DSA,

Here is a poem that my daughter Maddy had recently written about her sister Alanna (aged 4). Maddy was asked by our local group to write a short poem about her experience about having a sibling with DS to perform at a fundraising fashion show that we were doing. She wrote it that evening and her brother read it out at the show.

It was received well with smiles and tears and a big round of applause! I hope you like it!

*Maria Rose (and Maddy)*

## ALL ABOUT ME & MY SISTER

My sister as always has to be disabled.  
But very kind, I don't mind if Ashleigh is, that's her name.  
I don't mind if she's bossy because she can't help it.  
I try my best to help, not always I feel like it.  
I've always loved Ashleigh inside  
Because Ashleigh is my sister &

### Our wonderful skin and blister

We have a little sister,  
Her name's Alanna Rose.  
One of her cutest features,  
Is her little button nose.  
The first day that I saw her,  
I cried a little bit.  
As I didn't really understand,  
The full extent of it.

We took her back and welcomed her,  
Into our lovely home.  
And straight away we couldn't help  
But love her to the bone.  
When she was a baby,  
She never gained any weight.  
It's hard to believe that now  
When you see her lick her plate.  
Our sister was slow to start to walk,  
But she could bend like a top gymnast.  
Now we can't keep up with her,  
She's so very very fast.

Most people I know speak one language,  
But Alanna can manage two.  
One with her voice and one with her  
hands – She's taught all of us too.

I care about her.  
I don't like people taking the mickey  
out of her  
They don't know that she is the  
same inside.

I LOVE HER

*By Rebecca Callaway  
Aged 8*

She tells everyone I'm her best friend,  
Which makes me feel ever so proud –  
But that's not how I feel in John Lewis's  
When she shouts rude words out loud!

My sister has always surprised us,  
And will continue to I'm sure.  
She needs some help to get on her way,  
But with Alanna you always get more.  
She could be a supermodel,  
With a P.H.D degree.  
Then go sailing round,  
And do that single handily.

But if she doesn't fancy that,  
I hope she'll come with me;  
And live in my funky apartment,  
In Solihull-by-the-sea.  
I love my skin and blister – Dad's  
a cockney you see  
And if Alanna could pick a sister,  
I really hope she'd pick me.  
People say Alanna has the extras,  
Chromosome 21 causes such a fuss.  
But were the ones with the extras,  
The lucky ones are us!!!

*By Maddy Rose, aged 11*



# Dear DSA...

## Dear DSA,

Our daughter Maria is now 8 years old.  
When she was 1 she was in and out of the  
Luton & Dunstable Hospital with recurrent  
chest infections and pneumonia and when  
she was 2 and a half she went to Great  
Ormond Street and underwent keyhole  
surgery on her heart. Since then she has  
stayed out of hospital.

She has attended St Mary's RC Lower  
School since she was 3 and 3 months  
and every teacher has been absolutely  
fantastic with her, so keen, encouraging  
and so patient.

Maria has a dislocated patella in both  
knees which needs an intense physio  
programme and again the school has  
been very accommodating being able  
to fit this around her school day.

Since October 2007 she was very ill,  
lost a lot of weight and suffered with  
constant stomach cramps and after  
many tests she was finally diagnosed  
with Coeliac disease. We now have to  
keep to a gluten free diet, which can  
be difficult sometimes as she does  
not fully understand.

On Sunday 18th May 2008, at St Mary's  
RC Church, Maria was due to take her  
1st Holy Communion. St Mary's RC Church  
is massive and it was packed. Maria does  
not like big crowds or loud noise – at  
school assembly she will sit through the  
whole thing with her head in her lap and  
in the build up to it Maria was not keen  
on talking about her big day.

In the rehearsal she was very nervous  
and she wanted to hold her teacher's  
hand through the whole thing.

On the morning of 18th May we were  
up very early. I got her all dressed up  
and she looked beautiful, like a princess.  
Everything went according to plan, with  
time to spare!!

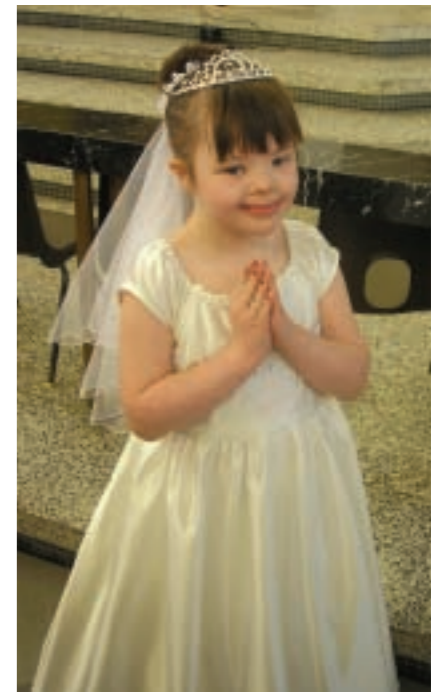
We got to the church and took her into  
the hall to meet the teachers and all her  
friends and we said good luck and that  
we would see her afterwards and that  
we would have a party.

We were so nervous for her, us, her  
teachers, priest and all our family and  
friends didn't think she would walk into  
a crowded church and sit up on the  
altar and take her 1st Holy Communion.

But we were all praying so very hard  
for her and the moment came for her  
and she did exactly what she was  
supposed to do.

The tears were flowing!!!! We were  
so so proud of her. We all had a  
wonderful celebration of Maria's 1st  
Holy Communion and thought we  
would share this story with all  
DSA members.

*Catherine Monti*



**Dear DSA,**

I am writing to express how very proud my husband and I are of our little boy; Ethan aged five and a half years.

We were unaware that Ethan had Down's syndrome until he came into the world on New Year's Day 2003. At the age of 23 both me and my husband found the news a huge shock as like many people we were uneducated as to what Down's syndrome actually was and meant. Despite the worry and shock we were determined to be the best parents we could for Ethan. Since Ethan has been with us he has taught us a lot about life and has brought so much joy into our family to which we are closer than ever before.

One of the benefits that Ethan has had is to be part of our family run business; a children's day nursery. As manager I went to work very soon after Ethan was born and therefore, Ethan was integrated with other children from a really young age.

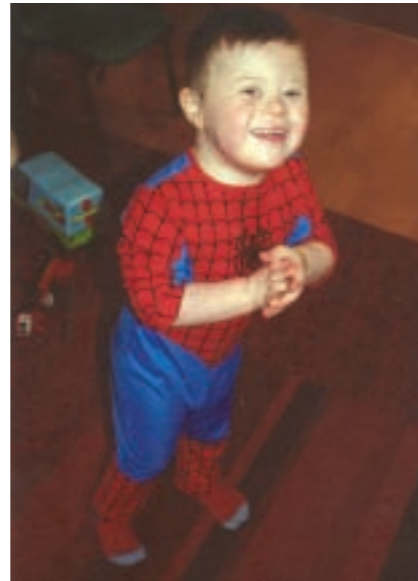
Ethan has progressed brilliantly from being at nursery as he learnt a lot from watching the other children. He was sitting up at six months and walking at 18 months. Ethan was always involved with group activities; he made very close friends and became

very popular with the other children. I feel that nursery encouraged Ethan to become independent, sociable and caring towards others.

Ethan now attends a fantastic school which specialises in special needs where he has made lots of friends and seems very happy. Despite Ethan having a speech delay he is like any other typical five year old boy, who loves all super heroes and riding his bike and scooter.

We often sit back and watch Ethan playing with his little sister, Demi-Mae and think how lucky we are to have such a unique and special little child, who we wouldn't change for the world.

*From very proud parents,  
Kirsty and Craig Shapter*

**Dear DSA,**

I am enclosing a photo of my son Luke who was 14 in July. He would love to see his photo in the magazine as he's had a few in there before.

We wanted to say a belated Happy Birthday to our dear son Luke, who was 14 on July 23rd. Hope you had a lovely day. We all love you very much. With love from Mummy, Daddy, Kelly, Amy, Lauren & Rob, both Nannies and Grandads.'

*Thank you very much  
Mrs. Woolley*

**Dear DSA,**

We have been meaning to write this letter for some time, but you know what it's like – how time passes so quickly!

We gained (and still do) so much from the DSA Journal especially the letters and photos, we couldn't wait to read about how all our children were doing and they all gave us so much inspiration and hope for the future especially when we had just had our little boy and were so uncertain of the weeks/years ahead and if we could cope as a family.

Our little boy Morgan is four years old and in the first few weeks after his birth we were in shock, worried, and terrified of his and our future, but then we realised that he was just a little boy who needed our love and encouragement and we would just wait and see what each new day would bring us.

Morgan has brought us so much love over the past four years, he is beautiful, determined, strong, kind hearted, has a great sense of humour and he embraces life and its challenges to the full with so much enthusiasm.

He is adored by all who meet him – he shouts "Hiya" to people in the street, bringing a smile to their faces, many say he has 'made their day'; he loves to mimic people and be the centre of attention.

We just wanted you all to know a little more about our precious little boy and reassure new parents as we were by others, that life can still be great, in fact we believe that Morgan has brought more to our lives than we could ever imagine.

We thought our lives were over when first told about his diagnosis, little did we realise it had only just begun.

*Yours  
Mike, Maxine and Morgan Wieland*



Please note that while we try and publish all letters we receive, there is not always enough room in the specific edition they are intended for. Please email your letters to victoria.clark@downs-syndrome.org.uk or post to Victoria Clark at the National Office address.

Dear DSA,

My son Stephen was diagnosed with ulcerative colitis in February last year. I wonder how many of you know what a devastating condition this is, one of the main symptoms being uncontrollable diarrhoea? This is an embarrassing and debilitating condition apparently rare in people with Down's syndrome.

He lived with it for just over a year and it did not go into remission in spite of all the medication that he was on, but he never gave up on anything.

He travelled independently to college from Ilkley to Leeds, by train and bus, four days a week during term time. He continued with all his social activities and was in a pantomime and only missed one cue in ten performances! We even went on holidays.

In March this year he had major surgery to remove his colon and now has a stoma and an ileostomy bag. He lives in supported living and copes with this independently and seems happy with it.

His health is now very much better but he will need more surgery in about 18 months time. He coped so well with his illness, with his operation and with his stay in hospital. I never cease to be amazed at what he achieves.

Does anyone else know of a person with Down's syndrome with this condition? It would be nice to be in touch.

Yours sincerely, Jane Whiteside

Please contact Victoria at the DSA on 0845 230 0372 if you would like to get in touch with Jane.



Dear DSA,

I enclose a copy of an article you printed in the DSA Journal in 1990 I believe! Following on from that I thought your readers may be interested to see the invitation to Nicholas' 40th party his sisters gave for him as a surprise – NICHOLAS ANTHONY, THIS IS YOUR LIFE! 70 family friends attended and in addition he gave a party for his own mates in his own home, to which we were not invited!

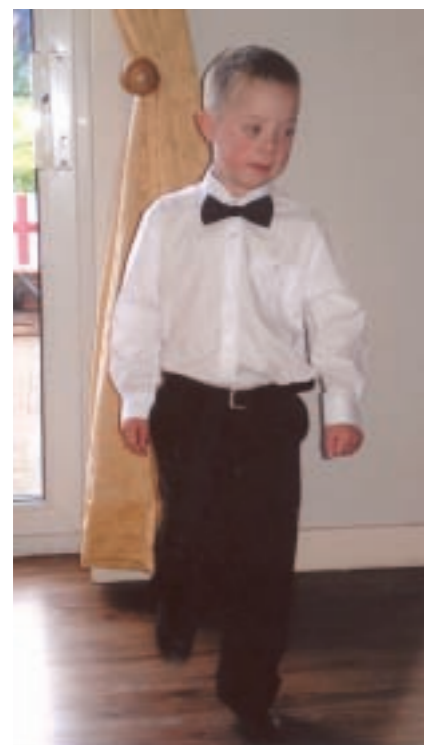
Nicholas is now living with another disabled young man in a flat less than two miles from us, on which they have a shared mortgage on an 'interest only' basis. They have lived there for seven years now, doing their own shopping, washing, ironing and cleaning. They have a support worker who keeps an eye on them. Nicholas comes home every weekend because we enjoy having him here, but he is quite happy to stay in the flat if not convenient. He works on Mondays only, as a cleaner at Eton College and the rest of the week is spent in his dance and drama groups, doing pottery, photography, whatever his current hobbies are or going to the gym or swimming clubs.

I married again after my article in 1990 and between us, my husband and I have 12 grandchildren, all of whom love Nicholas and he spends all his money on them. He hasn't married, but I tell him not too many men have so many nephews and nieces.

My first husband was a founder member of the Down's Children's Association (as it was known then) in 1969 with Rex Brinkworth, who was a great strength to us 40 years ago when our 'Mongol baby' was born and I have watched the Association go from strength to strength.

I hope this will be of encouragement to younger members of the DSA. Once the initial shock has subsided I can truly say Nicholas has brought us nothing but joy. He is a real 'people person' and has so many friends.

Yours sincerely, Sheila Rosser



Dear DSA,

I was wondering if you could put the enclosed photo in your Journal.

Tyler is 7 years old and has just passed his first dance exam – THE SAMBA. He loves music and dancing and attends a mainstream dancing school (Oakden School of Dancing).

I have also enclosed a photo of him going to the exam, dressed in his smartest outfit.

His sister Gabi (10) is a great help to him in the class and at home practicing.

Lisa Latham

