

journal

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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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Middlesex TW11 9PS
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**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.

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WALES

Suite 1
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Cardiff CF14 3NB

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Unit 2
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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
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www.dhg.org.uk



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**Nurturing Positive
Fatherhood**

**Further Education:
All You Need to Know**

**The Impact of labels
on Social Identity**



Welcome

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Carol Boys

Message from the Chief Executive

It's hard to believe that a month has already passed since the New Year celebrations. 2008 is set to be a busy year for the DSA with lot's of new projects and some major campaign work.

If you live with a person with Down's syndrome aged 16 or over, he or she will shortly be receiving a form from us called 'Tell It Like It Is'. This form asks adults with Down's syndrome to tell us about any cuts that have been made to the services that they receive from their Local Authority. The questionnaire has been drawn up in accessible form by the Learning Disability Coalition and we will use this information in our work to campaign against cuts to services and the lack of social care funding for adults with learning disabilities. It is crucial that we receive as many forms back as possible so that we can gather the evidence we need to present to Government. If you support someone with Down's syndrome please do encourage or help them to answer the questions depending on their level of ability. I can't stress enough how crucial this information is in the fight against cuts to services!!

Our focus on employment issues during 2007 was a great opportunity to find out more about the real experiences of our members with Down's syndrome. Some people had successfully secured paid employment whilst others were still battling the system to do so. Equally, there were a lot of people who were benefiting from, or trying to find, other meaningful activity such as voluntary work, day services or college courses depending on their level of ability. It is clear from our findings that in order to meet such a diverse range of need there must be an equally diverse range of solutions. The next step in our employment campaign will be based upon the need to build greater support for ALL adults with Down's syndrome – those who wish to work and those who

can't – to ensure that no-one with Down's syndrome is made to feel that their only choice is to 'stay at home and do nothing'. In the next few weeks we will feed back the findings from our campaign to the Department of Work and Pensions (among others) to highlight the issues that we believe are still not being addressed.

The DSA strives to be an organisation that is relevant to everybody with Down's syndrome – their families and carers – at whatever life stage they are at. Every year, we provide support and information for people dealing with pre-natal diagnoses, right up to those who are living with dementia. I hope you agree that this Journal reflects this diversity – from 'Child of mine' (p28), which follows a mother's experience of pregnancy and birth, through the importance of the role of fathers in school (p13), a special report on Further Education (p7), an update on the role of the Learning Disability Coalition in adult services (p3) to an overview of the new Older Carers Project (p4).

Finally, the Journal wouldn't be the same without the wonderful letters and photos that members want to share – not only with us but with other people who are going through similar experiences. Please do keep them coming in!

Carol Boys, Chief Executive

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Learning Disability

coalition update

The DSA is still heavily involved in the work of the Learning Disability Coalition (LDC), which is campaigning against the cuts to adult services and the tightening eligibility criteria that adults are facing in order to get these services.

There have been some very important announcements made recently about adult social care, most notably:

- The 2007 Comprehensive Spending Review (CSR) revealed that in the next three years, adult social services will only receive a minimal rise in local authority funding. According to the Local Government Association, this will not allow councils to even maintain current levels of spending.
- Cash-strapped councils have been tightening eligibility criteria for adult services, leaving many people with learning disabilities without vital support. Harrow council tried to change the eligibility criteria for adult services from providing for those with "substantial" needs to only providing for those with "critical" needs. However, this was met with a legal challenge, and pronounced "unlawful" by the High Court. Harrow will now have to reconsider the issue. This is very positive news, as it will hopefully make other London councils think twice about tightening eligibility criteria to such an extent.
- The CSR also revealed that Government will be producing a Green Paper setting out the key issues and the options for reform for Adult Social Care. This will be a critical document that will affect longer-term reform of the funding system.

The LDC aims to be heavily involved on the consultation of this document, to try to ensure that the voices of adults with learning disabilities are represented and heard.

- The Government protocol 'Putting People First: A Shared Vision and Commitment to the Transformation of Adult Social Care' admitted that "there is a need to explore options for the long term funding of the care and support system, to ensure that it is fair, sustainable and unambiguous about the respective responsibilities of the state, family and individual". It states "there is now an urgent need to begin the development of a new adult care system... a system able to respond to the demographic challenges presented by an ageing society and the rising expectations of those who depend on social care for their quality of life and capacity to have full and purposeful lives."

It is clear that Adult Social Care is finally being seen as a priority issue for Government, which can only be a good thing, but any changes must be coupled by realistic funding levels, or else any system transformations will still not give vulnerable adults the real choices they deserve.

It is important that the LDC now gathers enough evidence to make a concrete case for stopping the cuts and the tightening of eligibility criteria. We will also be holding a Parliamentary Event on 7th May to increase the backing from MPs and raise the public profile of the LDC.

For more information please go to www.downs-syndrome.org.uk and click on the link to the Learning Disability Coalition.

DSA visits 10 Downing Street

The DSA was lucky enough to be invited to a reception at 10 Downing Street hosted by the PM's wife, Sarah Brown. The aim of the reception was to raise awareness of the work of the DSA, and most importantly for Mrs Brown to meet some of our key supporters, without whom our work would be impossible. The reception was a very moving event, as it provided a chance for lots of members of the DSA to meet and share their stories. It was fantastic to see adults with Down's syndrome telling new parents about their achievements and experiences, from getting a new job to running the marathon!



Older Carers

project



The DSA has joined forces with two other charities, Respond and Help the Aged, to form the Older

Carers Project. The Project aims to raise awareness of the support services offered to older family carers of people with learning disabilities.

As people with learning disabilities are living longer, many parents or siblings in their later years find themselves caring for a dependent adult. They may need support in planning for what will happen to the person with learning disabilities once they die, or can no longer care for that person. They may also be unaware of the services that are now available to help them, or may be reluctant to try them if they have had negative experiences of statutory services in the past.

The Older Carers Project aims to equip GPs, nurses, pharmacists and professionals in older people's services with the information and resources to identify and reach out to vulnerable older families living with learning disability.

Down's Syndrome North East (DSNE) and Northern Rock (NR)

You may have seen in the media towards the end of 2007 articles connecting DSNE and the problems of NR. Both DSNE and the DSA want to reassure any members who may have been confused or concerned by the coverage, and as such DSNE Trustees have issued the following statement:

Unknown to DSNE we were named as the beneficiary of a trust set up by Granite Finance – part of a group of companies through which NR arranges funding for its mortgage business. Neither of these arrangements is unusual in the world of finance, and we now know that all major banks and lenders have similar set ups. The directors of Northern Rock have agreed that we should have been told about the nomination when it was made and have apologised. We are satisfied that it was nothing more than an oversight and that our name was selected because at the time we had been chosen as Charity of the Year by the staff.

We would like to assure you all that we are not connected to or part of the problems facing the bank and to reassure all

The Project also encourages these professionals to pass on the contact details of the relevant organisations when older carers come to them with specialist issues.

This unique collaboration between three voluntary sector organisations means that each charity brings different skills, knowledge and experiences of supporting either people with learning disabilities or older people.

The Older Carers Project team are planning on running a training conference for health and social care professionals in 2008 which aims to:

- Highlight the issues of older families living with learning disability
- Aim to equip professionals to reach out to families who are unknown or wary of services
- Aim to provide information and resources for professionals who come into contact with these families.

For more information about the Project, please email susannah.seyman@downs-syndrome.org.uk

members and supporters that DSNE has not been knowingly involved in any misuse of money. There are currently no fundraising activities being undertaken by the bank, its subsidiaries or staff in our name. We will only benefit from the charitable trust at some point of time in the future when the Holding Company is wound up.

We have had legal advice from the DSA from the start and they have also supported us by offering to help handle telephone calls etc from journalists. Of course the journalists are not interested in DSNE, but hope that they can pick up a negative story from us about the bank. We have a press statement which has been, and will be, sent to newspapers and other media organisations, and nothing more will be said to them.

In the unlikely event that supporters or other groups are approached by the press, please simply say "No comment - the matter is being dealt with by our Trustees and our legal colleagues at DSA". Should you have any concerns at all please refer them to one of the Trustees named in Grapevine.

Visual

timetable

The Education Support CD-ROM for schools continues to be one of the most requested items from our resources list.

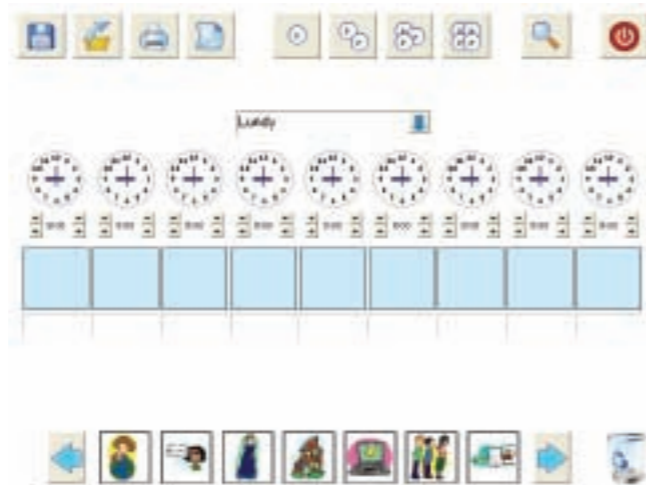
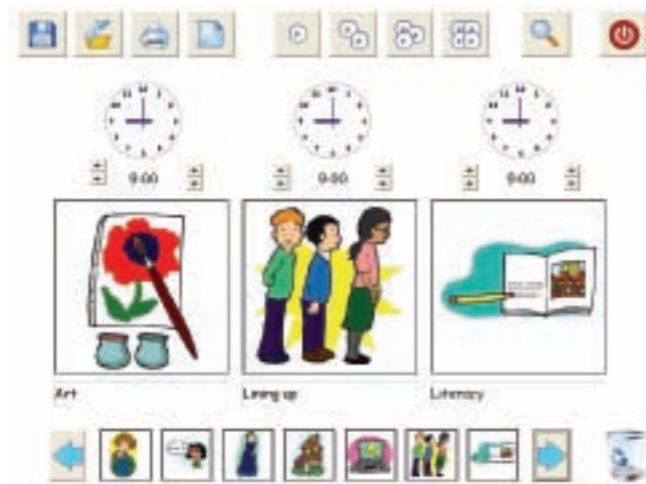
It contains copies of all of the DSA Education information sheets, our award winning education packs for schools, examples of curriculum maps for teachers to help with differentiation and a host of other material on assessment and examples of children's school work at all age groups.

The CD-ROM costs £5 and gives free access to hundreds of pounds worth of printed material. What many people don't realise is that the disk also provides a link to an additional website area for those with an Internet connection. On this area is all the updated information sheets, new publications, additional curriculum maps for teachers and more examples of children's work that can be added to as people make them available.

A new section now offers free software for teachers and support staff, as well as interested parents. The first new item to be made available is our visual timetable which has proved to be a really popular programme already and allows you to make and print your own timetables. You can plan a simple sequence of three events, a day or even a whole school week. The simple sequences can also be used to reinforce behaviour plans and add rewards for completing tasks.

The software provides a simple way of planning and sequencing your child's day, with the help of pictures. It provides its own set of 44 pictures and also allows you to import personalised pictures from your camera or computer.

To get your own free copy of the software "Interactive Visual Timetable" just go to the link on the home page of the 'education support CD' and download it. It can be freely copied for educational purposes or to use at home. You can also request a copy of the CD by calling the Down's Syndrome Association on 0845 230 0372 or email Bob at educate@downs-syndrome.org.uk for more information.



DSA

training update

Rachel Waddington, DSA Conference Manager

We had a cracking Learning Opportunities Programme last year with 1130 people attending our conferences and courses. As knowledge is further disseminated among individual networks, the benefits of information and training of this kind will be felt by a far greater number of people with Down's syndrome and so we are delighted with what we have achieved. Still, there is no resting on our laurels, and you should all, by now, have received through the post a copy of the Learning Opportunities 2008 Programme.

Can I please ask you to help us promote our conference events by passing this information on to the professionals in your son or daughter's life. Anyone can receive their very own free copy of the Learning Opportunities Programme by calling us on **0845 230 0372** and having their name added to our mailing list. We want to improve a whole range of services offered to children and adults with Down's syndrome but to do this we need to deliver information and training to practitioners.

We are offering the following conferences and courses in 2008:

EARLY YEARS

Early Years (0-2 years)

Early Years (0-2 years)

Family Weekend (under 2 years)

Exeter

Leeds

Suffolk

Tuesday 29th January 2008

Saturday 20 September 2008

Friday 14 - Sunday 16 November 2008

EDUCATION

Early Years Education

Early Years Education

Primary Education

Primary Education

Primary Education

Secondary Education

Secondary Education

Including Children with DS: 2-16 years

Access & Success: Supporting Positive

Behaviour and Effective Differentiation

3-day NVQ Accredited Course

3-day NVQ Accredited Course

Teddington (Greater London)

Sheffield

Southampton

Warrington

Norwich

Nottingham

Cheltenham

Aylesbury

Teddington (Greater London)

Thursday 8 May 2008

Thursday 2 October 2008

Friday 16 May 2008

Friday 3 October 2008

Friday 10 October 2008

Friday 18 January 2008

Friday 21 November 2008

Thursday 3 July 2008

Friday 25 January 2008

Gatwick

Norwich

Friday 18 January, Friday 1 February, Friday 7 March 2008

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

SPEECH & LANGUAGE

Early Years Speech & Language (0-4 years)

Early Years Speech & Language (0-4 years)

School-age Speech & Language (5+ years)

School-age Speech & Language (5+ years)

3-day Specialist SLT Course

Eating & Drinking Problems

Stratford-upon-Avon

Gatwick

Stratford-upon-Avon

Gatwick

Sheffield

Teddington (Greater London)

Thursday 6 March 2008

Thursday 16 October 2008

Friday 7 March 2008

Friday 17 October 2008

Wednesday 16 - Friday 18 April 2008

Thursday 24 January 2008

MISCELLANEOUS

Medical Issues in Children with Down's Syndrome

Dual Diagnosis: Autistic Spectrum Disorder

and Down's Syndrome

Looking Ahead

Five Nations Conference

Cardiff

Warrington

Teddington (Greater London)

Cardiff

Monday 28 April 2008

Monday 12 May 2008

Saturday 21 June 2008

Friday 11 - Sunday 13 July 2008

AGEING AND DEMENTIA

Positive Ageing

Dementia and People with Down's Syndrome

Reading

Sheffield

Friday 28 November 2008

Thursday 12 June 2008



Further Education

for young adults with Down's syndrome: all you need to know

By Dr Anne Marie Wright, CPD Co-ordinator, Faculty of Education and Children's Development, University of Chester

Introduction

Although leaving school is a stressful time for any young person and for their families, it can also be an exciting time which offers new beginnings and freedoms. Young people with Down's syndrome may regard leaving school as a positive step towards independence but, for their parents and carers, the prospect of their son or daughter entering adulthood may be a very daunting prospect.

It would be pleasing if this article could present a positive picture of post-school opportunities for young adults with Down's syndrome but sadly, as most parents and carers already know, the picture is not always an encouraging one. That said, at the time of writing, there is genuine cause for optimism. New opportunities are opening up as further, and even, higher education are widening their remit for participation and opening their doors to a more diverse learning community. The near future is likely to see more choice about what a young person with Down's syndrome can both learn and achieve and we must hope that, as a consequence of increasing inclusion within the school system and raised expectations, greater and more interesting employment opportunities will naturally follow.

When a young person with Down's syndrome leaves school, there are several possible options for continued

engagement in education or vocational training or, indeed, to prepare for work.

In a minority of cases, if a young person has attended a mainstream school, he or she may be offered a suitably differentiated learning programme in a sixth form, but these opportunities are rarely offered. There are also several specialist colleges across the country offering three-year residential courses for young people with learning disabilities. Places in these colleges are very hard to come by and residential provision of this kind is very costly. It has become increasingly difficult for young people with Down's syndrome who live in secure home and family settings, who are not at risk of disengagement, or of becoming involved with the criminal justice system, to gain funding to attend specialist colleges. Perversely the failure of mainstream colleges to offer meaningful opportunities locally, appears to be the remaining criteria for access to these opportunities.

In the main, young adults with Down's syndrome, as members of a wider group of students with learning disabilities, will be advised to continue their post compulsory general education or to embark on a vocational training course, in their local Further Education (FE) College. All FE colleges offer specialist provision for students with learning difficulties and this provision is available in two ways. Either through

specialist courses, known as 'discrete' courses, or through supported access to a wide range of mainstream vocational courses. Some colleges now offer programmes that combine access to mainstream vocational subjects and work experience with support from the college and include studying basic skills and independence skills in discrete groups. Students with learning difficulties are referred to, in FE settings, as students with learning difficulties and/or disabilities (SLD/D). In FE, as in all other post compulsory settings, there is no legal requirement for a statement of special educational need to be maintained.

FE colleges are exciting and busy places and the experience of learning in a diverse and inclusive environment, alongside other young adults, may be seen as the main advantage of FE. However, one of the main differences between school and FE, and one of the challenges of FE for students with learning disabilities, is that attendance patterns and course teaching times are fragmented. Some courses are for only 14 hours a week and students may find themselves with free, unstructured time as a result of staggered timetables, short days, half days or a three or four day week. Exciting for the student; terrifying for the parent or carer.

The FE curriculum

The FE curriculum is traditionally vocational but also offers GCSEs,

A levels and courses in basic skills. Because FE is non statutory, there are wide differences in the vocational courses that may be available. Some courses are offered almost everywhere, for example, Catering or Health and Social Care. Others respond to the needs of the local labour market and provide courses in Plumbing or Uniformed Services. Some colleges specialise in one particular vocational area, such as Art and Design, Dance and Drama or Horticulture. Students with learning disabilities can access a vocational course or they may choose to take a discrete course designed specifically to meet the needs of students with learning disabilities.

Some students begin their time in FE on a discrete course and then progress onto a vocational course at a later date when they have developed the skills and confidence. As described above, some colleges offer a programme that combines some mainstream and discrete learning opportunities.

Discrete courses are designed specifically to meet the needs of students with learning disabilities in the moderate to severe range. Courses are designed around the student becoming more independent and self sufficient. A young person's inability to travel alone is often, but not always, a key indicator of the suitability of a discrete course to meet an individual young person's needs. Discrete courses

often have titles such as, 'Towards Independence' or 'Skills for Living', or 'Preparation for Work'. They are most likely to offer a curriculum or learning programme which includes personal skills development, travel training and money management alongside independence skills, basic skills and general work skills. The current philosophy underpinning the long-term aim for this kind of curriculum is expressed as 'independence and activity in communities and in

employment' (Learning and Skills Council, 2005 p.2).

Vocational courses are available in a wide range of subjects. Depending on the qualifications that the young person has already achieved at school, a vocational course can be taken at Pre-Entry level, Entry level, Level One, Level Two or Level Three (see Table 1). Vocational qualifications can be taken alongside courses in Key Skills, Basic Skills or GCSEs and A levels. ►



Understanding the qualifications framework

The National Qualifications Framework (NQF) is a way of comparing different qualifications. Qualifications at the same level in the NQF all recognise a similar level of knowledge, skills and understanding across a range of subjects.

Table 1: The National Qualifications Framework

NQF level	Level indicators	Examples of qualifications
Pre-Entry Level	Learning is led by individual need but is measured against 'Milestones' equivalent to National Curriculum P Scales.	ASDAN Towards Independence College certificates.
Entry Level (Entry 1, Entry 2, Entry 3)	Learning at this level involves functional literacy, some reading and writing skills.	City and Guilds/ASDAN/BTEC Certificates/Open College Network (OCN), Awards in Life skills, basic literacy and numeracy skills, work preparation skills.
Level 1	GCSE grades D-G Learning at this level involves the ability to apply learning to everyday situations.	NVQ and GNVQ Vocational subjects* BTEC/OCR/ASDAN/Introductory Diplomas, Certificates and Awards.
Level 2	GCSE grades A*-C Learning at this level involves the ability to demonstrate skills, knowledge and understanding to subject or sector skills areas.	NVQ and GNVQ Vocational subjects* BTEC/OCR/ASDAN/First Diplomas, Certificates and Awards.
Level 3	AS and A Levels Learning at this level involves obtaining in-depth knowledge, understanding and skills, and a higher level of application.	NVQ and GNVQ Vocational subjects* BTEC/OCR/ASDAN/National Diplomas, Certificates and Awards Diploma in Foundation Studies (Art and Design).
Levels 4-8	Specialist learning involving high level of knowledge in a specific occupational role or study	Professional Diplomas, Certificates and Awards. Diplomas of Higher Education, Foundation degrees, BTEC Higher National Certificates and Diplomas.

*The essential differences between an NVQ and GNVQ are where the learning takes place and how learning is assessed. NVQs are directly work-related. In FE colleges NVQs are taught in simulated work settings, i.e. a catering kitchen or a hairdressing salon. GNVQs may combine classroom and work-based (vocational) settings, for example, on courses for Health and Social Care or Art and Design.

Discrete courses for young adults with learning disabilities are designed to sit within the national qualifications framework as the first rung of the ladder, at Pre-Entry or Entry Level. Technically, a young person should be able to move up or across the qualifications ladder, whatever their starting place.

Choosing a course

The decision about choice of course for a young person with Down's

syndrome is made after an initial assessment and interview. The young person is always very involved in making the choice about what they want to study and can be supported by a parent/carer, an advocate, a professional from a previous school or a Connexions adviser. They will most often have to choose between a discrete specialist course or a mainstream vocational course.

Although there are differences between

individual college policies, the admission requirement for a Pre-Entry or Entry Level course is most often that a young person can benefit from learning in a college environment and can make progress in learning and personal development. Situations will vary but a significant amount of additional support is usually built into these courses and is provided as routine, inside and outside of the classroom. More specialist, additional individual support for personal care or communication

or to manage social situations is then provided according to assessed individual need.

The admissions requirement for a Level One course is, most commonly, a student having an interest or aptitude in the subject and some functional literacy skills which are judged to be an ability to read and write at a basic level. It is likely that there would also be an expectation that the young person would have some independent social skills, such as an ability to find their way around the college building. Some additional support may be built into the course but this will be less than on a discrete course. Other support may be offered to meet individual need. The judgement about whether a young person can access a mainstream course is most usually based on an assessment of whether or not that person can benefit from the learning and the experience, and can make progress. Initial assessment could also involve a basic skills screening assessment.

The minimum admissions requirement for Level Two is usually two subjects at GCSE grade D. For Level Three, this would increase to five subjects at GCSE grades A*-C. The ability to travel independently or to manage personal care unsupported would not be part of the criteria for admission onto any programme, at any level.

The choice between a discrete and mainstream course

Ultimately, the student will be advised

to apply for a discrete or mainstream course according to his or her own wishes. The initial assessment and interview are very important and can be a useful time to ask these questions?

1. How long will the course last?
2. What is available after the course has finished?
3. What age are the other students on the course?
4. How many hours attendance is required in a week and for how many weeks in the year? What is the usual attendance pattern?
5. Is there any other provision, such as enrichment activity, outside of teaching time?
6. Is transport to and from college provided and, if so, what is the cost?
7. How are parents/carers involved in monitoring progress?

Within this context, it may be useful to consider some of the challenges that present themselves when a young person with Down's syndrome chooses a mainstream vocational course.

- Level One courses usually last for one year. Funding for progression to the next year of study is dependent on passing the Level One qualification. The student with Down's syndrome may not be able to achieve progression to Level Two.
- The students on the course who do not have learning disabilities are likely to have left school with few or no GCSEs and may have challenging behaviours associated with educational disengagement or disadvantage,

although this is not always the case.

- The student with Down's syndrome may be less mature and 'street wise' than the other students and are therefore more vulnerable to exploitation.

There are different challenges when a student chooses the discrete option. The discrete model was created at a time when most children with Down's syndrome attended a special school and, in this sense, the model is located in a segregative ideology which has now been superseded by a governmental commitment to inclusion. The arguments for an inclusive model of learning in schools are the same in FE.

- Expectations for achievement may be low and individual strengths and talents may be hidden within a learning disabled group culture. This may also apply to work experience opportunities.
- Learning may be cyclical and repetitive and qualifications may link to individual achievement rather than attainment of nationally recognised qualifications.

- Individuals are likely to be identified as part of a group of people with learning difficulties in the public spaces, such as the canteen or library.
- There is less opportunity for full social integration and it may be more difficult for an individual to pursue his or her individual leisure interests.
- Support levels are likely to be high and support may be visible in social spaces which may impede the ability ▶

of the individual student to take risks and enjoy the freedoms that other students have.

The law and reasonable adjustment Colleges have duties under The Disability Discrimination Act. In 1995 this Act brought in measures to prevent discrimination against disabled people in the areas of employment and service provision. The Special Educational Needs and Disability Act 2001 (SENDA) amended the DDA 1995 to cover education. The post-16 sections of Part 4 of the Act deal specifically with post-16 education and with related services such as recreational and training facilities provided by local education authorities (in England and Wales) and education authorities (in Scotland). Part 4 of the Act is based on the principle that disabled people should not be discriminated against in education. Education providers must comply with the duties set out in Part 4, as must others to whom those duties apply. The new duties for providers of post-16 education and related services came into force on 1 September 2006. (More information is available from the Disability Right Commission Code of Practice: www.drc-gb.org)

The duties require colleges to consider issues or access to buildings but also to learning and information. The law promotes the idea that all 'disabled' students, including those with a learning disability, have equal rights to benefit from and contribute to the learning and services available in educational institutions. It requires schools, colleges and higher education institutions to

make reasonable adjustments through providing auxiliary aids and services (which came into effect on 1 September 2003), and to make reasonable adjustments to the physical features of premises (which came into effect on 1 September 2005).

Colleges, as other educational providers, are required to be pro-active in totally removing barriers to learning and participation, not just in improving access, but also in promoting inclusive admissions policies and curricula. It is unlawful, therefore, to include unnecessary or marginal requirements for entry to a course. This is considered to be discrimination and would include, for example, not making a person's ability to travel to and from college independently, a criterion for attending a vocational course.

Course materials and curriculum resources are now modified as a matter of general practice, for example, instructions are provided for students with learning disabilities in Easy Read, with symbols, visual clues or orally. It is equally commonplace, for support worker and learning support lecturers or assistants to provide whatever additional learning support a disabled student may need in order to access learning.

Some cause for concern

Anyone who keeps a weather eye on the national press cannot have failed to notice that there has been some adverse criticism of further education in terms of the quality of its provision for both young people and older adults with learning disabilities. Criticisms of

poor quality have been directed, in the main, to discrete provision. As a consequence, and more worryingly for parents and carers across the country, since September 2006, 3,000 of the 20,000 students with learning disabilities in FE colleges have lost their places on discrete courses (Curtis, 2007). Both Ofsted, which is responsible for inspecting the quality of FE, and the Learning and Skills Council (LSC) which funds provision, report that courses for students described in the FE sector as having learning difficulties and/or disabilities (SLD/D) (Tomlinson, 1996) have not been meeting required standards.

In January 2004 Ofsted published an official survey of 22 colleges and found standards on discrete courses designed for students with learning difficulties to be poor, with the provision for students with severe learning disabilities giving the most cause for concern. The main weaknesses were that lecturers were not well qualified and had little specialist training; the classroom accommodation was inappropriate or poor; there was insufficient diagnostic assessment of individual students' needs and that all students were all provided with the same curriculum menu (Ofsted, 2004).

At the same time, Ofsted discovered that students with learning difficulties who had chosen the mainstream vocational option found it very difficult to progress beyond a Level One course and so found themselves, after one or two years, having to leave college and being forced into

supported employment schemes, for which they were not sufficiently socially and emotionally prepared.

The good news

The Learning and Skills Council (LSC) is responsible for planning and funding high quality education and training for everyone in England other than those in universities. In November 2005 the LSC undertook a consultation called, 'Through Inclusion to Excellence' to explore some of the problems in the ways in which FE colleges were providing for students with learning difficulties (LSC, 2005) and to tackle Ofsted's criticisms. As a consequence, in October 2006, the LSC launched a national strategy for learners with learning difficulties and/or disabilities called 'Learning for Living and Work'. This strategy set out a four-year plan for 2006-2010 and made a commitment to eradicate identified poor provision and to produce a set of national protocols for partnership working. These documents published by the LSC believe that the needs of this group of students are to achieve, 'independence and activity in their communities and in employment' (LSC, 2005 p.2). Colleges will only attract funding from the LSC if their courses begin to achieve these measures of success. It is difficult to predict exactly how FE colleges will respond to the new LSC directives but what is certain is that they will no longer be able to offer courses to students with learning difficulties that do not prepare them for independence and employment in ways that are meaningful and meet individual students' vocational aspirations.

All you need to know in summary:

- Young adults with Down's syndrome are welcome in FE colleges and can access a wide range of courses.
- The quality of provision for students with learning difficulties is mixed and some is poor. It is advisable to read the Ofsted report for your local college.
- FE colleges are inclusive and must work within the requirements of the DDA, making reasonable adjustments to ensure access and participation.
- The ability to travel independently cannot be an entry requirement for a college or a course.
- Some courses are special or discrete courses where all the students have learning disabilities.
- The majority of courses are vocational and offer opportunities for students with Down's syndrome to study alongside their non-learning disabled peers.
- Statements are not maintained in FE and it may be difficult for parents/carers to remain involved.
- Additional funds are available for colleges to provide small classes, additional teaching and/or learning support and extended timetables.
- One to one learning or personal support may be provided if it is assessed as necessary.
- Funding does not cover transport to and from college.

Being a student in an FE college, even if there are quality issues and challenges, can provide a space for significant emotional growth. The freedom to experience the journey from adolescence to adulthood in a busy, vibrant, mainstream environment can be a positive and heady time. It is a time when being a student can take precedence over being a young person with Down's syndrome. As with any emotional growth for anyone, at anytime in life, growth most often happens when we take risks. The FE experience is more likely to feel like a greater risk for parents and carers than it is for the young person. Risk can be managed and reduced by knowing some basic facts, asking some challenging questions and keeping fully involved (but perhaps from a distance)!

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Fairer to Fathers:

The role of schools in nurturing positive fatherhood

Professor Barry Carpenter OBE, is Chief Executive of the UK charity, Sunfield, which supports children with severe intellectual disabilities and their families. Barry is the father of Kate, a young woman with Down's syndrome, and has researched the topic of fatherhood for the last 20 years.

Introduction

Fatherhood in the 21st century is very different to how it was a hundred or even fifty years ago. Then, being a father, with all of the Victorian patriarchal overtones of authority and discipline, was largely undertaken within the context of a married relationship, with both parents living under one roof. In 2003, 41% of all births in the United Kingdom were outside marriage. This is a substantial increase when compared with the 1980 figure of nearly 12% and is mainly due to the increasing number of cohabiting couples (Office of National Statistics (ONS), 2005).

The UK also has the highest level of teenage pregnancy in Europe; in 2003, there were 26.6 live births per 1,000 girls aged 15-19 years and 149 live births per 1,000 girls aged 14 years and under in the UK (ONS, 2005). It is reasonable to conjecture therefore that a similar number of young men become fathers.

The social structure of fatherhood has changed generally for all men, and very specifically for a few (e.g. teenage fathers) (Cohen, 2001). Today's media frequently publish photographs of fathers carrying their babies, pushing prams, playing with their children. Prominent political figures (e.g. Tony Blair, David Cameron) are depicted as proactive fathers, alongside a whole

host of celebrity fathers from footballers to pop stars. By the end of the 20th century the acceptable father figure was "softer", more liberal and one who acknowledged the need to "get in touch with his feminine side" (Lamb, 2004).



Patterns of fatherhood have varied throughout history. When men were weavers, farmers or craftsmen and worked at home, they were involved with their babies. Industry changed all that, sending them into factories and keeping them apart from their children. Now things are changing again as more men work from home and have regular coincidental contact with their children (Carpenter, 2002).

The traditional definition of fatherhood within the stereotypical definition of family is no longer totally helpful to modern families. Families today are far more "self defined" (Carpenter, 2000) and therefore fatherhood itself needs not only to be redefined, but also to be re-assimilated by Society in its modern,

dynamic and ever-changing context.

All of the current social roles need to be accepted as "units of masculinity" (Tolston, 1977), alongside those often perceived as inherently masculine, such as "protector", "provider", "strong in a crisis", "emotionally competent" (Herbert and Carpenter, 1994). Expressions of fatherhood in a variety of modern media forms are now readily available to men. A recent issue of Dad (the magazine for new fathers) asked the question, "Can fatherhood be cool?" – a question variously answered by Pierce Brosnan, David Beckham and the author, Tony Parsons (2003), who gave an insightful analysis of his own response upon becoming a father:

"I didn't understand the love [my dad] felt for me and the pride he took in childish achievements until I had a son of my own. I looked at my tiny baby and there was some kind of chemical reaction – here was the most precious and beautiful thing I had ever seen, here was the best thing that had ever happened to me."

In another magazine, *FatherWork*, the social changes imposed on fathers are discussed in the context of political reform. Beverley Hughes, a UK Politician,

states that 'services which support parents should be geared to supporting fathers as well as mothers'. Hughes and Fisher (2006) call upon services to modernise to support other significant carers in the family, notably fathers. Within the context of the service development, guidance should be given that encourages service providers to think carefully about ensuring that their services are father-friendly. If fathers are now looking after children for lengthy periods of time, fathers need the same skills and knowledge that we have traditionally expected mothers to have.

Paternity leave is now available in the UK to all men in the time following the birth of a child. The rights of fatherhood are championed by the organisation, Fathers Direct (www.fathersdirect.com). They offer advice, resources and valuable links to dads at all ages and stages of fatherhood. To encourage services, Fathers Direct have developed a Fatherhood Quality Mark, which identifies and celebrates agencies which have positive strategies for strengthening children's relationships with their fathers.

A new resource, The Dad Pack (www.dad.info), has been produced by Fathers Direct. The pack is a basic toolkit for organisations to use in supporting dads in being, and becoming, more involved with their children. It covers issues such as pregnancy, birth, work, relationships, health, benefits, legal rights and responsibilities, and how to praise children (Fathers Direct, 2006). It

may seem that such approaches over-emphasise fatherhood, but this may be necessary to counterbalance stereotypical attitudes to fathers, and a lack of realisation that the demands of 21st century fatherhood are very different, both in context and delivery – for some men direct nurturing may be necessary. Are fathers born or created? Even now, seemingly innovative courses on working with families ignore completely the role and needs of the father (Moore, 2005).

Effective fatherhood has always been essential to society's well-being and that of its children. It is even more essential in today's transformed and transforming society, and strategies which engage men as dads throughout modern media and technology can ultimately only be to the benefit of our children and the well-being of the men themselves.

The needs of fathers of children with disabilities

Research around the needs of fathers of children with disabilities has been infrequent (Gavidia-Payne and Stoneman, 2004). In families of children with disabilities, mothers and fathers can react differently to the news that their child has a disability or special need (Fidalgo and Pimentel, 2004). Different family members may look to the father for support at a time when he is adapting to a new and sometimes difficult set of circumstances. The needs of the father, among them for him to be nurtured himself, often go unrecognised by professionals (Social Care Institute for Excellence (SCIE), 2005). Fathers

have been identified by researchers in this field as "hard to reach" (McConkey, 1994), "the invisible parent" (Ballard, 1994), the "peripheral parent" (Herbert and Carpenter, 1994).

Sheila West (2000), based on her research, described them as "just a shadow", where, generally, fathers felt that the support systems that were in place were beneficial to their partners, but not to them. Improved support, information and the opportunity to access services, fathers felt would enable them to be much more involved with their child. Carpenter and Herbert (1997) observed that fathers found it difficult to assert their involvement. Neither health and education professionals nor employers recognised the need of the father for inclusion in the family situation. Fathers were forced by professional structures and social expectations to fall back on the 19th century stereotyped role of "protector", of "being competent in a crisis", yet emotionally uninvolved.



Emotional reactions by fathers to the birth of their child with a disability vary (Rendall, 1997). Meyer (1995) tells how the birth brings about life-transforming experiences. For some, it is a challenge that allows them to ►

display aspects of their personality not previously acknowledged. For others, it causes stress, disorientates their life goals and affects their work patterns. Many fathers in the New Zealand study, *Perilous Passage*, spoke of their almost immediate worry about their child's long-term future (Bray, Skelton, Ballard & Clarkson, 1995). This study also reported that fathers consumed more alcohol and more frequently as a way of dealing with their emotional trauma. Throughout all of these studies, the provider/breadwinner role of the father is central, a finding confirmed by Contact-a-Family in their recent study (CAF, 2005). Conversely, a recent report from the National Deaf Children's Society (NDCS) stated that fathers of deaf children actually believe they are overlooked by service providers (NDCS, 2006).

What can schools do to support dads?

Whatever the school setting, there will be a father of a child with special needs/disabilities who has experienced some of the emotions and reactions described earlier in this article. It would be unrealistic to expect every school to have resources available to support dads directly, but they can act as a conduit. Schools, probably through the Special Needs Co-ordinator (SENCO), can have some key websites and contact details available.

More fundamentally, all schools can ask: Are we father-friendly? Do dads feel welcome in our schools? Do we engage fathers as supporters of their children's learning? Some fathers will have come

through early years programmes where they have been actively involved in the care and education of their child. Indeed, Family Services should "have specific strategies and activities which increase the involvement of fathers in the services" (DfES, 2003).

Hughes and Fisher (2006) describe the Daddy Cool programme at a Sure Start Children's Centre in Southampton, which has developed Saturday morning breakfast clubs for male carers and their children. It has a special magazine for fathers, and runs a weekly five-a-side football game for them as well as other activities. The result is a large increase in the number of dads at the centre, learning about childcare, first aid, debt management and a host of other issues vital to the lives of their children. What is the potential transference of such ideas to the concept and practice of other family-focused services in other settings?

There are a range of paper-based resources that schools could have available – the Dad Pack (Fathers Direct, 2006) or the Fathers Factsheet (CAF, 2005). Advice to staff is also downloadable from SCIE, who have produced a summarised literature review. Outcomes from the Recognising Fathers research project are also available via the internet (www.fpld.org.uk). Books written by fathers of disabled children are increasingly available (for example, *Ollie* by Stephen Venables, 2006). The National Deaf Children's Society has recently published a blog written by a father of a deaf child on its website (www.ndcs.org.uk).

For some fathers, support groups around disability might be a good way of meeting other fathers who are in a similar situation. In the CAF (2005) study, one dad reported how useful it had been to make friends with another father,

"You need support from people who "get it" – only dads who are in the same situation can really understand."

While a school may not run its own support group, it would be possible to network fathers to groups that may exist in the area. Not all groups need to meet physically; some are virtual. Sunfield School in Worcestershire, UK, runs an email group for its fathers – SunDads.

The same school has also developed a model of training, *Celebrating Families*, which specifically addresses the needs of particular family members and brings them together annually for their own training events (e.g. Mum's the Word, Siblings' Workshops) alongside a general family training programme (Carpenter, Addenbrooke, Attfield & Conway, 2004). Specific Dad Days have focused on such topics as housing, sex education, challenging behaviour and fatherhood. Men process information differently: research on fathers of children with disabilities has indicated that they tend to focus on the "big picture" (Gray, 1992). Their concerns are often for the future – employment, housing, work, money. Training needs to be tailored to these topics and to male brain modes of

learning and acquiring information (Baron-Cohen, 2003).

Many fathers have specific skills from their professional lives which mean that within a model of reciprocal partnership that relies on skill-sharing as an approach to problem solving and development (Carpenter, Attfield & Logan, 2006), they can assist many aspects of school policy development.

Thinking 'Dad'?

Do our schools think 'Dad'? There has been a worrying trend towards parents evenings being held between 4.00 p.m. and 6.00 p.m. when many fathers (and mothers too) may not have returned from their own day jobs. If only the mother is able to attend such parent-teacher interviews, then she again becomes the holder of complex, detailed information, which it is assumed she will transmit to the father. Where parents have different foci of interest in their child's education, this could cause conflict. Why are we putting such unnecessary pressure on relationships when some optional, later evening times would have enabled both parents to attend the consultation?

Among parents of pupils with special needs, many fathers would welcome the opportunity to attend their child's review meetings in school, but research reported by Carpenter (2002) discovered that many were given little, or no, notice of the review meeting date, and the school's expectation was often that the mother only would attend. Fathers in this study recommended that schools should always give them the option to

attend. To achieve this, they felt several months' notice in advance would help them either to plan time out, take paid or unpaid leave or, as one father who worked in a manual post suggested, arrange to skip a lunch break. Most of all, these fathers wanted their right to attend acknowledged and for the decision to rest with them.

Many schools are locked into operating only within defined hours, Monday to Friday. This may coincide exactly with a father's working hours and give him little or no opportunity to visit the school or participate in school-related activities. Can we not generate more flexibility in how school staff discharge their working hours? One school organised a termly Saturday morning computer club where dads supported their child with special needs; the school benefited directly in that several of the fathers were able to offer particular expertise regarding information technology. Another school organised a summer holiday working party, where fathers volunteered to carry out painting of classrooms. The Head reported that during these three days the fathers not only achieved a lot for the school, but bonded as a group, exploring their attitudes, feelings and thoughts around rearing a child with disabilities.



Conclusion

The Recognising Fathers (Foundation for People with Learning Disabilities, 2006) project has echoed some of the key messages found in the earlier research studies cited. From the interviews conducted during this project, it was apparent that many fathers of children with special educational needs are playing an active role in family life – through providing care to their children, supporting their partner and campaigning for resources. They are often balancing this with paid employment. The interviews in this study identified several aspects of good practice (e.g. flexible working patterns), but concluded with a series of major recommendations for policy makers, service providers and professionals.

What is new is that the Recognising Fathers study has articulated these messages in the context of 21st century fatherhood. The range of initiatives around fatherhood generally (e.g. paternity leave) may at long last mean that the messages will be heard and acted upon. Government policy and service provision need to be challenged, and, finally, fathers can be liberated from the "myth of manhood" that has trapped them within a previously unquestioned set of expectations, both in their role as providers and as family members.

Fatherhood needs to be offered status and equality, and the fathers of disabled children warrant respect and support. For the sake of these children, we need to be "Recognising Fathers". ▶

Getting used to glasses

Getting your pre-schooler's eyes tested is hard enough. But when you do go home with a small pair of glasses, how do you get your child used to wearing them? Below are some suggestions you may find useful.

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There are two aims when getting your pre-schooler used to glasses. They need to be confident in saying:

1. I now wear glasses (for however long).
2. Mum or Dad takes my glasses off. If I take them off, they will ALWAYS go back on.

First few days:

- Have some treats or rewards ready that your child particularly enjoys and does not get often.
- Put her glasses on, then take them straight off again. Don't wait for her to get worried about the change in vision.
- Do this five or six times a day, for a couple of days.

First week (or so):

- Put the glasses on and leave them on for a few seconds only.
- While doing this be happy and full of praise. Raise your hands in the air, sing, dance etc!
- Gradually increase the amount of time the glasses stay on – in increments of ten seconds only in the beginning.
- Initially, you do not want your child to touch the glasses while they are wearing them so you will need to be almost holding their hands down while helping them to do something they really enjoy.
- Once you can leave his arms free for a few seconds, let him play but as soon as you think he is going to



pull off his glasses, either hold his hands or you take the glasses off.

Next few weeks:

- Once your child is wearing the glasses for longer periods there will still be times when she will pull them off herself. You need to ensure that you put them back on straight away with a specific phrase – e.g. "glasses stay on".
- You want to ensure a situation where your child learns that glasses do come off at times, but will only stay off if it is Mum or Dad who takes them off.

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Tongue

protrusion

By Karen Henderson, a Senior Speech and Language Therapist

Tongue protrusion is very closely associated with Down's syndrome and is regularly cited as a feature of the condition.

It has been traditionally stated that this is due to the presence of an enlarged tongue, however current thinking favours a combination of physical and developmental factors, specific to each individual.

Tongue movement should be considered within the context of the whole body. All parts of the body are connected and factors affecting normal motor development in one area may also influence the mouth. In order to develop movement and skills, we must have a stable trunk. Without that stability, our function is affected. Think of a young baby – their body movements are uncontrolled and random, but become more organised as they learn to control various parts of the body. Once trunk stability is established, body parts such as arms, legs, head, etc can develop more refined movement. For example, before a child can reach and grasp a toy, they must develop control over the shoulder and trunk.

Similarly, oral stability depends on neck and shoulder stability, which is dependent on trunk and pelvis stability. A stable jaw is necessary for the development of controlled tongue and lip movements and as the range of tongue movement

develops, children develop a sense of their tongue's natural resting-place in the mouth (e.g. in the middle).

It is important to remember that not every child with Down's syndrome protrudes their tongue but also, that it is a normal part of early development. It may become exaggerated or persist due to one or many of the following factors:

- Children with Down's syndrome have a weak suckle as infants and learn to control the flow of liquid by protruding their tongue.
- Individuals with Down's syndrome have a smaller, higher arched hard palate which means that the tongue is contained in a smaller than average space.
- There is lower than average tone in the muscles of the tongue. This makes it appear larger because it is floppier. Tongue movement depends on the actions of a variety of muscles in the mouth and it plays a role in swallowing, breathing, chewing and speaking. Individuals with Down's syndrome have difficulty with producing and co-ordinating the necessary movements to control the tongue.

- During normal development, the tongue grows at a different rate to other parts of the face such as the jaw, which in the early years, normally results in the tongue having a high, forward position in the mouth. This, combined with a smaller oral space and low tone in the tongue, may result in the tongue protruding.
- The muscles of the tongue constantly correct and readjust the tongue's position in the mouth, based on the sensory feedback it receives. Many children with Down's syndrome have difficulty receiving and integrating sensory information and may not develop these skills as quickly or completely. Consequently, they may not be aware that their tongue is protruding.
- Tongue protrusion may also result from an inability to move the jaw separately from the tongue. This is a skill that develops over time and is dependent on jaw stability. Without this stability the tongue protrudes as the jaw lowers.
- Tongue protrusion may develop due to airway compromise such as large adenoids or tonsils, which are common in individuals with

Down's syndrome.

- The ability to self-correct a protruding tongue requires some degree of insight and motivation to change. Depending on a child's age and developmental level, this self-monitoring may not develop fully, or may develop much later.
- Many children with Down's syndrome have delayed motor development and therefore may not have the stable base from which oral-motor skills can develop.
- Upper respiratory tract infections, which block the child's nose, may cause them to breathe through their mouth rather than their nose. In mouth-breathing the jaw lowers and the tongue is no longer contained within the mouth. These infections may develop as a result of middle ear infections, which are common to individuals with Down's syndrome. This develops due to a dysfunction of the Eustachian tube, which is located at the back of the throat and is connected to the middle ear (its function is to equalise air pressure on both sides of the eardrum). If there is low tone in the muscles surrounding the entrance to the tube, fast-flowing fluid may enter the middle ear, causing an infection over time.

In my own experience of working with children with Down's syndrome, tongue protrusion has generally been a transient phase, often associated with periods of teething or throat

infections. Cases that have persisted have been a reflection of a more significantly reduced overall body tone and consequently, more significantly delayed oral-motor development. These children have also demonstrated more delayed eating and drinking skills, which is reflected in a reluctance to transition from smooth to lumpy foods and delayed biting and chewing skills. Biting and chewing relies on graded jaw movements and the ability to move the tongue in a variety of directions. In encouraging a child to experience biting and chewing safely, both areas can be developed at the child's own pace.

From an oral-motor viewpoint, there are a number of areas that can be focused on. While the primary focus is on improving oral-motor skills, there will be a knock-on effect in relation to feeding and speech development. Be aware of your child's level of development and consult with your speech & language therapist, physiotherapist and occupational therapist, to ensure you select an appropriate starting point. To minimise tongue protrusion, your child needs to develop some or all of the following:

- Stable, central base (i.e. control over the trunk, head, etc.)
- Increased oral/facial muscle tone
- Increased oral sensitivity
- Improved lip movements
- Improved jaw movements
- Improved tongue movements

As you can see, tongue protrusion may occur for a number of reasons.

Many children with Down's syndrome may simply be exhibiting a generalised delay in their development, of which tongue protrusion is one feature. It is important therefore, that a full assessment is carried out, to ensure that the correct remediation path is chosen. It would be inappropriate to focus on skills that the child is unable to achieve. In normal development, these oral motor patterns are generally established by the age of 24 months, but your child may have a developmental delay and difficulties with low tone, so starting any activities at this age may be inappropriate. Every child presents a different picture, therefore every therapy plan should be tailor-made.

It is essential that you consult with a speech and language therapist, occupational therapist and physiotherapist to get an overall picture of your child's physical, sensory and oral-motor development and discuss the value of working on this area. These are the professionals qualified to guide you through the process.

Without the possibility of meeting therapists, you could try some of the suggestions below. Eliminate any medical reasons (e.g. enlarged adenoids/ tonsils, teething, throat/ respiratory infections, etc.). Select one or two exercises to try, but be aware that doing them all at the same time could be harmful. Adults can often become overenthusiastic and if the child is unable to co-operate with the exercises, they may become ►



resistant to any form of intervention in the longer term. It is vital therefore that you are aware of your child's strengths and difficulties and give them lots of praise for any attempt that they make. They may require many opportunities to practice and will need you to demonstrate it clearly, in a way that they will understand. Observe your child and take note of the times their tongue protrudes, what they are doing at the time, how long it persists, if they correct it themselves, etc.

Before starting any practical exercises, remember:

- Don't do all the activities at the same time.
- These exercises should be done for short periods of time.
- Talk through what you are doing, each step of the way.
- Ensure you are both in a relaxed, comfortable position.

- Ensure your child is in a stable, supported position.
- Minimise distractions e.g. TV, radio, other people etc.
- Pause to allow time to swallow any saliva that may have accumulated.
- These exercises can be done throughout the day – washing/drying at bathtime (using a towel, sponge, facecloth, etc).
- Don't attempt this if your child has a cold.
- Stop if your child becomes distressed at any time.
- Be patient and be prepared to repeat the activity over and over again. It may take some time before the skill is achieved.
- Most of all, make it fun!

Practical ideas for developing oral sensitivity and muscle tone:

(NB These activities should not be done at mealtimes as this could lead to aversive behaviours around food).

- If your child is sensitive around their face, prepare them before you approach their face. Use slow, firm strokes over the hands, arms, shoulders, body and neck with a rough texture (e.g. towel, etc.)
- Using firm strokes/touch with a rough texture (e.g. towel, etc.) start at the sides of the face/forehead/chin and gradually work towards the centre of the face.
- Massage the cheeks using circular movements, particularly around the mouth.
- Use 2 fingers to press the top and bottom lips firmly together. Hold for a couple of minutes and release.
- Stroke firmly downwards on the area between the nose and top lip while using your finger to push the bottom lip upwards.
- Using your thumb and index finger, pull the top lip down, starting under the nose and working towards the top of the lip (without touching the lip itself). Do the same for the bottom lip, working from the chin to the lip. Support the jaw if necessary.
- Press the lips together by pressing one index finger below the nose and the other below the bottom lip – rotate the fingers towards the lips.

- Gradually introduce stronger flavours at mealtimes:
 - curry/Chinese sauces/garlic
 - chips: vinegar/garlic mayonnaise dip/brown sauce/ketchup/etc
 - tangy or bitter flavoured fruits and yoghurts: kiwi/lemon/forest fruits/ grapefruit/cranberry/etc.
- Extremes of temperature:
 - ice-cream
 - ice-pops
- Sensory toys:
 - "Bumble Balls"
 - Teethers that are textured/ vibrate/etc.

Practical ideas for developing jaw and tongue movements:

- (NB Do these at times when your child is relaxed and, at first, do not do these activities at mealtimes).
- When spoon-feeding your child, place the food centrally on the tongue and apply firm downward pressure. This will reduce tongue protrusion that occurs during swallowing.
 - As the protrusion reduces, place the food at the sides of the mouth, between the teeth. This will encourage munching and sideways tongue movements.

To stimulate biting, munching and sideways tongue movements:

- Use items such as teethers (ridged etc), foods that do not break up (bite & stay firm foods, eg dried apricots, bananas, Liquorice sticks, etc).

- Place the item in the mouth, between the teeth, along the line of the jaw and ensure that it is not placed so as to stretch the lips. Do not place too far back in case your child gags.
- Place on the best side initially, then move to the other side.
- If the child is not munching, pull the item out slightly and gently or press down.
- When you feel your child is confident about their biting skills, introduce food items. Initially use bite-and-dissolve foods (Boudoir biscuits, meringues, Skips/Snax, etc).
- If the child is not biting off the food, break it off for them while they are biting down on it. Do not force your child to take foods that their mouth is not ready to handle.
- Over time, gradually introduce chewier foods in the same way.

Practical ideas for developing lip movements:

- Using a mirror, make "oo" sounds (e.g. a ghost/owl/ monkey/wind etc.) and "ee" sounds (e.g. mouse, E-I-E-I-O, etc.) using exaggerated lip movements. You might need to gently push the lips from a tight stretched position (smile shape) to the round position (kiss shape).
- Practice kissing. You might need to gently push the lips from a tight stretched position (smile shape) to the round position (kiss shape). Put on some lip stick or face paint and make kiss marks on a mirror, tissue, paper etc.
- Sucking through a straw. Make a tight lip seal around the straw.
- Blowing bubbles, blowing cotton wool balls across the table, blowing whistles/party blowers, blowing bubbles in water with a straw, etc.



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Ask

IPSEA

Jane McConnell answers parents' questions about statements of SEN...

Q. My daughter is 10 and has a statement of SEN. She goes to our local school which is just over a mile away. I have to take her to school every day as the Local Authority says that as the distance is within "statutory" walking distance she is not entitled to transport – even if they did arrange something we would have to pay for it. Can this be right? There is no way that she is capable of getting there herself as she has to cross two busy roads and has a limited sense of danger.

A. This is an interesting question and variations on it are frequently being asked by parents from the DSA. The legal arrangements for the transportation of children with SEN to/from school has been very recently changed and we need to decide if they apply to your daughter's case and strengthen a claim for school transport. What has been introduced is the concept of an "eligible" child. If you can establish that your daughter falls within the definition, the law now states that your Local Authority must make the necessary suitable travel arrangements so that she can travel between home and school. Importantly, these must be provided free of charge. In order to decide whether your daughter is an "eligible" child and whether the provision of transport is covered by the new legislation you need to answer the following questions:

Is she an eligible child?

1. Is she of compulsory school age?

Generally from 5 years to 16 years old – subject to Education Act 1996 s.8 as to exactly when the school year begins and ends.

- Yes, as a 10 year old she obviously is of compulsory school age.

2. Is the home/school distance in question within statutory walking distance?

Statutory walking distance is currently 2 miles for children up to the age of 8 years old and 3 miles for children over the age of 8 years measured by the shortest safe route. See Education Act 1996 s.444 (5).

- Yes. Your daughter is 10 years old so the relevant distance for her is less than 3 miles.

3. Does she have SEN, disability, mobility problems?

A child is eligible if they are;

- a child with special educational needs;
- a disabled child;
- a child with mobility problems,

AND they cannot reasonably be expected to walk to the school.

- Yes. Your daughter has Down's syndrome and is recognised as having both SEN and a disability. You would argue that as a result she could not be reasonably expected to make the journey due to her lack of awareness of danger and the route she would need to take. If the LA were to dispute whether it would be reasonable for her to make the journey you should refer to evidence which should be detailed in Part 2 of her statement describing her needs.

4. Is she registered as a pupil at a qualifying school?

The definition of a Qualifying School

includes:

- a community, foundation or voluntary school.
- a community or foundation special school.
- non-maintained special schools.
- Pupil Referral Units.
- maintained Nursery schools.
- city technology college, a city college for the technology of arts or an academy.

Plus in the case of a child who has a statement of Special Educational Needs;

- an independent school (not a city technology, city college for the technology of arts or Academy) which:
 - is the only school named in the child's statement.
 - is one of two or more schools named in the statement and it is the nearer or nearest to the child's home.

- Yes. I am presuming that the school your daughter attends is a maintained school or falls within this list.

5. Is the school your daughter attends your nearest local school – if not, did the LA want her to attend a school nearer to her home?

The LA do not have to treat the child as eligible unless:

"no suitable arrangements have been made by the local education authority for enabling him to become a registered pupil at a qualifying school nearer to his home."

This will be a pivotal question for most parents. Statutory guidance details that:

- references to the "nearest school" are to be taken to mean the nearest qualifying school with places available that provides education appropriate to the age, ability and aptitude of the child, and any special educational needs that the child may have.
- for children with SEN the qualifying school may well be different than for other children.
- for a school to be considered suitable it must have places available.
- Yes. In your case you tell me that the school your daughter attends is the local school so I presume that the LA did not try to argue that she should have been educated somewhere else.

Often an LA may try initially to argue that a child should be in a different school but eventually agree – either by negotiation or by going to Tribunal – to name a parent's choice of school in Part 4 of a statement. This often happens when a parent feels a school further away than the local school would be the more appropriate placement. As long as that school is named in a child's statement under Part 4 then the LA will be liable to pay for transport under the new legislation. The only possible exception would be where it is actually written in Part 4 of the statement that placement at this school is conditional on the parent paying transport costs. If it does not specifically say this then the LA is liable.

Next steps

As you have answered yes to all the questions your daughter could be considered an eligible child.

Step 1

You now need to contact the SEN team

at your LA and ask them to inform the transport team that, having taken advice, you know that your daughter is an eligible child under the new transport legislation and is entitled to free transport.

The new legislation refers to "qualifying" travel arrangements. These include not only the LA actually making the arrangements itself but (and only with parental consent) –

- providing one or more escorts (whether alone or together with other children) for travel to/ from the relevant educational establishment.
- paying the whole or any part of a person's reasonable travel expenses.
- paying allowances in respect of the use of particular modes of travel.
- accepting any alternative arrangements made by the parents if they are made voluntarily.

Step 2

You now need to consider what would be the most suitable arrangement for your daughter and agree them with the LA.

The new legislation requires that **any travel arrangements proposed must be suitable for the child**. This will depend on a number of factors which include:

- they must enable an eligible child to reach school without such stress, strain or difficulty that they would be prevented from accessing the education provided.
- allowing the child to travel in "reasonable safety and reasonable comfort".
- a best practice journey time which equals a maximum each way journey of 45 mins for a Primary school child, and 75 mins for a Secondary school child. For child with SEN

and/or disability possibly a shorter journey time...

- escorts/drivers having enhanced CRB checks.
- escorts/drivers who have undertaken disability equality training.

Interestingly this does not necessarily imply a door to door service.

Step 3

Your new free travel arrangements begin for your daughter – bringing independence to both of you!

Don't forget if you need any further assistance at any time please contact the IPSEA team via the DSA head office and we can advise you.

What the law says

Education Act 1996 s. 508B LEA's in England: travel arrangements for eligible children

(1) A local education authority in England **must**, in the case of an **eligible** child in the authority's area to whom subsection (2) applies, make such **travel arrangements** as they consider necessary in order to secure that **suitable** home to school travel arrangements, for the purpose of facilitating the child's attendance at the **relevant educational establishment** in relation to him, are made and provided free of charge in relation to the child.

Education Act 1996 schedule 35 – definition of Eligible Child

Further definition can be found in statutory guidance issued in May 2007 by the then DfES (ref: DfES – 00373-2007) titled **"Home to School Travel and Transport Guidance"**. Part 3 deals with travel arrangements for eligible children. Available free from **DfES 0845 60 222 60**

Impact of the label

of learning disability on social identity and mental health

Holly Rawson is a Research Assistant at Sunfield Residential School and has a brother with Down's syndrome. Here, she summarises her university thesis which looks at the link between labels and social identity.

In Britain 40% of young people with a learning disability have a diagnosable mental health problem. This article will explore some of the issues of concern to young people with Down's syndrome (DS) that could leave them exposed to potential mental and emotional ill health.

Research writings dating from 1945 to the present day suggest that having a learning disability is not a neutral social identity, but a 'master status' – one acting as a powerful label that dominates and stigmatizes, often leading to denial or disavowal of the label. This disavowal carries with it a designation of social incompetence, as it is assumed that the individual is unaware of the reality of the label. With the medical model of disability still purveying a negative image of DS, and with prenatal diagnosis screening readily available and regularly accepted, the question arises as to whether this adversely influences social acceptance and stereotypes. Furthermore, as people with DS are often easily distinguishable by shared physical characteristics, it could be argued that their identity might experience negative impact due to stereotypical views of homogenous behaviour and capabilities of such a social group, despite the group being fairly disparate. With these negative attitudes prevalent, it seems inevitable that young people will be at risk of experiencing mental and emotional health problems.

With this in mind, this study sought to explore the ways in which young people with DS talk about their disability and how they manage their identity within interaction. Data was collected from an interview with a young lady, Britney (aged 26 years), and a focus group session with young men, Will, Mike, George and James (aged 14-18 years)*. The data was analysed using discursive psychology, which works to analyse psychological issues such as attitudes, emotions, prejudices and attributions as discourse by exploring how the speaker conveys these issues through interaction. This article details just a few examples taken from the sessions.

Analysis and discussion

An important finding from the study was that all participants demonstrated a good knowledge and understanding of DS and learning disabilities, refuting previous research stating that people with learning disabilities have limited understanding of this. For example, Will displayed an appreciation for the aetiology of disability: "I have to keep my Down's to my head because it's physical...my chromosome that makes one extra", with George also acknowledging that "It gets in mum's belly". Throughout Britney's interview, she talked of the personal emotional impact that an intellectual disability can have; an example of this is when she spoke about having learning difficulties. She said, "I can't get it out of my head... it's stuck in my mind... I have to cry it out".

In the interviews, there were also numerous demonstrations of understanding of the wider social implications of such a label. When asked if any of the participants' friends had learning difficulties, George replied, "I reckon Mike, 'cause he's just disabled", to which Mike responded, "Pardon?". Rather than requesting clarification, Mike's response seemed to be a reaction orienting to George's utterance as an insult. However, it was Will who offered a repair to Mike saying, "No you're not", suggesting an understanding of the implication of George's words and an appreciation that Mike might have been insulted. This is interesting as Will had already referred to all those who attended special schools in a derogatory manner. (Will attended a mainstream school while the other three went to a special school.)

Another main finding was that all participants were able to manage their identity competently in a way that was appropriate to the interaction. In the sessions participants adopted the identity of 'teenager' or 'young man/woman' and 'football supporter'. To achieve this identification, participants referred to activities such as playing computer games, sleeping in, playing and watching football, and drinking

beer with mates: activities commonly associated with these categories. The focus group members also engaged in 'typical' devices such as teasing each other ("Do you want your nappy changed?"), referring to nagging parents (adopting mum's voice, "Get up! It's time for school!"), and singing football songs: all subtle strategies used to reinforce an identity. This demonstrates a particular sophisticated social strategy that is frequently used by people in everyday interactions.

Conclusion

The analysis of extracts taken from the sessions displays the participants' distinct understanding of learning disability and associated social implications, in terms of their own diagnosis and of learning disability as a whole. Not only this but, contrary to previous findings that individuals with learning disabilities are incompetent social actors because they do not dominantly regard themselves as 'disabled', these participants demonstrated a sophisticated ability to manage multiple social identities alternative to that of 'intellectually disabled', in and according to interaction. By demonstrating

thorough understanding it is clear that not dominantly identifying themselves as intellectually disabled is not a mechanism of denial as some researchers and professionals may believe, but a choice in response to an understanding of society's negative perceptions of intellectual disability; to use a quote from Will, "Disabled means I can't do things [but I can] so I hate that word".

This project featured the voices of individuals willing and able to express their feelings in detail, but it may be that young people with less verbal ability unable to contest the identifiers projected by society are much more likely to be at risk from low-self esteem, high anxiety and challenging behaviour. It is of paramount importance that all young people are encouraged to express their identity within various social contexts and use multiple identifiers relevant to them; limited opportunity and ability for communication and outlet for expression can leave individuals at greater risk of mental and emotional health problems.

*All names used are pseudonyms selected by the participants themselves.



A Different Approach

to Learning to Play the Piano and other Instruments

By Vicki Horner, DSA parent member

In 1990, my second daughter Charlotte was born with Down's syndrome. My daughter Emily, who is two years older than Charlotte, started piano lessons when she was eight years old. I found myself pondering over the possibilities of Charlotte being taught to play.... and if so how?



As it turned out, when Charlotte was about 14, we were really lucky to have a leading light in the music field living nearby – Maxwell Steer became Charlotte's teacher.

He was very flexible and followed Charlotte's interest in the songs from the song bank on her keyboard. Charlotte followed the keys that lit up on the keyboard to demonstrate the notes from the tunes in the song bank. Maxwell would help Charlotte get the best from each piece by following the notes with her right hand.

Charlotte loved going and was happy with the idea that she was 'playing the piano.' I was pleased to see that she was enjoying something other than her school work. (At this age her social life was almost non-existent).

As part of his teaching philosophy Maxwell expected all of his students to perform at a small twice yearly concert he organised in a local school, for parents, siblings and friends. This builds confidence and self-esteem and is also a great opportunity to raise money for the music charity Cherubim.

Charlotte was also expected to participate. Her first piece was Jingle Bells, obviously supported by the song bank. She played with confidence and her efforts were appreciated by the audience, and of course, I was a very proud mother!

Teaching Method

Maxwell has taught many young students who initially struggled to read music. Because of this he developed his system of colour representations for the notes to allow early access to this initial complexity.

Charlotte was given a cardboard strip which we placed appropriately behind the keyboard. (See photo).



Maxwell also printed out the music sheet for each piece Charlotte had chosen from the song bank. Although the coloured key strip was useful, it was clear that she seldom read the music on the sheet as she was busy searching for the lighted keys.

Another aspect Maxwell worked on was using the correct fingers. Writing the numbers one to five on each finger of her right hand, and corresponding numbers above the notes, seemed to help. After a while he stopped producing the music sheets which seemed to be of little benefit. Limited progress was made. Even so, Charlotte was still motivated to play so I did not want to stop the lessons. I think we all finally came to the conclusion that if she was to progress further, she had to learn to read and play simple pieces with both hands.

The breakthrough came when Maxwell gave us a copy of his first book – *ColourMuse* – a compilation of pieces, many of which his students (past and present) had composed, produced with coloured noteheads. He has also included some lovely characters to help introduce new notes. Very child friendly!

Extra Support

From this point Charlotte began to really read music. She looked at the music (written in colour), then down to the cardboard strip behind the keys (more colour) and finally at the set of coloured stickers I pasted onto the keys themselves (more colour).



This provided continuous visual support from the music sheet right to her fingertips.

It also, for the most part, hid the lights, which proved to be not a bad thing and called for more concentration!

Charlotte learned to play small pieces with her left hand; right hand; and then both together. Relatively speaking, this was real progress. At the next concert my daughter read and played her first two handed 'bitty piece' on the piano! Followed by a blast of Camp Down Races on her keyboard aided by the song bank.

Lessons

During the lessons Charlotte now uses the piano and works on the

current piece in *ColourMuse*, always finishing with a belting performance on her keyboard – currently, Star Wars... (Which also amazes me, even with all the backing that the song bank provides, I think it's marvellous).

I can see progress in the way her fingers stretch and move across the keys, increased memory, the seriousness in which she tackles the piece and the enjoyment she gets as she and Maxwell work on her current piece together!

As I look back to the time of Charlotte's birth, I am reminded of the road we have travelled together, and the obstacles for which we have managed to find solutions.

Coming this far with the piano has been an idea that we have turned into a reality. Yes, it is safe to say that Charlotte will not be the next Mozart, nor do we know how far she will progress. But nobody can deny that progress is being made. Situations like this serve to remind me of attitudes and phrases of old such as –

“She won't be able to do this”

or *“Because she has Down's syndrome you should expect that this will be all she will do*” Or still more dreadful *“She will platform out at*”

(Implication being that no further development will take place!) and I smile.....

As parents, aren't we constantly trying to expose our children to many situations and create opportunities that will encourage interest and development? I made sure this ideal was equally applicable to my Charlotte when she was born with her disability.

Since her birth I have tried to live by this principle so when faced with a door that is firmly closed, I sincerely believe that to open it all one has to do is search until one finds the right key.

For more information about Maxwell Steer's teaching methods, visit <http://msteer.co.uk>

Vikki can be contacted on vikki.horner@mathsextra.com or 01747 861503

Child

of mine

Tessa Duffy, mother of Kieran and Director of Symbol UK, shares her personal experiences of having a child with Down's syndrome



All through the seven months of knowing, a vignette played over and over in the depths of my mind, over and over, again and again; causing no heartache and no need for panic. A prediction, albeit unknown, a preparation for what was to come.

He came quietly, the tension of the moment turning quickly to breath-holding expectation. All was still and yet everyone was moving fast; deliberate, focused efficiency, putting into action a polished plan

much rehearsed and seldom needed. Slowly it all became clear, as all eyes focused on the bundle of towelling that held my child in its arms, as if the strength of those stares could change the future and with a knowing of my own rehearsal, my life began again.

Briefly, I held him in my arms and he looked into my eyes, those almond eyes that glistened and cracked with the glare of the lights. Just as soon he was gone and my empty arms were held

by two warm, large hands which spoke the words I knew so well; 'we're worried about baby'.

'Kieran' I said, 'his name is Kieran', not Declan as planned, not now, not 'Declan the Down's'. In the quiet of the room, a voice I knew to be mine spoke of its own accord, 'You think he has Down's syndrome don't you'?

As I spoke I wondered where those words were from and just as soon I

knew that they were from my soul, the soul that had been practising that telling. No surprise, no shock just sorrow which was quickly pushed far, far away.

My son would be loved; as if by order of the mother I was yet to be. I needed to love him right from the very start and in those first moments of life I determined that this would soon be so, and I would never, ever be able to relive these moments, when love was undecided.

Later, as I lay in the bath the shaking started and for a moment I thought it wouldn't stop. My heart started to break into tiny pieces and the tears hot and fierce, fell, and fell, and fell. Those arms again, holding me as I grieved and shook and despaired. The panic, not ever a feature of the rehearsal, came swiftly and deeply and along with it came shock and resentment. At only hours into our life together, my fear was that he would never leave us.

What would happen to our plan? A plan which had never been articulated, that one day we would be done with child rearing and our lives would come back to us and be ours alone. I knew, rather than felt, this to be selfish, and I felt I was already changed.

Then the telling and desperate persuading of others that this was fine; it was okay, he was ours and he was lovely, no one dared to say

otherwise or show any regret. To do so was a betrayal I felt, but could not allow in others. To give it a voice gave it a life it must not have. I searched my memory for my seven months of preparation but however hard I searched, my rehearsal had not included 'after', I had no script prepared for this part of the story.

Later still, as I held my son in my arms replete with the trappings of this new life, I tried to listen carefully to the words coming at me, I heard and tried to understand, soon realising that the two were incompatible. It seemed that this small boy belonged to many, all of whom it appeared had a view. I couldn't look away from his face, the world around was just too full of stimulation I couldn't manage.

I was told that we were especially chosen, 'God only gives these special children to those who can cope... he'll be very loving... you'll soon learn to accept...'

I had an uncontrollable urge to growl, to clutch my baby, gather him up and slink away to my lair where I could lick him and cover him with my body. Instead a voice I recognised from before said thank you and nodded encouragingly lest the professionals abandoned us before our liaison even began.

I held on tight and soon realised I was holding tight to my son, my boy who had his mum. I dressed him in blue, I touched his pale, pale face

and blond, blond hair. His eyes opened and met mine, his tiny fingers entwined my fingers, he suckled and snuggled. His soft, rag doll little body moulded around my heart and slowly, slowly it swelled, piecing together again, mending like a shattered mosaic in rewind. I became breathless as my longing for my son came to rest in the precious face of this little boy.

My panic receded and was replaced by a longing, a longing for the future I wanted this precious boy to have, a future that would be his with all the love and power my knowing soul could bring to him. My fear that he would never leave us, was replaced with a new fear; a fear that he would one day want to leave and that thought made my heart bleed anew. He was the future and that future had arrived and with it a love almost unbearable in its passion.

Did I ever 'accept' as the years of his childhood have passed? No, I have not ever accepted that anything for Kieran needed to be less, never accepted the pain of his struggles or the hurt of certain exclusion whatever my efforts. Accept? No. Adapt? Yes. Adjust? Yes. Move over, accommodate but not compromise. He is love, he is joy and he is every golden moment of laughter and meaning. In those early moments of life I held the faith, he did the rest. Kieran is the only boy he could ever have been and for that, I will thank him for always.

Reviews

Book Review: *Understanding Down Syndrome* by Cliff Cunningham

Reviewed by **Stuart Mills,**
DSA Information Officer
ISBN 0285636979 Souvenir Press

Already established as the author of the definitive standard work for parents of children with Down's syndrome, this edition is fully revised for the third time. This work is informed by Cliff Cunningham's many years of involvement with a study of over 160 children born with Down's syndrome whose progress he has charted into adulthood. This is the largest survey of its type ever carried out.

This work is full of useful positive, factual and practical information for parents at the outset of their journey. For me, the most important aspect of this work is that its approach is sympathetic and

understanding when considering the early reactions and feelings that parents may have and how the family adapt and cope when a child is diagnosed. Cliff Cunningham never loses the human touch whilst presenting factual information. The work covers all of the initial questions that parents may ask about the causes, characteristics and diagnosis of Down's syndrome whilst also looking at future issues such as working with professionals and local services.

Cliff Cunningham is very much an advocate of the 'cafeteria approach' to information: laying the information out so that parents can choose what they wish to read. The information in this work is laid out in such a way that parents can easily find what is appropriate to them whilst avoiding information that

they may not feel ready to deal with.

In conclusion, Cliff Cunningham challenges us to question society's values towards people with disabilities and to question society's views concerning achievement and individual value.

Cliff Cunningham has been a Senior lecturer at the Hester Adrian Research Centre, University of Manchester and is currently a Visiting Professor of Applied Psychology at Liverpool's John Moores University. He is a respected international figure on the subject and was a member of the Scientific Research and Advisory Committees on both the European and the UK Down's Syndrome Associations, and is a frequent lecturer at international conferences on disability.

Book Review: *For Pete's Sake* by Yvonne Crabtree

Petan Publishing
ISBN 0-9553418-7-6
ISBN 978 -9553418-7-8

Mother Yvonne Crabtree says:

"My son, Peter, who has Down's syndrome, was born in 1979, when my husband and I were living in the United Arab Emirates.

Fairly early on, we realised that Peter was very different from the other children who we met through various playgroups, societies and schools and wondered if he had another condition, apart from the Down's syndrome. It was a very long time before we were able to obtain the correct diagnosis.

Despite his many problems, Pete is a bright boy, with a good command of language and a very cheeky sense of humour! We have always had lots of stories to relate about him and many of our acquaintances have suggested that I should put these stories into a book.

Having decided that I might do this, I contacted family and friends to ask for their memories of Pete – and was flabbergasted by the response! I had no choice then but to get on with writing the book.

My original intention was just to produce a collection of anecdotes but my editor strongly advised the need for a more balanced book – to show the other side of Pete's nature and to give a glimpse

of what life has been like for all of us. As I wrote on the back cover, it really has been a rollercoaster of a ride, but one that I honestly would not have missed."

Price £7.99, with a discount for two or more copies

To reserve a copy, please phone 01729 851806 or email: yvonne.l.crabtree@btinternet.com

All profits to the trust fund of the John Gaffney Home, Bradford.



Book Review: *Hands On Guides*

The Hands On Guides are a series of books for Early Years Professionals, which give practical advice about teaching young pupils with special needs. There are three books in the series, all written by two London Area SENCOs:

A Practical Guide to Pre School Inclusion

(ISBN: 9781412929356)

Includes:

- Advice on inclusive environments, play and planning to meet individual needs in early years settings
- Coverage of current legislation and what it means for the pre-school practitioner
- Quick-reference materials for planning and auditing early years settings
- CD-ROM with templates that can be customised to fit the readers needs



Working with Parents of Children with Special Educational Needs

(ISBN: 9781412945226)

Includes:

- Advice on working together with parents to improve the child's learning
- Strategies for communicating effectively with parents
- Help for the pre-school SENCO, showing how they can lead the process
- Tips for building successful links with other related professionals
- CD-ROM with checklists and photocopiable material



Developing Pre School Communication and Language

(ISBN: 9781412945240)

Includes:

- Advice on how to support language development in all children, including those with SEN
- Practical ideas for practitioners and parents
- Guidance on when to seek advice and working with other professionals
- Activities and case studies
- A CD-ROM with useful photocopiable resources



Published by Paul Chapman Publishing
www.paulchapmanpublishing.co.uk

Bulletin



The Blue Elephant Series

POPS Resources have just launched the next series in the POPS Reading Programme – The Blue Elephant Series.

The POPS programme is now used successfully in over 1000 schools supporting pupils with Down's syndrome, autism, communication difficulties and pupils on Reading Recovery programmes. The Blue Elephant Series of 16 books builds on the success of the Red Elephant Series, providing entertaining stories whilst moving the reader forward in small easy steps.

Over 85% of the words introduced in the Red Elephant Series are reused in the Blue Elephant Series, in differing contexts, to revise key vocabulary and consolidate progress made. A Speech Therapist script is included in each book of the Blue Elephant Series to guide you in using the book to develop a child's communication skills. Also included is a comprehensive

new section in our teaching manual on how to use the programme to improve a child's communication skills. The manual is free and can be downloaded from our website.

Some requests were made for social stories to help with issues such as behaviour. The Blue Elephant Series includes storylines on issues commonly experienced by children with additional support needs, such as Kal's frustration at not getting a turn to talk and being on his best behaviour when it is Mrs Pearce, his special helper's, birthday.

Games in each book

The use of simple games in the Red Elephant Series has been very successful in engaging children's interest. The Blue Elephant Series books have 6 pages of games including 'The Lotto Game', 'Find the Word Game', and the 'Word and Picture Match Game' to develop comprehension skills.



Word Cards

Word Cards are an important feature of the programme and support key vocabulary in every book. Also included in the Blue Elephant Series is a Sentence Building Set with starter words, joining words and grammatical markers carefully chosen so that a child can easily build simple sentences relating to each story.

For more details and to order please visit our website www.popsresources.co.uk



"The Child King" DVD

"The Child King", a holiday feature motion picture starring Peter Johnson, a teenage actor born with Down's syndrome, has been released on DVD. The movie will be sold exclusively via the Internet at www.thechildking.com

"The Child King" tells the story of Jeremy West (Johnson) who takes his skeptical younger brother, Jarret, on a magical journey to the North Pole to prove Santa Claus is real.

In the course of their magical adventure,

the brothers encounter a host of colourful characters – none more fascinating than a large man with a snow-white beard who mysteriously appears in various guises, offering the boys a guiding hand on their way North.

All producers' profits from DVD sales are being donated to the non-profit Child King Foundation. The foundation administers funds and disburses grants to organisations, charities and individuals that assist those with intellectual disabilities.



For more information visit www.thechildking.com or www.childkingfoundation.org



French Experience Holidays

Bonjour mes amis!

We had our first guest in June of this year and we enjoyed their company immensely. Here are some of the comments they made. *"The hospitality and kindness made our holiday a truly memorable French experience which we would recommend".*

Bread making –

"This is great fun! If we carry on at this rate we'll be able to open our own Boulangerie!"

We also had a fun afternoon chocolate making in Angouleme and got to take the chocolates home

"The chocolate was delicious; it didn't last

long at home"

If anyone out there is thinking of a holiday for 2008 then why not visit our website www.frenchexperienceholidays.com and see what we have to offer or contact us by e-mail on veronica.mechan@frenchexperienceholidays.com



NDCS Conference

Does your child with Down's syndrome have a hearing impairment? If so read on:

The Down's Syndrome Association is working in collaboration with the National Deaf Children's Society (NDCS) to facilitate a residential weekend conference for families of children with Down's syndrome who also have a significant hearing impairment. This

is aimed at families of children aged 10 and under. The free event has a limited number of places (families are invited to attend with siblings and possibly grandparents too, if so wished).

The conference will take place in London on the weekend of 29th – 30th March 2008. Speakers at the event include hearing

specialist Dr Patrick Sheehan and a representative from Tessa Duffy's team at Symbol (on language and communication development).

To register your interest please contact Julian Hallett, Operations Director on 0292 052 2511 or email julian.hallett@downs-syndrome.org.uk



Christmas Card Competition

Design your own Christmas card and see your card on the mantle pieces of your friends and family next year!

We want lots of lovely Christmas card designs for next year's Christmas card competition. If your card is chosen it will be made into our DSA design for Christmas 2008!!

Please send all designs along with your name, age and address to:

Alexa Dizon, Down's Syndrome Association, Langdon Down Centre, 2a Langdon Park, Teddington, TW11 9PS.

Please note that original artwork cannot be returned.





Caravan Holiday

The Ayrshire Branch of Down's Syndrome Scotland would like to offer you the opportunity of an affordable holiday in our luxury caravan in Haggerston Castle Holiday Park, near Berwick-upon-Tweed.

- Mini supermarket
- Restaurant and take away
- Kids clubs
- Kids Play Area
- Tennis Courts
- Bowling Green
- Football
- Evening entertainment

The six berth centrally heated caravan has three bedrooms and comes fully equipped with a TV/Video, fridge, microwave, hairdryer, iron and many more extras to make your holiday comfortable and stress free, with ramp access. It is strictly no smoking or pets allowed. It is situated in a quiet area with a short walk from all the park attractions. Holidays are offered for a week's break from Friday to Friday. The cost is inclusive of gas, electricity and entertainment passes.

And there are great new activities on offer at the SportsZone. You can discover how to shoot a bow and arrow like Robin Hood and fence like James Bond!

There is also a lot to see and do off the park too. You can visit Holy Island with its Castle and Priory, relax in the tranquil Hamlet of Bamburgh Castle and beach, as well as venturing to Alnwick Castle used as a backdrop in films and known to Harry Potter fans as Hogwarts school! These are all within a short drive away. Berwick Holiday Park also offers great access to the historic Hadrians Wall that extends to 73 miles of Roman fortification.

Season from March to October, 2008

Cost per week:	Peak	Off-Peak
	£260	£200

Peak season is May to September.

The caravan is situated close to Haggerston Castle's well-maintained 9-hole golf course, which has its own café with golf equipment for hire.

Haggerston Castle is in a beautifully landscaped, spacious country park with its own boating lake and golf course.

It also has:

- Luxury spa
- Indoor and outdoor heated swimming pools
- Bike Hire



There is a damage deposit of £25 refunded at the end of your stay, providing no damage is incurred. A non-refundable deposit of £50 is also required upon booking.

Priority booking has been given to Ayrshire members of Down's Syndrome Scotland who are able to book from the end of the previous season.

General booking for 2008 from all other organisations starts in January. Early booking is always recommended.

Bookings and enquiries to Simon Jenkinson, Tel: 01563 571 577, Mob: 07775 621 558



Our Vote our Voice

The organisation 'Outside the Box' have just launched an online election pack for people with learning difficulties called 'Our Vote, Our Voice'. It is a peer training pack designed in partnership with people who have learning difficulties.

The pack includes:

- Information about having your voice heard, making choices, finding out who is in charge and taking part in elections
- A list of useful contacts
- Ideas other people and groups have tried

- A glossary of difficult words

You can download a free copy of the pack at: www.otbds.org/vote/ourvoteourvoice
You can also order a hard copy free pack and the DVD by emailing peervote@otbds.org



Holidays for people with disabilities

Having worked in the UK for 26 years in the field of supporting people with a wide variety of disabilities, I found it almost impossible to find decent holiday accommodation abroad for people who were unable to leave their wheelchairs unassisted. Hence I have recently opened a holiday apartment in Andalucia, Southern Spain in the beautiful natural park on the edge of the Ardarles Lakes.

It is specifically though not exclusively designed to cater for individuals with disabilities and although the apartment is equipped to accommodate people with physical disabilities, we are also well equipped to accommodate people with any degree of learning difficulty. I am confident our accommodation is ideal for people who may wish to travel independently as well as those who may travel with companions or support.

The apartment comfortably sleeps 4 people, but we are happy to accommodate larger

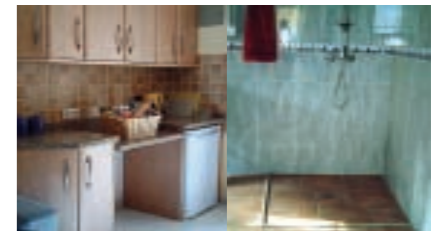
families if needed. It is fully equipped with a hydraulic bed with pressure relieving mattress, manual hoist, shower chair, and both foldaway and fixed handrails at the toilet and a wheel in shower. The kitchen is wheelchair friendly with ample floor and cupboard space and lowered worktop for wheelchair access.

Guests have full use of the pool in season, which is accessed via a pool hoist.

We are also able to arrange a wide range of accessible activities for guests, including quad biking, horse riding, archery, painting, fishing, off-roading, and possibly abseiling.

A fully wheelchair adapted minibus is provided for airport transfers (included in the price) and is also available for either self-drive or with a driver.

As a UK qualified nurse with an NVQ4 in care management, and an ex staff trainer, we are also able to offer our guests excellent



support packages as well with a choice of self-catering to full board provision. Activity packages can also be arranged.

We are less than 1 hour from Malaga airport and the Costa Del Sol, which provides theme parks, a zoo, and animal and dolphin parks where you can have your photo taken with dolphins or swim with a seal. There are also wheelchair accessible dolphin and whale sight seeing trips available from the coast.

For more information or enquiries please email enquiries@casa-del-lago-holidays.com or visit www.casa-del-lago-holidays.com



AmnioDex: Helping Women Decide About Amniocentesis Testing

Cardiff University in collaboration with Antenatal Screening Wales are conducting a research around developing a website to support women and their partners when they are offered amniocentesis.

The aim of the research is to examine their information and support needs when faced with this difficult decision and to develop a website that will address their needs. If you have been offered amniocentesis (whether you chose to undertake the test

or not), and would be willing to take part in a 30 minute research interview, please contact us:

Research officer:
Marie-Anne Durand
Department of Primary Care and Public Health, Cardiff University, Heath Park, Cardiff, CF14 4YS
Tel: 029 20 68 71 35
Fax: 029 20 68 72 19
DurandM@cardiff.ac.uk



Professor Glyn Elwyn
elwyn@cardiff.ac.uk

You can also visit our website:
www.informedhealthchoice.com




Be part of: Shifting Perspectives 2008 Photographic Exhibition

Richard Bailey is looking for children, teenagers and adults with Down's syndrome to photograph for the Shifting Perspectives Photo Exhibition and Calendar for 2008/2009

This year his focus is to cover:
Culture – Religion – Nationality

Richard would like to capture the many aspects of living successfully with Down's syndrome and for many people culture, religion and a strong feeling of nationality form a fundamental part of that person. If you hold religious or cultural beliefs that are different from 'mainstream' Britain or are from a different country, please get in touch.

Please contact Richard Bailey on 07956 971 520 or Xanthe Breen at the National Office on 0845 230 0372 or email xanthebreen@downs-syndrome.org.uk if you would be interested in taking part. Photos will need to be taken before mid-April.

www.justsamuel.co.uk

Our beautiful little boy Samuel was born nearly a year ago with Down's syndrome.

Over this time we have built a website devoted to him showing his progress and our experiences.

The site originally was intended as a family site but developed into Samuel's very own site.

We hope it will be a useful resource for other families maybe who have just been

told they are having a child with Down's syndrome and also to make people see children with Down's syndrome in a different light.

The site will be a continuously developing record of Samuel's progress allowing people to see just how our little boy does and the things he achieves.

I hope you will keep a regular eye on our site for updates.

Please visit: www.justsamuel.co.uk




Keeping One Step Ahead

'Keeping One Step Ahead' is a booklet produced by Down's Syndrome Wirral, which aims to bring together lots of information about keeping your child safe, both in the home and when out and about.

The author, Jeanette Appleton, has over 20 years experience of working with children and their families as an Occupational Therapist. She aims to arm parents with the information to keep them one step ahead of their child and anticipate dangers or particular problems.

Topics include clothing and incontinence, walking reins, car safety, fireguards, bathroom & kitchen safety, stairs, and more...

For more information contact downssyndrome@wirral.uk.net or call 0151 625 8406



love2read

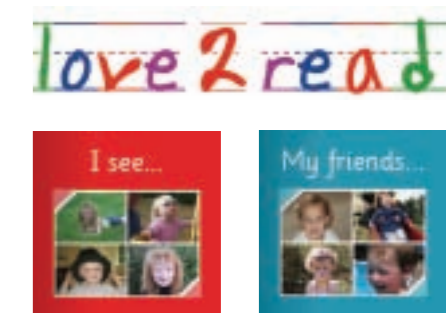
love2read's innovative website enables its customers to upload digital photos into specially designed book templates and add a personalised caption. Then the resulting book is professionally printed and delivered within a few days.

As people with Down's syndrome tend to have strong visual memories the books will be particularly helpful, as they combine important key words with

pictures of familiar images which plays to their strengths.

£2 per book goes to the DSA when you quote reference DSADONATION on the checkout page.

For further information or to order your own book visit www.love2read.co.uk
For any other enquiries contact caroline@love2read.co.uk




Safe & Sound First Aid Training

Safe & Sound are a first aid company that provides both in house and scheduled first aid training.

We currently work with private companies, the government agency SureStart, doctor and dental practices, schools and nurseries,

and the general public. Our trainers are all medical professionals, working primarily in accident and emergency departments.

Their experience means that they can confidently respond to questions that may arise during training.

We have scheduled courses in venues across London and are happy to run courses in private homes.

For more information please call Roma Felstein on 0208 449 8722 or visit our website www.safeandsound.uk.net

Current research

Memory research



We are looking for children and adults with Down's syndrome to be involved in our memory research conducted at the Institute of Psychiatry in London.

Some people with Down's syndrome develop memory problems later in life and this research will help us to have a better understanding of why it happens and what can be done about it. The studies involve attending our research centre in London for a brain scan and doing some puzzles and tests. One of the studies may also involve taking some tablets.

Travel expenses will be refunded and participants will be reimbursed for their time.

Visual development

For many years, our team at Cardiff University have been monitoring visual development in children with Down's syndrome. One of our important findings is that spectacles are needed more often amongst children with Down's syndrome compared to their typically developing peers. This can be for long-sight or short-sight and is mainly due to a failure in the natural eye development process after the age of 2.

Several other studies have shown that, for a typically developing child, the likelihood of long or short sight that requires spectacles, is influenced by the sight of his/her parents. In other words, there is a higher chance of the child developing short sight when parents are also short-sighted. Although there is much less evidence about the inheritance of long-sight, some studies support the idea that this, too, runs in families. These relationships have never been investigated in children with Down's syndrome, so the next step of our study is to

Research project thank you:

Dear Parents,

I am pleased to inform you that I've successfully completed the research study, which I began in 2002 and wish to say a big thank you for your invaluable contribution.

The report is available at the University of London library (Institute of Education). The title of the study is 'The 'Invisibility' of the Potential Child with Down Syndrome within the National Antenatal Screening

If you would like to take part, or would like any further information about the research studies, please contact Germaine Fung or Dr Giles Tan at:

Section of Brain Maturation, PO Box 50, Division of Psychological Medicine & Psychiatry, Institute of Psychiatry, De Crespigny Park, London SE5 8AF.

Tel: 0207 848 0984 Fax: 0207 848 0650
Email: Germaine.Fung@iop.kcl.ac.uk or Giles.Tan@iop.kcl.ac.uk

Institute of Psychiatry at the Maudsley

(REC reference numbers: 1997/076 and 2005/125)

determine whether the same relationships exist.

We need quite a few families to take part in order to work out this relationship and are hoping that as many people as possible will volunteer. We need to recruit families (minimum one child and one parent) with a child with Down's syndrome aged 5 years or older, whether the child or parents wear glasses or not. All you need to do is that you fill in a simple questionnaire and sign a consent form that will then allow us to obtain the results of your latest eye test from your local optometrist/optician. Please contact us as soon as possible by post or email to get your questionnaire.

Mohammad Al-Bagdady and Maggie Woodhouse
School of Optometry and Vision Sciences, Cardiff University, Maindy Road, Cathays, Cardiff CF24 4LU.
Al-BagdadyM@Cardiff.ac.uk

Programme: An Ethical Issue for Health Educators and Practitioners'

I am continuing this work through future publications that will help in raising greater awareness of the true impact of the law, public health policy and practice on private lives.

Dr Roja Sooben, Senior Lecturer in Learning Disability Nursing, School of Nursing & Midwifery, University of Hertfordshire
01707 285140 r.d.sooben@herts.ac.uk

People with learning disabilities and sex education

'Sexuality is often the source of our deepest oppression; it is also often the source of our deepest pain. It's easier for us to talk about – and formulate strategies for changing – discrimination in employment, education, and housing than to talk about our exclusion from sexuality and reproduction' (Finger, 1992: 9).

This quote comes from a disabled person. It suggests that, for people with impairments, sex and relationships are an area of their lives in which they experience discrimination. There are many negative assumptions made about the ability of disabled people to have sex and to be in fulfilling relationships.

For people with learning disabilities it can be even harder. Historically, people with learning disabilities have been seen as 'eternal children' and therefore not expected to have relationships or be sexually active (McCarthy, 1999). People with learning disabilities are also seen as 'vulnerable' and at risk of being abused. The eugenics movement argued that the procreation of people with learning disabilities should be discouraged to prevent their 'defective' genetic material being passed on and endangering the human race. Furthermore, at the present time in the UK, if people with learning disabilities do become parents, it is likely that they will have their children taken away. With all these negative stereotypes and judgements, what chance do people with learning disabilities have for relationships and fulfilling sex lives?

One national rights-based organisation is leading the way to try and find this out. CHANGE, an organisation that campaigns for the rights of people with learning disabilities, is working in partnership with the Centre for Disability Studies at Leeds University to undertake a 3 year ground-breaking research project to find out from young people with learning disabilities what their knowledge, hopes and dreams are in relation to sexuality and personal relationships.

The project came about when CHANGE found that many people with learning disabilities said they were never told about sex and relationships. People with learning disabilities said that if they had learned more about sex and relationships when they were younger they might have made different choices as adults. The professionals with whom CHANGE has contact also said that sexuality and relationships were a priority area to be developed due to increasing inclusion within all areas of life. This led CHANGE to put in a bid to carry out research about sex and relationships for people with learning disabilities.

They were successful and the research project started in January 2007. It includes the following aspects:

- A series of drama workshops with young people age 16-25 over a period of 18 months to find out their experiences and views.
- A national survey of special schools and colleges to find out what is taught in relation to sex and relationships education and what difficulties schools have in teaching it.
- Interviews with 20 parents of people with a learning disability to get their views.
- Focus groups with teachers to discuss some of the wider issues that come out of the survey.

If sexuality and relationships is an area in which people with learning disabilities have been excluded, then the importance of this study cannot be underestimated. It is an innovative, large-scale piece of research that hopefully will have implications for changing attitudes and ways of working with people with learning disabilities and will contribute to making relationships and sexuality a positive experience for them.

We are particularly interested in hearing from parents of young people with learning disabilities in the Leeds area, who would be willing to be interviewed about their views and experiences about sex and relationships in relation to their son/ daughter.

For further information about this research, please contact the Sexuality Team at CHANGE on 0113 2430202, E-mail: info@change-people.co.uk, or visit www.changepeople.co.uk

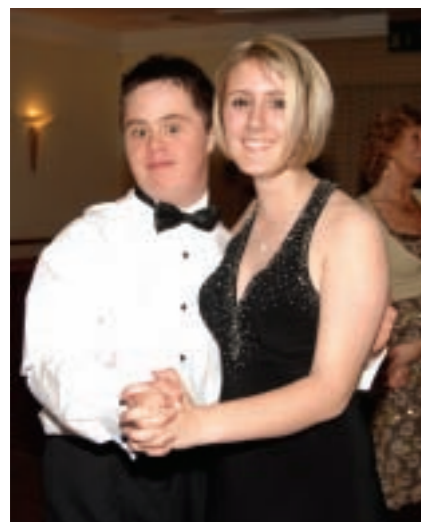
References

- Finger, A. (1992) Forbidden Fruit, *New Internationalist*, 233: 8-10.
- MacCarthy, M. (1999) *Sexuality and Women with Learning Disabilities*, Jessica Kingsley Publishers.

South East Wales Down's Syndrome Support Group

Our First-Ever Wales 'Summer Ball'

Mike Pickard, Chair of South East Wales Down's Syndrome Support Group, tells us about their fantastic fundraising event...



Almost 200 people attended our first-ever South East Wales Down's Syndrome Support Group 'Summer Ball' held at the Village Hotel in Cardiff on May 11th 2007. The event was the 'brainchild' of one of our parent-members, Angela Taylor who, supported by husband John, spent over a year pulling together the plans for what turned out to be a fantastic evening, enjoyed by everyone who attended.

We were delighted to have new patron of the DSA, former boxer and now Sky commentator, Nicky Piper, as our special guest. Nicky assisted in the Charity Auction, which had been

organised by Sara Pickard who is 23 and has Down's syndrome. Sara, who is a Trustee and Committee member of the group, wrote to a variety of sporting personalities to ask them to donate items to be auctioned at the Ball.



As a result, she received, amongst other things, a signed All Blacks shirt from New Zealand rugby coach Graham Henry, a signed Wales football from Wales coach John Toshack, a signed Wales rugby shirt presented by Wales rugby coach Gareth Jenkins, a signed glove from world champion boxer Joe Calzaghe and another boxing glove signed by Sugar Ray Leonard, as well as Welsh world Champions Joe Calzaghe and Enzo Maccaranelli, donated by Nicky Piper. From the proceeds of the auction and the raffle held at the Ball, our Committee decided

to donate £2000 for the work of the DSA nationally and we will be using the remaining funds raised to support the work of our support group locally, including supporting a 'Family Day Out' to Longleat in September for up to 100 children and young people with DS and their families, and we are planning to organise a conference for our members too.

So popular was the event that we are already in the process of planning a 'Black Tie/Posh Frock Cabaret Evening' for May 2008 and we hope to hold another Summer Ball in 2009!

Thanks to everyone who supported the event and helped in any way to make it such a brilliant night – we hope to have many more events like it in the future.



Peterborough Group celebrate 10 years

The Peterborough Area Down Syndrome Group has recently celebrated its first 10 years at Burghley House.



Group members in the garden of surprises during the celebrations....

The group started 10 years ago meeting at Peterborough Maternity Unit with a handful of parents wanting to meet each other. It has now grown to have over 60 members serving the Peterborough, Stamford, Bourne, Deeping, Wisbech and Huntingdon areas.

"I found it an enriching and emotional day for varying reasons, but felt very satisfied that for 'new parents' now, there is a thriving support group along side them and we should all be proud to have achieved this".

The group became a charity in its own right in 2003 with help from the Down's Syndrome Association and took the name Peterborough Area Down Syndrome Group. It is a parent-led group which raises money for various social events throughout the year - so far they have enjoyed a visit to Center Parcs, a bowling night, trips to see Grease in London, Disney on Ice and numerous other events. It also helps provide subsidised speech and language therapy for children with Down's syndrome.

The celebrations were held at Burghley with kind permission of Miranda Rock (who has just taken over Directorship from

her mother Lady Victoria Leatham), who's own son Cosmo has Down's syndrome. Miranda has also accepted an invitation from the group to be their Patron which is another measure of how far the group has come.

The trustees of the group worked very hard and relentlessly to make sure that the day was a resounding success. All group members and families, teaching staff, companies and individuals who offered support and financial help through the years and the Mayors of Peterborough, Stamford and Deeping were invited, and well over 250 people attended.

"We wanted to do something to thank everyone for all their help and support over the years,"

The day started with the families having fun in the garden of surprises, which is an interactive garden area where everybody can get wet by playing in the water fountains. This was followed by lunch and a children's entertainer before the speeches and the cutting of the cake.

A website has been set up to allow easier access for all.
www.peterboroughareadownsyndrome.co.uk

Here's to another 10 years and beyond!



Dear DSA...

Dear DSA,



I just wanted to write and tell you about my son Matthew and share some of the lovely photos we have of him and his sister together. He has brought so much joy into our lives we wouldn't change him one little bit.

Just over a year ago I gave birth (5 weeks early) to our son. He was delivered early because there were concerns about him not gaining enough weight along with numerous problems I was having carrying him at the time.

On 7th July 2006 my husband had our darling son in his arms whilst I was put back together! Everything looked fine to start with, we were taken to the recovery room where Matthew struggled to feed, at around 2pm it was suggested that he might have to go into special care for a short while to tube feed him and get his temperature up.

My husband, Nick, left to go and pick up my 14 year old daughter from school and bring her in to see her new baby brother. It was at this time that a consultant came to see Matthew, checked him over and said

that the nurse had some concerns that he may have Down's syndrome. He could take some blood now and get the results on Monday, or wait until Monday to have a blood test. I said I'd rather wait, I suppose I thought that it would all go away and my husband and daughter would never have to know, because looking at my son I knew there was no way he had Down's syndrome, he was just too gorgeous.

Matthew was taken into special care at 3pm. He was given a tube to feed from and was put in a temperature controlled cot to get it back to normal.

When my husband arrived back with my daughter we had to wait half an hour to see him. Christina couldn't wait and luckily no one had noticed how worried I had become since Nick left.

We stayed with Matthew until around 7.30pm and then had to leave so I could get back to the ward. I had just got into bed when two consultants appeared around the curtain. I knew what they were going to say, I just wanted to stop them as I didn't want my daughter to find out her brother may have Down's syndrome in this way. But it was too late, they came out and told us their suspicions in front of everyone. I think we all cried and acted like it didn't matter.

I knew Nick would be all right, he was my tower of strength when all I could feel was that my world had ended. It was Christina I was worried about; I didn't want her to reject him because of what her friends might think or her being embarrassed by his condition.

We all spent hours with him in special care and he was diagnosed with heart problems ASD & PDA and although worrying we were told it could have been a lot worse.

Matthew stayed in special care for one and a half weeks. His sister had gone away on holiday with a friend for the last

few days of his stay in special care, so we took him to meet her at the airport.

All my fears melted away when she rushed over and held him so tight with the love there for everyone to see. They have such a special bond, she proudly tells her friends about Matthew, and I need never have worried.

Matthew has shown us that Down's syndrome is not the end of the world, as I had first thought. Everywhere we go people stop to say hello or hold his hand.

Our family and friends have been so accepting and understanding from the moment we told them. I can't remember one person being sad or upset for us.



Matthew was sitting unsupported at 6 months, he can wave hello and goodbye, play peekaboo, say cat when he sees the cat and clap when we tell him he's a clever boy. Everyday we tell him how much we love him and thank our lucky stars that he's our very special Matthew.

Yours faithfully,
Caron Kettlewell

Dear DSA,

I am a student at Amersham & Wycombe college and I am currently studying National Diploma Photography.

My brother has Down's syndrome and he is 21. We also have many people with learning disabilities in my college, taking home economics and learning life skills.

I feel very strongly about raising awareness of Down's syndrome, and I would also like some of my photography to be published, so I have sent you some photos of my brother that I took, inspired by the DSA's work.

Yours sincerely,
Louise Haslam



Dear DSA,

I wanted to share our story with everyone...

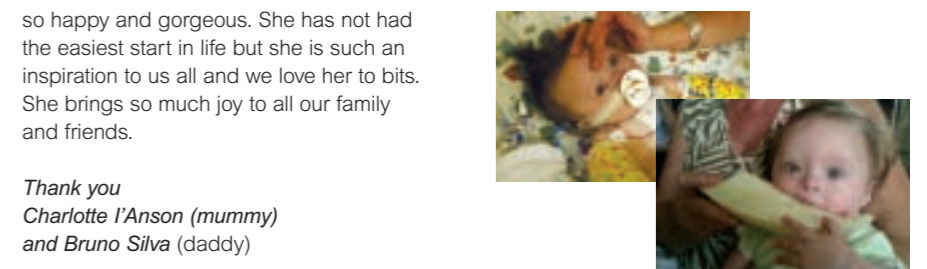
Maizy was born on the 28th December 2006. Since her birth our family has been on an incredible journey.

She was born three weeks early weighing a tiny 4lb, 3oz and diagnosed with Down's syndrome two days after she was born. We were in complete shock for the first 3 months but as time went on we started to enjoy our little girl. Then a heart defect was picked up and the rollercoaster ride began!

Maizy was diagnosed with having a large ASD and pulmonary hypotension, so was experiencing weight loss. She had open-heart surgery at Great Ormond Street hospital on July 2nd 2007 when she was just over 6 months old.

Since then she has grown from strength to strength. Every day she does something new that surprises us! She was a bridesmaid at our friend's wedding just 5 weeks after her operation on 11th August.

I wanted to share the photos of her looking



Thank you
Charlotte l'Anson (mummy)
and Bruno Silva (daddy)



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,



We are the Sansom family, sometimes known as 'Clowns for Down's'. Inspired

by our gorgeous daughter Maisie, pictured with her equally gorgeous older sister Kitty, we want to raise the profile of and raise money for the DSA. Along with a couple of close friends, we have started to enter the local fun runs and carnival dressed as clowns, usually giving out DSA stickers and spreading the message that Down's syndrome needn't be scary, or the end of life as we know it.

Maisie has shown us, and is now out to show the world, that Down's syndrome is just one thing on a list of things about Maisie. That list starts with 'gorgeous' and 'extraordinary'. Down's syndrome is way down the list!

As you can see from the news article, we get in the local press when we can and I (Fran) also sit on the local maternity forum at our hospital. We want to make sure that everyone gets a modern, non-stereotypical view of Down's syndrome, particularly now that antenatal screening is offered across the board.

The DSA is a wonderful support and resource. Bob Black has been particularly fantastic with education advice.

Keep up the good work. The Sansom Family; Rob, Fran, Kitty & Maisie



Dear DSA,

The article in the latest issue of the Journal about Down's syndrome on TV caught my eye as our daughter Katie was recently featured on the National Lottery show on BBC.

Katie was part of a TV show that ultimately helped the Rumbles Catering Project, where she works, to win a National Lottery award and £153,000 of lottery funding. Rumbles gives young people with learning difficulties training in catering and life-skills.

Katie really is a "star" and we are all very proud of her. You can see a short clip of Katie at <http://www.britainsbestbreaks.co.uk/video/lottery/katie.wmv>

Regards, Stuart Rickersey

Dear DSA,

After being told when I was pregnant that I was having a child with Down's syndrome, that she would have severe learning difficulties and a shorter life expectancy etc, I am delighted to write and tell you that my daughter Emma has in fact just started at Moorlands School in Leeds.

It is an Independent 'Mainstream' school and she is coping very well – in spite of the fact she is half the size of her peers and her speech is delayed due to her poor hearing.

She looks incredibly cute in her purple tartan



pinafore and is already getting lots of positive attention from all the staff and pupils.

My eldest daughter was privately educated and everyone said, 'Oh what a shame that Emma won't be able to go', but it just shows that with some determination and finding the right setting she can follow in her sister's footsteps.

Moorlands School deserves recognition for the fact that they were willing to meet me and Emma and assess her as an individual and not as just a child with Down's syndrome.

Kind Regards Johanne Walters



Dear DSA,

I have a son Nikolai, who is now 16 months old with Down's syndrome, and I wanted to share his positive story with families in the UK.

Nikolai has been modelling for a children's online clothing company (jackandabby), in New Zealand and recently his story was told on one of our current affair's national TV programmes.

You can see the 'Nikolai video' at: <http://www.jackandabby.co.nz> then click on media at the bottom left of the home page.

I would be more than happy for this to reach DSA members as I feel we should embrace and be proud of our children's achievements.

Kind regards, Jacqui Piskulic (New Zealand)

Dear DSA,

This is a photograph of my son Nicholas with the Captain of the Queen Elizabeth 2, together with his proud parents Michael and myself.

We were invited to a special dinner reception in the famous Queen's Room where the photo was taken. Nicholas lapped up all the attention with his enormous smile and thoroughly enjoyed the evening.

We were on holiday for 2 weeks in the Mediterranean with Nicholas's 8 brothers and sisters and grand parents,

stopping at 6 ports including Naples and Rhodes.

On the cruise he dined in the famous top restaurants enjoying à la carte food, sunning himself on the deckchairs and having a great time socialising with the other guests with his gorgeous catching presence.

Nicholas is the youngest member in a long line of seafaring ancestors who worked for the famous 'White Star Line' and 'The Cunard' line to which QE2 is of today.

Kind regards Elaine Moss

