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Erratum
that details of reference number 5 have now been updated and
development in Down syndrome: Play, move and grow. Burnaby, BC,
Canada: Down Syndrome Research Foundation.

Creative approaches to teaching number

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Forthcoming articles in Volume 4
The next issue will include:
• More on ICT
• Literacy and behaviour
• Using a Hookboard with children with Down syndrome

Cover picture: Dance group at the 8th World Down Syndrome Congress in Singapore, April 2004. Photograph by Marian de Graaf
Welcome to the first issue of volume 4 of *Down Syndrome News and Update*. We continue to have a range of content from around the world, from young people with Down syndrome, from professional practitioners and from parents, which enables us to share good practice and information between countries and continents. The Down Syndrome Educational Trust works with the European Down Syndrome Association and with Down Syndrome International to draw together the content for this publication. Our aim is to share practical, evidence-based information to contribute to the care, education and ultimately the quality of life of children and adults with Down syndrome and their families.

**International perspectives**

In this issue, we have articles from Italy and from the Czech Republic. We also have a report from the 8th World Congress in Singapore from Shona Robertson, a young woman with Down syndrome who is Australian but currently living in Indonesia. Shona works as a librarian in a preschool centre and she has just published a book of poems and paintings entitled ‘The Beauty of Life’ – this is featured on page 25. The longer report of the 8th World Congress draws attention to the wide range of activities and research going on around the world as it brought together delegates from over 150 countries. The Congress was a moving occasion and it really identified the extent of the worldwide community which is working to improve education, health care and life opportunities in so many countries.

**9th World Congress**

For those of you who could not make Singapore, plans are already well advanced for the next Congress which will be in Vancouver in August 2006 – we will keep you up-to-date with the plans for this meeting and with all the other international conferences that are happening. EDSA is meeting in Italy in December 2004 and there is an international symposium in February in Mallorca 2005.

**Features**

- **Using ICT**

  The first article provides readers with much practical information on the value of computers in the education of children with Down syndrome. It sets out the ways in which computers can assist the learning process and some key principles to consider when choosing software. The article then provides detailed information on a range of programs and how they can be used. Obviously it focuses on English language software and the resources for information and support available in the UK. However, many countries probably have similar resources and the principles should apply in any language. Children with Down syndrome are typically visual learners and the computer is an excellent teaching aid as it can play to this strength. Everything is visually presented on screen and you usually choose your answer with a mouse or motor response. You do not have to talk to show you understand – a great benefit for most children with Down syndrome as spoken response. You do not have to talk to show you understand – a great benefit for most children with Down syndrome as spoken answers are so difficult for them to produce even when they understand the question.

- **Learning number**

  The next two articles provide many creative ideas for teaching number using the Numicon approach. At the Trust we have been collecting information on the progress of children using Numicon and will shortly be publishing a summary of our findings. It definitely seems to help most children even though they may seem to take a long time to master the early stages of learning. Both articles show ways in which the activities provided by the scheme can be extended for children who take longer to learn. These activities are not difficult to create as the articles by a learning support assistant and a parent illustrate. Learning has to be fun, it has to encourage practice and to consolidate children’s understanding at each step.

The third article is perhaps aimed at maths teachers rather than parents and it explains the way in which the usual maths targets can be simplified and taught through everyday situations. The list of target activities for learning should be helpful to children in both primary and secondary schools. The experience of this Italian team identifies the same principles should guide teaching – give students real problems to solve, make learning fun and build in lots of practice.

**New projects**

Readers may be interested to note that in the Trust News several new grants mean that we will be focusing some attention on early intervention and the needs of the under-fives. This is exciting for me as I spent the early years of my career developing early intervention and the UK government is currently making this work a priority – more news of this in the next issue.

**Keep writing**

Please keep sending in your contributions – big or small – articles or letters and also try to help us increase our circulation by encouraging friends and colleagues to subscribe.

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http://www.down-syndrome.info/library/periodicals/dsnu/04/01

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Creative approaches to teaching and to differentiation

How do we create effective learning opportunities for children with Down syndrome?

The four feature articles in this issue have a common theme – how do we create effective learning opportunities for children with Down syndrome? Three of the articles are concerned with teaching number and mathematical concepts to children while the first provides a detailed guide to the use of computer software in the classroom across all areas of the curriculum and in preschool years. The last article is more theoretical, the first three are more practical but all include ways of approaching differentiation.

**Differentiation – is it really difficult?**

This word, differentiation, has become a BIG word in teacher’s vocabularies – at least this is my experience when running teacher training days for the inclusion of children into mainstream schools. For those not familiar with this word, it means adapting teaching methods and the content of the curriculum to allow individual pupils to learn effectively.

Adapting teaching methods requires teachers to take account of the child’s specific learning needs – for example, taking account of hearing loss, motor skill delays, speech and language delays and verbal short-term memory delays.

Adapting the curriculum means simplifying the content and selecting learning targets from the class lesson that are meaningful for the child with learning difficulties.

At the risk of being controversial and receiving some cross letters – I have to say that I sometimes feel that teachers and schools are often making too much fuss about the work involved in differentiation for individual children. We are sometimes involved in battles between schools and LEAs where schools are arguing for considerable extra teacher time to be funded to allow them to differentiate the curriculum for a particular child. In these situations, teachers seem to feel that differentiation is going to be a very large and time-consuming task when, in fact, it is often quite simple and straightforward.

**Using ICT for differentiation**

One very powerful tool to help teachers and assistants to plan differentiated lessons is ICT. In the first article, Mandy Wood explains the way in which ICT can help to adapt teaching and learning methods to take account of the learning strengths and weaknesses of children with Down syndrome – the first part of the differentiation task. She then goes on to illustrate the ways in which a wide range of available software can be used directly by children to learn at home and at school – the software already simplifying the learning – and also how many programmes can help teachers and assistants to prepare worksheets, to find pictures for topics and to support the learning of key objectives – the second part of the differentiation task.

There are training implications for schools, as teachers and Learning Support Assistants (LSAs) need to have some computer skills but this should surely be a requirement for all staff in our schools in the 21st century.

**Creative, practical approaches**

The next two articles, written by Emma Saunders, an LSA, and Wendy Uttley, a parent and maths lecturer, share their practical experiences of teaching number to individual children with Down syndrome. Both articles give clear examples of creative ideas thought up by Emma and Wendy, which led to them making simple but effective teaching materials and activities.

Emma’s article provides a number of ideas for developing an understanding of number, and money and time. Although her pupil is in primary school, many of the ideas could be adapted for older children still working on time, money and number in secondary education. Wendy’s article highlights the need for clear materials, small steps and much practice to consolidate learning at each stage – again a message which applies to children across the age range.

**Not rocket science**

I hope that reading these articles will allay the fears of some teachers and show them that differentiation is not difficult or complicated. It does require some forward planning – LSAs often do the practical work in preparing materials but they need to know lesson topics in advance and teachers should choose the simplified learning objectives for the child. It also requires time for LSAs to make materials and access to card, laminator and computer. However, many LSAs also become quite confident at simplifying the teacher’s messages as the lesson progresses and card and pens should always be at the ready in lessons in order to do this.

**An essential teacher skill**

Many children in all schools (some 20-30%) need the curriculum differentiated. There are children who learn more slowly in every class and many are let down by the school system at present. They also need individually planned lessons and more support – often they could be doing small group work with an LSA and a child with Down syndrome included in the group.

The UK government has recently published ‘Removing barriers to achievement’ and this document makes ‘personalised learning’ an expectation for all children. This means that schools will need to build in time for training and for planning. We hope that some of the examples of differentiation we include in this and other issues of DSNU may allay some of their anxieties.

Editor
Supporting learning and development with ICT

Mandy Wood
Psychologist, The Down Syndrome Educational Trust

This article identifies a number of reasons why ICT may be a particularly important tool for supporting the learning needs of children with Down syndrome and examines a variety of ways in which ICT can be integrated into teaching situations at home and at school.

This article:
• Outlines the advantages of ICT for children with Down syndrome
• Reviews some important issues in terms of supporting computer use
• Signposts readers to potential sources of advice and support
• Suggests some tips for choosing software for children with Down syndrome
• Identifies a range of software that could be used to introduce the computer and provide a foundation for future learning, to develop speech, language, literacy and numeracy

Computer assisted learning has been highlighted as offering particular benefits for children with Down syndrome.\[1-3\] Although detailed evidence to support this view is limited, it is easy to see how many of characteristics of computer-assisted learning reflect the specific learning style of children with Down syndrome.

The advantages of ICT for children with Down syndrome

Visual learning style: Children with Down syndrome have strengths as visual learners and find it difficult to learn from listening alone. Computer software and other forms of ICT can provide a source of both visual and auditory stimulation.

Non-verbal mode of response: The speech and language difficulties of children with Down syndrome are characterized by speech production skills which lag behind understanding and children often find difficulty in answering questions verbally. It is easier for them to show their understanding using a non-verbal mode of response, such as a touch of the screen, mouse click or key press.

Being in control: Spoken language difficulties can be a source of frustration, which may be expressed through undesirable behaviour as a means of controlling the people around them. The computer provides an environment where children can be in control and with practice can work unsupported, developing their self-esteem and independence.

Opportunities for practice and immediate rewards: Children with Down syndrome often need more opportunities for practice than their typically developing peers. The computer is able to present infinite chances to try the same activity, reproducing the exact experience over and over again and providing tireless positive feedback in the form of animations, music and sound effects.

Errorless learning: Well-designed software can provide activities that are tailored to the individual child’s level of skill in a specific area, creating an errorless learning experience. This means that the child is supported by the software, in order to achieve repeated success. Software can be programmed to respond to the child’s input and modify the way in which it presents subsequent activities.

Self-paced learning: The child is able to proceed as quickly or as slowly as he or she wishes; the computer will ‘wait’ for the child to respond without prompting them before they have had time to fully process the information and construct their response.

Improving motivation: A child’s attention span may be increased as the learning experience is enhanced with pictures, sounds and animation. One study using interactive commercial software suggested that attention span could be increased from less than 3 minutes to more than 15 minutes in children with mild to moderate learning difficulties.\[4\]

Clutter free working environment: Computer programs can provide a highly organised and predictable working environment that focuses the child on specific learning targets. It is important to note that this is not the case with all software and parents and professionals working with children with Down syndrome need to look out for software which provides an uncluttered and simple layout without a wide variety of distractions and complications.

Fear of failure: Children with Down syndrome seem to be particularly apprehensive about failure and may demonstrate a range of avoidance behaviours to escape...
from teaching situations that they perceive as potentially challenging. As noted above, computer software can be carefully programmed to meet individual needs and teaching activities can be graduated in very small stages. Older children soon learn that mistakes can be altered quickly and discretely.

**Assistive technology:** This term describes the endless range of adaptations that can be made to improve access to ICT for users with disabilities. Children with Down syndrome should be given the opportunity both at home and at school to access the same hardware and software as their siblings, friends and peers and this includes working towards using the mouse and keyboard. This will allow them to use computers in a range of locations in the wider community and promotes social inclusion. However, it is important to review the possible adaptations that are available. There are a wide variety of devices available and some of these may be helpful in developing the necessary skills to use a mouse or keyboard when the child is older and more developmentally advanced.

In the early years, it is useful to look for software, which is 'switch accessible'. Switches are simply buttons that can be depressed by the user as a command to the computer. A single switch cuts down the demands of the task allowing the child to concentrate on the effect of pressing the switch.

**Examples of alternative input devices: a miniature mouse and trackball**

**Supporting the use of ICT**

There are some simple general principles to consider when setting up an ICT-based activity at home or in school. Firstly, the child should be allowed to sit in a chair that is large enough to allow them to move around freely. They should be encouraged to stand up, stretch and wriggle whenever they feel the need; computer work should not be a static activity. Make sure the child is comfortable and can see the screen adequately and reach the keyboard, mouse or other input devices. Very young users who are not yet able to sit unsupported on a chair of an adequate height can sit on a parent or teacher's lap. I have recently seen the term ‘lap-ware’ used to describe software for the youngest of users!

![A large variety of switches are available from suppliers such as Inclusive Technology](http://www.down-syndrome.info/library/periodicals/dsnu/04/01/)

Some programs can be operated using two switches in the form of the two largest keys on the keyboard, the space bar and return key. There are many other alternative modes of input that may or may not be appropriate for your child as they progress and these include touch screens, trackballs, miniature mice for smaller hands (see below), joysticks, a large range of adapted keyboards, keyboard overlays (which cut down the number of choices that can be made) and even lower-case stickers for the keys. Allow you to configure certain features to the individual users needs. To take full advantage of the package's flexibility, it is important to monitor the child's changing needs. It is also important for adults to consider the child's level of motivation as, if interest begins to wane, learning will decrease. It may be important to switch to a new activity, returning to the former, to consolidate learning in the future.

Other sources of information

The field of ICT can provide a frustrating, potentially off-putting or even overwhelming ‘minefield’. However, help is hand in many forms. Email lists such as SENIT hosted by BECTA, provide almost immediate access to a plethora of experts who will answer what may feel like the silliest question with straight-talking clarity. Parents and professionals can exchange ideas...
and experiences with like-minded others, concerning all aspects of the use of ICT with children with special educational needs. BECTA's website also provides a wealth of information including a section specifically dedicated to SEN and inclusion. [7]

Parents, teachers and other professionals can also seek advice from their Local Education Authority, many of which will have links with consultants and advisory teachers specialising in ICT for children with special educational needs. By 2006, AbilityNet, [8] a national organisation who provide expertise on computing and disability, are aiming to ensure that every LEA in England has a team of four fully trained assessors, who will be able to assess the needs of individual children and make recommendations about suitable hard and software to promote their development and education. [9]

Organisations such as AbilityNet, Inclusive Technology, Semerc, and The ACE Centre Advisory Trust also offer a range of training, advice, assessment and support services. [8, 10-12]

ICT exhibitions such as BETT, The Educational Technology Show, held every year in Olympia and The Special Needs Fringe Event held at the same time in the Olympia Hilton, provide opportunities to try free demonstration software and attend seminars by leading experts and software suppliers. [13] Inclusive Technology also host regional events to look out for. [14]

Finally, reviews of hardware and software can be found on both the Internet and in printed publications. Reviews in general computer magazines may sometimes be biased; however, magazines such as Special Children regularly publish an ICT supplement containing a wealth of practical, up-to-date information concerning ever-changing government initiatives and funding opportunities relating to ICT and reviews by teachers and other professionals using ICT with children with special educational needs.

Financial support

On the topic of funding, in the UK, the BECTA Communication Aids Project (CAP) invites applications for additional funding to address the specialist ICT requirements of school-aged children with communication problems. [15] Funding for pre-schoolers is also available and parents and early years workers are directed to their local Early Years Development and Childcare Partnerships (EYDCP), part of statutory services in every local authority, who should be able to advise on local funding initiatives and charities who may provide grants. The local community volunteer service may also be able to provide details of organisations, which may be able to provide financial support to families. Finally organisations such as The Family Fund [16] based in York may also be to provide funding to individual families.

This year, the government has provided e-learning credits for every maintained nursery, primary and secondary school in the country to allow them to buy software. These credits should have been passed directly from the LEA to Head teachers, although some LEAs may have worked together with their schools and made orders in bulk to get better deals. The government deadline for spending e-learning credits is August 2004 and if they have not been spent by this point, they will no longer be valid.

Many other countries will probably have a similar range of initiatives.

Software for children with Down syndrome

Introducing the computer

Many programs can be used to develop your child's early ICT skills as soon as you feel confident to let him or her explore the computer. An understanding of 'cause and effect' is vital to the child's interactions with the computer; they need to learn that they can control the sounds that they hear and the pictures that they see through their own behaviour. Early skills include being able to interact with the computer through a single switch, key press or click and observe the effect of this behaviour. Once the child has mastered this basic skill, they need to learn that the computer will only respond if they control their behaviour, e.g. only pressing the switch at the appropriate time. The next stage involves learning how to make choices using one or more switches. Once this skill has been mastered, you can begin to use the computer to assess vocabulary and early number skills, as described below.

Switch skills

There are many programs available to develop switch skills, including the SwitchIt! series, Blob and Creatures. Once these skills have been mastered many programs can be configured for switch-access, meaning that children can be more independent in operating software. When choosing software to buy, check whether it is switch-accessible.

A variety of switch accessible games are available to purchase or free to download or play online and these may provide suitable leisure and recreational activities for children to play independently at home or during appropriate times at school.

Oops! from Inclusive Technology provides several simple switch-accessible games, whilst R.J. Cooper and Associates provide a free demo disk with lots of switch-accessible activities. Kids and adults alike will doubtless enjoy age-old classics like Pacman, Space Invaders and the 1970s game Simon, free to download from www.80smusicrocky.com/games.html. [18]

Many non-switch accessible programs can be configured for switch use if the child has not yet developed mouse skills and it is worth checking the catalogues carefully or contacting the suppliers. There are programs such as Switch Cursor from Resource and ClickIt! from Inclusive Technology, which can be used to make software
Supporting learning and development with ICT

Switch-accessible software: ‘SwitchIt! Jigsaw maker’ and ‘Blob 2’

There are a variety of free games and simple activities available to download from the Internet to develop children’s mouse skills: try http://ngfl.northumberland.gov.uk/ict/default.htm. Many parents report that mouse skills are tricky for their younger children with Down syndrome, but there are a variety of alternatives available to bridge the gap including devices such as the trackball (see picture on p.3), which has large ball that can be rolled with the palm of the hand and large buttons to click. I have heard of parents, who have bought a trackball for their child and been converted themselves! There are a wide range of devices available including mini-mice, which may fit more easily into a small child’s hand, but do your research carefully to ensure that you find the most useful alternative. Once the child has developed the ability to drag and drop with a trackball or mouse, programs such as My World, provide numerous activities spanning the early years, right through to activities to help to differentiate the secondary school curriculum.

It should be noted that although the primary aim of the software described above is to introduce the computer, develop an awareness of cause and effect and other skills that will provide a foundation to subsequent learning, all the programs described above, if used sensitively in a supported environment, could provide opportunities for children to communicate and extend their receptive vocabulary and use of language.

ICT in the pre-school years

I asked subscribers to the Down Syndrome UK email list to tell me about their experiences using ICT with under fives with Down
syndrome. Favourite programs included:

- Tizzy's Toybox
- Jump Ahead Baby
- Tizzy's Toy Box (for older users)
- Baileys Book House
- Speaking for Myself
- Reader Rabbit
- Various software from Fisher
- Tweenies

The BBC website was noted as “good for a sing a long!” and CBeebies section (www.bbc.co.uk/cbeebies) was particularly praised for the variety of switch accessible games including favourite characters such as ‘Bob the Builder’ and the ‘Fimbles’.

www.amazon.co.uk is a useful way of finding out about the range of software available for typically developing children and many of these programs will also be appropriate for children with Down syndrome, as a complement to other programs that may be simpler and less cluttered. Search under ‘software’ and then ‘children’s fun and learning’ or ‘education and reference’.

The following website may be useful for those working with the foundation stage curriculum as it provides a host of ideas for integrating ICT into the classroom. The activities may also be appropriate for those working with children with Down syndrome at higher Key Stages as activities to differentiate the curriculum: www.naturegrid.org.uk/infant/earlyict/index.html

Developing specific skill areas

The next section describes a range of software which aims to develop specific skills including speech and language, reading and writing and numeracy. As the individual needs and levels of development are so diverse for children with Down syndrome, it is impossible to make recommendations about age-appropriate software and it is recommended that whenever you are looking to buy software, you check with the supplier whether purchases can be returned if they turn out to be unsuitable.

Speech and language

There is a large range of software to promote development in this area, including programs that focus on speech sounds, phonological awareness, vocabulary development, sentence comprehension and story telling. Many programs are supported by text, others by sign language (some by both!).

In the early years, appropriate speech and language targets include being able to discriminate between and produce a range of speech sounds, increase the single word receptive and expressive vocabulary, supplementing this with signs as necessary and encouraging comprehension and production of two or three ideas/words together. Sound Beginnings is a great fun, configurable program from Semerc that encourages children to experiment with making sounds although it is not set up to only respond to certain sound sounds. This would be useful but much more complicated to program and train to individual users and thus more expensive. A very expensive application called Speechiewiewer does exist which includes all manner of games targeting children’s ability to produce a variety of sound sounds amongst other speech and language goals. This has been used successfully by children with Down syndrome in the schools in Portsmouth, in liaison with their speech and language therapist. It is a powerful tool which may be worth further investigation. See http://www.spectronicsinouz.com/library.asp?article=8342 for a detailed description.

Checklist for choosing software

- Does the program aim to address the specific learning outcome(s) that you want it to?
- What modes of input can the program be used with, e.g. switches, mouse, keyboard, touch screen etc.
- If the program uses speech or text to support the program, is the language appropriate to the child’s level of comprehension?
- If the program uses speech, is the speech quality and easy to understand?
- Does the program move at a pace that is appropriate for the child? Can the speed be altered?
- If the program uses text, is the text easy to read? Can you change the size, style or font?
- What other options are there that you can configure to the individual users needs?
- Are the tasks broken down into realistic and manageable chunks where success at one level does not lead to failure at the next as the next level is too difficult?
- If the software is for home-use, how does it tie in with the software used at nursery or school?
- Is the screen cluttered and full of distractions or is it orderly and easy for the child to focus on the specific task in hand?
- Does the software make good use of pictures, photographs, diagrams, symbols or signs to support spoken or printed information?
- Does the program support errorless learning, where the child is unable to make mistakes and is rewarded for their efforts no matter how small?
- Would the child be able to operate the program independently or would they need support from an adult?
Supporting learning and development with ICT

Programs such as Speaking for Myself, Identification Skills Builder, ColourCards Interactive, Making Tracks to Literacy, The My World Early Language and Literacy Pack all target appropriate vocabulary. A more expensive option is the excel-lent software from Laureate Learning, which has been specifically designed by language development experts for people with specific speech and language intervention needs. They provide a free demo disk, which includes First Words, First Verbs and their cause and effect program Creatures, mentioned above.[17]

For people who are willing to invest some time creating their own ICT-based speech and language activities, programs such as SwitchIt Maker and Chooselt Maker allow you to enter your own images and speech. SwitchIt Maker allows the child to ‘click’ through sequence of images, supported by text and sound while Chooselt Maker sets up a selection of images that the child is asked to choose between to demonstrate their understanding of a question. Used imaginatively these programs allow you to create activities that teach and assess children’s receptive language both at the sound, single word and sentence level. They can also be used to target any number of other learning objectives depending on your needs. Another way of creating your own activities is to use a program such as Powerpoint, which can also be supported using speech and text. A simple presentation can be created showing photographs of members of the child’s family or another category of vocabulary such as clothing, animals or toys, with the words underneath. The ‘action setting’ tool in the slideshow menu can be used to create links between one slide and another. This could easily be used to create an activity where the child was shown a selection of images as a teaching activity and then asked to choose between two pictures displayed together. Clicking on the correct picture might take them to a slide that shows the picture again on its own, supported by speech and/or text to say “Well done, this is the dog!” The incorrect picture would not be linked to another slide, therefore creating an errorless learning situation where the computer will only respond to the correct answer (see pictures). Where possible it is useful to use images with which the child is familiar, from their own environment. For example, if you were teaching prepositions you could take photos of the child ‘in’ the box and ‘under’ the box for example. Of course once you have developed a catalogue of digital images to use in computer based activities, the same images can be printed out to create activities for use away from the computer, such as dominoes, picture matching, selecting and sequencing activities. Clicker 4 can also be used to create similar activities and although this program might seem expensive for home-use the possibilities are endless in terms of creating teaching activities to cover all aspects if the UK curriculum from the foundation stage through Key Stage 4 and beyond! The DownsEd Vocabulary checklists provide suitable vocabulary on which to base your home-made speech and language activities.

In primary and secondary school years, one can see how programs such as SwitchIt! Maker, Chooselt! Maker, Powerpoint and Clicker 4 used in conjunction with a digital camera, could continue to be a highly effective means of creating tailored activities to target more complex sentences and more advanced vocabulary, relating to curriculum subjects for example. Clip art is now available to support much of the national curriculum subject vocabulary and this is useful for creating differentiated activities – try publishers such as Sherston.

Clicker 4

Clicker 4 has two main features called Clicker Writer and Clicker Grids. Clicker Writer is a talking, 'SpeechViewer': make the target sound and the farmer will pick the apples

'Dog'

'Where's the dog?'

'Well done! Here's the dog.'

My talking animal book

Homemade language activity using Powerpoint slides

'First Words' and 'First Verbs', from Laureate Learning

The mother is washing the baby.

Homemade language activity using Powerpoint slides
picture-supported word-processor that will read text back to you and illustrate key words or phrases with pictures above the text. It has a massive picture bank and the speech synthesizer recognises thousands of words. You can also record your own voice and upload your own pictures, photographs, sound effects and even movie clips. Clicker Grids are very easy to make; essentially you can create boxes containing either words, phrases or images that, when clicked, will trigger the computer to talk, play a movie clip and/or sound effect. Clicking a box can also lead the computer to take the user to another grid, just like clicking a link on an internet site. If you wish, you can set the program up so that clicking on a box will lead the computer to ‘send’ the contents of the box to Clicker Writer. This means that the teacher, assistant or parent can set up writing frames to allow children to create sentences by clicking on individual words or phrases. The screen can either be filled with just Clicker Writer, for users who do not require grids to construct written work, or just Clicker Grids, for activities that do not require the child to create their own written work or a combination of both. Talking books are created by setting the screen to Clicker Grids-only and a sequence of grids are linked together. The possibilities are truly endless and this is an excellent tool for differentiating the curriculum at all levels. The package includes many example grids to demonstrate the programs capacity and there is also a website where people can share the grids that they have created at www.learninggrids.com. An online tutorial which clearly demonstrates the full range of facilities of this program is available at www.cricksoft.com/uk/products/clicker/guide.htm.

Software to support literacy

Activities to introduce the printed word can be created in Powerpoint and Clicker 4. However, as the focus is specifically reading, it is important to remember to show slides/talking flashcards with just the printed word before introducing the picture and the word. Both these programs could be used to create your own ‘talking books’ where the child can press a switch to turn over the pages and listen to the text being read to them. One of the early reading activities that we recommend to parents of under-fives is to create personal ‘talking books’ with ICT-based programs such as Starspell, Wellington Square and The Oxford Reading Tree that has been designed to fit with the UK National Literacy Strategy. The graphics are up to date and the speech is clear. These packages are also suitable for introducing children with Down syndrome of any age depending on their literacy skills although secondary school children may find the pictures and games too childish.

Many teachers will be well-versed in how to integrate ICT into their literacy lessons. Programs such as Wordshark and Starspell seem to be particular favourites with teachers and parents alike. Starspell is a spelling program that may be a particularly effective for children with Down syndrome. It is uncluttered and uses pictures and sentences to support the individual target words. Teachers or parents can select from a hugely variety of highly structured spelling lists or create their own. Wordshark is another favourite for school-aged children to practice a wide range of literacy skills. Although, the graphics feel rather dated when compared with modern games, the activities cover a multitude of skills and ability levels and the activities and reward games are varied and imaginative.

Literacy box is another program that has been designed to fit with the UK National Literacy Strategy with CDs for use in Yr R, Yr 1 and Yr 2. The graphics are up to date and the speech is clear. These packages may be relevant for use with children with Down syndrome of any age depending on their literacy skills although secondary school children may find the pictures and games too childish.

Classic reading schemes such as Fuzzbuzz, Wellington Square and The Oxford Reading Tree now offer comprehensive packages incorporating ‘talking books’ with ICT-based vocabulary, grammar and phonics activities and paper-based activities

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http://www.down-syndrome.info/library/periodicals/dsnu/04/01/
for use in mainstream infant, primary and secondary classrooms. It is of course possible to create your own talking books, either concentrating on personal books such as a PowerPoint or Clicker conversation diary that could be emailed to and from parents (for the Internet-friendly family) or simplified versions of the books that other children are using in the classroom, whether that be the infants' big-book story or a page from the secondary school science textbook.

There are some excellent booklets available online that have been written to help people to create their own resources. It is worth looking at these as they also give information about how to avoid copyright issues! Download the guides from http://www.ace-centre.org.uk/html/publications/publicat.html. Once the images have been saved in Clicker 4 for use in a talking book, they would then be available for use in Clicker Grids to create reading comprehension activities such as re-ordering sentences, finding the missing word, sequencing images or sentences and retelling the story or extract. Incidentally, another program from the makers of Clicker 4 called Close Pro can be used to create 'fill in the gaps' or 'cloze' activities. The set up is similar to Clicker 4: text can be entered into top half of the screen, the teacher then selects words and phrases to be replaced with gaps and these word and phrases are sent automatically to a grid below, ready for the child to choose between them.

Cricksoft have also produced a range of talking books with reading comprehension activities using the Clicker format called Planet Wobble. There is a website for children and teachers to support this series at www.planetwobble.com including the opportunity for children to email the characters from the books. The site promises that every child will receive a reply. A target age-range has not been given for these books, however, the content of the stories and the characters seem appropriate for younger primary school children. The level of literacy may be appropriate for older children with Down syndrome although they may not be chronologically age-appropriate. However, they provide a good model to show how Clicker could be used to create reading comprehension activities to support more age-appropriate texts for older children.

**Number skills**

Again, programs such as SwitchIt! Maker, ChooseIt! Maker, Powerpoint and Clicker 4 can be used to create your own early number activities. You could, for example, design a series of slides each containing 'one more' of a particular item with the correct numeral next to it to encourage children to learn the count word sequence from one to ten. Each slide could contain a number line to provide a visual prompt. As children's skills develop, each slide could contain a question asking the child to count the number of objects and click the correct number on the number line. The corresponding numeral could be linked to another slide to say 'well done' perhaps accompanied by a favourite tune and/or picture. Personal books such as those described in Wendy Uttley's article on pages 15-16 could easily be turned into a talking book. Programs such as Jemima and Foundation Counting Songs are appropriate for pre-schoolers and primary aged children with Down syndrome. My World 3 contains an activity about Goldilocks and the Three Bears (see page 5) which could reinforce one-to-one correspondence and understanding of number related language like one more and one less, bigger and smaller and so on.

Tizzy's Toy box is a colourful and inspiring program from Sherston which is ideal for children with Down syndrome, in that it allows repeated practice at differing levels of complexity in a variety of skills areas. Amongst others, it contains a number of numeracy-related activities that may be motivating for primary school aged children with Down syndrome as would the activities from another CD in their range called 123 CD, which often uses the same arrangements of items as used in the Numicon scheme. Both programs may be suitable for independent use by some children but would be more effective as teaching tools when supported by an adult. Younger children would certainly need support from an adult or experienced peer.

School age children may enjoy programs such as Number Train, which ties in with the UK National Numeracy Strategy. The graphics are attractive and the activities are imaginative and configurable to use with only certain number ranges. Children with Down syndrome may find this a motivating way to practice skills as part of their numeracy lesson and to break up table-top work using other teaching methods. Also, Number shark provides activities to advance number skills using a similar format to its sister-program Wordshark, described above.

The picture below shows how I created a Clicker 4 activity to help develop money skills. Again, one can see that practically any learning objective can be targeted using Clicker grids. It is important to be in mind however, that although there is no doubt that Clicker is a superb resource, there would have to be time allocated for assistants or teachers to set up Clicker grids. Schools would have to develop careful forward planning and make decisions about how to manage this.

**Conclusion**

This article has provided a whistle-stop tour of some of the available software and has hopefully provided some inspiration as to the way in which programs such as Powerpoint and Clicker 4 can be used to create

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http://www.down-syndrome.info/library periodicals/dsna/04/01/
activities to develop speech and language, literacy and numeracy. I read in a recent article in the Special Children ICT Supplement describing how one inspired teacher had even used Clicker 4 to include children with special educational needs in the school play. He explained how sound effects and music for the play were entered into a Clicker Grid so that the children simply had to click the correct box at the correct time.

At The Down Syndrome Educational Trust, we have recently started to develop teaching materials and computer programs that are specifically designed to support early cognitive development. Our new ‘See and Learn’ materials will provide a range of carefully targeted activities and will assist with recording individual progress. These materials will start to become available during 2005.

Please keep us informed about your experiences of using ICT with children with Down syndrome. I would be particularly interested to hear about how people have used Clicker 4 successfully to differentiate the curriculum in mainstream school and look forward to including ideas in future issues of Down Syndrome News and Update.

References

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Laura Cryer from Semerc, Ann McDevitt (independent SEN and ICT consultant from West Herts.), Charlie Davey (assessor and education champion for AbilityNet), Paul Hawes (sensory software international), Jeff Hughes (Chartered Educational Psychologist), Rob Smith, (ICT co-ordinator at Sunfield School in Worcestershire), David Banes (Director of Operations at AbilityNet) and Jonathan Rourke (from the SENIT list).

Thanks also to Edward Beale, Victor J. Bishop, Colin Hill, John and Steph, Jean Hanrahan and Orla, Gillian Scott, Steve Booth and Danielle, Christine Chester and Anderley, Margaret Cahill and Down’s Syndrome London (who all contacted me through the DS-UK email list).

Thanks to Inclusive Technology, Semerc and Widgit for providing me with complimentary software, and finally thanks to Bob Black, as this article draws on work that we started together in our DSII book (see Resources box).

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ICT resources
Utilising information communication technology to assist the education of individuals with Down syndrome. By Bob Black and Amanda Wood (2003). Portsmouth, UK: The Down Syndrome Educational Trust. ISBN: 1-903806-29-1. This publication includes a comprehensive and up-to-date index of software suppliers.


A wide range of software, including many of the examples mentioned in this article, is available from The Down Syndrome Educational Trust’s Resources brochure.
I was asked to write an article to explain some of the numeracy activities that I have planned and delivered for Richard over his three years at infant school. I have tried to explain the range of activities that we have come up with and how I tried to fit them to Richard’s specific profile of needs, his likes and his dislikes. I have described four main areas of work that I have focused on with Richard including learning the Numicon shapes, number bonds and early addition, money and time.

Before discussing the activities, let me tell you a little bit more about Richard and myself.

A little bit about me…

I qualified as a nursery nurse in 1989 and since then have worked as a private nanny and within nurseries and playschools with children aged between 6 months and 5 years. I have spent the last 4 years working in mainstream infant schools supporting children with special needs including language pragmatic disorder and cerebral palsy. For the last 3 years, I have been supporting Richard, who has Down syndrome. He also has bilateral moderate hearing loss and uses a bone conductor hearing aid. Richard also has a visual impairment and wears glasses.

And a bit more about Richard…

Richard is a funny, affectionate, caring and wilful 7 year old who knows what he wants! Over time he has formed some special friendships with certain children in his split Y1/ Y2 class, most of whom happen to be Y1 children, though at playtimes he enjoys joining in games with other children. Nearly every child in the school knows Richard by name and you hear frequent cries of “hello Richard”.

Richard tends to use one and two word phrases in his expressive language, although he can understand sentences containing three information-carrying words, e.g. “put the horse in the box”. He is learning Makaton and Richard and I use signs to help us to communicate and show each other what we mean.

Richard’s numeracy skills have gradually progressed over the three years that I have worked with him. In this article, I have focused on the work we are doing with the numbers from one to ten as we are still working to consolidate his understanding at this level. However, this does not stop us from participating in and enjoying activities with numbers greater than ten with the rest of the class. For example, Richard loves joining in the counting with his classmates before each numeracy lesson. Richard is also able to count in twos. He has recently learnt how to copy some of the numerals to 10, some of which he can write independently.

Using Numicon

Along with 15 other children with Down syndrome in the local area, Richard participated in the Portsmouth Numicon project, co-ordinated by Dr Joanna Nye from The Down Syndrome Educational Trust. The study ran for twelve months and involved working for 10 minutes per day, as part of the numeracy hour, carefully progressing through the Numicon activities. We were supported by Jo, who visited us every half term and also ran workshops from the Sarah Duffen Centre. Jo encouraged us to not only stick to the structured activities as outlined on the activity cards, but also to integrate the use of Numicon materials into other numeracy activities within the classroom. I went a step further and decided to take Numicon into the playground!

Make a pattern

The photos on the next page, illustrate an activity that I designed as an extension to Activity 5 (Make a pattern) from the Foundation Stage Numicon Scheme, which aims to help the children to become familiar with the Numicon shapes. This activity involves showing the child one of the plates and asking them to make the same pattern using pegs on a board. We took this activity a step further. Richard chose two...
Number fun? You can count on it!

friends to help him and we took a variety of games equipment into the playground. The children took turns to lay out large number cards in a number line and then Richard put the appropriate Numicon plate under each number. Next, the children took turns to choose beanbags, quoits or markers to make the same pattern as the Numicon plate underneath. Richard demonstrated this to the children, as this is something that he uses regularly and is familiar with, therefore providing an excellent opportunity for him to take the role of teacher and develop his self esteem.

**Helping hands**

The next activity was based on a class activity where the whole class made handprints and numbered them in 5s up to 100. I had noticed that during whole class work where Richard’s teacher asks the children to show “How many?” in response to simple addition sums, Richard sometimes has trouble holding up the correct number of fingers. I thought that we could use the handprint idea to give Richard some extra practice and understand the “How many?” question more successfully.

Richard printed his hands and, with some help, cut them out. I made them into laminated cards, each card had a “5” handprint and then single fingers up to 10. Written above each finger was the number they represented. On the back was the sum you could make up i.e. 5 + 1 = 6, 5 + 2 = 7. See pictures below.

**Playing the game**

Richard selects a card, and then copies the handprint with his hands/fingers, by placing them on top and matching (see picture below). I would also hold up my fingers and say the sum 5 + 3 = 8, and count saying 5 and 3 makes 8. Richard then turns the card over to see the sum. Using a wipe board and pen, he copies the sum independently, (something that he has achieved quite recently). As a further visual reinforcement, I have the Numicon plates ready for Richard to look at. I ask if he can find 5 and 3 (or red and yellow) and encourage him to fit the plates together and see what new pattern they makes. Then I’ll ask him to find the plate that is the same as 5 and 3 together, i.e. the 8 plate, “Can you find the same, number 8?”

**How many ways to make 5 ?**

This activity was drawn from a Yr 1 worksheet, which showed 5 cut out pears with 2 plates. The children had to make a sum of ‘how to make 5’ using the pears and then to write the sum. I made the food ‘currant buns’, as Richard loves the song. I also made the plates much bigger, the squares for Richard to write the numbers in were enlarged and I laminated the sheet so that Richard could use it time and time again, and to give him confidence using the wipe pen. The laminated card was particularly practical when we first started using this activity, as Richard needed lots of practice to write the numbers. The laminated card allowed us to wipe them away quickly and easily. We would take turns to roll a die (I covered up the number 6!) and whichever number appeared face up became the number of currant buns that we would take and count on to our plate. The remaining buns were counted by the other person on to their plate. Richard would then write the sum on the sheet i.e.

\[
\begin{array}{c}
1 \\
+ \\
4 \\
= \\
5
\end{array}
\]

I also used a number line in this activity, to help Richard with copying the numbers. When we first introduced the activity, I used to write the numbers in ‘dot-to-dot’ to help Richard to become familiar with the numerals.
Number fun? You can count on it!

We sometimes use the currant buns to ‘go shopping’ and sing the song, taking turns in buying the buns for 1p, 2p, and 5p coins. See Richard’s toyshop activity below.

Ways to make 10

As Richard gained confidence with ‘ways to make 5’, we played the game in the same way, but using cut out sweets, and a pack of number cards up to 10. We turn the cards over one at a time, to decide how many sweets the first person gets.

Let’s go shopping

The following activity develops Richard’s pretend play, speech and language and money skills at the same time. Richard has his own special “toyshop” with toys brought from home and from school. Each has a price tag with the coinage stamped on the back to give a further visual clue. There are three shops; a 1p, 2p and 5p shop with toys that Richard selects and puts into his shopping basket. When he’s selected his toys he comes to my till and pays using “real coins”. I only put the three different coins in the purse for Richard to select from, but as Richard gets more confident, the prices will increase and there will be more coins to choose from.

There is lots of scope for language with this activity i.e. “How much?” “What can I buy for 2p?” and the names for all the character toys.

Time

Richard’s class have been learning about time during numeracy. Every child has an activity ‘time pack’ and Richard’s pack was adapted to suit him, though some of the worksheets were clock faces that simply needed enlarging and made into o’clock times rather than half past etc. Richard started off by making a clock using split pins to attach the hands and cutting out the clock independently. He then had a large clock face where he had to fill in the numbers using dot to dot, and then draw in the clock hands to make 9 o’clock. A simple sentence was written underneath “I go to school at 9 o’clock”, which Richard traced over.

Richard then went onto picture and time sequencing. He had to cut out and stick in simple pictures i.e. ‘wake up’, ‘eat breakfast’, ‘go to school’ and fill in the time (… o’clock) that he does each thing in a normal day. We both used the Primary Time Teacher clocks to make the same time. We then looked around the school to find simple props to do some acting. Once we had a practice, acting out the story of ‘Richard’s day’ using props like a pillow, bowl and spoon, school bag and bell, Richard put on a little performance for his class, to show them what he had learnt about time. He even took a bow at the end!

Another time activity that Richard enjoyed was matching the Makaton signs for the days of the week to the written words.

Moving on…

Richard will be leaving the infant school this summer and moving onto the Juniors in September. The transition has been well planned, with opportunities for Richard’s new LSAs to come over to the infant school and learn about the ways in which we have differentiated the curriculum for Richard, e.g. incorporating visual prompts, using practical activities such as role play, ensuring that the work is meaningful for Richard and set in the context of familiar experiences from his every day life and most importantly ensuring that the work is fun so that Richard is eager to try every activity. I have been lucky in that I have had excellent working relationships with all of Richard’s class teachers and I feel that good communication between us has been vital to help Richard put on a little performance for his class, to show them what he had learnt about time. He even took a bow at the end!
us understand Richard’s changing needs, and decide on appropriate targets for him. We have struck a balance between time spent in and outside the classroom. Every child in school spends some time on one-to-one work outside the classroom and this means that it has not felt unnatural for Richard and I to work, one-to-one, on his specific speech and language, literacy and numeracy targets at regular points during the school day. There isn’t always time for me to create differentiated resources for Richard and sometimes I have had to do this in my own time. However, as Richard gradually becomes more independent, there should be times when his assistants at the Junior school can take a back seat for a while in order to work on resources for future activities. This is also important for Richard’s development in terms of fostering his independence, self-esteem and self-help skills.

Richard has visited the Junior school several times and at present seems unperturbed by the impending change. The next issue of Down Syndrome News and Update will include details of how we designed a social story to prepare Richard for a change in assistants while I was on holiday, which we felt may have triggered changes to his behaviour if we had not planned for it in advance. We hope to use a similar technique over the final few weeks to help Richard’s transition to Junior school. Richard’s transition has also prompted a change for me too and I am currently looking for a new challenge working with families and children with special needs.

Richard’s day:
3 o’clock - time to go home

Richard has visited the Junior school several times and at present seems unperturbed by the impending change

Number resources

The following items are available from The Down Syndrome Educational Trust’s Resources brochure:

- A range of Numicon kits and accessories for use at home and in classrooms is available, from preschool to Year 2.

New BBC interactive resources

The BBC has produced a new and easy-to-use teacher resource to support the teaching of children with learning difficulties across the age range – preschool, primary and secondary – at bbc.co.uk schools/guide

The site can be searched for educational programmes by name, age group or subject. Search results give details and broadcast times of all the relevant BBC television and radio programmes, plus related websites. The information can be easily printed off.

Some of the Special Education Needs programmes are transmitted overnight on BBC Two’s Learning Zone, so remember to set the video the night before! Video tapes and DVDs of many schools programmes are also available on a cost-recovery basis (currently £6.40 each ex. VAT). In addition, BBC Worldwide produces commercial resources - Audiotapes, CDs, videos and teachers’ notes - to support some programmes. All resources are distributed by BBC Children’s Learning at www.bbcshop.com

Boost is a new online reading scheme aimed at improving literacy skills in students who entered secondary school with a reading ability below level 4. It has been designed to support as broad an audience as possible, including students with autism or dyslexia as well as those with less specific learning difficulties, and can be used at home as well as in the classroom: bbc.co.uk/schools/boost
An update on Sam and the progress he has made in numeracy using Numicon

Wendy Uttley
Parent, Mathematics Lecturer (Bradford College) and Group Coordinator for The Down’s Support Group, Bradford

Wendy describes how she imaginatively overcame her son Sam’s difficulties with the count word sequence using home-made materials.

In May 2003, I wrote an article about my son Sam, now aged 6, and how we were adapting and using the Numicon shapes to encourage him to learn the count sequence without having to sit and concentrate too much! We were working on the numbers one-to-five and I had made two books for him, one covering counting one-to-five and another six-to-ten.

However, we got stuck on ‘four’. For months and months, all Sam would say was ‘one, two, three, eight, nine, ten’ whenever he was asked to count.

We decided to work on just ‘one, two, three, four’. Saying ‘four’, counting ‘one, two, three, four’, having four kisses at bedtime etc. I set to and using Publisher, Flash Pro 2, a CD containing 10 000 images, (by ABA Materials, Australia) and Numicon shapes that I had scanned, I made a book for Sam focusing purely on the number four. (You can also find plenty of free clip art on the Internet).

On the first page I inserted four footballs set out in the Numicon shape ‘four’, with the wording “how many balls?” and a lift the flap to uncover the shape. On the next page the same picture but with the numbers 1, 2, 3, 4 written on the balls in the order I wanted Sam to count. This took some deliberating, do we go across or down; I opted for across since this is the direction in which we read. I placed another ‘lift the flap’ to show the number 4 and the written word four. I inserted the written word later, once we had had practice counting. I used the font “SassoonCRInfant” which writes ‘4’ rather than ‘4’, see Figure 1.

On the next two pages, I inserted a hand with four fingers held up again following the same format, then a four-legged animal with the question “how many legs?”, then various other arrangements of four items. This gave Sam practice in saying one, two, three, four, counting one, two, three, four, recognizing the Numicon shape and the numeral 4 and saying “four”. It also reinforced the cardinality of 4 objects. At school, he was still practising saying the number sequence 1 to 10 and I felt that once ‘four’ came, the missing ‘five, six’ and ‘seven’ would follow. And they did, in the form of “our”, “ive”, “ix” and “even” along with the gradual realisation (we are slow learners ourselves!) that Sam had struggled because these are the numbers that begin with the quiet “f” and “s” sounds.

We then moved onto five and I made another “how many” book, followed by six and recently seven. Sam is now consistently saying the number sequence one-to-ten correctly and we are now working on

Figure 1
An update on Sam and the progress he has made in numeracy using Numicon

counting/saying up to twenty. We have attached the Numicon shapes and digits up the stairs and round the corner into his bedroom, finishing with twenty above his bed and we practise saying them at bedtime.

At school he is practising recognizing and ordering the numbers one-to-fifteen and working out “one more” and he is doing very well writing the numerals which I have laminated onto A4 sheets using a “hollow” (outline) font and the Numicon shape picture, see figure 2.

The one-to-one counting of a set of objects up to seven is 98% consistent, although practice, practice, practice continues to be necessary on one-to-six. We have recently gone through a phase of Sam insisting on saying one, two, three, four, five, seven (no six) as if we’ve done six, and now we’re working with seven so this should come after five. I have now made books focusing, on the numbers one, two and three, as I did for four, five, six and seven. It is still good practice for Sam to read through these and I am in the process of trying them out on younger members of the Downs support group in Bradford.

We are also using a software package produced by Sherston called 123 CD, which I discovered, to my delight, set out the objects to be counted in the “Numicon form” so for example 5 is set out as

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• • •
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rather than

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•

•
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As I continue to move through this slow process with Sam, I have come to understand just how important it is that parents, and teachers, understand how our children learn and the stages that typically developing children progress through, stages that I missed with Sam’s typically developing older sister since they just happened. Because our children need to learn things so very thoroughly with incredible amounts of repetition and practice, and because the stages of number development are spread (in my experience) over years rather than months, we have to be very careful to do it correctly and consistently. The learning we build for our children must be strong or it will become “undone” as soon as we try to move onto the next stage.

Recently school have been working on number bonds up to five with Sam using the Numicon shapes and pegs to build towers. Homework was sent home, large numbers set out for addition on a sheet of A4.

```
1 + 1 = ?
1 + 2 = ?
2 + 2 = ?
2 + 3 = ?
4 + 1 = ?
```

We sat down with the sheet, a pen and the Numicon shapes. I selected two ones and a two shape ready to show Sam one and one are the same shape as two and to my amazement as soon as I pushed the two ones together he said “two”. We continued with the sums on the sheet and he finished them all correctly with ease. The only input from me was to select the two shapes to be added and move them together. He saw the answer instantly, without needing to match it to the correct shape and wrote the correct number in the box. I sat and waited, almost not daring to breathe, while he finished. I was euphoric. It was the most wonderful moment. It makes me cry just writing about it. I felt like phoning everybody up with the news.

Since then we have had a similar sheet on “take-aways” up to five and he completed the homework flawlessly.

I feel that Sam now fully understands one-to-five, inside out and upside down. His learning is “strong”, it is there for life.

Reference

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Mathematical targets and personal autonomy

Anna Contardi, Michele Pertichino and Brunetto Piochi

Italian Association for Down Persons, Rome; Interuniversity Department of Mathematics, Bari; Department of Mathematics “U. Dini”, University of Florence

This article explains how mathematical skills can foster independence for daily living and how we should always have high expectations for children with Down syndrome.

A learning path about logics and mathematics for children with severe learning difficulties is too often considered extremely difficult, or even impossible. Even though these children very frequently have difficulties in abstracting, we do not think this is a reason for giving up; we rather believe that this awareness should stimulate a different way of teaching. Without denying or undervaluing the hindrances, we actually believe that it is necessary to support the right of every child to learn as much as possible, even in the field of mathematics, as some good mathematical knowledge is an essential requirement to gain autonomy in life.

Social autonomy

The achievement of autonomy is a fundamental aim for the growth and the social inclusion of any person, even if they are disabled.

Italy has chosen full inclusion in school for children with disabilities. The outline law for the assistance, social inclusion and the rights of disabled persons (law 5/2/92 n. 104) asserts that “mainstream school aims at developing the potentialities of the disabled person in learning, communication, relationships and socialisation”. This concerns all subjects, since all of them are essential for the ripening of the individual and the accomplishment of the greatest autonomy for everyone.

What does being autonomous mean?

The answer to this question can be first answered in terms of capacity and behaviours:

- to know how to take care of oneself and one’s living places
- to know how to communicate (in different ways and by different means)
- to be able to get one’s bearings
- to know how to spend money
- to know how to use public services
- to know how to ask for help, etc.

The concept of autonomy we are referring to here is meant in its general sense, either as the capacity to observe and the awareness of one’s skills and limitations, or as the ability to move in the external world and to actively get in touch with other people or things: “Autonomy is not doing everything on one’s own. On the contrary it is knowing how to cooperate, ask and put things together”.[1]

Even though few people are aware of it, the knowledge of some mathematical concepts is an essential requirement for the development of autonomy, either in terms of behaviours or in a more general sense. The role played by mathematics in becoming autonomous is clearly pointed out if we consider that “Mathematical education contributes […] to form the necessary abilities in order to interpret (reality) in a critical way and to intervene in it with awareness” (Italian Syllabus for Elementary School, 1985).

Mathematical education must contribute to the cultural development of the citizen, in order to allow him or her to consciously take part in social life, showing critical ability. Starting from concrete experiences for the pupil, the teaching of mathematics must gradually initiate the use of language and mathematical reasoning as useful instruments to look at reality.[2]

This motivates the choice of training to the study of mathematics by means of aims and activities directly related to the reality of life and therefore to the achievement of autonomy. We believe that this option should be the discriminating principle for the choice of mathematical teaching methods and contents for disadvantaged pupils. Such an option makes possible a coherent use of activities and for developing and evaluating mathematical skills in the context of autonomy.

Please note that mathematical concepts are also present in activities which are generally thought...
as non-mathematical. Some trivial examples: recognizing, naming and classifying objects, even if following various and imaginative principles, are main mathematical aims; crossing a street (apart from possible coordination and motion problems) requires estimating distances, speed, orientation and direction; screwing in a screw or a light bulb implies the concepts of horizontal-vertical rotation and direction, and requires estimates of length and width.

Crossing a street (apart from possible coordination and motion problems) requires estimating distances, speed, orientation and direction; screwing in a screw or a light bulb implies the concepts of horizontal-vertical rotation and direction, and requires estimates of length and width.

A problem-solving approach

When thinking of mathematics, we must always recall that “[mathematical] theories derive and rise from several problems, and the concepts are developed on the questions that they have to solve, and the reasonings they intervene in”.

The central role assigned to problem solving by mathematical school syllabi of many countries actually suggests starting from the solution of concrete problems in order to acquire mathematical concepts. This kind of approach to mathematics is certainly closer to the learning characteristics of pupils with disabilities. But, if one agrees that “solving problems is a specific task of intelligence and intelligence is the specific gift of the human race”, then we believe that exploring and solving problems is a fundamental activity for all students in order to master concepts and abilities.

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We believe that exploring and solving problems is a fundamental activity for all students in order to master concepts and abilities.

For the teacher ...

At last, we want to point out that by means of problem solving activities a teacher can know the learning level and the demand for collaboration amongst pupils, even in emotionally involving situations. The suggestion of a problem implies the stimulation and the interest of a person, it issues a challenge, inciting towards personal research in which knowledge is used to produce a new solution.

In this case the pupil will draw on all his gifts and abilities (how many and whatever they are) to go beyond the difficulties of the problem. The deficiency is then no more a hindrance: when facing a problem everyone has got to react exactly in the same way others do, whichever knowledge level he or she has. We must not forget that a problem rules out by its very nature the immediate solution, the quick answer; there is a problem when it is necessary to work on the request to reach a solution.

Of course, a question cannot be a problem for everyone equally; it may be a problem for some people but simply be a more or less difficult exercise for others. It is the first-person involvement that sets up the personal necessity to solve a problem. This involvement allows the person to go beyond any intrinsic difficulty and to get to a conclusion. This is even more true in the case of people with developmental disabilities, where these difficulties are greater and the subjective stimulation to the solution is therefore essential.

Making learning fun

As for a person with disabilities, it is necessary to pay attention to both the cognitive and the affective-emotional fields. The first requires a special simplification of the passages in didactical suggestions to increase their intelligibility, together with an extremely concrete and effective approach; the latter calls for a choice of involving and reassuring situations and methods, to help the child to be confident of his own possibilities and to do his best. This function will be played by the choice for the setting of activities; playful situations and materials connected to ordinary life (the house, the meal, the toys, etc.) or recurring tales in common practice, therefore well known by children.
of every pupil, using this method to identify suitable learning targets. Moreover, problem solving gives us the chance to put into practice a different kind of working, leading to a better reassessment of knowing by means of tries and mistakes, in a collaborative, not competitive environment.

Such an organization of work within the classroom gives the child with disabilities better opportunities to socialize, but requires a more creative teaching method. During the same activity, it must be possible to make different requests to the disabled and to typically developing pupils, and among the latter as well, in order to meet individual needs or turn the gifts of the single individual to better account. Besides, when working in this way the pupil with disabilities can carry out many activities together with the whole class. There will certainly be moments of individual reinforcement of skills spent alone with the remedial teacher or with the teacher in the classroom; this will aim at strengthening or thoroughly analysing all that has been done with the classmates. In this sense, inclusion is not denied, yet it is reinforced and made appropriate to the subject involved.

### The choice of the targets

In order to develop a learning process in the logical-mathematical sphere for the disadvantaged pupil (and for all pupils), it will be necessary to start from the evaluation of abilities and work according to his or her needs; moreover the syllabus will not have to be concerned just with the sharing out in cycles and single classes, yet it should imply a global growth project regarding the different thematic areas.

In our opinion, the choice of the targets and activities to be suggested to these pupils must be, first of all, a choice of priorities: it is necessary to single out the important and essential goals, together with the abilities these pupils are lacking, in order to avoid them and protect the global result.

The following tables compare some basic mathematical targets (italic: on the left) with some of the activities which make them real in everyday life (on the right). Mathematical targets are chosen thinking of 6-14 year old pupils.

### TO RECOGNIZE, NAME, CLASSIFY

- To classify on the grounds of given attributes
- To combine objects and attributes
- To interpret the main logical connectives as set operations
- To develop the senses and be able to distinguish and separate
- To identify types of shops and products
- To get one's bearings in the departments of a supermarket
- To set the table, tidy up the room and put one's own things in order, etc.
- To use the 'Yellow Pages'
- To know how to look for books in a library

### TO RELATE, ARRANGE, CREATE CORRESPONDENCES

- To discover rhythms and regularities in series of objects, images and sounds; to create vice versa successions according to given rules
- To represent space / time successions, order relations and correspondences, all related to concrete situations
- To compare concepts of relation, correspondence and function in different contexts
- To be able to perceive and relate elementary visual and sound messages (doorbell, phone, switches, etc.)
- To know how to deal with some social rules (to play, to dress oneself, etc.)
- To listen to one's cardiac rhythm and reproduce musical rhythms
- To use public transports following the series of stops
- To understand the use of time sequences (morning, afternoon, evening)
- To organize a standard day
- To understand family ties
- To use the phone and the telephone book
- To prepare one's own schoolbag
- To associate every pupil with his seat in the classroom, locker, etc.

### TO HAVE A GOOD KNOWLEDGE OF THE CONCEPT OF NUMBER, KNOW HOW TO COUNT, PERFORM SIMPLE OPERATIONS

- To count on the number line (extended if possible) in a progressive and regressive way
- To compare according to quantity
- To read and write numbers
- To make simple calculations, both mentally and written
- To guess and know how to use the properties of the operations
- To know the concept of fraction as part of a whole
- To extend the concept of number: from natural to relative and rational numbers
- Ratios, percentages and proportions
- Multiples and divisors
- To be able to count money
- To use public transport
- To follow street numbers
- To do one's shopping
- To be able to read thermometers
- To be able to look at the calendar, the train timetable, etc.
- To buy things when they are on sale
- To cook following a recipe and make portions
### Mathematical targets and personal autonomy

**TO FOLLOW, SHOW, DRAW PATHS**

- To move along set courses
- To describe paths performed by other pupils
- To train the mind to develop visuo-spatial skills
- To orientate oneself in space
- To get and give right information
- To be able to help and get helped as for moving
- To be able to “play” (obstacle race, videogames, etc.)
- To arrange the furniture

**TO BE ABLE TO CHOOSE THE OPERATIONS WITHIN PROBLEMATIC SITUATIONS**

- To translate problems expressed through words into mathematical representations, being able to choose the suitable operations
- To single out problematic situations within experience fields and advance hypotheses of solution
- To identify data and meaningful variables in a problem
- To solve problems using different processes
- To organize shopping
- To make travel plans
- To organize a meal, a party, etc.
- To be able to use the phone in different situations and react properly to unexpected events
- To be able to use a vending machine properly, recognizing and using the instructions in sequence
- To know how to use ordinary tools (remote control, videocassette recorder, washing machine, etc.)
- To use a computer

**MEASURES**

- To know the main units of measurement and be able to use them properly
- To choose suitable instruments in order to measure
- Metric system
- To be able to read a recipe
- To be able to measure the height and weight of classmates
- To be able to measure properly in order to perform simple tasks and activities in the classroom (locker’s covering, curtains, etc.)
- To build objects (kites, little houses for animals, etc.)
- To arrange the furniture in the classroom

**FORMS, FIGURES AND THEIR FEATURES**

- To recognize the simplest kinds of geometrical plane and solid figures in the objects
- To measure the areas and perimeters of the main plane figures
- Study of the figures in a plane and in space starting from material models
- Lengths, areas, volumes, angles and their measure
- To be able to identify unknown objects, by means of the description of their shape
- To recognize the use of certain objects on the grounds of their shape (pots and pans, kitchenware, work tools)
- To recognize the most important road signs
- To use jigsaws or games implying the creation of figures (for example Tangram, Lego, etc.)
- To disassemble and reassemble objects
- To decorate a room

**TO WORK IN THE CARTESIAN PLANE**

- To identify positions and movements within the plane and represent situations by means of grids with positive integer coordinates
- Use of the coordinate methods in concrete situations
- To play everyday games (for example battleships)
- To be able to find a street or a path on a map
- To be able to interpret and use a map

**TO NOTICE THE (BASIC) TRANSFORMATIONS OF THE PLANE**

- To identify symmetries within objects and figures
- Enlargements and scale reduction
- Shadows, representations in perspective, pictures, paintings
- To be able to observe and understand shadows
- To recognize the scheme of the body (right/left, forward/backward, etc.)
- To be interested in art
- To trace figures (also by using three-dimensional techniques)
- To use the mirror and recognize the sizes of clothes
- To be able to use a photocopier, a camera, etc.
Mathematical targets and personal autonomy

Learning evaluation

The division of objects and mathematical concepts suggested above is not meant to be rigid and hierarchical, because they constantly intertwine; some pupils will probably be able to get to a higher level in some of them and not in others, or vice versa.

Such a distinction can be useful to the teacher in order to show every pupil the way to get to the highest level; besides, the teacher must be aware that the achievement of each level is valid by itself and that every pupil is entitled to improve as much as possible in this itinerary within the class.

Moreover, it is necessary for the teacher to understand how the same ability can exist and be simultaneously valued on different levels, also taking into consideration the features of certain kinds of disabilities or the individual needs.

To get a better look of what our idea means, consider the following examples:

- in order to value the knowledge of measures and of simple geometrical figures, it will be useful to suggest the creation of a frame for the picture of the class, paying attention to the manual ability of the student and consequently graduating this activity accordingly (from the simple cutting of a cardboard support to the cutting and mounting of wooden sticks);
- in order to value the mastery of calculation abilities we may suggest simple problems of transaction in an active way (from buying a snack at the bar to the organization of a small party).

Both of these problems are apt to be developed on different levels or enriched with economical concepts.

Evaluation and self-evaluation

It is important to point out that the evaluation must take place within the activities of the class. If the teacher is aware that many features of autonomy are to be obtained through the achievement of mathematical abilities, then the evaluation of the pupils’ competences regarding their autonomy will spontaneously allow the realization of their mathematical skills, involving the pupil as well. So, even the evaluation will represent a self-evaluation for the disabled pupil, a kind of self-discovery, a real instrument of personal growth; let’s remember an idea, (due to A. Canevaro): the development of a self-evaluation, in order to help the pupil to be aware of his situation: the evaluation of the disabled student should be carried out twice; at first with appropriate support, and then without. In this way the child will be led to understand his performance with or without the support while, at the same time, there will be an encouragement of his social integration.

In order to get to a self-evaluation, the targets need to be stated, agreed upon and objectively related to common situations, which should be easy to interpret. This may seem easy for language learning, yet it seems difficult when dealing with mathematics. The evaluation will be easier for the teacher if the planning of activities is provided with an observation scheme, where every mathematical competence is pointed out and can be used by different operational suggestions: in this way, the teacher will be able to realize the abilities of the pupil at the end of his evaluation.

Conclusions

There are many examples in literature showing the advantages of mainstream school, involving mutual teaching and the concept of “zone of proximal development”.[8]

Several methods we have drawn attention to and defined as extremely useful for learning, are the same for every kind of teaching and can be extended, in a more general way, to the mainstream school process of disabled pupils. These methods turn out to be useful to teaching, which is directed to the individuality of each pupil, fostering growth and taking account of each student’s paths and rhythms.

Personal autonomy represents an important achievement for every young person, therefore the importance of the activities based on the above-mentioned methods is evident, since they are meaningful and useful to everybody. Once more, it is necessary to acknowledge the ability of mainstream school to reach unexpected skills: even mathematics!

Anna Contardi, Italian Association for Down Persons, Rome. annacontardi@hotmail.com; Michele Pertichino, Interuniversity Department of Mathematics, Bari. pertich@dmi.uniba.it; Brunetto Piochi, Department of Mathematics “U. Dini”, University of Florence, piochi@math.unifi.it.

References


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http://www.down-syndrome.info/library/periodicals/dsnu/04/01/
Dear Parents,

Please allow me to introduce myself. My name is David Corcoran and I am a member of the academic staff within the School of Psychology at the University of East London. I have a BSc in Psychology and an MSc in Clinical Neuroscience. My specific area of interest is within autism and I have over ten years experience working in a number of settings with children/adults with autism and other learning disabilities. I am currently undertaking a PhD in which I will be researching the imitative abilities of children with autism and Down syndrome.

For the research to be viable it will need children with autism as participants, children with Down syndrome, and typically developing children to compare with. If you are a parent of a child with Down syndrome and you would like to help, I would really like to hear from you.

Proposed research:

The aim of the study is to look at the ability of children with autism to imitate others. I hope to demonstrate that this ability is impaired in this group compared with children with Down syndrome and typically developing children, who have been matched for age and intelligence. The ability to imitate is a fundamental aspect of child development and what I hope to show is that impaired imitation is at the root of the social disabilities in childhood autism.

The research procedure will involve the children completing a number of cognitive and imitation tasks that are fun and which most children enjoy. All research procedures will follow the British Psychological Society ethics guidelines. This research will be undertaken under the supervision of two Chartered Psychologists. Also, complete confidence will be given to those who take part in the study. This study has received the full support of the National Autistic Society and has received their ethics approval. I have enhanced clearance from the Criminal Records Bureau (Police check which schools use).

The research will take place in your home so naturally a parent/guardian will need to be there with the child. I understand that many parents work full or part time. If you would like to take part, but feel you are unable because of work commitments, I would like to stress that I can be flexible. The research procedure takes approximately an hour and a half, which I break up into two or three sessions.

The research is important as it will have clinical and educational implications. If you would like more information you can contact me on: 07957 164 952 or by e-mailing me at: d.j.corcoran@uel.ac.uk

Thank you for taking the time to read this. I look forward to hearing from those of you who wish to take part.

David Corcoran
Requests for participants

**Do people with Down syndrome have difficulties processing speech sounds?**

*Margriet Groen, University of Oxford*

We are currently planning a research study about hearing and language problems in children with Down syndrome. More specifically, we will try to identify what kinds of problems people with Down syndrome have in hearing speech sounds, and how this relates to their language skills. We are looking for families with a child with Down syndrome between 8 and 12 years of age, who would like to participate in the study.

The research will be carried out in the Oxford Study of Children’s Communication Impairments (OSCCI) group under the supervision of Professor Dorothy Bishop and funded by the Wellcome Trust. The study has been reviewed and approved by the Oxford Psychiatric Research Ethics Committee.

The study will consist of the following parts: Parents will be asked to fill out a questionnaire about their child's communication. This takes 10-20 minutes to complete. Then, during an initial assessment at home or in school, we will assess the child's language, memory and motor coordination. This takes about 2 hours with breaks. Finally, families will be invited to come to Oxford University for a half day for more detailed assessment of auditory processing. This takes about 4 hours with breaks. Travel expenses will be reimbursed.

If you are interested in the study, contact me by email (margriet.groen@psy.ox.ac.uk) or phone (01865-271374) or write to me at the Department of Experimental Psychology, South Parks Road, Oxford OX1 3UD, and I will send you an information leaflet that explains the details of the study. For more information about our research program in general you can also look on our website: http://www.psych.ox.ac.uk/oscci/.

Thank you for your help and I look forward to hearing from you.

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**What factors support effective inclusive early years education for children with Down syndrome?**

I am a final year student on a part-time BA (hons) Early Years Education Degree at Newman College, Birmingham. For my dissertation I am conducting research into inclusion in mainstream schools. I am distributing questionnaires seeking the views of parents and teachers, who are currently involved with the inclusive education of children with Down syndrome in Foundation /Key Stage One. All information will be treated as strictly confidential, and used only for the purpose of this study. If anyone is willing to participate by completing a questionnaire or telephone interview please contact me.

Carol Regan
“Strathmore”, Talbot Avenue, Little Aston, West Midlands B74 3 DB

e-mail: clregan@tinyworld.co.uk

tel: 0121 353 0295

Thank you,

Carol
A Literacy Bill of Rights

All persons, regardless of the extent or severity of their disabilities, have the basic right to use print. Beyond this general right, there are certain literacy rights that should be assured for all persons. These basic rights are:

1. The right to an opportunity to learn to read and write. Opportunity involves engagement in active participation in tasks performed with high success.

2. The right to have accessible, clear, meaningful, culturally and linguistically appropriate texts at all times. Texts, broadly defined, range from picture books to newspapers to novels, cereal boxes, and electronic documents.

3. The right to interact with others while reading, writing or listening to a text. Interaction involves questions, comments, discussions, and other communications about or related to the text.

4. The right to life choices made available through reading and writing competencies. Life choices include, but are not limited to, employment and employment changes, independence, community participation, and self-advocacy.

5. The right to lifelong educational opportunities incorporating literacy instruction and use. Literacy educational opportunities, regardless of when they are provided, have potential to provide power that cannot be taken away.

6. The right to have teachers and other service providers who are knowledgeable about literacy instruction methods and principles. Methods include but are not limited to instruction, assessment, and the technologies required to make literacy accessible to individuals with disabilities. Principles include, but are not limited to, the beliefs that literacy is learned across places and time, and no person is too disabled to benefit from literacy learning opportunities.

7. The right to live and learn in environments that provide varied models of print use. Models are demonstrations of purposeful print use such as reading a recipe, paying bills, sharing a joke, or writing a letter.

8. The right to live and learn in environments that maintain the expectations and attitudes that all individuals are literacy learners.


David Yoder, Karen Erickson and David Koppenhaver, University of North Carolina at Chapel Hill.

... these authors have been pioneers in the USA in promoting literacy teaching for students who, in the past, never had the opportunity to learn to read. They are developing a range of resources and training opportunities for students of all ages.

See www.med.unc.edu/ahs/clds
‘Shona Rocks’

Derek Robertson

Shona’s father, editor and publisher

After living for 10 years in Indonesia, Shona Robertson regards herself as Indonesian, but some of the bouncy Australian teenager who went to Jakarta in 1994 still remains.

Shona is a 22-year-old librarian with Down syndrome working in a large preschool centre in Jakarta.

She keeps pretty much to herself, but she has some dark secrets and some challenging insights which she shares in her new book of poems and paintings “The Beauty of Life”.

The book was launched in front of 800 international delegates at the 8th World Down Syndrome Congress in Singapore in April 2004, where Shona presented a paper on why her work is important to her. See page 35 for Shona’s report on the congress.

Her poems are mostly about the vagaries of growing up in an expatriate culture among warm and supportive friends and family, but life is not always smooth.

Shona has plenty of advice for those around her and some very firm ideas on how life should be lived.

Despite driving through the angry mob which gathered in the aftermath of the shooting of Trisakti students in 1997, and despite the conflagration which reduced much of Jakarta’s CBD to ash and rubble, Shona remains convinced that there is hope for Indonesia and her poems reflect her optimism.

They also reflect all the issues of kids growing up from the intolerable teenage burden of parents, to the love of pets, the support of siblings, and the fascination of food.

Some of the art work is Shona’s but the book is beautifully balanced by the inclusion of some wonderful modern art courtesy of the Opera Gallery of Singapore, Miami, NY and Paris.

This is a book to seize the eye and stir the soul.

Shona has it all together. Good sense and good humour in abundance.

This young lady rocks!

The photographs above and below

above: Shona speaking at the 8th World Down Syndrome Congress
below: with her grandmother

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http://www.down-syndrome.info/library/periodicals/dsnu/04/01/
CONFERENCES

14 - 19 June 2004
12th International Association of the Scientific Study of Intellectual Disabilities (IASSID) World Congress.
Montpellier, France.
http://www.iassid.org/communication/12th.htm

25 - 27 June 2004
International Mosaic Down Syndrome Association (IMDSA) Convention.
Virginia Commonwealth University, Richmond, Virginia, USA.
http://www.imdsa.com/Convention_Links.htm

9 July 2004
Exploring the relationship between learning disability and visual impairment.
University of Portsmouth, UK.
http://www.port.ac.uk

3 November 2004
Close to Dying: Responding to Dying and Death in Learning Disability Services.
The Welsh Centre for Learning Disabilities in association with the National Network for Palliative Care for People with Learning Disabilities.
Greenbank Conference Centre, University of Liverpool, UK.
E-mail: toddsp@cf.ac.uk

1 - 4 December 2004
International Congress: Genoa. Gate to Europe for the Culture of Disability.
1 December - trecentennial of the foundation of CEPIM
2-3 December - 4th European EDSA Congress

25 - 27 February 2005
6th International Symposium on Down Syndrome Specificity. Organised by EDSA and ASNIMO (Balearic Islands Down Syndrome Association), Palma de Mallorca (see page 27 for more details).

2 - 5 August 2006
The 2nd International Congress of IASSID-Europe.
University of Maastricht, Maastricht, the Netherlands.
www.unimaas.nl/congresbureau or http://www.iassid.org/

23 - 27 August 2006
9th World Down Syndrome Congress.
Vancouver Convention and Exhibition Centre, Vancouver, BC, Canada.
http://www.wdsc2006.com
6th International Symposium on Down Syndrome Specificity
Palma de Mallorca, 25-27 February 2005

Keynote presentations:

- MEMORY, Darlynne Devenny, Institute for Basic Research in Developmental Disabilities, New York, USA
- PERSONALITY, Deborah Fidler, Human Development and Family Studies, Colorado State University, USA
- LEARNING DIFFICULTIES, Giovanni Guazzo, Centre Futura d’Ottaviano, Università Federico II, Napoli, Italia
- INTELLECTUAL FUNCTIONING, Robert Hodapp, Dept. of Special Education, Vanderbilt University, USA
- NEUROBEHAVIORAL ASPECTS, Lynn Nadel, Psychology Department, University of Arizona, USA
- AGING AND SUSCEPTIBILITY TO ALZHEIMER DISEASE, David Patterson, Department of Biological Sciences, Eleanor Roosevelt Institute, University of Denver, USA
- DOWN SYNDROME SPECIFICITY, Juan Perera, “Príncipe de Asturias Centre”, University of the Balearic Islands (UIB), Spain
- HEALTH SUSCEPTIBILITY, Alberto Rasore-Quartino, Hospital Infantil Galliera, Génova, Italy
- LANGUAGE, J. A. Rondal, Unité de Psycholinguistique, Dépt. des Sciences Cognitives, Université de Liège, Belgique
- FAMILY AND PAIRS, Salvatore Soresi, Dipartimento di Psicologia dello Sviluppo e della Socializzazione, Università degli Studi di Padova, Italia
- EARLY INTERVENTION, Donna Spiker, Early Childhood Program Center for Education and Human Services SRI International, California, USA
- BRAIN, Krystyna Wisniewski, Department of Pathological Neurobiology, Institute for Basic Research in Developmental Disabilities, New York, USA

Congress venue and special collaborations:
The Symposium will be held at the facilities of the University of the Balearic Islands (UIB), with the special collaboration of the Spanish Ministry of Health and the Ministry of Education and Culture, as well as of local authorities and organisations.

Publication of the book:
Following the conference a book will be published by Colin Whurr of London on the subject “DOWN SYNDROME SPECIFICITY”. More information will follow shortly.
European Down Syndrome Association news

The objective of EDSA is to promote the complete development of persons with Down syndrome, regardless of racial, linguistic, religious, philosophical or political considerations. Any initiative which contributes to this end from the viewpoint of health care, education and instructions, and human development will be encouraged. The aim is to improve their health, training, adaptation to and integration in society so that each person can, to the extent that he or she desires, lead as normal a life as possible, within the framework described in the United Nations Declarations on Human Rights, and on the Rights of Handicapped Persons; in the European Convention on Safeguards of the Fundamental Rights and Liberties; and in the Constitution of his or her country.

International Congress: Genoa, gate to Europe for the culture of disability

1-4 December 2004

1 December 2004 - trentennial of the foundation of CEPIM - Centro Persone Down
2-3 December 2004 - 4th European EDSA Congress

We hope to bring you further details of this congress in the next issue of Down Syndrome News and Update.

Member countries of EDSA

| AUSTRIA | ITALY | SLOVAK REPUBLIC |
| BELGIUM | LUXEMBOURG | SPAIN |
| CZECH REPUBLIC | MALTA | SWITZERLAND |
| FRANCE | POLAND | UNITED KINGDOM |
| GERMANY | PORTUGAL | |
| GREECE | ROMANIA | Applicant members: |
| HOLLAND | RUSSIA | |
| IRELAND | SCOTLAND | |

A list of EDSA members with full address and contact details is available on the EDSA website:
http://www.edsa.down-syndrome.org
Care of children with Down syndrome in the Czech Republic

Dagmar Dzúrová, Eva Křížová, Eva Matějíčková and Jana Střihavková

Department of Social Geography and Regional Development, Faculty of Natural Sciences; Department of Medical Ethics, 3. Medical Faculty, Charles University; Association of Parents and Friends of Children with Down’s syndrome, Štěbrova 1691, Praha 8; General Practitioner, Zelený pruh 90, 190 00 Praha 9

Introduction

The latest concepts of care for children with Down syndrome have been realised, accepted and implemented abroad for many years. These concepts are not limited anymore to health care connected to life in special facilities often situated at secluded places.[1,2] Given the conditions in the Czech Republic, we must concentrate primarily on the inclusion of people with Down syndrome into society. To pave the way for the acceptance of these people by the general public is another priority. Assistance and help based on the principle of respect for personality, wishes and needs is another key element of the new approach. People with Down syndrome must be, above all, given the opportunity to live in an environment which they choose, they must get the opportunity to educate and assert themselves (reflecting a shift from segregation to integration and, even inclusion). [1]

The new approach to individuals with Down syndrome is based on the idea that accepting a diversity of individuals and accepting various challenges means enrichment of society. The handicapped are not the only “needy” ones, but also those who can teach and give others a great deal. So-called healthy people are given various tasks when working and living with individuals with Down syndrome and come to realise their own commitments to others and to society in general. It is certain that natural contact between individuals with a different mental capacities, cultivates human values and the ability to perceive and evaluate.

Information on secondary prevention of congenital defects has been collected in the Czech Republic since 1985 (obligatory reporting of innate defects in children was introduced in 1994). According to Sipek et al,[3] 4701 cases of Down syndrome, out of 4326 live births, were diagnosed in the Czech Republic from 1961 to 1995. In 375 cases pregnancy was interrupted as a result of prenatal diagnostics. The average incidence of Down syndrome in children was over 8 per 10,000 live births. Adding the results of secondary prevention, the average incidence is 9 per 10,000 live births. Based on data published by the Institute of Health Care Information and Statistics one can state that the Down syndrome detection rate has been increasing over the
In the last few years (related to the development of screening examinations),

The Czech state does not fund centres providing necessary services and support to children with Down syndrome and their families. There are Centres of Special Pedagogy (CSP) functioning which serve this purpose to a certain extent. CSPs provide early care without demanding financial remuneration. Statutory and legislative issues pertaining to their activities call for the establishment of other supportive civic initiatives with the status of a legal entity. The formation of the “Association of Parents and Friends of Children with Down syndrome” at “Díté” (Child), a CSP in the City of Prague, was a logical consequence of this situation. At the present time this organisation interacts with more than 100 families with children with Down syndrome nation-wide. In co-operation with SCP “Díté”, the association organises a number of activities for children and their families. The list contains timely care, rehabilitation exercises, development stimulation programmes, special therapies, stimulation by non-traditional toys in the interactive “White Room”, toy rental, consulting services including crisis intervention, assistance in integration of children in kindergartens and elementary schools, weekend programmes, courses, holiday stays, publication of a periodical, translations of professional literature, and co-operation with foreign specialists and organisations.

Through an independent parents’ organisation, the Czech Republic endeavours to engage in the worldwide movement to support people with Down syndrome. The European Down Syndrome Association (EDSA), headquartered in the Netherlands, is a major European organisation focusing on health care activities. EDSA is also a co-organiser of the world congresses of Down syndrome: Madrid 1997, Sydney 2000, Singapore 2004. Unfortunately, there is a lack of specialists, mainly physicians, in the Czech Republic who could and should get involved in international research and activities to enhance the health and lives of people with Down syndrome.

**Conclusion**

The high acceleration of development in which the speed of change exceeds the capacity of human adaptability and the development of a gap between the rational thinking and emotions are risks of the present society. On the other hand, there is an increasing tolerance and sensitivity towards diversity. This trend has had a positive influence on the approaches to children with Down syndrome and their families. Contact with people with Down syndrome may be an opportunity for us to stop, search our souls and find ourselves again. Individuals with Down syndrome like all other people have one thing in common – they need to be loved, accepted and live in a safe environment.

**References**

The 8th World Down Syndrome Congress
14-18 April 2004
Joanna Nye
Delegate from The Down Syndrome Educational Trust, Portsmouth, UK

Highlights of my trip to the World Congress in Singapore

The World Down Syndrome Congress takes place every 3 years and this time it was the turn of the Down Syndrome Association (Singapore) to host the Congress under the auspices of Down Syndrome International. The organisers have been working very hard since before the last Congress took place in Sydney in 2000. As well as having to organise a huge programme they have also had to contend with the SARS epidemic, which caused the Congress to be postponed from October 2003 to April 2004. The organisers did an amazing job with all aspects of the Congress, from the main programme of over 120 presentations and workshops, to the ‘Merlion’ programme for people with Down syndrome and the many social events. They were excellent hosts, making everyone feel welcome and well provided for in true Singapore style. Around 800 delegates attended the Congress, from over 30 countries, including researchers, professionals, family members and people with Down syndrome. This international conference was truly at home in such a multi-cultural country as Singapore.

The conference was divided into two main sections. The first two days of the conference were set aside for a medical programme specifically tailored to bring the most up to date medical research to professionals working with people with Down syndrome, and though I did not attend this section, I heard this included a wide range of topics which promoted much lively discussion. Professor Ben Sacks presented a very useful summary of the key areas discussed at the medical section during the main conference. The second section of the conference, which covered 3 days, was aimed at a wider audience of families, professionals and researchers from a wide range of disciplines, and had a parallel programme for young people and adults with Down syndrome.

The main section of the Congress kicked off in impressive style in the Opening Ceremony with welcoming speeches by the President of Singapore, Mr S R Nathan, and members of the Congress organising committee. These were followed by a welcome display of international flags paraded by children and adults with Down syndrome through the congress hall and onto the stage. A clarinet performance by Sujeet Desai, a young adult with Down syndrome and an accomplished musician completed the opening ceremony. The President went on to tour the congress venue, including the chil-
The stands included Down Syndrome International, Numicon, Shona Robertson’s Beauty of Life poetry book, Diana C Sipaco’s artwork, our own Down Syndrome Educational Trust stall and a host of other Down syndrome organisations from around the world.

Professor Sue Buckley then presented the plenary lecture, setting the scene for the whole congress by talking about ‘The keys to a life of quality for individuals with Down syndrome and their families’. She reviewed research evidence and identified the ways in which services, support organisations and families can assist people with Down syndrome to reach their potential, highlighting key issues such as speech, language and cognitive development and inclusion into mainstream society.

Quality of life, as well as being a recurring theme throughout many of the presentations, was the topic of two specific symposiums. The first was chaired by Professor Roy Brown, and started with a well prepared talk by Karen Gaffney, a young woman with Down syndrome from the US, who talked for around 20 minutes with no notes or overhead slides. She reflected on her life and achievements, including her experiences of being included in mainstream school and employment, and being part of a swimming relay team who crossed the English Channel. Roy Brown then went on to present the key areas that need to be considered when thinking about and researching quality of life for adults with Down syndrome and their families. This was followed by two presentations of resent research studies by Trevor Parmiter in Australia and Ivan Brown in Canada focusing on the quality of life for the whole family.

The second quality of life symposium, again chaired by Roy Brown, started with a very moving presentation by Maureen Stratford, wife of the late Brian Stratford. Brian had originally intended this to be his last conference contribution before reducing his international commitments and his wife was able to carry out this wish on his behalf. The presentation was about the work they have been doing in Guangzhou, China since 1996, first setting up a small parent support group for families of children with disabilities, which has gradually expanded to provide much needed services, as well as gradually extending the network of support groups across China. The history of the work provides a clear model for setting up similar services in other developing countries, an issue which is often highlighted at these international meetings. The next presentation was made by Justin Marshall, a young man with Down syndrome from the US and his mother, Margaret. While Justin eloquently described his life, reflecting on the role of his family, school, work and community in supporting his goal to be just like everyone else, his mum operated a Powerpoint presentation of, often very entertaining, photographs to illustrate his talk.

Jo Shearer from Australia then presented results from two recent research studies, which have involved interviewing young people with Down syndrome and their families. One of the key points made was how in the family with a child with Down syndrome, this one member of the family can become the focus. Care needs to be taken in making sure that all members of the family are equally valued, and supported when they need to be, which mean different members of the family are the focus at different times. Across families, the keys to success in achieving quality of life for all members varied and each had a different solution. This symposium was concluded by Juan Perera who set out how life has changed for the person with Down syndrome over the past 15 years and his vision of what challenges lie ahead for improving this picture even further, including genetic and medical research, full access to human rights and facilitat-
ing the optimum quality of life for people with Down syndrome.

Quality of life was also discussed in another session of individual papers, including a joint presentation by Kylie Scott, an adult with Down syndrome from Australia, and her mum Evelyn, on how they have discussed Kylie’s goals in life, what they need to do to achieve these goals and how this has added in extra goals to try to achieve. For example if you want to live in a home of your own, how can you earn enough money to pay for it, and still have enough time to enjoy leisure and social activities? These were the issues that they discussed for Kylie’s life, but it was also clear that these were issues that Evelyn was also wrangling with, and are issues for us all – the title of the talk said it all: ‘Life-do we live to work or work to live?’. The second paper in this session highlighted how vulnerable some people with a learning disability can be, as Ivan Brown from Canada presented data from a national survey on levels of abuse and neglect in children with intellectual disabilities. This data suggests that levels of emotional and physical abuse are higher in this group than in the non-disabled population. Another paper highlighted the need for physical activity to aid quality of life, both for physical fitness and for social opportunities (Dr Anne Jobling from Australia), and this was clearly demonstrated at the end of the session by the talk and performance by a hip-hop dance group from Japan (Love Junx, led by Anna Makino), who also entertained us during the Gala Dinner.

I was also very interested in the education session, which contained papers on practical strategies for developing reading activities with adults with Down syndrome and a programme for personal and social development. The first paper described a strategy for developing reading comprehension, which made a novel use of rebus pictures to aid comprehension (Michelle Morgan). The second investigated the important role that popular culture, such as favourite pop bands and television programmes, can play in education and presented examples from a trial with reading activities (Karen Moni). The third paper in this session presented a programme for developing personal and social development called ‘Right to know’ which has been put together by the Down Syndrome Society of South Australia. The programme looks very well put together, with clear and interesting resources presented in an appropriate format for promoting discussion. It covers a range topics such as personal safety, human relationships, sexuality and friendships – very important topics for all young people, but which often need to be discussed explicitly with those with learning disabilities.

The team from the Trust were very pleased to be able to contribute to several sessions. In addition to Ben’s contributions to the medical aspects of the congress, and Sue’s plenary talk, she also contributed to the numeracy symposium presenting an overview of the difficulties that people with Down syndrome often have with number skills. I then presented findings from two recent research studies; one on the longitudinal study of early counting skills, which shows a very positive picture for counting skills, but highlights some difficulties in learning and saying the count words; the second on the very recent Numicon research study conducted in Portsmouth schools which has found benefits of using Numicon on top of regular differentiation of the UK National Numeracy Strategy for some children with Down syndrome. I ran a practical workshop later in the day on how to use the Numicon scheme for teaching number skills to children with Down syndrome. The final contributor to the symposium was Rhonda Faragher from Australia, who is a maths lecturer and the parent of a child with Down syndrome. Rhonda made an entertaining and thought provoking presentation on how number skills are an essential aspect to quality of life, contributing to meaningful employment and leisure activities, which was illustrated throughout with photographs of the adults with Down syndrome she has worked with as well as her delightful daughter.
Other keynote talks described the most up to date research on medical and biological approaches to cognitive development (David Paterson), and the contrasting levels of inclusion that can be found in Asian-Pacific countries (Levan Lim). **Trevor Parmiter** presented a keynote speech at the end of the final day, which focused on the quality of life theme once again, and summarised much of what had gone on during the previous three days.

One of the highlights of the conference for me was seeing so many adults with Down syndrome contributing to the main sessions. Each session of presentations and workshops was professionally introduced by one of the team of Ambassadors, all adults with Down syndrome from Singapore. In addition to the individual talks, one session I attended was a workshop with a panel of adults with Down syndrome presenting comments on what they do in their lives and facilitated by Roy Brown and Jo Shearer. The rule at the start of the session was ‘no talking by the audience until we let you ask questions’! The group discussed a wide range of topics from school to jobs, to relationships to families, hobbies and travelling, difficulties they faced and their hopes and dreams for the future.

As well as the programme for researchers and families there was a whole programme running in parallel for young people and adults with Down syndrome, named the ‘Merlion experience programme’ after the half lion, half fish symbol of Singapore – a statue of which guards the entrance to Singapore harbour. From the programme, it seemed to cover a wide range of topics from music, dance and drama sessions to workshops on reading and writing, friendships, sexuality, use of the internet, and time management, and many workshops were led by adults with Down syndrome. From conversation with a number of adults who had attended the workshops, the programme appeared to have been very well organised and enjoyable for all. Shona Robertson’s review in this issue tells us more about her experiences attending this programme and the Congress in general. The young adults and the children in the crèche were supported by a team of volunteers from Singapore.

Events for socialising and making contacts were of course just as important as the talks and workshops for all the delegates. A cocktail reception welcomed us to the Congress on the Thursday night, with drinks and canapés and live music by several adults with Down syndrome. On the Saturday night the gala dinner formed the main social event with a lavish five course meal, the newly launched Honour and Pride awards, entertainment and finally a disco, with the Irish, the Canadian and the Australian contingents competing for the ‘life and soul of the party’ award! In addition, there was a cruise on the river on a junk boat and a buddy disco event, which I wasn’t able to get to, but heard they were as much of a success as all the other social events.

On Sunday, the excellent and very busy programme was brought to a close by an assembly of the board of Down Syndrome International, with speeches from the outgoing President Sue Buckley and the newly elected President, **Dr Balbir Singh** – who has been the driving force behind the organisation of the Congress in Singapore. Finally, a closing ceremony took place where an international panel of adults with Down syndrome presented their thoughts on the Congress and their visit to Singapore, and the Congress flag was handed over to the hosts of the next Congress, which will be held in Vancouver in 2006.

The 9th World Down Syndrome Congress will be held in Vancouver, B.C., Canada, August 23-27, 2006

[www.wdsc2006.com](http://www.wdsc2006.com)
8th World Down Syndrome Congress
Singapore, 14 - 18 April 2004
Shona Robertson
Delegate from Jakarta, Indonesia

I went to Singapore to the International Down Syndrome conference. It was at the Suntec City in middle of the Singapore and I stayed in a hotel with my mum and dad. I can't remember its name but we were on the 31st floor and it had a good view and the lift was scary cause you could see the city from the lift and I didn't like being outside the building because I am scared of heights.

The conference opening was spectacular and I loved it cause it was the most spontaneous event ever. They put on the most marvellous show with everyone carrying flags from every different country. I kind of loved that. That was the highlight for me, combining all the countries together to make one whole world conference.

I had a bookstand there to sell my books and so I got to meet lots of people who wanted me to sign my book. I met the President of Singapore and his amazing wife and I signed a book for him. I also saw my friend Matthew from Australia and met lots of Australians from South Australia where I used to live. They put on a great rock and roll dancing performance.

I enjoyed the Merlion Experience because I met new people and I loved Singapore. We had to watch the schedule to know when we were speaking and meeting to make good points on things. We went on a boat trip and I loved it. I was on the top of the ship. We went around the Singapore harbour and I totally enjoyed it. The people who came on the tour with us, the helpers were great. They are married and they live in Singapore and they always help out. When we were lost we just asked them questions like where we were supposed to be, what schedule we were on, what room we should be in, if we were supposed to be talking as a group or making speeches. They also took us down to the arcade for lunch just with our friends and helpers.

The kids from Japan did rap dancing and they were really fast and they were very fit. We should all do that.

One night we went to a disco. It was hopping, moving and I liked the music and the food was far too much for me.

I like politics myself and if the war on terror did not start there are so many wars going on and we need to stop them. I am concerned for this country's welfare and I would like to express my opinion on Asia specifically. I would also like to mention one other thing: To get more tourists. Asia is losing tourists over the Bali bomb and I don't blame Australia for being scared of this country, but they shouldn't be because Indonesia is a good country.

The conference was really good and my mum and dad enjoyed it too. If we can get the Iraqi children to join we could donate food and drink to them.

We could ask every country if they have kids with Down syndrome then they can join us at the 9th DS conference in Vancouver. I will be there to support the 9th DS conference and we should have people from every country I hope.
Trust news

25th Anniversary Dinner Dance
To raise funds, and to celebrate the Trust’s achievements, we will be holding a Late Summer Ball, with a Grand Draw, on Friday 24 September 2004 at The Guildhall, Portsmouth – with Lord Brian Rix as after-dinner speaker. For more details about this event, please contact Shelley Ducarreaux at the Trust.

New grants and donations
In the few months since the last edition of Down Syndrome News and Update, we have received a number of significant donations that will enable us to expand our direct services for local children and initiate new publishing activities to benefit individuals with Down syndrome across the world.

Early Development Groups
The Down Syndrome Educational Trust has received two large grants to expand our early intervention services for pre-school children with Down syndrome and their families. This funding comes in the form of a grant of £59,000 spread over 3 years from BBC Children in Need, along with a donation of £15,000 from the Peter Harrison Foundation.

Our Early Development Groups provide a unique early-years intervention programme informed by many years’ practical experience backed by the latest research on Down syndrome. Young children and toddlers with Down syndrome from throughout Portsmouth, Hampshire and neighbouring counties visit The Sarah Duffen Centre to attend the groups so they can benefit from a wide range of specially targeted activities.

During each session, the children and their parents participate in structured small-group activities designed to promote development, with a particular focus on speech, language, communication, literacy, numeracy, cognitive development, social skills and behaviour. We encourage parents to use similar activities at home with their children on a daily basis. The groups do not receive any statutory funding, and they are intended to complement not replace existing statutory pre-school provision for these children.

Over recent years, these groups have proved increasingly popular and by the end of 2003 the existing groups were full to capacity, yet more families were eager to attend. The new grants will enable us to expand our Early Development Groups over the next three years to meet this demand, so up to 25 children can attend the groups. Many more children around the country and around the world also benefit indirectly from the best practice models we develop for the groups and share through our publications and training workshops.

We will be offering places on Tuesday, Wednesday and Thursday mornings from September – families attend fortnightly, which is 6 sessions each term. The new grants will also enable us to reduce the fee to £3.00 per session and offer a number of free places to families on income support plus travel costs if needed. We will have more staff available and will be able to offer a more personalised service.

If readers know anyone who would like to come please pass on this information. If you run a group or know of support groups within 60-70 miles of Portsmouth please send us contact details.

See and Learn – new educational materials
We have also been successful in securing a number of large grants towards our exciting See and Learn publishing project. Through the See and Learn project we aim to develop a structured series of language-learning activities to promote and measure the cognitive development of children with Down syndrome. These grants – £10,000 from the Rufford Maurice Laing Foundation, £10,000 from Credit Suisse First Boston, and £2,700 from Ambac – will enable us to complete the initial planning stage of the project, undertake a pilot phase later this year, and start producing the first printed resources.

The See and Learn project aims to provide parents, teachers and speech and language therapists with a pro-
programme of structured and graded language-learning activities specifically designed for children with Down syndrome. The See and Learn activities will be will be based on the key principle of teaching reading to teach talking, and will be available as both printed materials and computer software, which can be used either separately or in combination.

This comprehensive language and literacy programme will provide activities to help children with Down syndrome to progress from their first words to grammatical sentences. It will enable parents, therapists and teachers to make full use of reading activities to develop the children’s spoken language, alongside interactive communication games and everyday communication experiences. The materials will help children build from a core vocabulary to 2 and 3 word phrases, and then to longer sentences, in the same order as they develop in typically developing children. They will also provide a range of activities focusing on speech sounds and verbal short-term memory.

**Video equipment – new training materials**

Our publishing activities received a further boost thanks to a grant of nearly £15,000 from the St James’s Place Foundation. This donation will enable us to purchase a comprehensive selection of video production equipment, including high quality camcorders and a computer for video editing and conversion of archive footage. Over the next few years this equipment will enable us to produce an enhanced range of videos and DVDs providing practical advice and information, and demonstrating teaching activities.

The donation is the result of the fundraising efforts of Simon Fleet and a colleague at St James’s Place Foundation, resulting in a total grant of just under £15,000.

**AdviceLine**

As the result of a grant of £25,000 from the CIBC World Markets Children’s Miracle Foundation earlier in the year, we have been able to reopen our AdviceLine service in a limited manner. We have also been selected by CIBC World Markets Children’s Miracle Foundation as one of the beneficiaries of their 2004 fundraising campaign.

In order for us to respond to the greatest number of enquiries in the limited time available, we would prefer you to join our e-mail discussion lists, or contact us by e-mail or letter rather than by telephone. The telephone AdviceLine is only open to calls on Thursday afternoons 14.00-15.30. See http://www.downsed.org/adviceLine for full details.

**Building work**

Building work by our landlords Portsmouth City Council started on our site at Easter and will continue until September/October. They have completed the work on our car-park, and over the next few months will start demolishing a rear section of our building in order to increase the play space available to the primary school on the adjoining site to our building. As a result of the demolition we will lose our existing playroom and part of our large hall, but we will have two new rooms created in the remainder of the hall later this year. At times, this work may affect visitors and our activities, though we hope to keep disruption to a minimum. Once the work is finished, we hope to be renovating and developing other areas of the building. Any offers of help will be gratefully accepted.

As a result of this building work, the total car parking area available to the Trust will be permanently reduced. There is now only limited on-site car parking. This will mainly affect visitors to the Open Days and Early Development Groups.

**Singapore World Congress**

Three members of staff from the Trust travelled to Singapore in April this year for the 8th World Down Syndrome Congress – ‘Global Progress in a Changing Era’. Professor Sue Buckley gave a keynote speech on Quality of life for individuals with Down syndrome and their families. Professor Ben Sacks made a presentation on the diagnosis and treatment of hyperthyroidism and another summarising recent medical research. Dr Jo Nye discussed her research on numeracy, including the use of the Numicon system. Jo’s travel expenses were generously supported by the British Academy.

You can read a report about the Congress elsewhere in this issue of News and Update. The Trust will publish abstracts and selected scientific papers from the Congress in Down Syndrome Research and Practice.

**Services and Training**

Our services and training activities have continued at the usual pace during the last 3 months, with 17 children seen for assessments in addition to visits from 5 new families and the usually early development groups. We ran 4 training days at the Sarah Duffen Centre and a further 8 at locations around the UK. We are fully booked for both assessments and training until January 2005.

**Publishing**

During the next 3 months the priority here will be writing to complete the DSii Development and Education series before starting on our newly funded projects in September.
The Trust is sad to inform its friends and supporters that Leslie Duffen passed away at his home peacefully but suddenly on Saturday 8th May 2004. Leslie would have celebrated his 80th birthday in November.

Leslie’s commitment to early reading and the progress of Sarah, his daughter, inspired the Trust’s first research projects. It was a letter from Leslie in 1979 that prompted Professor Sue Buckley to begin research into reading and language development. This research led to the creation of The Down Syndrome Educational Trust and The Sarah Duffen Centre.

Leslie supported our work continuously over the 25 years since his first letter to Sue. We were so pleased that he was able to join us with his family at the HMS Warrior dinner in December 2003 to mark Sarah’s new position as Patron of the Trust at the start of our 25th Anniversary celebrations.

Leslie was also a founder member of the Down’s Babies Group based in Birmingham during the 1970s – the forerunner of the Down’s Syndrome Association. He helped many families and professionals by speaking at training events and on an individual basis. Leslie made a lasting difference to the lives of many young people with Down syndrome and their families.

His obituary in The Times commented that, “His positive approach to his daughter’s disability, and the importance of the discoveries he made with her, were such that the perception and expectations of Down’s syndrome children [sic] were to change dramatically over the next 30 years. He was to inspire thousands of parents with his positive approach... When Sarah passed her driving test in 1990, he gave his usual reply to astonished enquiries: ‘Nobody told me she couldn’t.’” (The Times, 27th May 2004)

Leslie will be sadly missed by all who knew him and our thoughts are with his wife Dilys and daughter Sarah at this sad time. If anyone wishes to contact them, the family would like you to send messages to The Sarah Duffen Centre c/o Sue Buckley and we will forward them.

A service of thanksgiving for Leslie’s life and work was held at Ilsington Parish Church, near Newton Abbot, Devon, UK on Sunday 11 July 2004. Instead of flowers, the family requested that donations be sent to The Leslie Duffen Memorial Fund (see below).

The Leslie Duffen Memorial Fund

With Leslie’s family, the Trust is establishing The Leslie Duffen Memorial Fund. The Fund will be used to continue specific research studies into the educational and developmental needs of children with Down syndrome. To make a donation to the Fund, please use one of our usual donation methods but indicate your wishes to contribute to “The Leslie Duffen Memorial Fund”.

Sue Buckley awarded OBE

Professor Sue Buckley, the Trust’s Director of Research, has been awarded an OBE in the Queen’s 2004 Birthday Honours List for services to special needs education. The award, announced on 12 June 2004, recognises Sue’s unique contribution to research and education for children with Down syndrome over more than 25 years.

Sue Buckley said, “This is a very considerable honour, and really it’s to be shared with everyone who is involved in our work - not just me. Since our earliest days, our focus has always been to push the agenda of inclusion for children with Down syndrome, so they can be with others their age or with their brothers and sisters at school.”

Richard Peck, Chair of the Trust’s Board of Trustees, commented: “Sue Buckley is a most remarkable lady who, because of her dedication, expertise and enormous determination has been an inspiration to both parents and children alike. Her belief that each child with Down syndrome is uniquely capable has been a driving force in so many ways, but especially in improving their educational provision.

“In the twenty-five years that she has been dedicated to this work, she has never tired in her quest to improve the lives of individuals with Down syndrome, and this has earned her praise and gratitude from many people in the UK and around the world.”

He added, “Through her leadership and example, she has established a team of professionals at the Trust who impart practical help and advice that is second to none.”

New Chair of Trustees

At a Trustees’ meeting in March 2004, Richard Peck (formerly Vice-Chair) was elected as the Chair of the Board of Trustees, with David McConnell elected as new Vice-Chair. We are sure that supporters of the Trust would like to join the Board of Trustees and the senior managers of the Trust in expressing their sincere gratitude to Nicholas Elwin, the outgoing Chair, for his invaluable contribution to the Trust’s activities over the past seven years, and his steadfast positive leadership through some difficult times and recent period of rapid expansion.

The Trustees of The Down Syndrome Educational Trust are now: Richard Peck (Chairman) • David McConnell (Vice-Chairman) • Murray Parkin (Secretary) • Suzanne Drummond • Nicholas Elwin • John Hussey • David Thomas • Nicola Wainhouse

All of our Trustees are either the parent, grandparent or a relative of an individual with Down syndrome, and bring a wide range of professional skills to the Board.
Branch news and contacts

Canterbury
The Canterbury Branch held a Ball on Friday 4th June. The Branch meets every 3rd Monday at Northgate Community Centre. 9.30-12.00. This is mainly an early years group - we hope to get some structured sessions going this year – please contact me for more information:
Sarah Kent on 01227 453926 or e-mail AlexHector@aol.com

Berkshire
The Berkshire branch held a charity ball at Blue Mountain Golf Club, Bracknell, on 5th June. Guests enjoyed Pimms on the terrace, a 3-course meal, live band and Disco, as well as a Casino, Raffle and a silent auction. For more details of the branch contact:
Colin Stonehouse: c.stonehouse@ntlworld.com tel: 0771 904 3603 or 01344 823476.

Bristol
The group meets every Monday at Henleaze and Westbury-on-Trym Community Church, Eastfield Road, Westbury-on-Trym, Bristol. For more details contact:
Annabel Dixey, tel: 0117 9624735 or Marie-Louise Cook, tel: 0117 9686893

New from Greenhouse Publications
Created by JOAN GREEN • Illustrated by LINDA COMERFORD

FOUR NEW INTERACTIVE READING BOOKS
• **I have feelings too** - explores the emotional feelings experienced by teens, adults and seniors.
• **What happened and why?** - students examine pictures and are asked to make inferences about what might have happened in each one.
• **Pigs in space** - a study in prepositions, animals and rhyming words.
• **Who’s on first?** - sequencing pictures of events.

Other books in the Interactive Reading Book Series:
• How many? • What color is it? • I go to school • Things I do at home • Action! • Sounds good to me
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Also available:

INTERACTIVE COMMUNICATION CARDS in four sets: • Home and Health • Food • Recreation/leisure and community • Sensory and social emotional. All sets contain 120 original high-quality, full-color illustrations printed on heavy laminated card, with words printed on the front and back to encourage literacy.

THE VISUAL SCHEDULE FOR THE CLASSROOM contains pictures of school-day activities, to remind students of their daily activities in the classroom, and to teach vocabulary words, to read, to write, or to copy, trace or spell.
Forthcoming training events

Training at The Sarah Duffen Centre, Portsmouth, 2004

**Tuesday 28 September:**  
The development and education of children with Down syndrome in infancy and pre-school years  
– overview birth - 5 years  

**Monday 11 October:**  
Meeting the educational needs of children with Down syndrome in mainstream schools  
– Primary  

**Tuesday 12 October:**  
The Numicon approach to teaching number  

**Monday 18 October:**  
Speech and language development for children with Down syndrome from birth to teenage years (Day 1/2)  

**Tuesday 19 October:**  
Speech and language development for children with Down syndrome from birth to teenage years (Day 2/2)  

**Monday 8 November:**  
Supporting the development and education of children with Down syndrome (Day 1/2)  

**Tuesday 9 November:**  
Supporting the development and education of children with Down syndrome (Day 2/2)  

For further details and booking forms, send for our Services brochure, tel: +44 (0)23 9285 5330, or e-mail: brochures@downsed.org

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Down’s Syndrome Association

8 **July**: Seamless transition to mainstream secondary school, Darlington. For teachers and support staff working with pupils with Down’s syndrome at Key Stages 2, 3 and 4.

8 **October**: Transition to secondary school, Greenwich. For teachers and support staff working with pupils with Down’s syndrome at Key Stages 2, 3 and 4.

13 **October**: Dementia and people with Down syndrome, Teddington. For professionals and those supporting individuals with a diagnosis of early onset dementia. Bookings to Julian Hallett tel 029 20522511 or email dsa.wales@lineone.net

10 **November**: Dementia and people with Down syndrome, Bristol. Focusing upon services for older people with Down’s syndrome and dementia. Further details from Victoria Ralfs tel 01275 858230 or email vr_dsasouthwest@hotmail.com

http://www.downs-syndrome.org.uk
Aims and scope

*Down Syndrome News and Update* aims to provide information to meet the needs of a variety of professionals and parents caring for individuals with Down syndrome around the world. It covers a range of subjects including early cognitive development, speech and language, general health, medical issues, education, behaviour, numeracy, social skills, and issues in adolescence and adulthood. Information is presented through detailed articles, reviews, research summaries, case studies, news, and by correspondence.

*Down Syndrome News and Update* should be of interest to parents of individuals with Down syndrome as well as speech and language therapists, doctors, psychologists, teachers, and other education and healthcare professionals.

*Down Syndrome News and Update* aims to provide a platform for the exchange of experiences and observations, as well as the dissemination of practical information. It therefore welcomes a diverse range of submissions for publication from short correspondence to detailed ‘subject overviews’. It welcomes contributions from professional practitioners and researchers, and from parents and individuals with Down syndrome wishing to share experiences and views.

Guidelines for contributors

Longer articles and reviews

Articles may take the format of a detailed analysis of a particular subject or issue, or a summary review. Detailed ‘subject overviews’ should draw on current scientific knowledge and clearly explain how this guides our understanding of effective interventions. Articles should contain sufficient background and information to be understandable to readers with little or no previous knowledge of the subject matter.

Summaries of research are encouraged but should be accessible to a wide range of readers. Researchers are particularly encouraged to draw out implications for effective practice from research studies. Detailed academic papers presenting research findings should be submitted to *Down Syndrome News and Update*’s sister publication, the journal *Down Syndrome Research and Practice*.

Shorter case studies, resource reviews, and personal experiences

Accounts of personal experiences of parents, professionals and individuals with Down syndrome are welcomed. Ideally they should focus on a particular issue or concern. Both accounts of particular success and solutions, and accounts of difficulties or problems, are encouraged. Shorter or more general accounts of personal experiences may be submitted as correspondence.

Reviews of books, teaching materials, educational computer software, as well as Internet and other electronic media resources, are all welcome. Full details of the subject of the review should be provided; e.g. publisher, source, ISBN, price, etc.

News

News items are welcomed from around the world, and in particular from organisations supporting individuals with Down syndrome in their particular region or country. A diary is available for notifications of a variety of events. This will eventually be linked with an events database on The Down Syndrome Educational Trust’s web site.

Correspondence

Correspondence from readers is particularly encouraged, whether as feedback on previously published material or as an expression of views and experiences.

Editorial review

All submissions will be editorially reviewed with particular regard for comprehensibility to a wide range of professions and parents. If the reviewers recommend publication of an article, but suggest amendments to it, the person submitting the paper will be invited to consider those changes before a final decision to publish is made. The Editor reserves the right to edit notes, reports and other submissions when printing and publishing timetables make consultation with authors difficult.

Submissions

Papers submitted to the Journal should be sent to:

The Editor, Down Syndrome News and Update,
The Down Syndrome Educational Trust, The Sarah Duffen Centre, Belmont Street, Southsea, Hampshire,
POS 1NA, United Kingdom or e-mailed to dsnu-submissions@downsed.org
Manuscript Requirements

Please send four copies of your manuscript, which should be typewritten and double-spaced on A4 paper, with any tables or illustrations. At the same time, please submit your article on a 3½-inch floppy disk or CD in PC or Mac format. Most word processors’ file formats can be supported, though Microsoft Word files are preferred. If in doubt, Rich Text Format (RTF) or plain text (ASCII or Unicode) files are the most compatible. Tables and graphs may be submitted in most major spreadsheet packages’ file formats (Microsoft Excel preferred). Diagrams should be submitted as ‘vector graphics’ file formats (e.g. EPS, WMF, etc.)

Manuscript layout

Title and authors: The suggested title should appear on the first page of the manuscript. The name(s), title(s) and affiliations of the author(s) should appear on the second page. Where there is more than one author, indicate who should receive correspondence.

Formatting and layout: Sub-headings are encouraged, and should be typed in bold. If sub-headings are of different sizes, please indicate clearly. Please do not indent paragraphs, but use two double-spaces between paragraphs. One space should be left after a full stop. Please use as little formatting as possible. Quotations of about 20 words or more should be placed on a new line.

Citing references: Bibliographical references within the text should be made by citing reference numbers (the reference list should be in citation order).

Terminology and spelling: As this is an international and an inter-disciplinary journal the needs of readers from different backgrounds should be born in mind. Technical or other terms specific to a particular discipline should be avoided if possible; otherwise discrete explanations or a glossary might be added. Abbreviations, such as of journal titles, should be avoided. Authors should avoid the use of potentially devaluing terminology for people with a learning disability. The terms ‘children with a developmental disability’ or ‘with moderate/severe learning difficulties’ are acceptable. The terms ‘mental handicap’ and ‘mental retardation’ are not. The term ‘Down syndrome’ should be written in full, and ‘syndrome’ spell with a small ‘s’ except when in a title. Please refer to ‘children with Down syndrome’ rather than ‘Down syndrome children’. All papers should be in English and spellings should be ‘UK’ English.

Glossary: Where technical terminology is used, please provide a glossary before the references.

References format

A key list of up to 8 bibliographical references, cited in the text, should appear at the end of the paper. The list should be numbered and ordered in citation order. Entries should adopt the conventions described in the APA style guidelines as contained in The Publication Manual of the American Psychological Association 4th ed., 1994 (Subject Reference: 808.02 AME). Some examples follow:

Articles

Chapters

Article (World Wide Web reference):