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- The development of communication skills for children with Down syndrome
- An update on Katrina’s progress with maths
- A review of numeracy resources
- Review of reading research

Cover picture: Harry Sked and mum Lisa on the set of EastEnders! See page 102.
Editorial

Welcome to the second issue of volume 6. The articles and information in this issue cover a range of important topics and we would welcome your feedback on any of these.

International perspectives

This issue continues to feature the European associations that make up EDSA (the European Down Syndrome Association). We would like to thank Cora Halder, director of Deutsches Down-Syndrom InfoCenter in Germany, for collecting all this information and writing it for us. There has been considerable growth in the number of Down syndrome support associations in Europe at the local, national and international level over recent years and the work that EDSA does in linking and supporting them is most valuable. It has grown from a group of some 10 organisations to some 30 organisations from almost every country in Europe.

Cora has also provided us with a great report of the 9th World Down Syndrome Congress in Vancouver (pp 79–82). The World Congress is a regular event and readers may like to note that the next one will be hosted for Down Syndrome International by Down Syndrome Ireland in Dublin, Ireland in August 2009. Ben Sacks and I had the privilege of contributing to the 10th International Congress on Down syndrome held in Caracas, Venezuela (p 82) and meeting some of the needs of families, practitioners and organisations in South America. The opportunities available to individuals with Down syndrome and their families still varies widely across the world and this is an issue at the forefront of the work of Down Syndrome International and the World Congress.

We would draw readers’ attention to the work of ASNIMO, the Down syndrome association of Mallorca, Spain. They recently celebrated their 30th birthday and received a royal visit (see p 84–85) from the Prince and Princess of the Asturias. ASNIMO has been a pioneering force in Spain and has also inspired many others in Europe. The article gives some idea of the range of their work and services as they support individuals with Down syndrome from birth to old age. Their director, Juan Perera, has also worked tirelessly to support others across the world. The Trust has worked with Juan for a number of years and recently he and his team have translated most of the books in our Down Syndrome Issues and Information: Education and Development series into Spanish.

Features

• Working memory

The first article by Julie Hughes, Speech and Language Specialist at the Trust, provides readers with an overview of working memory and its importance in speech, language and cognitive development. Working memory delay is a central issue affecting the progress of children with Down syndrome and the article gives a range of practical activities that may help to improve it. This article and the next were written for ICAN to contribute to their Talking Point project.

• Teaching reading

The second article by Julie provides a guide to the benefits and methods used to teach reading to children with Down syndrome. In my view, involving children with Down syndrome in reading activities and supporting reading using the principles outlined in this article is the most important way to improve their spoken language understanding and use – including for the children who do not read by themselves – as it provides a structured and intensive language teaching experience for them.

• Education software

The third feature article by Bob Black, Education Information Officer for the DSA, provides a valuable update to new IT software resources to add to those recommended in his 2003 book in the DSii series. Of particular note is Sound Beginnings – software to encourage sound and word production – as speech discrimination and production are significant challenges for almost all children with Down syndrome.

• Inclusion

The fourth feature article, by Elaine Mitchell, shares the experience of one family as they seek successful inclusive education for their child. It highlights the successes and the difficulties and many readers will probably identify with some of it. It identifies the need for much more training in inclusion for teachers and ongoing support to develop good practice around an individual child. We hope that our Inclusion in Practice DVD (reviewed on pp 74 and 102) will make a small contribution to this training need. In the inclusion section, we also have two stories of the successes of inclusion for Charlotte and Kizzy, so please read these.

Resources and training

We review a very informative new DVD by Libby Kumin - What did you say? A guide to speech intelligibility in people with Down syndrome. This is a third DVD produced by parent Will Schermerhorn. We also publish our Portsmouth based training programme for 2007.

Looking forward

We would like to wish all our readers a happy and peaceful holiday season and every good wish for 2007. Please keep your contributions coming in – the copy date for the next issue is 30th January.

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Developing working memory skills for children with Down syndrome

Julie Hughes
Speech and Language Specialist, The Down Syndrome Educational Trust, UK

Working memory is a temporary storage and processing system essential to everyday functioning. It is the system in the brain that supports the daily processing of visual and verbal information as people go about their lives. As well as being essential for language processing, it supports activities that involve holding and manipulating information such as reading and understanding written information, planning and writing a message, or remembering and diaivating a phone number.

Working memory is made up of three components (see diagram):

1. the central executive – the part of the system responsible for processing information.
2. the phonological loop – responsible for the temporary storage of verbal information.
3. the visuo-spatial scratch-pad – responsible for the temporary storage of visual and spatial information.

Children with Down syndrome have a specific impairment in short-term memory for verbal information (i.e. the phonological loop) and this will make processing verbal information and, therefore, learning from listening, especially difficult for them. Their visual-spatial short-term memory is better than verbal memory, making the ability to learn from visual information a relative strength. This can (and should) be used to support weaker verbal processing abilities.

Intervention strategies that may help to develop the working memory system need to include activities to:

- improve phonological loop function – essential for spoken language learning as it is thought to hold the sound patterns of words. This phonological loop impairment will make processing of single words and speech difficult, and contributes to the speech and language difficulties that many children with Down syndrome face.
- improve remembering of lists of items – children with Down syndrome face short-term memory span difficulties when they are trying to remember two or more items. This may also explain some of the pattern of speech and language delays and difficulties experienced by many children right from infancy.
- improve attention and increase processing capacity – research with typically developing children suggests that increasing attention skills and increasing processing efficiency will aid memory skills as well as increase the storage capacity in the visual-spatial and verbal storage systems.

Intervention strategies

Reducing hearing difficulties
The first issue to address is hearing. If a child’s hearing is compromised then he or she is not going to be able to set up clear sound patterns for spoken words. Parents should insist that they are given full details of the hearing assessments carried out for their child, including copies of audiograms and/or tympanograms. They should also be advised on ways of helping their child to improve hearing and listening skills. Reducing background noise will help a child to hear and listen more effectively. Family members and teachers need to be made aware of the need to speak naturally, but clearly, making sure they have the child’s attention before beginning to speak. Whenever possible, the child should be able to see their face in order to make use of lip shapes and mouth shapes to help discriminate sounds. Signing is an important aid to understanding new words and to keep your child’s comprehension and communication abilities progressing. However, signing will not help your child improve auditory discrimination skills or learn the sound patterns of new words.

Therefore, it is important to encourage the ability to discriminate and produce speech sounds and words as well as using signs with children of all ages.

Auditory discrimination of speech sounds
Right from the first year of life, speech sound discrimination is important. Babies will benefit from having the opportunity to listen to a range of speech sounds and sound combinations in play situations. Parents can play babble games to encourage their child to babble. First, it will help to listen and copy back the sounds your baby is making, then to introduce new sounds and see if your baby will listen to and/or copy the new sound.

At about a year old, children with Down syndrome can begin to learn and copy speech sounds as a game, using ‘Sound Cards’. Sound cards are cards with a picture representation of each of the sounds of speech, usually with a picture and the letter it represents (e.g. Jolly Phonics cards). Your child will benefit from being shown the card and watching and listening as the sound is made. This will help your child to develop the sound patterns in his/her memory for the sounds of the home language. Once your child is familiar with each of the sounds on its own, they can be asked to point to objects that have similar names (e.g. dog/frog, red/bread, chair/bear). Older children can play the same type of game using more advanced vocabulary.

Word discrimination games

The next step is to develop your child’s ability to detect sounds and sound patterns in words – referred to as phonological awareness. Games such as identifying words that rhyme or don’t rhyme, or identifying words that start or end with the same sound...
will help to develop phonological awareness. Pairing speech sounds and letters is included in all phonics schemes when children start at school. This is an important skill and most children enjoy learning this letter-sound correspondence. At the same time, children are beginning to learn a ‘sight’ vocabulary, a number of words that they can recognise from the pattern of the whole word. This ‘sight’ vocabulary gives all children an important start in reading and helps to strengthen the letter-sound link, leading to the ability to sound out unfamiliar words and to think how to spell a word by thinking of how it is pronounced.

Children with Down syndrome should be included in all class reading and spelling activities. This will help to develop their sound discrimination, phonic (sound in print) and phonological awareness (sound in speech) skills.

**Activities to improve attention and to increase processing capacity**

Activities to improve your child’s attention can begin very early and should continue throughout the school years. With very young babies, face-to-face babble games encourage extended periods of attention, as do many of the early games you naturally play with babies. As children move through the pre-school years, attending to teaching games which require sitting still and following instructions are important, first one-to-one with an adult and then as part of a group. In a group, your child has to learn to attend to the ‘teacher’ and to wait until it is his/her turn. Reading books with an adult is another activity that many children enjoy and will extend the length of time they will sit still and concentrate on a task.

Increasing attention in situations that require your child to process information can begin early with simple choice tasks. The number of items offered for your child to make a choice can start at two and then increase to three or four. You can ask your child to choose one item from a choice of options and then to choose two items from a choice of options. At home, meaningful choices can be encouraged from early on, especially at mealtimes. For example, ask your child, “Would you like a banana or yoghurt?” while holding up each item.

**Activities to improve remembering lists or numbers of items**

Games to help children to remember two or more items can begin in preschool years and follow on from the simple choice activities as explained above. Hiding games can be introduced, when appropriate, by hiding items under a cloth – first one item, then two and asking your child what is hidden. Remove one object but leave the others and ask your child what is missing. Simple memory games can be extended for older children using objects or picture materials. Line up three pictures face down. Turn over the first and name it – then turn it back to face down. Ask your child to remember what was on the picture. When he/she can do that, turn over two pictures and name each one as you point to it. Turn the pictures back to face down position, point to each one and ask “what is it?”. If the child can do this, then repeat the activity with three cards.

Activities designed to teach children to remember items in the order they were given is known as rehearsal training. The game described above is just one example of a rehearsal training strategy. Your child will need lots of practice with this game and it may take a year or two to add an additional item to your child’s memory span.
Once your child understands this type of task, you can add variations within the games. Make up some cards with numbers on them. Use the number cards to encourage remembering longer sequences of numbers. You can also use this method to teach counting by putting the numbers in sequence (e.g. 1-5, 5-10, 11-15, etc.). You can also use it to help your child to remember a telephone number.

For children who can read, this game can be used to encourage accurate remembering of short phrases or sentences. This strategy will help with grammar as each of the ‘little’ words can be incorporated into the phrases and/or sentences (e.g. the, a, an, of, but). These words often get lost in connected speech, but this activity will help your child remember and use these words in phrases and sentences.

Auditory rehearsal
As well as using visual prompts to help your child remember information, it is important to play games that require listening only in order to improve auditory and verbal short-term memory. You need to be aware that listening games, when your child has no picture prompts, will be more difficult for your child. However, you can help your child progress from using visual prompts to hearing and remembering the spoken word. The adult and the child each have a set of three cards with matching pictures on each set. The child must be familiar with the words on the cards. The adult’s cards are face down and the adult names each card but the picture cannot be seen. The child then tries to remember which card is where and puts their card with the pictures in the same order as the adult’s cards. In this way, the adult says the name of each item, but the child is able to respond using the pictures. Listening games can be played with lists of words or numbers.

Grouping or organisation skills
Grouping items to be remembered by the categories to which they belong is yet another strategy for increasing the number of items that can be remembered.

The aim is to teach your child to organise and store information in memory by categorising – putting items into groups.

Sorting tasks will help your child with grouping and organisational skills. Place one item from each of two categories on the table (for example a cup and a sock), and then hand your child one item at a time from the remaining items (i.e. other eating items and other clothes), and ask him/her to find the category that it belongs to. Alternatively, lay down many items from one category on the table, with one item that does not belong to the same category and ask your child, “Which one does not belong to the group?”

Everyday opportunities
It is important that your child is able to incorporate memory skills into everyday daily living. He/she should be encouraged to use the strategies as a way of remembering useful lists or items, for example during a game, running an errand or reporting a message. The aim is for the skill to be generalised from the training situations to everyday life. To achieve this, it is important to practise these skills in other situations. You can help with this by asking your child to deliver messages to others or fetch things from another room. Giving instructions can also help to improve memory skills, as your child will have to remember one, two, three steps of information in order to complete a task. Ask your child to recall the steps of an activity or recall what he/she did at school. After reading a story, ask your child to remem-
Developing working memory skills for children with Down syndrome

Rehearsal strategy

Remember the main events of the story in sequence. Sequential songs such as ‘Old MacDonald’, ‘One, Two, Buckle My Shoe’ are very good for teaching sequencing as items in the song are ordered.

Traditional children’s games such as ‘Pairs’ and the ever-increasing shopping list (I went to the shop and bought a...) are good for memory practice. Kim’s game, where items are placed and named on the table, then one object is removed – “which item is missing?” is also a good game for memory practice. There is also a wide range of computer programs available for use at home or at school which will support memory and phonics practice.

Supporting working memory in the classroom

In the classroom, children will be given verbal instructions about the day’s activities and classroom routines. Much of the instruction during lessons will be given verbally. When children with Down syndrome are in an age-appropriate mainstream classroom, they may find this difficult as it challenges their verbal short-term memory abilities. It is, therefore, important to use as many ways as possible to support learning by using approaches that do not put an excessive demand on verbal short-term memory skills.

Visual support – information that is illustrated visually, with words, sentences, pictures and symbols through lists, timetables and writing frames can support your child’s learning in all aspects of lessons. Visual information in the form of pictures, words and sentences can be used to rehearse information from the previous lesson before continuing with a linked lesson, or to revise a whole topic.

Visual records to support verbal presentation – pictures and words will help to focus your child’s attention and help him/her to listen, by providing context or background for the teacher’s lesson presentation.

Visual records to support learning activities – tasks and activities can be described in structured and clear steps in a list or frame, with line drawings where possible to reinforce meaning. In this way, your child can be supported to complete each activity as necessary, and given explicit encouragement to read and rehearse the list, find out what to do ‘next’, and follow the list to completion.

Summary

The short-term memory and processing skills described as working memory have been shown to be important for learning to talk, for processing spoken language and for the support of everyday tasks. Aspects of the working memory system seem to be specifically impaired in children and adults with Down syndrome and these impairments could explain some of the difficulties faced by these children and adults. However, improving the functioning of working memory could have a positive impact on the speech, language, and cognitive development of children and adults with Down syndrome.

Recommended reading


Other memory resources

Books and Teaching Materials


Jolly Phonics from [http://www.jollylearning.co.uk/](http://www.jollylearning.co.uk/)

Software

*Mastering Memory. Available in children’s (2-11 years) and adult’s versions from [http://www.masteringmemory.co.uk/](http://www.masteringmemory.co.uk/)*

Teaching reading skills to children with Down syndrome

Julie Hughes

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Research supports the view that all children with Down syndrome will benefit from being read to and from being in reading instruction from an early age as these activities will improve their spoken language and memory skills. Children with Down syndrome learn to read in the same way as typically developing children. They build on their good visual memory skills but find it more difficult to use phonics. In other words, they benefit from learning to read through a ‘whole-word’ learning strategy initially, bringing in phonics knowledge at a later date. While children who are introduced to reading in their preschool years show the highest levels of achievement, studies indicate that teenagers and young adults can continue to develop their reading abilities if given appropriate instruction.

Benefits of reading instruction

Reading is a fundamental life skill. Print is all around us in our daily lives and we acquire reading and writing skills for practical use (street names, sign posts, adverts, instructions) and for pleasure (writing a card, making a shopping list, looking up a television programme). Reading will help children with Down syndrome to develop vocabulary and grammar knowledge and will give added practice, and therefore improve spoken language skills. Reading practice will also help to develop working memory skills. The ability to read and write facilitates easier access to general knowledge and the school curriculum and it supports the skills necessary for problem solving and thinking strategies.

There is also evidence for the beneficial effect of reading on speech and language skills. Case study records suggest that early reading activities encourage progress to longer utterances and improved grammar in speech. They also suggest that reading improves articulation and speech intelligibility (the ability to be understood by the listener). For most children with Down syndrome, language comprehension (understanding) is better than language production (talking/ signing). This means that children with Down syndrome understand more than they can say, probably due to a variety of issues, which may include problems with word retrieval, sentence structuring and speech-motor control.

Working memory difficulties may also contribute to the speech and language delays that children with Down syndrome often face, limiting the amount that a child can organise and say clearly in a sentence. Reading provides opportunities to practise saying sentences that a child is unable to generate spontaneously even through he or she understands them. When children are reading aloud, the sentence is organised for them and the print is available without having to remember it, so the demands on the working memory system are reduced and its capacity can be used to plan and articulate each word more clearly.
Principles for learning

Reading stories daily to children from infancy right through childhood will help them to learn to read. Children who are read to know that books are fun and provide entertainment. Children who are read to often have larger vocabularies and they will know that the words on the page have meaning and tell the story. One of the most important ways in which parents of children and teenagers with Down syndrome can help them to be ready to read and be interested in books, is to read to them and talk to them about the stories they have read.

It is important to teach whole words and to develop reading for meaning as the first step – learning letter sounds will come later. All children learn a visual ‘sight’ vocabulary of words, remembered and recognised as whole words. As they start to read, they slowly develop the phonic skills (letter sounds that make up words), which will lead to them being able to sound out unfamiliar words and spell. A child should have a sight vocabulary of at least 50 words, which can be read and understood with confidence in simple sentences, before teaching any phonics.

Hearing loss

The incidence of mild to moderate hearing loss in children with Down syndrome is high and remembering some simple guidelines can help to compensate for their difficulties. Many children may only have a small amount of hearing loss, although hearing levels can fluctuate, but even a small amount of hearing loss affects listening and can affect behaviour, performance and language learning. Therefore, it is advisable to take account of possible hearing difficulties at all times by gaining your child’s full attention before starting and working in environments that do not have competing background noise.

Getting started

Children can only read with understanding if they already know and understand the words, the grammar and the sentence structures used in the text. Therefore, it is important to introduce reading activities at each child’s comprehension level. Children with Down syndrome will usually be delayed in language comprehension compared with other children of the same age and it is important to begin with vocabulary that they understand and with short simple sentence structures. As children with Down syndrome progress and begin to read simple text with confidence, using language that they already know, reading then becomes a powerful tool to use to teach new vocabulary and grammar.

Reading activities can begin when a child understands 50-100 words and can match and select pictures (e.g. picture lotto games). The same method used in these types of activities will be used to teach sight words.

Picture matching

Reading activities can start by using pictures to match on a 2 or 4-picture lotto board.

- Choose a picture and say ‘This is a ….(cup) – which one is the same?’
- Guide your child’s hand to complete the task successfully, even if that means physically moving his/her hand to guide the picture to the correct match.
- Provide as much support as your child needs to be successful and take away support as your child becomes familiar with the activity. This is called ‘errorless learning’. It is important to remember that this is not a test and your child is meant to succeed each time.

- Practise this game until your child can successfully match all the pictures on the board with minimal, if any, support.

Picture selecting

- Using the pictures that your child has just matched with minimal support, ask him/her to ‘give me (or show me) the ….(cup)’.
- Guide your child through the correct response; continue to practise with these words until your child can select each picture when it is named.

Picture naming

- Children may name words using signs or spoken words.
- Articulation problems may mean that spoken words are not clear. Praise and encourage approximations to word-reading, as practice helps children to make their speech clearer.
- Show your child the picture and say ‘What is this? It’s a ….. (cup), can you say cup?’
- Encourage your child to imitate the word.
- Repeat words after they have been said or signed, providing
Teaching reading skills to children with Down syndrome

- Use ‘errorless learning’ and prompt children with the correct answer, until they can say the word without hesitation.

Once your child can match and select pictures confidently in this way, written words can be introduced. Words for reading can be chosen from your child’s own vocabulary (the pictures they are matching and selecting correctly each time). Once your child can match pictures, it is important to go back to the beginning and teach the same words, but in the written form (with no picture), playing the same matching, selecting and naming activities with the words. All children are likely to begin to learn to read with some of the words that are very familiar to them and are heard and used throughout daily routines, such as ‘Mummy’, ‘Daddy’, child’s name, brother’s and sister’s names, important people or pets. They are then more likely to be interested in reading games about words for their favourite animals, favourite food and drink, favourite toys and play activities, social words, and favourite places. Colour words and ‘big’ and ‘little’ can also be taught, as these can also be used to teach children to join words together in speech and sign. Reading colour, shape and size words often seems to help children to understand them. It is important to begin reading with words that are nouns, verbs, and adjectives so that you can move from single words to word combinations quite quickly. Children need only learn a small sight vocabulary to begin to join words together meaningfully and usefully. Choose a few nouns, a few adjectives and a few verbs to make up their first 8-10 words, so that you can build short phrases and sentences and make individual books right away. One example of a word lotto board could be ‘Mummy’, ‘Daddy’, child’s name, and sleeping. Once your child can match and select these written words, you could then make a little book with the simple sentences ‘Mummy is sleeping’, ‘Daddy is sleeping’, ‘child’s name… is sleeping’, with corresponding pictures of each person sleeping. You could then move on to eating, jumping, drinking, etc. Most children love looking at photos of familiar people, so this activity is an ideal way to maintain your child’s focus and attention while learning to read.

Recommended order for matching activities

- Picture to picture.
- Word to word (matching, selecting and naming) – no pictures.
- Word to picture (this can be used to make sure your child understands what he/she is reading).

Additional activities

- Once your child is able to communicate expressively, take what he/she says and make the shortest correct sentence out of it. For example, if your child says “sand” or “play sand” when asked “What did you do today?” then write “I played in the sand” in a little book and draw a simple picture of your child playing in the sand (simple stick-figure drawings are fine for this). This is an example of expansion – the term used when we speak to young children and expand their one and two word utterances. In this way, we are modelling simple, grammatically correct sentence use and your child is practising speaking in simple grammatically correct sentences when reading the sentence aloud.

- Make the above activity more formal by using it as a link between school and home – a conversation diary. At the end of each nursery/school day, an adult asks the child “What would you like to tell Mummy and Daddy about school today?” Take whatever the child says and make it into a simple, grammatically correct sentence, with a picture added for meaning. When the child gets home, he/she shares the diary with mum and/or dad, either by reading it or participating in supported reading (imitating word by word, or pointing to the words as they are read by an adult). Then parents make entries at home for the child to take to school, to be read with an adult at school.

- Make personal books with photographs or pictures that are tailored to your child’s particular interests – using words and simple sentences to label each picture.

- Make personal books about your child’s daily life – ‘My favourite animals’, ‘My day at the zoo’, ‘I can…’, ‘I like…’, etc.

- Action games where the word (verb) or sentence with a verb in it is read, and then the action is undertaken.

Learning about sounds

Young children with Down syndrome learn to read by remembering whole words and their meanings before they are able to separate out the sounds in words and apply their letter sound knowledge to the task of reading. They are, however, able to learn about letters, the sounds associated with the letters and their names. Therefore, young children with Down syndrome should have access to and enjoy typical pre-school (and school age) learning games about the letters and sounds of their lan-
Teaching reading skills to children with Down syndrome

Summary

The value of teaching reading and using reading activities to develop the spoken language skills for children with Down syndrome cannot be underestimated. Children should be introduced to reading in a fun way, first learning to read whole words by playing matching, selecting and naming games and then moving on to reading short sentences and longer sentences in topic books.

All the activities and reading should be based on your child’s interests and experiences, and needs to be linked to your child’s language comprehension levels (understanding) and language learning needs. Children who have not made rapid progress with reading will still have benefited from these reading games and activities, as they are powerful and enjoyable ways of improving their understanding and use of spoken language.

Recommended reading


Additional information

1. www.downsed.org
2. Address enquiries to: enquiries@downsed.org
3. All Down Syndrome Issues and Information books are available from The Down Syndrome Educational Trust. Please visit the downsed online shop at http://shop.downsed.org/

Other reading resources

Books
- Interactive reading books. Greenhouse publications.

Software
- First Keys 2. Early Literacy skills. Widgit Software Limited.
- On the Farm. Early literacy skills. Inclusive Technology.
- abc–CD. Talking animated alphabet. Sherston Software Ltd.
- Clicker. Talking word processor with ‘on-screen keyboard’. Inclusive Technology Limited.

All the resources above available from downsed at http://shop.downsed.org/

Pops books. Published by Daneth Limited. www.pops-resources.com
In an effort to take a broad overview of the software that is available and which would be of particular benefit to children with Down syndrome it has proved difficult to move on considerably from those programmes that have been identified in earlier articles and in the Down Syndrome Issues and Information book “Utilising Information Communication Technology to Assist the Education of Individuals with Down Syndrome” published in 2003.

I am confident in continuing to support the use of all the software that was identified then and, while some programmes such as Clicker and Speaking For Myself are in new versions (Clicker 5 and Speaking for Myself Plus), the only changes that are particularly relevant to this group of children are the improved sound, graphics and animation qualities of the programmes. The relevance of the content remains much the same, while some activities have been further developed to address the specific learning profile of children with Down syndrome.

In the intervening period, however, there has been a bit of a quiet revolution going on in schools with the proliferation of interactive white boards and a much greater use of resources on the internet, brought about by the increased speed and reliability of broadband connections in the UK. Schools are increasingly accessing traditional core curriculum material from sources such as BBC interactive and an increasing number of sites offering printable resources for use in the classroom. Homework and revision for school work has been pretty much revolutionised by content from BBC bite sized and some schools have even developed their own web sites to include a range of curriculum software and resources for students.

It is hoped that many students with Down syndrome will benefit from the opportunities that interactive white boards give to offer visual clues and key content reminders, as well as accessing the curriculum through the web alongside their class mates. It will certainly remain true that the majority of students in this group will continue to need individualised and differentiated material in many areas of the curriculum as they grow and progress through their primary and secondary school careers. The ability of ICT to offer specific software in these areas is still outstanding. In this article I hope to identify the main newcomers and re releases that will offer opportunities for parents and educators to target specific areas of development where children may encounter difficulties.

Early vocalisation

One quite specific area where the technology has allowed improvement is that of speech activation. Not to be confused with speech recognition, where little has changed in term of its relevance to children with Down syndrome, speech activation is simply the ability to operate some software activities by the means of vocalisation. For young children and for a few older children the opportunity to reward vocalisation or the simple production of voice sounds can be very encouraging, and there have been a few nice simple programmes that have developed this capability well, using exciting activities operated by voice stimulus. A simple microphone is all that is needed – voice input training or complicated configurations are not required.

Sound Beginnings offers two programmes (and one for Macintosh computer users). The programmes have been spe-
Educational software for children with Down syndrome – an update

Sound beginnings: This programme enables you to select appropriate sounds, words and phonemes, and has the facility to let you import your own pictures, relevant and personal to your child. Its features include:

- gradually revealing pictures through sound stimulus
- rewarding pupils to say specific words
- encouraging extensive language work development
- promoting fun experimentation with sounds.

Sound beginnings 2: All the activities can be configured to suit individual users. You can also track progress of an individual through printable user records. There is even a gallery that can be viewed showing saved screenshots from certain activities that a user has accessed, e.g. Counting, Flying, Painting, Racing, Placing (see screenshots on this page).

Speech Viewer Three advances these ideas to improve the accuracy of speech sounds by representing speech sounds graphically. It is a more formal programme and requires some familiarity with using its features.

Early language and reading development

Significant improvements have been made to a number of programmes that support the development of whole word sight vocabulary, reading and spelling. The newer graphics in Speaking for Myself Plus, along with the improved signing support for a larger number of stories and nursery rhymes, has improved the range of activities and appeal of this old favourite, bringing it into line with the best of the most modern software titles.

It is currently being translated into Danish, with plans for more languages to be made available in the New Year.

See It Say It from Resource Education is among the best of the single activity programmes covering this area.

The latest version (5) of the widely used Clicker programme makes it more understandable. The new speech engine generates new voices such as ‘Acapela Graham’ and ‘élan Lucy’ who, while computer generated, have at last started to sound less like demented robots and more like real people. There are some fun alternatives such as ‘Female whisper’ and ‘Robosoft’ which offer some light relief. A big bonus for Clicker 5 is that they now have access to the ‘Oxford Reading Tree’ resources, previously the sole domain of the Sherston Talking Stories series.

The new series available for Clicker 5 has a range of useful activities such as word practice – developing whole word recognition – and sentence activities, including building and understanding sentence construction using whole words and missing word activities. All these are narrated by Tony Wilson using the familiar characters from the well-known book series. For comprehension there are picture-based and word-based activities appropriate to the level of the story, to aid and enable children to demonstrate understanding of the text.

An innovative approach to developing vocabulary and language knowledge is taken by Don Johnston Software in Earobics and resource education have further developed Wordwork 1 and 2 taking their usual simple and clear approach to topics.

Supporting inclusion and free resources for parents

A range of titles hugely expanding the catalogue of software that ‘Supports Inclusion’ has been released by Sherston Software. Titles include Easy Keysi, Mini Matchers and a special

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http://information.downsed.org/dsnu/06/02
Educational software for children with Down syndrome – an update

Edition of Tizzy’s Toybox, another updated classic specifically addressing its usability with interactive whiteboards.

Their Skill Builders series cover most common activities from Listening skills to Observation skills, Matching and Sorting. An innovation from this company allows those with reliable and fast internet access to subscribe to the whole series and access them online without ever having to install or store CDs again. They also have a nice free area where you can try out some basic activities free of charge (see resources).

More free activities can be found at Inclusive Technology’s ‘help kidz learn’ area with more being added before we go to print.

Another hugely expanded series is the simple Switch It series from Inclusive Technology with new titles covering a vast range of good quality, basic skills activities including ‘Bob The Builder’, for those who don’t have time to create their own activities in Switch It Maker 2.

Switch It Maker 2 allows parents and teachers to create their own activities using the pictures and sounds supplied or by using their own digital photographs and recording their own or their child’s voice.

Resources

Sherston free online activities:
http://www2.sherston.com/freebees/ict.htm

Free online activities from Inclusive Technology:
http://www.helpkidzlearn.com/

BBC free resources for home and school:
http://www.bbc.co.uk/schools/index.shtml

Clicker 5 (Cricksoft www.cricksoft.com)

Speaking for Myself Plus (Topologica www.topologika.com/)

Sound Beginnings (Semerc, Granada learning www.semerc.com/)

See it and Say it (Resource Education www.resourcetkt.co.uk/)

Wordwork 1 and 2 (Resource Education www.resourcetkt.co.uk/)

Earobics (Don Johnston Software www.donjohnston.com/)

Oxford Reading Tree Talking books, Skill builders, Tizzy and Easy Keysi (Sherston Software www.sherstonhome.co.uk/)

Switch It Activities, Bob the Builder and Switch It Maker 2 (Inclusive technology www.sherstonhome.co.uk/)

Jane’s education

Elaine Mitchell

Teacher and grandparent, UK

Jane has Down syndrome, oral dyspraxia and a small hole in her heart. She had, when last tested before entering primary school, an average IQ and her understanding of language has always been at least age appropriate. The development of her speech has been delayed and has caused problems throughout her education.

Jane is my granddaughter. Before Jane’s first birthday I had been to The Sarah Duffen Centre in Southsea, the home of The Down Syndrome Educational Trust (DownsEd). I had worked as a SENCo in a main stream primary school where we had pupils with Down syndrome but until Jane was born I had never heard of The Sarah Duffen Centre. Following the advice given by DownsEd Jane was taught to sign from an early age using Makaton.

Jane’s pre-school education started shortly after her birth with Portage. Jane was ‘taught’ by her mother as she followed the guidance given by Jane’s Portage worker, Speech and Language Therapist and Occupational Therapist. At the age of three she started nursery school, both state and private.

The state nursery school had enhanced staffing, with a member of staff who was fully trained in signing and who was responsible for a group of up to four children with SEN. Jane was the only child in the group for some time. All the staff could sign so Jane quickly became a fully integrated member of the class. The only problem was that the nursery was not in the same area as the primary school which Jane would attend. To ensure that she remained in contact with the children she had grown up with at play-school, she also went to the local private nursery for two sessions a week. Again she had her own support worker and again all the staff could sign.

Starting Primary school

The transition to primary school was preceded by formal assessment and a statement was issued. This enabled the school to put in place the necessary staff for full time support by a trained Makaton signer and, at a later date, lunchtime support. The SENCo from the primary school attended a review meeting at the nursery and observed Jane for a few minutes. The reception class teacher did not visit the nursery, and the LSA was not released for such a visit, but visited in her own time.

During the summer term Jane had weekly, half-day visits to the school to ensure that she was familiar with the surroundings and staff. Her mother supported her on these visits and although Jane met her class teacher her LSA was never released to spend time with her.

On her entry to primary school Jane had almost no spoken language but communicated very well through using Makaton. Receptive language was age appropriate. She brought in her wake a Speech and Language Therapist (SALT) and an Educational Psychologist (EP) each offering advice. The Occupational Therapist (OT) began visiting Jane in school towards the end of the reception year. There was limited knowledge within the school about Down syndrome and none of the staff felt it necessary to learn to sign.

Within a few weeks of entry I was asked if I could give any advice. There had been a change in staff in the Psychology Department, which left the school without an EP. The previous EP had stated that Jane had covered all her pre-reading skills and there was no reason why she should not start reading. We were aware that her lack of speech may cause a problem and had carefully selected reading books that would be of use, books that could be signed. These books, together with other useful materials, were given to the school to use with Jane. As Makaton is a support to language you always speak as you sign. Jane also ‘spoke’ as she signed, but it was the signing which revealed her understanding. As the LSA was the only person who could sign she appeared to become increasingly responsible for Jane’s education. Too much responsibility seemed to be placed on her and she was never given any appropriate training.

Throughout the reception year I visited the school to talk to the SENCo, the class teacher and the
Jane’s education

LSA. There were many instances when Jane would not display the same level of ability in school that she did at home. On such occasions I would work with Jane in school while members of staff observed. Fortunately Jane always worked well with me and we were able to give the staff some proof of what she could do. However, this had limited success since Jane often refused to work for the LSA and would be taken to various members of staff, such as the SENCo or the Headteacher, for being ‘naughty’. Such punishment had little effect on her; she was getting away from her classroom and her work. She could have seen these punishments as a reward.

She was quickly gaining the label of a child with problem behaviour. Perhaps if the class teacher could have used Makaton such problems would not have arisen. It was suggested that Jane worked for rewards. Initially this suggestion was rejected but later tried. It had limited success since the rewards were not negotiated with Jane and were not viewed as rewards by her. It was more rewarding for her to watch the staff get annoyed!

To try to maintain Jane’s learning her parents found a teacher who specialised in teaching dyspraxic children and also had experience of children with Down syndrome. This was a success, as the teacher soon realised how manipulative Jane could be and was able to work with her on the appropriate level of work. Her tutor became a great support for Jane’s learning and also for her parents. Jane continued to learn at home and the discrepancy between her achievements at home and school continued to widen, even though her tutor had offered to work with the school. Her mother began to feel that she had been labelled as a ‘pushy parent’ and that her knowledge and experience were not valued as she was not a teacher. This was both frustrating and upsetting but Jane was making progress, was happy at school and her social development was fine.

Missed opportunities

Towards the end of the year the EP had become involved and it was suggested that a teacher from the special school meet Jane and her LSA. As a result of the initial meeting it was suggested that both Jane and her LSA would spend one half day, each week for five weeks in the special school, with Jane working with an appropriate group of children. Only one of these visits took place. One of the reasons which was given was that the school could not afford the transport; in reply Jane’s parents offered to pay for taxis or to use their own car. This offer was refused.

Communication on a daily basis was done through a home/school book. This was maintained as Jane was unable to tell her parents what she had been doing at school. Its use should have been to keep the parents informed and enable them to discuss, with their child, what had been happening. It was filled in by the LSA. The LSA was also delegated to receive the child at the beginning of the day and to hand her back when school finished. No parent wants to be confronted with a list of their child’s wrong doings. Negativity is not going to help the parent, the child or the relationship between the home and school.

A further issue arose when the LSA was ill. There was no one with whom Jane could communicate effectively. There was another LSA in the school who could sign but she was never used to cover for absence. On one occasion, whilst the LSA was not in school, there was an instance of ‘bullying’. Jane would come in distressed after play and no one was able to get to the bottom of the problem. Once the LSA returned to school, the problem was solved, Jane told her what had been happening and it was dealt with. With that wonderful thing referred to as ‘hind sight’ it would have solved many problems if two LSAs had shared the post.

Noticeable improvements

At the beginning of Year 2 there was a sudden improvement in Jane’s behaviour. The class teacher saw signing as an essential to enable her to work with Jane. A weekly, ten-minute meeting was also arranged to enable
the class teacher and parents to pass over information. The help that had been offered by the private tutor was welcomed. There began to be a closer working partnership between home and school and the frustration and anxiety that the parents had suffered for two years began to subside.

By this time the responsibility for Speech and Language Therapy had passed from the health authority to education. The programmes were set as usual but suddenly access to information was denied to the parents. SALT now only worked with the child and the school, whereas previously the information and programme of work had been given to both the parents and the school. The programme of therapy that was to be delivered daily was not shared with the parents. The result was that during school holidays, at weekends and when the LSA was ill Jane received no therapy. As Jane’s speech had always been a major issue this became a cause for concern. The problem was never resolved.

At the beginning of the summer term Jane began to receive two hours a week, school based additional tuition (SBAT) delivered by a specialist teacher. The specialist teacher gathered information from both parents and the private tutor. Jane was no longer able to avoid working in school. The SBAT teacher soon discovered that Jane could be very manipulative when she decided that she didn’t want to work. She knew exactly how to convince people that she could not do things, that the work was too hard and that she didn’t understand it. She had been perfecting these skills for the past two years.

It has taken almost 3 years of constant stress for the parents to establish some true meaning to the words ‘parent partnership’. There can be no doubt that the decision to send Jane to a mainstream school remains the correct one, but many of the problems which have arisen could have been avoided with more effective communication. I have come to understand why many parents of children with Down syndrome choose to send their children to special school for their secondary education. The choice between mainstream and special school can appear to be a choice between socialisation and acceptance within the community and appropriate education. The knowledge and expertise which does exist is not easily accessible to the mainstream school.

It was not until Jane was born that I began to fully understand the enormous strain that having a child with SEN puts on a family. It is so easy for small misunderstandings to grow out of all proportion, to cause sleepless nights and tears of frustration and helplessness. It is so difficult to maintain some semblance of normal family life, for the sake of the other children within the family, without the added strain and exhaustion of having to constantly fight for your child’s right to an appropriate education.

Jane is happy, mischievous, determined, devious and surrounded by friends and people who care about her. She is learning to read, write and work with number. Her academic achievements are now behind those of her peers, but that was always expected. With the differentiation of her work Jane will be able to continue to learn, and hopefully continue to stay with her friends. Her social development and her ability to communicate are more important than academic achievement. Even when she could not talk she usually managed to make herself understood. She has always initiated conversations, originally by using Makaton, but in recent months her speech has improved so much that she can often be understood by those who know her, but Makaton will still remains essential to her further development.

In many ways Jane is just like any child of her age. She enjoys swimming, Brownies, dancing class, gym club and going to school. Her achievements are those of the many people who have helped her since her birth and have supported her and her family throughout her life.

My sincere thanks go to all such people.

Despite this ‘tale of woe’, Jane is making progress in academic subjects and she is well integrated into the school community. Her academic achievements are a result of the efforts made by her parents and her tutor, but this is not the reason why I have chosen to write this article. Jane is fortunate that she has both a mother and a grandmother in education, as they have been able to make up for the limited knowledge within the school and maintain the constant battle to attempt to ensure that she has the academic education to which she is entitled.

At a recent conference, run by Sue Buckley and her team from DownsEd, it became apparent to me that many parents are, quite naturally, concerned about the education which their children are receiving but may I suggest that one of the main factors...
which should be constantly considered is that such children have a slower rate of development. There is time, lots of it, for these children to achieve their potential and the concern about their education should not overshadow the great pleasure and satisfaction that there can be in watching and taking pleasure in this slower pattern of development. Every small step in the right direction is celebrated with joy and relief. Please do not waste this precious time by becoming over concerned about the rate of progress that your child is making. It is a fine balancing act, but there is the knowledge and support available for parents, it sometimes just takes time and effort to access it. I feel that I am possibly ‘preaching to the converted’ but do try to stand back and enjoy their childhood, and share your experiences with other parents who may benefit from your knowledge and support.

My thanks go to all the people who work so hard to make the knowledge which we require available to us and to ensure, through their work and support, that our children can have the care and support which they deserve.

To finish on a positive note, the hole in Jane’s heart has finally healed and with a new headteacher in place, and intervention and support from the LEA there are now strategies being put in place to address some of the issues which have caused so much concern for Jane’s family. Her speech, as predicted by the speech and language therapist several years ago, has improved with amazing clarity and speed over the past twelve months. We were advised that she would not have any ‘useful’ language until she was 10, she celebrated her tenth birthday last weekend.

This article has been updated from one originally published in Special! magazine, 29, Spring 2006, and is printed with permission. www.nasen.org.uk

Elaine is a specialist teacher working in mainstream schools with SpLD students. She worked as a primary class teacher and a SENCo before starting her own business.

National Examinations 2006: Entry Level Passes in GCSE Year!

Congratulations to sixteen year old Charlotte Horner, who sat National Examinations in her GCSE year at Entry Level and passed Entry Level 1 for Mathematics and Science, Entry Level 2 for English and Food Technology and a GCSE pass for Art.

Charlotte’s work experience and Prom night were featured in the latest issue of Down Syndrome News and Update.

Charlotte is now at Yeovil College in Somerset and has settled into her daily routines. She continues to study basic skills in more practical ways and is also learning about skills for life. She has also enrolled on the Drama Course and is playing a ‘detective’ in her first play.
Dear Editor,

The last time I wrote was back in March 2004 [DSNU 3(4), p.141] and I feel it’s time I wrote again showing my great pride and inspiration for a little (not quite so little any more) girl called Kizzy.

I worked with Kizzy for 5 years in total as her support assistant within a mainstream school (2001-2006). As you can see from the school photos (top - reception year, centre - year 4) Kizzy has developed in so many ways.

This year she has shown maturity I only ever dreamed of seeing – It’s been a hard step for me ‘moving on’, I wanted to move further in my career which meant I had to move on however hard it was. However, Kizzy has taken it in her stride informing me “you can help other children”, after this comment I thought I had better make sure she fully understood what was happening and explained that I wouldn’t be there any more, when she turned, looked at me and said in a meaningful voice “don’t be silly of course you wont be, your leaving”. Now this was a potential tear jerking moment, but I thought about it and realised how far we had come in those five years; she had shown understanding, compassion, independence, a sign of coping and willingness to move on. I held back the tears and told myself that this should be a very proud moment, there no longer stood beside me that ‘little girl’ who used to wander off to find me when I was out of sight for only seconds but a girl fast approaching double figures who accepts change, talks about it, and deals with it in an appropriate manner.

This has in fact brought home to me that change is good – I still see Kizzy at least twice a week and have to say I certainly have higher expectations from her now – maybe this is a lesson to us all ‘every now and then take a step back, observe the situation and most importantly review it, after all a little finger maybe being wrapped around’!

Here ends my moral of the story, but so many thanks go out to that ‘big girl’ Kizzy and her mother Nicola for being the most supportive and inspirational people anyone could dream of when starting off in a career – A big thank you to you both.

Finally, I hope the photo of Kizzy with me after receiving her Key Stage Two Head Teachers Award at the end of the 2005-2006 school year does bring a tear to your eye – What an achievement!

Clare Andrews
Learning Support Assistant
Norfolk
Inclusion in practice - Educating children with Down syndrome at primary school

Reviewed by Maggie Hart

Education Co-ordinator for The Education Centre for Children with Down Syndrome, Darlington, UK

“I inclusion in practice – Educating children with Down syndrome at primary school” explores and explains the benefits and practicalities of including children with Down syndrome in a mainstream school setting. The film is broken down into ten comprehensive chapters which, when played in its entirety, flows easily, it also allows users to revisit and readily pick out specific chapters.

As a parent and a teacher, I found the first 4 chapters particularly interesting. The parents on the film highlighted a real desire for their children to be included in their local communities and, by immersing their children with other children in their local schools, the parents on the film seemed to feel that this was being achieved. The first four chapters show the key principles that need to be in place in order to ensure that a school is prepared in an inclusive way before the children arrived.

Planning ahead (chapter 3) identified that a proactive approach, rather than a reactive one, by the Local Education Authori-...
ciples that needed to be applied in order for children with Down syndrome to access the curriculum to the best of their ability.

- Staff must be aware of the particular profile of learning both their strengths and weaknesses that children with Down syndrome generally follow.
- Staff need to support every teaching and learning objective visually.
- Staff need to give children, who may not be talking yet, every opportunity to show their level of understanding by pointing/choosing/signing the correct answer.
- Staff must not forget that children with Down syndrome, like any other children, will have their own abilities, likes and dislikes that can be used to motivate the children.

The staff members that were interviewed for the film gave an honest account of their experiences of working alongside their children. They talk about the challenges some of them have faced and what they have done to overcome these challenges. What was really evident and positive, was the teachers’ and teaching assistants’ ability to get to know the children and their desire to find and discuss resources and techniques that would enable their children to participate and access the curriculum that they were following. Again, proper planning helped the staff to do this. Often Teaching Assistants were given the weekly lesson plans in advance and given the time to look over the plans in order to find, adapt and make appropriate resources to support the intended learning objectives.

Chapters 5 and 6 deal with the progression of number and maths and developing literacy and language skills. These chapters will be of particular interest to teachers who may be expecting a child with Down syndrome to enter their class or who already teach a child with Down syndrome.

Chapters 7, 8 and 9 deal with friendships, behaviour and encouraging independence. These are all areas that can be addressed easily at primary school if a strong foundation for a successful inclusive placement has already been established by the school (linking back to the importance of the need to forward plan.)

The main message that Sue Buckley, Gillian Bird and the rest of the people who have contributed in the making of the film, is that educating children with Down syndrome in a primary school setting is achievable and is being done well in some areas of the country. Parents need to take heart that inclusion can and does work, even if their own local authorities are not at a stage to incorporate inclusion at such a committed level that is evident in Portsmouth. Individual schools, which have an inclusive ethos, enable children with Down syndrome to be successfully included. I sincerely hope that parents will recommend this film to their schools, and that the schools in turn are inspired by it.

A personal thank you to The Down Syndrome Educational Trust, on producing such an excellent film that examines the wide range of issues relating to children with Down syndrome when discussing successful inclusion. I look forward to the release of the further films “Development in Practice – Activities for babies with Down syndrome” and “Development in Practice – Speech and language activities for toddlers with Down syndrome.”

Purchasing details
Please visit the downsed online shop at http://shop.downsed.org/

Language: English
ISBN: 978-1-903806-83-8
VAT Rate: 17.5% (UK Std rate 17.5%)

Price (GBP): GBP £13.53 (exc. VAT) / GBP £15.90 (inc.VAT)
Price (USD): USD $25.36 (exc. VAT) / USD $29.80 (inc.VAT)

Publication dates
Development in Practice – Activities for babies with Down syndrome will be available in late December 2006
Development in Practice – Speech and language activities for toddlers with Down syndrome” will be available in January 2007.

(DVD 59 minutes)
Written and Produced by Libby Kumin, Ph.D., CCC-SLP
Directed and Edited by Will Schermerhorn, Blueberry Shoes Productions

Reviewed by Julie Hughes
Speech and Language Specialist, The Down Syndrome Educational Trust

Many children with Down syndrome have an uneven profile for speech and language development. Communication skills are usually good and vocabulary development is delayed, but grows steadily, with understanding ahead of expression. Grammar tends to be a bit more problematic, and again, understanding is ahead of expression. Clear speech is more difficult, and continues to be an area of need for many children with Down syndrome. ‘What Did You Say? A Guide to Speech Intelligibility in People with Down Syndrome’ is an excellent resource for parents and professionals who want to know more about the areas that effect speech intelligibility (how well the speaker is understood by the listener). This DVD provides a thorough guide to speech development and highlights the difficulties that some children face. The information is presented clearly and concisely and key points are printed on-screen so that the information is accessible in a variety of ways. The viewer can listen to the commentary, note key-points written out on the screen, and gain information from the clips that give examples of areas of speech development as well as practical games and activities that promote clearer speech. A separate section called ‘Speech Intelligibility and Your Child’s IEP’ guides parents and professionals through the writing process for IEP goals that focus on speech intelligibility.

The DVD is divided into 8 sections that explain different areas that effect speech intelligibility. It highlights the most common difficulties that underlie speech intelligibility problems for children with Down syndrome. What could be a very confusing
and difficult topic to get across is explained in a way that is easily understood by the viewer, even if that person has little or no experience of how speech and language skills develop. The video clips of young adults speaking in a group are very inspirational and parents are treated to clips of games and activities to promote clearer speech, which will give them some ideas of how to get started at home. Many of the suggestions are very practical and can easily be worked into everyday routines.

Sections

1. **Anatomical Factors**: mouth, tongue and face.

2. **Physiological Factors**: movement of the lips, tongue, teeth, jaw, hard and soft palate.

3. **Neurofunctional Level**: muscle function, strength, tone and co-ordination; sequencing sounds and combining sounds into words.

4. **Perceptual/Speech Symptoms - what do we, as the listeners, hear**: volume (loud/soft); rate (fast/slow); pitch (high/low); resonance (sound made in nose or mouth); inflection; rhythm; quality of the voice (breathy, hoarse or harsh); dysfluencies (lack of smoothness in speech); hearing loss may be a factor.

5. **Pragmatic Language Factors**: social use of speech for interaction (e.g. initiating a topic, taking turns in conversation, stay on topic, end a conversation).

6. **Nonverbal Factors**: facial expression, gesture and eye contact.

7. **Language Message Factors**: the listener's familiarity with the topic.

8. **External/Environmental Factors**: how the environment and/or setting can affect intelligibility (e.g. background noise).

Although the influence of hearing loss may not be sufficiently stressed throughout, information about assistive technology such as loop systems and fm systems are explained in the DVD so that parents are made aware of the technology available and can make enquiries with the appropriate professional for more information.

The DVD goes on to address speech intelligibility in the Individual Education Plan (IEP). The section begins with an explanation of what an IEP is and then goes on to describe the components of an effective IEP. It explains to parents what to include in an IEP and even gives a helpful checklist. Examples of both effective and ineffective goals are provided so that parents can see examples of the ‘language’ used in the document. Although some of the information is specific to the US, the guiding principles that are set out would be appropriate for any child’s IEP, regardless of where they live. The information is practical and useful, and can be used as a guide, particularly for parents who are new to the process of IEPs.

This DVD would be a welcome addition to resources for parents and professionals. It highlights the importance of the SALT/parent collaboration, noting that treatment doesn’t just happen in the therapy room, but occurs all day, everyday. The clips are very inspiring and give examples of very young children who are just beginning on the journey as well as school age children and young adults who are well on their way. It will inform parents and professionals about the many areas involved in speech intelligibility and will provide a starting point for therapy options when addressing clearer speech.

**DVD: running time 59 minutes**
**DVD-R format**
**Available in NTSC**
**Available from Blueberry Shoes Productions.**
**Price $29.95**
**ISBN 1-890627-78-X**

See [www.blueberryshoes.com](http://www.blueberryshoes.com/) for details of how to order

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Two other DVDs by Will Schermerhorn are available from The Down Syndrome Educational Trust:

- *Down Syndrome The First 18 months.* Reviewed in DSNU 3(4).

Please visit the downsed online shop at [http://shop.downsed.org/](http://shop.downsed.org/)
The 9th World Down Syndrome Congress in Vancouver – first impressions

Cora Halder
Director, German Down-Syndrom InfoCenter

The World Down Syndrome Congress is held every three years, and this year the big event was organised by the Canadian Down Syndrome Research Foundation (DSRF). Well over 1000 delegates from many parts of the world came to Vancouver, not just to learn more about Down syndrome but also to celebrate it, because this international gathering is such a positive experience, with so many children and young people come together there.

“Making Waves” was the motto for this congress. Making waves was certainly a theme that ran through the opening speech by Andrea Friedmann, a 36-year-old actress who is perhaps best remembered in Germany from the TV series “Life Goes On”, in which she played the girlfriend of Corky (played by Chris Burke). Since then, she has appeared in many films, and last year she even had her own TV show. Andrea explained that the first wave was the decision of her parents not to put her in an Institution, as advised by the doctors, but instead to do everything they could to promote her development. Later waves were the founding of self-help groups, through contact with other parents, and then inclusion in mainstream schooling. Later in the Congress there were certainly some high points: people with Down syndrome showing that they could be independent, mix with other people, make their own decisions and advocate for themselves. Not everyone can reach the heights that Andrea has, but the important thing is not to give up but to carry on.

Andrea went on to talk about the terminology that is frequently used in connection with people with Down syndrome. She said: “I hate words like mentally retarded or disabled. I am challenged not disabled! Disabled means ‘can’t do’ but my friends and I can do anything. Many things are difficult for us, and it takes longer to do things, but if we try hard we can achieve a lot.”

Andrea received a standing ovation before hurrying off to the airport on the way to her next speaking engagement, just like any other celebrity.

On the Upside of Down

“On the Upside of Down” was the song for this congress, especially composed by Rick Scott, a popular Canadian writer of children’s songs. Throughout the four days of the congress, he was either on the big stage entertaining the whole audience, or in workshops with the children and young people with Down syndrome, and of course he performed at both of the evening
learning is always an issue for people with Down syndrome. There were numerous references to the importance of orderly and structured methods, which have been proved to be most effective for children with Down syndrome.

The problem that one is always faced with in these congresses is: which sessions should one go to? It would be possible to go to 15 talks a day if one never stopped – that would be 45 lectures in 3 days. However, there is not enough time to do it all!

I especially liked an exceptional exhibition of embroidered and knotted tapestries by the Canadian artist Jane Cameron. The first book that was given to me on the subject of Down syndrome 21 years ago was “Jane C. Symbolic thoughts in pictures and words” by Professor Max Klager. For me it was an enormously positive experience to see what people with Down syndrome were capable of.

The congress continued with a session by the Down Syndrome Medical Interest Group (DSMIG), and meeting of Down Syndrome International (DSI). In the evening was the Opening Ceremony, with a dinner, show, presentations and a special event for families with children – the days could seem lengthy without the chance to renew old acquaintances and strike up new contacts.

Exceptional people with Down syndrome

At the Opening Ceremony, various people with Down syndrome demonstrated their great abilities. An astonishing young Japanese pianist played his own composition, and also had a stand selling a CD of his music. A young lady from Vancouver Island, Erin Lane aged 20, was next on the stage. Ever since she could read and write, she has composed stories and poems and has now filled books with them. Their composition and style are created through an extraordinarily good feel for language. Erin’s poems tell of happy times and are meditative and reflective. She recited her words with self-confidence and spontaneity, and distributed signed and illustrated copies of her poems after her recital (see photo below).

Also amazing were the 40 Japanese breakdancers, who have been dancing together as a group for 5 years and the South Australian Rock’n’Roll dancers Club Slick. Throughout the congress they gave general dance workshops for all the children and young people present, and they also did dance demonstrations in the lunch breaks and in the evenings. Fantastic! Who would have thought, even 10 years ago, that people with Down syndrome would be performing real Rock’n’Roll on the dance floor?

The speciality of another young man, a dancer from Canada, was...
modern tap dance, in which he never missed a step.

Special teaching materials

The best of the new teaching programmes and resources come from Australia again this year. It is amazing how many of these come from the Down Syndrome Association of South Australia – not only have they put together a good reading and writing programme for young children, but also stimulating and attractive resources for teenagers and adults.

The “Right to Know” materials, for example, consist of a series of worksheets on the themes of Friendship, Sexuality and Personal Safety. The aim of this programme is to make it possible for students with Down syndrome to have the opportunity and knowledge to decide for themselves which friendships to keep up with and which to stop, and how to deal with their sexuality in an appropriate way, so that they can safely be part of society. There is also a comprehensive collection of worksheets that can be introduced throughout the school years. They are clearly structured and build on each other, so that teachers are led through the abundance of resources in small steps, allowing guidance for pupils from infancy up to young adulthood.

There are similar specially formatted materials for other subjects like History, Geography. Social Sciences and Nutritional studies. The subjects are the same as the mainstream curriculum in primary and secondary schools, so that the pupil with Down syndrome is being treated the same, and can participate in the class using their worksheets.

Such a wealth of resources should stand pupils with Down syndrome in good stead in inclusive settings. Unfortunately in Germany, this is not always the case, especially in secondary schools. If there is no differenti- ated material, the pupil cannot work at his or her own level, may get bored, and be either unable to improve their learning or feel overwhelmed by the general class materials - this can result in behaviour problems, with the child getting more and more difficult until they have leave the school. This is not inclusion! It is not the fault of the child but of the educational system that the needs of this group of students are not being met.

The South Australian Down Syndrome Association works together with teachers and pupils, and receives about $500,000 of state funding annually for this project!

DADS - a special self-help group

DADS (Dads Appreciating Down Syndrome) is an association founded by fathers for fathers of children with Down syndrome. It gives fathers the opportunity to talk to other men about Down syndrome and how it has changed their lives, something which, as a rule, they find more difficult than do mothers. That such a group was necessary was demonstrated by the speed by which its membership has grown. It started with 8 men in Indianapolis in 2002. At the monthly meetings, there are always new faces wanting to discuss health, developmental and legal issues, as well as individual opportunities for their children. There is now a network of DADS groups in the USA.

They organise regular recreational activities such as picnics and sports events. Each year they go with their children for a day’s fishing and also collect money at a big golf tournament. They hold workshops and have online support for fathers, grandfathers and siblings.

The quotations on the next page show how important this group has been for fathers.

Special chance meetings

For many years I have had known Professor Siegfried Pueschel, one of the best-known international experts in the field of Down syndrome, through written correspondence. Above all he is an enthusiastic reader of Leben mit Down-syndrom, about which he contacts us regularly. I was very happy to meet him in person
at the congress, where he was invited as a specialist.

Another high point for me was meeting Dennis McGuire and Brian Chicoine, who I hold in high esteem as professional authors of many articles about adults with Down syndrome. Some of their articles have also appeared in earlier issues of *Leben mit Down-Syndrom*. Both of these experts manage the Adult Down Syndrome Centre at the Lutheran General Hospital in Chicago. Since it was founded in 1992, more than 3000 people with Down syndrome have been examined and given advice at the centre.

McGuire and Chicoine presented their work and introduced the Congress to their newly published book *“Mental Wellness in Adults with Down Syndrome”*. The title of his talk was “Pride and Prejudice: Living with Down Syndrome in the Real World”. In his abstract he wrote: People with disabilities generally, and people with Down syndrome specifically, often face teasing and bullying when they are in the community. This session will equip those who support them to help them learn strategies for dealing with real world taunts and tortures. Moving past the insensitive advice of “just ignore it” participants will learn how to teach people with Down syndrome to understand teasing and bullying and how to respond to it.

He was an absolute supporter of inclusion, he said, but the subject that is rarely brought up is the added pain that people with Down syndrome feel ‘outside’, a pain that we don’t often notice because we are deaf and blind to their signals. Hingsburger, an overweight man, who even as a child was extraordinarily large, has felt the same throughout his life. He knows what it means to be excluded.

There is a saying in English: Sticks and stones will break my bones, but names will never hurt me! “Nonsense, Wrong, Lies” said Hingsburger. Words can cause pain very well. Words can hurt. Really hurt. When someone with a disability says that they are annoyed, have been pestered, to say “Just ignore it” is disrespectful; more than that, it seems to mean “Get off! Go away! I’m not interested. Leave me in peace”.

We will be publishing the useful tactics and strategies suggested by Hingsburger in the next issue of *Leben mit Down-Syndrom*. The role that DADS plays in my life goes further than things to do with Down syndrome - if I’ve had a good day I call them, if I’ve had a bad day I phone them five times!

Because of DADS I can now celebrate my child’s achievements.

Steve, father of Sky, age 3.

10th World Down Syndrome Congress to be held in Dublin

It is the custom to announce at the closing meeting where the next World Congress will be held. The country that will be the next host can now advertise this and invite people to the next big event.

So Pat Clarke from DSA Ireland, who is now responsible for the organisation of the 10th World Congress, showed a short promotional film about Dublin and mentioned some of the highlights which the Irish have in store. “Continuing the journey towards life long living and
The 10th International Congress on Down Syndrome: “Opening new doors. Answers to the challenges of the 21st century”

Asociación Venezolana para el síndrome de Down (AVESID), Caracas, Venezuela, 4-5 November 2006

Speakers at the congress were Arturo Alvarado, Ben Sacks, Elias Vived, Isodoro Candel, Juan Perera, Marisa Escudero, Maybe Bilbao, Nuy Planas, Sandra Forero, Sue Buckley and Waldon Parra. Among the topics covered were medical, psychological and psychiatric issues; occupational therapy and adapting water-based activities for people with disabilities; stimulating creativity and motor skills through music and movement; pre-linguistic intervention and improving attention in babies and young children; inclusion in school and the work place, and employment schemes.

The Association has also produced a 2007 calendar, a CD entitled “Cree en mí” and a DVD “El Gran Escape” featuring young people with Down syndrome having a great time shopping and going out on the town.

www.avesid.org

Watch this space!
www.wdsc2009.com
Research

Research into speech difficulties and dysfluencies in children with Down syndrome

My name is Rebecca Baxter and I am in my final year at University College London (UCL) where I am studying a degree course to become a Speech and Language Therapist. Before going to UCL I worked for 4 years as a Teaching Assistant with a young girl with Down syndrome. As part of my final year’s work I am contributing to this research project.

I am writing to ask for your help with some research that is being carried out jointly by The Down Syndrome Educational Trust in Portsmouth and the Speech Research Team at University College London.

The research that we are doing is investigating speech and language development and stuttering in children with Down syndrome. By doing this we hope to be able to help speech and language therapists to identify those children with Down syndrome that might be at risk of stuttering. It will also develop an assessment package for speech and language therapists to use when working with children with Down syndrome who experience problems with fluency.

We are looking for volunteers for two research projects

1) **Children with Down syndrome who are just starting to talk (one or two words).** The language development of this group will be monitored for at least a year. We would like to make audio and video recordings of your child and for them to do some language assessments. These assessments are done on a laptop computer using touch screen technology and children find them fun. The recordings and assessments will be done at The Sarah Duffen Centre in Portsmouth and should last around 30-45 minutes. We hope to follow the children for a number of years if funding permits us to do so.

2) **Children with Down syndrome (aged from 3 - 18 years) who are already talking.** We would like to talk to the parents in this group about how your child speaks and how they feel about speaking. This can be done on the telephone and takes approximately 15 minutes.

If you would like to help with either of these research projects please call Steve Davis on 020 7679 5399. We will then contact you to answer any questions you might have about the research and to arrange for a convenient time to do the language assessments.

Rebecca Baxter
September 2006
Speech Research Team, UCL Department of Psychology
University College London, Gower Street, London WC1E 6BT.
E-mail: stephen.davis@ucl.ac.uk
www.speech.psychol.ucl.ac.uk

Early communication and literacy skills: investigating how children with Down syndrome learn to read

As you may know, many preschool children with Down syndrome can learn a sizable sight vocabulary of written words. To advance to a level of literacy which will enable them to enjoy reading and to cope more independently with written information and instructions, readers also need to develop skills for decoding unfamiliar words and interpreting text. My study will investigate the role of phonological awareness (that is, being able to recognise and organise the sounds within words) in this crucial phase of early reading development. It is hoped that the findings will illustrate ways in which learning to read can be approached by children with Down syndrome, so that teaching can build upon their preferred strategies and cognitive strengths.

I will monitor each child’s progress over a period of two to three years. The assessments are sensitively designed to accommodate any hearing difficulties and delayed communication, so that all children are able to experience success, gaining positive feedback and encouragement. I am recruiting children who are aged between 3 and 5 years. If you agree to your son or daughter taking part in the study, I will begin with an initial visit to discuss the research and carry out a preliminary assessment taking about 1 hour.

I am a qualified teacher and have previously worked with children with learning difficulties in primary schools. If you are willing to join the study, or would like further information, please contact me.

Mrs Fiona Dalton, Department of Psychology, Royal Holloway, University of London, Egham, Surrey, TW20 0EX.
e-mail: Fiona.Dalton@rhul.ac.uk
Tel: 01784 414648 or 07808 68846

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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.

The Prince and Princess of Asturias came to Mallorca and visited the facilities of the Balearic Islands Down Syndrome Association (ASNIMO) on the occasion of its thirtieth birthday. The centre was the first centre built in Spain to provide comprehensive attention for people with this disability.

Prince Felipe and Princess Letizia toured some of the services at the Príncipe de Asturias centre, which has been ASNIMO’s headquarters since it was founded. The centre’s director, Dr. J. Perera, told them about the work ASNIMO does in areas such as research, care, training, health, advice and integration, and that it currently provides services for over 400 people with Down syndrome. The director highlighted the importance of specific and personalised education, focused on the autonomy that prepares young people to live and work in an independent way in today’s society.

Facilities

During their visit, the Prince and Princess were accompanied by the president of the Balearic Islands Government, Jaume Matas, the president of the Mallorca Island Council, Maria Antonia Munar, the Spanish Government delegate, Ramón Socías, and the mayor of the Town Council of Marratxí, José Ramón Bauzá, among other local dignitaries.

The tour around the ASNIMO facilities began at the Sempre Verd gardening centre, where the Prince and Princess greeted a group of twelve workers, their colleagues and employers.
Next, in line with the arranged programme, the Prince and Princess visited the Llar Sa Lluna, sheltered housing that provides a home for 12 older adults with Down syndrome. Then they signed a birthday greeting for the association in its visitors’ book, just as Her Majesty Queen Sofia did 11 years ago.

They also toured the Bakery and Patisserie workshop, where they sampled a piece of typical Mallorcan cake, then the dried flowers workshop, where young workers produce ornamental arrangements of dried flowers which are sold in florist shops around Mallorca.

Back at the central building, they went to see the Early Intervention services, and while there Princess Letizia cuddled several babies and showed special interest in the problems families encounter when a child with Down syndrome is born. Just a few days later the Royal family broke the news that Princess Letizia was expecting her second baby.

After this they continued on their tour around the psychotherapy, psychomotor therapy, speech therapy, careers guidance and computer services. They also stopped by at the Day Centre which caters for 12 people with severe added problems.

Professional interest shown by the Prince and Princess

During the visit to all these areas, the different staff in charge explained the specific programmes used by the different services and answered questions asked by the Prince and Princess who showed special interest in the techniques used, the evolution of those being helped, and the results achieved.

Before going on to the conference room, where several speeches were given, Their Royal Highnesses greeted a group of thirty people who work at local companies, and were informed about the school inclusion schemes that ASNIMO is running at 22 schools on the Balearic Islands, along with schemes relating to incorporation into the job market and independent living, as well as the Tutelary Foundation that was recently set up.

Afterwards the Prince and Princess stopped in the Hall of the ASNIMO main building and the Director showed them display cases exhibiting publications and prizes that ASNIMO has received over the years. Dr. Perera gave Princess Letizia a gift of the latest book published: “Down Syndrome, Neurobehavioural Specificity”, published by Wiley in the UK.

In the conference room and in the presence of over 500 family members and guests, Their Royal Highnesses presided over a simple ceremony in which Carlos Cruz, a 16-year-old boy, welcomed them and on behalf of his companions went on to express their desires to “be independent”, to live with maximum autonomy and be able to enjoy life, form relationships and find rewarding work.

In his thank-you speech, the centre’s director highlighted the work that the Association has done over the course of its 30 years in existence, during which it has served some 900 people with Down syndrome in the Balearic Islands.

Before the event finished, the Prince and Princess of Asturias unveiled a plaque commemorating their visit then chatted in the Centre’s gardens with families and guests.
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Who is who in EDSA?
compiled by Cora Halder
Deutsches Down-Syndrom InfoCenter

Introducing another seven members of EDSA

In this third article of the series “Who is who in EDSA?” I would like to present some information about EDSA members from the following countries:

- Downsnyroom Vlaanderen, from Belgium/Flanders
- Associazione Italiana Persone Down (AIPD), from Italy
- Association Francaise pour la Recherche sur la trisomie 21 (AFRT), from France
- APPT21, from Portugal
- ASNIMO (Asociacion Sindrome de Down de Baleares, from Spain/Balearic Islands
- Fundacio Catalana Sindrome de Down, from Spain/Catalonia
- Deutsches Down-Syndrom InfoCenter, from Germany.

The article gives details about the organisations and some general information about the situation of people with Down syndrome in these countries. However, it is only intended to give a short overview, so it is worth looking at the web sites of the different organisations to stay up to date with what they are doing.

It is just as important to cooperate with other groups on an international level as to work at creating a better situation for individuals with Down syndrome in our own countries. EDSA members can share ideas and learn from each others’ experiences – please note the dates of the European Down Syndrome Conference in Paris next year, timed to coincide with World Down Syndrome Day.

European Down Syndrome Conference
Paris, 23/24 March 2007

World Down Syndrome Day, 21 March 2007

annual EDSA meeting

see the web site at: www.diderotp7.jussieu.fr/AFTP for updates
Belgium/Flanders Downs syndroom Vlaanderen

Internet: www.downsyndroom.eu

Founded: 2001, as a non-profit organisation of parent members in the Flemish-speaking part of Belgium

Presidents: Pia Wösten and Allard Claessens

Members: 500

Finances: membership fees and donations

Main goals
Promoting inclusion, equal rights and equal treatment, respect for diversity.
Supporting families and persons with Down syndrome.

Services
- counselling
- seminars, courses
- family days

Publications
- our regular journal “Tripliek” is published 4 times per year
- information flyers

Awareness campaign
There has been no regular DS-awareness campaign in Belgium until now. But we organised various activities (e.g. invite a person with Down syndrome for breakfast or lunch!) on World DS Day in March 2006 and will do that again next year.

Projects and campaigns
Our main project next year is organising a congress in March 2007 on medical and development topics for parents and medical and therapeutic professionals.

General information
The main problems in Belgium for persons with Down syndrome, which should be urgently changed are:
- there are still many prejudices against people with Down syndrome
- there is no official support for inclusion
- lack of medical protocols

Numbers
Approximate number of children born with Down syndrome in Flandren/Belgium per year: We estimated that there are about 50 babies per year, but a new official number for 2005 was only 27 (probably due to prenatal diagnosis).
The approximately total number of persons with Down syndrome living in Flandren/Belgium is 3000.

Situation of babies and toddlers under 4 years:
Medical care, physiotherapy an early intervention are relatively good, but could be better in many places.

Situation of schoolchildren
About 50% of children up to 6 years are in mainstream kindergarten
About 10% of children (6-12 years old) are in mainstream schools
All other children go to special schools.

Situation of adults
Adults work in sheltered workshops or spend the day in day centres
They mostly live at home with their parents or are in residential care.
We do not know about older people with Down syndrome. They probably live in institutions or homes/hospitals for old people.

Veerle Vandeputte, contact person for Downs syndroom Vlaanderen in EDSA. Veerle has a son with Down syndrome.

The Journal of Downs syndroom Vlaanderen is published 4 times a year.
Italy: Associazione Italiana Persone Down (AIPD)

Internet: www.aipd.it
Founded: 1979. Non profit organisation
President: Giuseppe Cutrera
Members: 1500
Finances: membership fees, financial support from state, donations, selling materials/books, special events

Main goals
AIPD supports people with Down syndrome and their families (even if they are not members) through non profit activities.
AIPD supports research on Down syndrome and gives up-to-date information.
AIPD supports school inclusion, job training and the social life of individuals with Down syndrome following them from childhood to adult life.

Services
• counselling
• seminars, courses – library
• family days, leisure activities

One of our main projects, that we would like to publicise here is: The educational course in the acquisition of autonomy.
The impulse to autonomy, towards making people able to manage by themselves, rather than by others acting in their stead, is really the animating spirit of not just this project but more in general the policy and operational standpoint of the Association. We aim to help the whole family by: offering consultancy, for example, rather than direct help; by informing parents of their rights and, in general, at returning to persons with Down syndrome their role as subjects endowed with rights rather than objects of welfare.

The first educational course aimed at developing a capacity for autonomy in persons with Down syndrome was introduced in the AIPD association in Rome in 1989. The course, which was designed for boys and girls from 15 to 20 years, has been repeated every year with an ever greater participation and has been replicated in many other cities.

In order to face the problem of autonomy it is necessary to present oneself not only the objective of obtaining some skills, but also that of recognising and favouring the change in the subject’s condition of child to that of adolescent and then adult. It therefore, means creating a feeling and a way of relating oneself to others, a mentality of trust and of respect towards the adolescent. It is in such a climate that the adolescent may find greater motivation to learn and may grow as a person in an ever more global manner.
The programme of the course has kept account of the premises and has, therefore, at the same time developed its actions and turned its attention in this direction.

The structure of the course
The educational course for the acquisition of autonomy, takes place in free time and takes the form of a series of afternoon meetings (of about 3 hours each).
Each adolescent meets up, once a week, with a group comprising 8 or 9 persons with Down syndrome and 3 or 4 social workers. After a joint session the group divides up into subgroups of 2/3 persons with Down syndrome plus a social worker and a volunteer worker.
The greater part of the proposed activities take place inside the subgroup. In contrast, the whole group as such is involved in situations dedicated to pure recreation and enjoyment which are organised as parties in coincidence with such calendar events as the New Year, Christmas etc.
In order to draw up an educational programme in the context of external autonomy and define the areas to explore as well as the skills to reach it, it is necessary to answer the questions:

Anna Contardi, National Coordinator and contact person for AIPD
• What are the minimum skills needed to get by outside the home?
• What do I need for my daily life, for work, for my free time?

Publications
Our journal is called “Sindrome Down Notizie” and is published every 4 months.
AIPD has published a whole range of brochures, books and videos. They are listed on our website: www.aipd.it/materiale_informativo/pubblicazioni.shtml

Awareness campaign
The regular DS-awareness campaign in Italy takes place every second Sunday of October.
We did not organise anything on World DS Day 21.03.2006, we only distributed some information about it.

Projects and campaigns
Our main projects in the next years is to widen our activities for adults with Down syndrome (housing, job inclusion).
Successful campaigns or projects over recent years were our:
• Calendar Campaign 2002
• One cent, one opportunity Campaign
• Family weekends
• Courses in autonomy
• General information

Main problems in Italy for persons with Down syndrome are:
• no uniformity of services
• lack of jobs
• lack of housing facilities
These things should be urgently change:
• To get adult dignity for adults with Down syndrome (even though things have become better in the last 20 years)

Numbers
There are approximately 1000 children per year born with Down syndrome in Italy.
We estimate that there are about 40000 persons with Down syndrome living in our country.

Situation of babies and toddlers under 4 years
All children get public care services

Situation of schoolchildren
In Italy all children with disabilities have the right to attend public school from kindergarten to secondary school.

Situation of adults
Not all adults with Down syndrome work. The people who do have simple jobs in well organised, public and private companies. The job offer depends on the area they live in.
Most adults live at home. There are some housing facilities, financially supported by public administration.
We have no data of the number and the situation of persons with Down syndrome over 50 years.

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http://information.downsed.org/dsnu/06/02
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Main goals
- to give information on both medical and scientific data in trisomy 21 through the publication “Nouvelles du chromosome 21”
- to give funds for research concerning fundamental, clinical and therapeutic aspects as is done for other genetic diseases.

Services
- counselling
- seminars and courses

Publications
We publish a regular journal “Nouvelles du chromosome 21”, two editions per year, 13 issues since 1995.

Awareness campaign
We have celebrated the 21st March since 2005 with special actions:
- on 21 March 2005 we organised the First National Day for Research on Trisomy 21 “From the patient to the research: better understanding for better help” in Paris
- on 21 March 2006 we organised the First World Day for Trisomy 21 in Paris with the conference: “How to estimate and potentially cure mental retardation”.

Projects and campaigns
The main project for next year is organising a European congress in March 2007, celebrating World DS Day.

General information
The main problems in France for people with Down syndrome are:
- Not enough inclusion in schools
- Lack of work opportunities for adults
- Few opportunities for leisure activities

Numbers
The approximate total number of persons with Down syndrome living in France is 70,000.

Situation of babies and toddlers under 4 years:
- Medical care insufficient, but cardiac-care is good.
- Physiotherapy and early intervention are not good. Many children have psychomotor therapy on a weekly base.

Situation of schoolchildren
- about 70% of children up to 6 years are in mainstream kindergarten
- about 60% of children (6-12 years old) are in mainstream schools
- 5% of children (12-18 years old) are in mainstream secondary schools
Other children go to private schools, homes, special schools or therapy centres.
Situation of adults

About 40% of adults up to 35 years old are in employment, but only 20% of older people. They are mostly in special work places for handicapped people. Only very, very few will have a job in a regular work situation.

Young adults live at home or in special centres, older adults are at home and the very old persons live in institutions.

There are only very few housing facilities where adults with Down syndrome can live independently with only little support. There are between 5000 to 10,000 persons with Down syndrome over 50 years of age. Not much is known about their situation.

Portugal APPT21

Portuguese Down Syndrome Association

Internet: www.appt21.org.pt


President: Maria Teresa Palha (individual with Down syndrome)

Director: Miguel Palha (developmental paediatrician)

Members: no members, but the organisation is in contact with about 3000 families

Finances: selling teaching materials and educational software; some financial help from the state; some donations, also from parents; seminars and workshops; annual beneficial Christmas gala and Dinner

Main aims

• Parental help/support for families; early intervention programmes for children and parents.
• Researching new methods and offering intervention programmes designed to promote the development of children with developmental disabilities
• Inclusion of children with developmental disabilities in mainstream education

Services

• counselling
• rehabilitation and therapies: we work with paediatricians, psychologists, special educators, speech therapists, physio- and occupational therapists
• seminars, courses: we have a major annual conference in Lisboa and two other congresses in north and south Portugal. We organise workshops and seminars for parents and professionals. We have a library with books and up-to-date publications on Down syndrome and other developmental disabilities.
• we organise leisure activities for children (inclusive)
Publications
- We will start a regular journal again (we had one before)
- Manuals to support teachers’ work: communication skills in T21; learn to read to promote language; number skills.
- Educational software:
  - Mimocas games – to promote cognitive development, language and reading;
  - Mimocas numbers – to promote mathematical skills;
- Sign language workshop (also in English).

Awareness campaign
There is no regular Down syndrome awareness campaign in our country.
On World DS Day 2006 we participated in a congress, organised by a parent organisation in South Portugal.

Projects and campaigns
Main projects in the next years:
- We have developed intervention programmes and hope to publish them on a CD.
- We will translate our educational material.

Our most successful project in the last years was the founding of the new Developmental Centre.

General information
The main problems in Portugal for persons with Down syndrome are the lack of knowledge among teachers about the developmental, learning profiles etc. in children with Down syndrome.
These things should be urgently changed: The social attitudes and the labour policy towards the inclusion of persons with Down syndrome in the job market.

Situation of babies and toddlers under 4 years
All babies and toddlers have good medical care and receive early intervention which includes special education and physiotherapy.

Situation of schoolchildren
- all children up to 6 years go to mainstream kindergarten
- nearly all children (an estimated 90 %) are in mainstream primary and secondary schools.

There are only a few children in special education, but our organisation does not know about these children.

Situation of adults
Only some of the adults work, for example in local services, or public gardens.

Adults live mainly with their parents/families or in institutions.
Our organisation is in contact with only 4 persons over 50 years. We do not know how many older individuals with Down syndrome are living in Portugal.
Spain / Balearic Islands ASNIMO (Asociación Sindrome de Down de Baleares)

Internet: www.asnimo.com
Founded: 20 November 1976. Private, non-profit organisation
President: Juan Perera Mezquida
Members: 382
Number of users: 412 people with Down syndrome, of all ages
Finances: member fees 10%; State/community grants 80%; Donations 5%

Main goals
- to study and research Down syndrome from its specificity and apply scientific advances to educational practice in order to try and improve it;
- to offer the association’s beneficiaries a broad range of educational and care services for all the life phases of the individual;
- to orient all educational and care practices towards the autonomy and normalisation of people with Down syndrome.

Services
- Prevention and genetic advice: In this department, ASNIMO specialists analyse risk factors, inform about Centres and prenatals diagnosis techniques, and offer genetic advice to families or anyone who requests it.
- Early support: This service offers children with Down syndrome (from 0 to 5 years) the specialised education (sensorial, cognitive, motor and affective) that is necessary for their development to be as close to typical parameters as possible. Parents are offered information and guidelines for their child’s acceptance and education.
- Inclusion in mainstream schools: When pupils are 5 years old they go to classes at the mainstream schools in our Autonomous Community. In these schools, they have official support from an aural comprehension and language teacher and from a therapeutic educational psychology teacher. Furthermore, ASNIMO supports these centres with a service created in 1987 called Mobile Integration Support Units (UVAIs). This service is formed by practitioners specialising in Down syndrome (speech therapist, psychologist, psychomotor therapist, and educationalist) who regularly visit on a weekly basis those classrooms in which pupils with Down syndrome are included, making curriculum adaptations, acting as intermediaries with families, and giving special educational support sessions.

ASNIMO currently has 32 pupils who are receiving this service.

Special education units

Adapted Vocational Training Units (T.V.A.)
After Special Education, pupils go on to Adapted Vocational Training, where they are taught and prepared professionally, in this case, for work within the areas of Gardening, Administration and Commerce. In the school year 2004-2005, the TVA was used by 14 young people.

Speech therapy, physiotherapy, psychotherapy and psychomotor therapy as schooling support activities
In the last school year we provided support for children with Down syndrome from our centre and from mainstream schools. This is one of the services most requested by parents. The number of students registered varies between 16 and 32.
Assisted housing
We currently have two assisted housing units running.
The 220-day “S´Estel” assisted housing unit homes people with Down syndrome whose family homes are in places a long way from Marratxí. The home is open from Monday to Friday.
The “Sa Lluna” assisted housing unit is open 365 days per year, housing adults with Down syndrome without a family to care for them or whose family members are too elderly to be able to take care of them.

Health monitoring programme
ASNIMO has a Medical Unit. A paediatrician, a neurologist and a traumatologist, each attend twice per week, to look after the health of people with Down syndrome of all ages. The doctors produce reports on people with Down syndrome who request them and carry out medical explorations, regular check-ups, and specific consultations upon the request of families. The protocol followed is the “Preventive Medicine for Down Syndrome Programme”, published by FEISD (2005). ASNIMO also has a team of external medical advisors.

Resources Centre for Inclusion
The Centre that ASNIMO maintains in Marratxí has a collaboration agreement with the UIB (University of the Balearic Islands) and it is a training centre for professionals and parents, as well as a work experience centre for University students. It is also a centre for research and publications, equipped with a good library specialising in Down syndrome and a database, and it receives the main magazines from around the world on Down syndrome. Furthermore, every 3 years ASNIMO organises an International Symposium of a scientific nature on different aspects of Down syndrome.

“Sempre Verd” special employment centre
SEMPRE VERD INVERNADEROS S.L. is a Special Work Centre that was created in 1992. This means that it is a company with the duties and obligations of any company, that it competes in a free market, but that part of its workforce are disabled people, in our case, people with Down syndrome. Its promoter was ASNIMO (Down Syndrome Association of the Balearic Islands).
It boasts modern facilities with 3000 m² of aluminium and glass greenhouses, equipped with advanced technology (automatic programming of systems for watering, shade, humidity, airing, temperature, etc.), which is wholly dedicated to the cultivation and sale of tropical ornamental plants.
There are 18 people working at SEMPRE VERD, of which 10 are workers of both sexes, with ages between 23 and 45 years, with Down syndrome.
We believe in their potential and we train them at the Gardening Workshop so that they can become competent workers at this centre.

Job integration in ordinary companies
It is clear to our Association that the best thing we can do today for individuals with Down syndrome is train them to work, find them a job and give them support in that job. ASNIMO has five workshops for learning and training in gardening, computers, bakery, furniture restoration and dried flower crafts, where future workers receive specialised courses to prepare them for work. Afterwards – through the supported employment system – they are introduced into the world of work.

Publications
The teaching and professional activity of Prof. Juan Perera and his ASNIMO team has focused on the world of disabilities and very especially on Down syndrome, in which he is recognised as world specialist for his conference papers, research and publications. He is the author or co-author, among others, of the following texts:
- “Síndrome de Down: programa de acción educativa” (Cepe. Madrid 1990);
- “Síndrome de Down. Aspectos específicos” (Masson. Madrid 1995);
European Down Syndrome Association
news

• “Síndrome de Down: perspectivas psicológica, psicobiológica y socioeducacional” (IMSERSO. Madrid 1997);
• “Cómo hacer hablar al niño con síndrome de Down” (CEPE, Madrid 1999);
• “Síndrome de Down: revisión de los conocimientos actuales” (Espasa. Madrid 2000);
• “Vivir con el síndrome de Down” (CEPE, Madrid 2004).

Also around thirty articles specialising in issues such as early attention, language, education, work integration and psychology of Down Syndrome. His latest book, edited with Professor Jean A. Rondal of the University of Lieges, titled “Down Syndrome: neurobehavioral specificity”, was published in April 2006.

Currently he is translating and adapting to Spanish the educational modules published by The Down Syndrome Educational Trust of Portsmouth (UK).

General Information
The main problems with respect to people with Down syndrome on the Balearic Islands are:
• Access to secondary teaching in mainstream centres
• Job integration in ordinary companies
• Housing for adults

These things should be urgently changed:
• The training of good professionals in Down syndrome.
• More resources and support for families.

Numbers
In the Balearic Islands there are approximately 6 children born with Down syndrome every year. (Previously there were approximately 12 children born annually, so this might be the effect of pre-natal diagnosis).

Situation of babies and toddlers
Excellent. We have all the essential services and support.
– Medical care: excellent
– Physiotherapy: excellent
– Early support: excellent
– Other therapies: excellent
– Support for families: excellent

At our centre, services provided include physiotherapy, psychotherapy, psychomotor therapy and speech therapy when needed.

Situation of children of school age
Children of school age are included in mainstream schools. ASNIMO – as explained previously – has professionals specialising in Down syndrome who travel on an itinerant basis around the inclusive schools to give specialised support, both on a schooling level and in social skills. Through Individualised Curricular Adaptation (ACI), the educational objectives of each child are set and the specialised support necessary is provided to achieve those objectives.

In the case of children with Down syndrome who, owing to their unique characteristics, cannot be included in mainstream schools, they receive teaching in special classrooms at ASNIMO’s “Príncipe de Asturias” Centre.

Awareness campaign
In Spain, by advice from the UNESCO and with the approval of the European Disability Forum, the only day celebrated is on 3 December each year, the International Day of People with Disability.

Projects and campaigns
Our main projects for the next few years are:
• Extension of the SEMPRE VERD Work Centre
• Creation of two 365-day Assisted Housing Units
• Renewal of the ASNIMO kitchen facilities

Our main projects carried out in recent years were:
• Translation and adaptation into Spanish of the DSET modules
• Socrates Grundtvig Programme on Sex and Relationships Education of people with Down Syndrome in collaboration with another 5 European countries
• Organisation of the VI International Symposium on Down Syndrome held in Palma de Mallorca in February 2005, resulting in the publication of the book on “Specificity in Down Syndrome” which will be translated into several languages.

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Situation of adults

Only 7% of adults aged over 20 years are working in ordinary companies. Another 4% are working in protected companies or workshops. Work places are: Banks and Savings Banks, travel agencies, leisure centres, restaurants, launderettes, hypermarkets, garden maintenance.

Adults live in Assisted Housing or at their family home. Finding their own home follows the same pattern as any other person. Normal practice involves taking out a mortgage with a family member acting as guarantor.

We have 8 persons with Down syndrome over 50 years at ASNIMO of which 4 have Alzheimer disease. Their situation depends on the family situation, the medical care and educational support received, their intellectual level and the resources available to them.
• Seminars, courses for teachers, for parents, for doctors, for persons with Down syndrome.
• Library specialising in all disabilities including Down syndrome
• Family days, leisure time: Lectures for families, leisure promotion for persons with Down syndrome
• Down Syndrome Medical Center

Publications
Our regular journal is called: “SD. Revista medica international sobre el sindrome de Down” (DS. International Medical Review on DS.) It is published 3 times a year in Spanish, Catalan, and in English on the web.

We have published the following brochures, information flyers and books:
Edwards, J.P. and Elkins, T.E, Nuestra sexualidad, Spanish, FCSD.

Canadian Down Syndrome Society (CDSS), Sexualidad, las relaciones y yo. Libro de sexualidad para jóvenes y adultos, Spanish, FCSD: 1999.
FCSD, Services and methodology, (2a edició), English, Catalan and Spanish, FCSD: 2004.
Peralta, M., Mírame con otros ojos, Spanish and Catalan, FCSD: 2005.

Awareness campaign
There is no regular Down Syndrome awareness campaign so far. But we have proposed that the organisations celebrate the 21st March.

Projects and campaigns
Our main projects in the next years are:
• celebrating the 20th Birthday of our DS Medical Center (end 2007)
• preparing our next International Conference on Down Syndrome for 2008.
new publications: a book about Diet and Sports and another for new parents
Our most successful projects in the last years were:
• the organisation of the Medical International DS Congress in 2005
• the publication of “Sindrome de Down Aspectos Médicos Actuales”

A useful project tip for other EDSA members could be to collaborate with other medical publications.

General information
The three main problems in our country for persons with Down syndrome are:
• there is no pension provision for early retirement from work
• we have not enough inclusive jobs
• the idea of independent living with support needs more promotion

These things should be urgently changed:
• Pension for early retirement from work will become a big problem soon
• further quality training for old people who can not work or who have never been integrated
• housing, there are no options, and those promoted by the government are too crowded (residences and group homes)
• to have a house of one own is difficult for most people, because of their financial situation.

Numbers
In Catalonia between 20 and 25 children with Down syndrome are born per year, (that means 1 of 3000 children born alive.)
We have no official numbers of the persons with Down syndrome living in Catalonia.

Situation for babies and toddlers under 4 years
The services of our Foundation work very well. The Foundation is one of the Governmental Sectorised (since 1998) Early Intervention Centres and therefore public and free. Children with all kinds of disabilities or difficulties (not only Down syndrome) from birth to age 6 from a specific area of Barcelona city can attend the foundation.

Medical care is generally good. We have a Down syndrome medical centre that promotes a Down syndrome Health Programme to help families and other doctors.
The Foundation has also a physiotherapy service for those children who need it. Other therapies for toddlers are speech therapy and psychological counselling.

Situation of schoolchildren in Catalonia
• Approximately 19% of children up to 6 are in mainstream kindergarten. However, many children do not go to kindergarten, but remain at home or go to a mainstream nursery. We do not have specific data.
• 60% of children (6-12 years old) attend mainstream schools.
• Approximately 21% of youngsters (12-18 years old) are in mainstream secondary schools.
Children who are not in mainstream school settings attend special schools.

Situation of adults
Most adults go to special workshops. Some others work in an integrated work situation. The Foundation has a programme for integrated work.
Adults live with family or in residences. The Foundation has started an independent living programme with support where the person can choose with whom and where he is going to live.
Adults living on their own in their own place happen more often nowadays.
If adults do not live with their families, the options are: institutions, residences, or group homes.
Most of the big institutions have the whole continuum organised, from the special schools, sheltered workshops, special leisure time and residences or group homes.
We do not know how many persons with Down syndrome over the age of 50 live in Catalonia.
In the data base of the Down Syndrome Medical Center of the FCSD, with a total of 1800 persons, we have between 75 and 80 elderly individuals.
They live mostly in residences or remain inactive at their family home.
Germany Deutsches Down-Syndrom InfoCenter

Internet: www.ds-infocenter.de
Founded: 1987
Present director: Cora Halder
Members: 400 in the association, plus 4500 families and professionals as associated members
Finances: membership fees; donations; selling books, information and educational material

Main goals
To improve the life quality of individuals with Down syndrome. Our work is based on the values and principles of edsa.
Our mission is:
• to promote the well-being of persons with Down syndrome in all aspects of life, health, education, personality, autonomy and integration in the society
• to support families
• to promote inclusion
• to inform professionals and society by disseminating up-to-date information on Down syndrome
• to promote a positive image of persons with Down syndrome

Services
• counselling
• seminars, courses
• library
• family days/weekends, leisure activities
• leisure time for teenagers (dancing, cooking courses etc.) We also offer discussion groups for young adults
• a whole range of books about Down syndrome can be bought directly from the centre.

Publications
Our journal Leben mit Down-Syndrome has been published for 18 years and there are three issues a year.
We have published a range of information flyers, brochures and books, as well as one video.
For many years we have produced posters and postcards as part of our awareness campaigns.
We sell educational material, like signing cards (GuK) and the early intervention program “Kleine Schritte” both publications of the InfoCenter.

Awareness campaign
The German Down Syndrome Weeks have been held in October since 1996. This was an initiative of the InfoCenter. Many groups throughout Germany organised local events and the InfoCenter designed posters, postcards, cinema spots, advertisements etc. to use during the campaign.

On World Down-Syndrome Day, 21st March 2006, we initiated and supported the nationwide Do-it-yourself-Poster-Campaign with the slogan “Lass mich mal machen” (Just let me do it!).

Also on World Down Syndrome Day we started the medical clinic for children with Down syndrome in the Children’s Hospital of Nürnberg (cooperation between the InfoCenter and the hospital; this project has a role-model function in Germany).

In the future we will not celebrate our awareness weeks in October, but will focus on the 21st March. It is not possible to organise two main campaigns, because of lack of finance and staff.

Projects and campaigns
Our main projects in the next year will be:
• the organising of World DS Day. On this occasion we will honour one person with and one without Down syndrome, both for their outstanding work. Both awards (the golden Chromosome and the Moritz) have been granted regularly for several years.
• From 21st March onwards there will be an exhibition of art by three painters with Down syndrome in Nürnberg.
• We will also organise another Do-it-yourself-Poster-Action.
• We are planning several new publications (e.g. about nutrition and other topics).
• In cooperation with a publisher we will translate and publish the book “Mental Wellness in Adults with Down Syndrome” by McGuire and Chicoine.

A successful campaign in the last year was:
• the poster campaign 2005 with some prominent German actors. Posters were displayed all over Germany, mainly in buses, trains and in the main train stations. At the same time they appeared as advertisements in many magazines.

We have many useful project tips for other edsa-members:
• producing a first information map for new parents, and distributing this to all hospitals. Many parents tell us, that this information was the best they experienced in the first days after the birth of their baby.
• Our flyer about “breaking the news” as information for professionals has been distributed to all hospitals and to many gynaecologists and paediatricians. At the same time the content was published in the two main professional journals.
• With a yearly award for a person with Down syndrome (for outstanding artwork etc.) and one without Down syndrome (a professional in a special area connected to DS) you can draw the attention of the media and the public.
• our poster series were always very successful. The posters were not only used during the awareness weeks but decorate medical clinics, schools, libraries etc. for many years.

General information
The main problems for persons with Down syndrome in Germany are:
• lack of mainstreaming in schools
• lack of good medical and psychological care for adults
• lack of inclusive workplaces
• lack of housing options for adults who want to live more independently instead of in group homes

Before these things can be changed the whole attitude towards inclusion must be changed. Inclusion starts in ones mind! Also expectations about what individuals with Down syndrome can reach are still very low, therefore they do not get enough opportunities to develop to their full potential.

Numbers
We estimate the approximate number of children born with Down syndrome in Germany per year to be between 1000 and 1200.
The total number of persons with Down syndrome living in Germany is approximately 50,000

Situation of babies and toddlers under 4 years:
The situation for babies and toddlers under 4 years is sufficient, good or excellent. This depends on the area the families live in.
Medical care is good. Medical doctors should be more informed about how children and youngsters with Down syndrome develop, how they live and what goals they can reach.
Physiotherapy and speech therapy are mostly very good and are available for all babies and toddlers. Early intervention is on the whole very well organised and available for all children. In some parts of Germany pedagogues visit the children on a weekly base in the first 3 years.
Occupational therapy, horseriding, music therapy and many other therapies are available but must mostly be paid for by the parents.
Situation of schoolchildren
The situation for children up to 6 is good – about 90% go to their local kindergarten.
The number of children between 6-12 years old in mainstream primary schools is dramatically low. It varies from 2% in the southern part of Germany to perhaps 25 -35% in cities like Hamburg or Berlin.
The total number of children between 12-18 years old who attend mainstream secondary schools is even lower and varies between 0-5%.
Most children with Down syndrome in Germany still attend special schools. As the special school system is very established, it will be very difficult to change this situation.

Situation of adults
All adults with Down syndrome work. About 90% work in sheltered workshops, where they are involved in a range of (sometimes very mechanical) tasks. However, nowadays the workshops offer a lot more other working options as well, like gardening, pottery, woodwork etc.
A small percentage of young adults work in the mainstream work place, often assisted by a job coach service.
Younger adults live mostly in group homes (40 to 50 persons), some in small units with 6 to 8 persons. But there are still some very big institutions in Germany with up to 1000 individuals with a mental disability living there, among them many mostly older persons with Down syndrome.
Some adults stay with their parents, some live in special villages (anthroposophic-based), and very few live on their own, with a friend or as a couple, with as much support as needed.
The number of persons with Down syndrome over 50 years old is approximately 3000. We do not have exact numbers.
They mostly live in the big institutions, where they still have the option to work in a sheltered workshop as long as they are able to do this.
Medical and psychological care is insufficient as there is not enough knowledge among medical staff about the special problems they might have when getting older.
Inclusion in Practice DVD reviewed in TES

Inclusion in Practice - Educating children with Down syndrome at primary school was reviewed for the Times Education Supplement by Jonathan Rix, lecturer in curriculum, inclusion and learning at the Open University, and also the parent of a child with Down syndrome.

“The DVD is essential for teachers who lack the experience to cater for children with Down syndrome in mainstream schools.”

Read the whole review at: http://www.tes.co.uk/search/story/?story_id=2308669

EastEnders Down syndrome storyline

The Sarah Duffen Centre was featured in The News, the local evening paper in Portsmouth, as a result of the EastEnders storyline on Down syndrome.

Lisa Sked and her son Harry, who attend the Early Development Groups at The Sarah Duffen Centre, had contacted The News following their trip to the EastEnders set (see cover photo) to be filmed as part of a support group.

A reporter and photographer from The News visited one of the Early Development Groups in November to talk with parents and staff.

Mosaic Down Syndrome Group meeting

The Mosaic Down Syndrome UK group had a ‘Get Together’ weekend in Portsmouth, and visited The Sarah Duffen Centre in October 2006. Future ‘Get Togethers’ are planned for Blackpool in October 2007 and Orlando, Florida in October 2008.

See www.mosaicdownsyndrome.org for more about the group.
Another book in the Adult Living Series published

People with Down Syndrome and the Law (an Australian perspective) is the latest book to be published in the Down Syndrome Issues and Information Adult Living series. It has been written by Jorge Rene Galleguillos-Pozo, a former Professor of Law; Ian Bidmeade, a Legal Consultant; Graham Harbord, a specialist in employment law, and Vanessa Balnaves, a barrister and solicitor with experience in the rights of people with disabilities.

Please visit the downsed online shop at http://shop.downsed.org/ for details of how to order this book.

Carols at the Kings

A Carol Service organised by the Salvation Army was held in the Kings Theatre in Portsmouth early in December. Local schools also took part, and the concert raised over £2300 for the Trust.

Pudsey Cake from IBM

Kind hearted staff at IBM UK in Portsmouth asked their chef to make a Pudsey Bear cake for children attending the Early Development Groups at The Sarah Duffen Centre. They also donated an almost life-sized cuddly German Shepherd toy to raffle at the Christmas Party.

The 3 Peaks Challenge

Trevor Foster and Dave Hanks took part in the 3 Peaks Challenge in May 2006 and raised over £6000 for the Trust. This involved climbing Ben Nevis, Scafell Pike and Snowdon all within 24 hours. The 23 climbers endured almost constant rain and lack of sleep, and the guides were apparently amazed how many of the group succeeded. The photo shows Trevor presenting the cheque at the Sarah Duffen Centre.

Early Support update

Training is now available for introducing the use of the Early Support Developmental Journal for Babies and Young Children with Down Syndrome. The Trust has worked with Early Support to develop this training and the first Training for Trainers was held on 11th December at the Sarah Duffen Centre.

We would like to thank the parents who contributed their experiences on video for the training. In the first group of 20 trainers to be trained were parent organisers from 3 of our former branches in Darlington, Berkshire and Kent.

Training information for 2007 will be available on the Early Support website at http://www.earlysupport.org.uk/. We will also be running further training in Portsmouth so please check our website.

Darlington group

The former Darlington Branch of the Down Syndrome Educational Trust is now officially registered as a charity, number 1115300, and its new name is The Education Centre for Children with Down Syndrome.

The group runs two children’s groups weekly at the Education Village in Darlington and organised a Training Day in December on “Educating children with Down Syndrome in Inclusive Settings”. The speakers were Wendy Uttley, Patrick Sheehan, Maggie Woodhouse, Sue Buckley and Gillian Bird.

Check their web site at http://www.eccds.org.uk/ for up-to-date news from the Centre.

Christmas cards

Thanks to everyone who has bought the Trust’s Christmas cards this year. The most popular designs were those created by children who attend the Early Development Groups at The Sarah Duffen Centre. A total of 20,000 cards have been sent out this year. As well as raising money, and awareness of the Trust, the production and packing of the cards provides employment for seven adults with Down syndrome who work in the Production Studio.

Training calendar 2007

The following workshops are scheduled to be held at The Sarah Duffen Centre in Portsmouth, UK.

<table>
<thead>
<tr>
<th>Date</th>
<th>Level</th>
<th>Workshop title</th>
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<tbody>
<tr>
<td>19 March 2007</td>
<td>Key Topics</td>
<td>Supporting the development of infants with Down syndrome – birth to 3 years</td>
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<tr>
<td>23 April 2007</td>
<td>Skills in Depth</td>
<td>Strategies for managing behaviour and developing social skills – 3 to 16 years</td>
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<tr>
<td>30 April 2007</td>
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<td>Promoting speech, language and literacy across the curriculum (Key stage 1 and 2)</td>
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<td>14 May 2007</td>
<td>Key Topics</td>
<td>Promoting the development and education of preschool children with Down syndrome – 3 to 5 years</td>
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<tr>
<td>21 May 2007</td>
<td>Key Topics</td>
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<tr>
<td>11 June 2007</td>
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<td>Teaching maths and number skills to children with Down syndrome</td>
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<td>18 June 2007</td>
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<td>Educating children with Down syndrome in mainstream secondary schools – 11 to 16 years</td>
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<td>Supporting inclusion for children with Down syndrome</td>
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<td>Supporting the development of infants with Down syndrome – from birth to 3 years</td>
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<td>1 October 2007</td>
<td>Key Topics</td>
<td>Promoting the development and education of preschool children with Down syndrome – 3 to 5 years</td>
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<td>8 October 2007</td>
<td>Skills in Depth</td>
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<td>15 October 2007</td>
<td>Key Topics</td>
<td>Educating children with Down syndrome in mainstream primary schools – 5 to 11 years</td>
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<tr>
<td>29 October 2007</td>
<td>Key Topics</td>
<td>Educating children with Down syndrome in mainstream secondary schools – 11 to 16 years</td>
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<tr>
<td>12 November 2007</td>
<td></td>
<td>Educating young people with Down syndrome in mainstream further education – 16+ years</td>
</tr>
<tr>
<td>26 November 2007</td>
<td>Issues in Depth</td>
<td>Speech and language development for children with Down syndrome</td>
</tr>
</tbody>
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How to book

You will soon be able book places on our courses by visiting our online shop at http://shop.downsed.org/  
In the meantime, to book a place, please contact us by phone, fax or email.

About our courses

For further details about our training courses, please click on any of the links on the website on:  
Key topic courses • Issues in depth courses • Skills in depth courses

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.

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.

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*. 
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, PO5 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’ spelt 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):**