# Editorial

## Keys to successful early intervention

Supporting children and families through Early Development Groups
Gillian Bird and Mandy Wood .......................... 74

Early intervention in Kenya
Mrs A Panesar ............................................. 82

## Readers’ letters

A special Christmas present
Sara Thom .................................................... 100

Questions and answers
Katharine Frost .............................................. 101

Charlotte’s success with the clarinet
Anne Sidders ............................................... 102

## Regular features

Reviews ......................................................... 96

European Down Syndrome Association news ...... 103

Conferences .................................................. 107

The Down Syndrome Educational Trust news ...... 111

Down Syndrome International news ................... 115

## Learning from individual stories – practical ideas for reading, number and bike riding

Teaching Rina — my experience with non-English teaching materials
Ruth Palatnik .................................................. 84

Reading success in primary school
Nicola Baxter ................................................ 88

Individual Learning Time — unlocking potential
Leslie Duffen ............................................... 89

Bryony's early reading progress
Theresa Smissen .......................................... 90

More on the issue of early reading opportunities
Victor Bishop ................................................. 91

Using Numicon — a report from a special school
Kerrie Coleman ............................................. 92

Learning to ride a bicycle
Greg Sneath .................................................. 94

## Forthcoming articles in Volume 3

The next issue will include features on

- Software for language and literacy
- Night waking - causes and practical strategies

---

Cover picture: Matching printed words at the Early Development Group at The Sarah Duffen Centre
Photograph: The Down Syndrome Educational Trust
Editorial

Welcome to the third issue of volume 3 of Down Syndrome News and Update. We are delighted with the response from our readers and the increasing range of articles and letters being sent in. We hope that you agree that the lively exchange of ideas and the sharing of good practice from all around the world is making a worthwhile publication for the international community of parents and practitioners interested in promoting the welfare and quality of life of children and adults with Down syndrome.

International perspectives – becoming visible and participating

In addition to features and case studies from several countries, we have reports on the European Congress on Media and Disability held in Athens in June and the European Parliament of Disabled People in Brussels in November. The European Down Syndrome Association (EDSA) was represented at both meetings. The main themes of the Media and Disability meeting were improving the images of individuals with disability as portrayed in the media and increasing their employment in the industry. In her report, Cora Halder points out that individuals with learning disabilities were under-represented at the meeting and that there was no one with Down syndrome participating – an issue we all might consider within our own countries.

In the past two years the Associazone Italiana Persone Down (AIPD) has made great strides in promoting positive images of people with Down syndrome through a celebrity calendar. This has led to Giorgio Armani continuing this work with his Christmas campaign through Europe and the USA. Seven organisations working for the international community of parents and practitioners interested in promoting the welfare and quality of life of children and adults with Down syndrome.

EDSA held its first European Day for people with Down syndrome in November and hopes to co-ordinate this event in all countries in Europe in the future.

8th World Congress

We hope that some of our readers will be planning their visit to Singapore for this event, organized by Down Syndrome International, in April next year – there will be a UK party attending and we will report back on the Congress in DSNU later next year.

Features

• Early intervention

The first article in this section aims to share some of the practical games and activities used at The Sarah Duffen Centre with preschool children. Next year we will be developing training for parents or professionals who wish to run groups in their own areas. The next article highlights the great work being done by the Circle Academy in Nairobi, Kenya, where many children will still not access the range of services we take for granted in other countries. I have underlined some of the principles which might guide effective early intervention in my introduction to this section.

• Learning from case studies

The next section contains two inspiring articles, one from Israel and one from Ireland, on reading and number, sharing practical activities that have worked and encouraging parents and teachers of children who may not be the faster learners in their early years – followed by correspondence from parents on these issues. Some of our readers’ views may be controversial so keep the correspondence coming – I have given some of my views on the introductory page to this section!

• Readers’ contributions on recent themes

Greg Sneath’s contribution on teaching bike-riding continues our theme on motor skills. He has some useful tips – particularly using a scooter to improve balance while riding a bike with stabiliser wheels to increase pedalling strength and learning to use the brakes.

Anne Sidders tells us of another successful musician, as her daughter Charlotte is playing the clarinet and passing standard exams. Sara Thom shares her experience of finding that her daughter has a translocation form of Down syndrome and the additional implications of this for her and her husband. Katherine Frost has some questions related to the article on hearing in the last issue.

Please keep all your contributions coming and encourage others to subscribe. We are hoping to publish an article about the transition into adulthood and would be particularly interested to hear about your experiences with regard to services for people over the age of 16 and how you have continued to support the development of your family member with Down syndrome. Our new DSii book Utilising ICT in the development of individuals with Down syndrome will be available in the New Year and we would also be interested to hear from LSAs and teachers who have successfully integrated ICT into the curriculum as a tool for differentiation or to promote a specific area such as literacy or numeracy.
Keys to successful early intervention

How do we balance natural learning with intervention activities?

In most countries, it is accepted that children with learning or intellectual disabilities will benefit from early intervention and that is the theme of our first two articles. Early intervention programmes began in the 1970s when research indicated that both children and adults with learning disabilities need structured teaching and practice in order to help them to learn skills and activities that typically developing children acquire in their early years without explicit teaching – mainly all the skills that typical five year olds have when they start school such as walking, feeding, dressing, talking, socialising and managing their behaviour.

Smaller steps, more practice

The research indicated that we needed to break these skills into small steps and to find ways to teach them, building in much successful practice to help children achieve them. All children need practice to consolidate and improve their learning and they seem to do this naturally, as parents of toddlers know when they see them practise new skills such as standing or walking. Research with children with Down syndrome indicates that they need more repetition and practice to consolidate their learning and reach their ‘personal best’ in any skill. They may need much patient encouragement to practise enough through individual sessions and family or group games.

Ensuring success – errorless learning

The early research also supported the view that we need to scaffold children’s learning by showing them how to succeed – modelling an activity with the child by holding their hand to help them complete the task or to learn by imitating as we take turns at the task with them. In this way, they practise the correct sequence of actions to succeed at the task.

The benefits of groups

Many children and families benefit greatly from services such as Portage home teaching programmes, which provide a home teacher for the family in their own home in the first 3 years of life. This service is usually highly valued by parents and they learn how to extend their natural play and interaction with their child in order to help the child to overcome some of the effects of his or her disability and learn more effectively. However, one-to-one teaching can become quite demanding for children, as they are always under the spotlight and expected to ‘perform’ the task.

Groups can make the learning more fun as the children take turns, and children who already know the task can model the correct responses for others who are still learning. In the groups, children are also beginning preparation for preschool and school, where they need to be able to learn without one-to-one support and to take turns – sitting quietly while others have their turn. Fami- lies can also turn teaching activities into games by involving other adults or children in the family – this often persuades a reluctant learner that he or she would like to join in!

However, formal groups can also be quite demanding as they do require the child to sit, attend and to wait. Many toddlers with Down syndrome are surprisingly good at this but some do find it difficult and need to be gently encouraged to stay in the group – this is one reason why the pace of activities needs to be quite fast – small tasks which can move from child to child quite quickly.

Most learning takes place naturally

While we think that it is important for parents to understand what their child with Down syndrome needs to learn, the specific difficulties that are holding them back and to build in more teaching and practice to help them to progress, we need to stress that the children are learning during all their waking hours and it is all family interactions while feeding, bathing, shopping, walking in the park etc. that provide all the quality learning experiences. The group activities described in the next article are designed to help parents to be more effective in their natural communication with their child and to practise activities for perhaps 15 minutes a day. However, it is the all day/every day interactions within the family that really help children to learn – attending ‘therapy’ ses- sions will help to give ideas and keep up parents’ motivation but parents and therapists need to recognise that children do not learn to talk from these sessions alone. Therapy sessions are successful when we transfer our skills, knowledge and confidence to parents, and they then become more effective natural communicators and teachers at home.

Editor

© 2003 The Down Syndrome Educational Trust. All Rights Reserved. ISSN: 1463-6212
http://www.down-syndrome.info/library/periodicals/dsnu/03/03/
Supporting children and families through Early Development Groups

Gillian Bird and Mandy Wood
The Down Syndrome Educational Trust, Portsmouth, UK

This article aims to give you a flavour of the work that goes on at our weekly groups, for children aged 0-5. We have supplied descriptions of many of our activities with a rationale to explain the area of development that they aim to promote. We hope that it will provide ‘food for thought’ and inspire you to design activities of your own to support the early development of your children with Down syndrome.

Early Development Groups (EDGs) for pre-school children with Down syndrome run every Thursday at The Sarah Duffen Centre in Portsmouth. The sessions are currently attended by 36 families with children ranging in age from 13 months to 4 years and 4 months. There are eight groups, loosely divided by chronological age, with infants aged 12 months to 2½ years attending one week and those aged 2½ to 5, the next. We also welcome parents with babies aged less than 12 months to observe the group sessions and join the informal sessions in the playroom. Visiting professionals and those in training are also welcome by prior arrangement. Many of our families are relatively local to the centre although some travel much further for their fortnightly session.

This article provides an overview of the activities that take place during a typical session and describes the areas of development that they promote. Many of the activities can be incorporated into everyday family interactions or built into a 10-15 minute daily slot for focused work with the child. We aim to model activities to the parents to give them confidence in their own interaction and focused teaching at home. It should be noted at this point that the EDGs should be seen as a supplement to the statutory and voluntary services that should exist within the local community, e.g. Portage, speech and language therapy, child development centre and nursery or pre-school placements. We hope that this article might encourage people to model appropriate strategies and responses.

During the informal play session, families have a chance to talk to each other and the staff over a cup of tea or coffee. It’s a great opportunity to exchange ideas with other parents and gain individual advice regarding development and behaviour. Many parents have commented on the emotional support derived from the friendships formed with staff, (some of whom also have children with Down syndrome), and other parents who have shared similar experiences.

Each child has a confidential records folder where we keep information on their progress. Parents complete DownsEd speech sound and vocabulary checklists and at the end of each session, brief observations are recorded in each child’s file.
These records help us to set appropriate targets for families to work on at home and allow us to differentiate activities and resources according to each child's individual needs.

Each week the sessions are carefully planned to include activities to promote the different aspects of development such as social development, play skills, speech and language and an understanding of concepts such as number and colours. The variety of everyday objects, toys, pictures, musical instruments and vocabulary used within the sessions have been chosen to provide a positive multi-cultural experience and gender stereotypes are challenged in the toys, colours, pictures and sentences used in interactive play, vocabulary and sentence work.

The activities are varied each week and suggested follow-up work at home loosely leads into the activities planned for the next session. Whatever the variety or order of activities, the important things to remember are that the children need lots of positive reinforcement and praise; they need to experience errorless learning through modelling or prompting to achieve the correct response. The language used in the sessions is grammatically correct but natural, (not simplified), with some emphasis on the key words. The pace is relatively swift to maintain interest and the emphasis is always on teaching rather than testing. Signing is used to support the spoken word but signing is reduced for words that the children can both understand and produce themselves. The next section reviews the individual activities and the boxes include sample sessions for the different age groups.

Social development

Social development is considered to be a strength for children with Down syndrome, as they tend to be very good at ‘reading’ non-verbal cues in people’s faces, body language and tones of voice. The children tend to have good social understanding and behaviour and this means that they are particularly well suited to learning in a group setting such as the EDGs. The following activities are used to develop social communication skills such as joint attention, listening, turn taking, sharing and eye contact. We work hard to develop the children’s attention as it is a very important skill that underlies their ability to learn about the world.

The Register

The group leader starts by drawing the children’s attention to the register. This has the word ‘register’ and a list of the children’s names in big letters. The group leader starts by asking each child to identify him/herself, saying something like, “Is Alice here?” Children are rewarded with individual greetings for saying “yes” or “me”, pointing to themselves, holding up a hand, smiling or making eye contact depending on their age and individual needs. If someone is away, the group leader uses the opportunity to model negatives and pronouns, e.g. “Is Alice here? No, Alice is not here” or “she’s not here”. The “she” and “not” are emphasised and signed. Completing a formal register in this way not only develops age appropriate behaviour and prepares children for school, it also encourage turn taking, listening and learning from others.

Roll the Ball: A fabric ball is rolled ‘to and fro’ between the members of the group. The group leader might start by saying, “Look, it’s a ball” and signing ball. She might encourage everyone to say or sign ball and then roll it to one of the other children saying “now Alice has the ball”. Children should be encouraged to follow the ball and look at the person who has it. This develops shared attention to the ball and to the people they are receiving it from and rolling it to.

Maracas and Bells

This game introduces the instructions “stop” and “go”. Children are encouraged to take either maracas or bells from the basket. The game starts when the group leader says “go” and shakes the bells or maraca. This models the desired behaviour to the children, who are praised for joining in. The leader should smile while the bells and shakers are in motion. The next command should be “stop”, at which point the leader stops shaking the bells and sits quietly. This game encourages the children to make choices, listen, participate, follow instructions and develop shared attention. Children can be encouraged to sign ‘more’ if they would like to have another go. With the three to four year old children, we often ask “who would like to be the teacher now?” where the “who” is emphasised and signed. This child can be encouraged to start and stop the others. This develops understanding of ‘who’ and also of taking the lead.

Nursery rhymes

Children are offered the choice of two nursery rhyme cards, which display a simple picture to illustrate the rhyme. Parents may be asked to suggest two rhymes from the available selection, that the child knows and enjoys. This encourages pointing and making choices; it does not matter if the children do not understand the consequence of their actions at this point; they will come to understand this over time. The leader starts the singing, encouraging the children to join in. Often, they sing or sign the last word in each line or the key words in each line. Children can be encouraged to sign or say “again” if they would like to hear the song again.

Free drawing, puzzles and pretend play

In the 20 minutes at the end of the group session, children are encouraged to play independently while the parents discuss individual progress with the staff. Often the older children will be given felt tips and paper or puzzles to share. Additional sets of pretend play items could also be provided for the children to use during this time. Although, these activities will develop fine motor skills, it is also a good opportunity for the children to engage with play activities and with each other without an adult audience. It may help to develop intrinsic motivation, sharing and spontaneous communication and speech.

Pretend play skills

The group leader has a basket of pretend play items including a doll, brush, cup and plate with pretend food, flannel and bed cover. The leader will ask the child to “give dolly a drink” or “put the dolly to bed”, modelling the actions first. After the
child has demonstrated his or her understanding the leader encourages him or her to pass the equipment to the next child, by saying “David, it's your turn now”, signing the possessive ‘your’ (turn). This activity develops children’s comprehension of language at the two key-word level. The ability to link ideas in pretend play will support the ability to link ideas in speech. The game also develops shared attention, builds imaginary play skills and learning by watching others. Children can also be asked “Who would like to give dolly a drink?” etc. When children are able to indicate that they would like a turn, they are developing important social skills needed for inclusion in games with other children.

Speech and language

Our speech and language activities aim to develop speech motor skills, auditory discrimination, comprehension and production of single words (vocabulary) and early grammatical markers including amongst others ‘ing’ (present progressive tense), early prepositions such as ‘in’, ‘on’ and ‘under’ and pronouns such as ‘he’ and ‘she’. The content of the activities, e.g. the targeted speech sounds, vocabulary and grammatical markers or function words, take into account the children’s stage of language development. It is important to recognise that language comprehension is always more advanced than expressive language and therefore it is important to include activities that support comprehension and production separately. Also, the difference between levels of comprehension and production for individual children can be large; some children may understand large numbers of words but produce only a few words or signs. It is therefore important to plan activities for comprehension that are at the correct level and not take limited expressive language as an indicator of a child’s overall speech and language skills and knowledge.

For this reason, we target comprehension with activities at the single-word level for vocabulary development and use simple grammatically correct sentences with two, three and four information carrying words in our spoken language and in reading games. Similar activities are used to encourage expressive language at a level that is appropriate for individual children.

Blowing bubbles

The group leader blows a bubble and catches it on the bubble wand. The bubble is presented to the first child who is asked to blow the bubble. The action is modelled first to show the child what to do. This encourages the children to make an ‘O’ shape with their mouth, so developing oral motor control. Children normally go through a developmental sequence of popping the bubbles with their hands, then looking as though they are trying to eat the bubbles (although they are probably just trying to imitate the correct mouth shape!) and finally blowing the bubble. Children often find this a motivating interlude, which regains wandering attention and can be used to give a break between tasks which make higher cognitive demands. Again, the words or signs for ‘more’ and ‘again’ can be practised in order to request another turn.

Speech sounds

We use the DownsEd sound cards in the groups. A selection of cards can be worked through fairly swiftly, with the leader modelling the sounds and the children joining in where possible, either signing or producing the sounds. The children also enjoy choosing individual foam letters from a plastic wallet and jumping them back into the bag while making the appropriate sound, e.g. “b, b, b”. These activities promote auditory discrimination, speech sound production and develop the phonological loop, that is, the part of short-term memory concerned with processing verbal information. The second activity also develops knowledge of the sounds that correspond to the different letters of the alphabet (grapheme/phoneme correspondence).
understanding) of at least 50 words and they are able to picture match. One of the major aims of the EDGs for younger children is to model and engage children in activities that will help them to build a receptive vocabulary of 50 words. At this stage they will benefit from reading activities to develop their speech and language skills. The EDGs (for older children) focus on the reading as a way to develop children’s receptive and expressive vocabulary, their understanding of grammatically correct sentences and their ability to join words together in their expressive language. The use of reading activities will be returned to below.

The following activities are used to develop vocabulary. The targeted vocabulary is linked to the children’s developmental checklists, which indicate the general order in which words are acquired. The target vocabulary for younger children is drawn from the first developmental checklist (first 120 words) and in the older groups, we might begin to use some vocabulary from the second checklist (second 340 words). We include nouns and verbs so that the children are able to progress to the next developmental level, understanding and producing two words together, in two word utterances such as “Daddy sleep” or “dolly eat”.

The words are said to the children and vocabulary development is supported by signing. The signs are used as a bridge to the spoken word and help to ‘show what you mean’ as children with Down syndrome do not learn words easily purely from spoken input. Evidence suggests that children in sign-supported intervention programmes have bigger spoken vocabularies at five years old. \cite{3,4,5} We do not emphasise the use of signing to the same extent, however, if we know that the child can say the word for him or herself. In the following descriptions, note that the activities can be manipulated to encourage understanding and/or production, depending on the individual child’s speech and language needs.

**Matching, selecting and naming games**

We use matching, selecting and naming games to teach new vocabulary at the single-word level. For example, children are shown four of the DownsEd language cards, ‘picture-side up’. They have to match a corresponding set of pictures to them. Once this skill is mastered, they can be encouraged to select a particular picture to give to the group leader to ‘put away’ or ‘post’ in a post-box. This targets single-word comprehension. When the child ‘posts’ the picture, the group leader might say “the ball’s gone” or “the biscuit’s gone”. This paves the way to two-word understanding and could be used as an extension activity that parents and children can play at home with objects and pictures.

Children who can match and select certain noun or verb pictures are demonstrating their understanding and the next stage is to encourage production of the words. The following activity can target single-word production but can be adapted to target comprehension. We use a selection of the large ColorCards Nouns or ColorCards Verbs for group work, although our DownsEd Language Cards ‘word-side up’ or make our own cards with printed words on them. The children have to match corresponding printed words. Again, once they are able to word-match, activities can involve word selection and word naming (single-word reading). During teaching, we are the group, e.g. using simpler nouns and verbs in the naming part of the game (production) and modelling more complex ones to develop their receptive vocabulary.

Once the children are able to match, select and sign or say some pictures, we move onto matching single printed words. We use two sets of the DownsEd Language Cards ‘word-side up’ or make our own cards with printed words on them. The children have to match corresponding printed words. Again, once they are able to word-match, activities can involve word selection and word naming (single-word reading). During teaching, we are
careful to say the word clearly at the same time as the child looks at the printed word. The child then takes the printed word card and matches it to the same selection of four word cards.

The next stage is to match words to pictures. The words chosen may be from a particular category, e.g. animals or food, although the category name itself would not be introduced until the child has a much larger vocabulary. It is important that when you are encouraging the child to read/say a printed word, you show them the printed word and then the picture or object otherwise he or she will simply be telling you what the picture is and not telling you what the word says. This rule also applies to reading activities at the sentence level.

Games involving real objects provide a change. Children have the opportunity to handle a variety of toys and objects and engage with both the object and the activity. With the younger children, we use a feely bag containing first animal toys such as pig, duck and cat or first objects such as ball, keys and socks to promote comprehension and/or production of first vocabulary. The children are asked to take one out and then name/sign what it is. If children are not at the expressive level, the word is modelled and signed for them. At the end, the toys are returned to the bag or basket while the leader says things like, “Thank you Alice, the duck is in the bag” emphasising the noun ‘duck’ and modelling the preposition ‘in’.

At the moment, the children in our groups particularly enjoy an activity using toy vehicles. They are asked to choose a toy from the basket, which they are allowed to play with on the tabletop for a minute or so. The group leader then shows pictures of the toys and asks “Who has got the bus/train/helicopter?” matching the real toys to the pictures. Selecting can be incorporated by putting two toys in front of a child and asking them to put one of them in the basket. The group leader models the names to the children; as each vehicle is named, the child is asked to put the toy “in the basket”. Some children can name the vehicles for themselves. The final part of the game is to match the individual printed words with the same words (in the same size and font) on an A4 sheet of card. The children are asked to “find the same”, where the leader signs ‘same’, saying “Well done they’re the same” for a correct match. Children will need to be encouraged to ‘have a look round’ when they are matching words or pictures to ensure that they scan all four choices. These activities will help the child to build the skills necessary for reading and help the children to develop a sight vocabulary.

During activities, we use attribute words like colour and size and for more advanced children with particularly large receptive vocabularies, we may introduce attribute words such as prickly, smooth, heavy, light, soft or hard. Children are encouraged to feel objects and the words are modelled to them. We would not expect children to necessarily demonstrate their understanding, this would simply be an exercise to expose them to more complex vocabulary and prepare them for the type of activities they will experience at school.

**Grammar**

Children with Down syndrome tend to develop their understanding of grammar and function words like ‘in’, ‘the’ and ‘is’ from reading simple sentences and this is explained further below. However, there are a number of speech and language activities targeting specific function words like the pronouns ‘he’ and ‘she’ and the prepositions ‘in’, ‘on’ and ‘under’ which do not involve reading printed words.

**Prepositions**

The feely bag game described above can also be adapted for the older children to teach prepositions. The ‘tidy up phase’ now becomes the main focus of the teaching work. The children would be asked to put the items ‘in’, ‘on’ or ‘under’ the bag with the leader modelling sentences such as, “the duck is under the bag”. This activity targets comprehension and would be appropriate for the children aged around 2½ years and older. The group leaders have also played games involving the ColorCards – Prepositions and small world play equipment where children can be encouraged to put the boy ‘in the cupboard’, ‘on the
table’ or ‘under the chair’ and with large vehicles, for example placing the man or lady ‘in’, ‘on’ or ‘under’ the tractor.

**Pronouns**

With children aged four and above, we might show one of the *ColorCard Verbs* pictures and say “Look, he’s drinking”. This enables us to work on the child’s understanding of ‘he’ and ‘she’. At the comprehension level, children could be asked to select “he’s drinking” from a choice of two pictures, one of a man drinking and one of a lady cutting. At the production level, some children might be able to join two or more signs or words together to tell the leader what is happening in a certain picture. The same cards can also be used to practise negatives, e.g. from a choice of two pictures the child has to select “the boy is not drinking” where ‘not’ is emphasised and signed. This would only be appropriate for children with quite advanced receptive language skills.

**Reading**

Children who understand 50 or more words, who are able to match pictures can begin reading work at the sentence level, e.g. “The cat is sleeping”. The child is encouraged to point at each word as the parent and child read the sentence together. When carrying out a sentence reading activity, you should present the sentence on its own, (without a picture) to encourage the child to focus on the words and build a sight vocabulary. A picture to illustrate the sentence can be introduced afterwards, and the child can be encouraged to put the two together. Comprehension could be tested by giving the child two pictures to choose from. The activity can be differentiated for a child with more advanced language development by using sentences with more information carrying words such as “the cat is sleeping in the basket” or presenting a larger variety of pictures to choose from. A child at an earlier stage of language development could be encouraged to match single words to the correct sentence from a choice of two, e.g. cat, sleeping. It is important to remember that children who are unable to read independently or who have very limited speech production will still be benefiting from this type of activity. They will be increasing their receptive vocabulary and will be benefiting from the opportunity to learn from others in the group.

Variety can be introduced by asking the children to match phrases with real objects, e.g. the big cup, the small brick, the red ball. This game works at the two-word comprehension level and is therefore suitable for children who can understand at least 50 words. The same basic activity can be differentiated for children with more advanced language development, by adding more information carrying words and more advanced vocabulary, e.g. the stripy ball. To work on prepositions, you could encourage children to read the sentence with their parents and then, as mentioned above, create the scene with small-world play equipment, e.g. “the mouse is under/on the chair”.

**Personal books:** We have made our own small reading books to give children to read at home. The first one was about animals using single animal words, pictures and short phrases. We will build up the complexity of the sentences as we work on different concepts: “Here’s the white dog”, “The white dog is sleeping” etc. The older children are asked whether anyone would like to read their book to the group.

**Number skills**

**Number line:** Children point to the numbers along the number line from 1 to 10, saying the words where possible. The counting is supported by the group leader and parents and

the pace is swift so as not to put pressure on the child if they are unable to say the numbers. Some of the older children, with more advanced speech and language and cognitive skills, use a number line 1 to 20.

**Counting with the number line to develop production of the count-word sequence**

Sample of the activities we might use for infants aged 13 months to 20 months, to last approximately 20 minutes with only a couple of minutes or so for each activity.

- Welcome and register
- Speech sound cards: modelled to the children who may sign and say some of the sounds
- Feely bag of objects to practise first vocabulary, e.g. ball, fish, cup, teddy, car
- Memory game; toy animals hidden behind back, make the noise and say “oh what animal says ‘quack quack’?”
- Doll play: children are asked to “brush dolly’s hair” or “put dolly to bed”
- Roll the ball
- Bells and maracas
- First vocabulary picture cards; children take cards and turn them over one at a time
- Verb cards: first verbs, e.g. sleeping, eating, drinking, waving, clapping
- Nursery rhyme; choice of two, sing and sign

**Matching, selecting and naming the numerals:** Children are given a set of numbers from 1 to 10 which have been cut up individually to match with the number line. Once they have mastered matching, children can be asked to ‘gime’ the group leader various different numbers or name a number which is pointed to on the number line. This is a fairly advanced skill and is only practised with the older children.

**Counting objects:** The group leader asks each child “Would you like to count cars or eggs?” The ‘cars’ are six small plastic cars and the ‘eggs’ are six sparkly egg-shaped shakers which the children love. The child is encouraged to count the objects from one basket into another, counting together with the leader at
first. The concept of cardinality is reinforced by saying “Well done, there are six eggs in the basket”, with the emphasis on the six.

**Numicon matching**: DSNU has run various articles, (April 2002, February 2003, and May 2003) about Numicon, an approach to teaching number that encourages the use of visual and tactile representation of the numbers to aid calculation. We introduce the Numicon shapes in our groups for children aged between 2½ and 3½ years old. We lay the one, two, three and four shapes out in the correct order and then encourage the children to lay out a second set of shapes underneath or on top of the first set. Tactics such as modelling, prompting and handing the child the correct shapes can be used to help the child and promote errorless learning.

**Concepts**

**Colours**: A simple game to introduce colour involves matching coloured circles with coloured balloons on a picture. Reading activities can also work on matching the colour words and introducing colour into the personal reading books. The colour words can easily be emphasised and reinforced in many other games such as the ‘bells and maracas’ game mentioned above. Recently, we have tried a game to teach clothing words using items of clothing made from card and felt that are used to dress a cardboard doll. The group leader might show the children the picture of a doll and hide it under the flaps. The children are shown the pictures one at a time and have to try to remember them. The group leader might then show the children a picture of an apple and hide it. Then they would point to the flap with the cup behind it without saying anything (extra information from talking might affect their memory) and wait for the children to say/sign cup. Then they would point to the flap with apple behind it and see whether they can remember the second item.

**Motor skills**

Children are developing their tactile and fine motor skills when they are handling objects, turning over cards, lifting flaps, placing items ‘in’, ‘on’ or ‘under’ and completing inset puzzles. Free scribbling/drawing with the felt tips helps to refine the child’s grip, moving from the palmar grasp (using whole hand) towards the tripod grip (using 2 fingers and thumb).

**Food for thought**

Hopefully, this article has provided some insight into the work that goes on in the Early Development Groups and may inspire parents and professionals to work on similar projects in their own regions. Finally, the activities do not necessarily need to be carried out in a group as described in this article, they can also be played at home with other adults and/or brothers and sisters modelling the activities for the child with Down syndrome.

If you are interested in starting a group in your own area, please contact us, as we would like to offer you support and advice on a variety
of issues associated with running groups besides the activities themselves.

References


Further reading

This is a sample of the activities we might use for children aged approximately 30 months to 42 months, to last about 25-30 minutes.

- Welcome and register
- Speech sound cards; anticipate that the children will join in with more of the sounds
- Doll play: equipment to include doll, cup, plate, spoon, flannel, brush
- Word-to-word and word-to-object/picture activity: related to a specific topic, e.g. fruit, vehicles, clothes etc. expectations should be individual for each child
- Sentence reading: match sentence to picture, e.g. “the boy is reading”
- Picture cards: introduce some harder nouns, individually turn cards over, name and/or sign
- Picture cards: introduce some harder verbs
- Bubbles or bells and maracas to regain attention if starting to waiver
- Colour matching activity; match coloured circles to balloons, match the words underneath
- Counting to 10 on the number line and counting either eggs or cars

Sample of the activities we might use for children aged approximately 3 years 6 months to 4 years 6 months, to last about 35 minutes.

- Welcome and register
- Speech sound cards; anticipate that the children will join in with more of the sounds, jumping letters into the bag
- Reading activities; group to look at personal books that have been given for homework
- Matching sentences with two, three and four information-carrying words, choice of pictures
- Sentence including prepositions; construct the scene with small world play items, add in some picture cards of more complex prepositions, e.g. over, next to, between
- Picture cards to practise pronouns, e.g. he’s drinking, she’s waving and some harder verbs
- Picture cards: introduce harder nouns, individually turn cards over, name and/or sign
- Attributes vocabulary, “give me” the heavy/light one, sparkly/stripy etc
- Numicon matching shapes up to five on a baseboard
- Counting to 10 on the number line and listen to teacher count to 20 on the 100 square
- Counting activity; give me “four eggs”; errorless learning, present only the correct number of eggs to count and give the correct numeral
- Matching activity with plastic shapes or items of different sizes

Resources

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


Amanda.Wood@downsed.org
Early intervention in Kenya

Mrs A. Panesar

Circle Academy, Nairobi, Kenya

Circle Academy is an early intervention centre based in Nairobi, which supports children with special educational needs from two and a half years right through to ten years of age. Although we are well resourced for children with Down syndrome (thanks to the Down Syndrome Issues and Information books), we are also supporting children with cerebral palsy and microcephaly. We are staffed by a team of well-experienced professionals that include a special needs teacher, class assistants, a physiotherapist, a speech and language therapist and a music teacher.

We have developed a learning programme that is suitable to variation in learning styles, interests and experience of our children. In addition we provide support in the form of special aids and equipment. In those pupils with specific impairments that influence their access to general learning opportunities, additional educational aims are incorporated into their curriculum.

As far as possible we try to integrate these special aims into mainstream learning experiences. The children’s progress is facilitated through careful consideration of the level of the tasks, the presentation and balance of activities and degree and style of assistance provided.

Social functions include games and sports challenges, music and dance performances, visits to relevant exhibitions, animal parks, shopping malls and other places of interest.

At Circle Academy the interrelationships between children’s learning achievement and their social and personal development are very positive because the children are valued and are secure. They trust the teachers, who absolutely love and understand them, in return for the unconditional love that our children shower upon us.
Learning from individual stories – practical ideas for reading, number and bike riding

In the next section, parents and teachers share many creative ideas for teaching skills and continue to debate the early reading issues

Case studies
Reports of the progress of individual children have two major benefits:
1. All the creative ideas that succeed with particular children are shared for the benefit of many more children.
2. The children’s stories give a picture of the wide variation in rates of progress for individual children and, if we are able to print enough stories, we will build up examples of successful ways to teach those children who learn fast and those who learn more slowly – an issue that has been raised in the last issue and this one – see Letters Pages.

Variability in children’s learning profiles
The first article describes the ways in which Ruth Palatnik developed reading games and activities for her daughter Rina, emphasizing that she chose topics which contained important messages, as well as choosing words and sentences at an appropriate level for Rina – so she maximised the benefit of each activity. Ruth wrote to us on the issue of how parents feel when we publish articles on the children who make rapid progress with reading in their early years, and she has now shared the ideas she used to help her daughter to make progress during her primary school years. The letter from Nicola Baxter makes the same point – her daughter did not seem interested in early reading but took off in school, learning in mostly the same way as the other children in the class and using phonics like them.

Nature versus nurture plus genetic variation
The letters from Leslie Duffen and Victor Bishop both address these issues – and the message we should perhaps take from research and from readers’ experiences at present is that life is complicated! Children’s progress is influenced by our early input and teaching activities but it is also influenced by genetic variation – children with Down syndrome are not all the same. They have their own personalities and their own profiles of strengths and weaknesses – if we put 10 babies in the same household and gave them the same input, they would still all be different in their rates of progress. To complicate the picture further, we do know that nurture influences nature, as brain development takes place over many years and is influenced by input, learning and activity.

Value progress while offering all opportunities
The key may be to simply value progress while offering all opportunities. By this I mean, as parents, teachers and therapists, we need to encourage each child to learn and progress at their own pace, and to enjoy life. I have watched many children with Down syndrome over many years – many ‘slow starters’ suddenly surprise us with spurts in development while others continue at a slower pace than some of their friends but make steady progress well into adult life. However, we will not know if any child is going to benefit from any intervention – such as early reading – unless we give them the chance to try. We need to set up learning games that will make the activity fun and prevent failure and see how the child progresses. We also need to recognise that the reading games are speech and language games and that all children will benefit from us engaging in them together – just as they benefit from shared book reading – even if they are not showing that they can remember the words yet.

Giving up too soon
The article on learning with Numicon highlights this issue – making clear that at the start, Richard did not take to the activities and quickly became ‘frustrated, tired and fed up’. However, his teacher and support assistant continued by setting small targets, using the same activities for short periods and focused on building his confidence. They were rewarded as he began to understand the system and take off. This pattern is seen for all children – for example – learning the first 10 words takes weeks but children suddenly realise that everything has a name and then learn new words at a much faster rate. Much patient input is often needed for a slower learning child before we suddenly see the gains. It is, therefore, very important to make the learning fun while building in lots of successful practice as emphasised in the discussion of early intervention on page 73.

Many thanks to the authors of these articles and letters – please keep sending us your stories.

Editor
Learning from individual stories - practical ideas for reading, number and bike riding

Teaching Rina – my experience with non-English teaching materials

Ruth Palatnik

Parent and registered nurse - Israel

Ruth Palatnik describes her experience of teaching her 9 year old daughter Rina how to read. When Ruth discovered the lack of resources available in Hebrew, she started to explore her own ideas and create materials at home.

Today parents and teachers of children with Down syndrome are lucky, in that a wealth of information is available to us. Publications from DownsEd such as Down Syndrome News and Update and Down Syndrome Issues and Information are colourful and up-to-date. In addition, publishing houses such as Woodbine House and Brookes, amongst others, frequently publish titles related to children with special educational needs. These sources, not to mention the Internet, supply us with a wealth of information.

In addition, parents and teachers today have a vast array of resources from which to choose. Due to the increasing amount of integration in America and Britain, there is a thriving market for resources for people with special educational needs. The result is an ever-growing range of “special educational needs” English language materials including phonics and language cards, specialized workbooks and software packages. The “cherry on top of the whipped cream” is that these items can be obtained with speed and convenience via Internet shopping. There are, however, two major drawbacks that arise for many of us who live outside Britain, Australia, Canada, and the United States: cost and language.

Cost

Many parents who live in non-English speaking countries are still battling against school systems that have not embraced integration. Even if laws favouring inclusion have been passed, it takes time for theory to become practice, just as it took time in the US and England. As a result, parents trying to include their children may often find themselves footing bills for therapists, learning assistants, and other items not paid for by the government. We paid about $4000 last school year just for our daughter’s therapists and teacher.

Parents with expenses like these, as well as teachers in countries whose budgets are not supportive of integration, may find purchasing professional-quality materials, virtually impossible. The problem is excac-
Language

When Rina was small, at the pre-reading level, I did not find language a problem. I was able to buy all sorts of “surplus” discount-priced picture books, colouring books, etc., and it did not matter that they were in English. Picture cards, matching games, etc. are probably readily available in any country due to their use for typically developing preschoolers. However, once your child (student) reaches the level where you want to start teaching him/her (non-English) reading, language becomes a barrier to many teaching materials. Languages differ not only in alphabet and vocabulary, but also in phonics, sentence structure, etc. Also, cultural differences will affect how suitable even purely visual materials are for use at home or in the classroom.

Our need for proper material

My daughter Rina, now 9 years old, has always studied and spoken in Hebrew. Last year she progressed to the first grade reading level and is therefore not part of Rina’s vocabulary. Hebrew is not my mother tongue and this also contributed to the problem.

There were not enough illustrations to catch and hold the interest of my “bouncy” daughter.

They contained sentences, which were too long.

They were culturally inappropriate.

We wanted to provide Rina with materials that would be culturally appropriate, colourful, with short, easy sentences, and of topics that would interest her. In addition, at times we wanted to provide reading materials that would help us obtain other non-reading objectives. These usually were books centring on themes such as holiday seasons, trips, and family celebrations.

One booklet featured drawings of a girl, wearing leg braces, drawing a picture. This story was used to introduce to Rina the idea of “disabilities”. We felt this was important not only to start the process of Rina’s self-awareness of her challenges, but also so that she would react positively to others with disabilities. In addition, we were able to write sentences to say ‘the girl drew slowly, carefully choosing which colour to use’ and at the end of the story it was noted that ‘she felt satisfied with her drawing’. This was to reinforce the concept of working ‘slowly and neatly’, which was (and is) important for Rina. Therefore, with one story we worked not only on reading and language, but also reinforced behaviour “slogans” and opened the door to discussion of disabilities.

Home-made materials: my experience

We based most of Rina’s reading materials on pictorial sequence stories of three or four panels, or on very expressive pictures from picture books (Figure 1). Line drawing sequence stories are usually readily available in pre-school workbooks or in special education materials.

First, I wrote a text to tell the story. At the beginning, I would write texts of only four or five sentences. As Rina gained proficiency in reading, I was able to write a text of longer length. Then I was able to match 4-8 pictures to the text. Other sources of topics for stories were family events and outings. Even the simplest event could be expanded to a story, e.g. taking care of the neighbour’s bunny for a few days, a day trip.

Once I had chosen a text and pictures, I would produce a week’s worth of materials from the basic story. I usually typed out the text, typing each sentence separately using ‘word art’ in Microsoft Word. I used a slanted black text and straightened out on the page. This way I could move the text around the page and adjust its size easily. The biggest advantage of using ‘word art’ was that I could manipulate the text and pictures irrespective of each other. Handwritten text with cut out pictures (see “Pictures” below) can be made very cheaply. An advantage of computer materials is that copies for other children can be readily made and adapted if needed. Another, advantage was that I could easily change the font, to provide Rina with experience in reading different styles of type.

I constructed booklets of four to eight pages. Eight paged books were made easily of four sheets of paper glued back-to-back, to form two individual two-sided sheets (Figure 2). I laminated them and then sewed them together down the middle. After tediously sewing several books together with needle and yarn, I discovered that I could sew two laminated sheets together using sewing machine with no problem.

Additional reading practice: worksheets

To reinforce her reading, I made several other types of worksheets and materials, with varying styles each week.

First, I would print out or photocopy a second copy of the pictures used in the story. I found that the result is clearer if this is done before laminating the book. I usually lami-
nated these second pictures as well, at the same time as the book, as Rina is hyperactive and often was tempted to try to destroy materials, which lamination prevented. Then the aide would write out on construction paper single sentences of the text. Rina could then read the text and match these to the pictures. If the book was based on a sequence story, these pictures of the sequence enabled the aide to work with Rina on her speech. I made materials in this way, virtually every week.

Some of the stories were based on one large picture and Rina’s aide suggested printing out individual verbs, nouns and/or very short sentences, which could be read and placed on the appropriate place of the large picture. If two figures in the picture were doing the same activity, one male, and one female, this enabled us to work on differentiating between masculine and feminine verb forms.

A memory game of individual nouns from the text, as well as similar sounding words, could also be made, along with matching pictures. This game encouraged Rina to read carefully, rather than guess the words. I would print or draw the cards with eight cards to a sheet of paper. I would colour the back of the cards with oil pastel, one colour being used for the word cards and another for the illustrations. This way the pictures and words would not show through on the other side. Then I cut them out and sent them, along with the other items to be laminated, (Picture 3). I was lucky to have a cheap lamination store nearby. My ten-year-old son was nicknamed “the lamination kid” by our local printer, as I invariably sent him running before the weekend to laminate all the materials for the following week. Laminating in bulk can be cheaper than doing it in bits and pieces.

Sometimes, I prepared a memory game to fit the topic rather than the text.

For example, the week that I prepared the story about the girl with a leg brace, I fashioned a Pelmanism-style memory game. This game has word/picture cards for children with disabilities and their aides, e.g. “blind girl” and “seeing-eye dog”. The cards are placed face down and the child has to try to find the pairs. The memory games have the advantage of allowing reading and memory practice. However, if your child has trouble with memory games, it might be preferable to play with these cards face up, so as not to discourage them from this reading practice. Memory could be worked on in a separate non-reading activity.

In a variation of the above, Rina had to draw a line from the words to the matching pictures on worksheets. I often used this format to match phrases, rather than single words, to a picture. Often I intentionally tried to make the phrases sound similar, to discourage guessing, e.g. a red plant, a red plate, a crooked plant, a cracked plate.

I was able to make questions to check comprehension by putting single sentences of the text to a clean sheet of paper, and altering them slightly. This was easy to do if the text was typed in single line sections with word art. The questions could be fashioned as either ‘true/false’ or ‘fill in the blank’, (Figure 4).

I created more worksheets by copying lines of text on to a clean sheet and then handwriting the same line of text underneath in cursive writing. A lined writing space was then provided for Rina to copy the word(s). Again, one added picture made the sheet that much more appealing. As she progressed in her reading and writing ability, she sometimes even wrote a three or four sentence story, (with help) related to the sequence. Her story was either the original story in ‘her own words’, or a similar story on the same topic.

A further type of language worksheet was made by taking a sentence from the story, and altering it to a different tense. The verb would be erased and replaced by a blank line. It could also be changed from masculine to feminine or from singular to plural. Rina would then fill in the blank with the missing verb form. Depending on the level of the child, this could be done either by letting the child cut out the answer from a “basket” of possible answers, and pasting it in place, or by copying the correct answer from a “basket”. A more able child could write the verb from his/her own knowledge without a “basket” of possible answers. A similar and easier format was to take
an action picture from the story, and a similar picture of the same verb, but in the opposite (M/F) form. Then the child cuts and pastes (or writes): he, she, Rina, Joshua, Grandpa, etc, placing them below the correct verb form. This can be expanded to include plural verb forms as well.

**Pictures**

The pictures we used came from many sources. The easiest source of was photocopies or scans of the sequence on which the story was based, or digital photos of family events. I bought a digital camera thanks to the wonderful article by Honor Mangan in *Down Syndrome News and Update*[^1] and have found it very useful. The ability to download the pictures when needed meant that I could write a booklet on family events while it was still "news". This outweighed the lower quality of the pictures compared to regular film. Scans of large multi-faceted pictures, for example, of an open-air market with many booths allowed me to select several small sections of the picture for individual sentences.

Another easy to use source was clip art collections. The drawback of using scanned pictures or clip art is the cost of the ink used in printing them. Often I printed in black and white to cut the colour ink costs. If I wanted to add some interesting colour, it was easy to do with art pens, especially if I set the printer to print with a less strength of ink concentration, which also saved ink.

I am not an experienced computer user, but quickly enough I discovered that I could easily turn and flip pictures by pasting them to windows "paint" program, and clicking "picture". In "paint", I am also able to doctor pictures that do not fit my cultural norms. I found no need for fancy graphics programs, which I wouldn’t know how to use anyway.

I also highly recommend using pictures from the cheapest source, cutouts from magazines, advertisements, etc. About four or five years ago, I started to make a file collection of pictures. All year I saved magazines, and in the summer, I "paid" one of Rina’s brothers money to cut pictures out and file them away alphabetically. We also found pictures in pre-school workbooks, mail order catalogues and bad family pictures, the shots that were too embarrassing or ugly to put in the family album! One day my teenage son brought home a catalogue from a local supermarket, for phone orders. The small pictures were perfect additions to recipe cards we wrote out for Rina. Reading the grocery list and recipe card allowed her to gain yet more reading practice, as she learned to make salad, hot dogs, etc. The addition of a small picture to the card made it more appealing for Rina to read. The pictures were sorted and filed in two ways; by initial letter in a card index box, with one envelope for each letter of the alphabet or in a large ring binder with plastic pouches for different topics such as:

- Family pictures
- Holidays
- Verb (action) pictures
- Various categories (foods, furniture, etc.)

This binder was especially useful for making worksheets on categories and “what’s different?” and for making books or worksheets on specific topics such as holidays, the dairy, etc. The filed pictures were also good to add to hand drawn pictures. I am not very artistic but adding a cutout picture to a simple hand sketch made the final effort more colourful, interesting and identifiable.

**Software**

There is no real substitute for the excellent special-needs software being produced in English. Theoretically, one could make a non-English reading book/game using Microsoft’s “PowerPoint” presentation program.

However, you will probably discover, as I did, that your child will learn to read more quickly than one can make the required number of presentations, especially if you are doing all this in your “spare” time.

For a teacher or school, this might make a good long-term project, although it would probably be more cost effective to buy rights to translate existing software, and market it in one’s country. However, cultural differences may make software from different countries unsuitable for you.

PowerPoint can be used effectively for other purposes though; once when Rina had some behavioural problems in Kindergarten, I made a “social story” presentation about a girl who hit others and then learnt not to. This proved to be a useful resource.

**Useable software for non-English materials**

CD-ROMs for making flashcards and lotto boards, which can be used with any language, are available from ABA materials (http://www aba-materials.com) and “Picture This” by Silver Lining Multimedia, available through Woodbine House (http://www.woodbinehouse.com).

**Reference**


---

[^1]: The following items are available from The Down Syndrome Educational Trust’s Resources brochure:


**Videos:**


© 2003 The Down Syndrome Educational Trust. All Rights Reserved. ISSN: 1463-6212

http://www.down-syndrome.info/library/periodicals/dsnu/03/03/
Dear Professor Buckley

I wanted to say an encouraging word to parents who have found that their child with Down syndrome is not making much progress with early reading. I had read all the advice and tried to work on this with my daughter Kizzy from three-and-half onwards but she showed very little interest and made almost no progress in matching and recognising words, although she could match enthusiastically in other contexts. She was otherwise a lively and alert little girl with no medical concerns and good hearing. Seeing other parents succeed with reading with children of a similar age made me feel that I had failed her.

However, we enjoyed looking at books together from the time she was a baby and she also learnt all her letter sounds at nursery before she went to school.

The good news is that as soon as she was at school (mainstream with full-time support) she took to reading straight away, following the same scheme as the other children and learning in the same way. She surprised me by making use of phonics from an early stage as well as sight recognition to aid her reading. Now at six and eleven months she is very much enjoying reading, has started to read by herself for pleasure, and is as successful as many of her classmates. Her younger brother has just started school and she delights in helping him with ‘his’ reading.

Maybe I simply wasn’t the best teacher for her, but I’m inclined to think that she was just not quite ready and that other activities we did together were all helping her to access reading as soon as the readiness and the right context came together.

On another matter, I understand the distress some parents feel about seeing news of ‘high achievers’ with Down syndrome, but I do think you are right to try to raise expectations. If my children were typically developing I’m sure I’d be the classic competitive mother. But I feel that one of the important things that my daughter (and now my adopted son) have taught me is that there is so much more to celebrate about a person than where they come on any kind of scale.

Our Young Down’s Group in Norwich recently had the huge pleasure of a visit from Sarah Duffen and her father. It was wonderful to meet Sarah, to hear that she had shared the driving on the long journey, and to see her having fun with the little ones and chatting to parents. I’m sure I wasn’t the only parent there to be inspired by her and encouraged to have the highest hopes for our much loved children.

Yours sincerely,

Nicola Baxter
Norfolk, UK

Support for parents seeking good inclusive education

network 81

We are a national network of parents working towards properly resourced inclusive education for children with special needs.

Helpline for FREE advice and information

0870 7703306
Monday - Friday 10am - 2pm
(calls charged at national rate)

We can offer advice to parents on a range of topics including:
• choosing a school
• inclusive education
• education law and the Code of Practice
• communication with schools and Education Authorities
• local and national organisations available to help parents
• a range of literature, including a handbook for parents

1-7 Woodfield Terrace, Chapel Hill, Stansted, Essex CM24 8AJ
Fax: 0870 7703263 • E-mail: network81@tesco.net • Web: www.network81.co.uk
Registered Charity No. 1061950

© 2003 The Down Syndrome Educational Trust. All Rights Reserved. ISSN: 1463-6212
http://www.down-syndrome.info/library/periodicals/dsnu/03/03/
Dear Sue,

I am writing to comment on points raised by Ruth Palatnik and Jill O’Connor in the September 2003 issue of Down Syndrome News and Update.

‘Nature’ versus ‘nurture’ is a controversial issue that will not be resolved until a large number of children has been brought up from birth in the optimum conditions for maximum intellectual growth. This is a long way in the future if only because we still have only limited ideas on what these ‘optimum conditions’ are. Certainly no child, with or without Down syndrome, has yet been brought up under these conditions.

When I say that my daughter Sarah was ‘congenitally above average’ I am making a statement unsupported by any evidence except that her achievements are above average – so that she may well have had a head start. However it is impossible to separate the effects of Sarah’s learning environment, since birth, from the effect of her congenital ability. Elsewhere, I coined a phrase ‘Individual Learning Time’ (ILT) and gave some quantitative estimates of the levels of the ILT that Sarah has had from an early age – though not as early as I now wish – and to a limited extent is still having. Most children, with or without Down syndrome, achieve nothing like these levels of ILT. I believe that without this input Sarah would now be illiterate, inarticulate, innumerate and physically inactive – whatever her congenital ability.

The word ‘quantitative’ in the last paragraph raises an important point. In most human activity it is taken for granted that the degree of success in that activity is directly proportional to the time spent in achieving success. Only in education is this factor completely ignored - to the extent that we simply do not know the extent of individual learning time in, for example, learning to read or in any other learning. It certainly bears no relationship to class teaching time.

Ruth asks for suggestions about the levels that children can be expected to achieve at certain ages in - for example - reading. I do not think that these can be divorced from the amount of ILT that the child has had and is having, and the age at which he starts learning. Of course there will be a range of achievement in our children, as in all children, but we simply do not yet know what the upper level of that range of achievement is, in reading or anything else, under optimum learning conditions.

Jill suspects that most people with Down syndrome are working ‘proportionally nearer to their limits’ than the rest of us. Well, maybe, but I agree far more with her earlier suggestion that we don’t really know the limits of the potential of anyone, with or without Down syndrome, because our usual home and school environments are far removed from the optimum for maximum growth. Every year we can read of a six year old taking GCSEs, or some such. This probably happens because his or her educational environment has been much nearer to the optimum than usual. Asserting that such a child must have been born as a ‘genius’ is a rationalisation of our failure radically to improve the educational environment for all our children. The conventional part time, class teaching, school education is nowhere near the optimum, even if it is started early enough.

Ruth suggests that parents can be discouraged if too much is made of the ‘high achievers’. Thirty five years ago I would have been immensely heartened and encouraged to hear that there was even one person with Down syndrome who was at any level of achievement. I can assure Ruth that it was very much more discouraging to be given no hope at all than to be given too high a target to aim at. High expectations must be better for any child, given the necessary action, than aiming too low or not aiming at all. Parents can surely put up with some disappointment in their children’s achievements if they know that they have given all the time that they can to help their children develop, using the best advice available to them. No parent can do more.

Leslie Duffen
Devon, UK
Dear Professor Buckley,

I felt I had to write and say how inspired I felt by your talk in Harrow on Saturday. To hear you speak so passionately and eloquently brought me close to tears a number of times during the day. Thank you so much. I am a single mother of four children, the youngest of whom is 5 and she has Down syndrome, and I have been trying for years to get down to Portsmouth to hear you speak but domestic circumstances have prevented me, so I was thrilled to be able to hear you in Harrow. I was originally inspired by a video you made about learning to read and I decided then to try it out with Bryony, with the result that she was reading fifty-odd flashcards at 2 and a half, and now at 5 is keeping pace with her peers in Class 1.

I found the concept of errorless learning to be crucial factor in Bryony's development. For example, when I first introduced flashcards to her, they had the word on one side and the picture on the other, so if she didn't always get the word right, I turned it over and she correctly identified the picture instead. This always delighted her!

Although Bryony reads fluently and willingly to me, she has recently stopped Her writing is not as advanced as her reading but we're working on it. She likes to write in her own way for hours on end but doesn't take very well to suggestions for improvement!

I can't tell you how grateful I have felt over the last five years, and every time things get difficult I just have to dip in to the literature I've collected from you and I feel inspired to go on again. You must be very proud of the world of possibilities you've opened up for people with Down syndrome.

Thank you again,

Yours sincerely,

Theresa Smissen,
Hertfordshire, UK
More on the issue of early reading opportunities

Sue,

What a great issue with articles by Erik de Graaf and Rosie Cross! I will photocopy the article by Cross for Emmanuel’s violin teachers. Regarding Maria Kotlinski’s 98th percentile, that is one point I always make in my “Early Literacy and Down syndrome” presentations (the last one was a week ago to the New Orleans Down Syndrome Association that had a booth at National Down Syndrome Society) is that my son has mental retardation/developmental delays, and just like Maria or Sarah Duffen, if my son had been tested at age 24 months for word recognition, he would have scored 99.9%, not because he could sight read 10 words, but rather all other children had not been taught to sight-read yet. The last thing I want to give my audience is the impression that what Emmanuel is accomplishing is far past attainable to most of their children. The purpose of my talk is so we have less parents asking themselves like Ruth Palatnik from Israel on page 57, why didn’t I start to teach my child with Down syndrome to read earlier.

My son Emmanuel (12/21/1996) read a welcoming speech at the 2003 NDSS Conference in St. Louis, I enclose the PowerPoint screens. My son is being raised bilingual English/Spanish and is tutored in French. The objective was to show parents with toddlers with Down syndrome that an early sight-reading, visual based programs like the Love & Learning kits for ages 0-3 (http://www.loveandlearning.com) or Glenn Doman’s “How to teach your baby to read” (flash cards) is a good adjunct to early intervention.

Regards,
Victor J. Bishop,
USA
Using Numicon – a report from a special school

Kerrie Coleman
Class teacher, St. Ita’s Special School, Drogheda, Co. Louth, Ireland

Class teacher Kerrie Coleman gives a personal account of her experiences with Numicon. She explains how she was inspired by a training in Ireland, to devise an individualized programme for her student, Richard. Although he didn’t take to the activities straight away, he made slow but steady progress and within six months, his confidence and number skills had rocketed.

Background
In the spring of 2002 I heard about Numicon from a parent of one of my pupils, Richard, who also happened to have Down syndrome. I was seeking any information on Maths materials which could help children with Down syndrome as this had been an area where Richard had been having difficulty and appeared to be making little or no progress at all.

At this stage Richard was almost 13. He was assessed as having “Moderate Learning Difficulties” with his intellectual functioning placed in the Moderate General Learning Disability range.

Our experiences:
I attended a Numicon workshop in Slane, Co. Meath, organised through Down Syndrome Ireland and facilitated by Vikki Horner. From this workshop I was left feeling inspired by Vikki’s work with her own daughter using the Numicon system and couldn’t wait to test out this equipment on Richard. I felt that this innovative approach to teaching number would certainly hold the key to Richard’s achievement in Maths!

I returned to school full of enthusiasm for the potential of Numicon, not just for children with Richard’s specific needs, but for other pupils in our school with mild learning difficulties. Following discussion with Richard’s mother, we decided to begin using Numicon in school first and then to follow up with home reinforcement of the activities we covered, once we got into the swing of things!

In September 2002 we began! Richard started Numicon activities every morning with his Special Needs Assistant (SNA) under my close supervision. At first this took place in the classroom, but later in a separate room, due to the distractions of a noisy and busy classroom, which affected Richard’s concentration. Initially it was not easy – Richard had difficulty handling the equipment and would become easily frustrated, tired and fed up after only short sessions using the equipment. I had naively thought that he would take to it straight away and that progress would be swift!

Having experienced the evidence of Vikki Horner’s success with her own daughter, I had thought this would be the case for Richard! I did not realise how individual our approach to Numicon needed to be to suit Richard’s own learning needs.

At first I did not realise how individual our approach to Numicon needed to be to suit Richard’s own learning needs

We set simple targets for each week and made sure we kept to the same routine, time span and set of activities every day. This mattered for Richard’s feeling of confidence and security. Familiarity is very important to him. We kept a working log/diary of each week’s activities, highlighting difficulties and successes. We also kept a copy for communicating with home for comments on any difficulties that were occurring and where we could offer additional support. This was a vital link. We were not afraid to adapt and make changes where necessary.

From September to mid-term break in October we worked on Numicon in school only, focusing on the first four activities. Following mid-term break Richard began reinforcement of these activities at home and we began working on activities 6 to 10 in school. Each day we revised the first four and then would focus on the new activity for a week at a time (or longer if necessary) until Richard had confidently grasped the concept of the task.

Although I felt he was doing well, progress did appear to be very slow and quite minimal at this stage – we just kept going!

Following the Christmas holidays we were up to activity number 7 – so it had taken us from September to get this far. We were not...
Learning from individual stories - practical ideas for reading, number and bike riding

Sure whether this was in keeping with other children whose needs were similar to Richard. We did not really know what to expect, but kept on with our structured routine and schedule. Richard certainly seemed to be enjoying the activities and his self-esteem and confidence were improving. By February, Richard’s abilities with Numicon began to take off – it was almost as if the penny had dropped and he took off like a rocket! Since then there has been no stopping him. We are amazed at what he has achieved, considering his number ability before we began using Numicon. He has worked through the remaining activities of the Foundation Stage with terrific speed and accuracy and confidently completes addition and subtraction tasks using his Numicon shapes both in his written and oral work. We could not have imagined the progress he has made using Numicon. He is truly a success story following the Numicon approach to number. I feel that his confidence and delight in achieving in Numicon has had a positive affect in all areas of Richard’s school life. There has been visible improvement in both his ability to follow instructions and his concentration levels.

Richard’s abilities with Numicon began to take off – it was almost as if the penny had dropped and he took off like a rocket!

All credit to Richard for working so hard with both his SNA and myself – we are all very proud of him for all he has accomplished in this school year. I do feel that only for the great partnership between school and home (his very supportive Mum and helper Trish), he would not have succeeded so well. For us it has been a team effort!

Our experience of Numicon in a Special School setting has been very positive and we continue to be excited by the potential to succeed in number work which it holds for pupils like Richard, who need an extra helping hand along the road to school success!

We are currently using Numicon with different pupils within our range of ‘Mild Learning Difficulties’ and are finding it an effective approach to number work. We will look forward to hearing about other school’s experiences with Numicon. We hope they are as positive as ours have been in helping pupils like Richard realise their full potential. It may not suit all children, but for Richard it has been the key to his mathematical success!

I feel that his confidence and delight in achieving in Numicon has had a positive affect in all areas of Richard’s school life

Kerrie can be contacted by e-mail on: kerriecoleman@eircom.net

PUPIL PROFILE

My name is Richard Leonard. I am 14 years old. I live in Stamullen. My favourite food is sausages. I like listening to music. My favourite singer is Robbie Williams. My favourite TV programme is Eastenders. I love playing football with my friends. My best friend is Mark Reilly. I am in Pre-senior with Mrs Coleman and Mrs Callan.

Richard ‘finding the missing number’ with his SNA, Grainne Finglas

This article was previously published in Footsteps Magazine Summer 2003, and is reprinted with permission.

Number resources

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


Numicon kits

- ‘At Home’ Teaching Kit
- Foundation Kit
- Year 1 Kit, for schools or single users
- Year 2 Kit, for schools or single users
- Foundation Plus pack
Learning to ride a bicycle

Greg Sneath
Parent - Hampshire, UK

Teaching our daughter Katrina to ride had been a vague sort of goal for several years, and we were surprised how very quickly it all fell into place (eventually).

Initially, it was impossible to find a way to motivate her to take an interest in riding a bike at all! She was very happy to watch all her friends and neighbours riding, but did not want to do so herself – although her pride and joy when she did manage it, was tremendous.

The first indication that she might eventually take to riding came when we trialled a special 3 wheeler suited to her size. She knew it was just for her. It was sturdy and secure. She could pedal it easily because of the accommodating gear ratios, and her feet didn’t slip off the pedals because it had toe clips. The sales representative brought the bike to our house and she took great delight in riding alongside her brother and sister. She managed it easily, with just a little guidance and reassurance for the steering and braking.

Our unbounded enthusiasm for this progress was only thwarted by the exorbitant price tag of the three wheeler. Funding can be found, apparently, but instead we spoke to a local bicycle dealer and established that many of the redeeming features of the three wheeler ‘might’ be incorporated into the standard ‘off the shelf’ bike. For some bikes with gears it might be possible to fit ‘extender’ bolts onto the rear axle so that trainer wheels could also be fitted. (we intended to leave it in just one easy gear) Alternatively, it might be possible to alter the size of the front or rear sprockets to make it easier to pedal. Toe clips to stop the feet slipping out are easy to fit on the right sort of pedals, although if the child also wants to remove their foot from the pedal you may want to leave the straps off, and just have the front clip to stop their foot sliding forward.

For various reasons we didn’t advance far enough down those options to justify converting the expression ‘might be possible’ to ‘definitely worked / failed’. Instead winter came, and so did a change in employment. We were generally distracted from the current cycling ambitions.

Our daughter pre-emptively took what I now consider to be the most advisable course of using a friend’s scooter instead. She was way ahead of us, because I see now that in terms of learning balance, the scooter is far superior to training wheels on a bicycle. I only had to watch all the other children lean the wrong way, ‘out of’ the corners when trainer wheels were removed, to realise that balance is not part of the ‘training’.

So, for us, the scooter was the answer for a long while, especially for balance. We encouraged her to glide along with her foot up as much as possible.

Having invested in trainer wheels on a standard bike, it was pleasing to realise they were still essential for gaining the strength to pedal, and for learning how to use the hand brake. Indeed, I’d underestimated the hand brake. My daughter very sensibly put her foot down and adamantly refused to ride the bicycle, even with the trainer wheels on, until one day it occurred to me to spend more time teaching her how to use the brakes with more confidence.

So, for a year or more, it was the scooter for keeping up with siblings and neighbours, and also for learning balance and steering. It was the bicycle with trainer wheels for learning to pedal, and learning the brakes – hopefully with as little time as possible learning to lean the wrong way when cornering. (I was unsuccessful in restricting her bike riding to straight lines only).

Over the summer school holidays all the children in the street were enthusiastically cycling about the limited space available to them. A neighbouring family took all the children out for a bike ride, with my daughter on a half bike trailer unit. She loved it, and seemed to accept the challenge that we could all go
Learning from individual stories - practical ideas for reading, number and bike riding

riding places if she learned to ride independently.

She seemed confident with braking and pedalling now, so off came the trainer wheels!

In preference to trying to hold the seat or handle bars, I fitted an old toddler harness around her chest and grabbed a firm hold in the middle of her back. Her balance wasn't too bad except on the corners. We practised that for some time, occasionally with me also guiding the handle bars on the tighter corners until she started to get the hang of it. It didn't take long.

**Much to the stress of my cardio-vascular system, Katrina started riding along the cycle path, unaided for longer and longer distances**

Then came the hard part. To build confidence we sought the long straight runs on a cycle path. I was running along side holding firmly onto the harness in the middle of her back. It wasn't long before she didn't need any support at all for short periods. Well, that is provided I could help get her started, and then could grab hold when she veered off the path, and again when it was time to stop. The independent cycling bit between times was pretty good.

Much to the stress of my cardio-vascular system, Katrina started riding along the cycle path, unaided for longer and longer distances, with only the very occasional desperate lunge from me to catch her from the edge of disaster. Before long she learned how to stop unaided, and then after a while how to set the pedals in the right place to start unaided. Then, of course, with the long stretches of clear runs came invaluable confidence and enthusiasm.

Daily practice saw her riding more and more comfortably along the path with me jogging less and less comfortably along side to catch her when needed.

... she took great delight in riding free and easy into the far distance in pursuit of her brother.

It was with great pride and a sense of real achievement that I followed at my own sedate pace. She waited quietly for me just around a distant corner, unharmed but comfortably spread eagled on the muddy verge with another cycling enthusiast watching over her with what could be described as a very kindly air – considering his own front wheel now lay in a twisted mangled wreck entwined with my daughter's bike.

Katrina mastered the bicycle at 7 years of age and is cheerfully riding independently now, but with the wisdom of hindsight we are spending time in the open grassy parks, practising looking well ahead to anticipate and negotiate obstacles.
The Down Syndrome Nutrition Handbook

by Joan E Guthrie Medlen, R.D., L.D.

Published by Woodbine House, Bethesda, MD, USA, 2002

Reviewed by Tracey Parkin

Diabetes specialist dietician and mother of a child with Down syndrome

I was asked to review this book for two reasons, one because I am a registered dietitian and two as a parent; one of my daughters has Down syndrome. On receiving the book, I was a little overwhelmed as I was told it was a handbook, but in fact it looked more like a telephone directory! The author is an American registered dietitian, who specialises in promoting healthy lifestyles for people with disabilities and their families. She also has a son with Down syndrome. I felt this wealth of experience in particular the practical experience as a parent shone through when reading this book.

The book is divided into 4 key sections:

- Section 1. Building healthy attitudes
- Section 2. Nutrition related concerns for people with Down syndrome
- Section 3. Teaching healthy choices to encourage healthy lifestyles
- Section 4. Learning activities.

Each section is clearly laid out and easy to read. Key facts or helpful hints are summarised in a box, enabling you to access this information more quickly.

**Section One**

Section One focuses on three topics; successful eating, breast or bottle-feeding and the feeding relationship. This section clearly describes the progress of weaning and how this relates to oral motor skills with lots of suggestions of foods to use. The author focuses on three key aspects:

- physical, getting food into the mouth
- sensory, managing the smell, taste, feel, sight and sound of food
- emotional, managing how you feel about eating.

Clear steps are given to help with problem areas of eating. Understanding why the problem arises makes it easier to understand the type of solutions that are suggested. The question of when to ask for help is also raised and is an important one. As a parent there are so many things that we have to consider and work on with our children as well as our usual family and work lives. It can be easy for things to get out of hand. It’s hard to be perfect all the time!

I would have welcomed a chapter on breast-feeding; I struggled with this and there are some very practical ideas on how to position the baby for feeding, keeping them awake for the feed and encouraging correct latching-on. This information could be invaluable to new mums who want to breastfeed. The feeding relationship gets you thinking about how you use food, and patterns of behaviour around food, as these are set early in childhood and strongly influence adult behaviour. Is food used as reward or punishment, are mealtimes associated with stress as you try to get your child to eat? These emotions can have a strong association with food, and can lead to eating when not physically hungry but in response to emotions; when happy or sad; or if the event is stressful, a reduction in food intake as the process of eating is an unhappy one. The positive relationship between food and mealtime experiences is strongly emphasised with lots of ideas on how to engage children.

**Section Two**

Section Two looks at five areas:

- Nutrition
- Physiology
- Coeliac disease
- Diabetes
- Alternative therapies.
It clearly outlines what happens to food normally during digestion and how people with Down syndrome have different energy requirements, needing 10% less energy than other children and adults their age. The need for nutrients such as vitamins and minerals based on current evidence is the same as outlined for the rest of the population, taking into account age and sex. Unfortunately, all the nutrient reference values listed are American, some of the UK reference values differ as well as being measured in different units. Despite the differing units, the table outlining the nutrients, lists their functions and what happens if deficient. The descriptions give a useful guide as to why these nutrients are needed in the diet.

The signs, symptoms and treatment of Coeliac disease and Diabetes, are clearly explained including on-going monitoring for diabetes. Blood test measurements are all in American units mg/dl this may cause confusion as in the UK a different measure mmols/l is used. Differences in healthcare delivery are also highlighted as in the UK we do not have Certified diabetes educators, and access to healthcare and routine tests differ.

Practical information on the management of constipation, a common problem, is also described in detail. Alternative therapies are discussed clearly and the author presents a balanced view of what is currently known and what is needed from future research in this area. It also provides a clear outline of things to look for when looking at research papers including how to decide whether the research was well designed and evaluate the quality and validity of the study presented.

**Section Three**

Section Three focuses on practical issues teaching your child to make choices, nutrition education for all ages and stages, food and school, weight management, fitness and activity, cooking and the art of menu planning. This chapter makes excellent use of the author’s wealth of practical experience. There are numerous ideas to work at with the child, teenage and adult to help put them in charge of their diet and lifestyle including weight management. The use of symbols and pictures to help with meal planning and snack choices, and a chapter on activity and what is normal activity. This includes looking at heart rate to help determine whether your child is being worked at a level they can manage or being pushed too hard. The ‘cooking corner’ includes practical tips such as starting written recipes with a reminder to ‘wash hands’ and finishing with ‘tidy the kitchen’! Pictures and colour codes for measures used for those with limited reading ability also clearly outlined and illustrated. Aspects on letting go, giving your child responsibilities is very poignant as it is easy as a parent to do the things that need doing as we are quicker at it. If we always do this, how will they learn for themselves? Good reminders are provided throughout on this theme.

**Section Four**

Section Four is loaded with activities from learning to balance the diet, what is a serving size, looking at snacks and combinations of foods at mealtimes, activity and very importantly goal setting. The goal setting activities are designed to engage the child or adult in developing their ability to manage their diet and activity through simple steps that they set. There is also discussion on the need to plot these achievements long term to illustrate their successes over time. Planning meals and recipes was very enlightening, lots of practical ideas given including the use of symbols and pictures to enable this process to work for those with limited reading ability making the whole topic of activity and diet accessible to all. Ideas are also given on role-play, as a means of helping groups of children and adults to learn to problem solve.

Overall, I feel this book is well written; it ties together the evidence of what is known with masses of practical ideas, and games to put this information into practice and focuses the whole time on engaging the child, teenager or adult with Down syndrome. Healthy eating and active lifestyle is not what you do to the individual, it’s what you share as a family. I feel that this would be an invaluable resource to professionals and the information that it contains would be very useful for parents. The only disadvantage is that as an American publication there are a variety of features, which are not applicable to readers from other countries, e.g. the contact lists for further information, references to legislation and rights in America, blood measurements and nutrient values, are in different units and some values may differ between countries. Also, some of the foods mentioned are American and are not available in the UK. A guide to UK equivalents would be helpful. I felt that the resources are excellent but are based on the ‘food pyramid’. In the UK the ‘balanced plate’ is the tool that is used to get food messages across. However if these resources were adapted I think they would be invaluable to healthcare professionals and parents alike as practical and simple to use.

Allowing for this, as a parent, I would have valued access to the practical information available in this book. If the resources, contacts, measures and specific foods where altered to reflect the UK, I feel it would become a best seller!

---

**The Down Syndrome Nutrition Handbook - A Guide to Promoting Healthy Lifestyles** is available from The Down Syndrome Educational Trust, priced £17.50, item ref: BOOK/0870
Speech and Language Intervention in Down Syndrome

J. A. Rondal and S. Buckley (Eds)

Reviewed by Nicola Grove
Senior Lecturer, Department of Language and Communication Science, City University

The book aims to provide a state of the art review of research into the speech and language development of this extensively researched group of people. It functions as something of a celebration of the tireless work to benefit children and adults at the Down Syndrome Educational Trust, edited by two of the foremost experts in the field. The chapters in this volume are all written by people with a proven track record, not only in research, but also in practical intervention.

The book opens with an excellent overview of the themes and topics covered in the book, locating language intervention with individuals firmly in the context of a psychosocial model across the lifespan. This is followed by a series of chapters reviewing work into prelinguistic development, speech acquisition and the associated study of phonological working memory; aspects of language (semantics, grammar and pragmatics), literacy and language development and finally, two chapters covering welcome new ground on the topic of language intervention with older people.

Much of the recent research in Down's syndrome relates to the issue of speech skills; how and when they are acquired in comparison to typical development, and the underlying causes of syndrome-specific problems. The early chapters have a strong focus on this area, and there is some overlap and repetition of information, which could perhaps have been avoided by a broader focus in the chapter on prelinguistic development. Phonological working memory is hypothesised to lie at the root of many difficulties in the acquisition of morphosyntax, and Conners does an excellent job of deconstructing this complex area for the reader. Moving from speech to language, there are authoritative overviews of lexical and morphosyntactic development by Mervis and Rondal. Buckley's chapter on literacy and language development takes these findings forward in a readable and informative account of the exciting recent research in this area, which has profound implications for both education and therapy. Her arguments for text-based approaches are well known, but I felt there was room for some discussion of the role of graphic symbols, particularly for the students who failed to develop beyond a logographic stage of reading. One of the most difficult decisions in special education is whether to go down a text based or a graphic route, in the face of wide scale adoption of literacy through symbols, yet a lack of valid assessment procedures. This registered as rather a missed opportunity for me. Powell and Clibbens, in their chapter on augmentative and alternative communication glance at the role of graphic symbols, but focus primarily on the role of signing in language development, providing a succinct summary of research and welcome counter arguments to those who fear that the introduction of augmentative methods may have a negative impact on speech. Pragmatics is an area of fairly recent interest in the study of Down Syndrome, so it was perhaps to be expected that Abbeduto's chapter on this topic would be less weighty than others. There are sensible suggestions here, but some key references are omitted and the chapter was something of a disappointment when compared to an earlier book edited by the same author which went into considerable detail on referential communication, speech acts and conversation management by people with learning disabilities.

Finally, the two chapters on working with adults are complementary, with Rondal focusing more on academic research findings, and Jenkins providing a sensible, grounded and optimistic account of what can be done across the lifespan.

There is some variation between writers in the extent to which contributors consider the broader context flagged up in the introduction, and the extreme variance in this population, with Buckley's chapter exemplary in this respect. I was also conscious of some discrepancies between the conclusions drawn by different authors – for example relating to morphosyntactic development post adolescence. All in all, however, this is a book to be strongly recommended to practitioners and researchers alike, offering genuinely new insights and ideas in how best to develop communication, and clarifying areas in urgent need of further investigation.

1 Rosenberg, S. and Abbeduto, L. (1993). Language and communication in mental retardation. LEA
Speech and Language Intervention in Down Syndrome

J. A. Rondal and S. Buckley (Eds)


Reviewed by Karen Imrie

Specialist Speech & Language Therapist, Yorkhill NHS Trust, Glasgow, UK

This book includes a collection of papers from recognised authors in the field of Down syndrome. It incorporates chapters dealing with the different aspects of language and communication development i.e. memory and speech. It also includes information relating to A.A.C., literacy and bilingual issues, whilst covering the stages from early intervention through to adulthood.

The authors stress the importance of collaborative and inter-agency working and highlight the key role played by parents and carers as Active Participants in any therapy process. A major strength of this book lies in the authors' abilities to describe recent findings in this area and to transfer this knowledge into practical applications which can be integrated into therapy aims.

The book is well researched and provides the reader with considerable reference links, highlighting the increasing amount of interest and research being carried out in the area of communication.

Speech and Language Intervention in Down Syndrome will be a valuable tool for both Speech and Language Practitioners and Undergraduates developing an interest in this field.

A well-deserved media award

We are happy to tell you that our book Living with Down Syndrome has won a photobook prize from the German book trade (http://www.fotowettbewerbe.de/fotowettbewerb/fotobuchpreis.htm).

Andreas Reeg and myself went to Stuttgart to receive the prize (no money - just honour...) and for an interview with SWR 4 (an important German radio station).

We regard this as an important step from the (natural) interest of people involved with the subject of Down syndrome towards a greater public. Maybe this can help to open some eyes and minds.

We already had quite a lot of good press for the book, mostly in the national and international magazines of organisations related to Down syndrome. The big German magazine Stern will be publishing an article about Andreas Reeg and our book, probably in February (they had to postpone the promised publication date because of the Iraq war).

The book is also selling not too badly – compared to the prognosis of our book distributors – and we have had a lot of orders from the USA.

There has been a first exhibition of the photos in Wuppertal, Germany, and Andreas Reeg is thinking about an exhibition tour. If you have any contacts that might be interested in showing the photos, please let us know.

In the meantime, we hope you enjoy our shared success with us.

Best regards,

Barbara Karpf

Kehrer Design / Kehrer Verlag, Heidelberg Ringstraße 19 B 69115, Heidelberg, Germany

Tel: ++49 (0) 6221-64 920-10
Fax: ++49 (0) 6221-64 920-20
E-mail: barbara.karpf@kehrerverlag.com
http://www.kehrerverlag.com/
A special Christmas present

Sara Thom

Parent, London, UK

Charlotte

Alexandra Moir was born at Watford General Hospital in the Active Birth Unit, 17 December 2001. Born just one week before Christmas, Lottie came as a very special Christmas present to parents Sara and Dom.

Introducing Lottie

It had been a wonderful pregnancy and a great birth, I couldn't believe my luck. I'd loved almost every moment of being pregnant and when labour started, Charlotte took only 6 hours to arrive; it was the natural birth I had always hoped for.

But, soon I began to think there was something different about our little girl. I don't know what it was; her eyes, her neck, something made me think 'Down syndrome'. The midwife agreed and later that morning, the diagnosis was confirmed.

One of the most difficult things at this early stage, was phoning our family and close friends. We told them "and by the way Charlotte was born with Down syndrome, we can't wait for you to see her, she's lovely". Our friends and family were great and although some tears were shed, we made sure we celebrated Lottie's birth and as far as possible it was a happy time.

The next day Charlotte was taken by ambulance to another hospital in London to have her heart checked. It was horrendous waiting for her to arrive. I felt so powerless; she looked so tiny in the incubator as she was wheeled in by ambulance men and several other medical staff. Fortunately, the doctor found nothing wrong with her heart. Back at our local hospital, she was transferred to the Special Care Baby Unit and I was able to hold her for the first time, breastfeed her and to begin to really fall in love with her, which I did, very, very quickly!

A few minor health concerns, including jaundice and wet lungs, kept us in hospital for a few more days but, all in all, she was a healthy little girl. The nurses all fell in love with her. She was such a calm child with big, alert eyes and although we were naturally a bit shocked we just wanted to get home and have Christmas with our little girl.

Another shock

Before going home, we had to deal with another shock. The paediatrician brought us the news that Charlotte has translocation Down syndrome. Either Dom or I were a carrier of the extra chromosome, meaning there was a significantly higher risk than usual for any future children also having Down syndrome. This was a huge blow to us. Although we were very much coming to terms with having a child with special needs, the thought of either one of us being a 'carrier' and the thought that we might never have children without additional needs was awful. We then began to think about that we may never be able to have grandchildren and this really upset me! We’d been so lucky with regard to Charlotte’s health, next time we might not be so lucky. This was the worst news yet.

We were urged to go for genetic counselling but we decided just to concentrate on our new arrival and enjoy Christmas, now just two days away. We took Charlotte home and life was great; she breastfed beautifully and virtually never cried, she was a dream child!

Early Intervention

I arranged for Portage when Charlotte was a few weeks old, which I have found invaluable for both encouragement and support alone. Physio, occupational and speech and language therapy were arranged for us at our local hospital. I sometimes feel unworthy of such fantastic support.

I soon began using a few Makaton from signs with Lottie. At first it was unnatural and I consistently forgot to sign what I was saying, but my interest in signing never waned and I was determined to persevere. I decided to concentrate on just two signs and I built from there. At 19 months, Lottie now knows and uses about a dozen signs. She is able to tell us she is thirsty, that she would like to eat, that she is ready for sleep, that she wants to go home, and my own personal favourite that she wants “more” ...of anything! We are continuing to teach her new signs and the rewards are great. I have encouraged friends and family to sign with Lottie and have copied out key signs and sent them to grandparents, aunts and uncles, godparents and friends. Charlotte also has a few words and says a few phrases very clearly.

Genetic testing

About 6 months ago, we decided we would go for genetic testing and arranged this at the local hospital. We were urged to go for genetic counselling but we decided to concentrate on our new arrival and enjoy Christmas, now just two days away. We took Charlotte home and life was great; she breastfed beautifully and virtually never cried, she was a dream child!

We were urged to go for genetic counselling but we decided just to concentrate on our new arrival and enjoy Christmas, now just two days away. We took Charlotte home and life was great; she breastfed beautifully and virtually never cried, she was a dream child!

Early Intervention

I arranged for Portage when Charlotte was a few weeks old, which I have found invaluable for both encouragement and support alone. Physio, occupational and speech and language therapy were arranged for us at our local hospital. I sometimes feel unworthy of such fantastic support.

I soon began using a few Makaton from signs with Lottie. At first it was unnatural and I consistently forgot to sign what I was saying, but my interest in signing never waned and I was determined to persevere. I decided to concentrate on just two signs and I built from there. At 19 months, Lottie now knows and uses about a dozen signs. She is able to tell us she is thirsty, that she would like to eat, that she is ready for sleep, that she wants to go home, and my own personal favourite that she wants ‘more’ ...of anything! We are continuing to teach her new signs and the rewards are great. I have encouraged friends and family to sign with Lottie and have copied out key signs and sent them to grandparents, aunts and uncles, godparents and friends. Charlotte also has a few words and says a few phrases very clearly.

Genetic testing

About 6 months ago, we decided we would go for genetic testing and arranged this at the local hospital. Waiting for the results to come back was awful, I convinced myself I was the ‘carrier’ and worried about the effect it would have on my relationship with Dom. I came home from work one evening and there was a message from the genetic counselor. She said she had some wonderful news she wanted to share with us. She explained that although Charlotte has translocation, it was a fluke and Dom and I have perfectly healthy, ‘normal’ chromosomes! To us, this meant that we not only have one wonderful daughter, we also have the possibility of having other children without special needs and possibly grandchildren at some stage. We were over the moon.

Charlotte is a truly amazing child and I wouldn’t change a thing about her. We’ve been given the opportunity to raise a very special little girl. I’m proud and honoured to be her mother.
Dear DSNU team,

I read with great interest the articles on hearing loss in the September issue of DSNU. It was very well timed as my 3 year old twins have recently been given hearing aids to help their hearing loss, so the issues are all very current for me. They have had persistent glue ear, having been tested every 6 months or so, and are both now hearing at around 60 decibels across a range of frequencies. They have not had any ear infections as far as I know.

The use of hearing aids is supposedly going well. Laura and Natalie are not showing any signs of sound discomfort. However, it takes one to one support to get Laura and Natalie to keep them on for any length of time. Without one to one support they pull them out after a few minutes, and as you can imagine, it is hard to give them both one to one support for very long each day! Especially as I have 2 other young children. It is also hard for me at this stage to detect whether they are hearing better with the aids, as I am so busy trying to keep them in. This may all improve over time, but at the moment it is quite hard work having hearing aids.

My consultant audiologist is against grommets, saying that with persistent glue ear the grommets can come out, necessitating repeated general anaesthetics to put new ones in, and periods of hearing loss in between the time the grommet comes out and the operation to put a new one in. She is advising hearing aids as a non-invasive treatment of the hearing loss resulting from glue ear.

Having read your article, I'm concerned to find the right way forward, and about the potential risks of long term damage to the middle ear. It would be very helpful to me if you were to expand on your views in relation to the advice of audiologists like mine, in particular:

- what are the disadvantages of using hearing aids to treat hearing loss caused by glue ear?
- how common it is for grommets to come out repeatedly, and how often do they typically come out?
- the advisability of repeated anaesthetics to put grommets back in
- the risk of having periods of hearing loss after a grommet has fallen out

It would really help me work out the next steps to take, to have more information on this.

Thank you,

Katharine Frost
London, UK

Dear Katharine,

I have tried to answer your queries as concisely as possible.

Firstly, if the hearing aids work, then the children will benefit, however, it is still important to treat the glue ear itself and not just correct the hearing loss. There are two reasons for this; firstly, the infection rate is higher in children with Down syndrome, leading to a higher incidence of otitis media and secondly, untreated passive (uninfected) glue may lead to long term hearing problems. [1-3] The issue of anaesthesia should not be cause of anxiety since repeated anaesthetics are not harmful, per se. If and when grommets are extruded (pushed out), periods of hearing loss should be very short, since the grommets should be quickly replaced. Grommets do come out, and this may happen in as little three months but may stay in place for 12 months or more. We feel that the benefits of improved hearing for speech and language, an area of specific impairment in children with Down syndrome, is worth the trouble.

Best wishes,

Ben

Ben Sacks, Professor of Developmental Psychiatry and medical adviser to The Down Syndrome Educational Trust


© 2003 The Down Syndrome Educational Trust. All Rights Reserved. ISSN: 1463-6212
http://www.down-syndrome.info/library/periodicals/dsnu/03/03/
Charlotte’s success with the clarinet

In response to your article by Rosie Cross about music lessons for children with Down syndrome, I thought you might like to know about my daughter Charlotte.

Charlotte is now 11 and has been playing the clarinet since she was about seven. For the last year she has been taught in school by Felicity Edwards of the Hertfordshire Schools Music Service. In the summer, Charlotte took her Grade 2 exam and passed, to everyone’s delight, with Distinction!

Felicity feels Charlotte is progressing well. She produces a good sound and reads music without difficulty. The trickiest parts of the syllabus for her are the aural tests-she is improving with practice but finds singing back a tune and remembering and repeating a rhythm quite difficult.

Charlotte started on a Lyons C clarinet (specially developed for young beginners) but has recently progressed to a full size Bflat instrument which has been ingeniously adapted for her small hands by David Blyth of Britannia Music in St. Albans.

Charlotte has also joined in Junior Wind Band days run by the county music service and we are hoping she will play in a band regularly when she moves to senior school next year.

Anne Sidders
Hertfordshire, UK

MELODY MUSIC DAY
21 February 2004

After the huge success of the Music Day for people with learning disabilities held in February 2003, a similar event is being organised by Rosie Cross on 21 February 2004 at mac, the Midlands Arts Centre, Birmingham. The Music Day is for teachers, parents, carers and people with learning disabilities.

Rosie Cross will report on what has grown out of the first Music Day, and on the foundation of Melody, a charitable organisation to promote instrumental music teaching for people with learning disabilities.

The day will include demonstrations of teaching techniques, and an afternoon concert by young people with learning disabilities.

Visit www.melody.me.uk for booking forms or more information.
European Congress on Media and Disability, Athens, 13-14 June, 2003

Cora Halder
Deutsches Down-Syndrom Infocenter, Germany

Introduction

The European Congress on “Media & Disability” was held in Athens on the 13 and 14 June 2003. Disabled and non-disabled people, who represented the media or European disability organisations were invited. There were two main topics to be discussed: improving the image of people with disabilities in the media, and employment of people with disabilities in the media.

The Conference was held within the framework of the European Year, organised by the EDP (European Disability Forum), and made possible with the support of the European Commission and the Greek Presidency of the European Union. Some 300 people had come to Athens to take part in this Conference; at least one third of these were people with a disability. The participants came from Iceland to Cyprus, from Ireland to Bulgaria; they had in common that they all worked for television or radio stations, in advertising agencies, as journalists for newspapers or magazines or that they were engaged in disability organisations, like Juan Perera and myself, who took part as representatives for EDSA.

Improving images

Improving disability portrayal by the media was seen as one of the best ways to change attitudes in society towards disabled people. Television, especially, plays a key role in influencing the way that society looks at disability. Advertising agencies can also contribute to viewing disability as just one more element of human diversity. They should increase the presence of disabled people in advertisements, in the same way as has happened over recent years with people from different ethnic backgrounds.

Good and bad examples of media campaigns, films, spots or clips from different countries were shown. Some of these films got under your skin, like the one about people who stutter, but at the end I just had this feeling of pity, “oh dear, those poor people”. And that is something which should not happen nowadays.

The one and only contribution on Down syndrome was a two minute spot, produced by Spanish television. I did not like that one either, it was too sentimental, “Look, aren’t we friendly and nice! Please let us take part”.

There were some very provocative and self-confident clips from Denmark and Holland, which were special productions for the year 2003. They showed a humorous, open and much more normal way of treating people with a disability. A very sensitive film about a blind painter was shown by a Spanish film producer.

A topic which was also discussed was the influence of the terminology used in the media: there are still many descriptions used in talking or writing about people with a disability, which are very offensive, ignorant and wrong.

Employment

Employment and recruitment of disabled people in the media was the other main topic. Andalusian TV in Spain employs only 30 people with a disability out of their 1455 employees and in the Spanish television industry as a whole, it comes to only 0.8% (the percentage of people with disabilities in the population is 10%). One of the reasons for this is that there are not enough opportunities to be trained in this area. It is crucial that more disabled people can have a proper education in journalism and can then be offered jobs in television, radio or in the print media. With their input, there will be more guarantee of an adequate representation of the topic of disability in the media and it will bring in their views on all other topics as well. The numbers from ZDF (Zweiten Deutschen Fernsehen, a German company) are relatively good – 180 of the 3600 employees have a disability, that is a percentage of 4.7%. German law says that 5% of the employees of a company must have a disability. If a firm or company does not reach this quota, they have to pay a special tax.

Impressions

Two lectures made quite an impression on me. Nuria Del Saz Gaitan is a young blind newreader with Spanish television. She made her speech, prepared in Braille, in English. While she was ‘reading’ with her fingers she could ‘look’ at the audience. At the same time a film was shown about Nuria’s workplace, a very good example of successful inclusion.

The other lecture I liked was by Richard Rieser of Disability Equality in Education, UK. He gave an interesting historical overview about images of people with a disability in the media, using examples from the archives, about stereotypes and how this should be changed.

But where were the people with Down syndrome? I was very disappointed to notice that there was not one person with Down syndrome taking part in this conference. It came as a shock to me to realise that,
European Down Syndrome Association news

among the large group of people with a disability, the ones with learning or mental disabilities (such as persons with Down syndrome) are very much on the periphery.

Contributions came from people with a physical handicap, or from blind or deaf persons. There were sign-language translators, there was good access for people in wheelchairs, but had anybody thought about easy language for people with a cognitive problem? No! People with a learning disability were hardly mentioned during the conference, and when the representative of the BBC was asked if the BBC employed people with learning disabilities, the lady answered “I’m afraid not, we have not looked into that at this stage!”

As a main outcome of the congress, the participants adopted a final declaration to combat the insufficient and inadequate representation of disabled people in the media and to encourage the production of action plans by each media to improve the image of disability; as well as the accessibility and employment of disabled people.

The participants also agreed on the establishment of a permanent network where European media and disability organisations will work together in order to take forward the aims of the “European Declaration on Media and Disability”.

A special dossier on Media and Disability is published by the EDF and can be found under: www.edf.feph.org

First European Day for people with Down syndrome, Bruges, 23 November 2003

EDSA declared 23 November 2003 as the first European Day for people with Down syndrome. On this day, in all European countries, attention was drawn to persons with Down syndrome, and Down Syndrome Flanders organized a meeting which focused on all aspects of their lives, from birth onwards, including the employment situation.

We hope to have a write up of the meeting in the next issue of Down Syndrome News and Update.

Member countries of EDSA

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

A list of EDSA members with full address and contact details is available on the EDSA website: http://www.edsa.down-syndrome.org
European Parliament of Disabled People meets in Brussels
10-11 November 2003

C.A. Zuithoff
General Secretary European Down Syndrome Association

On November 10-11, 300 delegates and observers representing the disability movement from 28 European countries held a unique event in the Chamber of the European Parliament in Brussels. This event marked the tenth anniversary of the adoption of the UN standard rules on the rights of disabled people, and the European Year of People with Disabilities 2003.

This historic opportunity for Europeans with disabilities to present to their political demands and speak up for their rights, was hosted by the European Parliament for Disabled People (EPDP) and supported by the European Parliament.

Following a two-day debate and a fruitful exchange of views, the delegates adopted a resolution on the follow-up to European Year 2003 and a manifesto for the forthcoming European Parliament elections, including the following key demands:

- the need to adopt new horizontal legislation that will protect disabled people from discrimination, in all fields of life, a request that already has the support of the European Parliament;
- the new EU Constitution to ensure that all legislative measures on non-discrimination against disabled people are adopted by qualified majority voting instead of the current unanimity system;
- to make next year’s European Parliament (EP) elections more accessible for people with disabilities and disabled candidates.

In his opening speech Theo Bouwman (Greens/EFA, NL), Chair of the Employment and Social Affairs Committee, said the committee had decided that “the ownership of the event would belong with disabled people from across Europe, representing the great diversity of the disability movement at local, national and EU levels” and promised that the committee “will continue its efforts to combat discrimination on grounds of disability – both in the labour market and more widely”.

For Yannis Vardakastanis, President of the European Disability Forum (EDF), co-organiser of the event, the EPDP is a major step towards the new directive: “Today we have seen again that the EP supports this request. The European disability movement will continue its campaign, at national and at European level, to achieve this key objective that will change the lives of millions of people”. What better contribution to a social Europe can there be than EU-wide protection against discrimination for Europe’s disabled people?

Pat Cox, the President of EP, declared: “The EPDP symbolises the importance of contact and dialogue between EU citizens and their European institutions”. “The event leaves us (the parliamentarians) the duty to follow up and to deliver”. “You’ll not stand alone, we’ll be there, standing with you”, was his message to the delegates.

Winding up the event, Employment and Social Affairs Commissioner Anna Diamantopoulou stressed that the Commission was seeking to mainstream disability into everyday activities and into all policies. She believed that now was not the right time for the new horizontal legislation. Already the endorsement of the existing directive on non-discrimination at work, which also protects disabled people, was causing many problems to the Member States and these needed to be resolved first.

This press release can also be downloaded from the European Parliament website: http://www.europarl.eu.int/press/index_en.htm, and EDF website: http://www.edf-feph.org/EPDP2003/press_en.htm. The following material is also available on the EDF website:

- the pictures of the event
- the final version of the Manifesto and the Resolution adopted
- the complete transcription of the event

E-mail: zuithoff@planet.nl
Individuals with good language required

The Oxford Study of Children’s Communication Impairments (OSCCI) is a research programme based at Oxford University, which is funded by the Wellcome Trust and directed by Professor Dorothy Bishop. A recent study by OSCCI researchers has shown similarities between the language impairment which affects most people with Down syndrome and that which affects children with specific language impairment (SLI). These are children who have language difficulties that cannot be explained by learning disability, hearing loss, neurological problems or psychiatric conditions. The similarities between the language profiles of people with Down syndrome and SLI could mean that their language difficulties have similar causes. For some time OSCCI researchers have been investigating the idea that people with SLI have a problem with hearing differences between sounds. Such a problem could interfere with understanding and producing speech. Volunteers with SLI and people with normal spoken language skills have visited our laboratory. In one session, they have been asked to make decisions about sounds played by a computer, and have completed some language tasks. In another session, we placed small sensors on their heads. The sensors were attached to a special cap like the one shown in the photograph. They measured the tiny amounts of electrical activity that are produced by brains in response to sounds presented over headphones. To make sure that volunteers try to ignore the sounds, we asked them to watch a video at the same time. Our research has shown that some people with SLI do have difficulty hearing the difference between the pitch of sounds (for example hearing the difference between a higher and lower note on the piano), and that these people have different brain responses to the sounds. We are now planning to do similar research with young people with Down syndrome. One interesting question is whether the brains of people with Down syndrome with especially good language skills respond differently to those who have poor or average language abilities. To investigate this question we are keen to find people with Down syndrome who have very good language skills. These would be people whose speech is easy to understand, who speak in well formed sentences and use good grammar. For example, in a recent study of the language produced by teenagers with Down syndrome we showed them a picture book and asked them to tell the story. One picture showed a boy climbing a tree. A teenager with average language said ‘a boy on tree’, but one with very good language said ‘the boy started climbing the tree’. If you have a teenager or young adult in your family, or in your class at school or college, whose language sounds more like the second example, we would be keen to hear from you. Taking part in the research would involve travelling to Oxford with a parent, so the family would have to be in reasonable distance of Oxford. We would pay travelling expenses and some compensation for parents’ time. If you would like to know more about the study you can contact us and we will send you a video that explains exactly what would happen on a visit to the OSCCI laboratory. Families can decide if they would like to help with the study after watching the video. You can telephone Mrs Faith Ayre on 01865 271386, or e-mail her at faith.ayre@psy.ox.ac.uk, or write to Mrs Faith Ayre, Department of Experimental Psychology, University of Oxford, South Parks Road, Oxford OX1 3UD.

Down Syndrome UK Research Forum 2003

On the 27th and 28th October the 7th Down Syndrome UK Research Forum meeting was held at the Sarah Duffen Centre. 19 researchers attended and 12 presentations of current research were made. While this was a smaller meeting that usual, lively debate and discussion continued throughout the two days, including during lunch breaks and the evening dinner. Participants represented the University of York, the University of Bristol, the University of Plymouth, the College of St Mark and St John (Plymouth), The University of Oxford, The Universitat Ramon Llull (Barcelona), the University of Portsmouth, the University of Edinburgh, and the B&G Centre (Istanbul, Turkey). Presentations covered a range of topics including: literacy, memory, signing, auditory deficits, language, cognition, numerical skills and emotion. Full abstracts will be included in the next issue of Down Syndrome Research and Practice.
Bradford’s Three-Day Conference

Wendy Uttley

Group Coordinator, Down’s Support Group, Bradford, UK

After many months of planning our three-day conference, from 24 - 26 September, happened at last and what an event it was!

The first two days were attended by nearly 200 delegates from Bradford and the North of England; a mixture of parents, teachers, learning support staff, speech and language therapists, educational psychologists and pre-5 workers. The atmosphere was electric, with parents brimming over with enthusiasm and wanting more, two days sitting on a plastic chair was not long enough for some!

We set up displays on every thing we felt was appropriate from Numicon, speech and language development and home made materials to software, library books and other resources, Bradford Down’s Support Group information, Love and Learning, DownsEd and DSii information packs. It was a wonderful experience to have so many people gathered together for a common purpose; the education and development of our children with Down syndrome.

On the first morning of the conference, I was very nervous but by the second I was excited, things had gone so well, everybody seemed to be enjoying themselves. I relaxed.

On the third day, we experienced a different atmosphere. We had planned a day for the professionals. One full day’s training for Speech and Language Therapists (35 attended), one full day for people involved in educational training. This session attracted 40 delegates, mainly pre-5 workers attended. Unfortunately, primary and secondary schools were extremely under represented. There was also a half-day training for health workers, aimed at health visitors, school nurses, ENT staff and in fact anyone in health who has contact with children with Down syndrome. Disappointingly, only 13 attended. Trying to publicise this session through the health service had proved difficult and those attending were delegates who had been directly contacted by parents. Despite information being sent to Primary Care Trusts and Hospital Trusts in May we found that the message had not got through.

This third day proved a challenging one for the DownsEd team as, on reflection, we realised that some delegates were uncomfortable with the “inclusion” they were practising and therefore were somewhat defensive.

We are aware that there is a big demand for outreach in the Bradford area and our next step, once affiliated to the Down Syndrome Educational Trust, is to put together some training modules based on the work of DownsEd and deliver them here in Bradford; either in schools or to groups via an evening session.

A parent’s perspective

An incredible number of delegates attended each day of the 3-day conference held at the Carlisle Business Centre...
Centre in Bradford. The conference was seamlessly and professionally organised by the Down’s Support Group, Bradford. Organising parents, carers and professionals into 3 separate groups and then managing their time, lunches, the Surestart crèche and the content of the conference must have been a logistical nightmare for Wendy and Peter and other committee members.

As a new parent, a new member of the support group and an education professional, I am pleased to say how efficient, empowering and inspiring the whole event was, and would like to express my gratitude for this opportunity.

The speakers on the first two days included Professor Sue Buckley, Dr Jo Nye, Professor Ben Sacks and Gillian Bird from The Down Syndrome Educational Trust in Portsmouth. Professor Buckley set the tone for the whole conference with a succinct and useful schematic profile of development for children with Down syndrome based on the Trust’s groundbreaking and world leading research.

Jo Nye shared research and evidence about the success the Trust has had in teaching numeracy to children with Down syndrome by using a visual learning based resource called Numicon. We had a chance to use the Numicon equipment and it became obvious that a visual system of understanding number may be easily taught using this excellent resource.

Professor Ben Sacks led a lively and thought provoking session that tried to give an insight into one area of psychology: Operant Conditioning. As the professor pointed out, one session only touches the tip of the iceberg in this area, but he helped us focus on behaviour modification by looking for reinforcers of behaviour, that is anything, which is presented after a behaviour that makes it more likely that the child will perform the behaviour again. He gave valuable advice about avoiding eye contact and not responding to inappropriate behaviour. He said that the best way parents can help to change their child’s behaviour is to devise a strategy or an agreed plan to deal with inappropriate behaviour and stick to it.

Professor Buckley led a session that focused on the positive benefits of building upon the strengths we know that children with Down syndrome have to build a bridge to further learning, development and improvement. This can be helped by strategies that were outlined in some detail to teach reading, writing, speaking and listening and linked to the session about number and Numicon and the behaviour sessions. A key message is that inclusive schooling, social groups clubs and experiences are the most beneficial for children with Down syndrome or any child with Special Educational Needs, but that parents, schools, carers, families and friends will have to work hard to achieve these, maybe even setting up opportunities themselves.

Gillian Bird gave positive and inspiring examples of the work that can be done and the range of attainment and abilities among children with Down syndrome in inclusive schools in Portsmouth. It was informative to have real examples of the children and young adults work, and to have the theory and research placed into reality.

The final question and answer session on Day Two began with the question “When are you coming back to our area again?” which I think succinctly sums up the majority feeling about the conference and the knowledge and advice shared by the members of the Trust.

Unfortunately, I could not attend Day Three, but I know that it was well attended, with a pleasing mix of parents, carers and professionals.

The key messages that inclusion, visual learning and social and emotional understanding may be successfully harnessed to help improve working memory, speech and language development, numeracy and literacy are invaluable. I feel these messages provide a powerful way forward to help us educate all our children; indeed, they are good educational practice in any setting.

Tim Curtis, parent
Sue and Roberta Buckley and Mandy Wood were pleased to attend the Down’s Syndrome Association (DSA) Annual Conference and AGM on 11 October at the Holiday Inn in Kensington, London. Sue has been a member of the Association since it started in Birmingham in the 1970s and was accompanied by her daughter Roberta, (34) who has Down syndrome. Roberta took part in a programme of activities for adults with Down syndrome covering topics such as ‘how to talk with your doctor’ and ‘healthy eating’. The AGM itself was sandwiched between two interesting lectures by Professor Tony Holland and Tessa Duffy, the DSA Speech and Language Adviser.

Tony Holland lectured on ‘Ageing and Down syndrome’ presenting the results of his latest study on this topic. His talk centred on the incidence of Alzheimer’s Disease in older adults with Down syndrome. He remarked on the discovery in the 1980s, that Alzheimer’s may be linked to the excessive deposits of a protein called amyloid and explained that the gene for this protein is found on chromosome 21 linking to the higher incidence of Alzheimer’s in people with Down syndrome, who have an additional copy of this chromosome. Tony stated that the incidence of Alzheimer’s is roughly the same in people with Down syndrome as in the general population; however, the age of onset is roughly 30 years earlier. For example, you might expect 10% of the general population aged 70-80 to have Alzheimer’s, whereas in Professor Holland’s study 10% of the people with Down syndrome aged 40-49 were diagnosed with Alzheimer’s.

This said, Tony highlighted that in his sample of 50-59 year olds, 60% of people did not have Alzheimer’s. He warned that health professionals should be wary in diagnosing the disease, as the early behavioural signs can simply be due to a mismatch between cognitive abilities and changing roles and demands in adult life. He noted that there are a variety of aetiologies, which cause similar symptoms including depression, hypothyroidism and sensory impairment. He also indicated that it is important that parents and carers help the adult with Down syndrome to keep a ‘life story book’ documenting a person’s qualities, skills and abilities at different points throughout their life. Records such as this will be extremely useful in highlighting the loss of function or changes in personality and behaviour. During the question and answer session, Sue highlighted a recent study of 1000 adults in Chicago. In this study one third of adults were losing some cognitive function in line with the Alzheimer’s diagnosis, however, only 9% actually had the disease. She went on to underline the importance of checking all possible causes and continuing with regular thyroid checks throughout adulthood.

After a delicious three course buffet lunch, we were invited to participate in a workshop hosted by Tessa Duffy, entitled ‘Communication for Life’. Over lunch, people were able to watch a new video that Tessa has produced called Now We’re Talking as an introduction to her session. She indicated that staff who work with people with Down syndrome need high expectations for speech and language, to be able to say “yes, she’s doing really well, but we know she can do even more”. She also said that they need a good underpinning knowledge of the strengths and additional needs associated with the typical profile of Down syndrome. She indicated that there are a number of key areas that can be targeted in early intervention including attention, memory, vocabulary, movements for speech, eating and drinking to develop oral motor skills. The next stage is to focus on supporting understanding, combining words, using grammar and the social use of language. In adolescence, she suggested that intervention should address assertiveness, social skills and fine-tuning of speech to further increases intelligibility. She also said that work should focus on the particular words that young people will need to function in their chosen school/college courses and/or work placement.

She went on to say that speech and language intervention and development can carry on well into adulthood and highlighted the case of a 45 year old man who had resided in a long-stay hospital and who had no communication, who made great improvements in just 12 speech and language sessions.

During the AGM, Tessa asked the meeting whether the DSA would like to be involved in assisting the Royal College of Speech and Language Therapists in adding a section to their professional standards, a book called Communicating Quality, specifically about Down syndrome. The standards currently have sections on various client groups outlining speech and language needs relating to different groups; however, there is no section specifically about Down syndrome. Tessa asked for a member...
to make a formal proposal on this issue. The proposal that the DSA support specific guidelines for individuals with Down syndrome was proposed and accepted unanimously. During the workshop, Tessa asked the assembled delegates to break into smaller groups and discuss the speech and language service that they would like to see offered to people with Down syndrome and the standards they would expect from their therapist. She gave us some ideas regarding ‘best practice’ and then asked each group to concentrate on a specific age group.

We had a super day in London, and look forward to collaborating on further projects in the coming year.

Summary of group discussion of parents and professionals working with school-aged children with Down syndrome

**Best Practice for Speech and Language Therapists (SALT)**

Speech and Language Therapists should be:
- Competent to work with the client with Down syndrome
- Well informed
- Skilled and experienced
- Timely with their advice and intervention
- Able to offer evidence-based practice
- Able to work collaboratively and disseminate their findings

**Summary of the discussion in the school age group:**

- SALTs should provide help with speech motor skills, the effects of hearing loss, working memory difficulties
- SALTs should provide a follow-up service
- SALTs should visit once per half term and present a programme that can be delivered by trained Learning Support Assistants through group work and one-to-ones
- Assistants need direct training by the SALT, who would model the activities to them. SALTs should meet the assistants and not just the SENCO
- Clear and fair guidelines about how a client qualifies for speech and language therapy
- Assessment of the specific needs of all children with Down syndrome as specific speech and language impairment is a very well documented part of the syndrome
- SALTs who work with children with Down syndrome should be well informed about their specific developmental profile
- Parents would also like some training from the SALT on how to deliver speech and language activities to their children, possibly being involved in trainings with the LSAs so they have a better understanding of the programme that is being provided at school
- SALTs should have a consultancy role
- SALTs need to actually ‘know’ the child; parents and teachers felt that often the children do not show their full repertoire of skills in a diagnostic assessment with an unknown SALT. Possibly need to revise how the information is collected
- SALTs should be involved in facilitating access to the curriculum, possibly targeting specific vocabulary and so on
- SALTs could provide training to teachers, assistants and parents about how typically developing children acquire language
- Parent consultation is a ‘must’ at every turn; genuine partnership with parents is vital
- SALTs need to help provide pragmatic solutions such as targeting specific vocabulary that a person needs to participate in social situations

We would be very interested to hear your views on your experience of speech and language services for people with Down syndrome of all ages. Details on how to get in touch or contribute an article to DSNU can be found on the back pages of the journal.
Trust news

A roller-coaster year

As I write the Trust news just as we go to press in December, it is clear that we have had a rather stressful year here in Portsmouth, with its high points and its low points.

The highlights

Increasing demands and positive feedback

We have been very busy with training events here, around the country and abroad, with services to preschoolers and to children in schools, with assessments and with number research plus publications, website and mail order work. We receive a great deal of positive feedback from families and professionals and this is rewarding, especially when we are struggling to keep up.

New research

We were pleased to be able to establish a small study of the use of the Numicon materials and approach to teaching number thanks to a grant from the Esmeé Fairbairn Foundation. The grant enabled us to employ Dr Jo Nye and to keep her expertise in number research in the country and abroad, with services to preschoolers and to children in mainstream and secondary schools and will be reporting her findings early in the new year. We have an application out for funding another, bigger study of number research plus publications, website and mail order work. We receive a great deal of positive feedback from families and professionals and this is rewarding, especially when we are struggling to keep up.

New psychologist

The grant that has enabled us to employ Mandy Wood is an example of many successful applications. Mandy is learning fast herself in the last high points and its low points.

year, and joining Gillian on school inclusion work later in the year. The inclusion support in Portsmouth covers children of all ages and abilities. Much of the assessment work that we do is also around inclusion issues. We view our ‘hands-on’ services as a way of identifying models of successful practice, which we then share with others through our publishing and training work. We also collect data on the children we are supporting, and that is how we are able to conduct expensive, longitudinal research such as that published on reading and on inclusion in the mainstream schools.

We are still not able to respond to all the requests for help and advice arriving by phone, letter or e-mail as quickly as we would like but we do try to get to everyone eventually. We have bids out for money to develop a comprehensive advice service on developmental and educational issues – so we hope one of these will be successful.
Appointing Patrons

We are pleased to announce that we have six Patrons who have accepted our invitation to become the first or Founding Patrons at the start of our 25th Anniversary Year. They are Sarah Duffen and Francis Kenny – pictured here on HMS Warrior at our recent fundraising dinner on 13 December 2003. Most readers will know that it was a letter from Leslie Duffen, Sarah’s father, received by me in 1979 that started the research programme in 1980 and led to the establishment of the Trust in 1986. Francis took part in one of our early research studies and both Francis and Sarah will be extremely able advocates for our work and for people with Down syndrome. Jane and Leslie Grantham, Michael Morpurgo and Rosa Monckton have also agreed to be Patrons and we are honoured to have their support. We will be publishing more information about our Patrons and why they are supporting us in the next issue, and more on the HMS Warrior event in the next Funding News.

Appeals

We are delighted to be beneficiaries of the Giorgio Armani Christmas Appeal on behalf of children and adults with Down syndrome. Seven organisations across Europe and in the USA are benefiting from the Appeal. Our local Portsmouth newspaper, The News, is supporting us and KIDS – another charity working to support children with disabilities and their families in the UK – through a ‘Child’s Play’ Christmas Appeal. The News has run stories every day for the past two weeks and published some very positive messages and great photos. We appreciate the positive effect that these campaigns will have on attitudes to Down syndrome as much as the money which will be raised.

The low points

We started the year with the news in January that Portsmouth City Council had decided to withdraw the 50 year lease agreed in June 2002, even though the draft papers were already with our solicitors, because the adjoining school needed more play space. We only received 2 working days warning that the full Council were to consider a proposal to evict us and demolish this building. A weekend was spent preparing our case for that meeting and the Council Executive meeting two days after the full Council meeting. We achieved a stay of execution and the Council ordered a review of the situation. After some months of uncertainty, we have agreed to a compromise involving some further demolition of rooms and a reduced car park. We are still waiting for the lease to reach our solicitors and will not feel entirely secure until we sign. We had to spend much time on our case to stay, and call a public meeting to get a decision, so a stressful and time consuming business, especially for a small staff team already fully committed to the work of the charity.

Funding crisis

As readers will know, in May we became very concerned about the downturn in charitable income and we had some difficult Trustee meetings as we considered what steps we could take to protect the future of the Trust. With help from many individuals, and the unexpected Armani Appeal, we have raised the necessary funds and are able to sleep a little more peacefully as we approach the end of our financial year. However, during our 25th Anniversary year we will be working with our Trustees and supporters to try to build a small reserve to tide us over the inevitable fluctuations in charitable income. We much appreciate the support that our Trustees give us and we have welcomed four new Trustees in recent months, David McConnell, John Hussey, David Thomas and Nicola Wainhouse, who are all parents/grandparents of children with Down syndrome. We also said goodbye to retiring Trustees Vikki Horner and Barrie Barker during the year, both of whom have made considerable contributions to the work and the funding of the Trust over more than 5 years as Trustees. Their contributions have been much appreciated and both will continue to support our work in other ways. Vikki is developing her work as a consultant and trainer in the use of structural approaches to teaching number and Barrie and his wife Sharron are major fundraisers. They organise several events each year and, in addition, Barrie and his friends in City Connection – a great band – give all the money they earn to the Trust.

Publishing and website delays

Despite our best efforts to prioritise time for working on the remaining books in the Down Syndrome Issues and Information Develop-
New Year’s Disco

at The Sarah Duffen Centre

We are planning to hold a New Year’s Disco from 7-10pm on Saturday 17 January for older children and teenagers (9 to 17 years). Come and strut your stuff and make sure you’re in the groove as you enjoy the sounds and light show of DJ Nigel’s Disco. Soft drinks and snacks will be on sale, bring along your brothers and sisters dudes!

E-mail: shelley.durcarreaux@downsed.org or phone Shelley on 023 9289 3882 if you’d like to come along.

Branch news

Canterbury

We are planning another Ball, hoping to beat the £4,000 we raised last year. It will be either before or after Down’s Awareness Week.

If anyone is interested in helping, we hope to either have a raffle / auction at the event too.

The Canterbury Branch meets every 3rd Monday at Northgate Community Centre. 9.30-12.00. This is mainly an early years group, we hope to get some structured sessions going next year – please contact me for more information:

Sarah Kent on 01227 453926 or email AlexHector@aol.com

Berkshire

The Berkshire Branch held a golf day on Friday 24 October at Blue Mountain Golf Course in Bracknell. Tickets were £35 per head including dinner.

Please contact: Colin Stonehouse c.stonehouse@ntlworld.com tel: 0771 904 3603 or 01344 823476.

Bristol

Congratulations to the Bristol Branch on the production of their first newsletter. Congratulations also on their progress during their first year. They now provide speech and language therapy sessions for children from 18 months to 11 years and Numicon sessions for preschool children. They plan to expand the speech therapy service with another therapist joining them in January – if you live in the Bristol area you can contact Annabel Dixey, 0117 9624735 or Marie-Louise Cook, 0117 9686893 for details.

ment and Education series we still have several to finish. We hope to mail these early next year and appreciate the patience that everyone has shown. Our planned online shop is also behind schedule and these delays are stressful for everyone here as we wish to meet our targets and there are just not enough hours in the day, especially when we have to deal with unexpected crises such as the building and funding issues this year. However, we hope to catch up in the first 3 months of next year and then to address the planning issues needed to meet project deadlines as we review our 5 year strategy with our Trustees.

The next 25 years

In January we will be working with our Trustees to update our plans and priorities for projects for the next 5 years. We would welcome any advice and ideas from readers at this stage. We will probably put out our plans for comment and feedback from our members as we develop them. Meanwhile, on behalf of everyone involved in the work of the Trust, may I wish you a happy and festive holiday season.
New from Greenhouse Publications

Created by JOAN GREEN • Illustrated by LINDA COMERFORD

INTERACTIVE COMMUNICATION CARDS

for children and adults at home, in school, out in the community, in rehabilitation centres or hospital settings.

INTERACTIVE COMMUNICATION CARDS have been designed by special educators to enable and enhance communication opportunities for persons with communication difficulties, delays and/or disabilities. The pictures can be cut out, attached with velcro and placed in communication books. The pictures can also be used in AAC devices or kept as full pages for making choices. There are 4 sets:

- Home and Health
- Food
- Recreation/Leisure and Community
- Sensory and Social Emotional

All sets contain 120 original, high-quality, full-colour illustrations printed on heavy, laminated card stock with words printed on the front and back to encourage literacy. Each packaged set includes a page of common comments (yes, no, choice, thank you, no thank you, please, more, all done, help, I want, I don’t want and I don’t know), and 4 sentence strips that apply to the vocabulary of a set. Each set also contains 120 hook Velcro coins for attaching to the back of each picture card and 4 loop Velcro coins for the sentence strips.

THE VISUAL SCHEDULE FOR THE CLASSROOM

contains 3” x 3” pictures of school-day activities, including those of elementary and high schools. Identifying words are printed on the front and back and 66 Velcro dots are also included.

VISUAL SCHEDULE CARDS can be used to: remind students of their daily activities in the classroom; inform parents and caregivers of the student’s activities for the day; make transitions easier, showing the classroom a picture of where they are going; ask questions that can be answered by showing an appropriate picture (e.g. “How do you get to school?” Answer: Bus); teach vocabulary words, to read, to write, or to copy, trace or spell.

CONFERENCES

POSTPONED from 31 October - 2 November 2003. New date to be confirmed soon.

International Mosaic Down Syndrome Association (IMDSA) Convention, Orlando, Florida, USA.
http://www.imdsa.com/

NEW DATE: 14 - 18 April 2004

8th World Congress on Down Syndrome, Singapore. (Theme: Down syndrome: Global progress in a changing era) Organised by Down Syndrome International
http://www.down-syndrome-int.org/congress/current/

14 - 19 June 2004

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

For a regularly updated list of conferences and events, visit the Down Syndrome Information Network at:
http://www.down-syndrome.info/news-events/events/
Down Syndrome International

- Down Syndrome International is a federation of organisations and individuals committed to ensuring the quality of life and human rights for all people with Down syndrome.
- DSI organises the World Congress on Down Syndrome every 3 years with a host country – the 8th will be in Singapore in April 2004.

DSI news

8th World Down Syndrome Congress
Suntec Singapore International Convention & Exhibition Centre, Singapore
14 - 18 April 2004

Down Syndrome: Global Progress in a Changing Era

Contact DSI for registration details at enquiries@down-syndrome-int.org or tel: +44 (0)23 9285 5330.

An exciting and varied programme is being developed with contributors from many countries worldwide.

Keynote Presenters
- Dr David Patterson, USA – Advances in genetics
- Professor William Cohen, USA – Health issues
- Professor Ann Turnbull, USA – Family issues
- Professor Roy Brown, Canada – Quality of life
- Professor Sue Buckley, UK – Speech and language

Check website for the latest information – http://www.down-syndrome-int.org/
Forthcoming training events

Training at The Sarah Duffen Centre, Portsmouth, 2004

Tuesday 11 May:
The development and education of children with Down syndrome in infancy and preschool years
– overview birth - 5 years

Monday 17 May:
Meeting the educational needs of children with Down syndrome in mainstream schools
– Primary

Tuesday 18 May:
The Numicon approach to teaching number

Tuesday 8 June:
Meeting the educational needs of children with Down syndrome in mainstream schools
– Secondary

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

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

Tuesday 12 October:
The Numicon approach to teaching number

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

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

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

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

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

Down’s Syndrome Association

4th February 2004: Down’s syndrome and Autism – Dual Diagnosis
An important joint conference with Autism West Midlands. An invaluable event for all parents and professionals supporting children who have Down’s syndrome and the additional diagnosis of an autistic spectrum disorder. Speakers include those with a health and education background, a researcher and a parent. More details from Julian Hallett on 029 20522511 or e-mail dsa.wales@lineone.net.
Aims and scope

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

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

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

Guidelines for contributors

 Longer articles and reviews

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

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

Shorter case studies, resource reviews, and personal experiences

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

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

News

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

Correspondence

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

Editorial review

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

Submissions

Papers submitted to the Journal should be sent to: The Editor, Down Syndrome News and Update, The Down Syndrome Educational Trust, The Sarah Duffen Centre, Belmont Street, Southsea, Hampshire, 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):