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• Supporting families and children through Early Development Groups
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Welcome to the second issue of volume 3 of this publication. Since we re-launched Down Syndrome News and Update in this new format early last year, we have received much positive feedback. Even more encouraging, we are receiving an increasing amount of contributions and correspondence from readers. This is helping us to create a lively publication, which enables parents and professionals worldwide to share their experience and ideas. Subscriptions are continuing to grow but we need to expand our readership to cover the costs of production and to ensure that the information reaches a wide audience, so please ask friends or colleagues to subscribe, or become members of the Trust. Later this year a web-based version will be available to subscribers.

International perspective

In this issue, we continue with an international flavour, with features and contributions from authors and correspondents in Australia, Holland, Romania, Germany, Israel and around the UK. We have a report from the VIII International Symposium on Down syndrome held by the Fundació Catalana Síndrome de Down in Barcelona in May. We have an update on the 8th World Congress now being held in April 2004 in Singapore, and readers may like to note that the Early Bird registration date is now 14th November 2003. The Congress has been delayed by the SARS outbreak but now plans are well in hand for an exciting and informative meeting next spring. We are keen to maintain our international perspective as we have so much to learn from one another. Issues for families, services and individuals with Down syndrome have much in common in all countries.

Contributions and letters

Please continue to send in letters and articles. We welcome reports of the activities of associations – large or small, families’ views and experiences, as well as articles and reports of practical programmes and research, so please think about writing for us. We also welcome news of conferences and events, new resources and forthcoming publications. A sincere thank-you to those who have sent in the articles for this issue and previous ones – please keep writing about all the interesting projects and examples of good practice that we know you are engaged in, so that they can be shared with others. The next issue will be mailed in late October – so contributions by 15th October please.

Features

• Hearing

The feature article by Ben Sacks and Amanda Wood aims to provide factual information for parents and carers on hearing, causes of hearing loss and the assessment of hearing, to enable them to obtain precise information from assessments. They also discuss treatments and the issue of grommets. They identify that there is not a consensus on the best way to treat children but recommend grommets and draw attention to the important work of Sally Shott on this issue in Cincinnati. Hearing is a very significant issue for children and adults with Down syndrome and, in my view, not always taken as seriously by specialists in audiology and Ear, Nose and Throat (ENT) consultants as it should be. In the editorial comment, I have emphasised the role that hearing loss may play in the profile of speech and language difficulties experienced by most children with Down syndrome. Sally Shott’s work indicates that it is definitely possible to reduce the incidence of hearing loss for children with Down syndrome. It will be interesting to see what difference her treatment has made to the speech and language progress of this group of children.

• Music and the piano

The article by Rosie Cross describes her work with children with Down syndrome as a piano teacher. She argues that children with learning disabilities should be welcomed as pupils by music teachers. She does not suggest that they have to be exceptional to benefit, but that many undergraduates will enjoy learning to create tunes and will achieve varying levels of skill. She describes other benefits of music lessons that have been observed by parents, including better motor co-ordination for other every day tasks such as using a knife and fork, improved speech and communication, and increased confidence and self-esteem. Rosie’s pioneering work is encouraging other music teachers to become interested in teaching children with learning disabilities and she has founded Melody – an organisation for anyone interested in promoting involvement in music (see page 44). We feature a drummer with Down syndrome with this article and we know of a number of adults in pop bands. We hope to feature some more young musicians in future issues so please send in any stories that you have on this theme, plus pictures.

• Public speaking

In the last issue we printed some of David de Graaf’s presentation to a meeting in Luxembourg. In this issue, David’s parents describe how they developed his public speaking talents. Readers will observe that he uses the same props as the rest of us when we are asked to make a presentation – using slides with his key points on. However, David has gone a step further with his parents’ help – he can now present his talks in English as well as his native Dutch by reading English with adapted phonology based on Dutch sounds. In the days of computer literacy and Powerpoint use in schools and at home, we hope this account will encourage parents and teachers to use the same approach with other young people, for school presentations as well as for public speaking.

• Parent Associations

The article by Jill O’ Connor from Australia reviews the way in which her own association in New South Wales has developed over the past 22 years and identifies the very important role that parents have played in supporting other parents and in changing services. The changes for the better in attitudes towards disability, in education, health care, living and work opportunities, in most countries have been the result of parent power. Many parents not only meet the extra needs of their child but also find the personal resources to advocate and create change by establishing associations like the DSA in New South Wales. Jill touches on another issue that is a concern to all these organisations and is also raised in a parent’s letter on p. 57 – being sensitive to the needs of the parents of children who make slower progress than most and have more severe levels of disability. This is a difficult issue, which has no easy solution as we need to celebrate the achievements of all our children and to still raise expectations in the minds of the general public. We can, however, keep reminding support groups to be sensitive to the feelings of these parents and ensure that we do try to cater for everyone’s needs.

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The significance of hearing loss for children with Down syndrome

Is hearing loss a neglected issue? Is it always properly detected and treated?

The first article in this issue provides readers with an account of hearing loss and hearing assessments, including a photocopiable audiogram, because we believe that the damaging effects of hearing loss are underestimated by many audiology and ENT specialists and that parents are not always given adequate detail when their child’s hearing is assessed.

Hearing and spoken language

It may surprise readers to learn that the effect of hearing difficulties on spoken language development has been more difficult to demonstrate than might be expected. In many studies of the speech and language skills of children and teenagers with Down syndrome, hearing is measured on the same day as the tests of speech and language and usually hearing losses account for little of the variation seen in language skills. However, it may not be the hearing on the day – at the age of 7 or 13 years, for example – that explains speech and language profiles. It is more likely to be the hearing status of the child between birth and five years, at the time when language acquisition is usually rapid. To investigate the real impact of hearing at this stage we need to conduct longitudinal studies, following the same children over several years before school age.

This has been done by Jon Miller and researchers at the University of Wisconsin in the USA, but they did not find a significant effect of hearing loss on the children’s progress. However, they point out that they only assessed hearing on the days when the children’s speech and language was being monitored and, as conductive loss is a fluctuating condition, there is no way of knowing how well these children were hearing between the assessment visits.

Observations

In my view, based on working with babies and preschool children for many years, hearing loss due to middle ear ‘glue’ problems does play a significant part in delaying the spoken language progress of many preschoolers. Many parents report that they observe an immediate improvement in hearing following grommet operations – and often an obvious improvement in the child’s attempts at sounds or words. We know that a number of factors are involved in the speech and language difficulties of our children, including verbal or phonological short-term memory difficulties and difficulties in producing speech sounds. (Phonology is the technical term for the speech sound system). It is possible that, because their short-term memory system for perceiving and storing speech sounds and words is impaired to some degree, the effects of mild hearing loss on their ability to hear and discriminate speech sounds is greater than it would be for a typical child.

Effects on speech

Miller and colleagues, in a recent review, suggest that the impact of hearing loss appears to be on children’s phonological speech processing and speech production rather than on their word and sentence level understanding. This might be because the meanings of words and sentences in everyday contexts may be understood without hearing precisely every sound in the word – the general word sound pattern may be enough. However, in order to discriminate ‘bat’ from ‘cat’ or ‘man’ from ‘van’ – single sound discrimination becomes important and, if the child does not hear all sounds accurately, he or she has no stored information that is adequate for enabling them to copy or say speech sounds accurately.

Long term effects

I am also aware of the findings of studies such as those of Marcell and colleagues referred to in the article, which highlight the long term chronic effects of middle ear ‘glue’ – with 40% showing abnormal middle ear function as young adults. These young people had more difficulty with speech discrimination and language tasks at the time of the study and poorer language comprehension than those with good hearing – suggesting that their hearing loss had a long term effect on their speech and language development and that it was continuing to impair their speech processing abilities on a daily basis.

I am not sure that all audiologists or ENT specialists realise that a mild hearing loss may have a greater impact on the speech and language development of a child with Down syndrome than for a typically developing child, because of their additional phonological memory and information processing difficulties. I am also not sure that all specialists realise that there is a risk of long-term middle ear damage from untreated ‘glue’ ear.

I would encourage all parents to ensure that the specialists involved with their children are aware of the specific risks of conductive hearing loss for children with Down syndrome and, if children have persistent ‘glue’ producing 40dB losses or more, I would recommend that parents ask to be referred to the hearing impaired service for the assistance of a teacher for the deaf, as parents have reported that this is usually very helpful.

Reference

People with Down syndrome tend to have a significantly higher incidence of hearing problems than other groups. This article examines some of the causes and treatments of hearing loss and outlines the assessment process.

The importance of hearing cannot be overemphasised and surveys suggest that as many as 80% of people with Down syndrome will have some problem with hearing.\(^1\) The vast majority of children acquire language primarily by hearing what is being said by those around them, and good hearing is involved in the development of speech and language as well as socialisation. These, as well as other factors, have a profound effect upon the general intellectual development of the child. The early detection and treatment of hearing deficits is, therefore, essential for the child with Down syndrome.

In this article we will examine the normal working of the ear and some of the problems associated with Down syndrome, discuss how hearing is assessed and how to interpret an audiogram, review some of the common treatments for hearing impairments and evaluate the benefits of regular checkups and interventions. The final page includes photocopiable resources, including a ‘blank’ audiogram and word and sentence cards that could be used with a child before, during or after a trip to the audiologist.

**Hearing**

Before we look at the problems associated with Down syndrome, let us consider the normal working of the ear. Sounds, which are pressure waves in the air, travel along the external auditory canal where they meet the eardrum. This is the gateway to the middle ear, an air-containing cavity containing a chain of three small bones (ossicles) which connect the eardrum to the oval window. The sound waves cause the eardrum to vibrate, which in turn produces movements in the ossicles. This produces vibrations on the oval window (a small membrane separating the middle ear from the inner ear). These pass through the fluid in the inner ear and then stimulate the hair cells of the cochlea differentially, depending upon their frequencies and pressures. At this stage, the information contained in these pressure changes is transformed (transduced) into nerve impulses, which travel along the acoustic nerve via complex routes to the brainstem and brain, where sound is perceived. Anything which interferes with any stage of this transfer chain will affect hearing.

On average, the air pressure in the middle ear is the same as the surrounding atmospheric pressure and this is regulated by the Eustachian tube which communicates between the middle ear and the upper part of the throat.

**Hearing loss**

- **Conductive loss:** This is common, and is caused by interference with the function of the middle ear by infection (otitis media) and/or...
Hearing disorders in children with Down syndrome

**Glue ear.** However, excessive wax or other foreign bodies can also cause obstruction of the outer ear canal. Balkany[3] suggests that middle ear problems account for 83% of hearing loss in children with Down syndrome.

- **Sensori-neural loss:** This occurs when the cochlea or the acoustic nerve is damaged. There is evidence to suggest that this type of loss increases in later childhood[3] and this is a good reason to continue with routine assessments even if a child does not show signs of conductive loss.

Some children have a mixture of sensori-neural and conductive loss.

**Wax** in the external ear canal may interfere with hearing and can be softened with eardrops or removed by syringing or use of an appropriate instrument. The latter procedures must be performed by an experienced professional.

**Glue ear** is one of the commonest conditions involving the ear and has a particularly high incidence in children with Down syndrome. A mucoid secretion accumulates in the middle ear and stops the ossicles from vibrating freely, therefore reducing hearing levels. Children with Down syndrome tend to have stickier ‘glue’, which is less likely to drain away, and more likely to become infected. The Eustachian tubes are often less effective in allowing drainage from the middle ear, as they tend to be narrower in children with Down syndrome.

‘Glue ear’, and the associated hearing loss it causes, tends to fluctuate across time and certainly children seem to be less affected in the warm summer months. Glue ear can be treated in three ways: insertion of grommets (called pressure equalisation tubes or PETS in the US), microsuction and tonsillectomy.

The insertion of grommets in the eardrum allows the fluid to drain out of the middle ear into the external auditory canal. Grommets are tiny tubes with flanges at each end, which are inserted through the eardrum, allowing the glue to drain out. This is very effective as long as the grommets remain in position in the eardrum. They do become extruded (pushed out) after about three to twelve months but they are almost always helpful in allowing drainage and therefore improving hearing. We shall return to the use of grommets in our evaluation of the benefits of screening and intervention. Drainage from the middle ear can also be achieved by perforating the eardrum with laser apparatus. These perforations tend to heal fairly quickly but many clinicians feel that this is a very worthwhile procedure for draining the middle ear.

**Microsuction** involves sucking the fluid out of the middle ear using a thin needle which is inserted through the eardrum. This usually has to be repeated several times but can be very effective. It has the advantage that there is no discharge into the external auditory canal to be dealt with.

There is anecdotal evidence to suggest that a milk-free diet may help to reduce mucus production that leads to infections and glue ear. Dr Jennifer Dennis from the Down Syndrome Medical Interest Group suggests that parents try a two week trial and, if this is successful, seek professional advice on maintaining a balanced, milk-free diet.

We feel that treatment of glue ear for children with Down syndrome is imperative. Various authors imply that untreated glue ear in children with Down syndrome may cause permanent changes in the functioning of the middle ear. Marcell discusses reduced mobility of the eardrum in 40% of a sample of young adults which may have resulted from years of untreated glue ear[5]. Balkany indicates that there may even be a permanent change in the mobility of the ossicles[2].

**Middle ear infections** (Otitis Media) are particularly common in children with Down syndrome. This is due to the problems of poor drainage of the sticky glue and the fact that people with Down syndrome are more susceptible to infections of all kinds. The treatment of middle ear infections usually involves antibiotics and, potentially, one of the interventions listed above.

**Sensori-neural hearing loss** is a poorly understood set of conditions in which the inner ear or cochlea malfunctions. The phrase is sometimes used to include problems in other parts of the central nervous system as well. It may be present from birth or develop in later life and the higher frequency tones are mostly affected. This may have a serious effect on understanding, since it is these frequencies which give speech most of its intelligibility. This type of hearing loss is often overlooked in the early stages because these children do not always behave as if they are deaf. They respond to many different sounds but tend to hear a rather low frequency rumble containing little real information. Those who can lip-read may sometimes be able to communicate to some extent. There is no cure in this group of conditions and those who benefit from the use of hearing aids continue to depend on them indefinitely.

**Assessment**

Having reviewed the range of hearing difficulties for children with Down syndrome, let us turn to the assessment of hearing. Children with Down syndrome should be tested in a properly equipped and staffed audiology centre, as special testing techniques are sometimes required. Where possible, children with Down syndrome should be tested by staff with experience of children with special needs. The following descriptions of the tests are intended as a brief introduction to the subject.

- **Tympanometry**, also known as Impedance or Compliance testing, is a commonly used test which allows the audiologist to check the movement of the eardrum under test conditions. It is painless although it does require some co-operation from the child. The test allows the audiologist to detect a possible cause of conductive hearing loss.

- **‘Oto-Acoustic Emission Test’ (OAE):** This test is used in the British Isles to assess all infants shortly after birth. It does not require active participation from the subject and is, therefore, suitable for very young children. The test detects and analyses certain sounds which are produced by the inner ear, in response to the test equipment.

- **Pure tone audiometry:** This can be used if children are able to understand instructions and to
respond when they hear a sound, e.g. by raising their hand or putting a peg in a hole. There are a number of versions of this technique, the principle of which is to test hearing by producing tones of known loudness and pitch in small increments. The child signals whenever he hears a specific tone and the responses are plotted on a chart – the audiogram (see below). There are adaptations of this test that are suitable for use with children with a range of more complex and additional needs.

Following initial checks for newborns, a child should receive a full hearing check at about nine months of age, another at about 18 months and then annually until ten years of age. After the age of ten, testing every two years is considered sufficient. However, parents of children with Down syndrome should always ask for additional hearing checks if they feel that the child’s hearing has altered in any way between routine appointments.

A visit to the audiologist may result in an audiogram (see Figures 2, 3, and 4), a visual representation of the specific sound pitches (frequencies) and loudness (intensity) levels that the child can hear with each ear. The audiogram covers the range of frequencies from 125 to 8000 Hz (cycles per second), and the range of loudness from zero to 100 dB (decibels). In Figures 2, 3 and 4, note how the frequency values along the top, double in value. Each value, from left to right is one octave higher than the last. The decibel values down the side are recorded in ten decibel increments. Perceptually, the sound seems to double in loudness every ten decibels. The audiogram shows the loudness at which the child can hear each frequency of sound. Hearing loss is often referred to as mild, moderate, severe or profound. The corresponding decibel ranges for these terms can be found in Figure 5. Sometimes you may be shown the hearing for each ear on separate audiograms. As a rule the left ear is shown by a cross (x) and the right ear by a circle (o).

A person with normal hearing will have two lines (one for each ear) from the lowest frequency tested to the highest frequency, at the level of about zero decibels. Figure 2 shows the audiogram of a person with normal hearing in their right ear; notice how the line is straight showing no deviation from the zero grid line until the high frequencies. This means that for all the frequencies apart from the higher ones, the person is able to hear the sounds even when they are very quiet. Figure 3 shows the pattern for a person with a mild conductive loss of about 35 dB. The line starts at about 40 dB showing weakest hearing for the lower frequencies and then levels out at about 35 dB. Figure 4 is an audiogram for a child with a sensori-neural loss, which becomes more severe in the higher frequencies.

The information from the audiogram can be used in conjunction with the photocopyable ‘speech banana’ on page 42 to determine which sounds the child will have difficulty in hearing. In very simple terms, you can see that higher frequency losses tend to affect consonant sounds whereas loss of lower frequency losses affect vowel sounds.

Parents should not feel embarrassed if they do not understand some of the technical terminology used by professional staff and should always ask for clarification if this is needed. Box 1 contains some questions that you may wish to ask at your appointment.

So far, we have explored the normal working of the ear and some of the problems associated with Down syndrome. We have noted that there are many effective interventions for ear complaints and finally we have outlined the assessment process itself. The ultimate question, however, is how effective are these interventions and what possible benefits are there for a child with Down syndrome?

Specific speech and language delay, difficulties in auditory processing and poor phonological awareness are typical of children with Down syndrome. It is not hard to see how these delays could be intensified for a child with a hearing loss. Psychologists have discussed the connection between language and thought for many years. It is clear to see how much of our thinking takes place in a verbal form, sometimes we even say that we are ‘thinking aloud’ when inner speech becomes public! If one can make
Box 1: Questions to ask the audiologist

- What kind of tests will you be using and what are they used for?
- What did the tests show?
- Will the hearing change over time?
- Can the hearing loss be treated?
- Which sounds will be most affected and what can I do to help?
- How sure are you that the results are right?
- What do I need to do next and do I need to come back for more tests?

the connection between hearing, language and thinking, it is plain to see that it is vital that we intervene at the earliest opportunity, if there is a chance that a hearing loss could be detected and managed in a child with Down syndrome. Many studies have indicated a relationship between educational, language and emotional development and even mild hearing loss. Balkany showed that there was a statistically significant difference in the IQ of typically developing children with a mild hearing loss and matched controls. For children with Down syndrome who may be less able to compensate, even the slightest hearing loss may have deleterious effect on general intellectual development.

Despite the clear need for routine screening, there is controversy with regard to the treatment of detected hearing losses. There is much anecdotal evidence linking the insertion of grommets and the extremely rapid advances in receptive and expressive language. However, Sally Shott, an eminent ENT specialist in the USA, has recently provided strong empirical support for their use. She conducted a study of 48 children with Down syndrome aged 2 years and under. She found that 83% of this sample required grommets due to chronic middle ear infections, 12.5% had occasional ear infections that were treated with antibiotics and only 4.2% had not had any ear infections. After her intervention, only 2% had a residual mild hearing loss. She advocates meticulous ear cleaning, examination and aggressive treatment starting soon after birth, for all children with Down syndrome. She speculates that this style of continued intervention may have a major impact on the development of speech and language.

Some ENT surgeons are less enthusiastic about the use of grommets in children with Down syndrome because they feel that they are extruded more quickly and that continual replacement may scar the eardrum. They may recommend hearing aids instead of medical/surgical intervention. However, the authors feel that the many benefits of grommets, including effects of improved hearing upon language development, socialisation, general intellectual development and self-confidence, far outweigh the possible difficulties.

In conclusion, one can see that children with Down syndrome are at particular risk of some degree of hearing impairment due to a number of physiological differences. There are a range of middle ear problems that can be treated successfully if the children are taken for routine cleaning and examination from birth. It appears that this may be vital for children with Down syndrome in order that they develop to their full potential. The article has also answered some of the specific questions about what to ask the audiologist and how to interpret the audiogram. Hopefully, this will lead to empowered parents and guardians who will feel confident that they can use the information they have been given about the child’s hearing loss in order to capitalise on their child’s strengths and sensitively address areas of weakness.

References


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‘Oliver’ Kids Clip

by Phonak Hearing Systems

This clip, priced £2.50 + VAT, helps to ensure that children’s hearing aids do not get lost or broken.

The Oliver Range is especially designed to support the needs of hearing impaired children. A brochure of all the Phonak products is available online at www.phonak.com by phone (01925) 623 600, or email: info@phonak.co.uk

Phonak UK Ltd.
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Photocopy these words and phrases onto card and cut up to make flashcards. Make a few more up with family names and the name of your specialist. Add ‘Velcro’ dots to the back for a simple sentence maker which can be used for early reading activities to assist your child in learning to read and talk about their hearing. This may provide a focus for a discussion with a child about what will happen when you visit the audiologist. Why not take photos of your visit and make a hearing book or add them to your conversation diary?

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Teaching children with Down syndrome to play the piano

Rosie Cross

Piano teacher - Birmingham, UK

How can music teachers differentiate their methods for children with Down syndrome? One teacher explains her success and how she encouraged others to take up the challenge

Over the past ten years I have heard many heart-breaking stories from parents wanting to give their children with Down syndrome the experience of learning a musical instrument, but unable to find a teacher willing to take them on.

I believe very strongly that people with learning difficulties, however severe, have as much right to play a musical instrument as the rest of us. What is desperately needed is more teachers who are prepared to teach them, and who will persevere when progress seems elusive.

When I agreed to teach Tom, my first pupil with Down syndrome, I had done nothing like this before. Tom and I have learned together – and his mother, Helena, has become a great friend and supporter.

Tom has a very good aural memory and does not find it difficult to learn by rote. He doesn’t read music, but enjoys having his music on the music rest, like his brothers and sister. The pictures on the page remind him which tune to play.

At first Helena and I did try to teach Tom to read music, but I have found over the years that it is not necessary for him to read notation to be able to play the piano. We do a lot of creative improvisation together, and this is what he enjoys the most.

Children with Down syndrome have a well-developed aural memory and a gift of mimicry. Pieces can be taught by rote – and may take a long time to achieve. I have looked at a vast array of books for the young beginner and can thoroughly recommend the books published by the American music publishers, Alfred. The books A to E for the very young beginner have unlimited material in the five-finger position and are based on tonic-dominant harmony. The presentation is for very young children, but this certainly doesn’t bother Tom, who is working through book 4 at the age of 17.

As with all young piano pupils, the first target is to learn how to use their fingers on the keys. This can take a long time for a child with Down syndrome. Starting on the two black notes, we do a lot of work with the index and middle fingers of each hand. This can then be extended to the fourth finger, using the three black notes.

In between, we play a lot of games and do other musical activities. It’s vital to encourage a lot of improvisation from the very beginning. Children with learning disabilities are often very good at illustrating pictures or stories on the keyboard. They don’t get as worried as my other pupils about living up to what is expected of them and they are often delightfully uninhibited.

So many music teachers have said to me: “I would love to teach pupils with learning disabilities, but I don’t have the experience and I don’t know where to start ...”. It was to start to show them that they did have the necessary skills and experience that Helena and I began to work on the idea of a Music Day that would bring together teachers, parents and young people with Down syndrome, to show teachers what can be achieved, and to talk about taking my ideas forward.

Response to our plans for the event was overwhelming, and many more people wanted to attend than we could accommodate. The 130 people who came to the Music Day in Birmingham enjoyed a concert performed by people with Down syndrome and other disabilities, on piano, violin and other instruments – including bagpipes. Our guest speaker, Lucinda Mackworth-Young,
As well as organising events such as an annual Music Day, Melody is developing a website to promote instrumental teaching for people with learning disabilities. By joining Melody, teachers and parents will gain access to suggestions for effective teaching methods. We also hope to gather and share more ideas from other parents and teachers about what has worked for them.

Teaching children with Down syndrome is a slow but rewarding pathway to tread. It is definitely not for the teacher who sees teaching mainly in terms of examination successes. Both teachers and parents must be prepared to accept that there will be failures, and there will be lessons when we seem to get nowhere. This is fine! We must learn to feel good about these sessions as well as the ones that have gone well.

For teachers, actively involving parents – in both lessons and practice – is essential for success. Progress can be extremely slow. Ziekel, a young pupil with Down syndrome, came for lessons for a year and seemed to make only slow progress. Then he suddenly took off, and he now enjoys improvising and illustrating a story in music, using the whole keyboard. His father, Colin, tells a story – it may be one about Ziekel himself, or it may be based on a tune that he particularly enjoys – and Ziekel illustrates what is happening on the piano.

With improvisation, I find that it’s best to start with very simple ideas. I draw a happy smiling face and ask my pupil to illustrate it on the piano. Then I draw a sad face and ask him or her to do the same – to draw a picture of the face on the keyboard. Then you can ask the pupil to play one or the other and someone else – perhaps Mum or Dad – has to guess which one it is.

(Teaching like this is not to be confused with music therapy. Improvisatory music therapy is a means of establishing meaningful communication and relationship with disabled and emotionally disturbed people in a way that transcends the need for speech.)

How to measure success is a matter for discussion. The usual landmarks of achievement – passing exams, entering music festivals – do not apply. Tom comes from a family where the other children are progressing steadily up the Associated Board grades. What we have done in his case is to undertake two Associated Board Performance Assessments. We set our own agenda for these and keep a record of what he has played each time, so that progress and development can be traced. This means that Tom has his certificates to show, just like the others.

In other families, it may be enough for children to perform to a sympathetic audience. As part of the first Melody Music Day last February, people with learning disabilities came to Birmingham from all over the country and took part in a concert that gave magnificent proof, if it were needed, that they can both take and give pleasure through playing a variety of instruments: piano, violin, trumpet, even the bagpipes!

The benefits are not confined to the immense joy that comes from being able to play recognisable tunes and performing to an appreciative audience. When Tom first began to learn the piano, his mother noticed that he was suddenly able to handle a knife and fork properly for the first time. Better co-ordination, improved speech and communication and increased self-confidence and self-esteem have been noted by other parents.

It is still early days, but membership of Melody is building fast. There are details of how to join on the website at www.melody.me.uk – or you can contact me for information (see address details below). At this stage we need as much help as possible from people willing to pay the modest annual membership fee and give us their support.

I am starting to give lecture demonstrations of what can be done, helped by some of my pupils with Down syndrome. I intend to spread the word that people with learning disabilities have the same right to play a musical instrument as anybody else, and that teachers already have all the skills needed to lead them into the wonderful world of music. All they need is a little help and guidance, which is what Melody can provide.
Introducing another talented musician who has Down syndrome

These photos were sent to us by fellow band member Alan Courtis. Alan holds a degree in Communication Sciences from the University of Buenos Aires, where he currently runs an annual music workshop for people with disabilities, as well as workshops throughout the USA. He also teaches music for people with disabilities, and has written articles on art and disabilities for magazines in Spain, Canada and Argentina. E-mail: reynols@hotmail.com

Study: Educating Children with Down syndrome

I am conducting an online study of parents’ and teachers’ experiences with teaching children with Down syndrome. I am an assistant professor specializing in child and educational development at Trent University, Canada. My area of speciality is the educational needs of children with Down syndrome. I serve as a consultant to parents, teachers, and school board personnel. I am interested in the collective stories parents and educators have to tell.

There are two surveys. One is for parents and one is for teachers. They can be found at http://www.trentu.ca/psychology/aarcher. More detailed information about the surveys and about my research interests can be found there. Another survey entitled ‘Stories of Compassion’ might also be of interest to your members.

This research has been approved by Trent University’s tri-council committee on ethics. All submissions are anonymous. Returned email surveys contain the phrase ‘nobody@postmaster’ in the FROM column, thereby ensuring anonymity. If you have any questions about this study, feel free to contact me, the principal researcher, at aarcher@trentu.ca at any time.

I thank you for your time and your assistance with this link.

Anne Archer

Anne Archer, Ph.D.,
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It all started with the question: ‘What does one do if one does not speak very well, one’s speech is quite unintelligible and one is asked to give a talk in school?’ When our son David (born in 1984) was ordered (rather than asked) to do so many years ago, we did our utmost to invent a way to keep it from being a flop and just another failure experience. Realising that he could read much better than he could talk, and that his reading was also far more intelligible than his spontaneous speech, we came up with the idea of an oral presentation with subtitling. We produced a series of cardboard ‘screens’ for David to hold up in front of the class. On the front there was a picture and a very short statement in catch words printed so large that it could be read from all corners of the class room. On the back, facing towards David, there was a full sentence relating to the picture on the front that David could read relatively easily. The class, then, at least had the catch words, while David could read the extra information aloud. That worked quite well. A few years later we realised that from there it was, in fact, just a short step towards a PowerPoint-like presentation. Hopefully our experiences, described below, will stimulate other people to do something similar.

We began by making a simple presentation on a laptop using the programme Presentations (by Corel, long ago the precursor of Microsoft’s PowerPoint). Therein we had David ‘tell’, so to speak, about his own life with Down syndrome, as he was living it. By showing photographs he explained what he did in life, what he liked and what he didn’t like, what he found easy and what difficult. Of course, all this could only be done in close co-operation with David himself. It was our intention that, while presenting, he would read the short texts on the successive screens aloud. In that way, his audience could at least read along with him where they could not understand his speech. In doing so, David would be understood quite well, we hoped. But, apart from that, we thought that the simple fact that a boy with Down syndrome in front of a group, with quite some flair and a mouse in his hand, operating his own laptop, proved to be able to read aloud reasonably well should make a very positive impression. Towards the end of 2001, we put the concept to the test on a stand at a symposium of obstetric and gynaecology nurses. That afternoon, David, standing beside the laptop, did his presentation almost a dozen times with much flair and dedication, albeit only before a very small group of listeners each time. But he enjoyed it very much, getting all that attention and telling his own story.

A few weeks later, we threw him in at the deep end by letting him give that same presentation in front of an audience of about 80 baby clinic professionals, physicians and related personnel at the Leyden Academic Medical Centre. There, for the first time in his life, he sat in front of his audience, facing it and reading from his own laptop screen into a microphone, while his ‘slides’ were projected in a huge size on the wall behind him. And it went all right! So, all in all, this concept proved to be a powerful method of having more information given by somebody with Down syndrome himself, particularly promising for the less (and possibly far less!) able speakers.

Another ‘exercise’ opportunity presented itself during an ‘open day’ at Parc Spelderholt, a venue for the education of individuals with a disability towards a more inclusive life. Presenting from a stand behind his laptop was by then a mere routine.
again. Spread out sitting behind the
computer, in front of the fairly well
filled lecture theatre, we wanted
him to have some interaction with
his audience right from the start of
his presentation, more or less in a
comedian’s type of way. (David loves
cabaret!!) We anticipated what would
happen via the dialogue below. With
this type of text we wanted to express
that he was not pitiful and that it was
all right to laugh at his presentation.
And, judging from the reaction of
the audience, it worked:

D.: Good afternoon!! I am David.
Do you have Down syndrome as
well???

Audience: much buzzing

D.: No ?? I was afraid of that!!!

Audience: laughter

D.: Is there nobody else with
Down syndrome in the audience?

Audience: yes, here (from the
public and set up beforehand!)

D.: Oh, good!! I thought I was out
here totally on my own. Now, is
there a doctor in the audience???

Audience: cheering

D.: That’s a safe feeling!!

We then had him draw a paral-
el between physicians on the one
hand and individuals with Down
syndrome on the other. Aren’t there
many incorrect stereotypes upheld
about both groups? Yes, there are.
After making that point, David asked
the professionals present to avoid
stereotyping individuals with Down
syndrome any longer. So he pro-
cceeded screen by screen with:

“You and I have very much in
common! 46 chromosomes!! I only
have one more – that’s all. All per-
sons with Down syndrome have one
extra number 21: The smallest chro-
some of them all. It’s influence
can only be very small!! Therefore
it is not people WITH and people
WITHOUT Down syndrome. So, it is
not: ‘you’ as opposed to ‘us’. Because
there is NO clear boundary between
what they want / like / are able to
achieve. They are much more equal
so far.

And after that very important
statement he continued by explain-
ing how he could do some things less
well, and that that aspect was called
‘handicap’. Successively he showed
how many things he could do well
and, consequently, where he clearly
had no handicap at all, e.g. swim-
m ing below the surface. Further-
more, he outlined what had become
very normal in 2002 for individuals
with Down syndrome, like good
medical care for everybody, a better
upbringing at home, more and more
children getting their education in
mainstream schools. He came to a
close with the question: ’No more
babies with Down syndrome? Yet,
our government wants fewer babies
with Down syndrome. Baby in the
belly …… and away with it….. Still
a ‘you’ (pointing towards the audi-
eence) as opposed to ‘us’? (pointing
towards himself)? I hope that I have
made you think ….’

For us as parents it proved
extremely thrilling to watch David
in action – loosely making jokes
between his ‘fixed’ (and extensively
rehearsed!) texts, initially clearly
a bit nervous – and not being able
to intervene. (If we had done so, in
front of the large audience, it would
certainly have been to his disadvan-
tage!) But he did a wonderful job and
certainly made people think.

A few weeks later David was invited
to give a ‘keynote presentation’ at the
Dutch Fifth Day of the Child with a
Chronic Illness, and that would be
even more thrilling, because an
audience elsewhere was expecting to
hear both Marian and myself on that
same day. Therefore, David, accom-
panied by the present SDS director,
Mrs. Jeannet Scholten, travelled to
the lecture theatre near the centre
of the country, without either of his
parents near at hand. And as we were
told by others, from the organisation
as well as from the audience, it went
OK again. A new development was
that we had taught David to stand
up in front of the audience instead
of remaining seated, as he had done
so far.

The Secretary of State

Around that same time our Sec-
retary of State for Welfare, Mrs.
Clemence Ross, announced that
she was planning a working visit to
be informed about Down syndrome.
She wanted to talk with SDS officials
and, much more importantly, with
individuals with Down syndrome
themselves. Because she liked the
idea of officially opening the new
SDS office outside our own house,
where it had been for the first fifteen
years of its existence, ‘using’ David
was obvious again. As his parents,
we knew very well that

A new development was
that we had taught
David to stand up in
front of the audience
instead of remaining
seated, as he had done
so far.

Presentation for the
Secretary of State (in
centre of photo)
Individuals with Down syndrome can also give a presentation!

accurate, local weather forecast in order to determine whether he could travel to his internship by bike, how he went to school for one day a week and what kind of difficult language concepts he had to master there to become a ‘care assistant’, what his hobbies were, etc. While doing so, we were able to illustrate a fair number of the screens with digital photographs that David had taken himself.

No longer in his native language

All in all, at that stage we had already concluded that the development from an ‘oral presentation with subtitling’ towards a computer-presentation for David had been a very good one. So much so, that we were not afraid of trying the next step: a presentation like he had given for the Secretary of State, but this time not in his own native language.

Because of all his (forced) rambling around the Dutch school system and the loss of time in a very unwilling secondary education scene, David has had hardly any kind of structured education in a foreign language. However, he has a keen interest in that, so we attempted to add more or less phonetically written cues in smaller print underneath the lines of his actual presentation in English or German. And in the course of time, David learned to read below his original lines, while we gradually learned how to write these phonetics-adapted-for-David. That is to say, we had to devise English sentences that were first and foremost pronounceable for David rather than being ‘optimum’ English. In addition, using real phonics would have required David learning quite a number of extra graphemes. Much too time consuming!

And then the first test happened, notably a presentation in English at a symposium in Luxembourg. Upon arriving at the theatre he had to adapt to the fact that his computer was, totally unexpectedly, standing somewhere amidst his audience and not in front of it and, in addition, he had to hold the microphone in his own left hand (to be able to operate the mouse with his right one) instead of having it fixed in front of him. Notwithstanding that, he did it again and enjoyed very, very much to be able to do so.

The future

In the meantime, an official invitation for David to present an updated version of it all at the next World Congress on Down Syndrome in Singapore has already arrived. This time we’re really getting somewhat nervous.

Modesty

During the development of the English version of the presentation we deliberately took the time to add two screens to put the entire presentation as well as David’s capabilities in clear perspective, notably:

However
Houwegewur
I did not write this speech myself. 
Aj did not rajt dis spietsj majself
But
But
Many VIP’s have their speeches written for them ..... 
Menni Vie Aj Pie’s hef dèr spietsjes rittun for dem ....
And still they know very well what they are talking about. 
En still dee noo verrie wel wot dee aer tokking ehbout. 
And so do I! 
End so doe ay!

Also:
Olso: 
I do not speak English. 
Aj doe not spiek Inglisj
But: 
But: 
Many singers sing in English but are unable to speak it! 
Menni singers sing in Inglisj but aar uneebul to spiek it!

And so do I!
End so doe ay!

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http://www.down-syndrome.info/library/periodicals/dsnu/03/02/
Taking a longer wider view ..... 

Jill O’Connor 

Information Officer, Down Syndrome Association of New South Wales, Australia

The value of parent associations - reflections on 22 years of achievements

This paper is a transcript of the address I gave as guest speaker at the Annual General Meeting of DSA NSW on 25th August 2002 and is reprinted from DSA NSW Newsletter, Spring 2002. The thoughts are not original – they have arisen from many casual, and some very personal, discussions between families and staff over a long period, and they merit explicit acknowledgement in a more formal forum.

Since my position at DSA NSW is “Information Officer”, I thought I should offer some thoughts about what we know about Down syndrome and the people it affects. But I’m not about to provide a list of facts or research findings (you can check our website, read the Newsletter closely, or make an individual request to the office for that!).

As an organisation, we have come a long way in the 22 years the Down Syndrome Association of New South Wales has been established, and I’m increasingly conscious of how far we have to go – there is still much to learn, many families who need support and information who are not getting it, and new issues and opportunities are arising at a rapid rate.

As the children of the founders of the DSA grow into adulthood and dare we say even early middle age, we are still learning about their abilities and their needs, and about how our community responds to them.

My years at the DSA, have allowed me to see the “Down syndrome community” through a different prism, because of the contact I’ve had with so many families and professionals over a sustained period – a longer and wider view, in addition to the personal insights Declan has provided. But it is nevertheless a personal view and I am conscious that hindsight still provides the greatest acuity.

The birth incidence of babies with Down syndrome has changed little in 15 years in New South Wales and we are continuing to support new families more effectively on a number of measures: reaching more of them; better professional education; using information technology; outreach to previously unsupported families; using better information about what families want and need; having better staffing levels to allow for more timely responses.

When Declan was born in 1985, we had easy access to the information that was available, although it was somewhat more limited than now, and we were very grateful for that. But I am deeply indebted to those intrepid parents who through the years had the strength to defy the conventional wisdom and to bring their children up at home.

They sowed the seeds of our communities’ and families’ realisation that people with disabilities, including Down syndrome, are perfect as they are, not broken, not needing to be fixed, but needing an environment that supports their development throughout their lives. Rather like the rest of us! In the wider community, that realisation still has some way to go, and even within the “disability field” attitudes continue to be challenged and challenging.

We still hear the language of illness applied inappropriately to people with Down syndrome, about their disability (betraying an underlying “disability as pathology” mindset), and ironically we also hear of health concerns dismissed as “part of the disability”, with the unnecessary neglect of treatable health problems.

Those pioneering parents, who defied those chilling conventional wisdoms gave us the freedoms and services our children and adults benefit from today. We might still sometimes encounter prejudice, ignorance and poor practice within education systems, for example, but we now have a groundswell of support and mountains of information and experience about better practices to draw upon. We now receive more requests for information and training from schools than complaints from parents about schools denying children their educational rights.

The children of our pioneers had no legal right to an education at all, and they were responsible for “special education” existing at all. We are the direct inheritors of their commitment and energy, and we should never lose sight of that. With much easier communications, we now have access to amounts of information, often at the press of a button, that has been a huge boon to us in many ways. We have ready access to medical and educational information, for example, from experts around the world. The degree of co-operation and generosity in making information readily available is remarkable, and unlike many other, more competitive fields. And it is noteworthy that a high percentage of the professional experts are parents of people with Down syndrome (such as Dr Sigfried Pueschel, Prof

I am deeply indebted to those intrepid parents who through the years had the strength to defy the conventional wisdom and to bring their children up at home

We now receive more requests for information and training from schools than complaints from parents about schools denying children their educational rights

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We can too readily ignore how much effort it might take to achieve an apparently ordinary goal, or we do not acknowledge the effort separately from the achievement.

The reality is that our children are likely to live long lives, for which we need to know how to prepare them, and to ensure that the services they will need are in place.

Sue Buckley, Dr Phil Matthieis, Dr Len Leshin (to name a few).

What we “know” changes over time, and we need to be able to let go of some ideas to take on new ones. But it pays to keep a sense of humour and perspective. In a recent email discussion, Cheryl Ward, in Virginia, reminded us that when her daughter, Stefanie, was a baby (in the 1980s), it was often said that people with Down syndrome could not read. Those who had learned to read were labelled as the exception. Now we know that most people with Down syndrome can expect to learn to read, we worry about those who don’t, and label them as the exception. I recall being told (by someone with some authority) that children with Down syndrome were unable to develop the thought processes required for imaginative play, but I had to advise my son’s teacher, when he was 8 or 9, not to be concerned about his mental health when he pretended to be Sgt. Micky McClintock from the television drama “Police Rescue”. I wonder what the other 9 year old boys were playing?

Access to information and communication has also improved our provision of resources and support to families from diverse cultural and language backgrounds. We have swapped translated resources, for example with many other organisations like ours, including recently, the DSA of Lebanon, DSA of Hong Kong, and last month with Steve Booth, an English parent, formerly an Arabic translator in the British army, who sent us his translation of “Welcome to Holland” into Arabic.

It has also opened our eyes to how rich we are in terms of the support we can offer each other with a comparatively high degree of comfort. Most people with intellectual disabilities throughout the world still indeed “suffer” from discrimination to a far greater degree than most of us will ever encounter.

These are just a few examples of the progress we have made. The DSA of NSW is well regarded for the quality of the support we provide on a state-wide basis, on what is and always has been a very tight budget, with a very small input of government funding.

I would like to highlight just two of the areas in which I think we need to develop our skills and resources, and I would value your input about how we can do so, as staff, and I know that the Committee is interested too.

Firstly, there is increasing recognition at a bureaucratic level (if not at a political level) that as the population in general is ageing, so is the population of people with intellectual disabilities. The reality is that our children are likely to live long lives, for which we need to know how to prepare them, and to ensure that the services they will need are in place, to ensure they will continue to enjoy the quality of life that people in this country are entitled to expect.

Just last week I was asked to address a meeting of regional planners from the NSW Dept of Ageing, Disability and Home Care about issues to do with ageing and dementia in people with Down syndrome – an important opportunity for us to have input about long-term services.

Di Cook, one of our founding members, is chairing a subcommittee looking into what we need to know about options for living in the community, and to make recommendations about where gaps exist in the types of options available and how they might be filled. We are only too aware that the quantity of service provision is nowhere near sufficient for the need.

Information about ageing processes and health in ageing is becoming more readily available, and its collection and dissemination are priorities.

The second issue is less well defined, and perhaps less comfortable, but needs to be addressed nonetheless.

We have all fought our own “battles” small and large for, and sometimes within our families, and for our children’s rights and needs. Fortunately for many of us, the day to day experience of family life including a member with Down syndrome can be relatively straightforward: our children enjoy good health, and quality of life, have had access to a better educational experience than would have been possible in the not too distant past, have access to a great variety of life’s experiences because of our own and the wider community’s attitudes, and they are a delight to us. We don’t always know what the future holds, of course, but we are generally optimistic. Many of us have said that had we known how well we would be able to meet our child’s needs and build a good family life, we would not have felt so very concerned about the diagnosis of Down syndrome. Our children have been our very best teachers.

We celebrate our “stars” and are delighted and often surprised by their success, the variety of their achievements, and their determination. And so we should celebrate! We are encouraged by looking at the achievements ahead of us, and hope that our children will reach for the heights as well.

But sometimes we overlook an important point that we all really do know: all people are unique, including all of those with Down syndrome. All families are different, our values differ, our experiences with our children are different. There is no “one size fits all” way to live. We hate to be stereotyped, and we hate it when people with Down syndrome are stereotyped.

We can all draw inspiration from the achievements of others – but do we really measure our worth as people by the same yardstick as elite athletes such as Cathy Freeman or Ian Thorpe’s sporting achievements, or the most elite achievers in any other field? While we are encouraged by such success and admire the achievers’ talents and work, we do not feel diminished if we don’t “measure up” on the same scale.

Yet all too often we apply such external measures to people with disabilities, sometimes even to our own children. We might give credit to achievement itself, as is due, but not enough to the qualities that made it possible: the willingness to put in hard work and persistence in the face of perhaps repeated failure. We can too readily ignore how much effort it might take to achieve an apparently ordinary goal, or we do not acknowledge the effort...
living that he will have to work much harder than most to live an ordinary life. Like most people with Down syndrome, he knows he has a disability and that the rest of us are glad that we don’t. How much easier would it be to just let someone else do everything for you, make your decisions, do your thinking? Sometimes the effort wears him out – so we take a break and regroup.

One thing that is guaranteed to get me ranting (there are others!) is an assumption or even a suggestion that a lack of skill or developmental
progress, or unwillingness to participate on the part of a person with an intellectual disability (especially my Declan!) can be laid at the feet of "laziness": usually a hasty, ill considered response from someone completely lacking in both insight and empathy – and don’t even mention, that convenient scapegoat "stubbornness" !!!!!

It doesn’t say anywhere in our constitution, our aims, vision or mission statements that DSA NSW will support people with Down syndrome only if they achieve “x”, “y” or “z”. The driving force behind the foundation of the DSA in 1980 was that parents (of then mostly young children) knew that they could support each other better than they had been supported in their children’s early days. As those children have grown and continue to grow into adulthood, and eventually to old age, we have no brief to set “entry limits” of any kind. You just have to have Down syndrome, be a family member of someone who does, or to be interested in someone who does.

However, “tea and sympathy” are rarely enough! We need to base our support strategies on real knowledge. We need to know what families need and want, and how they want to be supported, as their needs change over time, and as they vary from family to family. So we need to make it possible for the voices of those families who may feel marginalised even within the “Down syndrome community” to be heard. We can only report the stories that people are willing to tell, or have the means and time to tell – influencing any one of these might be a starting point. We have a good grasp of the outlines of the big picture, and much of the detail, but we are still filling in gaps. It is a little like the TV pictures you see with faces pixilated at low resolution – you know it’s a face but you can’t quite distinguish the features, and it changes as they move, just when you thought all would be revealed.

There is a trend in publications about people with disabilities and their families towards a greater acknowledgement of the variety of our experiences. More families are “coming out”! When I first joined the staff of DSA NSW in 1989 we had a small library of about twenty books – everything that was currently published in English, two articles that were occasionally disseminated to enquirers – one on a 1981 research study of vitamin supplementation (which showed no benefits) and some very po-faced “advice” about masturbation!

Both the lay and professional literature has blossomed since then, and our library has grown to more than 800 items that fill a room when half are out on loan, we have two filing cabinets of information articles that we send out in response to several requests each day, and a website of about 100 pages with links to fifty other sites.

We’ve been through a long period where we were necessarily concerned to counter the unnecessarily dark and dire prognostications made about people with Down syndrome, and we need to continue to do that. But we are now becoming more self-critical and analytical about the qualities (the breadth and depth) of what we know and what we do with it.

Ann Penhallurick will be presenting a workshop on building adult lives with people with intellectual disabilities, and the values we bring to the experience, at our Families’ Weekend Conference in October, and Lorna Parker, our keynote speaker at the conference, will be looking at how the theories of multiple intelligences can be applied by and to people labelled with intellectual disability. I am confident that both speakers will push us to fresh insights about our families and the people with Down syndrome whose interests we hold dear.

Another trend I’ve appreciated in lay publications recently is a growing tendency to “lighten up” a bit. It’s easy to be very earnest about issues to do with disability, but the ability to see humour in some pretty serious situations gives us a sense of perspective, as well as being an effective teaching tool. Incisive cartoons allowing people with disabilities to have their voice heard, Cindy Johns’s article about her shock at the unexpectedly rapid onset of adolescence (that she described as her very short 12 year old son going into the bathroom and coming out a very short 13 year old with a moustache and hairless legs), and a string of slick one line responses to frequently-expressed platitudes come to mind.

I’d like to leave you with some thoughts on difference, values and perspective from one of my favourite funny men, and Declan’s, the wise Scots philosopher Billy Connolly, who said that “there is no ‘normal’ – there’s just you, and then there’s everybody else” and on another occasion, that “there is no bad weather, just the wrong clothes”.

Reprinted from DSA NSW Newsletter, Spring 2002.

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When I first joined the staff of DSA NSW in 1989 we had a small library of about twenty books ... our library has grown to more than 800 items
New websites

Down Syndrome Ireland have recently changed their name to ‘Footsteps - Down Syndrome Ireland’ and have launched a great new website. The website contains accessible information about the work of the organisation and services available. The site is attractive and easy to navigate with beautiful pictures of children and families, which change every time you re-open a page. The ‘pressroom’ invites members to submit news stories that might be of interest to all. Other pages include full listing of library resources available, information about sponsorship and events, medical advice and an online form to register an interest in becoming a volunteer. There is also a downloadable booklet for new parents.

This is a fantastic new resource with a full range of information on speech, language and communication. Developed by ICAN, Afasic and RCSLT, this site provides a wealth of material for parents and professionals. There is comprehensive information regarding typical language development across the age range with tips to support your child and a page about learning English as an additional language. There is information about the full range of speech, language and communication difficulties experienced by children and sound practical advice about how to access speech and language therapy and what to expect from this service. Other areas include frequently asked questions, a directory of resources such as useful organisations, books and fact sheets, news from I CAN, Afasic and RCSLT, a glossary of commonly used terms and information about how you can get involved in the site by sharing your ideas and experience. Colourful, comprehensive, well-connected and user-friendly, this is a ‘must visit’ site for anyone with an interest in speech, communication and language.

http://www.footsteps.ie/index.html

http://www.talkingpoint.org.uk/
Augmentative and Alternative Communication Developmental Issues

Edited by Stephen Von Tetzchner and Nicola Grove
Published by Whurr Publishers Ltd, London, 2003
ISBN: 1 86156331 0                      Approx. £35.00

Reviewed by Anne Naylor (M.Spec.Ed)

This book outlines augmentative and alternative communication and examines the developmental achievements of children using these communication systems. The authors discuss studies of individual children and groups of children, and describe strategies used by these children to resolve their communication difficulties.

According to the information on the back cover, the aim of the book is to

"Inspire a shift towards a developmental understanding of augmentative and alternative communication in both research and clinical practice, leading to new knowledge and a better basis for intervention practices, and thereby to improved social and societal participation for children using augmentative and alternative communication."

This book would be very helpful for parents and professionals working with children who use alternative or augmentative communication systems. It is written in an academic style and is well referenced. However, the use of jargon, particularly in theoretical discussions, makes some sections difficult to get through. I found it all relevant and interesting, but much easier to read once I got past the first few chapters.

As the parent of a child with Down syndrome I found the following three chapters most relevant and interesting:

• Chapter 5 – Manual signing as a tool of communicative interaction and language: the development of children with Down syndrome and their parents
• Chapter 6 – A longitudinal study of sign and speech development in a boy with Down syndrome
• Chapter 12 – Late development of independent conversation skills with manual and graphic signs through joint activities

The first few chapters examine the development of alternative communication forms; joint attention and lexical development in typical and atypical communication; memory and strategic demands of electronic speech-output communication aids and the development of communication with alternative means from Vygotsky’s cultural-historical perspective. Despite the fact they are interesting and informative, these chapters are very theoretical and rather heavy going.

Chapter 5 describes a longitudinal study into the communication of a group of children with Down syndrome. It looks at how manual signs were used to augment the children’s early communication and language development, and to provide a shared communication system for families. There is comprehensive information about typical developmental patterns of speech development and challenges faced by people who have Down syndrome. There is a description of children with Down syndrome who are exposed to manual signs early in life, their language acquisition and changes in their language environment. Implications for intervention are also discussed.

Chapter 6 follows the communication development of one boy from childhood to age seventeen. There is very detailed information about his language development, and I could relate much of his story to my own son’s language development. I found it fascinating to have an insight into his use of sign and speech over time. This boy was introduced to manual signs when he was three and a half years old, started using signs at age four, and manual signs and gestures were his main means of communication for the following eight years. He started to speak when he was twelve years old and at the age of seventeen, speech had become his main form of communication (although he needed to support it with manual signs and gestures). The description of his language development illustrates some features that appear to be critical to effective use of other communication modes than speech. It provides a unique insight into the long-term language and speech development of a child with Down syndrome over a period of seventeen years.

Chapters 7 to 11 examine environmental influences on aided language development; co-construction in graphic language development; child-driven development of alternative communication; narratives in manual sign by children with intellectual impairments and aided communication and the development of personal story telling.

Chapter 12 looks at the challenges of adolescence for the adaptation of the language environment of people who use alternative means of communication, specifically a group of students who improved their conversational skills, resulting in enhanced peer interaction.

Chapters 13 to 16 include topics such as supporting the development of alternative communication through culturally significant activities in shared educational settings; patterns of language use in Hindi speaking children with cerebral palsy; teacher training and Blissymbol learners.

The book provides comprehensive information about augmentative and alternative communication developmental issues. It is based on research, and uses the experiences and skills of people who communicate using alternative language forms to provide insights, including references to social and cultural situations. This information provides an important knowledge base to help professionals and parents plan and provide a rich language environment: one that truly supports the communication development of children who use alternative or augmentative forms of communication.
Living with Down Syndrome

Winner of the Yann Geffroy Award for 2003 for new documentary photography, given by the Grazia Neri Agency in Milan

Andreas Reeg
Published by Kehrer Verlag Heidelberg
Hardbound, 24 x 30 cm, 96 pages, ca. 50 full-page color plates
Bilingual: German/English
Text by Cora Halder and others
ISBN 3-933 257-32-8                     28.00 EUR

Schlappi, the singer of the electro-pop band “Station 17”. Steffi Fahnenschreiber, the swimmer. Eva Maria Härd with her beloved “Pumuckel” dolls. Marco Huber, always correct and a soccer enthusiast. Andreas Reeg’s empathetic photographic portraits present four unique people with Down syndrome.

Reeg accompanied these people in their everyday life for many weeks. His pictures evoke terms like strength and tenderness, familiarity and dignity. The result is a book that compels the glance and gives courage to those affected – an important artistic contribution in 2003, the European Year of People with Handicaps.

The volume of photographs is supplemented with a text introducing readers to the topic of Down syndrome. The author, Cora Halder, traces society’s changing approach to the syndrome from its first description in 1866 by the English physician John Langdon Down to the current discussion of the ethical consequences of prenatal diagnostics.

Today, some five million people all over the world live with this disability, which is triggered by the triple presence of chromosome 21. “Only in a society that knows, accepts, and cherishes people with Down syndrome can they lead a happy life,” says Cora Halder. Andreas Reeg’s photographs are a plea for this conviction.

The Photographer
Andreas Reeg, born in 1971, studied Visual Communication and Photo Design in Dortmund. Reeg lives in the Odenwald region and is a freelance photojournalist. Since 1996, he has participated in numerous exhibitions and book projects. In 2002, he was nominated for the Photo Award of the Körber Foundation Hamburg. In 2003, he received the Yann Geffroy Award of the photo agency Grazia Neri in Milan. He has published in the periodicals Stern, DU, Die Welt, Nikon News, Schwarzweiss Magazin, and many others.

New from Woodbine House
By Libby Kumin
£17.50

Speech and Language Intervention in Down Syndrome
Edited by Jean Rondal and Sue Buckley
Whurr Publishers Ltd.
£35.00
Available from The Down Syndrome Educational Trust
Prints Charming?

We were delighted to receive these beautiful photographs and an email from eight-year-old Peter Cahill’s father, Paul, in County Kildare, Ireland. We are always on the look out for good quality photographs for our publications including Down Syndrome News and Update and our series Down Syndrome Issues and Information. We will certainly be considering these shots for our forthcoming and revised DSii modules on social development, motor skills, education and family issues.

We would like to thank all the families who have sent us photographs in the past. We are now working on a series of books on issues for adults with Down syndrome and are looking for photos of adults of any age. We are particularly interested in photographs of adults participating in religious activities of any denomination for our book on spiritual development. Please send prints by post (see inside cover for address) or high resolution digital images by e-mail to Linda.Hall@downsed.org. Prints will be scanned and returned immediately.

... with sisters Tara and Rois

... with ‘Puzzle’. Puzzle was supplied by The Irish Guide Dogs for the Blind. He was training to be a Guide dog when it was discovered he had an eye problem. His excellent temperament and training makes him an ideal companion for a child with special needs.

... at school. Peter has just finished in Senior infants, and here he is with his teacher and classmates, and taking part in the school sports day.

... and just having fun!
Dear Professor Sue Buckley,

I received with great interest a few days ago volume 2 and issue 1 of DSNU. A few points-
1. I would like to see more labelling of the pictures you use, with the setting and age of the child, for example.
2. While it is inspiring to read about the very high functioning children who have Down syndrome, I think that when a child is very much higher than the norm, it might be good to mention that fact. (For example, as Leslie Duffen did, writing “was congenitally above average” in “Sarah’s Sporting Achievements”). My daughter Rina has a “mild” level of retardation, but she is not one of the “stars” in her abilities. (We do work with her a lot, and have accomplished perhaps more than a friend of mine who has a daughter with quicker grasp.) While I realize that I need not – and should not – compare Rina to other children, and be happy for all and any progress that she makes,.... it can sometimes be discouraging to read about an overly high amount about the very high functioning children. When I read, for example, about Maria Kotlinski reading over 1000 words at age 5, I was VERY hard for me not to ask myself why did we start teaching Rina to read only at age 3½, and if maybe I should have worked more with her.... (Although I am extremely pleased that Rina is reading now quite well at age 8½.) It would have been easier for me to tune out that self-critical voice if a note had been inserted somewhere to mention that this level of achievement is well above the norm.

A note by the editor might say, something like “While not every child can reach this level at such a young age, we at the Sarah Duffen Centre recommend that sight reading be started when ........, and when this is done, at least x% (or ‘many’) of children with Down syndrome can reach a reading vocabulary of 300 - 600 words, between the ages of x-y.”

I am not even saying that this need be always done – but sometimes, please, to help us put things into perspective.

For example, in Vikki Horner’s articles, she mentions at what level her daughter was studying before the work with Numicon began, and what progress was made. This gave me a big incentive to work a bit more with Rina on her Maths work (I bought Numicon materials for her last year, and we have been using them, although Maths has taken a definite back seat to reading this year.)

3. I especially liked Vikki Horner’s article on number bonds. This is exactly the area we are working on, and I did not feel that the Numicon activities cards gave us enough suggestions. THANKS!

4. Also, Honor Mangan’s idea to use a digital camera is fantastic!

5. Finally, your nice layout and beautiful photos made Rina’s older sibling pick up the magazine and look them over. She suddenly realized that all my talk about “the sky’s the limit” is true!

I hope to soon write for you an article on making reading materials (which can help both your non-English teaching readers, and those with limited monetary resources).

As always, I tell my acquaintances from the US – if you want REAL, USEFUL information, check out the materials put out by DownsEd. DOWN SYNDROME NEWS and UPDATE is no exception. Thank you!

Ruth Palatnik,
Israel

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**Editor’s comment**

Thank you for your very positive comments and suggestions. It’s great to hear that your family, including Rina’s siblings, are finding DSNU and our other materials useful. We will certainly try to include more captions with our photos and would encourage our contributors to supply suitable information with any photos sent to us. We will also try to provide more information about the level of functioning of featured children where possible. It is recognised that without this information, it is easy to question why every child is not achieving at this level. However, we uphold the belief that these stories are vital to increase expectations. Jill O’Connor raises a similar theme in her article in this issue, p.51 where she notes that “the Down Syndrome Association have sometimes been criticised for being “too positive””. It is our aim to celebrate and support the achievements of children across the spectrum including those with more complex and additional needs and we would encourage readers to submit articles relating to the development of these children.

With regard to your comments about reading, we would advocate that parents and supporters start reading activities with their children when they have a vocabulary of about 50-100 words and they are starting to use two words together. The age at which a child with Down syndrome will be at this point varies immensely, however they will typically be able to produce 50-100 words between 36-60 months although comprehension is usually ahead of production.[2] This falls in line with starting reading activities at around three and half years of age as you did with Rina. Maria Kotlinski’s achievements are exceptional; she was within the 98 percentile of all children of her age.[2]

We look forward to your article on reading materials, particularly as we will be running an article on early intervention in our next issue of DSNU. Once again, thank you for your letter and we hope you continue to enjoy reading DSNU.

Mandy Wood (Assistant Editor DSNU)

**References**


When Caroline started at the local village primary school, there were 11 pupils in her class – if someone had a party, they all went to the party, so inclusion came naturally and easily. As the years have gone by, it has become far more difficult to maintain a friendship circle. In South Wiltshire mainstream education at secondary level is virtually non-existent for pupils with Down syndrome (we think Caroline is the only one) and I often feel we are in a no-mans-land for social inclusion.

Having said that, she does have a small group of friends at school who she has been with since year 7, but (because of their home circumstances) for any contact outside of school, the initiative and supervision has almost always had to come from me. Caroline at 16 does not always appreciate outings with Mum in tow!

Caroline is apparently very confident at school. She did go through one reluctant phase to attend in Year 9, which we discovered was due to a problem with a small group of girls picking on her (and others). Her excellent Support Assistants and SENCO dealt with the situation and since then, there have been no real problems in this area.

Academically her progress is largely governed by the style of teaching and the teacher’s ability to differentiate the work. We were all thrilled when she achieved an E in her GCSE Biology module this year. She also loves Maths. She did an extra year at Primary School so, although already 16, she will move into Year 11 in September. The big question mark at present is What then?

As a family we are actively involved in our church in Salisbury and this is where Caroline has most freedom to be independent and interact with others. She loves the Friday night and Sunday morning teenage groups (but she does have to put up with her Mum and Dad being two of the leaders!) and has recently taken up singing with our very inclusive music group. In addition we have other people of varying ages with Down syndrome and other disabilities who are regular members of our congregation, so it’s a place where everyone is different and everyone is normal.

As far as trying to mix Caroline with others with learning difficulties, because of her mainstream education, she is more capable and independent compared to her peer group. She goes to Fizz Club (a special needs group) at the Leisure Centre, but although the other participants are friendly towards her, she gravitates towards the helpers. This may be because two of the helpers are 18 year old lads!

A recent addition to aid socialisation has been a joint initiative through Social Services and Alabaré (a Christian organisation doing some great work with people with learning difficulties in our area). They have set up a scheme with three girls from one of the other local schools who are near Caroline’s age. So far they have had three ‘meetings’ – an initial ‘getting to know you’ session with pizza and video in our home, an afternoon bowling and more recently playing crazy golf. Caroline was fully involved with the setting up of the group – choosing what they might do etc., and everyone has been careful to encourage Caroline to feel equal with the other girls – part of the group, rather than being looked after.

Finally, I wanted to comment on Annette Bertram’s letter about Aimee and her imaginary friends. Caroline developed imaginary friends after her 17 year old sister Sarah died of cancer in 1999. I thought it was part of Caroline’s grieving process. I am sure it helped her through her grief to be able to talk to her ‘friends’, but I wonder if she would have acquired them anyway.

‘Imaginary boyfriend’ became a problem at school and she began to be teased, so between the SAs and ourselves we agreed ‘friends should stay at home’. (Because she does have her real group of friends at school we were confident we were not isolating her by doing this.) In the main this has worked, although we had to give her points for initiative when the imaginary telephone call to the imaginary friend at home took place!

Overall I believe she feels happy with the life she leads, it is me who is saddened that she does not have the opportunity to be fully integrated into a vibrant group of friends like her sisters Sarah and Rebecca enjoyed in their teenage years.

I’m looking forward to hearing of other parent’s experiences through News and Update and maybe what challenges lie ahead for socialisation for young adults. I’m sure we as parents will have one thing in common, we’ll all agree that maintaining a social diary for our children is very hard work!

Marilyn Evans
Wiltshire, UK
July 2003
Teaching Sofia to talk and to read

Sofia was born with a medical diagnosis of Down's Syndrome and many medical problems:
- congenital heart defects (ASD and VSD) and underwent open heart surgery when she was 3 months old. I believe that her endurance is still not the end of a well child, and she still has her moments of mottled skin (sometimes, not very often any more, her extremities get purple and Mapleton does some kind of what I call “black magic” to help Sofia by pressing in some points of the front and back of her chest area).
- Sofia has had feeding problems, and aspiration. Sofia is still aspirating fluids.
- Sofia has had 3 sets of ear tubes. The last set was put in in January 31, 2003; after having several hearing tests done indicating a minor hearing loss.
- Perennial Upper Respiratory Infections; during the winter months she is very often given antibiotics.
- Probable Allergies (since we started lactose free milk her face has cleared up), Hypotonia, etc., etc.

I suspect that you all know what Sofia's Mom has been doing since Sofia was born... Basically what I have done, or tried doing, with Sofia is to have the thought process that the brain is an organ whose growth is happening at a larger pace in the earlier parts of her life; therefore, cognition is the most important early intervention that I can do for my daughter (opposite to what the DDC therapist that was coming to the house had – take care of the medical problems first, and then work on cognition for your daughter).

Here is the procedure that I started during Summer 2001 and that has been working successfully with Sofia. The procedure might be a little cryptic since my background is in computers. If you need any explanation or any other information, please do not hesitate to contact me. I have a home video of Sofia and myself showing Step #5, where Sofia is already recognizing the labels and proceeding to match the labels with the pictures only!!

The materials you will need are:
- any materials you feel necessary to teach the meaning of the printed word you want to teach, (e.g. assistive technology has made this task much easier)
- 2 sets of picture with label (printed word) cards • 2 sets of label (printed word) cards • 2 sets of picture only cards.

Note that I have been using sets of 4, as also noted in the University of Washington's process, because Jeffrey Freed notes that right brained children pick up things slowly doing, but which has proven fruitful already, as I already shared with you:

“I do not know how much I owe you for all the help your publication has provided to my daughter and my family!”

I have to share with you that last summer we bought the Love and Learning first kits (Note that we have learned the Kit #1; skipped (for now) Kit #2 and started working on the Kit #3, after doing Pat Oelwein's Color/Animal (Brown Bear’s) Module) and started working on “The elephant is big.” sentence, practising the sentence over and over again... and the other day Sofia, took a book with a lion, and said “The lion is sad.” I was so impressed that I said to Sofia to tell her dad. Sofia took the book with her to the kitchen, where her dad was, and said: “Dad, the lion is sad.”... totally amazing... like we say here, totally cool !!!"

Also, reading-wise, etc., I am doing an independent project with the Speech Language and Hearing Department in the University of Colorado in Boulder, in which I have compiled all the research I have done since Sofia was born; with a mother's perspective. At the end of the semester I have to do a presentation for the students. I attached a draft of my research to the end of my goals in the video-sessions are: (1) Sofia will read the following 10 written words (fly, swim, walk, dance, sit, drink, float, jump, run, and laugh) from cards with 80% or greater accuracy with no picture, gestural, or verbal prompting; (2) Sofia will read, or say from memory, the following 10 written 3 word combinations (fly red bird; swim orange fish; walk black sheep; dance brown bear; sit purple cat; drink gray elephant; float yellow duck; jump green frog; run blue horse; and laugh white dog) from pages with 80% or greater accuracy with no picture, gestural, or verbal prompting.

Margarita Sobrino, Colorado, USA
March 2003
Kylie Scott, 23, of Canberra, Australia, was selected to represent Australia in the Special Olympics 11th World Summer Games in Ireland during the week of 21st June 2003.

The Australian team was hosted by Armagh, Northern Ireland, prior to the commencement of the games. Kylie played tennis and won the silver medal in her singles division and came fourth in the mixed doubles.

Leyton Hewitt, Australia’s number one tennis player, left Wimbledon to go to Dublin and was on hand to give Kylie some professional tips!!

This is an extraordinary achievement – Well done Kylie!!!

Kylie and her mother Evelyn came to England to visit friends and stayed with us for a few days. I met both Evelyn and Kylie at the 7th World Down Syndrome Congress in Sydney Australia in March 2000, and have kept in touch since then.

Vikki Horner, Wiltshire, UK

The official website of the 2003 Special Olympics is at

http://www.2003specialolympics.com/
The objective of EDSA is to promote the complete development of persons with Down syndrome, regardless of racial, linguistic, religious, philosophical or political considerations. Any initiative which contributes to this end from the viewpoint of health care, education and instructions, and human development will be encouraged. The aim is to improve their health, training, adaptation to and integration in society so that each person can, to the extent that he or she desires, lead as normal a life as possible, within the framework described in the United Nations Declarations on Human Rights, and on the Rights of Handicapped Persons; in the European Convention on Safeguards of the Fundamental Rights and Liberties; and in the Constitution of his or her country.

VIII International Symposium on Down Syndrome, Barcelona, May 2003

Cora Halder
Deutsches Down-Syndrom Infocenter - Germany

The Fundació Catalana Síndrome de Down organised their VIII International Symposium on Down Syndrome in Barcelona on 15 and 16 May 2003. Around 250 participants, mainly from Catalonia and other parts of Spain plus some 30 from abroad, listened to a range of topics presented by speakers from the USA, Canada, Argentina, Italy and Spain. The title of the conference was: Building the future. Questions for today. Answers for tomorrow.

The Fundació had invited specialists on the topic “Working with parents”. One of these specialists was Marta Golano, a clinical psychologist in the Early Intervention Center of the FCSD in Barcelona. She spoke about the importance of the mother-newborn relationship and how professionals can support the parents during the baby’s first years. She emphasized that there might be a risk to this relationship after a baby with a disability has been born and that this can sometimes result in a delay in the child’s development. This can be avoided with the help of professionals.

“The relationship between parents and professionals” was also the subject of Elsa Coriat, psychologist and Coordinator of the Coriat Center in Buenos Aires, Argentina. The discussion between parents and professionals about what is the right treatment for the child can be very difficult and there are a lot of failures in understanding between the two groups. This is partly due to various theoretical and ethical positions within the professional field, and partly because parents experience moments of extreme anguish, desperation and anger, when they do not see their child making any progress, or when they interrupt their child’s treatment for reasons which are not clear to the professional. Elsa Coriat gives examples of how cooperation between a multidisciplinary team and the parents functions.

M. Jose Miquel and Beatriz Garvia, who both work for FCSD, talked about “Working with parents of adolescents and of adults with disabilities”. The emphasis of this speech was on topics like overprotection, facing up to the child growing up, the anxiety caused by their attempts at independence, sexuality and so on. Very often these parents no longer have the contact with professionals that they did in the first years of their child’s life. Older parents are also very settled and often do not want changes. Problems which arise because the disabled adult is unhappy with his or her situation cannot be solved by the parents alone – they need professionals to support them and their child.

The two speakers from the USA gave both very interesting and lively presentations. Douglas Fisher, from San Diego State University, spoke about “What have we learned from inclusion and how can we get inclusion to work at school?”. Fisher, who worked for many years as a teacher himself, showed pictures of children and youngsters with a disability and told success stories about how inclusion in school can work and what it means for an individual later in life. He showed incredibly easy solutions, mostly ideas from other pupils, that could make it possible for the person with the disability to stay at school, even if the authorities were trying to segregate this person, because they saw a problem. The influence of inclusion is enormous, for all students! The student with the disability automatically has a circle of friends who will support him or her later in life and the other students have gained social competence and an understanding of human differences. This was a very good talk, which must have convinced people who are against mainstreaming.
Jay Klein, who is the director of the national Home of your own Alliance program of the University of New Hampshire, USA, achieved the same with his speech on living in the community. After his talk you were convinced that living on one’s own in the community with as much support as necessary, is a real option for every disabled person, regardless what his or her difficulty might be. Klein talked about supported living and exactly what this means: he first focused on institutions, homes and group homes and showed why these living options have nothing to do with the concept of supported living in the community. He then gave examples of people who have become members of their communities, developed relationships, organised their own support, and who have gained the respect of their families, neighbours, co-workers and friends. He also showed strategies for overcoming the common barriers that people encounter as they move out of institutions or group homes into their own homes.

A Spanish example of supported living was presented by Josep Ruf, coordinator of the FCSD program I’m going home, followed by Josep Martinez who introduced the Els Xiprers School in Barcelona, a school for everyone. The FCSD’s Job Integration Program Collaborate was presented by Marius Peralta. “The Identity of Handicapped Persons” was the subject of Dario Ianes, a psychologist from the Edizioni Centro Studi Erikson in Trento, Italy. He gave a general overview of some psychological aspects which are important for the development of a solid and strong self-sufficient identity in the mentally handicapped person. His reflections were based on the new concepts on human identity recently defined by the WHO.

Further contributions were on job integration (M. Josep Delor, Tarragona) and on social and affective relationships in individuals with disabilities (an excellent talk by Dorothy Griffiths, Canada).

A highlight of the symposium was the ceremony of the presentation of the VIII Ramon Trias Fargas Award. Dr. Mara Dierssen, from the Genomic Regulation Research Center in Barcelona, received this prestigious bi-annual Spanish award for her scientific work on mouse models of Down syndrome. In her speech Mara gave a short overview about her research on mouse trisomies (see DSNU 3(1), February 2003).

As visitors from abroad, and not able to understand the Catalan language, we were dependent on the English translation which unfortunately did not work out so well. We also noticed the language barriers between the Catalan and the Castillano speaking participants, and how complicated (and costly) it is to present everything (speeches, discussions and written materials) in two languages, where one language would do as well, something an outsider like me cannot really understand. I wondered why there were almost no persons with Down syndrome at the conference (except for a very few at the information stands) and no own presentations by adolescents or adults with Down syndrome. A topic like job integration for example would have been much more impressive if somebody with Down syndrome had presented it. But I was delighted with the conference venue: the famous Casa de Mila or La Pedrera, one of the beautiful and interesting houses designed by Gaudí! It was a good feeling to be a guest in such a special ambience.

EDSA Board Meeting, Barcelona, May 2003

The Board had a productive meeting with a focus on approving new documents to guide the EDSA movement and the Down Syndrome Associations in different European countries. New statutes for EDSA were approved following work on them led by Monique Randel from Germany. A Medical Checklist was approved, based on work by Dr. Alberto Rasore from Italy and this was passed for final editing to Dr. Agustin Seres from Barcelona. A document for families prepared by a team led by Pat Clark from Ireland was also approved. These documents will be printed and distributed to all members in the coming months. Work is in progress on a Code of Ethics under the leadership of the President, Professor Juan Perera from Mallorca, and guidelines are being prepared for member countries wishing to organise a meeting for EDSA. Members will be aware that the Aims and Objectives of EDSA were published in issue 2(4) of Down Syndrome News and Update. In the past two years, the membership of EDSA has grown considerably and almost all European countries are now represented. The work during this time on these guiding documents has contributed to building a firm foundation on which to take the work of EDSA forward. EDSA has also raised its profile within the major disability forums in Europe and is playing an active role in the European Disability Forum. The work of the Treasurer Pat Clark and others had put the finances on a healthier footing. Under its current President, Secretary (Cees Zutthof from Holland) and Board, EDSA is going from strength to strength and is increasingly able to provide genuine support and guidance to newly formed associations, especially in Eastern Europe, as well as to set standards for associations and for the guiding principles which should protect the human rights of individuals with Down syndrome throughout Europe.
Dear Members,

Irina and I had great pleasure in attending The First International Congress of Young Disabled People. The event took place between June 30th and July 4th in Swansea University and was organized by a steering group made up of disability voluntary organisations, young disabled people, Welsh Assembly Government Officials and a Welsh Assembly Government Minister. The Welsh Assembly Government contributed £125,000 toward the initial cost of staging the event. Rights into Action covered all the delegates’ expenses during their stay in the UK including local travel, accommodation, meals and any leisure activities. They also collected money from families and covered some air travel expenses.

The Congress was a high profile event attracting 110 delegates with a wide range of disabilities (motor and mental deficiencies, blindness, deafness), aged between 14 and 24 and 45 support workers. They came from 37 countries (Afghanistan, Armenia, Bangladesh, Belarus, Bulgaria, China, Columbia, Cyprus, Czech Republic, Denmark, England, Estonia, Finland, France, Germany, India, Jamaica, Kazakhstan, Kosovo, Malaysia, Mongolia, Mozambique, Nepal, Netherlands, Pakistan, Palestine, Philippines, Romania, Russia, Scotland, South Africa, Sri Lanka, Switzerland, Uganda, Ukraine, Wales and Vietnam) and spoke 48 languages. The working language of the conference was English and all delegates either spoke English themselves or came with people who could interpret for them.

The aims of the Congress were to look at how the rights of disabled children and young people can be upheld, to develop strategies to facilitate this in delegates’ own countries and to devise an action plan so that the work can be continued after the Congress.

As a part of health and safety policies and to ensure that all delegates were protected at all times, there were policies in place to promote the protection of children and vulnerable adults and an anti-bullying policy. Copies of these statements were contained in the ‘Welcome’ pack, which was given to everyone on arrival.
The programme

Delegates and their support workers arrived in the UK on the Saturday and Sunday and travelled to Swansea University. They were able to take a tour of the venue and meet other delegates. The official Welcome to the Congress took place on Monday morning. There were opportunities to get to know each other, to agree the rules of the Congress so that everyone was safe and able to have fun and to meet the Welsh team and learn about their roles.

Then all the delegates were split into small groups of approximately 10 people according to their mother tongue – these were named ‘home groups’ and were coordinated by a member of the Welsh team. Each day started with a half hour meeting of each home group, where delegates played games and told the others if there were any problems or if anyone had been unhappy during the previous day.

All workshops were focused on drawing out from the young people their views on the issue being discussed through a variety of interactive means. It is important to mention that it was not a conference in the traditional sense of the word; the emphasis was not on the young people listening to others speak, but on them communicating and on their views being heard. The workshops were run by Dynamix, a team of professional facilitators. Their methods were participative, inclusive, non-judgemental and explored serious issues in a fun way.

The workshops on Monday afternoon, aimed to define what is serious issues in a fun way.

and explored which rights are most important for disabled children and young people to claim. Delegates finalised the issues they would be discussing during the rest of the week. The final agenda included education, attitudes, integration, independent living, access, employment, communication between people with and without disabilities, ‘having a say’ and leisure. The delegates agreed that the main targets for the congress were “to begin, to share, to be a part of change and to have fun. To make it work they settled rules and a slogan, “we fight, join and hand down”.

On Tuesday and Wednesday, delegates discussed the wider issues of education, communication and access over a series of three workshops. There were also one session workshops on topics such as employment and leisure.

From the delegates we found out that:

- In Bangladesh, “There are only special schools and no chances for the disabled. Due to their poverty most children with disabilities are illiterate at home.”
- In the Czech Republic, “The attitude of society towards people with disabilities is negative. Many ordinary people are afraid and do not accept the disabled, considering that they are different and non-educated”.
- In France, “President Chirac declares ‘Years of Disabled People’ and the authorities talk a lot and don’t do very much. There are also a lot of barriers to going to theatres, etc. Young adults try to find ways to see disabled people and how to live with their disability”.
- In Germany, “There are special schools and mainstream schools, jobs and training, the disabled work with non-disabled people and choose their desired job”.
- In Holland, “There is inclusive education but also a patronizing attitude and lack of dignity in institutions. Still medical model and starting to make laws to change that”.
- In Romania, “Things are starting. People’s attitude need to be changed”.
- In Wales, “People’s attitudes are a problem. Disabled people get bullied and not spoken to directly or confronted; disabled people work with non-disabled”.

Some surveys gave very interesting results, for example, responses to the following statements can be seen in Table 1:

<table>
<thead>
<tr>
<th>Statement</th>
<th>Agree strongly</th>
<th>Agree</th>
<th>No opinion</th>
<th>Disagree</th>
<th>Disagree strongly</th>
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Table 1: Results

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http://www.down-syndrome.info/library/periodicals/dsnu/03/02/
European Down Syndrome Association news

International priorities:

- To elect leaders to represent young people with disabilities nationally, continentally and globally, who would take responsibility for networking and developing an independent organisation linking young people with disabilities and international organisations.
- To acquire funding or some kind of financial support from the government or private sector to support activities such as:
  - Having a congress for all countries, including poor countries, to participate in events and have their own organisations
  - Having an Internet web-site
  - Having representation on the media through magazines, TV, radio, etc
  - Having a paid co-ordinator to run the project and organisation.
- To make the congress a regular event, moving around to different countries with different cultures.
- To ensure that international and national governments have disabled people participating in development of legislation because they are the experts. The agreement was along the lines that the pattern should be that there should be “NOTHING ABOUT THE DISABLED WITHOUT THE DISABLED”
- To be a part of the drafting of the UN Convention on the promotion and protection of disabled people.

National priorities

- To lobby national governments to ensure they include disability issues in all laws and development programmes whether they be social, economic, political or educational
- To inform people in other countries such as heads of government, politicians, the media, teachers, parents and other organisations about Rights into Action
- To put pressure on national governments to involve young disabled people in decision making at all levels
- To ask national governments to financially support Rights into Action Network in the future
- To ensure that equally means equal duties and responsibilities as well as equal rights!

This exciting and motivating event finished on Friday evening with a very enthusiastic party and disco where participants had the opportunity to meet together as a group for the last time.

On Saturday, the delegates said their goodbyes and travelled back to the airport.

drama workshop in which delegates prepared a five-minute sketch about the congress, which was filmed and shown on Friday afternoon. There also was a music workshop, in which delegates prepared an ‘anthem’ for the congress!

Thursday evening had a Welsh theme, with traditional Welsh food, a play by some of the Swansea delegates and a Twmpath, a traditional Welsh folk band, traditional Welsh dancing and modern dancing. The delegates were pleased to be joined by the Lord Mayor of Swansea and other important officials.

On Friday morning, the delegates travelled to Brangwyn Hall, the most beautiful and imposing building in Swansea. Preparations for the afternoon session continued. After lunch, they met with professionals, authorities and those with power over the lives of people with disabilities. The delegates talked to the professionals in small groups about issues which are important for people with disabilities. The professionals told everyone what they would change.

This congress allowed people with disabilities to decide upon a number of priorities at national and international level.
The bulletin of the European Disability Forum has published a special issue on “Media and Disability”. Under the Greek presidency of the EU, the European Congress on Media and Disability was held in Athens on June 13-14 2003, where 300 delegates representing the media, policymakers, academics and disability organisations met to discuss the importance of the mass media in portraying people with disabilities. Examples of good and bad adverts and fiction were shown, and their role in the way society looks at disabled people was discussed.

Articles in this issue include:
- New public procurement legislation to include disabled people in the labour market
- Italian presidency of the EU: what commitment to disability issues?
- A European parliament of people with disabilities
- Disabled people in the future Europe
- A barrier free Europe for young people with disabilities
- Second ad hoc committee meeting on the UN Convention on the rights of disabled people
- Improving disability portrayal: a new challenge for European media
- European Declaration on Media and Disability
- Between beggar and Batman: the image of disabled people in the media
- Interview with Peter Radtke
- Disability and the media: the role for advertising
- Employment and recruitment of disabled people in the media
- 2003 Agenda (diary of events for August - December)
- 2003 web initiatives
- How to become a member of EDF

http://www.edf.feph.org (available in English or French translation)
Down Syndrome International news

- 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 is focusing on dissemination of information in collaboration with other organisations.
- DSI is developing a website at http://www.down-syndrome-int.org/
- Membership is open to individuals with Down syndrome, parents, practitioners, researchers and organisations.

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

Down Syndrome: Global Progress in a Changing Era

Early Bird Registration Date extended to 14 November 2003. 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

the DOWN SYNDROME Educational Trust

Training at The Sarah Duffen Centre, Portsmouth

- 22nd September: Meeting the educational needs of children with Down syndrome in mainstream schools - Primary
- 24th September: The Numicon approach to teaching number
- 13th October: The development and education of children with Down syndrome in infancy and preschool years
- 20th October: The development and education of children with Down syndrome – Cognitive, birth to 5 years
- 21st October: The development and education of children with Down syndrome – Social, birth to 5 years
- 3rd/4th November: Supporting the development and education of children with Down syndrome (2 day workshop)
- 10th/11th November: Speech and language development for children with Down syndrome from birth to 11 years (2 day workshop)

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

Building work may affect training next year - book this term to avoid disappointment

Trust staff are providing training or contributing to the following events – for details please contact the organisers.

- 9th September: the BA Festival of Science – Salford. www.the-ba.net
- 14th - 17th September: Brothers of Charity, Roscommon, Ireland – Eileen Neilan, 0903 28500
- 19th September: Plymouth Portage – Diann Davis, 01752 314369
- 20th September: Staffordshire Parent Partnership – Janet Foley, 01785 356921
- 24th - 26th September: 3 day programme for Bradford – Wendy Uttley, 01274 820483
- 10th October: Swindon DSA – Nicky Palmer, 01793 640234
- 22nd November: S.West Thames – Helen Long, 0208 3377638

Down’s Syndrome Association training events

Including children with Down’s syndrome in mainstream schools
3/10/2003 and 4/10/2003
Telford Moat House (Junction 5 M54), Forge Gate, Telford TF3 4NA.

Friday sessions are aimed at teachers, support staff and others working with children with Down’s syndrome in mainstream primary schools, with sessions on Saturday for parents and carers.

Transition to and inclusion in mainstream secondary schools
6/11/03
National Centre for Deaf Blindness, Cygnet Road, Peterborough PE7 8FD

A one day conference for teachers, support staff and others working with students with Down’s syndrome in mainstream schools at Key Stages 2, 3 and 4

See http://www.downs-syndrome.org.uk and follow the links to Information – Training and Conferences or contact Bob Black, e-mail: bblack@downs-syndrome.org.uk
Trust news

Something to smile about

Our new psychologist, Mandy Wood, joined us at The Down Syndrome Educational Trust in July following a successful interview in April. After a period of training, she will be providing direct services to children, families and schools, and contribute to our research, training and publishing activities. We asked Mandy why she hasn’t stopped smiling since she got here!

Why am I smiling? I haven’t stopped since Sue offered me the job! So, let me tell you a little bit about myself and what I’ve been up to over the last 4 weeks. I completed a psychology degree at The University of Exeter in 1997. I loved everything about it but hadn’t a clue what I wanted to do next. It wasn’t too long before I started as a learning support assistant at a local sixth form college. Working as an assistant was great; I got to sit in loads of fascinating lessons, that I’d never studied myself including Biology, Chemistry and even Japanese. I started teaching part time at first, completing my PGCE by distance learning at the same time. I have taught on a wide range of course including GCSE, AS and Access Psychology, GNVQ and AVCE Health and Social Care and a variety of courses for students with severe and moderate learning difficulties. I also acted as a Student Support Officer and Course Co-ordinator. Despite a jam-packed schedule, I managed to squeeze in some examining work too.

When I started off in education, I went in thinking that I would be doing all the teaching and ‘they’ would be doing all the learning. This of course wasn’t the case. I was lucky enough to be given the opportunity to work for some young people with and without disabilities, who taught me about determination, drive and perseverance, about the qualities which get you to where you want to be. All along, I’d known I wanted to work as a psychologist and when I saw this post advertised, I knew it had to be mine! I could combine my love of psychology with direct work with children, families and practitioners.

I have been here for a full month, today in fact, so let me give you an idea of what I’ve been up to. Although, I have lots of skills that I hope I can bring to the Trust, I have a LOT of stuff to learn as up until about four months ago, I had very little knowledge of Down syndrome. So, there’s been a lot of reading; journals, magazines, websites, books, letters, reports, you name it I’ve been reading it. I’ve also visited a couple of our local secondary schools and met lots of families who have come for assessments. You know you work somewhere special, when you’ve met people from Ireland, Switzerland, Spain, Cyprus and even Pakistan within just a month! I’ve got to know lots of the standardised tests used for assessments and the types of questions asked and over the next few months, I will be learning about how to write up an assessment report. I’ve also taken great pleasure, in participating in some of the Early Development Groups (EDG), once again meeting some super tots with their family, friends and supporters. I’ve been asked to work as assistant editor on News and Update, so I’ve been doing some writing and editing too. Sue and I have also been here re-organising the library which has helped me to get to know where everything is kept and I’ve learnt about how academic references are managed on our internal database so that I can root out any more reading that I might want at the touch of a button.

So what am I looking forward to? I’m looking forward to the ‘family weekend’ at the end of August and the EDGs starting up again. I’m looking forward to attending our Bradford conference in September and giving a presentation at the Surrey conference in November. I look forward to the Christmas parties, fair and ball in December and to taking a more active role in assessments and leading EDGs for myself, to helping with the writing and the research, meeting more families and professionals… In fact, I don’t think I’ll stop smiling for a while yet!

Services and training

During the school holidays we have had an Open Day, a Family Weekend and many visitors coming for assessments, so although our regular services are not operating we keep busy. The Family Weekend was well attended and, from the feedback we received, a valuable event for the families who came. We are not sure whether we will be able to hold any weekend events next year as the building issue is not quite finally resolved.

Training events held at the Centre may also be affected by building works so we have not yet published a programme for next year and we advise readers to come to events here this term in case we do not run them again next year. Please pass this information on to local schools and professionals. We are happy to run training events over 2 or 3 days around the country if any DSA group wishes to organise this in their area. We have worked with groups in the Wirral and Bradford on such events this year and this does mean we are able to reach all the parents and professionals in your neighbourhood, many of whom would not find it easy to travel to Portsmouth.
Our Early Development Groups start again in September and are fully booked, with 36 families attending. We may be able to take more children in January now we have Mandy working with us and we welcome parents of new babies at any time. We are not yet able to restore the AdviceLine but we are seeking funds to do so and maybe this service will start again next year. While our general free AdviceLine service is suspended, we are still offering a service to members.

Building

Portsmouth City Council have decided that we will be able to stay in our building if we demolish a further section of the building and share car park facilities with the local school. There are still details to be worked out and leases to agree, so we will not feel totally secure until leases are signed in a few months time. If all goes to plan, demolition work will be in hand next spring and will cause some disruption as part of our hall will be demolished and our playroom will need to be relocated.

Research

The Numicon project is going well, with all schools participating enthusiastically. Informal observations suggest that the scheme is very successful for most children with Down syndrome involved in the study. The study has one further term to go before the final results are collected. The Trust is once again pleased to be able to support the annual Down syndrome Research Forum meeting for UK researchers in October (see page 72), and already the list of attendees is looking impressive.

Publishing

I am still having to apologise for delays to the final books in the Down Syndrome Issues and Information Development and Education series – several weeks of my planned writing and editing time in June and July were taken up with negotiations with the City Council and public meetings regarding the building issue. We expect to have the remaining books for the preschool age group shipping in October and the remainder for primary and teenage groups in November. We are very aware that many folks have had a long wait but hope the books will be worthwhile once you do receive them. We now have 8 adults with Down syndrome working in our printing and production studio and we hope to take on more as the work grows.

Adult series

The first books in the Adult Issues series of Down Syndrome Issues and Information are in production and we will begin publishing them before Christmas and hope to have the series complete by next Easter in time for the World Congress in Singapore. Funding for this series has received a boost as we have been awarded a grant of £20,000 from the Freemasons’ Grand Charity. We will have more detail on this series in the next issue.

Funding

Many thanks to everyone who responded to our appeal to raise funds sent out with the last News and Update. The trend in income from charitable donations and events has improved somewhat over the last three months but we are still need all our readers to help if they can as we are still concerned that we will have a shortfall at the end of the year. Many readers have raised funds by organising events or sending in donations and we will acknowledge these in full in the next issue of Funding News, which will be out later this year. There are many ways in which you can help us, from coffee mornings to larger events and we can provide help with planning, tickets and publicity – just contact howard.hurd@downsed.org or linda.ball@downsed.org

Branching out

Canterbury

Readers in the Canterbury area will be pleased to know that a new branch has been set up, and that they raised nearly £4000 at their “D.A. Ball” earlier this year. They are looking for more members and, particularly, people willing to help on the committee. They currently have lots of parents of pre-school and Key Stage 1 children involved but would like to encourage parents of older children and young adults to come along and join the fun. This summer, they had a successful play session at The Northgate Community Centre in Canterbury and they hope to continue with monthly sessions either there or at Faversham gym.

Anyone interested should contact Sarah Kent on 01227-453926 or email AlexHector@aol.com

Berkshire

The Berkshire branch is planning a Golf Day at The Blue Mountain Golf Club in Bracknell, date to be arranged. Please contact Colin Stonehouse c.stonehouse@ntlworld.com tel: 0771 904 3603 or 01344 823476.

Contact details for Bristol branch

Annabel Dixey, 0117 9624735 or Marie-Louise Cook, 0117 9686893
We have booked HMS Warrior, in Portsmouth's Historic Dockyard, for a Christmas Ball. Owing to the limited number of places available for this very special event, please contact us as soon as possible if you would like tickets.

E-mail shelley.ducarreaux@downsed.org or sharron@flinthouse01.freeserve.co.uk for further information, or phone Shelley Ducarreaux on 023 9289 3882.

For a virtual tour of the ship, see http://www.hmswarrior.org/

New Interactive Language and Reading Books from Greenhouse Publications


WHAT ARE INTERACTIVE READING BOOKS? Utilizing the power of visual strategies, beginning readers learn to associate pictures with words. Students move original, velcro-backed drawings to match, identify, label, sequence and create sentences while learning to read! INTERACTIVE READING BOOKS are fun and rewarding for children with and without special needs.

The pictures can also be used to teach the meaning of words by playing matching and selecting games. They can be used as part of speech and language as well as literacy programmes, as they cover much basic vocabulary.

now available from The Down Syndrome Educational Trust - see our Resources catalogue

Forthcoming events

Christmas Ball on HMS Warrior
December 13 2003

BOOK NOW

Christmas Ball on HMS Warrior, Saturday December 13 2003

We have booked HMS Warrior, in Portsmouth's Historic Dockyard, for a Christmas Ball. Owing to the limited number of places available for this very special event, please contact us as soon as possible if you would like tickets.

E-mail shelley.ducarreaux@downsed.org or sharron@flinthouse01.freeserve.co.uk for further information, or phone Shelley Ducarreaux on 023 9289 3882.

For a virtual tour of the ship, see http://www.hmswarrior.org/

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Christmas Fair, Saturday November 8 2003 at The Sarah Duffen Centre

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Christmas Party for the under-eights, Saturday December 6 2003 at The Sarah Duffen Centre

❄ ❄ ❄

see next issue for further details of these events
Conferences

17 - 20 September 2003
4th European Congress: European Association for Mental Health in Mental Retardation, Mental health and mental retardation: A lifespan multidisciplinary approach, Rome, Italy.
http://www.ptsroma.it/MHMR2003

27 - 28 October 2003
UK Down Syndrome Research Forum Meeting. The Sarah Duffen Centre, Portsmouth, UK. For details see below.
http://www.downsed.org/research/

POSTPONED from 31 October - 2 November 2003
International Mosaic Down Syndrome Association (IMDSA) Convention, Orlando, Florida, USA.
http://www.imdsa.com/

11 - 12 December 2003
3rd Seattle Club Conference for Research into Intellectual Disabilities. The University of Edinburgh, UK.
http://www.education.ed.ac.uk/seattle/

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/

To all Down syndrome researchers and postgraduate students

You are cordially invited to the next meeting of the UK Down Syndrome Research Forum to be held at The Sarah Duffen Centre, Portsmouth on the 27th and 28th October, with the support of The Down Syndrome Educational Trust.

The meeting will start at 10.30 on 27th October and finish at 3pm on 28th October (these times can be adjusted to suit participants). The Forum is a friendly support group for those working in the area of Down syndrome research. The format, for those new to the Forum, is informal presentations of work in progress by those attending. The group really are very helpful to one another and shared work or useful advice on how to take a project forward have been outcomes from earlier meetings. The Trust will provide buffet lunches on both days and there is no fee for attending. We can advise on bed and breakfast accommodation at reasonable prices but at present the Trust is not able to subsidise travel or accommodation costs, though we would like to be able to and may be able to in the future.

If you plan to attend, please let Jo Nye (uk-research-forum@downsed.org) know as soon as possible, with the title plus a short abstract of any presentation that you wish to make and we will then put a programme together.
Aims and scope

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

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

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

Guidelines for contributors

**Longer articles and reviews**

Articles may take the format of a detailed analysis of a particular subject or issue, or a summary review. Detailed 'subject overviews' should draw on current scientific knowledge and clearly explain how this guides our understanding of effective interventions. Articles should contain sufficient background and information to be understandable to readers with little or no previous knowledge of the subject matter. Summaries of research are encouraged but should be accessible to a wide range of readers. Researchers are particularly encouraged to draw out implications for effective practice from research studies. Detailed academic papers presenting research findings should be submitted to *Down Syndrome News and Update*’s sister publication, the journal *Down Syndrome Research and Practice*.

**Shorter case studies, resource reviews, and personal experiences**

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

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

**News**

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

**Correspondence**

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

**Editorial review**

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

**Submissions**

Papers submitted to the Journal should be sent to:

The Editor, Down Syndrome News and Update,

The Down Syndrome Educational Trust, The Sarah Duffen Centre, Belmont Street, Southsea, Hampshire, POS 1NA, United Kingdom or e-mailed to dsnu-submissions@downsnet.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 ‘Zip’ disk in PC or Mac format. Most word processors’ file formats can be supported, though Microsoft Word files are preferred. If in doubt, Rich Text Format (RTF) or plain text (ASCII or Unicode) files are the most compatible. Tables and graphs may be submitted in most major spreadsheet packages’ file formats (Microsoft Excel preferred). Diagrams should be submitted as ‘vector graphics’ file formats (e.g. EPS, WMF, etc.)

Manuscript layout

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

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

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

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

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

References format

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

Articles

Chapters

Article (World Wide Web reference):