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Down Syndrome News and Update

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.

For further guidelines for submissions, please (see pages 104 - 105).

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We are seeking additional members for the Editorial Board. If you are interested in assisting by reviewing submissions and/or contributing reviews or articles, please contact the Editor at the address shown below for further information.

We would particularly welcome advisors from a variety of countries.

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EDITORIAL

Welcome
Welcome to the second issue of *Down Syndrome News and Update*, which will be published four times a year. The aim of this publication is to keep readers up to date with the latest information on the health, development and education of children and adults with Down syndrome. Our target audience is practitioners, particularly teachers, speech and language therapists, psychologists, health visitors, general practitioners, social workers and family members, particularly parents. What we think these readers will share in common is a need to access quality information about Down syndrome when they first have a child with Down syndrome in their school, practice or family and then a need to keep that information up to date.

The Down Syndrome Educational Trust is involved in providing a wide range of training and over the last seven or eight years the demand for training has shifted from requests from special education and specialist services to requests from mainstream education and mainstream services. We are delighted by this shift, of course, since the philosophy underpinning all our work is the right of all children and adults with Down syndrome to be full citizens and included in all aspects of mainstream life in the community. This means access to all the resources everyone else in their age group has access to, particularly in education and to the social life of their communities.

We have begun to form an Editorial Board with staff from The Down Syndrome Educational Trust on the basis of their expertise to launch the publication. We will be inviting other colleagues around the world to join us. We intend to have regular articles and information on development, education, speech and language, health, and research. Each issue will include a range of articles, reviews of research, reviews of resources, news and correspondence.

In this issue
The first article is the second of a two-part discussion of our ten year experience of supporting individual children with Down syndrome in inclusive education settings.

The first part focused on the issues of attitudes, whole school culture and successful planning at school and class levels. This part focuses our research on speech, language, literacy and memory development and the implications of the work for understanding the development of mental abilities. We tend to take for granted our ability to think, remember, reason and plan - yet these are core mental abilities. Over time we build up a large store of knowledge about the world and the people in it and then using thinking, remembering, reasoning and planning skills - we can use that knowledge to perform tasks and behave appropriately in our everyday lives.

Most of us think, remember, reason and plan using inner speech - we think in words. Language is the central skill on which all our other mental abilities depend. Any child who is delayed in learning to understand and use language (either in speech or sign form) will be delayed in developing thinking, reasoning, remembering and planning abilities. In other words, I am arguing that language delay always leads to cognitive delay.

Our research, and similar studies of children without disabilities, shows that speech, language, short-term memory and literacy skills interact to support one another. Progress in one skill leads to progress in another. No progress in one may slow down progress in another. We argue that reading instruction is particularly important for children who do not learn very efficiently from listening - and that being able to read can boost speech, language and memory skills. This has important implications for classroom practice and the curriculum and we describe the principles for successful literacy and language work in the classroom.

The next article picks up some of the same themes. Ann Nunn describes her experience of teaching her son Simon to read, some 25 years ago. She used similar principles, building his reading lessons around topics he was interested in. She argues that intellectual development is the result of stimulating education, social experiences and learning opportunities - still being denied to too many significantly disabled children.

The third article, by Ben Sacks and Frank Buckley, provides an overview of the theories being used to promote the use of “nutritional supplements” for children with Down syndrome. They take the
reader through the evidence as it stands at present, pointing out that in some instances proponents tend to distort the evidence for deficiencies or biochemical abnormalities and then to propose unproven remedies for abnormalities of function that may not exist. They then review the evidence for efficacy and safety of the formulas being strongly promoted to parents at the current time. There is no evidence of effectiveness or safety, but potential for harm - especially when given to young babies.

I hope that our readers will pass copies of this article to other parents and to their general practitioners and paediatricians. As the authors point out, individuals and organisations promoting these substances (and profiting from their use) have web sites and literature full of inaccuracies and wild speculation. However, as they list many references, used inaccurately, even the busy medical practitioner will be misled, as he or she is unlikely to have time to research the issue themselves.

The next article is a report by Drs. Susan and Peter Bliss of a conference held by an organisation in the UK, the Down's Syndrome Research Foundation, which is promoting the use of supplements. The main speakers for the conference were from The Warner Clinic in the USA - an organisation promoting a variety of unproven therapies for children with Down syndrome. Susan and Peter Bliss are parents of a daughter with Down syndrome, so they well understand the difficulty parents experience in weighing up the evidence for new treatments. They were not impressed by Jack Warner and his colleagues and give a balanced account of the day. Many professionals in the audience, including doctors from the Institute of Child Health who attended, were very critical of the presentations and publicly dissociated themselves from the views being expressed. Several expressed shock at the way parents’ emotions and vulnerability are played on by those promoting ineffective remedies for financial gain.

The Research Update in this issue summarises the wide range of research presented at the 1st Biennial Scientific Conference on Down Syndrome held in Vancouver, Canada in April this year. There were many interesting presentations covering a wide range of topics. If I were to pick out those that I found the most interesting in terms of their future potential, they would be the work of Dr Jennifer Hill Karrer and colleagues in Kansas, USA.

Dr Hill Karrer is studying evoked brain potentials in infants. This technology is proving to have the potential to mark the development of specific cognitive skills and may prove to be a way of demonstrating the effects of interventions on stimulating specific brain development in the future. The report by Dr Dale A. Ulrich on the effectiveness of treadmill exercise for accelerating the age of walking in babies deserves further attention. Progress with motor skills influences all the other social interaction, exploration and learning that children can engage in. In our experience, most children with Down syndrome could benefit from much more skilled and intensive support from physiotherapy services than is on offer at present.

The final article in this issue, by Angela Byrne and Frank Buckley, continues their introduction to the Internet and its resources. This article focuses on the sites on Down syndrome. The Internet has enormous positive potential in that it makes so much information so easily accessible. However, it also makes much misinformation available. Quality is therefore a worrying issue. Books and journals are reviewed by editors and by scientific peers before the contents get into print. No such system reviews the quality and accuracy of information on web sites or Bulletin Boards. This is one reason for the development of a web site by The Down Syndrome Educational Trust. This site will only carry material and views that are of an acceptable standard, i.e. objective and supported by evidence.

We also include some news items and conference information at the end of this issue. I do hope you are finding this publication valuable. Please do encourage others to subscribe. At present The Down Syndrome Educational Trust is subsidising the publication, so we need to increase circulation if we are to stay in production.
The development of mental abilities

We would like to draw the attention of all teachers to recent psychological research which stresses the dynamic and interactive ways in which mental abilities develop in all children and in particular, the significance of speech and language, working memory and reading development to all children’s intellectual progress. We will draw on our own research with children with Down syndrome to illustrate the issues but identify for you the main sources of similar research with non-disabled children. We will also identify the practical implications of this research for classroom practice.

Background

Since 1980, we have been studying the learning difficulties of children with Down syndrome in order to develop ways of helping them to reach their full potential. It has become clear that the patterns of development and the processes involved are similar to those seen in many other children with learning difficulties within regular classrooms.

Our starting point was the study of reading skills in pre-school children with Down syndrome[1] after receiving a letter in 1979 describing the early reading progress of a child with Down syndrome and the effect that this seemed to have had on her intellectual development. This child was Sarah Duffen, hence the name of our Centre.

The letter was from Sarah’s father, Leslie and in it he described her exceptional development as follows.

Sarah began to learn to read at the age of 3 years 6 months. At 7 years she had a Griffiths DQ of 83 and a reading age of 9 years. At 11 years, she can read the following sentences with understanding: ‘The soloist was not in a convenient position for seeing everyone in his audience’. ‘Psychology is a science which seems to fascinate both the adult and the adolescent student’. She can also write such sentences, spelling all the words correctly. Sarah reads extensively for pleasure and has completed all but one year of her education within the normal school system.

As Sarah was born in 1968 this account was truly remarkable. One of us (SB) has an adopted daughter with Down syndrome, Roberta. She was born in 1969 so was only one year younger than Sarah. We were therefore
very familiar with the current literature and beliefs about the intellectual abilities of people with Down syndrome when we received Leslie’s letter. It was assumed that the condition always led to severe learning difficulty (in those days still described in the UK as severe subnormality) with IQ’s (Intelligence Quotient) or DQ’s (Developmental Quotient) below 45 and that learning to read was certainly beyond anyone with Down syndrome.

It was actually Leslie’s observations about the effect of reading on Sarah’s spoken language development that interested us most. He states

Sarah’s reading ability has considerably helped the development of her speech. The critical discovery was that Sarah read, remembered and later used, in the correct context, sentences that she was quite incapable of remembering when she just heard them.

The development of spoken language skills is considerably delayed in most young children with Down syndrome. In our view, words are the most effective vehicle for knowledge acquisition and therefore a key to mental ability, so that anything that might boost the children’s rate of language acquisition was worthy of study.

Leslie’s views were met with great scepticism by all the experts that he talked to when Sarah was a child, since his views contradicted conventional wisdom. It was considered that the language of children with Down syndrome was retarded because they lacked the intelligence to do any better. But what is intelligence?

We had a feeling that at least some of this argument was circular. If by intelligence we mean the ability to think, reason, remember and therefore to learn, then words and the child’s comprehension and use of speech would seem to us to be a critical tool for developing intelligence. Even if genes play some part in determining a child’s IQ (we prefer the term learning potential), any difficulty in mastering a first language would seem likely to hamper the expression of the child’s potential.

Research evidence
With a team of colleagues and research students at the University of Portsmouth, Elizabeth Woods, John MacDonald, Irene Broadley, Angela Byrne and Glynis Laws, we have conducted a variety of studies over the past 18 years that shed some light on these issues. For the purposes of drawing out the relevance of the work for understanding some of the reasons for learning difficulties in a wide range of children, we will describe our most recent research, some of which is still in progress. Our earlier studies are described in the references listed at the end of the article for those who wish to follow the development of our understanding and evidence on these issues [1-5].

In 1990, with John MacDonald and Irene Broadley, we embarked on a study of short-term memory development in children with Down syndrome. Our attention had been drawn to the fact that many children with learning difficulties, including those having difficulty with reading and number, show delays in the development of working memory skills [6].

In 1994, with Angela Byrne and John MacDonald, we set up a longitudinal study to follow the progress of reading development in children with Down syndrome in mainstream classes and two groups of typically developing mainstream children, slow readers and average readers - all in the same mainstream classes. We have just collected the fifth set of data for this study. We are interested in the reading progress of all the children and the way in which they are developing strategies for reading and spelling. We are also interested in the links between the children’s language skills, working memory skills and reading [7-8].

Research with typically developing children indicates that there are reciprocal relationships between these skills. Two large longitudinal studies, one in Wales and one in Cambridge, set up to study the factors which influence children’s reading acquisition have produced the same results. (These studies are reviewed in detail in [9].)

They both show that children who come to school with more advanced language knowledge learn to read faster in their first year than those with less language knowledge. They also show that children who have better working memory skills learn to read faster in their first year in school than those with poorer working memory skills.

In the second year in school, reading progress and the child’s level of reading skill begins to effect progress in language and short-term memory development. The children with the higher reading ages at the beginning of year two, show more progress in language
comprehension and in working memory skills during the year than those with lower reading ages at the beginning of the year. Our case studies of children with Down syndrome [5] and one longitudinal group [10] study show exactly the same beneficial effects of learning to read. Using data collected in the memory training study, those who are being taught to read show significant gains in memory spans and in language comprehension over a 4 year period when compared with a comparison group. The children with Down syndrome in the comparison group were not significantly different in cognitive ability 4 years earlier, but have not been taught to read.

Reading ability and the activity of reading is, in some way, accelerating the children's development of memory skills and their acquisition of language knowledge. Why should this be so?

**Reading and language**

The gains in language learning are probably the easiest to understand. Being able to read gives a child access to a whole world of new information and they will learn new vocabulary and some new grammatical constructions from print. Children's language learning usually proceeds with amazing ease. By 5 years of age, typically developing children have, on average, vocabularies of some 2,000 words. However, the biggest vocabulary explosion is between the ages of 7 and 16 years when children typically learn about 3,000 words each year. By 7 years most children in the UK are becoming usefully literate. Garton and Pratt, in their book “Learning to be Literate” [11], present a very clear discussion of the interactive effects of spoken language and literacy during development in the pre-school and school years.

However, there is considerable variation in the rate of speech and language development of children. Some children are late to begin talking and while they may seem to catch up, this is not always the case. Standardised tests may show that they are at least a year or more behind on knowledge of vocabulary and grammar when they start school. These children are often the slow readers. This turned out to be the case in our 1994 study. Though not identified as children with obvious learning difficulties at the time, the slow readers among the mainstream children were shown to be one year or more behind the average readers in their class on all the language comprehension measures that we used [7].

If their reading progress is initially being delayed by their speech and language knowledge, then this quickly becomes a vicious circle, as we know that rate of reading progress influences rate of acquisition of new vocabulary and grammar. New vocabulary equals new knowledge, so slower vocabulary learning means slower knowledge acquisition.

**Reading and working memory**

Working memory is the system that you use for the immediate processing of information. It consists of a central executive, where the processing is done, and two short-term memory stores. One memory store is called the visual-spatial scratch pad and this holds visual information long enough for you to process it for meaning. The other memory store is called the phonological loop and this system holds auditory information such as speech long enough for you to process it for meaning [9].

The phonological loop underpins a child’s verbal short-term memory ability (VSTM). The capacity of a child’s VSTM can be measured using digit span tasks. These are found in all standardised ability tests such as the British Ability Scales. Short-term memory spans increase with age during childhood. The average digit span of a five-year-old will be 3-4 digits and that of a 16-year-old will be 6-7 digits. (The digit span is the number of digits a child can remember and repeat in the correct order when he or she hears them spoken at the rate of 1 per second.) Research shows that the main reason for this growth is increasing efficiency at speech perception and speech production. The evidence is that verbal working memory is a speech-based system and a child’s span reflects his or her articulation rate. Typically, speech fluency goes up with age. This research is well reviewed in a recent article by Sue Gathercole if you wish to read it in more detail [12].

One of the reasons that a child's reading progress influences their working memory development is that learning about letter sounds and seeing words in print both sharpen a child's perception of sounds in words, so lead to faster speech perception. Children who are not progressing with their reading show delay in the development of their working memory i.e. digit span does not grow. Poor VSTM may lead to difficulty with processing spoken language in the classroom and in remembering instructions. Another factor influencing growth in VSTM is the child's explicit use of strategies such as rehearsal, silently or aloud, of material to be remembered. Children seem to become
proficient at rehearsal at about the time they become proficient in silent reading.

A child’s working memory performance has also been shown to influence spoken language development in a variety of other ways including speed of learning new vocabulary in pre-school and school age children. An excellent review of this research and its significance for teachers is to be found in a book entitled Working Memory and Language Development by Sue Gathercole and Alan Baddeley [9] written when they were both at the University of Cambridge. They are now at Bristol University. This book also provides an excellent review of reading development and the links between reading progress and working memory.

In a more recent review paper published this year, these authors argue that the phonological loop’s main function is as a language learning device [13]. Many mainstream children with reading comprehension difficulties and with number difficulties turn out to have poor working memory performance for their age, so working memory research is an important area to keep in touch with at present.

Memory training for children with Down syndrome
In our 1990 research project, we demonstrated that working memory performance could be significantly increased for children with Down syndrome by teaching the children memorising strategies [14]. Rehearsal games taught the children to use rehearsal in memory tasks. Grouping games taught children to use categorisation to improve their memory skills. However, unless the skills were consolidated and used, the memory gains were lost over the next three years [15].

Significantly, reading progress appeared to have an effect on maintaining and improving the memory span gains achieved by the memory games for this group of children. In 1995, four years after the training, the children with Down syndrome who had become readers in that time had continued to improved their memory spans, those who had not become readers, had lost the training gains [10]. This is the result that one would predict based on the studies of reading and memory in typically developing children.

Alphabetic versus logographic reading strategies
Current research on the strategies that children use as they learn to read indicates that children progress from a logographic stage, where they are remembering words by their visual patterns (sight vocabulary), to an alphabetic stage when they can sound out unfamiliar words using their knowledge of letter-sound correspondences (phonics). Writing and spelling activities helps progress to an alphabetic stage.

Children’s literacy progress will be delayed if they have difficulty in moving to alphabetic strategies. The most common reason for such difficulty will be poor auditory discrimination of sounds or poor phonological awareness (ability to discriminate the sound patterns within words).

Most primary teachers will be well aware of this and be making full use of games and activities to develop their children’s auditory discrimination and phonological awareness skills. They may not be aware that at the same time they will be helping working memory development.

In our 1994 research, when we compare the groups, our children with Down syndrome are having more difficulty mastering alphabetic strategies than the other two groups of mainstream children. Surprisingly after 2 years, the reading performance of the children with Down syndrome has progressed as much as that of slow readers - that is, in 1996 they were still not significantly different on a standardised reading test.

However, the children with Down syndrome were significantly worse on tests of alphabetic skills, so we conclude that they are maintaining their reading skills by relying on logographic, visual memory strategies [16]. However, as with all group data, the group comparisons conceal individual differences. Within the group, some children with Down syndrome were mastering alphabetic strategies. These children turned out to all have reading ages over 7 years. This would be the level of competence shown by typical readers when they begin to show alphabetic skills [9].

The mainstream children in the slow reader group, while significantly better at using alphabetic strategies than the children with Down syndrome, were significantly worse than the children who were average readers. While we interpret the poor alphabetic progress of the children with Down syndrome as a result of poor hearing and poor discrimination for speech sounds, we do not know the reason for the delay in the slow readers.
It may have surprised the alert reader to note that some of the children with Down syndrome are reading as well as some of the non-disabled children in their mainstream classes. In our experience, based on supporting many children with Down syndrome in mainstream classrooms, this is often the case. The other slow readers can benefit from being in small group instruction with the child with Down syndrome that can be arranged in the class by making full use of the learning support assistant.

What are the implications of this research?

The importance of speech and language
It highlights the way in which the development of mental abilities is a dynamic building process. Working memory function influences rate of vocabulary learning. Speech and language skills influence ongoing working memory development. Reading development is influenced by and influences growth in both areas. They have continuous reciprocal influences on each other - or in different terminology - progress in one “bootstraps” progress in another. Working memory influences speed of processing information and learning.

If a child does not learn to read, this will not only have the obvious disadvantage of denying him or her access to books and the obvious benefits of literacy, but may also slow up the development of the working memory system. It may also slow his or her vocabulary learning.

Many children with learning difficulties that become apparent in the primary classroom have subtle difficulties in auditory discrimination and speech processing. They will be less efficient than most children at learning from listening. Yet talk is the main mode of instruction.

Our children with Down syndrome have the same profile of difficulty, though will probably be more severely affected. For them and for all the other slow learners, we would recommend a two-pronged attack on the difficulty.

Firstly, to try to improve the underlying processing skills with sound games to improve auditory discrimination and phonological awareness, and memory games to improve memory spans.

Secondly, we would use teaching strategies which emphasise visual support for learning as much as possible. For example reading schemes like “Breakthrough to Literacy”, which use flashcard sets so that words are tangible and can be manipulated to build sentences that the child can then copy, can be helpful. This reduces the working memory load which will be required if the child has to write his ideas straight to paper.

Reading as a language activity
We would ask teachers to think of reading as a language teaching activity as our children with Down syndrome need to build up their grammar. They can learn grammar when they see it in a way they cannot when they only hear it.

While the grammar learning difficulties they have may be more severe than for most other children, it is only a matter of degree. The pattern is the same for other children with speech and language delay and for those with hearing loss.

A child’s mastery of grammar will be demonstrated when he or she is asked to write a story. This forces the child to try to put their ideas into grammatically correct sentences. It is a very important activity in all primary classrooms - and this is why we encourage a language approach to reading. We suggest that the child spends time in writing about the things that he or she does or is going to do, every day. The child will choose from flashcards and build sentences with them first - then write.

In this way, the child is given the opportunity to maximise his or her development of language for everyday communication. This method will also maximise success in reading comprehension, as the child will find it easy to read with comprehension about activities he or she has participated in. Diaries and project books made in this way can be taken home and shared with the family.

We would always build confidence by teaching a small sight vocabulary, including family names, when a child begins reading. (We do this at 3 years of age or even earlier with children with Down syndrome.) First we teach a sight vocabulary that can be used to build short, grammatically correct sentences so that the child can make diaries about his or her own daily experiences - and understand that we read for meaning. Once the child has a forty to fifty word sight vocabulary and can use it in this way, we then use the words the child can already read with confidence to teach
them about letter sounds and the use of alphabetic skills.

We find many children in classrooms who have learned letter-sound correspondences - so can sound out letters and even blends correctly as a game - but can not use this knowledge to sound out a word for decoding a new word when reading or for spelling when writing. Research studies suggest that the need to spell when writing drives consolidation and use of alphabetic knowledge, so it can be counterproductive to use the flashcard words to copy for sentence building for too long. The child needs to move to trying to spell familiar words without the prompt, once confidence is building.

Old-fashioned practice is the key to learning, particularly for the slow learners - so word lists sent home for practice at reading, writing and spelling can be a great help for the child.

**Visual supports**
This approach to reading emphasises the importance of visual support for learning and we would extend this principle across the curriculum. Visual support such as number strips and digit cards can also be helpful for number progress.

**Using computers**
Technology has revolutionised the learning opportunities for the slower learning child. There is an ever-growing range of excellent software for special needs, though in our experience, not all mainstream teachers are yet fully aware of what is available and software reviews will be a regular feature of this journal.

The computer has many advantages for the less able child. It presents information visually and can offer lots of fun practice at all basic learning for reading, number etc. and for writing. It is under the child's control and therefore the learning progresses at the child's pace. The child can be an independent learner with the computer. Finally, but maybe most importantly, the computer does not get impatient or irritated!

We would take these same principles and apply them when working with older children with learning difficulties in secondary education.

**Conclusions**
We have drawn attention to the recent and ongoing work which demonstrates that for all children, mental abilities develop in a reciprocal and interactive way. Central to this development is the language system in the early years, and then reading progress. The efficiency of the working memory system, used for all immediate processing of information will be influenced by language and literacy skills.

Therefore a focus on language, working memory and literacy in the curriculum is essential for all slow learners in the classroom including children with Down syndrome.

In this article we have tried to provide an overview and to explain the key issues. Readers wishing to explore the research and its relevance to classroom practice in more depth will find more information in the references provided. We provide a range of one and two day workshops at the Sarah Duffen Centre for parents and for professionals at which we can go into more detail on the practical application of these findings in order to help children at home and at school.

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References


AN INTELLECTUAL WITH LEARNING DISABILITIES

Ann Nunn

Editor's Note: Simon does not have Down syndrome, he has another genetically determined disability - Cri du Chat syndrome. However, Simon has benefited greatly from being taught to read by his parents, despite having a range of difficulties that meant the professionals advising the Nunns thought reading was way beyond his capabilities.

The approach Ann Nunn describes uses similar principles to the methods we advocate. She taught sight vocabulary and phonics over time. She always selected vocabulary for the topics that Simon was interested in and made his own books and diaries. We know that the majority of children like Simon - labelled "severe learning difficulty" - still do not have appropriate reading instruction. Ann Nunn, like Leslie Duffen when he first wrote to me about Sarah's progress (see first article in this issue), stresses that Simon's intellectual capacity was developed by the teaching and experiences he received - and that being able to learn from books opened up a whole world of information for him.

The interest, determination, dedication and vision, shown in the teaching the physically disabled to progress in walking etc with tremendous input from the immediate family, is rarely apparent with those with learning disabilities, as my own experience has shown.

Our son Simon is an Intellectual with Learning Difficulties. His intelligence has been developed by education, by stimulation and stretching, and by encouraging his confidence in his mental abilities.

Simon was born thirty years ago. My husband told the doctor something was wrong and at nine months the genetic syndrome Cri du Chat was diagnosed. Within one week of diagnosis [1,2] we had five requests to see doctors in London. We were then in North Essex - no offer of transport, no sympathy, no offer of counselling. Were we going to be guinea pigs?

We did not attend.

Then one day, I saw Simon looking at a grocery box on the floor. He seemed to be wondering what the markings were all about. I used to draw his favourite pictures, truckloads of pipes or hymnbooks or a garage, (a bit repetitive) and label the relevant parts with words. So, I started to teach him the alphabet, slowly, with illustrations personally relevant to him, each letter accompanied by words and pictures on posters. We began to work. "A" was for Angel, "C" is for cab, "G" is for garage, "P" for pipe etc. At that time, I felt this to be a pointless operation, but nevertheless after the lesson, stuck each poster on his bedroom wall. He was nearly five years old and used to wake at 3am to beat up the furniture and tear the bedding and wallpaper.

However, I began to realise that during this early morning destruction and chaos, he was also studying the posters, and there was evidence that he had learned what they taught! So, I began to teach him to read, again using the words that were relevant to him personally. I used these in combination with "keywords" that were listed at the back of the "Ladybird" Key Reading Books. We never actually used these Ladybird books for reading because the text was not relevant to him [3]. At every session, I would paint a hasty popular poster, illustrating our new words.

By the age of six and half years, he had reached the reading stage of the last reading book - Book Nine. Even for a normal child this would be very satisfactory, but so much more for one so handicapped.
At this stage, I discovered to my amazement, that I had used two recommended methods, phonetics and word analysis. Simon loved spelling and experimenting with words. He had a set of plastic letters that he would play with on the floor. He and his dad used to spend hours playing with different combinations of letters. For example - wear, where and ware. Also, taking a group of letters and changing the first letter in bear, dear, ear, fear, gear etc.

A natural progression was to keep a written and illustrated record - "Fun Books" or diaries of places visited, about books read, interesting people he had met, ranging from road builders to civil engineers, and from museums to traction engine rallies. His interests are wide and varied, and he now commands a vast knowledge on many subjects and is politically and socially aware, as well as having a flair for languages. His personal library is huge, and we supplement this with a fortnightly visit to the library, choosing six adult books and six children’s books on a wide range of subjects. Investigations, questions and projects played a major part in Simon’s development and he has shown a remarkable gift for storing information.

It has always proved most fruitful to build upon his interests and/or to encourage his self-respect by saying “You are a clever bloke, you can easily do this!” In fact he is an extremely intelligent person, but this has only become apparent through developing and teaching and building on his interests.

At the age of ten, we received a visit from an Educational Psychologist. She did not believe it was possible for Simon to read, so, to convince her, I handed to Simon a piece of paper on which was written, “Please will you fetch me an orange?” To her amazement, he did just this, and thereafter we could enter a more sensible dialogue with the lady.

Following this visit, Simon started a local special school for a few mornings a week. There he enjoyed chatting to the teachers, but otherwise was bored. They would all sit round a table to play a game, and just as they were about to begin, Simon would get up and go to find a book to read. I got to know the other school children, and realised that a large proportion of them would have been capable of learning to read like Simon had, given the opportunity. But the teachers wrote it off as an impossibility, and that there was “not enough” staff anyway. Actually, they could have done it with the right approach, if they had wanted to, since there was in fact a very high staff - pupil ratio. They first had to believe that it was possible, then enquire how to go about it, and then to be prepared to free one member of staff permanently, for one-to-one sessions. However, at the end of this period at school, the Educational Psychologist confessed that Simon had not been placed in the right school for him and that it was probably doing him more harm than good.

Richard, a friend who was an actor, was due to play the leading role in “The Taming of the Shrew” and we decided to take Simon to see it. Richard told him all about the plot and the theatre and about putting on the play, but doubted whether Simon could behave well for that length of time or to concentrate or be sufficiently interested. Meanwhile we gave him a thorough drilling in socially acceptable behaviour in a theatre. To our great surprise and delight, Simon behaved very well and was totally engrossed, and even laughed at the most subtle jokes and innuendoes that many people had missed. However, we later took him to a concert, and forgot to drill him in the correct behaviour expected. It was a very embarrassing experience and I could have crawled under my chair!
I came to realise that Education is - “The communication of enthusiasm.” When we think back to the school subjects in which we had done badly, we can identify that teacher enthusiasm was probably an ingredient that was lacking. Tolstoy had some interesting things to say about this method of education [4, p. 65].

Very much later, I heard about a professor, now in Jerusalem, who had to teach the children who had survived the concentration camps. At first he found it utterly impossible to get through to them using conventional teaching methods. He concluded that the fault was not with the children, but with him and that he would have to change. With this attitude, he succeeded in his task, and then went on to teach “retarded” children and the products of his labour usually went on to higher education. His theory is that “Intelligence Increases with Education” and his methods had included bombarding, stimulating and stretching his students. My methods of teaching Simon very much concur with the theories of the professor. A one-to-one relationship and a close friendship enable me to use his own interests and get through to him.

I would like to put in a word to any readers who are professional carers. Do not be too hard on parents if they do not attend your meetings etc. Their lives and those of their families, are more devastated and blighted by their experiences than anyone can know. Also, a word to friends and acquaintances of such families - do not let them become isolated. It is a natural consequence to become isolated, but do not let it happen. Another caution, most parents in our position, love their children passionately. They may not want you to talk about what is wrong with their child, and will pick up on any negative thoughts. They often only want to hear positive things, and then they will share their treasure with you.

The results we achieved are so incredibly successful, that our son is now an “Intellectual with Learning Disabilities.” He has an avid appetite for books, a huge personal library, is politically and socially aware and has a sparkling sense of humour. He loves to type out stories on the computer. Teaching him was an enormously rewarding experience. However we remain a socially handicapped family because Simon can be very disruptive and has difficulties in mixing in the normal social scene. But being able to learn to read has opened so many doors to him that his life is full of interest.

It is of great concern to me that I see so many people with learning difficulties living a “half life” - under achieved - unstretched intellectually - underdeveloped and unable to read, albeit well trained in social skills! I would like to get my vision through to several groups of people. The first group of people is the parents. The second group of people are in the “system.” How can I get this through to the policy makers, the theorists, the educators and the accountants?

References
MULTI-NUTRIENT FORMULAS AND OTHER SUBSTANCES AS THERAPIES FOR DOWN SYNDROME: AN OVERVIEW

Ben Sacks and Frank Buckley

Theories advocating the supplementation of various vitamins, minerals, amino acids, enzymes, hormones and the drug Piracetam, in various quantities, are sources of considerable controversy within the Down syndrome community. Although vitamin and mineral supplements have been proposed sporadically since the 1940s, little scientific evidence has been accumulated that suggests that their use, or the use of any single ingredient, has any benefit as a general therapy for individuals with Down syndrome. Moreover, research into the general effects of vitamins and minerals in humans, and particularly the long-term effects of supplementation over and above average dietary requirements, is still progressing. An overview of supplementation theories in Down syndrome, and some of the issues that are raised by the advocates of such theories as well as some associated issues is presented.

Keywords: Down syndrome, health, nutrition, vitamins, minerals, amino acids, Piracetam, unorthodox treatments

1. Introduction

Claims for the usefulness of multi-nutrient formulations in improving or alleviating certain features of Down syndrome are not new. Neither are such claims for such formulations restricted to Down syndrome. Claims of benefits for individuals with other disabling conditions have been made as frequently [1]. It would be quite remarkable if similar multi-nutrient formulations, that conveniently ‘side-step’ the rigorous tests required of medications, should be shown to be beneficial in a range of conditions as diverse as Down syndrome, autism, fragile X syndrome, attention deficit disorder, Parkinson’s disease and cancer.

Nor is the controversy that is ignited by such claims new. Despite lacking rigorous scientific examination, such ‘treatments’ attract committed adherents who become convinced that they observe clear ‘benefits’ and that these are attributable to the ‘treatments’. Proponents of such therapies claim that observations of ‘improvements’ in individual cases provide evidence of the therapies’ usefulness. Meanwhile, others question the scientific validity of such claims and insist that anecdotal observations are insufficient to demonstrate general usefulness.

Some proponents of unproven therapies do seek to support their claims with ‘scientific’ rationales. In the case of multi-nutrient formulations and Down syndrome, these rationales rely on assertions about the mechanisms and effects of the various biochemical processes in which nutrients are, or may be, involved. As might be expected, many of these start with the effects that the presence of the additional chromosome 21 has, or may have, and then suggest that the multi-nutrient formulations (or constituent ingredients) ‘correct’ or ‘compensate’ for these effects.

These rationales usually appear to be ‘scientific’, and, indeed, some seem quite plausible. However, simply because assertions appear to have a scientific basis, does not mean that they are necessarily firmly grounded in scientific fact, nor that the treatments are of any use. Theories are only confirmed as fact through scientific observations under controlled circumstances. The only approach to the difficult problem of ascertaining the usefulness of treatments is to rely upon the evidence provided by properly conducted clinical trials. Unfortunately, some proponents of these formulations are quite prepared to
make extensive therapeutic claims without any supporting clinical evidence.

Moreover, some proponents seem inclined to try and support their position with speculation about the motives, abilities or even ‘hidden agendas’ of those who disagree with them. We were recently forwarded a copy of correspondence from one proponent regarding an article (by a respected medical professional) that was critical of multi-nutrient formulations. Despite the proponent also being an ‘academic’ scientist (who therefore should have known better), the response was based more on vitriolic personal attack than rational debate. When the arguments ‘degenerate’ to such tactics, they do not assist anyone.

In this article, we hope to outline some of the background and some of the issues involved in this debate. We have referenced many of our statements fairly thoroughly for those wishing to investigate further. As far as possible, we have tried to keep the article as accessible as possible to an audience with a variety of backgrounds, and where we think a reference is similarly accessible, we have marked it with an asterisk (*). Also, where possible, we have provided references to material that is freely accessible on the Internet.

2. Background to ‘nutrition therapies’

2.1 Early speculations
Speculation as to the chromosomal difference in Down syndrome was made in the 1930s and suggestions of the possible amelioration of the effects of Down syndrome with nutritional substances can be traced back nearly as far. Various therapies involving vitamins and minerals have been advocated as useful in Down syndrome, and other conditions resulting in mental disabilities, since the 1940s and 1950s. Henry Turlkel advocated one such therapy from 1940 [2]. Described as an ‘orthomolecular therapy’ [3], his “U series” contained around 50 substances and claims for its effects included “straightening of the first finger, regression of premature ageing, improvement in IQ, and improvement of aesthetic appearances” [2]. In the UK, Rex Brinkworth suggested a similar formulation some 20 years ago [4].

2.2 Developments in the 1980s & 1990s
Further interest in such therapies was rekindled during the 1980s when Ruth Harrell and colleagues reported that vitamin, mineral and thyroid hormone supplementation improved IQ scores and caused “physical changes toward normal” in a group of mentally deficient children [5]. However, this was a poor study, and subsequent attempts to replicate its findings failed. Yet, following these claims, a number of parents and doctors adopted the Harrell protocol.

2.2.1 HAP CAPS
A derivative of Turlkel’s “U series” (called “HAP CAPS”), developed during the 1980s, is currently promoted by Dr. Jack Warner and colleagues through “The Warner Clinic”. It contains a variety of vitamins and minerals [6]. There have been no structured studies of the effects of “HAP CAPS”. Warner claims that records on the 4,200 ‘patients’ who have received “HAP CAPS” are kept, yet admits that no attempt has been made to analyse them in any systematic way. Neither have these records been made available for others to analyse. Yet, he and his ‘clinic’ continue to promote this formulation with unsupported claims, such as the formulation being responsible for speech improvements, the tightening of ligaments, attaining ‘normal’ height, and even curing cardiac defects in developing babies when administered to pregnant women. It is also claimed that patients ‘regress’ to their previous state if the tablets are discontinued. At a recent presentation by Warner and colleagues in London, the few medical professionals in the audience voiced considerable criticism of Warner’s claims, pointing out that evidence was required. Moreover, they pointed out that some ‘results’ were exceedingly unlikely to have been influenced by the formulation. (A report from this conference from two parents who attended appears in this issue on pages 84-85).

2.2.2 “Nutrivene-D” and “MSB”
In the late 1980s, Dixie Lawrence Tafoya, the mother of a child with Down syndrome, began investigating and subsequently modifying Turlkel’s formula. A supplement similar to her formula was marketed by “Nutri-Chem Labs” in Canada as “MSB” in the early 1990s. In 1996, Lawrence started promoting a formula called “Nutrivene-D”, manufactured by International Nutrition Inc. in the USA. A non-profit company was established, called the Trisomy 21 Research Foundation and it set up a “Scientific Advisory Committee” which reportedly controls modifications to the “Nutrivene-D” formula (though not the MSB formula).
Television programmes, broadcast in the US during the past few years, have drawn considerable attention to these formulas [e.g. 7,8]. Both of these programmes included claims from parents who were using these formulations that they were having improvement on their children’s cognitive and physical development. Similar claims are propounded through various Internet sites, including ‘before and after’ pictures and glowing testimonials, and through seminars.

### 2.3 Cautionary reactions to recent developments

Warnings about these various formulations’ efficacy and safety being unproven have been issued by national Down syndrome organisations and respected professional bodies in the USA: The National Down Syndrome Congress (USA) has issued position statements on “HAP CAPS”, “Megavitamins”, and the drug Piracetam (see below). The statement on Piracetam concluded that “without the benefit of studies and research information on the usefulness, effect and risks of Piracetam we cannot recommend its use at this time.” Both statements on vitamin, mineral and amino acid formulations concluded that:

*I. To-date, no vitamin or mineral nutritional supplement is known that will alter significantly the intelligence, physical characteristics or behavioural features of Down syndrome and, thus, none are supported by the National Down Syndrome Congress.*

*II. Any substance that is claimed to significantly affect intelligence must be carefully evaluated with control individuals utilised and multiple variables measured such as thyroid function, other nutritional substances being taken, stimulation and general state of health.*

*III. Certain vitamin supplements are potentially toxic and can alter liver function. Vitamin A in excess can cause neurologic and dermatologic abnormalities. Vitamin C in excess can cause urinary tract irritation and frequency. Long-term effects of megavitamin therapy are not known.*

*IV. Metabolism of cells in persons with Down syndrome may indeed be altered but, to-date, no specific vitamin or mineral regimen has been found in any way to ameliorate the features of Down syndrome as noted before.*

*V. Claims made by certain programs that particular vitamins ‘relieve’, ‘improve’, ‘promote’, ‘delay’ or ‘aid’ aspects of Down syndrome are not scientifically proven in persons with Down syndrome.” [9*,10*]

In 1996, the American College of Medical Genetics stated that it was not aware of any scientific proof that treatment with amino acids supplements and Piracetam could improve cognitive function in children with Down syndrome [11*]. During 1997, the National Down Syndrome Society (USA) issued a position statement that stated:

*The administration of the vitamin related therapies — e.g. the vitamin/mineral/alpha acid/hormone/enzyme combination, has not been shown to be of benefit in a controlled trial, that the rationale advanced for these therapies is unproven, and that the previous use of these therapies has not produced any scientifically validated significant results. Moreover, the long term effects of chronic administration of many of the ingredients in these preparations are unknown. Despite the large sums of money which concerned parents have spent for such treatments in the hope that the conditions of their child with Down syndrome would be bettered, there is no evidence that any such benefit has been produced.” [12*]

Other Down syndrome organisations around the world have also issued similar position statements. Similarly, respected professionals involved in the care of people with Down syndrome, and respected professionals involved in research, have cautioned parents and professionals against the use of these various formulations, old and new [e.g. 13,14,15*,16,17,18].

Nonetheless, the publicity, various promotions, and anecdotal testimonies to these formulations, are inviting to parents anxious to help their children, and many have chosen to use them. Advocates of these formulations estimated 12,000 people with Down syndrome were receiving “some form of specialised supplement” world-wide in 1996 [19]. It is understandable that parents are tempted to try a therapy that appears to hold promise, particularly when assured that they are not harmful, and when associated with the various ‘positive’ connotations surrounding vitamins and minerals [20*]:

*“Told that the nutritional therapies can’t hurt and might help, many parents decide that the therapies are ‘worth a try’. Also, with so much research in Down syndrome focusing on prenatal testing or presenile dementia, many parents feel abandoned by the medical*
establishment. For these parents, the supplement promoters seem to be the only ones interested in 'ending the implications of Down syndrome', as one newsletter puts it."

3. The speculation

The manufacturers do not, themselves, explicitly promote these multi-nutrient formulations as 'treatments'. This avoids legislative definitions of medicines (and therefore the controls that accompany substances being defined as 'drugs'). However, the manufacturers do make some statements about Down syndrome, which we presume they intend readers to relate to their formulations. Moreover, the advocates of 'targeted nutritional intervention', do make various statements about the theories behind these formulations.

3.1 General claims of nutritional deficiencies

It is suggested that individuals with Down syndrome are deficient in certain nutrients. There is no clear evidence to support this statement. It should also be noted, that, in general, nutritional deficiencies have severe, and therefore clear, consequences. These are not apparent in the vast majority of individuals with Down syndrome consuming a reasonable diet.

3.1.1 Ascertaining general nutritional deficiencies

Unfortunately, many of the reports of deficiencies have a number of methodological problems that raise questions about their validity as reliable indications of the general nutritional status of individuals with Down syndrome. Many involve small samples, some only examine individuals living in institutions, and some utilise measures that are questionable.

Many variables need to be considered when investigating the nutritional status of any given population. Ideally, in addition to blood or serum levels, these should include detailed measures of dietary intake, and the levels 'stored' elsewhere in the body.

3.1.2 Vitamins

Deficiencies of vitamin A [21,22], vitamin B12 [23] and vitamin C [24] in individuals with Down syndrome have been reported. Other studies have failed to provide evidence of deficiencies in vitamin A [25,26,27], vitamin B12 [28], or vitamin D [29].

3.1.3 Minerals

A considerable number of studies have looked at the role of zinc in Down syndrome. Serum levels of zinc have been reported as below normal [30,31,32,33], as well as plasma levels [34,35,36] and whole blood levels [24]. One study, however, did not find a general deficiency [37].

Whole blood levels and plasma levels of selenium have also been reported to be below normal in children and adults with Down syndrome [38,39]. However, a larger study failed to observe lower plasma levels of selenium in children or adults with Down syndrome [40]. It did note higher levels of selenium in the erythrocytes of children with Down syndrome and that these children reached adult levels of selenium in the erythrocytes earlier than the control group. There was no difference in levels of selenium in the erythrocytes of adults with Down syndrome and the control group.

3.1.4 Amino acids

Imbalances in amino acid levels have been claimed in adults with Down syndrome [41]. Lejeune and others [42] suggested that supplemental amino acids would balance the blood levels, making the biochemical workings of the body normal. A recent study of 22 children with Down syndrome did find slightly raised plasma concentrations of one amino acid. However, it found no other imbalances [43]. It concluded, "that when studied under carefully controlled conditions there are no differences in amino acid concentrations between control children and Down syndrome patients that would justify dietary supplementation, as recommended by Professor Lejeune."

3.2 Theories of ‘imbalances’

3.2.1 Superoxide dismutase and reactive oxygen species

The roles of reactive oxygen species in numerous processes in living organisms has been, and continues to be, an area of considerable research. Much of it is complicated and not yet fully understood. Molecules called reactive oxygen species are present in all human beings. They arise from natural biochemical processes in all aerobic organisms. A very common reactive oxygen species in human metabolism is the 'radical', superoxide - a by-product of ordinary respiratory processes. Superoxide molecules are reduced to hydrogen peroxide by one of a few enzymes, called the superoxide dismutases, depending on location. Hydrogen peroxide is a 'non-radical' reactive oxygen

species and it reduced to water by either catalase or glutathione peroxidase, again depending on location. One of the gene sequences on chromosome 21 is involved in the production of one of the SOD enzymes - copper-zinc superoxide dismutase (SOD1). Proponents of nutritional formulations suggest that the ‘overexpression’ of SOD1 requires treatment with antioxidant vitamins based on an argument that runs much as follows:

(a) the additional copy of chromosome 21 in individuals with Down syndrome leads to elevated levels of the SOD1 enzyme, and
(b) elevated levels of the SOD1 enzyme increase the reduction of reactive oxygen species to hydrogen peroxide, and
(c) without corresponding increases in levels of glutathione peroxidase and/or catalase to break down hydrogen peroxide, levels of hydrogen peroxide remain elevated, and
(d) the elevated levels of hydrogen peroxide lead (indirectly) to elevated levels of damage (or, ‘oxidative stress’) to cells and DNA, and
(e) this additional damage leads to premature ageing and dementia (and, according to some more excited advocates, mental retardation), and
(f) that antioxidant vitamins can intervene in this process by ‘mopping up’ the ‘loose’ reactive oxygen species.

As a theory, this is plausible but unproven. There are a number of studies indicating increased levels of SOD1 in individuals with Down syndrome in blood cells [44,45,46,47,48,49,50,51,52,53]. Levels in other tissues have not been determined. However, a number of these studies have indicated that there may be mechanisms that compensate for the effects of increased SOD1 levels (in blood cells) by elevating levels of glutathione peroxidase and/or catalase to meet the demand for reducing hydrogen peroxide [44,45,46,47,49,50,53,54] or through interaction with other superoxide dismutases enzymes [47]. There is no direct evidence that elevated levels of SOD1 are causing increases in levels of hydrogen peroxide.

Furthermore, it is not clear whether supplementation with high doses of antioxidant vitamins would be an effective intervention. Antioxidants have been a particular source of hope for beneficial effects, both for general proponents of vitamins’ curative or preventative effects, and for proponents of nutritional supplementation in Down syndrome. Although epidemiological studies suggest protective effects from diets that are rich in antioxidants, clinical trials have so far not been successful [55,56,57,58,59,60]. We therefore find it difficult to agree that this argument provides “the logic behind using additional antioxidants in Down syndrome” [61].

3.2.2 Cystathionine beta-synthase
Another gene on chromosome 21 is involved in the production of the multifunctional enzyme, cystathionine beta-synthase. It is suggested that the cystathionine beta-synthase is overexpressed in individuals with Down syndrome, and that this ‘over-stimulates’ the reaction of homocysteine with serine to form cystathionine. It is further suggested that this leads to the ‘disruption’ of a number of other biochemical pathways and (among other things) causes a depletion of the levels of folate. One study has indicated elevated cystathionine beta-synthase levels [62] and two have not [63,64]. The US Food and Drug Administration has funded a study to examine some of these issues which should be completed in 1999.

4. Concerns

4.1 The lack of scientific evidence of efficacy or safety
One of the problems with evaluating treatments that include anything up to 50 different ingredients is identifying which component is doing what. It is quite conceivable that some of the ingredients are doing something useful, while others are not. Well-constructed clinical trials of the effects of particular substances are required if we are to significantly advance our understanding of these theories. Such trials would need to be based on reasonable hypotheses, double-blind in structure, with adequate controls and be amenable to appropriate statistical analysis.

4.1.1 Studies of individual nutrient supplementation
Studies of the effects on individuals with Down syndrome of supplementation with vitamin B6 have shown no improvement and side effects were reported [65,66,67]. There is some evidence that zinc plays a role in thyroid function and the wider immune system [36,68,69,70,71]. Studies on the effects of zinc supplementation have reported reduced infections [36,72] though another failed to find a correlation between zinc deficiency and
the recurrence or intensity of infections [35]. Lockitch et al. [33] observed only fewer instances of cough and fever and no changes in other clinical variables in a double-blinded crossover trial of zinc supplementation. They concluded, “Long-term, low-dose oral zinc supplementation to improve depressed immune response or to decrease infections in children with Down syndrome cannot be recommended.”

Selenium supplementation has been reported to lower infection rates [73] and to influence immune system function in people with Down syndrome [74]. It has also been postulated that selenium supplementation may enhance the activity of glutathione peroxidase in erythrocytes and perhaps lead to improved protection against reactive oxygen species (see discussion of SOD1, above). However, selenium supplementation has been observed to decrease glutathione peroxidase in erythrocytes [73], leading the researchers to conclude that “Until we gain more knowledge about the biological functions of selenium in man and the role of oxygen metabolism in the development of presenile dementia in Down syndrome, universal selenium supplementation in Down syndrome patients cannot be recommended.”

Tryptophan (an amino acid) is included in relatively large doses in both the ‘day time’ and the ‘night’ formulas in Nutrivene-D. Tryptophan is used in a large number of metabolic processes including the synthesis of serotonin. However, studies to see if supplementation with 5-hydroxytryptophan (which the body uses to make serotonin) produced any apparent benefits were negative [75,76,77].

4.1.2 Studies of multi-nutrient supplementation
Considerable scientific effort has been spent investigating the effects of individual supplements and high-dose multivitamin supplements. As commented elsewhere [14]: “…glowing reports of the use of supplementary multivitamins and nutrients to overcome malabsorption in a group of Down syndrome children are published every so often, and such reports require many hours of investigators’ time to sort out the evidence and determine whether there is any underlying validity to these claims. What has happened is that after an enormous amount of research effort on the part of many physicians and families, the indiscriminate use of a standard cocktail of vitamins and minerals for all children with Down syndrome is discredited by double-blind studies, and the Down syndrome community sits back waiting for the next dramatic claim of miraculous vitamin therapy to pop up.”

Various studies investigated the claims that earlier multivitamin preparations were beneficial to individuals with Down syndrome during the 1960s, 1970s and 1980s. As Mary Coleman, a respected paediatrician and researcher, has summarised [78*]:

“Because of the claims of Haubold et al. [79], Turkel [2,3] and Harrell et al. [5] and because physicians understood so little about metabolism in Down syndrome and hoped that children with Down syndrome perhaps could be helped, an enormous amount of time and energy was spent at university research centers checking these claims. Studies were undertaken, using placebo, double-blind and other scientific techniques comparing children receiving these therapies to untreated controls, by White and Kaplitz (1964) [80], Bumbalo et al (1964) [81], Bremer (1975) [82], Hitzig (1975), Coburn et al. (1983) [83], Ellman et al. (1984) [84], Smith et al. (1984) [85], Menolascino et al. (1989) [86] and Bidder et al. (1989) [87]. The controlled studies were uniformly negative finding no difference between the treated and untreated children, except for the complex Bidder study which documented an actual decrease in developmental progress and various side effects of the multivitamins and minerals. No study that adhered to even minimal scientific methods documented any definite improvement or even suggestive trends in intelligence, speech or language, neuromotor function, height or health. Preuss et al. [88*] reviewed the literature in 1989 and flatly stated that indiscriminate multivitamin therapy was not useful in Down syndrome.”

4.2 Use of the drug ‘Piracetam’
Although not a nutrient, Piracetam is often recommended as ‘part’ of ‘targeted nutritional intervention’. Advocates claim that “Piracetam enhances communication between the right and left hemispheres of the brain, a critical aspect of information processing, which is the foundation of learning and remembering, and is an integral step in both understanding spoken communication and formulating speech.” [19] This statement is not supported by direct evidence of any kind.

Piracetam is a member of a family of structurally-similar compounds often referred to as ‘nootropics’. The nootropic racetams’ biochemical actions and their effects on
seizures, cognition and memory (to name a few) have been studied since 1965. However, no commonly accepted mechanism of action has yet been established, and clinical uses of the racetams are limited [89].

The only reported study that we are aware of that involves individuals with Down syndrome was not blinded and not controlled [90]. The manufacturer of Piracetam does not encourage its use in individuals with Down syndrome and does not intend to pursue research into the drug's use in Down syndrome. However, introductory studies of the use of Piracetam in Down syndrome are taking place in North America. A study in Canada was completed in April of this year, and should be reported on some time in the next year.

Though not considered particularly serious in short-term clinical use, common side effects of Piracetam are diarrhoea, weight gain, depression and insomnia. The consequences of the long-term use of Piracetam are unknown but problems can occur in individuals who have been taking Piracetam if it is withdrawn abruptly.

4.3 Misleading promotions

Proponents of unorthodox therapies seem prone to inaccurate statements and unsupported claims of efficacy.

4.3.1 Incorrect or misleading statements

It should be noted that the manufacturers do not claim that their concoctions are ‘treatments’ per se and that this avoids the legal definition of a ‘medicine’ in some countries. However, the manufacturers seem content to postulate theories on their web sites in the hope readers will perceive there to be positive benefits from their products. For example, statements on one manufacturer’s web site, such as “many children with Down syndrome suffer from malabsorption, celiac disease and lactose intolerance”, “all nutrient needs may not be met in the diet alone” and “the excess activity of superoxide dismutase may be very damaging” [91] are exaggerations or speculations or both. In our opinion, they are unjustifiably alarming, given current scientific knowledge.

Even more misleading is the claim (on another manufacturer’s web site) that “This extra or ‘overexpressed’ chromosome causes the depletion of body stores of antioxidants, amino acids, digestive enzymes, and other essential nutrients. Consequently, metabolism, growth, and development patterns are negatively impacted in individuals with Down Syndrome.” [92] This manufacturer goes on to state that “Targeted Nutrition Intervention (TNI), is the replenishment of the depleted stores of essential nutrients in very specific and targeted amounts that may possibly reduce the effects of the metabolic imbalance” (our emphasis). This sounds ‘scientific’ and precise (indeed the manufacturer claims that their supplement is “the most technologically advanced formula for Down Syndrome”), yet, again, these statements do not stand up to serious scientific scrutiny.

Other advocates are less restrained than the manufacturers with incredible unsubstantiated claims for the effectiveness of these formulas [19]:

“The use of Targeted Nutritional Intervention in patients with Down syndrome may help relieve and/or prevent many of the disabling effects of Trisomy 21, including mental retardation and chronic illness.”

They also seem quite content to offer confident unsubstantiated reassurances about the safety of these formulations:

“Targeted Nutritional Intervention, in the form of Nutrivene-D, when properly administered, IS definitely safe. The ingredients found in this supplement are available through dietary sources - the foods your child eats. Sadly, it is impossible for anyone to adequately enforce a diet to insure that all nutritional needs are being met. It is not harmful to give your child with DS Nutrivene-D.” [19]

4.3.2 Misrepresentations of Down syndrome

Perhaps the most disconcerting statements made in support of nutritional supplementation are those that misrepresent Down syndrome. Some advocates of nutritional supplementation seem to believe the outlook for children with Down syndrome is extremely bleak. We have witnessed numerous claims such as Down syndrome is a “progressive, metabolic, degenerative disease that if left untreated, would lead to poor health, mental retardation and ultimately premature death” [cited in 20]. These are at best mistaken or, at worst, deliberate attempts to mislead.

It is well known that individuals with Down syndrome are faced with a number of medical and cognitive challenges. However, despite these difficulties, it is wrong to assume that
the outlook for people with Down syndrome is bleak. Indeed, in many of the world’s societies, the outlook has never been more positive. Advances in medical care, effective developmental and educational interventions, and opportunities to learn, work and live in ‘normal’ social environments are helping them to overcome many of these challenges and to lead more independent and fulfilling lives than ever before. Many of the most significant advances have resulted from general scientific advancements that are not specific to Down syndrome such as modern cardiac surgery and the development of antibiotics. Other advances continue to be made at an increasing rate.

One wonders why some advocates of these therapies make such misrepresentations. If some people using these formulations have misconceptions about the potential of children with Down syndrome, then it would be of little surprise to hear startling anecdotal claims that these ‘treatments’ have surprising effects. Meanwhile, the fact that children not on these supplements are making similar progress is frequently overlooked.

Unfortunately, as noted elsewhere, “This tactic tends to prey mostly on the parents of infants and young children with Down syndrome, who are most vulnerable to the suggestion that they might be bad or neglectful parents if they don’t give their children these products.” [20]

4.4 Perspectives on nutrients
“The mystique, the magic, the allure of vitamins have fascinated people from the time the word was coined in 1912. Undeniably, the micronutrients produced miraculous cures in cases of gross deficiency diseases. These wonders inspired speculation about vitamins’ other health-giving and health-preserving actions, speculation built on public announcements about the role of vitamins in human nutrition. In our consumer culture, vitamins became a symbol of the benefits of science available to all. Yet the scientific evidence remained inconsistent and in dispute. Increasingly sophisticated studies produced more questions than they answered, and we continue to debate the crucial role of vitamins in good health and the significance of vitamins for optimal well-being.” [93]

A vitamin is simply a substance, present in foodstuffs, required in small quantities for the normal functioning of the body. Yet, the cultural views and perception, business interests, and science surrounding vitamins have had a remarkable history. Over the past 50 years, a variety of claims for the curative or preventative effects of vitamins have been made, yet few have withstood serious scientific scrutiny. Claims for “mega-vitamin” or “orthomolecular” therapies have not been restricted to Down syndrome. Other diseases, disorders and disabilities have been similarly targeted with dubious claims of cures and prevention, including Parkinson’s disease, Alzheimer’s disease, autism, epilepsy, and even the common cold and cancer.

Whilst scientific study has generally discounted these wilder claims for the effects of vitamins, considerable debate continues about their precise effects and the levels required to promote good health, and, in particular, the ranges within which they are safe, whether individually or in combination. Many nations have guidelines as to the recommended quantities of various nutrients that people require, on average, to maintain good health. Although these are occasionally contested and are modified from time to time in the light of advances in scientific understanding, they represent the best approximation of what are safe and adequate intakes at the present time.

4.5 Potential safety issues and uncertainties
These formulations are promoted as supplements. Individuals with Down syndrome who consume a well-balanced diet, and who have no additional medical problems, are already most likely receiving their recommended dietary allowance (RDA) from ordinary food sources. It is therefore important to remember that the doses provided by these supplements need to be evaluated as additional to average intake. Despite their advocates’ expressed confidence in their safety (see above), and claims that they are “referenced” to recommended dietary intakes, there is, again, insufficient evidence to support such certainty.

Primarily of concern is the lack of studies of the effects of long-term nutritional supplementation (whether of individual nutrients or multi-nutrient mixtures) over
and above an ordinary diet. We cannot therefore be confident of any predictions of the outcomes of such actions. Furthermore, it is known that many nutrients’ actions can depend on interactions with other nutrients, and that some form of ‘balance’ may be necessary to promote individual nutrient’s effects. Dosing with supplements may interfere with such ‘balances’.

There are also specific concerns about individual nutrients. Nutrivene-D and MSBPlus supplement vitamin A (retinol) at around RDA levels (US and EC), and beta carotene at around 2½ to 3 times RDA levels (US and EC). High doses of vitamin A can accumulate in the liver and can be toxic. Although beta-carotene (often proclaimed as the ‘safe form’ of vitamin, as opposed to retinol) appears to be free from immediate side effects in high doses, longer term effects of supplementation are unknown. Elevated risks of disease have been observed in clinical trials involving vitamin A supplements. These observations recently led the European Commission’s Scientific Committee on Food to recommend further research, “thereby allowing the establishment of an upper safe limit for beta-carotene intake both alone and in combination with other antioxidants to be used for the general public and for special population groups at risk.” [94]

The antioxidative effects of vitamin C (ascorbic acid) in doses above RDA levels have been questioned [95,96,97]. Pro-oxidative effects from vitamin C have been observed in human adults ingesting 500mg/day [98] - half of that provided by Nutrivene-D or MSB for older children.

Concerns about the neurotoxicity of supplementary doses of vitamin B6 in the UK led the government to propose tighter controls over supplements containing vitamin B6 [99] (and to a predictable outcry, led by the supplement industry eager to protect its £35m. p.a. trade in B6 supplements [100]). The three nutritional supplements promoted for use in Down syndrome supplement vitamin B6 at between 12 and 17 times RDA levels.

We are fully aware that none of these studies and concerns conclusively demonstrate that these supplements are harmful. However, we believe that they are more than adequate to demonstrate that categorical assurances about the safety of these substances cannot honestly be given, that a degree of caution would be prudent, and that they emphasise the importance of properly-designed controlled studies.

5. Conclusions
It is quite natural for people who care for, or treat, individuals with conditions that cannot be completely rectified, to wish for ‘cures’. Psychological factors, such as denial, anxiety, fear, and anger, often occur, and these can sometimes cloud our judgement. Moreover, these can fuel our desire to feel that we are ‘doing our best’ for those close to us. Sometimes these desires, needs and emotions can distract us from the basic issues. The absence of clear answers can be frustrating and, in such circumstances, it is understandable that we may wish to seek out apparently plausible explanations.

There are undoubtedly many exciting possibilities for further advancements in the care of individuals Down syndrome, as well as further challenges. Advancements in our understanding of the roles of the gene sequences on the additional chromosome are likely to be the sources of future advancements. The idea that we could intervene in biochemical processes that are ‘disrupted’ by the extra genetic material present in Down syndrome (whatever they may be) is admittedly alluring. The view that any such intervention is likely to yield a ‘cure’ is, unfortunately, deceptively simple. It is important not to overlook the fact that, as well as biological determinants, there are numerous environmental influences that contribute to the progress and well being of all people. The additional chromosome in individuals with Down syndrome is critical, but we should keep it in perspective.

It is important to emphasise that, like the population at large, the range of abilities, problems and differences at the molecular biology level in people with Down syndrome is enormous, and that a great deal of work remains to be done.

“There is a great deal we do not know about Down syndrome in spite of many advances in recent decades. Everyone who cares about the special needs of these children welcomes advances in the field if they are based on solid evidence. Indeed, there may be malabsorption of vitamins or
minerals in some children; there may be co-
enzyme methods of curbing the elevations of so
many biochemical products measured in these
children. There may be a way to protect these
children by altering their immune systems in
a positive way. We look forward to future
scientific research.

“Until then, we must be careful not to
interfere with the metabolism of children with
Down syndrome until we understand what we
are doing. Properly handled from birth with
knowledgeable educational and medical care,
the overwhelming majority of children with
Down syndrome now have great potential for
a good life and it is important not to
experiment on them for the sake of an elusive
miracle cure.” [78]

Generally, the best care for people with Down
syndrome should be broadly based in that
appropriate emphasis should be given to
educational, language, medical, leisure,
emotional and social development. Any signs
and/or symptoms should be dealt with
according to current medical practice and the
screening protocols for cardiac, thyroid,
hearing and other functions should be carried
out according to prevailing recommendations
[17,101]

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Conference report

CONFERENCE REPORT: “IMPROVING THE OUTCOME FOR CHILDREN WITH DOWN’S SYNDROME”

Susan Bliss and Peter Bliss

A conference, entitled “Improving the outcome for children with Down syndrome”, was held at the Institute of Child Health in London on 1st June, 1998. At this conference, a number of speakers from the Warner clinic (based in the US) presented claims about various unorthodox therapies, including the use of a nutritional supplement (called HAP CAPS). In this article, two doctors (who are the parents of a child with Down syndrome) present a report of, and their reactions to, some of the presentations.

Introduction
We are the parents of a young child with Down syndrome and in common with many other parents we often find ourselves having to evaluate various interventions or treatments which may be beneficial.

Our purpose in attending this conference was to find out more about nutritional intervention for children with Down syndrome. We were aware of the fact that this is not recommended by the Down’s Syndrome Association (for England and Wales). The conference was organised by The Down’s Syndrome Research Foundation, (not part of the Down’s Syndrome Association), the expressed aim of the foundation is to promote research into Down syndrome.

The conference was held in The Institute of Child Health in London, seemingly giving it medical authenticity that appealed to us as doctors. We find ourselves more sympathetic to a scientific approach to new therapies, requiring proper research methods before claims of effectiveness are made. However, we are primarily parents and if we felt that something useful was being denied we would be every bit as keen as the next parent to procure it even if this meant conflict with our medical colleagues.

The purpose of this article is to impart our own views of the day that has left a lasting impression on us.

The conference
The day started with a presentation by Professor Sue Buckley from the University of Portsmouth and The Down Syndrome Educational Trust, discussing cognitive aspects. She presented recent research data and it’s implications with particular reference to speech, language and reading. She summed up by stressing the need for properly evaluated research before interventions could be endorsed.

Then followed an interesting personal and anecdotal presentation by Mrs. Ramachandran, the mother of a girl with Down syndrome and a woman of admirable energy and altruism, who had set up a centre for people with Down syndrome in southern India, where she lives. She concluded by praising Dr. Jack Warner (see below) and stated that she had started giving her daughter nutritional supplements as directed by the Warner clinic. She seemed to be convinced of it’s benefits and said that she was recommending it to others attending her centre.

The next four speakers were from Warner House Center for the Study and Treatment of Trisomy Disorders. Dr. Jack Warner is the President of the centre that appears to offer a multidisciplinary treatment programme including nutritional intervention. His presentation was extraordinarily inaccurate, unscientific and insulting, and it soon became the subject of heated debate. Dr. Warner appeared to have little insight into the sorts of lives led by the majority of young people with
Down syndrome today (i.e. largely integrated within a family unit and participating in as many of society’s activities as possible). He seemed to be stuck with the stereotypical view of the institutionalised person portrayed in some outdated medical textbooks, and thus attributed the attainments of the children attending his clinic to nutritional intervention rather than to natural development in a more stimulating environment.

There were many benefits claimed for Dr. Warner’s therapy including improved physical appearance, physical growth, hair growth and ability to live an independent adult life, but he presented no data at all. He does not appear to have published any of his results despite the claims to have treated 4,200 individuals. Unbelievably, the only evidence he could come up with for the effect of the nutritional intervention was that when children stopped taking the treatment for reasons of family break up or natural disaster (these were the two examples he gave) their condition worsened. It was extraordinary that he did not even acknowledge the fact that the major life event could have had something to do with the change in the child.

In response to this presentation there was a vocal representation from the members of the medical profession present, who were at pains to distance themselves from Dr. Warner. They felt it important to make parents aware of the glaring deficiencies in his work. There were a number of parents who had already invested time and money into obtaining nutritional supplements and they seemed convinced that they had seen improvement in their children as a result. There was a reluctance to accept that this improvement could have happened anyway. The discussion realistically got out of hand and as such only a few people were able to express their views. There appeared to be a sense of anger towards some of the medical profession; parents felt information regarding this therapy was not freely available and wanted to know why a trial had not been set up.

The other speakers from Warner House were interesting, particularly a behavioural optometrist but they did not add to the main thrust of the day.

The meeting ended with a presentation by Dr. Cornelius Ani who had reviewed the literature on nutritional intervention in Down syndrome. He gave a lucid account of the science behind nutritional intervention, then detailed the published studies. These were hampered by small numbers and lack of randomisation and overall were inconclusive. He concluded that a large randomised trial of early nutritional supplementation in Down syndrome versus no nutritional intervention could be justified on scientific grounds but that there would be major logistic difficulties to be overcome before such a study could go ahead.

At the end of the meeting there was a consensus of opinion that more research is warranted. However there was an apparent gulf between those parents wishing to pursue every available therapy to help their child and the medical profession whose training teaches a considered scientific approach, which may be perceived as obstructive.

**Conclusion**

As parents we came away from the meeting with strong feelings that the evidence to date is insufficient for us to wish to pursue nutritional supplementation. Whilst supporting the concept of a randomised trial of early nutritional intervention in Down syndrome we wonder how many parents would be prepared to enter a trial where they had no say whether their child received nutritional supplementation or placebo? They would also have to accept that the results may not be arrived at in time to be of use to their own children.
In April, I was fortunate to be invited to contribute to the 1st Biennial Scientific Conference on Down Syndrome. The conference was hosted by the Down Syndrome Research Foundation and Resource Centre in Vancouver. It attracted an audience from around the world. The conference was an interdisciplinary meeting, and it is hoped that a similar scientific meeting will continue to be held biannually in different parts of the world. There are tentative plans for the next one to be in Australia, following the 7th World Congress on Down Syndrome in Sydney during March, 2000.

This conference was planned to meet the needs of both researchers and professional practitioners. The programme began with a workshop for managers of services for adults with Down syndrome led by Professor Roy Brown of Flinders University, Adelaide in South Australia. Roy is well known for his “Quality of life” approach. Registration and a welcome reception followed and the scientific research programme of the conference covered the second and third days.

On the fourth day a more practical programme was offered to delegates who could register just for that day. This is a good model for such a meeting as the organisers made full use of speakers who had come from all parts of the globe. A number of them presented both scientific papers and practical workshops sessions on different days.

Epidemiology
Dr Patricia Baird, of British Columbia, gave the first paper on the scientific programme on Longevity in People with Down syndrome and its implications. She presented a review of studies of life span, pointing out that for people born with Down syndrome between 1940 and 1952 only 3% lived to 50 years of age but now over 50% will live beyond 50 years. Dr Baird then presented the data from a survey of the population in British Columbia where she and colleagues had traced 703 males with Down syndrome and 638 females. The birth rate for this cohort was 1 in 795 live births. 71% of the group survived to age 30 years. In this part of the life span the main mortality period was the first year of life.

Genetics and biochemistry
Dr David Patterson from the Eleanor Roosevelt Institute, Denver, USA gave a paper entitled “Identification and analysis of genes important for cognition”. He described the work that he is involved in which aims to identify and understand the functions of all the genes on chromosome 21. If the function of particular genes can be linked to any of the neurological, neurophysiological, cognitive, behavioural or characteristics of Down syndrome then it may be possible to apply this knowledge to reduce the cognitive delays and difficulties experienced by most people with Down syndrome. Dr Patterson emphasised that such work required a broad spectrum of approaches spanning molecular biology, mouse genetics and human behaviour. He is working with a consortia of many partners and further information on this work can be found on http://www-eri.uchsc.edu/.

Dr Charles Epstein of the Department of Paediatrics, University of California, San Francisco, USA outlined New Directions in Genetic Research. In his paper, Dr Epstein described the potential contribution of mouse models to our understanding of the effects of trisomy 21 on development. He explained that more than one type of trisomic mouse has been developed and it was hoped that the study of the chromosomal regions and the genes which contribute to the behavioural, learning and neuronal abnormalities in these animals will give insights into the links in human trisomy 21. The ultimate goal is, of
course, to understand the mechanisms with a view to developing effective therapies.

The poster by Dr Jovanovic and Dr MacLeod, of the International Center for Metabolic Testing, Ottawa, Canada addressed the issue of increased oxidative stress in Down syndrome. The authors argue that, because of genetic overdose and the elevation of copper-zinc superoxide dismutase in the cells of individuals with Down syndrome, potentially damaging levels of hydrogen peroxide are generated (see the discussion elsewhere in this issue, pp. 70 - 83). Following from a study in which trisomic cells responded to the addition of anti-oxidants when studied in a test-tube, this study attempted to measure the effects of antioxidant supplements in 166 children with Down syndrome and their siblings. The results were negative leading them to conclude that “Dietary influences on the oxidative stress status failed to show any significant correlation. Therefore intervention in dietary habits only may not be enough to alleviate deleterious consequences of oxidative stress”.

Pre and post natal experiences
Included in the programme was a symposium on prenatal diagnosis, covering process, reliability, options and ethical issues. The first paper in the symposium, entitled “Prenatal testing for Down syndrome: The value and meaning of biomedical tests”, was presented by S.R. Rubin and Dr William Cohen of the Pittsburgh School of Medicine, Pennsylvania, USA. They described a study in which they had interviewed 15 families from the Down Syndrome Center to ask them about their experience of screening. Only four of the 15 families reported receiving non-biased counselling and adequate information on prenatal testing. Nine of the remaining 11 families reported that they were either misinformed or did not get complete information.

Six of the 15 families were not explicitly told testing could help the family prepare for the birth of the child with Down syndrome. Of the eight families that did not get prenatal testing because they would not terminate the pregnancy, 5 believed that it would have been helpful to know the diagnosis before the birth of the baby. Four of the 15 families asserted that they saw no value from information gained by prenatal testing and diagnosis. Three families stated that it is better to learn about the diagnosis of Down syndrome after the child is born. The presenters emphasised that clinicians should recognise the wide range of thoughts and feelings that families have about prenatal screening and be more flexible and sensitive to these views in their approach to offering the service.

The second paper, also on “Antenatal and postnatal parent experiences” was by Dr Margaret Kyrkou, Judi Thornley and Dr Roy Brown, Flinders University, South Australia. This paper echoed a number of the themes from the previous one. The authors had interviewed parents of children with Down syndrome under five years of age about their experience of antenatal and post natal care. Here again parents had a wide range of views, describing good and bad experiences. Families differed in their views of what they wanted from services and in their needs. Recommendations for professionals to be more sensitive and flexible in their support of parents were made, suggesting that experience of services in Australia is similar to that in the USA.

The developing world
Two papers drew our attention to issues in India and in China. Dr Sayee Rajangam from the Division of Human Genetics, St John’s Medical College, Bangalore, India described the information that he had collected on the health, development, education and occupation of a group of 511 children and adults with Down syndrome. In this group, 88% were Trisomy 21, 4.3% were mosiac and 7.4% translocations. Dr Rajangam reported the incidence of the additional common health problems including congenital heart defects, vision, hearing, hypothyroidism, leukaemia and skin conditions. The rates of all these varied from figures given in Western countries and the reasons for this might warrant further investigation. The incidence of most of these conditions was less in the Indian group. Of those that had completed secondary education (21), three had been employed and two women with Down syndrome had married. The need for continued family counselling and support across the life span was emphasised.

Dr Hongjun Su, from the International Centre, University of Iowa, USA reviewed the situation in China in a paper entitled Down syndrome in China: breaking the silence and overcoming the invisibility in the world’s most populous country. Dr Su indicated that despite the estimate of between 3.4 and 6 million children with mental retardation in China, many of them with Down syndrome, Down syndrome is still struggling to break the silence and overcome its invisibility in contemporary
China. She suggested that three major factors may contribute to this situation. Firstly, a long tradition of a hierarchical, regulatory approach to the care of individuals with disabilities, secondly, limited economic resources and thirdly deep-seated social and cultural attitudes to disability. Dr Su discussed the medical, educational, employment and other resources available in China and the concerns held by parents and professionals.

These two presentations reminded the audience, the majority of whom were from North America, of the very different conditions and life chances facing those born with Down syndrome in different countries. This is an issue which the recently formed International Federation for Down Syndrome has on its agenda, since in many countries we have a great deal of knowledge and expertise that could be shared with developing countries.

Speech and language
I presented a paper entitled Speech, language and literacy development in children with Down syndrome in which I reviewed recent research on the typical profiles of development within the speech and language domain, rates of progress and variability. Having described the typical delays and difficulties experienced by most children with Down syndrome as they learn to speak, I considered what we know about the underlying causes and about effective approaches to remediation. In the last four years the leading researchers in this area have reached considerable agreement on the key strategies to be used in an effective speech and language programme. All agree on the need to use multi-sensory approaches, including signing and reading, to teach language and on the importance of auditory discrimination and speech work alongside language work from the first year of life. The next challenge may be to understand the reasons for the wide variability in rates of progress and to move from a general description of the needs of children with Down syndrome as a group to identifying that there may be subgroups with special needs within the population. For example, some children have much more severe phonological difficulties than others and some have autistic like pragmatic profiles. There is a need to be able to identify children at greater risk in a particular communication area early in order to tailor advice to the individual. There is also a need to develop programmes which train parents to be the main therapists. Firstly, in most parts of the world speech and language therapists are in short supply so using their time to pass their skills on to families, which can be done in group sessions, may be the most effective way to use their time. Secondly, communication skills are developed by successful communication experiences for children throughout their waking hours. Those who communicate with them in all these naturally occurring episodes are in the best position to be effective in helping them to improve their speech and language skills if they are given the necessary skills and knowledge.

Motor skills
There were several papers and poster presentations on aspects of motor skills and motor control. The first by Matthew Heath and Digby Elliott from the Universities of Waterloo and McMaster, both in Ontario, Canada, was on “Cerebral asymmetries for speech production in persons with Down syndrome”. They presented the results of an experimental study designed to identify which side of the brain is involved in speech production in individuals with Down syndrome using mouth asymmetry as an indicator. It has been hypothesised that asymmetrical mouth opening during speech reflects the direct access by muscles on the right side of the face to the speech production systems in the left hemisphere in the brain. The results for the study confirmed this prediction and there were no differences between individuals with or without Down syndrome. This finding is consistent with the model put forward by Elliott and colleagues which argues for a dissociation between speech perception and speech production mechanisms in people with Down syndrome. Instead of both being in the left hemisphere (the common pattern) they suggest that speech perception is in the right hemisphere in Down syndrome and that this separation may contribute to some of the speech and language difficulties. While this is an interesting theory, which might have some practical implications, it would seem timely to use brain imaging techniques to provide more precise and conclusive evidence than can be gained from the techniques being used at present. Such studies would need to account for potential changes in localisation of functions in the brain as a result of age of input and rate of development of skills as has been demonstrated in children with Williams syndrome.

Two posters addressed issues relating to the development and measurement of motor skills. The first by Dr Russell and colleagues at the Neurodevelopmental Clinical Research Unit, McMaster University, Hamilton, Canada was
entitled “Development of gross motor function in children with Down syndrome”. They pointed out that the measurement of progress with gross motor skills for children with Down syndrome has relied on the use of norm-referenced assessments and they argued that the Developmental Quotients provided by such assessments did not provide useful information for parents. Their poster described the results of a study of 123 children assessed twice over a six-month period using the GMFM scale. The aim was to measure the reliability and validity of the GMFM as a measure of change in motor function and to create growth curves describing the motor development of children aged from one month to six years.

The GMFM was shown to have excellent test-retest and inter-rater reliability. However, correlations of change in the GMFM with parent, intervenor and video-rater judgements of change were lower than predicted while trends in GMFM changes according to age and severity subgroups were as predicted. The GMFM was relatively more responsive as a measure than the Motor scale of the Bayley Scales of Infant Development -II. The researchers have developed growth curves to describe the relationship between GMFM scores and age for children described as having ‘mild’ versus ‘moderate or severe’ motor impairment. This work could be extremely useful to physiotherapists and parents, especially as the gross motor growth curves are provided for the two groups of children, recognising the variability in the level of motor impairment experienced by infants with Down syndrome.

The second poster on motor skills was from Dr Christine Blais, Department of Child Studies, Brock University, St Catherines, Canada. The poster on “Speed-up effects and automaticity in individuals with Down syndrome” presented the results of a study which compared the improvement with practice on a motor skill task of ten individuals with Down syndrome with that of ten intellectually disabled peers. Improvement in performance was recorded and initially reflected just a ‘speeding-up’ effect but as practice progressed there were changes in the decision making components of the task. The authors argue that the students in the study showed qualitative and quantitative improvements as a result of practice i.e. they were improving their skills and strategies, not just ‘speeding up’ as earlier researchers have argued. This is a welcome approach as the importance of practice in improving the performance of almost any human behaviour during typical development, from speech clarity to memory skill, is often overlooked when describing and interpreting the difficulties and delays seen in children with disabilities.

Not only do our children with Down syndrome nearly always show delays in starting to develop a skill, the difficulty they have in executing it also restricts the amount of practice they get compared to typically developing children, further compounding both delay and qualitative improvement. The issue of practice and training becomes important in interpreting the significance of many research studies. Psychologists in particular, do not always seem to take account of this delay in using and perfecting emerging skills in explaining performance differences. One way of doing so would be to give children with Down syndrome sufficient training trials on tasks to reach their optimal performance before carrying out the experimental trials.

Dr Dale A. Ulrich described a study on “The impact of treadmill exercise on the rate of developmental progress in infants with Down syndrome”. Infants with Down syndrome walk independently about one year later than the typically developing child. In this study, 30 infants with Down syndrome were randomly assigned to the treadmill practice group or to a control group. The infants entered the study when they could sit independently for 30 seconds and left when they could walk independently. The researchers predicted that treadmill practice would strengthen the neural organisation that initiates the stepping pattern, increase leg strength and develop the postural control mechanisms needed for walking. In a previous study the researchers had demonstrated that infants with Down syndrome can produce consistent alternating steps when supported upright on a small motorised treadmill, an average of 13 months before the onset of walking. In the present study, the infants in the treadmill group were supported on the treadmill for 8 minutes per day, 5 days per week. The results indicated that the infants in the treadmill group were walking independently 92.7 days earlier than the control group. Since walking brings independence and the opportunity for exploration leading to social and cognitive gains, this is clearly an important finding if it can be replicated.

The last session on motor skills was a symposium on “Issues in the control and co-
ordination of individuals with Down syndrome”. The first paper was on “Control of goal-directed limb movements in adolescents and young adults with Down syndrome” by Digby Elliott of the Department of Kinesiology, McMaster University, Ontario, Canada. Dr Elliott drew on studies which have been conducted over the last ten years in his laboratories to argue that young people with Down syndrome perform controlled movements better on the basis of visually presented instruction than when the movements are cued verbally. If reaching or gestural movements can be organised on the basis of visually presented information, adolescents and adults with Down syndrome perform as well as others matched with them for mental age. If the movements have to be based on verbal instruction, then those with Down syndrome are slower and less precise in executing the movements. The explanation suggested is based on Dr Elliott’s model of functional dissociation of the areas of the brain responsible for movement organisation and verbal processing. However, the processing of verbal information may be more difficult for individuals with Down syndrome than the processing of the visual cues irrespective of brain location. Maybe there is a need to match control subjects on verbal ability specifically, including comprehension for grammar and on verbal short-term memory in order to unravel these issues further.

The second paper in the symposium was on “The effects of visual field perturbations on whole body sway in Down syndrome” by Drs Richard Van Emmerik, Michael G. Wade, Brian Hopkins and Walter Davis from the Universities of Massachusetts, USA, Minnesota, USA, Lancaster, UK and Kents State, USA. These researchers are studying the movement responses made when a person is in a ‘moving room’ apparatus in which walls can be moved to create the impression of whole room movement. The children with Down syndrome (mean age 10.6 years) showed exaggerated response compared to children of the same age. A final paper on “Postural responses of people with Down syndrome to variation in optical flow” by Dr Michael Wade of the Department of Kinesiology, University of Massachusetts, USA reported a further study using the same moving room equipment and the same children. The children with Down syndrome were again more sensitive to the experimental conditions and the results were discussed in relation to various theories of postural dynamics.

Feeding and swallowing
The final paper by Dr Don van Dyke, Christy L. Wallach, Dianne M. Mc Brien and Yutaka Sato from the Departments of Paediatrics and Radiology at the University of Iowa Hospitals and clinics, Iowa, USA was entitled “Videofluoroscopic evaluation of swallowing and nasopharyngeal reflux in individuals with Down syndrome”. Dr van Dyke described the findings of a study of 21 individuals with swallowing and growth concerns. The patients ranged from one to twelve years, with a mean age of 3.6 years and 16 had major swallowing difficulties. All the patients were evaluated clinically and with videofluorographic imaging studies. Dr Van Dyke reported that 10 of the 16 (63%) had significant medical complications such as congenital heart disease, esophageal atresia, duodenal atresia and/or other chronic disorders. He and his colleagues found a range of specific difficulties which included problems in chewing and moving food around in the mouth, in arranging the food in a suitable shape and form to swallow, delayed swallowing and nasopharyngeal reflux.

The nasopharyngeal reflux was frequently noted on the imaging studies though less frequently reported in the history taking and clinical examination. I was pleased to note that this is now an area of research investigation as swallowing and choking difficulties seem to be quite a prevalent problem among the children we meet in our early intervention service. The difficulties that some of the children have lead to feeding difficulties as they are often unwilling to eat foods of certain textures and resistant to moving on to food that needs to be chewed. In particular, managing food that is runny but contains lumps is often a challenge. Once a child has experienced choking they are not keen to try new foods. This is an area where preventative strategies could come into play early if parents receive advice on how to encourage movement of the tongue and to use food textures systematically to give experience and build competence. Drinking can also be an area of difficulty where not all infants seem to be able to co-ordinate swallowing and breathing, so are prone to choke when attempting to use a cup.

Infant cognitive skills
Dr Jennifer Hill Karrer, Dr Rathe Karrer and colleagues from the Smith Mental Retardation and Human Development Research Center, University of Kansas, USA presented a poster on their event-related brain potential (ERP) studies of infants entitled "A new correlate of visual recognition memory in early infancy".
They compared the patterns of ERP components recorded from 6 month old infants with a particular interest in a new component, Nc2, which this research group have identified and believe is a marker for the development of visual recognition memory. For infants with Down syndrome, the peak for Nc2 was much later and larger than in the non-Down syndrome infants, despite no observed difference in attentional behaviours. The author's suggest that the differences and trends and topography of Nc2 may imply that it represents transitions from stimulus encoding to recognition memory in infants. ERP techniques are proving to be effective in beginning to map development and differences in brain function and cognitive functions in a number of laboratories. They are non-invasive, only requiring recording electrodes to be fixed to the scalp, and therefore cheaper, easier and safer to carry out than brain imaging studies which involve injection of radio-active tracers.

Dr Ingram Wright, Vicky Lewis and Glyn Collis of the Psychology Department, University of Warwick, UK presented a poster entitled “The development of representation in children with Down syndrome”. The study compared the children’s capacity for imitation with their sensori-motor skills. 18 children with Down syndrome were compared with 18 typically developing children matched for object permanence level. The children with Down syndrome performed similarly on tasks involving a two-location search and a comparable imitation task. In contrast, the typically developing children performed poorly on the imitation task. In a second study, the children with Down syndrome performed as well as the comparison children on a search task involving imitation but were unable to perform a non-imitative search.

The authors conclude that children with Down syndrome develop mental representations at a different rate to typically developing children. They also point out that these results challenge the view that there are causal connections between different representational domains. This is an important point. The belief that there are causal links across domains, i.e. the child must show a particular stage has been achieved in one domain before we can expect progress in another, often leads to the false assumption that a child is not yet ready to learn a new skill in a particular domain. In my view, the only way to find out if a child is ready to progress is by giving the child the opportunity to learn the next steps. The skills that a child with a disability shows in different domains of development may be very uneven if compared to typical norms.

Research initiatives
The work of the Jerome Lejeune Foundation for Research in France, created less than three years ago was presented in a poster by Drs Marie-Odile Rethore, Clotilde Mircher and Corinne Bebin of the Hopital Notre Dame de Bon Secours, Paris, France. The two major aims of the foundation are to fund fundamental and clinical research projects and to create multi-oriented care centers (medical and social). The foundation has already awarded four research grants and is funding a medical centre providing services to 1500 patients. It is estimated that over 50,000 individuals with Down syndrome in France and several thousand others with genetically determined syndromes such as ‘cri du chat’ and fragile X. The Foundation will be concerned with all genetically determined causes of developmental disability.

Myra Madnick, Executive Director of the National Down Syndrome Society (NDSS) based in New York, USA outlined the research initiative that the NDSS had agreed with the National Institute of Child Health. The NDSS will contribute 200,000 dollars and the National Institute of Child Health 800,000 dollars for each of the next three years, creating one million dollars each year for research in Down syndrome. Researchers would be able to put in bids for projects and applications would be accepted from the international community as well as from those in North America. This is obviously an exciting initiative that will increase the knowledge base and contribute to improving the lives of individuals with Down syndrome.

Quality of life
Professor Roy Brown of Flinders University, South Australia presented a paper on “Quality of life in Down syndrome - relevance to research and practice”. He outlined the components of quality of life models and stressed that these placed emphasis on the dignity and well-being of the individual. Adopting the model puts the emphasis on individual choice and control for the person with a disability. It means listening to what the individual says and respecting his or her perceptions of their own life situation. Roy argued that societies and services needed to make a radical shift if they were to take on the principles of quality of life and empowerment. This paper struck a chord for me as I have watched my daughter with Down syndrome...
blossom in her twenties into a self-confident and independent adult as a result of being supported by a service with the values Roy was describing. Her earlier experiences in special school and further education had resulted in learned helplessness, low self-esteem and dependence as she was told what to do, given few choices and constantly reminded that she was ‘different’. These were the only services available to her in the neighbourhood and typical of many in the UK at that time.

**Imagery**

A second paper from Flinders University was presented by Roy Brown and Eddie Bullitis, a postgraduate student. The paper was entitled “Images of consciousness” and it described an exploratory study of the use of internal mental imagery by adults with Down syndrome. The authors stressed the importance of mental imagery in mental processes, for example in anticipating, thinking, planning and problem solving and reminiscing. Despite this, imagery has largely been a neglected topic in learning disability research. In a preliminary study involving individuals with intellectual disability, including some with Down syndrome and non-disabled students, the authors were exploring imagery and ability to become imaginatively involved in situations. The adults with Down syndrome seemed more able to imagine and visualise than others with intellectual disability but not Down syndrome. This seems to be an exciting new area of research with far reaching implications. It was suggested that being involved in drama activities could increase ability to imagine and that this could be encouraged from childhood. Many of us have seen the professional standards of acting ability achieved by individuals with Down syndrome in theatre companies. We are also familiar with the ability of children with Down syndrome to be good mimics and the presenters of the paper suggested that we could be thinking of developing imagination from early childhood. It is also a skill which supports reading stories with understanding, as we need to be able to imagine the people and the actions as the story unfolds.

**Parent’s views on therapies**

Dr. Bonnie Patterson, of the Department of Paediatrics, Cincinnati Center for Developmental Disorders, Cincinnati, Ohio, USA, presented the results of a survey of parents’ use of alternative therapies. In order to determine the prevalence of use of alternative therapies, which seem to be increasingly popular, a survey was sent to 321 families of children with Down syndrome. Dr Patterson defined alternative therapies as therapies based on over simplified scientific theory, claiming to be effective for a wide variety of conditions and supported only by anecdotal evidence. The survey listed 55 different forms of alternative therapies and parents were asked to report on a scale of 1 - 4 how helpful the intervention was for their child if they had tried it. Only 75 (23%) of families returned the questionnaires. Of these, 36 (48%) reported using at least one alternative therapy. Parents who were college graduates were more likely to be using them (59% of those parents NOT using any were not college graduates). Twenty five (33%) of the families were using multi-vitamin supplements, twenty buying brands such as Nutrivene-D, MSB or Hap Caps, the other five buying from local pharmacy. These families mainly had children under five years old. Unfortunately the small return rate of the questionnaire in this study makes the results very difficult to interpret.

**Siblings**

In the next paper, Dr Marcia Van Riper from Ohio State University, Columbus, Ohio, USA discussed ‘The sibling experience in families that include a child with Down syndrome”. Information was collected from 75 families using self-report instruments designed to assess family demands, family resources, family appraisal, family coping, family problem solving communication and sibling well-being. Results indicated that as a group the siblings of children with Down syndrome feel very competent and self-assured. In addition, their parents report a low incidence of behaviour problems. There was a significant relationship between sibling well-being and two other measures, family demands and family problem solving communication. The siblings in the study reported that the positive effects of having a sibling with Down syndrome far outweighed the negative aspects. According to one sibling, ‘I sometimes am frustrated when J misbehaves and my mother doesn’t discipline him as much as I think she should. I have many more positive feelings towards J than negative though’. Another sibling wrote, ‘I love my little brother and wouldn’t give him up for all the money in the world’. A third sibling wrote, ‘He’s very special. Sometimes I think of what it would be like with a ‘normal’ brother his age. I don’t think it would be that fun’.

**Women’s health**

Dr Margaret Kyrkou from the School of Special Education and Disability Studies, Flinders University, South Australia discussed
Premenstrual Syndrome (PMS) in women with Down syndrome. Dr Kyrkou has designed a PMS questionnaire for women with Down syndrome. She described the responses of 25 women and the range of PMS symptoms that they may suffer. She pointed out that the only way that they may have of expressing their distress is behavioural, so that diaries should be kept to chart mood swings or behaviour changes that occur to relate them to the hormone cycle in women.

The final day of the conference was a programme for local practitioners and parents and so some speakers presented again. The day began with prospects for new therapies for Down syndrome by David Patterson in which he gave his views on the possibilities for pharmacological therapies or gene alteration techniques that might be developed in the next decade by studying trisomic mice. This was followed by my paper, entitled “Accelerating cognitive development in children with Down syndrome”. I argued that speech and language development is central to cognitive development and that it is possible to accelerate speech and language development using visual methods of instruction such as signing and reading. I also used data from our research in the UK to illustrate that reading can improve memory function.

The third paper was on “Learning the hard way: cognitive development in young children with Down syndrome” presented by Dr Jennifer Wishart, of Moray House Institute of Education, Heriot-Watt University, Edinburgh, Scotland. Dr Wishart drew on her research on early learning to argue that children with Down syndrome tend to make inefficient use of existing cognitive skills, and are at risk of increasing use of avoidance strategies when faced with new learning situations. She also suggested that they fail to consolidate newly acquired cognitive skills into their repertoire and grow reluctant to take the initiative in learning tasks. If all these characteristics are typical of children with Down syndrome they all seem to me to be possibly socially mediated and targets for remediation, provided parents and teachers are aware of them. Each of these issues needs further investigation across a range of learning tasks to give more information on which to develop positive strategies. If Dr Wishart is right, it suggests that many children with Down syndrome are underachieving for reasons we could address.

The afternoon was given to practical sessions on services for children or for adults. I attended the sessions presented by the staff of the PREP programme in Calgary on the range of services that they offer to children and families. I learned a great deal and will include an article on their work in a future issue.

You can see that the conference was extremely interesting and that a wide range of research on many aspects of Down syndrome is in progress around the world. The organisers at the Down Syndrome Research Foundation and Resource Centre should be congratulated on initiating such a successful meeting and it is to be hoped that others will follow.

I was honoured to receive the first Scientific Award at the conference on behalf of all my colleagues at The Down Syndrome Educational Trust and the Centre for Disability Studies at the University of Portsmouth in recognition of our contribution to knowledge.
Introduction
In our previous brief introduction to the Internet [1] we described the Internet as a network of interconnected computers and explained the World Wide Web as a collection of documents stored on those computers in a format accessible to computer programs called ‘browsers’. We noted that these documents are interwoven by ‘hyperlinks’. We also commented on the facilities for communication provided by e-mail and newsgroups. All of these features of the Internet offer immense possibilities for the quick and cheap exchange of information. However, the scale of the Internet and the ease with which anyone can publish anything do raise some potential disadvantages.

In this article, we intend to provide an overview of information and communication resources related to Down syndrome, and to discuss some of the strengths and weaknesses of the Internet. We begin with a review of methods for locating information and a discussion of strategies for evaluating the trustworthiness and usefulness of material. A number of web sites and discussion forums specifically focusing on Down syndrome and a number of related resources are then outlined.

We should apologise in advance for two failings of this article. Firstly, the rate of change on the Internet is rapid, and it is likely that new resources will have appeared prior to this article being printed and mailed. Secondly, the review of resources is inevitably incomplete given the fact that we have not had the time to examine every web page that mentions Down syndrome. Moreover, our lack of competence in numerous languages has prevented us from investigating many non-English language sites. Nevertheless, we hope that you will find the article interesting, and we would welcome submissions for future reviews of web sites in Down Syndrome News and Update.

The scale of the Internet
The figures describing the size of the Internet are both currently daunting and rapidly escalating. Whilst estimating these statistics is far from being a precise endeavour, the following approximations at least offer a feel for the scale of the Internet.

There are around 30 million ‘hosts’ (unique, registered network addresses) on the Internet (with around 5.3 million connected at a given point in time) [2]. There are over 2.5 million web ‘sites’ [3], and conservative estimates suggest that there are over 320 million publicly-accessible ‘documents’ on the Internet and that only around one third of these are indexed by any given ‘search engine’ [4]. There are currently over 29,000 newsgroups being fed through ‘Usenet’ [5] offering discussions ranging from issues in nuclear physics through to the finer aspects of garden sheds. It has been estimated that there are between 100 and 130 million people accessing the Internet throughout the world, and around 69 million people using the World Wide Web (Table 1) [6,7]. Whilst the majority of these are in North America, the rates of growth of users within other regions is much more rapid.
Finding information

So, how is particular information found among this huge and diverse range of material? There are many ‘search engines’ available on the Internet. ‘Search engines’ are basically huge databases of web pages that can be searched using keywords or phrases. Some rely on links being submitted, whereas others utilise computer programs (‘spiders’) that follow links from page to page and build up their own lists of pages. Some check multiple indexes in order to provide (‘meta’) search results, and some offer limited reviews and commentaries about different sites. No single ‘search engine’ is complete, and they have various strengths and weaknesses [4,8].

However, these ‘search engines’ are just the beginning of the searching process. Generally, they rely on matching words or phrases to identify content. Many words can obviously be used in many different circumstances, so the more precise the word, the more precise the results are likely to be. Identifying phrases can dramatically improve search results (i.e. lots of pages include the word “down” and the word “syndrome”, yet far less contain the phrase “Down syndrome”). Sometimes considering what is not wanted can be a very effective way of getting improved results from ‘search engines’. For example, many mail lists and bulletin boards have web-based archives of messages which are frequently indexed by ‘search engines’ and therefore excluding such words as “message” or “thread” can help exclude them from search results. Table 2 illustrates the effects of additional qualifications to search criteria on the results obtained from two of the larger ‘search engines’.

Another method of finding useful information is make use of lists of links to sites concerning a particular topic compiled by others who have already done the searching. Whilst these are not always current, they can often link to some of the most useful sites. The most thorough list of sites relating to Down syndrome is available on Len Leshin’s “Down Syndrome Health Issues” site (see below) [10]. Once you have found a place to start, following others’ references and links can frequently lead to further related information.

Identifying trustworthy information

Anyone can pretty much publish anything on the Internet resulting in a tremendous range of content. At the more useful end of the spectrum are numerous journals, various newspapers, legal and government information and lots of genuinely helpful ‘personal’ sites. Unfortunately, the less useful and potentially offensive content includes the dubious diatribes and a wide variety of pornography. Due to the disparate nature of the Internet, enforced control over content or censorship are virtually non-existent.

In an article, recently published in a UK newspaper, it has been suggested that the Internet “is a seething mass of fraud and disinformation”. [11] Whilst this is an extreme view, it has some validity. It usually does not take very long, when browsing the web (particularly if you rely on general search engines and are not looking for information of specific minority-interest), to come across “hoaxes, liars, conspiracy theorists, political extremists, people offering dubious financial propositions, and pornographers.” [11] Although some systems exist to exercise control over material that is browsed, they are not reliable [12]. Within minority-interest subjects, discreditable information is also not too hard to find. (As commented on elsewhere in this issue [pp 72 - 83], information of debatable quality about Down syndrome and nutrition is particularly prevalent on the Internet.) However, it should also be noted that literature of dubious value is not only an

<table>
<thead>
<tr>
<th>Region</th>
<th>Internet Users (000's)</th>
<th>% of total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Africa</td>
<td>800</td>
<td>1%</td>
</tr>
<tr>
<td>Asia/Pacific</td>
<td>19,300</td>
<td>15%</td>
</tr>
<tr>
<td>Canada &amp; USA</td>
<td>70,000</td>
<td>54%</td>
</tr>
<tr>
<td>Europe</td>
<td>31,700</td>
<td>24%</td>
</tr>
<tr>
<td>Middle East</td>
<td>750</td>
<td>1%</td>
</tr>
<tr>
<td>South America</td>
<td>7,250</td>
<td>6%</td>
</tr>
<tr>
<td>World Total</td>
<td>129,800</td>
<td></td>
</tr>
</tbody>
</table>

Table 1. Estimated numbers of Internet users by region.

<table>
<thead>
<tr>
<th>Search criteria</th>
<th>Results</th>
<th>AltaVista</th>
<th>HotBot</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Down syndrome” OR “Down’s syndrome” OR “Downs syndrome” OR “Trisomy 21”</td>
<td></td>
<td>25,128</td>
<td>8,159</td>
</tr>
<tr>
<td>As above, with addition of: AND research AND reading</td>
<td></td>
<td>3,313</td>
<td>887</td>
</tr>
<tr>
<td>As above with addition of: AND memory AND “cognitive development”</td>
<td></td>
<td>124</td>
<td>49</td>
</tr>
</tbody>
</table>

Table 2. An illustration of how additional criteria for inclusion and exclusion result in fewer and fewer search results. [9]
The Internet does contain useful information. There is a fantastic range of reliably informative and entertaining material that is easily accessible to suitably equipped people around the globe. The issue is thus how to distinguish the sensible from the senseless and the factual from the fictional. Although some indicators of quality exist, such as reviews and ratings of sites by various organisations, they are unreliable [13]. Therefore, there is no simple answer [though for suggestions see 14,15]. A greater freedom to publish (as facilitated by the Internet) empowers authors to speak freely and requires readers to be critical. Readers need to be mindful of the sources of the information they are absorbing, appropriately critical in their evaluation of statements or views, and self-critical of their own ‘instinctive’ reactions to certain suggestions or claims.

Down syndrome information
Resources for general information and references to other sites

The Down Syndrome WWW Page [16] includes lots of helpful information. Highlights include some helpful “Frequently Asked Questions” pages (“FAQ’s”), a collection of articles and essays, forthcoming conferences and events dates, and a huge list of contact information for organisations around the world.

What’s Up with Downs? [17] is a site produced by Michele Kehler, a mother of a child with Down syndrome. It includes a number of short articles by other parents, a “New Parent Letter” by Michele, and an interesting personal perspective on “TNI”.

Down Syndrome Health Issues [18] is an excellent resource, maintained by Dr. Len Leshin, a paediatrician in Corpus Christi, Texas, and the father of a child with Down syndrome. Topics covered in essays available on the site that are specific to Down syndrome include genetics, amino acids, arthritis, atlantoaxial instability, Coeliac disease, epilepsy, minerals and vitamins, obstructive sleep apnea, and Piracetam. There are also general medical essays, “Abstract of the Month”, and a recommended book list. A list of current research ongoing in America has recently been added, and, as noted above, the list of other web sites maintained here is thorough and is frequently updated.

Down Syndrome Quarterly [19] is one of the two multi-disciplinary journals specialising in issues relating to Down syndrome. Apart from subscription information and details of the contents of past issues, this site includes “Health Care Guidelines for Individuals with Down Syndrome” (produced for the Down Syndrome Medical Interest Group), and articles about vitamin therapies and growth hormones.

The National Down Syndrome Society (US) [20] provides some general and clinical information on Down syndrome in ‘question and answer’ format and well as information on educational issues. Details of publications on Down syndrome and related topics are also listed.

National Down Syndrome Congress (US) [21] offers information about this national US-based organisation, including position statements on a variety of topics.

UK resources for Down syndrome [22] These pages provide a comprehensive list of organisations in the UK for Down syndrome, advice on education, legal advice and disability resources. There are also links to health advice and International DS web sites as well as information on joining a mailing list for Down syndrome.

The Riverbend Down Syndrome Support Group (US) [23] offers a web site with a number of articles on a variety of topics, including speech and language, literacy, communication and inclusion.

DownsNet [24] is the information resource being developed by The Down Syndrome Educational Trust. It currently includes all of the articles from the first four volumes (12 issues) of the academic journal Down Syndrome Research and Practice and a number of articles from past issues of DownsEd News. In the pipeline are further articles, a searchable directory of Internet resources concerned with Down syndrome, an online bibliographic database, discussion forums (newsgroups), a searchable directory of organisations around the world that are connected with supporting people with Down syndrome, and more.
Down syndrome-related information on the web

**The Centre for Studies on Inclusive Education (CSIE)** [25] gives information and advice about inclusive education and related issues. The Centre, which was set up in 1982, is fully committed to working towards an end to segregated education. Their site contains information about inclusion, including useful summaries of legislation and details of publications available from CSIE.

**Family Village** [26] offers large lists of links to resources, information and communication opportunities for persons with mental retardation and other disabilities, and their families.

**The Waisman Centre** [27] at the University of Wisconsin-Madison (US) is dedicated a centre which is dedicated to the advancement of knowledge about human development and developmental disabilities through research and practice. Their web site includes information about current research activities.

**The American Association on Mental Retardation** [28] web site offers information about the association, abstracts from the current issues of their periodicals (the *American Journal on Mental Retardation* and *Mental Retardation*) and excerpts from their newsletter.

**International Association for the Scientific Study of Intellectual Disabilities** [29] is an international and interdisciplinary scientific organisation to promote world-wide research and exchange of information on intellectual disabilities. Their web site offers information about the association, forthcoming conferences and past newsletters.

Other useful starting points

Various national *libraries* [e.g. start at 30,31,32,33, also see 34] offer access to searches of their collections, and reprint ordering services. *Government* information sites offer access to legal and policy information [e.g. start at 35,36,37]. Numerous sites offer access to health, medical and psychological information [e.g. start at 38,39,40].

**Conclusion**

The Internet offers vast opportunities for communication and information dissemination. A huge range of material is available, though locating quality information is not always straightforward. A considerable amount of useful information about Down syndrome and related issues is available, and is continually evolving and developing.

In future issues of *Down Syndrome News and Update*, we will offer more detailed site reviews and links to interesting new sources of information. We would welcome reviews and suggestions of material for inclusion.

**The authors**

Dr. Angela Byrne is a Psychologist at The Down Syndrome Educational Trust and Assistant Editor of “*Down Syndrome News and Update*” and of the journal, “*Down Syndrome Research and Practice*”.

Frank Buckley is a Trustee of The Down Syndrome Educational Trust, and Operations and Finance Director of its subsidiary company, DownsEd Limited.

**Notes and references**

5 Based on the number ‘carried’ by Demon Internet’s news servers as at 2nd August, 1998. There are some that Demon Internet refuses to carry. Full current list available from: http://www.demon.net/services/news/list.html [Accessed: 1998, August 2]
7 For other headline Internet usage statistics, gathered from a variety of market research sources and links to original sources, see Headcount.com at http://www.headcount.com/ [Accessed: 1998, August 2]
Searches conducted on 2nd August, 1998.


Foundation fractions
Review by Bob Black

Focusing on fractions this a teaching tool. It clearly explains the attributes of halves and quarters. Reading ability is of minimal importance as the program has good spoken instruction and clear one-word instructions help you to move on through each section, although sometimes the explanations are rather short. The words used to explain fractions are clearly explained themselves and it looks very useful to introduce the basics of fraction concepts. The screens are very clear and I particularly like the pictorial approach to adding fractions, which gives a practical value as well as a theoretical one as with numbers alone.

Exercises include: • Learn about halves • Find the shape • Matching halves with mighty Mick • Learn about quarters • Halves as quarters • 20 questions • Matching quarters with mighty Mick (Each section has three levels of difficulty)

This is a good support program for those struggling with number concepts. The spoken explanations are clear and always backed up by visual demonstrations. It is limited to halves and quarters which could also assist with time telling.

The main problem for children that I have used the program with so far is that the matching games with Mighty Mick run too fast even at their slowest setting/easiest level. This was frustrating, so you would be forced to use paper exercises anyway. This could defeat the usefulness of the program for the slower child, but useful reinforcement of basic fraction concepts.

Platforms: PC & Mac (CD), Price: £29.37, Publisher: E-Soft, Tel: +44 (0)1302 890000, Email: Guildhall@glukok.demon.co.uk, Web site: http://www.glukok.demon.co.uk/

Foundation mouse skills
Review by Bob Black

This little program introduces the essential mouse skills like moving the pointer, selecting objects, single and double mouse clicks. Its very formal manner may appeal to teachers and to some children as it clearly demonstrates and gives language to, the different activities needed when using a mouse to access any other program.

In my experience, children with Down syndrome seem to take great pleasure in learning by making mistakes, even if this process can be quite frustrating for those around them. However, a bit of discipline does not go amiss, and this little program could cut short the frustration time for both adult and child.
It contains individual activities with spoken prompts and rewards for the following activities:
- How to move and click
- Practice by choosing pictures
- Practice with selecting items on the farm
- Creating dot to dot shapes
- Creating dot to dot pictures
- How to double click
- Practice double clicking
- How to click and drag/move items
- Practice moving objects

These are well thought out exercises that will also encourage listening skills, reinforce shape recognition, and encourage choosing skills.

Platforms: PC & Mac (CD), Price: £29.37, Publisher: E-Soft, +44 (0)1302 890000, Email: Guildhall@glslukok.demon.co.uk, Web site: http://www.glsukok.demon.co.uk/

**Foundation tables**

**Review by Bob Black**

Very easy to use and clearly shown on screen, the multiplication tables are firstly spoken in children voices and then a series of exercises to test memory and recall. Find the picture uncovers a series of fun, cartoon animals as the correct answers are chosen from a multiple choice style frame.

I particularly like the next section, which in some ways is harder. Called “Balancing Tables” it offers a weighing scale animation that has a line from a table on one side and has to be balanced from a similar multi-choice grid. Errors are noted with a spoken prompt like “this is too much” or “this is too little” This section gives good visual representation and could help a child with the concept of multiplication as well as tables.

The last section called “Beat the Clock” is a very configurable and sets a variable time limit and presents the problem in a fruit machine format that was popular with the older kids that used it.

Platforms: PC & Mac (CD), Price: £29.37, Publisher: E-Soft, +44 (0)1302 890000, Email: Guildhall@glslukok.demon.co.uk, Web site: http://www.glsukok.demon.co.uk/

**The author**

*Bob Black* is the Development Officer for the South West region of the Down’s Syndrome Association (England & Wales). He has a daughter with Down syndrome. He may be contacted for advice about software via email at bob@include.demon.co.uk
NEWS

Schools Link Service - Cambridgeshire and neighbouring counties (UK)
This service offers a link between primary, secondary and special schools of children with Down syndrome in Cambridgeshire, Suffolk, Norfolk, Essex, Bedfordshire, Oxfordshire, Hertfordshire and close border. It provides support, advice and sharing good practice between head teachers, teachers, special educational needs co-ordinators and learning support assistants. Link meetings take place every term at various schools to discuss mainstreaming, setting targets, inclusion, academic skill development and teaching practice, reading, writing, spelling and numeracy skills to include SATS, physical and social development, peer relationships, behaviour management, adolescence and sexual development of children with Down syndrome.

The Link is run voluntarily, but supported by outside agencies to include speech and language therapy service, occupational therapy service, physiotherapy service, children’s disability team etc who input specialist advice in their field of practice.

Gerardine Ward-Wilkinson, who organises the Link Service is currently updating the Service’s schools list. If your child attends a school in the areas noted above, please write giving details of the school name, address, telephone number and name of head and class teacher.

Address: 2, Turpyn Court, Cambridge, CB4 2RN. Email: mwbloxam@aol.com

Funding news from The Down Syndrome Educational Trust

New refurbishment bid submitted
The Down Syndrome Educational Trust has submitted a bid to the Millennium Festival Fund for £936,000 towards expanding the facilities and resources at The Sarah Duffen Centre in Portsmouth, and to run a series of “Down Syndrome in the 21st Century” conferences in the year 2000.

Supporters of the Trust may recall that plans for developing the Trust’s resources were put on hold earlier in the year, following difficulties over lease negotiations with Portsmouth City Council (who manage the property that the Trust occupies). The delays caused by these difficulties had led to the loss of a previous grant for £356,000 from the National Lottery Charities Board, which was to contribute to refurbishment of a “Family Services” wing. More recent negotiations have begun to yield progress, and a number of positive options for the redevelopment of the site are now under consideration.

As currently planned, the total project will cost £1.74 million, and will provide additional playrooms, assessment and observation rooms, teaching and seminar rooms, social and leisure facilities, and additional accommodation for professional staff. The balance of the costs will be met with the £762,000 awarded to the Trust from the UK government Single Regeneration Challenge Fund.

Funding being sought for extended range of new research projects
In conjunction with the plans to expand The Sarah Duffen Centre (above), The Down Syndrome Educational Trust is seeking funding for a number of new research projects. As well as further studies of speech and language development, reading, and memory, studies of social skills development and behaviour, adolescence and the transition to adulthood, and vocational training and employment access are also planned.

Positive discussions have begun with some funding organisations, and with partners for the projects involving Further Education provision.
DIARY DATES

Fourth European Down Syndrome Conference: Creating Challenges
10th-13th March 1999 - Malta

Organised under the auspices of the European Down Syndrome Association (EDSA) and the
International Down Syndrome Federation (FIDS) by the Down Syndrome Association of Malta in
collaboration with the Department of Psychology at the University of Malta.
The Conference aims at bringing together persons with Down syndrome, parents, professionals
and others interested in the field in an atmosphere of mutual respect and collaboration. The
programme will consist of a number of plenary and specialist sessions, which may either focus on
issues for particular groups or issues of general interest. Papers are invited for presentation at the
Conference, as well as proposals for themes for symposia, thematic sessions and plenary sessions.
For further information contact:
Conference Secretariat Down Syndrome Association, 45 South Street, Valetta VLT11, Malta.
Tel: +356 235158 Fax: + 356 236197 E-mail: johnpeel@waldonet.net.mt OR: Scientific
Secretariat, Dr Mark G. Borg, Department of Psychology, University of Malta, Msida MSD06,
Malta. Tel: +356 32902269

American Association on Mental Retardation 123rd Annual Meeting - Visions
for the new millennium.
24th-28th May 1999 - New Orleans, Louisiana

For further information contact: AAMR, 444 North Capitol Street, NW Suite 846,
Washington, D.C. 20001-1512, USA.
Telephone: +1 (202) 387-1968 or (800) 424-3688, Fax: +1 (202) 387-2193,
Email: info@aamr.org, World Wide Web: http://www.aamr.org/

Canadian Down Syndrome Society Conference
May 1999 - Victoria, British Columbia, Canada

For further information contact: Canadian Down Syndrome Society, 811 - 14 Street N.W.,
Calgary, Alberta, Canada T2N 2A4,
Tel: +1 (403) 270-8500, Toll Free Inside Canada: 1-800-883-5608, Fax: +1 (403) 270-8291

The Seventh International Down Syndrome Congress
23rd-26th March 2000 - Sydney Convention and Exhibition Centre, Darling Harbour

The conference aims to provide an opportunity for people with Down syndrome, their parents,
carers and families, and interested professionals to address the major issues and hear the latest
developments from international experts.
For further information contact: Congress Secretariat, Seventh International Down Syndrome
Congress, GPO Box 2609, Sydney, Australia 2001,
Tel: +61 2 9241 1478, Fax: +61 2 9251 3552, E-mail: down@icmsaust.com.au

New Millenium - Research to Practice
International Association for the Scientific Study of Intellectual Disabilities (IASSID)
1st - 6th August, 2000 - Seattle, Washington, USA.

The 11th World Congress of the IASSID plans to bring together more than 1,500 people for an
international exchange of knowledge and ideas. Participants will be able to develop networks of
colleagues which can lead to collaborative research and consultation. One of the major benefits of
the World Congress is the opportunity for colleagues working in different parts of the world to
become acquainted with each other's research, innovations and exemplary practices. Attendees
will also be able to consider ways in which these research advances can have a beneficial effect
upon supports for individuals with an intellectual disability and their families.
For program information contact: Dr. Neil Ross, President-elect, Association de Villepinte (IASSID), 28 rue de l’Eglise, Villepinte 93420, France.
Tel: +33 1 43 85 12 06, Fax: +33 1 49 36 11 54, E-mail: njross@compuserve.com
IASSID Homepage Address: http://www.waisman.wisc.edu/iassid/

Tell us about your events
If you have any forthcoming events that you would like included in forthcoming Diary pages in Down Syndrome News and Update, feel free to send us information (address on page 105, or email news-and-update@publishing.downsnet.org). Once we have it up and running, events will also be added to an events database which will be accessible from the DownsNet web site (http://www.downsnet.org/).

For information about any of the events at The Sarah Duffen Centre, please call for a copy of our Training Events brochure.
INFORMATION AND GUIDELINES FOR CONTRIBUTORS

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
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 successes 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
Address for correspondence
Articles, reviews and correspondence should all be sent to:

The Editor, Down Syndrome News and Update, The Sarah Duffen Centre, Belmont Street, Southsea, Hampshire, England, PO5 1NA.

Manuscript requirements for longer articles and reviews
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 3 1/2-inch floppy disc in PC format. Word processors’ file formats that can be supported are (in order of preference): Word for Windows 97, Word for Windows 95, Word for Windows 6, Word for Macintosh 5.1, WordPerfect 6, WordPerfect 5, Works for Windows 4.0, Works for Windows 5.0, or Rich Text Format (RTF). Tables and graphs may be submitted in the following spreadsheet packages’ file formats (in order of preference): Excel 97, Excel 95, Excel 6.0, Lotus 1-2-3, or Quattro Pro. Graphs and diagrams that are submitted as ‘graphics’ file formats should be saved as (in order of preference): Graphics Interchange Format (GIF), Portable Network Graphics (PNG), Corel PhotoPaint (CPT), TIFF Bitmap (TIF), Adobe PhotoShop (PSD), or Windows Bitmap Format (BMP).

Please ensure that your address is attached and, where possible, include direct telephone numbers, fax numbers and electronic mail addresses.

Format
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. All papers should be in English and spellings should be British.

Sub-headings are encouraged, and should be typed in bold. If sub-headings are of different sizes, please indicate clearly. Bibliographical references within the text should be made by citing a reference number in brackets, e.g. “(2)”. Notes are encouraged for additional detail and commentary where appropriate and should be referenced with small roman numerals in brackets, e.g. (iv).

Terminology
As this is an international and an inter-disciplinary publication, the needs of readers from different backgrounds should be born in mind. Technical or other terms specific to a particular discipline should be avoided if possible; otherwise discrete explanations or a glossary might be added. Abbreviations, such as of journal titles, should be avoided.

Authors should avoid the use of potentially devaluing terminology for people with a learning disability. The terms ‘children with a developmental disability’ or ‘with moderate/severe learning difficulties’ are acceptable. The terms ‘mental handicap’ and ‘mental retardation’ are not. The term ‘Down syndrome’ should be written in full, and ‘syndrome’ spelt with a small ‘s’ except when in a title. Please refer to ‘children with Down syndrome’ rather than ‘Down syndrome children’.

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

References
A full list of bibliographical references, cited in the text, should appear at the end of the paper. The list should be numbered in order of citation in the main text.

Articles

Chapters

Article (World Wide Web reference)
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