Contents

Editorial

Sue Buckley ................................................................. ii

The significance of early reading for children with Down syndrome

The use of a reading program and signing to develop language and communication skills in a toddler with Down syndrome
Laura Lee Dickinson .......................................................... 2

Teaching reading to develop language
Joe and Susan Kotlinski .......................................................... 5

Teaching Charlotte spoken language through reading
Geoff Rozen ........................................................................ 7

Teaching Nazli in Turkish and English
Mim Kemal Oke ................................................................. 8

The early reading skills of preschoolers with Down syndrome and their typically developing peers - findings from recent research
Michele Appleton, Sue Buckley and John MacDonald ......................... 9

Learning to count and to understand number

Wiltshire Pilot Project - Numicon (March 2001-July 2001)
Claire Ewan and Caroline Mair ................................................... 12

More news with Numicon
Vikki Horner ........................................................................ 15

Learning mathematics at school and .... later on
Elisabetta Monari Martinez ..................................................... 19

The inclusion of students with Down syndrome in New Zealand schools
Bernadette Holden and Pauline Stewart .................................... 24

Letters: Successful inclusion for Luke ...................................... 29

Providing effective speech and language therapy for children with Down syndrome in mainstream settings:  
a case example
Gillian Bird .......................................................................... 30

Down Syndrome International (DSI) news .................................. 32

European Down Syndrome Association (EDSA) news .................. 34

The Down Syndrome Educational Trust news ............................. 41

Conferences ....................................................................... 43

Reviews ............................................................................. 44

Down Syndrome News and Update provides information to meet the needs 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, issues in adolescence and adulthood, information technology, and educational materials and resources. Information is presented through detailed articles, reviews, research summaries, case studies, news, and by correspondence.
Editorial

Sue Buckley

New format

Welcome to the first issue of Down Syndrome News and Update in its new format. We hope to develop this publication to be a useful resource to parents and practitioners, by bringing you up-to-date information on a range of topics. Please let us know what you think of the new design - the work of Linda Hall, our artist and designer.

International perspective

We are publishing in collaboration with the European Down Syndrome Association and Down Syndrome International, therefore we will be hoping to keep our readers informed of the activities of the international community of individuals and associations that is active on behalf of people with Down syndrome. I have the privilege of travelling a great deal, both in the UK and abroad - I have already visited four different countries this year and it will be eight by the time we reach the end of the year. I am aware of the wealth of knowledge that there is to be shared between different countries and we hope that this publication will contribute to this sharing of information.

Editorial and Review Board

We will be expanding the Editorial Board to reflect the international focus over the next few months and if any reader would like to offer their services, please contact us. We aim to have a Board that reflects the issues from the perspective of a range of different countries and also reflects the range of readers - parents, teachers, speech and language therapists, early intervention teams, doctors, physiotherapists, workers in parent associations, researchers...... and more. We also need readers willing to review new publications for us so do consider how you might help us to develop the publication.

Contributions

In this issue we have featured contributions from parents, researchers and practitioners from 5 countries and news items from many more. Please consider writing for Down Syndrome News and Update. We also want news of the activities of associations and individuals, and the details of forthcoming conferences so that we can promote them in print and on our websites. We hope to encourage debate about issues on a letters page and in this issue we invite your views on the way speech and language therapy might be delivered, but would also welcome views on any other topic relevant to our readership. The copy date for news items and letters for the June edition is 30th May 2002 - send them earlier if you can. Feature articles will be used as soon as possible but might not appear in the next issue. This will depend on space and on the feature themes. We are particularly keen to share examples of good practice and we know that there is much innovative practice out in the field, in many countries. If you know of an innovative project or teaching approach, for example, please ask those who have developed it to write a piece for us.

Features

Topics featured in this issue are reading, number and inclusion in school, with the issue of effective provision of speech and language therapy raised for further discussion in later issues.

Teaching reading to teach talking

In the reading feature, the focus is on the benefits of reading activities to support the spoken language development of children with Down syndrome. Difficulties in hearing, auditory processing and verbal short-term memory hamper their ability to pick up their first language from listening – the way most children do – and using print to make the language visual definitely helps most children. The focus of the articles from parents and a research team is on reading beginning in the preschool years. In my experience, starting reading activities early will produce the greatest gains but across the age range from primary school to adulthood, involvement in reading can help individuals with Down syndrome to improve their spoken language.

Four parents share their experiences of teaching their own children to read before they went to school. We hope this will encourage other parents to try the same approaches. The research report is also encouraging in highlighting reading skill as a strength for many children and resources to guide parents and teachers are listed at the end of the section.

Approaches to understanding number

Many children and teenagers find learning to understand and use number quite a difficult challenge yet it is such a useful skill in everyday life, especially in relation to using money. We have contributions from a parent and from psychologists on the potential benefits of a new number teaching system, Numicon, and a challenging article from an Italian lecturer in mathematics describing the achievements in algebra of some teenage students. There is clearly much more to learn about the effective ways to teach the maths curriculum to students with Down syndrome. Practical resources are listed and we would welcome more contributions on this topic.

Successful inclusion in school

In many countries inclusion of children with Down syndrome in mainstream classrooms is developing fast, and some countries already have some years of successful experience to share. We have an article from educators in New Zealand providing guidelines to successful inclusion followed by an example of success provided by a parent and a description of the support that this child, his parents and teachers, received from a speech and language therapist.

News and reviews

News from EDSA and DSI is featured, and news from The Down Syndrome Educational Trust including advances information on a software development project See and Learn and a on a teaching package Teaching Reading to Teach Talking.

Sue Buckley is Director of Research at the Down Syndrome Educational Trust, Portsmouth, UK, and Emeritus Professor of Developmental Disability at Department of Psychology in the University of Portsmouth, Hampshire, UK.
The significance of early reading for children with Down syndrome

Some readers will know that the work of The Down Syndrome Educational Trust began in 1980 as a result of the observations of a parent. In 1979 Leslie Duffen wrote to Sue Buckley about the progress of his daughter Sarah, then 11 years of age and attending a mainstream school. Sarah was making exceptional progress for a child with Down syndrome and Leslie felt that a major reason for this was her early reading experience. He had introduced her to reading from the age of 3 years and he felt that she had learned to talk from seeing rather than hearing the language. Sue and her colleagues began to research Leslie’s suggestions and found that they were able to teach a sight vocabulary to preschoolers with Down syndrome and that it did help their language and cognitive development in the way Leslie predicted.

Twenty years on, research from around the world has demonstrated that children with Down syndrome do indeed have specific difficulties in learning from listening due mainly to hearing, auditory processing and verbal short-term memory difficulties. These difficulties will significantly impair their ability to learn their first language from listening and, in turn, language delay leads to increasing cognitive delay. Our experience leads us to believe that reading is one of the most powerful ways of helping children with Down syndrome to overcome their speech, language and cognitive difficulties. However, many professionals working in early intervention services are still not aware of the importance of early reading activities, so many parents and children do not receive the help and advice that they need at the preschool stage.

Parents and teachers in other countries have also been discovering the power of print for children with Down syndrome and we include here some examples of the progress of children in the USA, New Zealand and Turkey described by their parents. We hope that these examples will encourage parents, speech and language therapists, early intervention and preschool staff to realise the benefits and importance of early reading activities. These children were all taught by their parents and we hope that everyone will see that no special knowledge is required. We have recently published a guide to teaching reading to preschoolers[1] and we have made several videos in recent years which show children with Down syndrome engaged in reading activities to encourage everyone.[2] No special knowledge is required – every parent teaches their child to talk, and using reading to teach talking just follows the same principles with the use of print.

At the end of these features on early reading we include a summary of a recent research study which compared the reading skills of preschool children with Down syndrome and preschool typically developing children of the same chronological age over a three year period. Both groups learned initial sight words at the same rate, and progress after 3 years clearly demonstrated that reading ability is a strength for many children with Down syndrome.

References
1. Reading and writing development for infants with Down syndrome [DSii-07-02] (see page 10)
2. Reading videos (see page 10)
The use of a reading program and signing to develop language and communication skills in a toddler with Down syndrome

Laura Lee Dickinson
Spotsylvania, Virginia, USA

My son, David, is a rambunctious four and a half year old who, since he was a toddler, has excelled in communication skills and absolutely loves to read. In fact, he can currently read several hundred words. I say this not to brag (well, maybe just a little), but to give other parents of children with Down syndrome encouragement.

David was born on February 16, 1996, and diagnosed with Trisomy 21. From the day he was brought home from the hospital, we read to him.

My husband purchased the book The Read-Aloud Handbook, by Jim Trelease, the day before David was born. The reasons given in this book for reading to your infant and the personal success stories it described spurred us on.

We read an average of ten books to him per day. To keep his interest, we read books with bright, colourful illustrations and rhyming verse, and always read with enthusiasm in our voices. A favourite first book was The Little Dog Laughed and Other Nursery Rhymes, illustrated by Lucy Cousins.

He seemed to enjoy reading time very much and, by 9½ months old, he was turning the pages for us.

The December 1997 issue of Down Syndrome News, the newsletter of the National Down Syndrome Congress, contained a condensed article by Dr. Libby Kumin entitled Literacy and Language. In this article, she made a case for using reading and signing to help children with Down syndrome learn language. When David was one year old, we began taking him to Dr. Kumin’s speech and language clinic at Loyola College near Baltimore, Maryland. The therapists there had us begin teaching David sign language (Signed Exact English). They also mentioned that other parents had spoken of success with a reading program called Love and Learning,[1] saying that it helped with their children’s articulation.

I had read two books on teaching children to read: How to Teach Your Baby to Read by Glenn Doman and Teaching Reading to Children with Down Syndrome: A Guide for Parents and Teachers by Patricia Oelwein.[2] Glenn Doman’s book promotes teaching infants and toddlers to read sight words, the ABCs, and then numbers and other concepts. Like the Glenn Doman method, with Love and Learning the parent teaches the child by showing him the material quickly and without testing. There are no prerequisite skills, and the young child is less likely to tire of this method than one in which he is constantly drilled.

As David began learning to sign and to read sight words, I came to a couple of realizations:

1) there were no indications that his visual or long-term memory was affected by Down syndrome
2) his desire to communicate was not affected by Down syndrome

I had read that children with Down syndrome are often visual learners. I had also read that the brain grows the fastest and is the most receptive to stimulation in the first few years of life. These facts motivated me to continue teaching David. I wanted to take advantage of his strengths and work with him as much as possible, at the optimum time, to help maximize his potential.

Signing helps to bridge the gap between a child’s receptive and expressive language abilities. The amount that your child under-

"We read an average of ten books to him per day. To keep his interest, we read books with bright, colourful illustrations and rhyming verse, and always read with enthusiasm in our voices."
stands far exceeds what he is able to communicate to you. It seems obvious that communicating is more desirable than not communicating. Signing helps to prevent the child (and parent/caregiver) from becoming frustrated. As a toddler, David was with a baby-sitter two days per week. When David had just turned two, the sitter said that she could communicate with David, whereas she couldn’t with another non-disabled boy she cared for who was the same age. One morning, I left the list of words that David could sign with the sitter. When I picked David up that evening, I asked her if I needed to show her any of the signs. She laughed and said it wasn’t necessary. David had shown her the signs she didn’t know as she read through the list!

I believe that signing also facilitates the child’s cognitive development because you are able to affirm that what the child is thinking, and then expressing through signs, is correct. For example, the child signs “hear vacuum” and you can say and sign “yes, Mommy hears the vacuum” or “no, Mommy hears a truck.” Studies have shown that fears of further delays in speech due to the use of signs are unfounded; in fact, signing may help to promote speech. The article How Manual Sign Acquisition Relates to the Development of Spoken Language: A Case Study, by Theresa Kouri of the School of Speech Pathology and Audiology, Kent State University, documents one of the studies which have found signing to have a positive influence on learning to speak. The January/February 1998 issue of the newsletter Disability Solutions contains a great how-to article on teaching signing.

After learning his first sign, ‘more’, which took a couple of months of modelling, David learned new signs quickly. At 15 months, he was signing ‘more’ and ‘book.’ By 18 months, he had added ‘cookie’, ‘eat’ and ‘milk’. We began using Love and Learning with David when he was 15 months old. His signing and reading really took off when he was about 21 months old. The ease with which he learned signs was demonstrated when he was taught the sign for ‘paper’. A therapist showed him the sign one morning; and, with no reinforcement, he signed ‘paper’ days later when his dad gave him a piece of paper to play with.

I was amazed at the way he could associate the spoken word with the written word and the manual gesture. An interesting observation of David occurred when he was almost two years old and I was showing him the word ‘kiss’ in a book from the first Love and Learning kit. It had been several months since he had last been shown this word; and on all previous occasions, I would say the word and kiss his cheek. He had more recently been taught to blow a kiss using his hand. When I showed him the word ‘kiss’ on this later occasion (with no verbalization or gesture on my part) he immediately blew a kiss! He had taken two pieces of information that he had been taught separately:

1) the written word ‘kiss’ is associated with the spoken word “kiss”

2) the spoken word “kiss” is associated with the gesture for blowing a kiss, and he had combined them on his own. I went so far as to confirm that no one else had ever shown him the word ‘kiss’ while blowing a kiss. Another enlightening article, in the September 1997 issue of Down Syndrome News, mentioned similar findings with other children during a research study. The title of the article was Reading before talking: Learning about mental abilities from children with Down syndrome, by Sue Buckley.[3]

I had read that there is usually an explosion of vocabulary when a child is around two years old, and we were trying to take advantage of it.

By that age, David was signing about 75 words and reading at least 60 words. He would demonstrate his reading skills through the use of signs and pointing. The Love and Learning program is such a convenient way to expand the child’s vocabulary. A child who has mastered the kits has a receptive vocabulary of at least 500 words. If the parents sign the words as they read the books to the child, they are helping to keep the child’s expressive vocabulary growing along with his receptive vocabulary.

The Love and Learning reading program was surprisingly easy to use with David. He loved the videos and would request them several times a day. He enjoyed the Love and Learning books just as well as any of his other more colourful books. My husband and I believe that reading to him as an infant set the stage for his receptiveness to the program. If you make reading aloud a cuddling time with your infant, it will be a very pleasant part of everyday life for him and you will most likely have a toddler who begs to be read to. If you don’t start early, you may have a toddler who won’t sit still for this activity that he is unaccustomed to and, therefore, doesn’t appreciate. I have spoken with mothers of toddlers with and without Down syndrome who say that their child is perhaps more active than mine and has a shorter attention span. They have trouble reading to their child. When David was put on steroids at 22 months old, for an unrelated illness, we were afraid that he wouldn’t sit still for reading time because steroids tend to make a child hyperactive. We were pleased to see that he didn’t have the same problem with reading time. Although he would tire of a particular book sooner, he continued to love to be read to. There is no doubt in our minds that reading aloud to David when he was an infant facilitated the use of the reading program with him as a toddler.

My only difficulty in teaching David to read and sign was keeping ahead of him, teaching him new signs and showing him new books, so that he was continually challenged. In addition to using commercial children’s books and the Love and Learning books, I created several books using photographs of household objects and people in his life. Using a thick felt tip pen, I labelled each pic-

"I was amazed at the way he could associate the spoken word with the written word and the manual gesture."

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ture with the appropriate word in plain lowercase letters. I also placed labels on the actual objects in the house such as the refrigerator.

The first Love and Learning book consists simply of the lowercase alphabet, one letter per page. I not only used this book to teach David the ABCs, but it was also an aid in getting him to vocalize. By two years old, he was trying to say the letters when he saw them. At that point, he was making vocal approximations for b, d, f, i, j, m, o, p, r, v, w and y in advance of my saying the letter. It may have helped that I had always exaggerated the sounds. By 27 months, he could recite the alphabet in its entirety, pronouncing all letters intelligibly except for g and h.

David has demonstrated tremendous progress in his acquisition of speech and language since he turned two years old. At two years, David began using word approximations, usually signing the word as he tried to say it. At two and a half years, he began putting two words together and he used signs less frequently. At three years, David was saying phrases/sentences of one to four words, with two and three word phrases being predominant. He could say words such as “clock”, “leaf”, “blower” and “hangers” clearly and with good enunciation of the consonant blends and word endings. He was intelligible to people outside of the immediate family without them first knowing the context in which he was speaking.

He was also beginning to learn grammatical structures. He understood and used plural and possessive forms, he used the suffix “ing” appropriately, and he used the pronouns “I” and “me.”

At four and a half years old, David continues to make progress in all areas of speech and language development. He has increased the length of his spontaneously generated sentences. A recent language sample obtained from his private speech therapist revealed a mean length of utterance of 5.0 morphemes per utterance with an upper morpheme boundary of 10. This calculation places David within normal limits for children his age. I have also heard him string sentences together on many occasions. For example, he has said, “Daddy, I ate all my graham crackers. Please give me some more.”

Standardized diagnostic testing was performed when David was four years, four months old. He was given a total language comprehension age of 3-5 to 3-8. His receptive and expressive vocabulary skills were found to be within the average range for typically developing children. David now uses pronouns (he, she, you, it), articles (the, a), plural and possessive markers (s), and asks Wh-questions (who, what, where). He initiates and responds appropriately to topics of conversation and continues to improve the intelligibility of his speech.

David still enjoys exposure to the written word through books and the Love and Learning videos. Because the written word has more long-term value to David than does signing, I suggested that the written word be used during speech therapy to help increase David’s length of utterance.

His speech therapist at school has successfully used written sentences to cue David to add words such as “is”, “the”, “of” and “in” to his speech.

David’s length of utterance.

He can think of no greater joy than the feeling you get when your child begins to communicate with you. Signing, used as an initial method of expressive communication, can give the child the opportunity to achieve the cognitive growth that speech promotes before the child has the ability to speak. Reading to your child from birth hasnumerous and immeasurable positive effects including increasing attention span, providing opportunities for the child to hear speech, teaching the book’s content, expanding the child’s vocabulary and laying the groundwork for a lifelong love of reading. The written word can also be used as an effective tool in speech therapy. It is also great fun to teach your child to read, especially at such a young age. The sooner you begin with the child, the easier it is; and that early stimulation may make a difference to that growing mind.

References

1. Love and Learning
P.O. Box 4088
Dearborn, Michigan 48126-4088
(313) 581-8436
http://www.loveandlearning.com


Resources

Disability Solutions
9220 S.W. Barbur Blvd. #119-179
Portland, OR 97219-5428
(503) 244-7662
http://www.teleport.com/~dsolns

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http://www.down-syndrome.net/library/periodicals/dsnu/02/01/
Teaching reading to develop language

Joe and Susan Kotlinski
Michigan, USA

Love and Learning was founded 15 years ago to help special needs children develop language and reading skills. Our earlier experience of working with our own daughter, Maria, who was born with Down syndrome, convinced us that reading was an attainable goal for her and one which could bring her much enjoyment as well as serve as a vehicle for learning. As our work with her continued, it became apparent that reading dramatically impacted on her language development as well, and our work with other children showed us that the gains Maria made were possible for them also. In fact, the more Maria taught us about the potential of children with Down syndrome and the more we learned about the related work in reading/language being done in other places, the more convinced we were that a major breakthrough was taking place which would require a re-evaluation of the potential of these wonderful children.

We made our first books, audio tapes and video tapes for Maria soon after her birth when we were unable to find anything commercially available that was appropriate for her special learning needs. We based the origin and development of our materials and technique on the understanding of three basic concepts. The first is that a child’s language development starts soon after birth. Research done by psychologists at the University of Washington in Seattle indicate that infants as young as six months are able to discriminate between variations of specific vowel sounds and will respond to those sounds most typically used by the adults with whom they interact.

This study indicates that rather than being a passive receiver, an infant is in fact organizing and categorizing these small units of language called vowels into meaningful categories. This finding is consistent with the current interest and research into the importance of a child’s first three years as it relates to brain development. The importance of this early period in an infant’s life is now being recognized for all children, not just those with special needs. But if these are crucial and important years for typically developing children, they are particularly so for a child with learning difficulties.

So it is important that we maximize the advantage nature gives us in these early years to impact on our children’s later development by providing stimulation and learning opportunities for them. This is, of course, the thrust behind early intervention.

The second concept upon which Love and Learning is based is that teaching reading to a child with Down syndrome actually enhances language development. Our experience with Maria when she was very young was that the words she learned to read were those she most readily incorporated into her spoken vocabulary. Equally amazing to us was the rate at which she learned to read. At 3½ years she could read and comprehend 250 words and we found her articulation measurably improving. By 5½ years, she could read and comprehend over 1,000 words and was evaluated to read at the 98 percentile of all children of her age. The fact that articulation and vocabulary increase with reading ability was something we heard from many parents whose children use our materials. Children with Down syndrome are typically visual learners and since reading is language made visual, it is the ideal means of helping with expressive language, normally a deficit area for them. The ability to read also is a powerful and dramatic way to reverse the stereotypes many people, some professionals included, hold about our children. In addition, the ability to read and the praise it elicits from others enhances a child’s self-esteem. And of course, reading opens up an entire new world of learning and enjoyment that we want all children to experience.

The third concept basic to the Love and Learning technique is the thoughtful use of new technology coupled with parental involvement. Technology here refers to video tapes, audio tapes, computer programs and especially television, all of which can be powerful teaching tools.

Television in particular, through the use of specifically designed educational video tapes, can have life-changing benefits for a child with special needs. We can use it to present stimulating, fun material that fosters learning even as it entertains. When special videos are given guidance and reinforcement by a parent and/or teacher, their possibilities are extraordinary. We have successfully used videos to teach language (English), reading, geography, maths and even foreign languages. And because we can play these videos over and over, the child gets the repetition he or she needs to master the skill or concept without the parent having to do it all.

“Our experience with Maria when she was very young was that the words she learned to read were those she most readily incorporated into her spoken vocabulary.”
Maria’s reading history

6 months
We began showing Maria lower case alphabet flash cards, one time through the alphabet each day, spending 1-2 minutes. The alphabet was used not to teach reading concepts, but rather to give Maria examples of simple sounds that she might try to imitate.

12 months
We began using an alphabet/word audio tape at nap and bed time. This was not intended to be sleep learning and Maria was awake most of the time the tape was playing. She would usually not fall asleep until all the letters of the alphabet and associated words were said. We made a video tape for her using these letters and words and added flashcards with these same words as well.

At about 1 year of age Maria developed myoclonic seizures and required medication. The medication stopped the seizures but had the side effect of dulling her sensitivity/response to sensory input. Her lack of response to audio stimulation was initially diagnosed as a moderate-to-severe hearing loss. Further testing indicated that her lack of response was due instead to the seizure medication. We continued using the audio tape, video tape and flash cards.

2.5 Years
Maria was taken off of the medication and the seizures did not return. At about this time she started talking back to the audio tape as it played. She also started to name some of the letters when she saw them on the flash cards. Over the next year she started to recognize words.

3.5 Years
Maria had a reading vocabulary of about 250 words.

5 Years
Maria had a reading vocabulary of over 1000 words. In addition she could read and translate 100 words in French and Spanish. Evaluation by the school psychologist to determine education placement showed her to be reading in the 98 percentile.

8 Years
Testing related to Maria’s Individualized Educational Plan found that she was reading at a fourth grade level with a comprehension level at second grade.

9-16 Years
Reading continues to be Maria’s area of strength. She especially enjoys reading the dictionary and encyclopedia. Her word recognition has always been at or above her age level. Comprehension of stories and subject matter has not been as high.

If, after repeated viewing, our children can memorize the dialogue to their favourite movie, shouldn’t we give them a chance to learn something far more useful? By using television and video technology thoughtfully, we can present a wide, exciting array of topics in a manner which greatly facilitates learning.

Our first learning kit teaches the names of the letters but, more importantly for language development, we work on the sound that each letter makes as we stimulate vocalization. Parents whose children use our materials have observed that knowing how letters sound enables their children to reproduce the sounds that make up the word. Often a child who is leaving off the last consonant has been able to correct his pronunciation by going back and looking at the letters which comprise the word. Kits #2-7 continue working on improving pronunciation, vocabulary, comprehension and reading skills as we model simple sentences, teach conversational skills and more expressive vocabulary. Each learning kit includes progressively more material, all of which is presented in a simple, direct format which allows the child to focus on what is being taught. The key to the process is consistent use of the materials. The time required of the parent each day is quite short but spending that small amount of time five days a week over weeks and months is what enhances learning and builds up long-term memory.

After sharing our technique and materials with other families for a number of years, we were excited and delighted to discover of the work Professor Sue Buckley at the Sarah Duffen Centre in Portsmouth, England. She has been researching the relationship between reading and language development in children with Down syndrome since 1980 and her work indicates that reading can indeed be a ‘way-in’ to spoken language for them. Dr. Libby Kumin, author of Communication Skills in Children With Down Syndrome, has acknowledged the importance of teaching our children to read when she wrote:

“Literacy - the ability to read - opens many doors. Until quite recently, it was thought that only an exceptional child with Down syndrome would be able to learn to read; that most children and adults with Down syndrome could not learn to read. Pat Oelwein at the University of Washington, Sue Buckley at the Sarah Duffen Centre in Portsmouth, England and Joe and Sue Kotinski, parents from Dearborn, Michigan, were able to look beyond those negative predictions and make an effort to teach children with Down syndrome to read. Their efforts were so successful they necessitated an entire re-examination of the potential of children with Down syndrome to read.”

We are finding that one of the ‘many doors’ opened by reading is language development. We believe that the work being done today in this area will contribute to a greater understanding and appreciation of our children’s abilities and potential.
Teaching Charlotte spoken language through reading

Geoff Rozen
Christchurch, New Zealand

Charlotte was born in October 1995, in Christchurch, New Zealand; she is the younger of our two daughters. From birth Charlotte attended the ‘Champion Centre’ which is a multi therapist clinic based in our home city. The sessions were once weekly and the therapists included music, computer work, speech and language, cognitive development and physiotherapy. Although this support was important to Charlotte and us, we felt that we wanted to extend therapy to help Charlotte in all areas.

The Champion Centre did not support sign language and refused to discuss this option. Charlotte’s delayed speech and the frustration she felt in the difficulty of communicating concerned us. By the age of two Charlotte had a vocabulary of 30 to 40 words but could not put two words together. When asked to repeat the phrase, “hello Mummy”, she would only say “Mummy”. Her comprehension was typically well advanced of her speech and she could recognise 15 letters and all the numbers to 5.

When Charlotte was aged 2½ we attended the Asia Pacific Down Syndrome Conference in Auckland, New Zealand. One of the speakers was Professor Sue Buckley, who we had heard of via articles sent to us by my sister, a paediatric nursing tutor in London. We attended her lecture at the conference plus an extra day’s course designed for teachers of children with Down syndrome. We were fascinated with her information but wondered if it was too good to be true.

On our return home we started the program straight away with Charlotte, which initially were flash cards, (without picture prompts, just text) of words she would use everyday. Within 2 weeks she was matching, selecting and reading eight words of familiar objects e.g. “Mummy”, “Daddy”, “cat”, “cup”. She loved the work and would get the word cards out of the cupboard and test herself! Next we introduced simple two word phrases e.g. “Hello Mummy” “Charlotte’s drink”. Within a few weeks she could repeat the two word phrases and quickly started to create her own like, “T.V. on”, “clap hands”. We found it easier to make our own flash cards and continued to extend the number of words, until Charlotte had developed a large enough sight recognition vocabulary to move on to books. We visited the library weekly to get early reading books, often just two or four words per page. Charlotte would read these over and over and stunned us with her ability to learn and retain new words.

Her language progressed along with her reading and her grammar continues to improve. Charlotte adores reading and devours books at a great rate.

Charlotte started at our local school six weeks ago with a teacher aide for one-hour morning and afternoon. Her reading ability is the best in the class and this gives her tremendous self-esteem and confidence. We are so thrilled with her progress and are sure the reading program has been invaluable to us.

“She loved the work and would get the word cards out of the cupboard and test herself!”

Charlotte on her 5th birthday

“Within a few weeks she could repeat the two word phrases and quickly started to create her own like, ‘T.V. on’, ‘clap hands’.”
Teaching Nazli in Turkish and English

Mim Kemal Okè, Istanbul, Turkey

A letter from Nazli’s father

Now about Nazli. Nazli is almost ten and is now going to a mainstream school called ENKA in Istanbul, Turkey. The school is partially run by Americans, based on multiple intelligences and the Berkeley GEMS programme.

Nazli is the only child with Down syndrome in the class, but although there is a special instructor for her at school this year she has integrated herself fully with the rest of the class. Nazli is now in the third year and we have no specific problems in her development. She is taking ballet and piano lessons and she’s quite a girl indeed.

She is trying to speak English full sentences at home.

Nazli knew how to read and write before she went to school. As a matter of fact she started to read when she was 3½.

Nazli was 1 year old when we visited The Sarah Duffen Centre in the UK and Sue and Gillian showed us the flash cards. Thanks to you we learned how to teach her to read. With the material you gave us we started first of all with flash cards, Makaton and Portage at home. Of course we adapted them to Turkish. When she was 3½, she could use short sentences; we started to practise with non picture sentences. Her pronunciation and grammar have always been exceptionally good. She is talkative at home but she improved at school. She refuses to speak on the phone and says “I cannot see them father”.

With respect to second language: Nazli went to a mixed prepschool run by an English lady where she started to get used to hearing English. ENKA is a bilingual school and Nazli loves reading the Ladybird series. Again we taught her English by using the same Buckley method, i.e. using flash cards, but this time they were in English. Now she can make sentences in English.

We love her and we are ever so grateful to you.

Nazli
The early reading skills of preschoolers with Down syndrome and their typically developing peers - findings from recent research

Michele Appleton, Sue Buckley and John MacDonald

Department of Psychology, University of Portsmouth, and The Down Syndrome Educational Trust, Portsmouth, UK.

Reading ability is a strength for pre-schoolers with Down syndrome, and they may read as well as typically developing peers at six years of age.

The issue of early ‘sight word’ reading, beginning in the preschool years, discussed in the individual case studies, needs further consideration. Some early readers with Down syndrome find ‘sight word’ learning very easy and it appears to have very positive effects on the development of their spoken language skills and general cognitive development. A recent research study[2-3] shows that preschool children with Down syndrome are able to learn sight words just as fast as age matched typical preschoolers.

Reading progress

The progress of 18 children with Down syndrome was compared with the progress of 18 typically developing children of the same age (2 to 4 years, mean age 4 years 1 month), when their parents taught them to read a ‘sight vocabulary’ with the researcher’s support. In the first year of the study, both groups progressed at the same rate. After six months the average ‘sight vocabulary’ learned was 15 words for the typically developing group and 17 words for the children with Down syndrome. There were large individual differences in the number of words learned in both groups. Some children learned no words and some learned 66 or 67 words, in both the typically developing group of children and those with Down syndrome. By the third year of the study, when the average age of the children was 6 years 7 months and they were in school, the progress of the readers in the two groups (defined as those who can score on reading tests) was compared. These readers (16 of 17 typically developing children and 11 of 18 children with Down syndrome) are at a similar level for reading and for reading comprehension on standardized tests (see Figure 1). Their test scores are not statistically significantly different from one another.

This data supports the view that reading ability is a significant strength for children with Down syndrome and that, for many, the visual discrimination and visual memory skills needed to learn sight words are not delayed for their age. At the stage when all children’s reading progress is largely supported by logographic skills (sight word reading), the readers with Down syndrome (61% of the group) are keeping up with their peers on reading and on reading comprehension. Their progress supports the evidence that visual processing and visual memory skills are less impaired than other areas of their cognitive skills and should definitely be used to support all learning.

Can we predict reading success?

We do not know why some children with Down syndrome who go on to become readers are not significantly different (in statistical terms) on the language measures at the start of the study as there is wide variation in the abilities of both groups of children. However, on average, the readers are ahead by 2 months on the Reynell Expressive Language measure and by 6 months on the Reynell Comprehension measure at the start of the study. After 3 years, the readers are now 8 months ahead of the non-readers on Expressive Language and 11 months ahead on Comprehension.

Do we have evidence of benefits for spoken language?

There is some evidence that reading progress is having an influence on spoken language development from the data collected during this study. The children with Down syndrome who go on to become readers are statistically differently on speaking tests (see Figure 1). Their test scores are not statistically significantly different from another.

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while 4 did not. Our findings do not allow us to predict who will become readers and who will not from their scores on language or mental ability tests at the start of the study. We do not have any firm data on how often parents of any of the children actually found time to teach their children, though we encouraged a minimum of 5 to 10 minute sessions, 3 times a week. Daily practice is the ideal, just for short periods of time.

**In summary**

The findings from this study suggest that the visual discrimination and visual memory skills which support early sight word reading are a strength for children with Down syndrome and they are as good at learning printed words as their age matched typically developing peers. There is also evidence that reading progress had a positive influence on the rate of spoken language development, including expressive language. It was not clear why some children became readers and others did not – a more detailed study, recording the time spent in reading activities and documenting progress more frequently might shed some light on this issue.

**Early start**

It may be particularly important to begin to use reading activities by the age of 3 years in order to have the maximum effect on the children’s speech and language development, as the years between 3 and 7 are the time when researchers into child language development believe that the brain may be most ready to develop language, particularly grammar. This argument has been explained more fully by the second author in a review of the literature on speech and language development in children with Down syndrome. In the authors’ experience, the children with Down syndrome who are exposed to early language teaching through reading from this young age do make the greatest progress with reading, writing and speaking in their school years.

**Benefits at any age**

However, other research suggests that reading activities will still have a significant beneficial effect on spoken language development if started in the school years – it is never too late to engage children and teenagers with Down syndrome in meaningful reading activities and practical guidance is available for, preschoolers, 5 to 11 year olds and teenagers in the new Down Syndrome Issues and Information series (see Reading Resources).

**References**


3. Speech and language development for individuals with Down syndrome - An overview [DSii-03-01]


5. An overview of the development of teenagers with Down syndrome (11-16 years) [DSii-01-06]

Sue Buckley, Emeritus Professor of Developmental Disability, University of Portsmouth, UK, and Director of Research and Training, The Down Syndrome Educational Trust, Portsmouth, UK.

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**Reading resources**

- Reading and writing for individuals with Down syndrome – An overview [DSii-07-01]
- Reading and writing for infants with Down syndrome (0-5 years) [DSii-07-02]
- Reading and writing for children with Down syndrome (5-11 years) [DSii-07-03]
- Reading and writing for teenagers with Down syndrome (11-16 years) [DSii-07-05]
- Reading videos from The Down Syndrome Educational Trust:
  - Reading skills in pre-school children with Down syndrome Ref. VIDE/0010
  - The development of language and reading skills in children with Down syndrome Ref. VIDE/0020
  - Understanding Down syndrome (2) - learning to read Ref. VIDE/0040

- Love and Learning http://www.loveandlearning.com
- Hooked on Phonics http://www.hookedphonics.com

For items available from The Down Syndrome Educational Trust, please send for a Resources brochure.
Learning to count and to understand number

Many children with Down syndrome find number difficult – more difficult than reading – but new approaches give cause for optimism.

The next three articles are on the theme of number and mathematics. Many children and teenagers with Down syndrome seem to find number more difficult than literacy. As with all skills there is a wide range of individual variation in progress with some children enjoying number and progressing well to a level where they can carry out calculations with numbers to 100 or a 1000 and understand ‘tens’ and ‘units’. This level of achievement will help them to understand decimal money systems, weighing and measuring. However many children find number difficult and there is little research as yet into the reasons for this.

One factor could be the typical auditory processing and auditory working memory difficulties as, in order to count, a child has to learn the number sequence at least to ten (as numbers after ten or twenty can be worked out in most counting systems). Calculating typically involves manipulating numbers ‘in mind’ in silent speech which may also be difficult for the individual with Down syndrome. Materials which make numbers and the relationships between them concrete and visual may be expected to help children with Down syndrome as they have strengths as visual learners. For this reason, we have been excited by the potential of the recently designed Numicon system to support the learning and understanding of number for our children. The Numicon system is particularly well thought out as the materials illustrate the nature of the number system accurately. The Numicon number shapes show that each next number is one more equal unit - and this helps children to understand the real nature of the number system and the orderly relationships between numbers.

The Numicon system is not just a set of materials, it is a whole approach to the teaching of number for all children which aims to encourage the use of visual and tactile imagery for the numbers to aid calculation. The materials come with a full range of activities which start by encouraging children to see the patterns and symmetry of the system and to be able to recognise the plates by shape and colour, including games to identify them by touch when hidden in a bag. It is important not to skip over these early activities as the full benefit of the system will be lost if the children do not establish concept images for numbers.

Experiences of Numicon are described in the following two articles. In the first article, two psychologists in the county of Wiltshire, UK, describe the results of a pilot project in which they evaluated the use of Numicon with children in junior and middle schools. In the second article, Vikki Horner, the parent of a daughter with Down syndrome now 11 years old, describes her experience of using the Numicon approach with Charlotte.

The third article is from Elizabetta Monari in Italy and it describes her work teaching mathematics to pupils with Down syndrome in Italy. She illustrates the ability of teenagers in high school to learn algebra, and the ability of a man in his fifties to learn to count and so challenges the low expectations that we may have for the mathematical abilities of children and adults with Down syndrome. Elizabetta puts forward the view that it is counting and calculating that children with Down syndrome find difficult - not all branches of the mathematics curriculum. With her ‘Mathematics tree’ model, she also challenges the view that calculating is a necessary prerequisite for other aspects of mathematics and argues that difficulty in calculating should be addressed by teaching the use of a calculator, for example, and should not prevent children enjoying and understanding other aspects of mathematics. Elizabetta’s examples certainly challenge the assumption that mathematics is difficult for pupils with Down syndrome and hopefully will encourage teachers and parents to experiment further with maths with their children. It is especially important to encourage teenagers to continue to develop their maths skills. They are often more interested at this age as they can see the practical benefits in their daily lives as they handle money and weigh and measure materials for cooking, or for design and technology or on a work placement.

Editor

Numicon shapes 1 to 10, as ordered shapes and showing different ways of adding to 10
Wiltshire Pilot Project - Numicon (March - July 2001)

Claire Ewan and Caroline Mair
Wiltshire Psychological Service, UK

A small pilot project indicates the potential of Numicon for 10 to 12 year olds.

Introduction

Numicon begins with the premise that the richer a person's concept image is in terms of number, the more competent they are likely to be in arithmetic, particularly mental arithmetic.

There is a tendency, nowadays, to move very quickly towards symbols in mathematics. However, symbols are arbitrary and do not necessarily develop the child's number concept, and although the child may be able to write and manipulate symbols, in order to develop mathematically they need a firm, clear and rich number concept. Otherwise, there is a danger that the pupil can arrive at the correct answer but without necessarily knowing why.

The development of concept images for number is closely linked to the tendency to look for patterns. Human beings are programmed to find patterns, and find these in nature, in other people's behaviour, even in clouds in the sky. However, recent numeracy teaching has tended to deprive children of patterns, yet a clear number concept depends very largely on the understanding of the patterns of relationships in numbers.

This is particularly relevant to children with Down syndrome who tend to be good visual learners, and are good with patterns, but tend to have poor auditory memory.

The literacy skills of children with Down syndrome tend to exceed their numeracy skills, and numeracy difficulties are frequently reported as being of concern amongst teachers and teaching assistants working with pupils with Down syndrome.

Recent numeracy teaching does not tend to make use of patterns, but relies heavily on counting. Children are asked to count large numbers of randomly arranged objects and pictures, and also to learn how to count on using a number line, neither of which help them to develop their number concept in terms of the consistent patterns in the numbers being used.

The Numicon materials specifically address this and aim to develop the richness of the pupil's number concept, with the Numicon materials providing information for the pupil on position, action, pattern, colour and shape.

It is very clear to see, from a Numicon plate, whether a number is odd or even, with the tendency to see in the patterns being very clearly illustrated by the typical responses of both adults and young children when presented with such a plate, that there is either 'one missing' or 'an extra one', when compared with the next Numicon plate, either larger or smaller, which will be an even number.

In addition to shape, each Numicon plate has a different colour, and in the early stages the colours also act as cues to the identity of the number plate. Each number plate has its own particular shape and pattern, and the concept image is enriched even further by the practical use of the number plates which involves touching, feeling and moving the plates in relation to one another. This develops tactile awareness, awareness that the quantity remains the same even when the shape changes in orientation, and also provides vital information about the relationships of numbers to one another, concepts such as 'bigger', 'smaller', and 'in between' for example, which are not provided by the written numeral.

Research in Sussex with Key Stage 1 children

The Numicon approach was originally developed in an Infant School in East Sussex with the support of a research grant from the Teacher Training Agency. It was designed for use with children in mainstream at the beginning of their educational careers. Numicon was adopted in the nursery and reception classes, at first in a very informal way, and then gradually developing the children's number concepts one upon another as they matured. The approach was extended into Year 1 early in 2000 and it is hoped that the Year 2 programme of teaching activities will be available next year, taking children up to the end of Key Stage 1.

It was found that the materials were very popular with the pupils, who were encouraged to be imaginative with them, and that strong visual imagery and understanding of pattern were being developed.

The tendency to move too quickly into symbols was resisted, and in the early stages it was important to ensure that the pupil knew the pattern, and how it related to other patterns rather than naming the numeral.

At the Infant School in East Sussex it was found that the children's UK Key Stage National Assessment results improved markedly after using Numicon, number concepts were richer and more firmly established and that children understood and enjoyed mathematics.

The Wiltshire Numicon Pilot Project

It seemed that the principles of Numicon should make it very applicable to the needs of pupils with Down syndrome, and one mother in Wiltshire had already begun to make use of the Numicon materials after having travelled far...
and wide to find an appropriate mathematical programme for her daughter.

The research group consisted of 11 pupils in Key Stages 2 and 3 (8 to 13 year olds), all with Down syndrome, seven being in mainstream schools with support, two in special centres attached to mainstream schools and two in special schools. The group included four boys and seven girls.

The children in mainstream schools were supported one-to-one with a teacher assistant in a small group and in classroom situations, with some children having access to one to one support for a large proportion of their day. The other children were taught as part of a small group either in a specialist centre or in a special school, and children received between 10 to 15 minutes on Numicon every day except during school holidays, with two parents working formally on activities at home.

The children varied greatly in terms of their strengths and difficulties, their personalities, attention control and motivation for maths activities.

The pilot project was introduced with a training day presented by the designers of the Numicon Maths System; Dr Tony Wing, Senior Lecturer in Mathematics Education at Brighton University, Romey Tacon, Headteacher and Ruth Atkinson, Maths Co-ordinator at the Infant School where it was developed.

As far as possible teachers, and teaching assistants attended the training day, at which a Year 1 kit of Numicon materials was distributed. One kit was issued for each school or pupil, with the agreement that the schools would be able to keep the materials at the end of the project - an agreement which they were later very motivated to remind us of!

After the training day, staff were keen and enthusiastic, and most pupils took to the materials, enjoying the shapes and colours, and it became clear that the children rapidly developed their concept images and recognition of the patterns. Two educational psychologists were involved in the project, one in the north and one in the south of the county, and all children taking part in the project were assessed for vocabulary levels and the development of basic number concepts using the British Ability Scales II (BAS II) Naming Vocabulary and Basic Number Skills assessments. The Basic Number Skills assessment was repeated at the end of the four month project to quantify the progress which was made.

Most pupils quickly learned how to order the plates in size without having to count individually. However, some pupils needed reminding to think in terms of patterns and to apply their knowledge of Numicon plates when presented with problems.

Because of their previous teaching, many of the children found it difficult to think in terms of patterns when presented with real maths problems and tended to revert to old strategies of lines and dots, and we felt that this may be a reflection of the fact that this was the approach they had been using throughout their school careers until the introduction of Numicon.

It was found that children who were encouraged to use the Numicon materials in maths lessons and when presented with maths problems tended to be particularly successful on the follow-up assessment where Numicon materials were allowed.

It was found that some children needed specific teaching of number language for example, ‘big’ and ‘small’, and this highlighted gaps that may otherwise have been overlooked at this stage.

Children rapidly felt confident about using the materials and were not threatened by its use. The multi-sensory nature of Numicon was found to be very helpful to the pupils, including activities such as touching and feeling the Numicon shapes without being able to see them, and activities like these quickly helped to establish the children’s understanding and made use of attributes such as size, colour and pattern to help them to identify the shapes. Children quickly learnt to see the number without counting, with many children achieving this within days and one child developing an understanding of numbers 1 to 5 within three weeks, where this understanding had largely eluded her before.

It was clear that the depth of the children’s concept image was increasing as a result of using the materials, and that the materials were also facilitating the development of language, providing information about position, relative sizes, odd and even.

One child began to use the Numicon materials to estimate, and another who had previously hated maths became confident, boasting of her ability and staying on task much longer than previously.

As with other teaching, it was found that some skills were lost after a break for a holiday, but these were rapidly regained after a few days.

**Key issues**

It was found that the use of materials identified large gaps in the understanding of mathematical concepts and language, and that this was picked up quickly using the Numicon materials: children enjoyed the materials very much, becoming very motivated by them, and possibly rather dependent upon them, although this was to be expected after such a short term project. Generalisation and extension activities are part of the Numicon approach and it would be necessary to move towards these rapidly, and to include these at the earliest stages.

A specific request was also made to consider the ways in which Numicon can be used to develop and extend the children’s understanding of money.

**Discussion**

The results are variable, but show an average gain on the number assessment of five months during
the four month period of the study.

We consider these results to be extremely pleasing in view of the fact that the children do not normally make one month's progress per month, yet the average gain exceeds this, and many individuals have improved their skills at a much faster rate than the average.

The pupils who have done best are generally those who are in mainstream schools with one-to-one support for numeracy.

However, this group was also the group who attended the day's training. The special school group and the special unit group were given individual introductions to Numicon when they entered the project but it was clear that the day's training was necessary to ensure the most effective use of the programme.

In addition, the special school group had the added difficulty of a very mixed class situation which was not conducive to the regular use of the programme, and this is reflected in the results obtained.

Despite these difficulties, many positive comments were made from all those involved in using the Numicon materials and there was a strong motivation to continue the programme, expressed by all the participants, no matter how effective the programme had been in implementation.

In all groups, it was also found that participants very rapidly saw the application of Numicon to the needs of other pupils, and we received many telephone calls asking if it was permissible to include other pupils in a small group, as it was very clear that they would benefit greatly. This was permitted, providing the focus for the study, namely the development of the numeracy skills of the children with Down syndrome, was retained. Many positive comments were received including:

“This was the first time the child was able to complete maths with any real understanding.”

“This is the first time the child is completing mathematical tasks independently.”

**Issues**

One or two participants mentioned that children were getting fingers stuck in the holes of the Numicon shapes. This was a particular issue in larger groups, and very mixed ability situations.

The children worked particularly well in one-to-one and small group situations but more difficulty was encountered in the larger classroom situation (12 or more special needs pupils).

There was an issue of overcoming earlier learning, with children still tending to think in terms of lines and rows rather than in terms of the Numicon patterns, and also tended to revert to earlier learning when difficulty arose. None of the children had, of course, been introduced to Numicon as their first introduction to numeracy.

In connection with this, it was found that some children needed a considerable amount of time to become familiar with the materials.

Without full training some teachers and teaching assistants may have been tempted to move too quickly through the activities rather than consolidating the images and concepts, once again emphasising the importance of the full day's training.

It was felt that the pupils needed specific activities to help them to generalise and many needed more consolidation at particular levels, and other staff suggested that extension activities would be useful, and money in particular was identified as a need.

**Main conclusion**

As most of the children's skills were approximately half the level of their chronological age, we would have expected approximately two months progress in numeracy in four months. On average the children made five months progress with a range of one months progress for a child who was not using Numicon on a daily basis up to 11 months progress in the four month period, made by a child who had been using Numicon for six months previously and was also working on activities at home.

There were some issues raised, but none were fundamental concerns. Attitudes of both staff and pupils were extremely positive, and there was a strong determination to continue with Numicon after the project was over.

**References**


Claire Ewan, Educational Psychologist, Local Education Team (North District), Unit B6, Tyak Centre, Vincents Road, Bumpers Farm Industrial Estate, Chippenham SN14 6NQ. Tel: 01249 659202.

Caroline Mair, Educational Psychologist, Local Education Team (Salisbury District), Unit B6, Tyak Centre, Vincents Road, Bumpers Farm Industrial Estate, Chippenham SN14 6NQ. Tel: 01249 659202.

Table 1. Results of the Project

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Note: figures in brackets represent age appropriate scores when the child was allowed to use the support of Numicon materials.

Table 1. Results of the Project
More news with Numicon ...

Vikki Horner
Wiltshire, UK

I continue to write about my personal experiences with Numicon as I hope to inspire some of you into wanting to experience the ‘magic’ that these materials have brought into my home. Those of you who are parents will know what I mean when I say that I am filled with joy each time I watch my daughter demonstrate a newly acquired skill no matter how tiny the achievement and this is continuing as she works with Numicon.

It was Christmas 1999 when I was first told about Numicon. This person’s enthusiasm was contagious and I found myself contacting the company to purchase a school kit. (The parent kit was not available then.) Could this be what I have been searching for all these years? As I looked through the activities and the materials I instinctively wanted to get this into school, so I kept half of the kit and at the start of the January term I took the other half into school and nothing more was said (I will come back to this shortly as it is an important point).

Although we had made a start, due to family commitments and an imminent trip to Australia, it took me until April 2000 to really establish a firm routine. A small amount daily is far better than a lot once a week. By August that year Charlotte had begun to recognise the Numicon shapes and had learnt to order them from 1 - 10. She was able to connect the numerals to the shapes, do some simple addition and had progressed, for some of the activities, to numbers beyond ten thus taking her into place value. With this mastery of skills I wanted to capture it on film and I knew just the person to do this! We continued working with the programme and introduced Cuisenaire rods. Cuisenaire rods are another visual structured set of materials and they help children see numbers as wholes and also their values. The staircase activity for example is a very useful way to teach understanding of values of each rod and their relationship with each other. Filling the trays from the outside in, provided an introduction to subtraction. Three months later the ‘video person’ came again.

Generalisation of skills

Being able to use a learned skill in a different situation or setting, has always been difficult for Charlotte. During those early months without the school liaison, I began to have suspicions that the number skills being learned at home were not crossing over into school. I recall the disappointment I felt each time a school report or Teachers Information Sheet (TIS) came home, eagerly expecting to see some upward movement for maths only to find that the arrow of progress was still stuck on horizontal!!! Yet I knew she had been making progress at home and I had some video footage which supported this progress. So why was there no movement in school?

Then by chance the Educational Psychologist made a visit to school toward the end of last year to observe Charlotte in a Maths session and sent me a copy of her report. It was so depressing that I arranged to have a meeting with her at home to discuss what I had been doing with Numicon. Caroline watched the video footage...
and immediately saw that these materials had the potential to help many children who were struggling with number. Around that time the Wiltshire Psychological Service was planning a small project to help a group of children with Down syndrome prepare for transfer to secondary schools in Wiltshire. Then followed discussions between Caroline Mair and Claire Ewan (EPs from the Psychological Service) and myself, and Professor Sue Buckley (Director of the Down Syndrome Educational Trust) and Dr Tony Wing, (Senior Lecturer in Mathematics Education at Brighton University). In February 2001 everything was in place to start a small Pilot Study to evaluate the Numicon materials. The training of school staff was set for February and the start date was 1st March 2001 and was to run for a period of four months.

Going back to my earlier observation regarding the generalisation of learned skills, during the training day some of the video footage I had taken was shown and Charlotte’s teaching assistant told me that these skills were not coming into school. I have made this point before; it is as though Charlotte was learning maths at school and maths at home as two different languages, storing the information in two separate compartments. We discussed this at length and decided that in order to draw those skills across into school we both had to be doing the same activities initially, using the same language and where we used ‘bridges’ (I talked about this in a previous article) we all used the same words the same prompts and so on, until she started to make connections.

All the schools taking part in the study found their own way of recording their child’s progress. Charlotte’s school and I both made our own record books with sections for all the activities. This made the extra work involved in recording straight forward by simply writing down the task and observations as they happened, together with any comments or explanations the child made. The head teacher suggested that we exchange books at the end of each week as a means of communicating progress. This worked extremely well as we both benefited from this exchange.

However, my role began to change slightly after seeing the positive way the staff were working with my daughter. She was now making those vital connections in school and the feedback was encouraging so I began to relax! Feeling confident that Charlotte was working with Numicon each day, I was able to step back and think about what would be the best way to use my time. I am currently putting together a variety of games to assist generalisation and extension.

**The Teaching Programme**

All children starting to use this approach to teaching number must begin with the **Foundation Stage** (Nursery & Reception) work cards, as they introduce the child to number through pattern. The first set of activities help the child to familiarise herself/his self with the 10 Numicon shapes. If your child is older, she/he would still need to start with these activities, but you may find that the child will work through them quite quickly and eventually find her/his level within the reception activities. This can be a very positive experience for the child as she/he would begin to feel a real sense of achievement and this will help build confidence and self esteem.

The **Nursery Activity** cards introduce four key ideas which are: pattern, order, counting and compression (seeing numbers as wholes). Working with activities like matching shapes, making patterns with the pegs and shapes, swaps, find the shape in the feely bag for example, the children begin to recognise the ten Numicon shapes and start to make the connections between this structured imagery and the numerals they represent.

Ten of the children in the study started from this point and it was reported that they quickly made progress at their own levels; one child commenced with the Year 1 activities as she had previous experience and had already worked through those activities successfully.

Whether it is the Pilot Study or regular work in schools, the natural progression with this approach would be to follow on using the work cards from the Reception stage. This set of materials addresses seven key ideas in the activities and work, they are building on from the work in the Nursery - more pattern, ordering, counting, compression, and including place value notation, addition and subtraction. Children learn to build ‘blocks of flats’ to help learn number bonds; using two spinners and an overlay with numbers to 6, a set of numeral cards laid out in sets of threes; they learn to add the two numbers, identify the card and turn it over. Another activity, which my daughter still loves to do, is hunt the peg. This helps children with addition and subtraction, (hunt the peg now has a variety of additional dimensions in our house!) the wrapping paper game for esti-
learning should come from school. No argument there - because of the powerful visual imagery of the Numicon materials it is one way of opening the numeracy door for our children so, working toward the ideal situation, Numicon should become part of your child's daily maths routine in school, and ideally for 15 - 20 minutes each day during the National Numeracy Strategy hour, allowing time for other aspects of maths to be taught in whole class teaching. The first introductions should come through the accompanying teaching programme and not as apparatus to support other number work as it is like putting the cart before the horse. Let the child become familiar with the structured imagery, begin to see the connections between the images and the numerals. Once an activity or 'big idea' is achieved, this is the time to use Numicon as a resource supporting the teaching, and also introducing other materials and activities for generalisation and extension teaching, being mindful that the child may still need to use the Numicon shapes as a way in, for example -

- Playing the marble game to practice 'doubles' or 'times tables' using a wooden cut-out with lots of 'tunnels' each tunnel having a number placed above the entrance. As the child rolls a marble through a tunnel the child doubles that number, 2 2's are 4; 2 4's are 8; (child may get this right) then 2 8's are 16.
- Let the child choose 2 eight shapes, and if you are familiar with the 'bridge' strategy - the prompt is tens and units, that should be enough to allow the child to do what has already been learned in another situation, in order to find the answer. The child should lay the eight shape above the other eight shape, place a ten shape on top and quickly see that it makes one ten and six units, and finally see the answer - sixteen.

I visited some of the schools in October with Jackie (the 'camera person') taking video footage of the children to support the findings. Watching as they worked through their activities, placing the numerals beneath an already perfectly sorted number line from one to ten. The confidence as they try to be the teacher, and the fun both the child and teaching assistant are having is plain to see. It was grand to watch Charlotte and Mrs Guy, her teaching assistant, play a game with an ordinary pack of playing cards looking for pairs that would add up to ten - number bonds. Watching them both enjoying themselves was a joy to see. (despite the camera) Charlotte was working with such confidence not to mention the addition of a few of her special 'tricks' as Mrs Guy closed her eyes!!

As I continue to work with my daughter the most noticeable observation is that she is just as confident and enthusiastic about using the Numicon materials and still asks to "do some more of that maths." I am also aware of the 'maths' becoming more evident in Charlotte's daily life. The regular setting of the table at meal times has reached a point where prompts are no longer necessary, all I say now is "please set the table". In other situations where numbers are needed I am noting...
Number skills

- It is important to set up good communications between the parent/carer and staff who will be teaching the child number using Numicon. Parents are a good resource!
  They are devoted to their child and want to help them succeed. Because it may take a little time mastering an activity, parents can be supporting, reinforcing, same/similar activities at home through homework schemes for example.

- Always start by using the programme of activities and work through systematically, because they have been carefully designed to scaffold the learning taking place. Using Numicon as a resource can come later.

- Model correct language when teaching an activity.

- Remember - there is no rush to move through the programme, our children need lots of repetition.

- Turn taking - always give the child/children plenty of opportunity to explain what they are trying to do because when they can do this you know they have learnt it.

- Generalisation and extension of skills. With every learned skill using the Numicon materials, both parents and teaching staff should find other activities/games to enable the child to learn to use that skill in another situation. Always have the Numicon shapes to hand as they will prompt the child.

- Numicon as a resource. This would be an appropriate point to use Numicon to support other activities to assist generalisation and extension skills.

- Bridges. A prompt that will remind the child to use what she/he already knows in a new situation.

- Consolidation - children will need to be reminded or need to repeat occasionally, previously learned number skills especially after a break in the school term.

Looking back over the years and remembering the effort and the struggle of it all, which amounted to little success. Then working with Numicon at home where she started to make connections, it still brought with it a hurdle to overcome with the generalisation difficulties that became apparent at the start of the study. I am mindful of the need to also overcome earlier learning approaches as I continue to observe pockets of confusion. At the start of the study Charlotte was 10.9 years old with a maths age of 4.6 years. However, after getting the partnership right with the school and setting up the ideal situation, my daughter gained 11 months bringing her maths level to 5.5 years. We will be assessing her progress again shortly and it will be interesting to see the results. I can’t help wondering where she would be now had she been exposed to Numicon when she was first introduced to number in her pre-school years. We may get some insight to this question once the National Study, currently being planned to start in the spring, is completed. Until then I am content with the knowing that progress is being made.

Conclusions

Like every new project, there is always an unknown quantity that reveals itself after using something new for a period of time and from assessment and evaluation. The following points are as a direct result of the past eighteen months working with the Numicon materials with my daughter, together with the experience gained over the last seven months working for Numicon Limited, and also, still more valuable are the insights that the Wiltshire Pilot Study has given us.

Finally, a lot of ground has been covered in a relatively short period of time and I look forward to gaining more ground and sharing it with you at a later date.

Acknowledgements

I would like to thank my daughter Charlotte for her hard work and my daughter Emily for her help and patience with me as I too had to learn new skills. My thanks also extend to Dr Tony Wing, Romey Tacon, and Ruth Atkinson, the designers of the Numicon approach and to all at Numicon for providing us with a key to the numeracy door. To the Wiltshire Psychological Service and especially Claire Ewan and Caroline Mair whose idea it was to start a short project to help this group of children and for allowing us to tag along and create extra work for everybody! To the many Lion’s zones in Wiltshire, who generously funded the Numicon materials for each child to use in school. My thanks go to all those in school teaching and supporting my daughter and to the staff, the schools and the children for helping us to gather this information for the study. A special thank you to Jackie Calderwood whose video skills captured the ‘magic’ that I see every time I watch the video. To Gillian Bird and Sue Buckley at the Down Syndrome Educational Trust for providing the vehicle to research these materials and who will ultimately make sense of it all for us!

Vikki provides popular workshops on the use of Numicon for parents and teachers - contact her for details.

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Learning mathematics at school .... and later on

Elisabetta Monari Martinez

Teenagers learn algebra and adults learn to count at 51 years old – much still to learn about number ability

Introduction

Do students with Down syndrome learn mathematics?

In 1974 Cornwell[1] said they only learn to count by rote, with no conceptual understanding. These difficulties in counting were used to account for their general difficulty in concept formation and abstraction.

In 1978 Gelman and Gallistel[2] defined 5 principles to divide the counting skill.

In 1987 Sue Buckley and Ben Sacks[3] published a study on 90 teenagers with Down syndrome who had received little early intervention and did not attend mainstream schools:

• only 18% of the sample were able to recite numbers or count objects beyond 20,
• about 50% could only do some simple addition,
• few could do simple multiplication or division,
• only 6% were able to use money and to manage independently in a shop.

In 1988 Janet Carr[4] presented data taken from a longitudinal study of 41 young adults with Down syndrome: at an average age of 21, the maths skills compared to those of a typical 5 year old child, but the reading skills compared to those of an 8 year old.

In 1988 Gelman and Cohen[5] found that children with Down syndrome learn the 5 principles late, but they could be trained by exercises (see Macquarie programme of Thorley and Woods, 1979[6], and research by Joanna Nye and Gillian Bird, University of Portsmouth, 1995[7]).

In 1991 Caycho, Gunn and Siegal[8] found counting skill had a correlation with the development of receptive language and then it could depend on the educative program and on the adult-child interactions.

In 1994 Billie Shepperdson[9] studied the reading and number abilities of two groups of English people with Down syndrome, the people of the first group were born in the sixties and the other were born in the seventies: as teenagers the seventies group had better performances in mathematics than the sixties group at the same age, maybe due to the better learning opportunities and, if teaching continues, they keep on improving into the adult years.

In more detail, in 1995, Nye, Clibbens and Bird[10] found a correlation between numerical ability and receptive grammar.

Some researchers found a significant correlation between mental age and numerical ability, others (as Baroody, 1986[11]) did not.

For the above reasons, special education teachers considered teaching academic skills in mathematics not useful but frustrating, and preferred to focus on community living skills such as the practical use of money and the ability to tell time.[12, 13] This was a notable idea, which helped many disabled people to reach autonomy!

My question is: Are we sure they cannot learn more? Are we sure about what is basic in mathematics and what is the best path to follow in order to teach to each student?

School inclusion in Italy

In Italy, the inclusion of students with disabilities in mainstream classrooms has been warranted by law in elementary and middle schools since 1977 and in secondary schools and universities since 1992.[14] Students with Down syndrome may go on to secondary school, but, until now, no one has been able to get a secondary school diploma: they usually get a certificate of their achievements. So far no one with Down syndrome has attended University. In any case, in an inclusive environment, the teachers and children are motivated to try more academic skills, following the achievements of the typically developing students.

Inclusion in mainstream schools gives the child the opportunity to study different topics and try various activities. [15, 16, 17, 18, 19] The desire to work in the same way as their peers, gives them the will to do their best!

To have successful inclusion we need two conditions:

• to have the freedom and the imagination to close the handbook of special education sometimes and to try a real daily adaptation of the program of the class to the child; to prepare individualized tests, which have to be taken at the time of the class test;
• collaboration between the teachers of the class and the support teacher of the child with special needs, so that the child is a pupil of all the class teachers and not only of his support teacher. Even in severe cases, when a support teacher is present all the school time, students with special needs are very sensitive to the class teacher’s attitude towards them: the class teacher has the authority of the ‘true’ teacher and, on the contrary, the support teacher is considered a ‘friend’.

When these two conditions take place together, the child becomes a ‘genius’ in mathematics, as nobody would have believed before!

Despite good intentions, successful inclusion is not easy. In 1985 Anna Contardi studied how the inclusion of all the students with Down syndrome in the middle schools of Rome works. In the logical-mathematical achievements the students with Down syndrome retained what they had learned in elementary school, but did not improve. Sometimes they did worse. The author wondered whether these results were due to the characteristics of students with Down syndrome or to the manner of inclusion. We believe we have to adapt inclusion to the character of the students, and the teacher’s expectations of the student’s abilities play a basic role in improving learning. Hence better formation of the teachers is needed. On the other hand, Contardi tested the logical-mathematical achievements mostly with indicators of arithmetical skills, where students with Down syndrome have more difficulties.

**Our experience**

Since 1994 I have been counseling teachers in schools to adapt the mathematical program for students with Down syndrome. Usually the parents contact me at the Associazione Down Padova, to which I belong (also as a parent) and ask me to meet the teachers. Often my intervention is not limited to mathematics, but involves the entire curriculum and other aspects of inclusion. This activity has allowed me to follow up 20 cases of students with Down syndrome, included in regular classrooms, as summarized in the box below.

This evaluation was done taking interviews with teachers and parents, school records and homework into consideration.

Hence we have students with Down syndrome who learn to solve problems, to use fractions, to solve algebraic expressions (Figure 1), to measure, to solve geometric problems, to draw geometric figures and diagrams, to use the computer. They are given slightly different tests when tested with their peers and if there are difficulties in mental calculation we suggest visual prompts, such as some simple memory device to carry, or a pocket calculator.

In difficult cases, the desire to use money or the ability to tell time gives them the motivation to begin to study mathematics and enjoy it.

Since 1996 I have organized and managed continuing education courses at the Associazione Down Padova for adults with learning difficulties. In a course for illiterate adults, a 51-year old man with Down syndrome is learning to read, write, count and tell the time (see Figure 2). He is so enthusiastic to learn and that gives us a joyful feeling! Other adults maintain and improve their mathematical knowledge. Adults who have attended mainstream schools have much more mathematical ability than those who have not.

**What difficulties (and strengths) do we observe in mathematics?**

- Difficulty in reciting fluently the sequence of numbers beyond 20 for errors in the change of the tens. The use of rulers can help.

<table>
<thead>
<tr>
<th>20 students with Down syndrome attending regular schools</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Chronological age:</strong> from 7 to 18 years</td>
</tr>
<tr>
<td><strong>Gender:</strong> 14 males and 6 females</td>
</tr>
<tr>
<td><strong>School:</strong> 12 in elementary school, 6 in middle school, 2 in secondary school.</td>
</tr>
<tr>
<td><strong>Good social integration in the school:</strong> 18 students</td>
</tr>
<tr>
<td>‘Good social integration in the school’ means the student remains in his or her classroom most of the time, is happy to stay there (often does not want to leave), is welcomed and loved by his or her peers and participates in the social activities of the class.</td>
</tr>
<tr>
<td>Follows most of the class program with some changes: 11 students (5 females)</td>
</tr>
<tr>
<td>‘Follows most of the class program’ means the student follows the class program, adapted at a lower level, with simplifications and changes and takes class tests (with simplified tests). In some topics the program can be shifted backwards usually one or two years to fill some gaps. Even with these limits, they improve their mathematical academic skills, as nobody would have believed before.</td>
</tr>
</tbody>
</table>

Frequently other students who have the same disabilities: 6 students (2 with hyperactivity, 1 with depression, 2 with relational problems, 1 autistic).

Severe speech problems: 6 students (1 deaf)

Other problems in addition to Down syndrome: 6 students (2 with hyperactivity, 1 with depression, 2 with relational problems, 1 autistic).

The adapted mathematical program is usually followed conforming to the global program, but differs for two students who are weaker in mathematics than the others and two students who are stronger in mathematics.
Number skills

- Difficulties in counting backwards.
- There are no difficulties in learning the procedure of counting objects.
- Difficulties and slowness in remembering multiplication tables and in doing mental calculations. When the aim is not the operation, we suggest the use of a pocket calculator.
- There are no difficulties in working on sets, which means the classification of objects according to one or two or more characteristics, and in logic, i.e. negation, relations, tables of true and false, short chronological sequences, cause-effect relations.
- In problem solving, there are no difficulties if we first teach the students to visualize the problem, by making a sketch or by objects, and write the arithmetical solution afterwards.
- Difficulties in measuring lengths because they do not properly fix the zero point of the ruler.
- The students learn the procedures slowly, but when they have learned them, they perform the procedures carefully and in the right order. In the beginning, a visual representation of the procedure helps.
- There are no limits of age to learn mathematics: students need the opportunity and an aim, for instance autonomy.

These difficulties were observed in many students, though not in everyone, and sometimes they overcame them. For instance there are

![Figure 1. Examples of work by Italian teenagers learning algebra](image1)

![Figure 2. Learning to count at 51 years of age](image2)
students who do mental calculations.

**What are the possible reasons for these difficulties?**
- Problems in short term memory (span and organization)
- Problems in long term memory or in explicit memory
- Possible problems in receptive grammar, i.e. in understanding sentences and in language
- Instability of learning, i.e. sometimes students forget what they have learned. Hence special attention should be paid to ensuring that learning is strongly consolidated
- Delayed maturation: progress is often observed into the second decade of life, in areas where learning is usually completed into the first. This suggests that educational efforts should not be abandoned after the early years, but have to be continued through the teens and after
- There are problems in remembering all the items of a sequence, but, after they are learned, there are no problems in remembering the right order of a sequence
- There are no problems in implicit memory, hence they learn well by ‘doing’
- Problems of self-esteem

**Discussion**
Sometimes the difficulties in arithmetic, the slowness in learning and the difficulty in retrieving what they have learned, discourages teachers from continuing in the study of mathematics, and they prefer to go back and repeat what the child is not able to do. I do not agree with this attitude, because they need to do exercises, but they also need to have a positive image of themselves: hence it is better to follow their interest and go on with the program, helping them in what they are not able to do or allowing them to use some device to fill the gaps.

**What is basic in mathematics?**
Usually people believe that arithmetical skills are the basis of the entire mathematical knowledge, because they are the first step in learning mathematics and because all people know them. This is illustrated in the ‘old’ maths tree in Figure 3. Arithmetic is important, but there is much more that can be learned satisfactorily, and supports such as calculators, visual and other aids can be used to fill the gaps for the arithmetical difficulties. Persons with Down syndrome have notable logical abilities, abilities in space organization, in performing procedures, in understanding and using symbols: these are basic abilities, more important in daily life than arithmetical skills, and taking these as a basis, mathematical knowledge will be built up. This suggests a different conception of maths, illustrated in the ‘new’ maths tree in Figure 3. Here arithmetic is seen as one branch of maths but not a prerequisite for learning other aspects of mathematics. I have reached this conviction by observing persons with Down syndrome and by listening to their teachers and parents, and I am doing research in this area.

**How can we stimulate mathematical learning?**
The more important motivation to study mathematics is to learn what everybody else is learning, which means to be included in the mainstream school. Other stimulation can be given by social or individual games and by aims of autonomy, also for children in school (for instance, to learn the schedule of the day and of the week, calendars, telling time, use of money). It is important also to give an active role to the child and believe in his/her abilities.

**Conclusion**
Most of the students have a successful inclusion in school and follow the class program in mathematics, adapted at a lower level, with simplifications and changes and take class tests (with differentiated tests). Usually they are not weaker in mathematics than the other subjects: it may happen, but the converse may also occur. We have to change our attitude about what is basic in mathematics and give more value to logical and mathematical abilities which do not involve computations. There are children who are good in mathematics and who like mathematics. Courses of mathematics for adults are also useful, because they can learn what they have not learned before. There are no limits of age in learning mathematics.

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Number resources

| Number skills development for individuals with Down syndrome – An overview [DSii-09-01] | Number skills development for teenagers with Down syndrome (11-16 years) [DSii-07-05] |
| Number skills development for infants with Down syndrome (0-5 years) [DSii-07-02] | Numicon ‘At Home’, Nursery, Reception and Year 1 Kits available from The Down Syndrome Educational Trust |
| Number skills development for children with Down syndrome (5-11 years) [DSii-07-03] | |

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The inclusion of students with Down syndrome in New Zealand schools

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Some guidelines for successful inclusion

Introduction

Inclusive Education has evolved as a movement to challenge exclusive policies and practices and has gained momentum over the past decade. Inclusion has become the most effective approach to address the learning needs of all students in regular schools and classrooms.[1]

The inclusion of students with Down syndrome in regular classes in New Zealand has been accepted practice for over ten years. Even before this some students with Down syndrome were educated in the mainstream. Sometimes this came about through rural necessity (there were no local special schools or special classes) and sometimes through parental choice. Today, many students with Down syndrome are included in their regular, neighbourhood schools and many parents, teachers and education specialists believe that all students with Down syndrome can be successfully included.

There are numerous examples of successful inclusion in regular schools evident throughout New Zealand (Service Leaders, Inclusive Services, SES, personal communication). Often these instances are simply accepted as appropriate day-to-day practice. Research suggests[2] that students with special needs who are educated in mainstream settings engage with a wider social group and more often obtain paid, competitive employment in later life (compared to students with special needs educated in segregated settings). Kavermann and Bourke in 1998[3] suggest that there is considerable support for including students with special education needs in the regular secondary school class and that teachers and teacher aides usually demonstrate a commitment to exploring ways to make inclusion successful. The debate is no longer about the rights of children to be included, rather it is about how they can best be included. The end result of this is that it is now more likely than ever before that regular classroom teachers will find themselves teaching young people with Down syndrome.

All students in New Zealand must have their education programme based on the New Zealand Curriculum. For most students, including some with Down syndrome, participation in all areas of schooling is possible without adaptations or modifications to the curriculum. For some, adaptations are needed. Curriculum adaptations and modifications can range from quite simple measures (such as providing written guides) through to the application of assistive technologies. The Special Education 2000 (SE2000) policy sets in place a system of resourcing for students who have high or very high special needs. Most students with Down syndrome have been verified under SE2000 as having high or very high needs and qualify for the Ongoing and Transitional Resourcing Scheme. A major advantage of the SE 2000 policy is that it removes much of the term to term funding uncertainty that used to exist. A further advantage is that the allocation and use of funding is a far more transparent process.

To support the inclusion of all students the Ministry of Education have published the Independent Educational Plans Guidelines (1998)[4] and the Guidelines for Assistive Equipment: Supporting Students with Special Education Needs (2000).[5]

This article is about those modifications and adaptations that are seen to be particularly helpful for students with Down syndrome. Although teacher aide (paraprofessional) support may be necessary to support some of the modifications and adaptations it is important to guard against over-dependence on adults as this can interfere with the development of peer interactions, reduce personal control, separate student from classmates and create a high level of dependence.[6]

The suggestions contained here have been gathered from both teachers and the specialists providing students with Down syndrome with support. In addition many of the practices can be found within the literature on including students with disabilities within mainstream settings. Although the suggestions here will provide practical assistance for teachers who have children with Down syndrome in their classes, many of the suggestions are appropriate for learners with a wide range of abilities and special needs.

Down syndrome: Some basic facts

Down syndrome is the result of an extra chromosome 21 in every cell. It is one of the most common genetic birth conditions occurring in around 1 in every 600 - 700 babies.[7] Although the incidence of Down syndrome increases with the age of the mother, most are born to mothers under 30.[7]

Although people with Down syndrome have an element of intellectual disability, it is no more possible to give a precise statement about the future potential of a child with Down syndrome than it is to give such a statement for any other child. We now know that there is a wide range of cog-
Inclu sion

Specific characteristics seen in this group of students\cite{11,15} include:

- difficulties with auditory short-term memory
- speech and language difficulties
- cognitive delay
- sensory difficulties (hearing and vision)
- difficulty with generalising from one situation or setting to another
- strong visual awareness and visual learning skills
- short concentration span
- delays in fine and gross motor skill development
- auditory processing difficulties

Working with students and young people with Down syndrome

Our model (Figure 1) for working with students with Down syndrome\cite{16} has five components that need to be considered for successful inclusion: structure, teaching approach, environmental adaptation, social and behavioural adaptation, and curriculum adaptation.

This model, supported by the practical strategies gathered by SES Inclusive Services teams, provides a guide to the domains that need to be considered during curriculum adaptation. Many of the ideas that fit within this model are based on both research and good practice observed in schools. Again it should be noted this model and the strategies that support it are appropriate for a wide range of students, not simply for those with Down Syndrome.

Structure

Many students with Down syndrome achieve better when they are learning in structured environments. Structure allows students to be able to predict the sequences both in the school day and during specific educational programmes. For many young people, and particularly for those with Down syndrome, predictable, easily seen and understood structures will increase success and decrease anxiety.

Good practice structure examples include:

- Individual Education Plans (IEP). These record the major goals and the way that they will be achieved. IEPs are a team process that include teachers, parents/caregivers and any one else who has a responsibility for the young person’s educational programme. The setting of goals and the writing of the IEP can of course also involve the student. IEPs are at the core of the education process for many students.
- visually mediated communications, individualised to particular students.\cite{17} These include easily read timetables, colour coded maps of school and community environments, work schedules, and choice boards (charts with pictures of activities to aid choices).
- communication notebooks, used both at school and between school and home. These allow families and teachers to easily share events, activities, successes and issues.
- individualised telephone books for social skill development. Students can use these to call friends and to initiate contacts (the initiation of social contact is a skill that needs to be explicitly taught to many children who have special needs).
- task outlines, describing the beginning, middle and end of each task so that clear expectations are provided.
- personalised instructions that focus the individual's attention on the task and activity at hand.
- explaining the day’s timetable at the beginning of each day before moving onto specific activities. As activities are completed they can be crossed off.

Teaching approach

Students with Down syndrome benefit from seeing the overall task before specific components of a task are attempted. This teaching approach allows for easy prediction on the part of the student and again will contribute to the reduction of anxiety.

Good practice teaching approach examples include:

- task analysis and chaining. Students learn through a series of do this and then this steps. This chaining procedure can be used to systematically teach sequences.\cite{18} For example, when teaching sandwich making, each step is listed and then taught as a sequence just as it would be when teaching how-to-use calculators, basic maths calculations or letter shapes for writing.
- numbers teaching through ‘100s’ boards. Number boards are powerful learning tools (and have been for generations of children) when developing early maths understandings.

<table>
<thead>
<tr>
<th>Structure</th>
<th>Teaching approach</th>
<th>Environmental adaptation</th>
<th>Social and behavioural adaptation</th>
<th>Curriculum adaptation</th>
</tr>
</thead>
</table>

Figure 1. Essential components to consider for the successful inclusion of students with Down Syndrome in the school setting.
Manipulating actual numbers on the board is beneficial at all stages.

- daily charts for learning letters, numbers, sequences of days and months. Always stand away from the chart and use a pointer to ensure that the student can see the whole alphabet or series of numbers.

**Environmental adaptation**

All students learn best when the learning environment is adjusted to meet their specific needs. Whenever young people experience difficulties it is worthwhile to check that the barriers to their learning are not the result of being unable to hear or unable to see. Teachers need to be sensitive to the learning environment of children with Down syndrome as these young people may not have the communication, confidence or social skills to be able to say what is wrong.

Good practice environmental adaptation examples include:

- ensuring that the student is seated within a group in the main body of the classroom (avoiding social isolation). This can be done even when additional space may be needed for assistive technology or ancillary help.

- recognising and compensating for hearing difficulties. Current research indicates that up to 78% of all children with Down syndrome have a conductive hearing loss. A ‘pass’ on routine school testing may give a false positive as hearing is likely to fluctuate throughout the year.

- dedicated spaces, clearly named, and available for the storage and organisation of personal materials.

- a variety of materials for use in written work: whiteboard, blackboard, thick lined paper, felt tip pens, thick pens, regular pens and crayons, for example. Children with Down syndrome often have fine motor difficulties (difficulties with writing and using ball points and pencils). The use of felt tip pens on laminated sheets or on paper can provide motivation for written work because visual success can be achieved easily.

- excellent lighting in the classroom. Many students with Down syndrome have difficulty seeing.

- Auditory sound field equipment set up in the classroom may benefit students who have difficulty focusing on the speaker above the noise in a regular classroom environment.

**Social/Behavioural considerations**

All students need to feel they are valued. This is the key to both immediate self-esteem and, for the longer term, the development of the skills and confidence necessary for living as independent, socially capable adults. Developing relationships and friendships can be difficult for young people with Down syndrome. It is important for teachers to expect and encourage appropriate social interactions between the student with Down syndrome and his or her peers. The teaching of specific social skills such as initiating a conversation, taking turns and listening to others can be very helpful and will probably create social interactions that would simply not take place if these skills were not taught. Understanding the thoughts, intentions, desires and emotions of others is an area of particular difficulty for students with Down syndrome.

Good practice social/behavioural examples include:

- always modelling appropriate interactions with students at all times. For students with special needs this can be critical as these young people are more likely to become confused when the adult behaviour around them is either punitive or inconsistent

- encouraging group participation through the use of cooperative learning strategies and buddy systems.

- providing programmes in the area of ‘mind reading’. These programmes teach the skills for such things as: reading facial expressions and recognising and understanding emotions.

- teaching social skills in context. Examples of strategies to assist these skills include: assertiveness training, role plays based on positive and negative examples, circle of friends, cognitive behavioural therapy (Stewart & Kendall, 1997), and social stories.

- encouraging, expecting and providing social opportunities at home and school. These include telephoning friends, inviting peers over, participating in organised groups such as scouts, brownies, and sports clubs, attending the school disco, the annual ball and school camping.

- providing opportunities for learning age appropriate sexuality behaviour (in accordance with the curriculum guidelines). This is done in consultation with parents and with specialist advice (for example in consultation with an SES advisor or psychologist). Content might include naming of body parts, menstruation, appropriate touching, safety, masturbation and relationships.

- increasing the student’s independence in the self monitoring of avoidance strategies.

**Curriculum adaptation**

Curriculum adaptations are not unique to young people with Down syndrome. Many young people require their educational programmes to be adapted. New Zealand teachers are skilled at providing multi-level programmes and within our education system there is recognition of the concept that one size does not fit all. The extent of curriculum adaptation
will vary across the seven learning areas with some areas requiring quite extensive changes and others only minimal change. Curriculum adaptation will lead to greater opportunities for individual success and as success occurs there is a positive effect on self-esteem. This is true for both the student and the teacher.

Good practice curriculum adaptation examples include:

- increasing the opportunities for success. Although all students need frequent positive reinforcement research indicates that students with Down Syndrome require four times more positive reinforcement than their peers.[30] Although the provision of such high levels of reinforcement can seem daunting it can be provided in a variety of ways and forms. Examples of this include the use of both tangible and non-tangible reinforcers, peer reinforcement and simple star charts.
- reducing the complexity of tasks. Young people are often required to understand complex multi-dimensional tasks presented to them in the form of complex multi-dimensional directions. For all students, and particularly for those with Down syndrome, it is important that the complexity of tasks is reduced. This can be done through the breaking down of tasks in to their component parts and the teaching of the parts as a sequence.
- using appropriate, simple language and ensuring that the instruction/direction is understood. It often helps to use concrete examples.
- providing numerous opportunities for practice. The Rainbow Reading Programme (1998)[32] which involves tape assisted reading, has been used successfully with young people with Down syndrome.
- focusing on the essential skills that will assist in the development of independence in post school years.[31] These skills include managing money (and money machines), arranging social activities and social lives, simple budgeting, self-care and establishing and sustaining friendships.
- ensuring that all curriculum activities and tasks are both age and ability appropriate. Although this is sometimes difficult it is important, for example, that the reading material is both age and ability appropriate
- providing assistive technology, both hardware and software. Examples of commercially developed computer software suitable for students is available through the Centre for Assistive Technology at Specialist Education Services.
- arranging for additional physical activities and programmes to be available. Programmes such as the Sensory Awareness Programme[33] which is designed to improve gross motor skills and the Halberg Sports Programme, where students can meet others with physical and intellectual challenges can be valuable adjuncts to the school curriculum.

Conclusion

There are a number of key factors which appear to increase the likelihood of successful inclusion in a regular class setting. These factors include that each student with Down syndrome is a valued member of the school community and all team members have high expectations of the student. It is important that there is a staff member who takes the key coordination role for the student. In addition class teachers must feel empowered and supported in providing appropriate curriculum and programmes for all the students in their class, including those with Down syndrome. This can be achieved through ongoing training, access to specialist support and therapies, robust team based IEP development and true partnerships between the school, the parents or caregivers and external specialist agencies.

The inclusion of students with Down syndrome, as indicated earlier in this article, is no longer unusual. The challenges that arise from this include outcome research questions (do children with Down syndrome fair better in the long term from inclusive settings) as well as day-to-day teaching and learning practice issues. In the meantime the identification of good practice issues, such as those outlined in this article will provide the initial guidance for the meeting of both of these challenges.

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References


Inclusion resources

Education for individuals with Down syndrome – An overview [DSii-16-01]
Education for individuals with Down syndrome – Whole school issues [DSii-16-05]
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Letters – successful inclusion for Luke

It was our wish that Luke should go to mainstream school when the time came, and he followed his older brother Matthew and sister Emily to Wildground Infant School (our catchment school). Wildground had never before had a child with Down syndrome at the school prior to Luke’s arrival. He was welcomed into the school and from the very beginning everyone has worked hard to make it a success. We always felt able to go in and to discuss any worries or concerns we had and the school did the same with us, and really any problems were dealt with straight away.

When Luke was in Year 2, the children in the class were included when a few difficulties arose, for example it was noticed that some children would speak to Luke in a rather stilted or babyish way or would finish a sentence for him or add in what they thought he was going to say. Whilst Luke was out of the class his Year 2 teacher, Mrs Gardiner, spoke to them about this and explained that they were to give him a bit longer to let him say what he was trying to say and not to baby him.

Luke has been fortunate in Year 2 and 3 to be with the same class of children are very kind and caring towards him (the Educational Psychologist noted in her last report that there was a caring ethos in the classroom). One of my favourite stories of Luke’s time in Year 2 is one that moved me to tears when I was told about it. Luke’s teacher, Mrs Gardiner, would choose a child before lunch each day to stand up and say a prayer. When Luke was chosen he would stand in front of the class with his hands together and say “thank you dinner ladies”, the class who were to repeat the prayer would say “thank you for the dinner ladies”. They would sensitively fill in the words Luke had left out, something they had not been told to do, but an example of what a lovely class they are.

It has also been beneficial for Luke throughout his time at school to be sat in the classroom next to children who are good peer role models in manner and behaviour and who are likely to be sensible and help him in a sensible way.

After Luke’s first year at school we were all frustrated by his lack of progress with speech and language. Following several months of asking for a change of speech therapist and pointing out our dissatisfaction with the one we had (she was unable to treat Luke as an individual, and gave everyone with Down syndrome the same speech therapy regardless of age, ability etc.) I obtained a list of private speech therapists and contacted Sue Thomas and we have never looked back. Again, Wildground School were happy to work with someone that we were paying. Sue told me that she visits many schools in Hampshire, but Wildground was her favourite and everyone was always friendly and helpful, the teacher, the learning support assistant and Special Educational Needs Co-ordinator (SENCO) all worked together and gave up time to spend with her on her visits. Most importantly Sue said that when she left the school she knew that the work and programmes she set would be implemented and Luke would have made progress by the time her next visit came around. Sue was also able to give us things to do at home, one example being when Luke was 4 years old and she first came to us, he would stand in the kitchen and say “iscuit” or “ink” for ‘biscuit’ and ‘drink’. Sue told us to stick pieces of card on the biscuit barrel with “can I have a biscuit” written on it and Luke would read this out before he could have a biscuit. It worked on all sorts of things, e.g. “can I have a drink?” or “Can I have a video on?”

One of the main reasons that Luke’s inclusion has been such a success is that everyone has always been open and frank about everything and as the SENCO once said to me, “we are all on a steep learning curve, but we are all working together to make sure that we get it right for Luke”. Every member of the staff at Wildground from the head teacher, Mrs Kemp, his teachers, Mrs Dixon his LSA, and the lunchtime assistants all worked hard to make his inclusion a success and we can never thank the school enough for their commitment and dedication.

Luke has now moved on to Wildground Junior School and his first term there was smooth and problem free thanks again to the two schools working closely together to achieve this.

Luke also benefits at home from being part of a loving family and having an older brother and sister who are good role models (most of the time anyway!) It is also nice to see him annoying his younger sister Sophie by reading the words in her school reading book before she does.

Jane Randell
Providing effective speech and language therapy for children with Down syndrome in mainstream settings – a case example

Gillian Bird and Sue Thomas

Sue Thomas, Specialist Speech and Language Therapist, has been working with Luke since he was 5 years old, at his parent’s request. They pay for this provision as it was their wish to see an independent therapist who could allocate more intensive time to school visits, and felt that the benefits of following Luke through the school years would give their overall objectives for him consistency and ongoing measurement. Consistency is usually a strong priority for parents and encourages active participation from them (see Luke’s mother’s letter). I contacted Sue to find out how she had worked with Luke and I have summarised our discussion.

During the three years that Sue has been working with the school and Luke’s parents, Luke has moved from being at between the 1 to 2 word comprehension level on the Derbyshire Language Scheme and using single word, unclear speech to now, aged 7 years 11 months, having comprehension at the 4 word level on the Derbyshire and using 3 words/ideas in a sentence e.g. “the boy gave the girl her book”. Luke now listens really well and has a short-term auditory memory span of 4 items. He now initiates communication and dialogue with his peers, which is of enormous benefit to his self-esteem and confidence.

Of course, Luke learned to read at school. They have made full use of conversation diaries and he can say long, familiar sentences. He can read, spell, and is just at the stage of writing a sentence independently. As well as all the reading together and reading aloud that Luke has experienced through differentiated work, they have also used reading deliberately as speech and language therapy. For example, reading aloud slowly, emphasising the patterns of words and sentences, from ‘walking’ (‘ing’ part emphasised) or watched (ed emphasised with a ‘t’ letter sound), to reading whole phrases with exaggerated intonation and syllable formation.

There has also been an emphasis on an adult – usually the Learning Support Assistant (LSA) – reading the text and Luke pointing and then reading word by word, not too fast. Sometimes a tape recorder was used with this method, so that Luke could hear himself. Clusters and polysyllables have been worked on in this way. Sue did not work much on individual sounds with Luke (although he could read and learned letter sounds through literacy) but did do a lot of patterning work, for parts of words and words in sentences.

Sue also included a lot of general language work, and successfully used the Derbyshire Language Scheme activities, particularly implementing receptive language and listening games initially.

Sue pointed out that Luke is very well behaved and has worked very hard. He has had excellent support from an LSA who received training, including training in the Derbyshire Language Scheme, a Special Needs Assistant course, a speech and language therapy course for LSAs. Consequently, she has a good understanding of how language and communication skills develop. Sue has also helped the school with differentiation of the curriculum for Luke, from about Year 2.

For success she thinks three things are particularly important–

- the quality of the programme
- the time spent with school and parents
- a positive attitude to supporting mainstream education with age-appropriate treatment and full inclusion.

Her way of working is:

- spend half a day in school once every term, observing the LSA doing speech and language activities with child (she films sometimes)
- work with the child
- meet with the LSA, Special Educational Needs Co-ordinator (SENCO) and the child’s class teacher
- devise activities and demonstrate these to the LSA, SENCO and class teacher. Visit parents at home, for discussion and demonstration of activities, and make any adjustments
- write up programme and send

This could take much more time than a typical speech and language therapy visit, especially the demonstration of activities, and monitoring how they are delivered by the LSA. However, Sue does not think this is needed more than once per term. She has some two weekly sessions (where working for a school contract or because it is specified on child’s statement) and thinks this is too often - the children have not had enough time to practice the activities to show sufficient progress and for her to be able to monitor this.

With all school age children she thinks this is the case, even for speech work, provided the LSA has been shown and taught how to do the speech work. Twice a term would be a maximum she thinks, and that once a term really is adequate, with a programme of
a high quality and enough material for the educational team to follow and use. It is the quality of the daily speech and language interaction with a child and daily practice of extra activities that will make a difference to their progress, rather than therapy sessions.

She is obviously thrilled with Luke’s progress.

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Comments please

The best way to provide speech and language therapy is a controversial issue so please write to us with your views as parents, teachers, therapists or assistants. In the next issue we will be publishing guidelines on good practice for speech and language therapy services from birth to adulthood to continue the debate.

Editor

This is a very practical book aimed at providing the information and resources needed to enable parents, teachers and classroom assistants to understand the language demands of the inclusive classroom and to enable children with Down syndrome to access the language of the classroom. It is a large format, similar to the other specialist books on reading and motor skills in this Woodbine House series.

It begins with an overview of language needs in schools and the specific difficulties that may influence the abilities of children with Down syndrome in the inclusive classroom. Key points are given as bullet point lists and the language needs are divided into the language of the curriculum, the language of instruction, the language of the hidden curriculum, the language of testing, the language of classroom routines and social interactive communication. Each of these topics is introduced in the overview chapter and then has a full chapter devoted to it.

In addition, there are chapters on the communication team, evaluation and eligibility for speech and language services, the use of the IEP in planning for a communication support programme, helping children learn in inclusion and augmentative and alternative means of communication. The format of all the chapters is excellent. The key points are clear and the chapters are full of illustrations of children’s work, adapted worksheets, techniques for differentiating the curriculum and increasing access to all the learning opportunities in school. It is a wonderfully accessible and practical resource book which would be useful in any school that is including a child with Down syndrome, in any country. There are some references to the educational legislation rights in the USA and which may not be directly transferable to the situation in other countries, but even here, the basic principles can be easily applied to the situations elsewhere.

This book is about helping children with Down syndrome access the curriculum and the language of the classroom, it is not a book about how to improve the spoken language skills of children with Down syndrome. It is assumed that children will have access to a speech and language therapist who will be providing them with individual therapy support. Of course, increasing access to the language of the school and the class will be likely to improve children’s speech and language progress, but their specific needs will still require a planned programme. A good speech and language therapist supporting a child in an inclusive setting will be able to provide advice and activities which do target the individual child’s speech and language needs and give advice on adapting classroom work to increase its accessibility. However, all the activities and advice in Libby Kumin’s book could be implemented by classroom assistants and teachers, if there is no regular speech and language therapy support available.

Sue Buckley

Classroom language skills for children with Down syndrome

Libby Kumin

Published by Woodbine House, Bethesda, MD, 2001. £16.50

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http://www.down-syndrome.net/library/periodicals/dsnu/02/01/
DSI news

Down Syndrome International is a federation of organisations and individuals committed to ensuring the quality of life and human rights for all people with Down syndrome.

DSI organises the World Congress on Down Syndrome every 3 years with a host country – the 8th will be in Singapore October 2003.

DSI is focusing on dissemination of information in collaboration with other organisations

DSI is developing a website at http://www.down-syndrome-int.org/

Membership is open to individuals with Down syndrome, parents, practitioners, researchers and organisations

Report on conference ‘promoting the resilience of intellectuals with intellectual disability in Africa’

The conference was held in East London, South Africa, from the 3rd to the 5th of October 2001 with the 2nd being set aside for pre-conference workshops.

The original brief for the conference emerged from the fact that Down Syndrome International wished to have an executive committee meeting in South Africa in the second half of 2001. The East London branch of Down Syndrome South Africa offered to host a conference at the same time if the following conditions could be agreed to:

1. The conference would focus on intellectual disability not specifically Down syndrome.
2. Other organisations would be drawn into organising the programme (particularly Disabled People South Africa - DPSA, Disabled Children's Action Group - DICAG and the Office for the Status of Disabled People - OSDP).
3. The conference would focus on the human rights aspects of intellectual disability.
4. The conference would focus on inclusion in all aspects of life.
5. The conference would be Africa wide.

All this was agreed to.

The thinking behind these conditions was as follows. Firstly, Down syndrome associations tend to have a narrow focus and are often not fully part of the broad disability movement. On the other hand the broad disability movement often focuses on physical and sensory disability with intellectual disability seen as a poor third. This conference was seen as an opportunity to bring these groups together. Secondly, many conferences on intellectual disability have focused on the genetic, preventative and medical aspects, firmly located in the medical model. With the focus on inclusion, the conference located the debate in the human rights model. Thirdly, by targeting Africa we wanted to establish links across the continent.

The conference organising committee has been very successful in achieving these goals:

1. The organising committee has consisted of representatives of all these organisations.
2. Over 250 people attended the conference from twenty different countries.
3. Rather than following the traditional conference paper/poster approach, the conference was both this and a workshop. A number of themes around inclusion were identified and for each theme there was a workshop in which invited speakers addressed the issues around that theme. This allowed the conference organising committee to go way beyond the traditional conference approach.
4. Inclusion International was well represented by Don Wills (president) and Robert Martin.
5. We had enormous interest from across Africa and speakers (both invited and presenters of papers) came from Uganda (the minister), Zimbabwe, Lesotho and Zambia.

In addition, there were participants from Botswana, Tanzania and many West African countries.

6. A powerful feature of the programme was the self-representation (or self advocacy) by adults with intellectual disabilities. Three adults spoke in the plenary sessions (Robert Martin, Shona Robertson and Thabo Papo). In the workshop sessions a number of adults with intellectual disabilities presented (Robert Martin, Elizabeth Motale, Bongani Bushula, Bradley Summers, Shona Robertson, Andrew Parker, Andile Tshele, Nomsa Malomo, Lerato Moletsi, Cornelia Fowler, Craig Groenewald).

7. We specifically targeted parents and adults with intellectual disability. There was a good response from DICAG and from several rural areas (including relatively remote rural areas such as Maluti and Bushbuckridge). In addition, there has been a good response across many countries in Africa (particularly from the Down Syndrome Associations). At least half of the delegates were either parents or adults with intellectual disabilities.

8. The closing declaration (see later) was adopted unanimously. We are still discussing how to move forward with the declaration. Matthew Parks (the DPSA parliamentary officer) attended the conference and was part of the drafting team and presented the conference declaration.

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http://www.down-syndrome.net/library/periodicals/dsnu/02/01/
9. The DSSA AGM was held during the conference and two adults with Down Syndrome were elected onto the committee.

10. We generated exceptionally good media coverage. The event was covered by national television and national and regional radio. The local newspaper (the Daily Dispatch) gave us superb coverage before, during and after the conference. We were covered by community radio stations and community papers. Journals and magazines such as the Teacher, the SADTU magazine, Hi-Lite (the local business magazine) featured articles.

11. The focus was broader than Down syndrome. Most of the workshops/sessions covered transversal issues such as education, employment, sport and recreation, parenting, Specific issues covered included fetal alcohol syndrome and autism.

But above all we generated enormous interest and discussion around intellectual disability. There have been so many positive comments from delegates.

In terms of the future, the biggest prize is to link adults with intellectual disabilities and parents with their counterparts across Africa and with Inclusion International. We feel we have had some success here. Secondly, we would like to shift the focus of intellectual disability from the medical model to the human rights model. This was definitely achieved. Thirdly, we want to continue the process whereby adults with intellectual disability occupy centre stage and besides contributing to the conference proceedings, we would like to support the process whereby they occupy positions of power within organisations. Fourthly, for South Africa we would like to continue to strengthen the links between specific disability organisations (e.g. DSSA) and the umbrella bodies (DPSA and DICAG).

Above all the conference was a moving experience for all delegates. We shared (often deeply personal issues) and learnt from each other. We made deep (and hopefully abiding) contacts. But more, we enjoyed ourselves in celebrating the diversity of humanity.

The East London Declaration on Intellectual Disability

We, the delegates of the Conference Promoting the Resilience of Individuals with Intellectual Disability in Africa, assembled here in East London, South Africa from the 3rd - 5th October 2001, hereby reaffirm our commitment to the promotion, protection and implementation of the human rights of individuals with intellectual disability. We recognise the necessity and urgency for including individuals with intellectual disability into all areas of community life. In order to achieve this goal we urge governments and communities in Africa in the spirit of the African Decade of Disabled Persons to:

- Develop mechanisms for ensuring access and support for all learners with intellectual disabilities to educational opportunities within single, inclusive education systems that ensure that all learners are able to learn and develop to their full potential; and participate and benefit equally in the process of teaching and learning.

- Recognise the unique contribution that individuals with intellectual disability have to make in a society that values diversity and facilitate their participation in all aspects of community life.

- Disseminate accurate information on the causes and prevention of intellectual disabilities.

- Acknowledge and promote the right to self-representation of persons with intellectual disability or their chosen advocates in all areas of decision making which affect them in any way.

- The rights and needs of persons with intellectual disabilities should be recognised and championed at all levels by the entire disability sector through the promotion of self-representation and cross-disability solidarity and the adherence to the principle of “nothing about us without us”.

- Provide support to families of persons with intellectual disabilities through counselling and other services.

School to Work Transition (SWT), should be provided for school leavers with intellectual disabilities. Advocates, educators and providers are urged to replicate SWT in their communities with existing resources. National coordination and capacity building is required in order to support these initiatives, learn best practices from them, and motivate rational government policy and long-term funding for them. Governments must train their own officials and all school educators on inclusive education and SWT and respond to the needs for SWT with support, consistent policy and funding.

Economic empowerment projects, support, and strategies that create inclusive, non-segregated productive and meaningful options for all levels of people with intellectual disabilities must be implemented at local levels. Best practice information and training are needed for educators, service providers, people with intellectual disabilities and their families. Government policy makers, officials and other role players need awareness and training in best practices so that policies and funding that promote integrated economic empowerment can be implemented and segregation eliminated. National coordination is urgently needed to share best practice information, document success, and assist government in policy change.

Affirm the rights of individuals with intellectual disability to make informed choices with regard to reproductive rights and personal relationships.

Provide access to health care services which respect the dignity and privacy of individuals with intellectual disabilities and which facilitate informed decision-making.

Sport and recreation policies of governments should facilitate sponsorships, accessibility, education, training and participation at all levels.
The European Down Syndrome Association seeks members from all the countries of Europe, whether or not they are in the European Community at this time. EDSA promotes international conferences around Europe and it makes a priority of helping countries with less well developed services for individuals with Down syndrome. Recently EDSA members have provided training events in Russia and in Romania, as well as support to the new parent group in Luxembourg. The last two events are reported in the following pages. The EDSA Board meets twice each year and membership is open to associations. Two representatives, a parent and a professional, from each member country sit on the EDSA Board. The next major EDSA event is the meeting in San Marino in May 2002. EDSA plays a major role in supporting associations in Europe and in networking information across Europe.

The 5th International Symposium on Down Syndrome supported by EDSA was organised by Professor Juan Perera, current President of EDSA, and his organisation on Mallorca, ASNIMO, in collaboration with other groups as illustrated on the programme cover. The theme of this Symposium was Meeting the Educational Needs of Children with Down Syndrome – particularly in inclusive education settings. The photograph shows members of the organising groups at the opening ceremony, with Professor Perera third from left.

It was a practical programme aimed at meeting the needs of teachers and education professionals and speakers included members of the UK Education Consortium – a group of education professionals committed to promoting inclusive education in the UK. Some 400 delegates attended from many countries. The speakers included: Bob Black, Education Officer for the DSA (England, Wales and Northern Ireland); Sandy Alton, Specialist Advisory Teacher, Oxford Education Authority, UK; Jane Beadman, Educational Psychologist, Devon Education Authority; and three staff from The Down Syndrome Educational Trust: Pat Le Prevost, Specialist Speech and Language Therapist; Ben Sacks, Developmental Psychiatrist and Sue Buckley, Psychologist.

At the end of the 3 day meeting, conclusions were drawn together and circulated, highlighting the principles which emerged during the Congress and these are printed below.

CONCLUSIONS

1. The identification of the specific difficulties associated with Down syndrome, naturally leads to the design of more effective pedagogical and medical tools for the rehabilitation and education of people with Down syndrome.

2. In the educational field, the Symposium unreservedly supports the following principles: a) The normalisation and inclusion of all children with Down syndrome in mainstream schools; b) the provision of specific support and curriculum adaptation within the same school by specialised staff; c) the application of new technology in the classroom as a specially useful strategy.

3. For inclusive schools to be effective for children with Down syndrome, it is necessary to train specialists from University and establish mixed support teams (public-private).

4. Specialised and preferential attention must also reach individuals with Down syndrome who have other additional and serious limitations or needs that prevent their effective inclusion into mainstream centres. They can be educated in special centres, with family support, ensuring the highest level of normalisation possible in each case.

5. Special attention must be given to the child’s early years through de-centralised specialised services for early attention to the child with Down syndrome and family.

6. Finally, the Symposium calls attention to the current importance of adult life for persons with Down syndrome, including programmes of transition into adulthood and to self advocacy, so that the services provided are adapted to their rights, needs and demands and guarantee both independence and a good quality of life.
EDSA news

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EDSA news

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On October 12th 2001, a semestrial Board Meeting brought the different EDSA members to Luxembourg, where the newly founded national association “Trisomie 21 Lëtzebourg asbl” hosted the meeting in the Eurohotel in Gonderange, a small village close to the capital.

The agenda encompassed a total of six different topics. The meeting opened with the approval of the minutes of the Palma board meeting, which was just a formality.

The discussion of the different issues running under the heading of Status of the EDSA Action for 2001 however proved much more time-consuming than anticipated. The EDSA Identity Document prepared by Professor Juan Perera and presented by Professor Jean Rondal in particular gave rise to a lot of debating, which was somehow to be expected, given its fundamental nature. Thus, the different members were granted some extra time until the end of the year to send in their comments. The subsequent presentation of the first version of the European Preventive Medicine Protocol for Down Syndrome by Professor Rasore went much more smoothly. The same was also true for Professor Sue Buckley’s proposal for a collaboration between Down Syndrome International and the EDSA, which would consist primarily in having them work together to adopt the peer-reviewed research journal Down Syndrome Research and Practice, as their official research publication and to use Down Syndrome News and Update to carry news of their events and activities.

Regarding the European Disabled People Day, Monique Randel suggested the sending of EDSA email greeting cards featuring Down syndrome topics to all people concerned. Work on the Database on Down Syndrome Scientific Bibliography, aimed at compiling all bibliographic data on Down syndrome published worldwide in the last five years, has progressed pretty well and Professor Perera was able to submit an impressive draft version.

The secretary’s part contained no stumbling block either. Cees Zuithoff first gave a brief summary of the European Disability Forum assembly general of June, 2001. In the ‘New Members’ category, EDSA welcomes the national Romanian association represented by Mrs Liana Vizlan among their ranks while a new Belgian organization, Downsyndroom Vlaanderen, based in Flanders and represented by Cedric Depuydt and Katrien Hutsebaut also applied for membership. EDSA aims to represent all countries in Europe, EU, EU applicants and non EU countries.

Following the secretary’s intervention, treasurer Pat Clarke outlined EDSA’s present-day financial situation, which can be qualified as sound. This did not however prevent him from reminding the slightly less conscientious members to pay their membership dues.

Finally, Professor Rasore gave some details of the program of the European Congress to take place in San Marino in May and Professor Rondal presented a new scientific magazine, Journal de la Trisomie 21, written in French and published by APEM and the University of Liege.

Frank Mergen/Cees Zuithoff
EDSA news

Symposium in Luxembourg

Following the EDSA board meeting in Luxembourg, the local association “Trisomie 21 Lëtzebuerg asbl” organized in collaboration with the ISERP, the Luxembourgish school for preschool and primary school teachers, a symposium on Down Syndrome and Language Acquisition (“Down Syndrom und Sprache”) in Walferdange on October 13th. With an audience of over 200 people, this event clearly illustrated the high level of interest this topic met with among both professionals and parents. The main languages of the symposium were German and English.

After a short welcome speech by Professor Paul Dumont (representing the ISERP) and Dr Frank Mergen (president of Trisomie 21 Lëtzebuerg), EDSA president Professor Juan Perera analysed in his lecture the challenges the New Europe poses for people with Down syndrome.

In the first full lecture, Inclusion in education - the benefits and the keys to success, Professor Sue Buckley of the Down Syndrome Educational Trust (pictured left) drew on 13 years of experience of supporting the inclusion of children with Down syndrome in mainstream schools to describe the way in which inclusion is organised and the curriculum delivered for children from 5 to 16 years. To the great interest of the audience, she also included data from a study comparing the effects of special and mainstream education on achievements in teenage years. These data suggest a definite advantage for inclusion into mainstream schools over education in specialized institutions with the competent peer model emerging as the single most important factor responsible for these findings. As this lecture addressed a number of highly sensitive issues in the present Luxembourgish situation, it was followed by a most lively discussion.

The next speaker, Mrs Monique Randel (pictured right), analysed in her intervention titled Warum fällt es Kindern mit Down Syndrom so schwer, zu lernen und vor allem sprechen zu lernen? (“Why do children with Down syndrome have such a hard time learning in general and learning how to speak in particular?”) what the anatomical and morphological factors at the basis of the learning difficulties are before developing strategies to overcome these shortcomings. In particular, she stressed the importance of a challenging environment taking into account the interests and abilities of the child.

After the lunch break, Professor Buckley explained in her second lecture, Teaching reading to teach language, how reading can be taught to support the spoken language development of children and teenagers with Down syndrome. Practical examples of children's work and outcome information from longitudinal research studies of reading progress illustrated her developments.

As last speakers, Luxembourgish pre-school teachers Marianne Damiani and Brigitte Stammet talked about their experience with the early reading methods advocated by Professor Buckley with a child with Down syndrome in their mainstream pre-school class. Their conference Das frühe Lesenlernen mit einem Kind mit DS in einer luxemburgischen Vorschulklasse (“Early Reading with a child with Down syndrome in a Luxembourgish pre-school class”), which put a special emphasis on how this individualized technique contributed to the creation of positive learning environment for every child in the class, was richly illustrated with film sequences and drew a lot of interest as it showed that these techniques can also be put to good use in the Luxembourgish context with its bilingual tradition and without any detrimental effect on the other pupils.

Frank Mergen
First conference on Down syndrome in Romania

European Disabled People’s Day (3rd December 2001) was celebrated in Romania in a special way. This country has had a problematic attitude towards all people with handicaps and has a bad reputation because of the treatment of disabled children. Now, for the very first time in Romania, a congress on behalf of people with Down syndrome has taken place in Craiova, a city in the southern part of the country.

The event was sponsored by Unicef and World Vision, two organisations who are active in Romania, especially in the service of disadvantaged children. Without their financial support the conference would not have been possible.

But it was the commitment of the chairlady of a small parents’ organisation, Liana Vizlan, which brought Unicef and World Vision together and convinced them of the necessity of holding such a conference. Liana Vizlan, who had the idea of organising the Down syndrome conference, managed within four months not only to find professionals from different countries who were willing to speak in Craiova, but also managed to bring parents and professionals from all over Romania together.

Conference participants had no expenses. There were no congress fees and even the travel costs and one overnight stay in the Craiova Hotel, where the conference took place, were paid for by Unicef. This is necessary in Romania, as ordinary people just do not have the money, (even if they have a great interest in the topic) to spend on things other than their daily living needs. The same applies to the institutions, who cannot afford to send their staff on seminars etc.

Altogether there were about 100 professionals – doctors, teachers, speech therapists and physiotherapists – from all parts of Romania who met in Craiova. Most of the parents (also about 100 people) came from the area around Craiova. Because the organisers had also planned a party for the children on the same day – a Nicolaus party with presents, music, food and drinks – many families had come with their children, aged from 1 to 25 years. Among the official guests were the Inspector for Special Education in the Ministry of Education and Science, the directors of Unicef and World Vision Romania, and politicians from Craiova and the surrounding area. One of the conditions Romania has to fulfil, if it wishes to become part of the European Community, is to improve the situation of people with disabilities. This may be one reason that in recent times politicians have shown more interest in these topics. The same can be said about the media, who report more often about persons with a disability.

Mrs. Vislan wrote to EDSA for the first time in May 2001. She then came in contact with some of the representatives of European Down syndrome associations and was able to take part in the EDSA meeting in Luxembourg in October 2001. In the meantime Aldo-cet, the parent organisation, had applied for membership in EDSA. Through these EDSA contacts, it was possible to find professionals who were willing to travel to Craiova and give presentations to the audience there.

After the opening words from the official guests and the organisers of the conference, Cees Zuithoff from the Netherlands, secretary of EDSA, presented his talk “The Challenge for Down Syndrome People in the New Europe”, the goals of EDSA, marked the need for integration and made it clear, that all the changes we have seen in the western European countries were only possible due to the commitment of the parents.

The empowerment of parents is an important message, especially in a country like Romania where civil rights did not exist for many years and people are still in a process of learning to stand up for themselves. The presentation by Professor Alberto Rasore Quartino from Genua, Italy was entitled “Health Care Guidelines from Infancy to Adulthood” and certainly made a deep impression on the audience. In a country where most of the children hardly ever see a doctor, there is still a very long way to go until all children receive regular check-ups. But with this conference the first step has been laid on the long road. Cora Halder from the German Down Syndrome Info-Center talked about “Learning Aspects in Down Syndrome”. All speeches were made in English and translated into Romanian by two interpreters, who were well prepared.
In the afternoon there were different workshops to choose from. Professor Rasore met with several paediatricians and other medical doctors for an intensive professional talk. Sam Campbell from the Scottish Down Syndrome Association and Cees Zuithoff held a workshop for parents – they talked about intervention, mainstreaming in school and at work, life as a family and many other topics. The follow-up discussion took hours. There were so many questions to be answered and at seven o’clock in the evening the families were still there (from 9 o’clock in the morning!) Parents had also many questions for Professor Rasore, who came to this workshop later. We all noted how enormous the need is for information in this country. The other professionals, teachers etc. participated in a workshop with Cora Halder on Speech development and (early) reading. To hear that children with Down syndrome are able to learn to read and especially the ‘early reading’ topic is quite sensational news for the Romanians, then only few children here attend school and very few have been taught to read or write up until now.

Jeanette Schouten (Netherlands), director of the Stichting Down’s Syndrome talked about Development and Education of Children with Down Syndrome and as an example she used her experiences with her own son, which made her speech authentic. She discussed the topic of ‘mainstreaming’ in school and showed parts of the Dutch film Down to earth.

This was a very successful conference. We were able to provide important information and could show the Romanians how much is known about Down syndrome nowadays, and that it is possible to get access to this knowledge. The exhibition of books, journals, videos and other material about Down syndrome from the different participating countries had a magnificent effect. I saw parents looking at all this literature with tears in their eyes. Tears of sadness and anger that they never had had anything like this in their hands before, but also tears of happiness and gratitude that at least now, times seem to be getting better.

This conference was certainly a very impressive experience for the Romanian parents, but also for us, as speakers. Here we become aware of our own high standards of support and learned to be grateful again for that, what has been changed for the better in our own countries. At the same time we feel obliged to share our knowledge and give our support to those who need it so much.

The conference also had another positive effect in that people got to know each other. Many professionals who are working with children with Down syndrome had never met one another. The conference gave them the opportunity to meet, to exchange experiences and addresses.

This conference was the beginning of a cooperation between different schools, institutions and clinics, who are now trying to build up a professional network in Romania, so that together they can work for a better quality of life for individuals with Down syndrome. Also the foundation of a national parent organisation has been planned.

The Down Syndrome Educational Trust was pleased to be able to provide complimentary copies of the Down Syndrome Issues and Information Development and Education Packs for the Romanian Association, which Sam Campbell carried with him in his luggage.

Report by Cora Halder, Deutsches Down-Syndrom Infocentre

**Down Syndrome News and Update Issue 2:2**

The next issue will include features on

- **Friendships**: friendships, identity and social inclusion in schools and communities
- **Teenagers**: meeting the educational needs of teenagers with Down syndrome
- **Speech and language**: specific guidelines for effective speech and language therapy from birth to adult life
- **Employment**: a fuller report on the success of this work project at The Down Syndrome Educational Trust in Portsmouth.
- **San Marino conference**: summaries of papers presented at the EDSA international conference in San Marino, May 2002.
New websites for The Down Syndrome Educational Trust

Summary
The Down Syndrome Educational Trust has re-designed its two main websites: http://www.downsed.org/ and http://www.down-syndrome.info/ so they are easier to use and easier to navigate. The new framework also improves website performance, and will enable The Trust to provide enhanced subscription options, searchable databases of information, and on-line purchasing, ordering and booking for publications and services (all due mid-late 2002).

Internet track record
One of the primary aims of The Down Syndrome Educational Trust is to disseminate quality information and advice about Down syndrome as widely as possible. Since early 1996, the Internet has become an integral part of the Trust’s dissemination strategy, enabling it to provide information to the widest possible audience.

The Trust has published information on the Internet since early 1996. Over the past 6 years, use of its Internet services has grown to over 4,000 regular visitors per week from over 90 different countries around the world, and serving 6,000 visitors per week at peak times. To cope with this increasing demand and permit the provision of an extended range of services in the future, The Trust has recently launched a comprehensive re-development of its web-based services.

Benefits for users
In April 2002, the Down Syndrome Educational Trust launched re-designed versions of its two main websites:

• The Trust’s own website at http://www.downsed.org/
• The Down Syndrome Information Network (published and maintained by The Trust) at http://www.down-syndrome.info/ (Note: the previous www.down-syndrome.net address is now being re-directed to www.down-syndrome.info).

With these new-style websites The Trust aims to provide an enhanced Internet resource to the international Down syndrome community of parents, professionals and researchers involved with the care and education of individuals with Down syndrome.

The new look websites offer the following immediate benefits to its users:

• Easier to use and easier to navigate, with improved navigation systems and easier access to our other websites.
• Improved performance, in terms of time taken to browse the website and access each page.
• More regularly updated news and information about the work of The Down Syndrome Educational Trust.
• A more future-proof platform, making it easier for us to enhance our websites in the coming months and years to provide an extended range of services for users and subscribers (see below).

Coming soon
The Trust plans to add the following new features to the websites during mid to late 2002:

• Extensive new content for the Down Syndrome Information Network, including online versions of modules from the ground-breaking Down Syndrome Issues and Information publishing project.
• Foreign language versions of key information resources.
• The DownsEd e-visitors centre at http://e-visitors.downsed.org/ for enhanced subscription and personalisation services.
• The DownsEd online shop at http://www.downsed.com/ for purchasing and ordering books, publications and other resources direct from The Down Syndrome Educational Trust, and for booking places on The Trust’s workshops and conferences.
• An online searchable database of Down syndrome resources at http://www.down-syndrome.info/resources/ including other websites, books and publications from a wide range of organisations.
• The latest Down syndrome news and events from around the world at http://www.down-syndrome.info/news-events/ including conferences, health matters, etc.

More information
For more information:

• visit The Trust’s website at http://www.downsed.org/
• visit The Down Syndrome Information Network at http://www.down-syndrome.info/
• send an e-mail to webmaster@downsed.org
Employing adults with Down syndrome

In January three adults with Down syndrome, Ellie, Jonathan and Phillip, joined our staff team on Mondays as part time employees after a couple of months of training, and a further three, Roberta, David and Derek, began their work experience on Wednesdays. As the photographs show, our printing, production and mail order activities provide a range of work. The teams make booklets, cut covers, drill booklets, make up the DSii packs by putting booklets into ring binders, make up plastic boxes and insert language teaching materials, pack parcels, stuff envelopes and frank the mail. On workshop days they help look after delegates, make coffee, stack the dishwasher and clear the kitchen.

We have been surprised and pleased with the speed with which they have all learned the tasks and with their productivity.

We have to be sure that we plan to have enough work ready as each team steadily increases the amount they can get through in a day. The UK benefits system restricts their availability for paid work, so each person can only receive a part-time wage. The Down Syndrome Educational Trust is funding the workers’ travel costs to the Centre. Our daily working lives have been enriched by our new colleagues and we hope to be able to expand the number of adults we employ if the printing work continues to grow.

Shortage of space in this issue has required us to hold the feature article on this work project, with a contribution from Southern Focus Trust, the supported employment agency working with us, in the next issue.

Teaching reading to teach talking - new materials

As part of the See and Learn project, The Trust will be producing flashcards, sentences and small books to provide parents and teachers with the core materials that they need to use reading activities to develop children’s spoken language through reading. We are aware that many parents do not feel confident about starting reading activities on their own. The materials will provide a graded programme to teach vocabulary and grammar in developmental order, based on the material already available in the Speech and Language modules in the Down Syndrome Issues and Information series. These printed materials will link with the computer software language and reading activities in the See and Learn series. Publication date will depend on how quickly we attract funding but we hope to have some materials available by the end of 2002.

We need your help

Our aim is to raise £150,000 over the next two years so that we can develop a brand new range of custom-made computer software for use at home or at school with children with Down syndrome.

Key features of the software:

- Developed by The Trust’s psychologists, based on the latest research into the cognitive development of children with Down syndrome and many years of hands-on experience.
- Modular format, with modules covering different levels of language, literacy, numeracy, memory and thinking skills, so you can select modules to suit your child’s current level of development.
- Low cost per module, much lower than existing ‘special needs’ software.
- Specifically designed for children with Down syndrome, to take into account their particular learning strengths and learning styles.
- Allows as much practice as necessary over a wide range of activities, with ‘errorless’ learning to provide children with early experience of success to encourage further learning.
- Makes use of strong visual elements, to build on the visual memory and visual processing abilities of children with Down syndrome.
- Encourages independent learning, but also provides a structure for parent and teacher assisted learning.
- Clear and uncluttered standard screen layout, to minimise visual distractions and make the software easy to use.
- Incorporates ‘scoring’ systems so parents and teachers can monitor and record their child’s progress, and then send this data to The Trust for evaluation and research purposes.

We have already started initial work on this project, but we can’t do this alone. We need your help. If you can send us a donation, no matter how large or small, you will be helping us get this exciting project off the ground and make it easier for us to secure major grants from trusts and companies.

Please send your donations to The Down Syndrome Educational Trust at our normal address. Make cheques payable to “The Down Syndrome Educational Trust”, but write “See and Learn software appeal” on the back if you want to earmark your donation for this project. If you are a UK taxpayer, please complete a Gift Aid form so we can reclaim the tax on your donation.

We really appreciate any help you can give us!
Conferences

9 - 11 May 2002
2nd International Conference on Down Syndrome:
Hosted by the European Down Syndrome Association.
http://www.sanita.segreteria.sm

1 - 5 October 2003
8th World Congress on Down Syndrome, Singapore
http://www.dpa.org.sg/DSA/DS8Congress.htm

23 - 24 May 2002
Down Syndrome UK Research Forum Meeting, Sarah Duffen Centre, Portsmouth, UK
(Contact: jo.nye@downsnet.org) Deadline: 13th May 2002

28 May - 1 June 2002
American Association on Mental Retardation (AAMR) Annual Meeting, Orlando, Florida, USA

12 - 15 June 2002
1st IASSID (International Association for the Scientific Study of Intellectual Disabilities)-Europe Regional Conference, University College Dublin, Dublin, Ireland.
http://www.iassid.org/europe/first-conference.htm

5 - 7 July 2002
National Down Syndrome Society (USA) National Conference 2002, Nashville, Tennessee, USA
http://www.ndss.org/

2 - 6 August 2002
The International Society for the Study of Behavioural Development (ISSBD) 17th Biennial Meeting, Ottawa, Canada http://www.issbd.uottawa.ca/

23 - 25 August 2002
National Down Syndrome Congress Convention, Denver, Colorado, USA
http://www.ndsccenter.org/old/

14 - 19 June 2004
12th IASSID World Congress, Montpellier, France
http://www.iassid.org/communication/12th.htm
Reviews

‘The Down to Earth Group’ video is intended for people with Down syndrome who are aware of their condition, and who wish to understand more about it. It has been designed for group work - as a starting point for people with Down syndrome to discuss their condition together.

The video centres on six (particularly able) adults with Down syndrome discussing what it means to them to have the condition - the highs and the lows. The video explores the science of Down syndrome (chromosomes, etc.), delicate and emotive subjects like bullying and victimisation, common health problems, equality and wanting to be treated the same as everybody else, and fun, happiness and enjoying life - all presented by people with Down syndrome, for people with Down syndrome.

The video emphasises the value of people with Down syndrome being able to form a group and discuss their condition - to promote understanding, alleviate feelings of isolation, and identify with one another. We feel this is a good idea - as part of an otherwise varied and integrated social life. (We wouldn’t want to see people with Down syndrome mixing only with other people with the condition.) The six adults appear to have benefited considerably from having the opportunity to relate to others who encounter the same difficulties, and from making new friends with whom they have something in common.

Having now watched the video ourselves, we would like to watch it with Sabine, 18, who has Down syndrome - if she would like to. We would guess that Sabine’s difficulties and abilities are about average for someone with Down syndrome. However, we anticipate that quite a bit of the video will make little sense to her: the one, possibly unavoidable, downfall of ‘The Down to Earth Group’ video is that it features very able adults with Down syndrome - who have a sound grasp of concepts like independence, victimisation, tenacity, equality, etc. It is great that they do - but it does mean that the video may be fully accessible to only a minority of very able people with Down syndrome, as opposed to the average majority.

‘The Down to Earth Group’ video is nevertheless a helpful starting point for adults with Down syndrome of varying abilities wanting to explore their condition - as well as an inspiration for the potential of people with Down syndrome. The articulation of all the group members, the determination of them to rebuff blows and to be their own advocates - and the musicality of one in particular - are wonderful.

Vera and Zoë Holland,
mother and sister of Sabine aged 18 years

New Journal in the French language

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Aims and scope

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

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

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

Guidelines for contributors

**Longer articles and reviews**

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

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

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

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

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

**News**

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

**Correspondence**

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

**Editorial review**

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

**Submissions**

Papers submitted to the Journal should be sent to:

The Editor, *Down Syndrome News and Update*,
The Down Syndrome Educational Trust, The Sarah Duffen Centre, Belmont Street, Southsea, Hampshire, PO5 1NA, United Kingdom or e-mailed to dsnu-submissions@downsnet.org
Manuscript Requirements

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

Manuscript layout

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

Abstract and keywords: Articles should be preceded by an abstract or summary of up to 400 words. Keywords or phrases should be provided that accurately identify key concepts of subjects discussed within the paper. These should preferably not exceed 12 and should be separated with commas.

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

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

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

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

References format

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

Articles


Chapters


Article (World Wide Web reference):