## Research studies – what can they tell us?

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Cover picture: Barrie and Sharron Barker with daughter Maisie at the door of 10 Downing Street (see page 120 for full story). Photo: Roy Owen Roberts

## Regular features

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## Down Syndrome News and Update Issue 2:4

The next volume will include features on
- Friendships: ways to encourage friendships and increase social inclusion
- Numicon and understanding number – a chance to take part in a study
- What do we know about motor skills? – practical implications
- Research Update: a summary of recent findings
Editorial

Sue Buckley

Readership

The new format and content of Down Syndrome News and Update is proving popular and the number of readers is growing steadily. Members of the Down Syndrome Educational Trust and members of the European Down Syndrome Association receive this publication as part of their membership and we hope that other organisations will draw their member’s attention to the publication and be sure to have it in their libraries.

International perspective

In this issue, we continue to include articles from around the world. We have features from individuals in Ireland and Scotland and on the newly formed International Mosaic Down Syndrome Association and its conference later in the year in the USA. We have reports on the work of EDSA and from member organisations on their activities in Germany and Romania. Enclosed with this issue are details and booking forms for the 8th World Congress on Down Syndrome in Singapore. We would like to share information about the work of organisations in different countries and the publications and resources available so please write to us about the work of your organisation and any innovative projects that you have.

Editorial and Review Board

We are still seeking members from different countries to serve on an Editorial Board. We would like the Board to reflect our readership and include parents and practitioners. Please contact me if you would like to contribute in this way and to help us to build up contributions from a wide variety of contributors and countries.

Contributions

We are keen to have contributions from parents, practitioners, and researchers which include reports of the activities of associations, family views and experiences and individual stories or case studies, as well as articles and research reports. We also want news of the forthcoming conferences, publications and activities of associations. We will publicise these in print as well as on our website and the websites of the European Down Syndrome Association and Down Syndrome International. If you know of any innovative projects or teaching approaches, then please ask those who have developed them to write a piece for us.

Letters please

We would like to encourage an exchange of views on significant issues between our readers. In the last issue, we thought that some of the views expressed in the inclusion and speech and language therapy features would be controversial but we have not received any letters. In this issue, we have articles on bilingualism and Mosaic Down syndrome and we would like to share the experiences of families so please write to us.

The next issue will be mailed in late January so letters by 15th January please.

Features

Topics featured in this issue are research updates on the progress and achievements of teenagers with Down syndrome, the question of bilingualism and the development of children with Mosaic Down syndrome, and setting up services and self-help groups.

• Research studies

The first three articles provide information to frequently asked questions and we have also used them to discuss the value and limitations of research studies.

The importance of parents – The article on teenager development is the second article presenting information from one of the Trust’s recent research studies. It highlights the range of achievements of teenagers with Down syndrome and stresses the need for parents to encourage independence in all areas of self-help and practical skills. The study suggests that school environments do not have much influence on daily living skills, social independence or social inclusion in the community, as the outcomes are the same for teenagers from mainstream or special schools. The implication here is that the main influence on the teenager’s progress in these areas is in the home not the school. In contrast, school environment has a significant difference on spoken language and literacy skills.

Two languages are OK – The first research study on the effects of exposing children with Down syndrome to two languages shows, contrary to current advice given to parents, that learning a second language has no negative effects on progress in a first language. This will be very reassuring to parents in bilingual families and communities and highlights the importance of collecting evidence rather than making decisions based on ‘guesswork’ or ‘common sense’, though we still need larger longitudinal studies to answer all the questions.

Mosaic Down syndrome poses difficult issues – there is little information to guide parent expectations and some children do not look as if they have Down syndrome so should those around them in schools and in the community be told the diagnosis?

• Self-help groups and services

In this section a mother describes how she and other parents have established a preschool development group to encourage others to do the same, working with services or employing experts if necessary. We also discuss the needs of families and the way in which services and parent groups can work together to provide comprehensive help.

• Inclusion update

The development of inclusive education is a worldwide phenomenon and we highlight the progress being made in Bahrain. Here some private schools have children with Down syndrome fully included with assistant support in the mainstream classroom, in the same way that we have in the UK. The government is moving to develop inclusion in its schools by establishing special classes as the first step. There is a very positive attitude to progressing inclusion and a willingness to learn throughout the community.

The second feature highlights the success of Stuart Campbell, a pioneer in the Scottish school system who has just achieved examination passes and has written to us to share his achievements.

Next issue

The final issue in this volume will be published in January and, as we will be completing the remaining books in the DSii Development and Education series in the same month, we expect to get the 4 issues of volume 3 out in 2003 without delays. We would like to wish all our readers a happy and peaceful holiday season and to thank everyone for their support.

Sue Buckley

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.
Research studies – what can they tell us?

Is research any better than ‘common sense’?

I have been involved in designing and carrying out research studies into the development of children with Down syndrome since 1980. Research is the core activity of The Down Syndrome Educational Trust and it underpins everything else that we do, but why do we consider research to be so important? I will try to answer that by considering the information in the first three articles in this issue. These three articles focus on three questions that parents often ask:-

- What can we expect our baby with Down syndrome to be able to do when she is a teenager?
- Our baby has Mosaic Down syndrome. Will his development be the same as children with standard Down syndrome?
- Our family is bilingual, I am English and my husband is Spanish. Should we speak two languages to our baby with Down syndrome?

In addressing these questions, we have looked for research evidence to help us to answer them. Some readers may say why look for research findings – what can research tell us that our everyday experience cannot? What are the advantages of research findings and what are some of the limitations? We can explore some of the answers to these questions by considering the content of the three articles.

On the first question, we do have some information on the development of teenagers with Down syndrome based on surveys of representative groups of young people and in the first article, we provide quite a detailed overview of the range of achievements of teenagers in Hampshire, UK. We have surveyed the progress of teenagers twice, first in 1987 and again in 1999. Each time we traced all the teenagers in a geographical area in order to have a sample of teenagers that would include teenagers from a wide variety of family situations and a sample that would include teenagers of all abilities and needs. The first study included 90 young people and the second study reported here involved 46 young people.

Representative samples

These numbers indicate that the first benefit of conducting a research study is that we can collect information from large numbers of people. The authors working on this study have many years of experience in this field and we know many teenagers with Down syndrome but if we relied on our experience only to describe the progress of teenagers, we would not have had the detailed knowledge of as many teenagers. The second benefit is that we used the same standard measures with all the teenagers, so that we have the same information for each person. If we had relied on our knowledge of individuals, we would not have had the same information for each person, measured in the same way.

Factors influencing progress

If we collect enough measures, we can investigate individual differences such as the effects of school placement on progress as reported in the last issue, or the effects of health or behaviour difficulties on progress.

Research often contradicts common sense

The research findings on the progress of bilingual children illustrate this point. Most teachers and therapists have advised parents to use only one language assuming two will be more difficult and may delay progress in a first language. The evidence is that this is not the case – learning two languages seems to have no negative effects. It is not wise to rely on ‘common sense’ as evidence on which to base advice.

Research is not always helpful to individuals

The article on Mosaic Down syndrome illustrates this point. Research suggests that, as a group, these children may be less delayed than children with standard Down syndrome but this does not allow the parents of a baby to predict future development as the progress of the two groups actually overlaps considerably. Some children with Mosaic Down syndrome will be less able than some with standard Down syndrome, even though the group as a whole are less affected. This means that we need to look more closely at early developmental progress to see if we can predict later progress more accurately.

Research provides objective evidence

Research is about testing our assumptions and common sense beliefs by collecting unbiased evidence to answer specific questions. Our inclusion research illustrates the importance of this. We hoped to find that inclusion would benefit all aspects of development but our findings show no differences in social and practical skills, much larger benefits for speech, language and literacy than we had predicted and some friendship issues to be addressed. Only by being open to collecting evidence – often over many years, can we find out how best to help the development of our children and how best to design educational provision for them.

Editor
The achievements of teenagers with Down syndrome

Sue Buckley, Gillian Bird, Ben Sacks and Tamsin Archer(1)

The Down Syndrome Educational Trust
(1) Now at the National Foundation for Educational Research

Part 2 - What do we know about the progress of teenagers with Down syndrome, their daily lives and their needs?

The teenage years are a time of considerable development for all young people as they move from dependence on their families towards independent adult lives. This article follows on from the first article in the last issue (Down Syndrome News and Update 2.2 p.46) and presents the findings of our recent research study in more detail.

This study collected information on all aspects of the development of a representative group of 46 teenagers. The reader is referred to the first article for details of the research and the data collection.

Considerable progress is made in teenage years

The previous article presented the broad trends and indicated clearly that teenagers with Down syndrome are making considerable progress in all areas of their development during their teenage years. On page 47 of the last issue Figure 1 illustrates significant progress in practical daily living skills, in social skills and in spoken language and literacy between the ages of 10 and 20 years. There is considerable variability in the progress of teenagers with Down syndrome, with some acquiring skills faster than others, but everyone tends to still be making significant steps forward. We certainly do not have evidence of a ‘ceiling’ or ‘plateau’ in development for individuals with Down syndrome in childhood that used to be suggested by teachers and researchers.

It is also clear to us from our practical experience that most young people with Down syndrome continue to learn many new skills and increase in confidence and independence right through their early adult life. For example, the first author’s daughter Roberta, made significant progress in practical and social independence and in spoken language, and some progress in numeracy and literacy, between 20 and 30 years of age. (She was a slow starter and unable to copy her name legibly, read more than some 10 key words, or count to 10 at 16 years of age. Her speech was difficult to understand and mostly she communicated in 2 in 3 keyword ‘phrases’ and she liked her mum to help her with most daily living tasks. She is now considerably more independent and able in all areas, as readers of Living with Down syndrome will know).

What levels of achievement can we expect?

The first article identified some of the main trends in achievements and factors such as inclusion in education, which may influence them. However, it does not give the reader an idea of the actual skills that teenagers with Down syndrome may have in each area of development or the range of individual differences. The range of achievements for the whole group of 46 Hampshire teenagers is described in this article, with some comments on the implications of our findings for parents, teachers and carers.

Personal care and daily living skills

Personal care and hygiene

Most teenagers with Down syndrome are well on the way to personal independence and privacy in the...
The achievements of teenagers with Down syndrome

area of self care. Almost all teenagers (some 85%) can dress and undress without assistance and manage most fastenings. A similar number can choose and find their own clothes each day and some 70% can choose appropriate clothes for the weather. Most teenagers (some 85%) choose their own new clothes and show a preference for fashion styles.

However, only about half the group are completely independent when we consider personal hygiene as, while 92% can wash in the bath unaided and some 80% dry themselves unaided, only half of the teenagers can run a bath without help, only a third could wash their hair without help and only 10% could cut their own nails. Almost everyone was fully continent day and night (95%) and could go to the toilet without a prompt. However while some 90% could manage their clothing unaided in the toilet, 25% were still receiving assistance to wipe themselves, and 20% did not flush the toilet. While 65% washed their own hands without prompting, 35% did not. This means that overall some 35% of the teenagers still needed supervision in the toilet. (Those in mainstream schools were a little more independent in toileting, with some 25% still needing some help. The information was collected from parents and we cannot be sure that the teenagers need the same level of help at school without asking their teachers).

Almost everyone could clean their teeth and brush their hair unaided, but less than half actually did brush their hair daily without help, presumably because parents felt that they could improve their teenager's appearance if they still helped. This raises the issue of encouraging independence. Parents need to be very aware of the importance of being independent for self-esteem and personal growth. It is not easy to let go and to accept that, while teenagers are learning to be competent they will not make as good a job of the tasks as when parents do them, but they will only reach a good level of competence if allowed to try for themselves.

It is easy to continue to provide help for 11 and 12 year olds without considering what is age-appropriate and the need to begin to encourage independence and privacy. Most teenagers with Down syndrome will need more practice to become competent and therefore this should start early. The shower is often easier to manage than the bath, especially for washing hair and rinsing it adequately. Nail clippers are easier to learn than scissors, and learning to be fully independent in the toilet takes time and practice. In each area, teenagers need to begin to take over the tasks over a period of time, with parents teaching them how to do the tasks rather than doing them for them.

Mealtimes and cooking

Almost all teenagers (95%) could eat and drink completely independently though some 30% still needed assistance with cutting up food. Almost everyone (95%) could serve themselves from serving dishes on the table and 90% could help themselves to salt, pepper and sauces. Everyone could be taken out to eat in a restaurant. When it comes to making meals and snacks, everyone could help themselves to a biscuit, 95% could get a glass of water, some 64% could make squash and 82% could get a glass of milk without assistance. Half of the teenagers could make a sandwich, a piece of toast and a cup of tea or coffee. About a third of the teenagers could use a can opener, about 25% could use the microwave oven and only 10% could use the grill or the oven. In other words, beyond simple snacks, most teenagers could not prepare or cook a meal. However, most of them (80%) could lay and clear the table and about half could wash and dry the crockery.

Learning to prepare and cook meals involves taking risks, using knives, hot pans, boiling water, grills, open gas or electric rings and hot ovens. However, in later teens, some young people become very skilled in cooking and many take catering courses. Like learning to carry out all personal hygiene tasks, teenagers will only learn to cook safely if they are able to learn the necessary skills, in small steps and with supervision.

Independence and responsibility in the home

Most teenagers (86%) had their own bedroom and 65% - 70% took a pride in their room and kept it tidy. Almost all (90%) put up their own pictures and posters. Some 14% of teenagers helped with household chores. However, in terms of being able to be left alone at home, about a third of teenagers could be safely left for short periods of time but only 7% for longer periods.

We certainly do not have evidence of a ‘ceiling’ or ‘plateau’

Parents need to be very aware of the importance of being independent for self-esteem and personal growth

Most teenagers had the privacy of a room of their own, and were beginning to take some responsibility for tidying. We did not ask about doing the laundry or ironing, but most teenagers should be encouraged to learn all the domestic tasks which will enable them to care for their own rooms, laundry and shared areas in the house as they approach adulthood.

The main reason that parents give for not leaving teenagers alone for long is their limited ability to deal with the unexpected. Most teenagers could be trusted not to do anything inappropriate or dangerous if left alone, but most teenagers could not yet use the telephone independently to call for help in an emergency. Some families...
There were no overall significant differences in the personal or social independence skills of teenagers in mainstream or special schools

Exercise will also improve gait and posture, breathing and general fitness

Social independence outside the home

Of the mainstream teenagers, 22% could go to a local shop alone, 83% had pocket money, 44% could cross roads alone and only one teenager walked to the school bus alone. Of the special school teenagers, 30% could go to a local shop alone, 65% had pocket money, 35% could cross roads alone and 13% walked to the school or work bus alone. It was only the oldest teenagers (over 17) that were travelling about independently in the community.

This means that most teenagers could not travel about the local neighbourhood without supervision. Learning to be independent in the community is another area that involves risk taking. However, the necessary skills will only be learned if a teaching programme is planned and the young person able to learn over a period of time, in small steps. For example, when crossing the road, a teenager can be encouraged to identify the right place to cross – usually a proper pedestrian crossing with lights to stop the traffic – can press the light and be in control of deciding when to cross, while still being accompanied by an adult or another teenager. Similarly, bus skills can be learned by allowing the teenager to take the lead in asking for the fare and handling the money, with an adult in the background to help if necessary. Slowly, the support can be faded in small steps.

For some teenagers, the use of a mobile phone will aid their safety and independence – and reassure parents that they are safe. Important numbers can be stored so that they can be dialled with one key press if the teenager needs assistance. The level of independence attained during the teenage years will vary considerably between individuals, and most young people with Down syndrome will continue to develop their independence significantly during their young adult life.

There were no overall significant differences in the personal or social independence skills of teenagers in mainstream or special schools and there was no significant improvement for teenagers in 1999 compared to teenagers in 1987 (see the first article in the last issue for details of these findings). The teenagers in the mainstream schools had not made the significant gains in social independence in the community that we had predicted would result from being in a local school. When we wrote about the findings of the 1987 survey, we encouraged parents to raise their expectations but we have little evidence that this has happened.

Motor skills

In the 1999 survey, everyone is able to walk, to climb stairs with one foot on each step and some 90% of teenagers can jump with both feet together and hop on one foot. Everyone can throw and kick a ball and almost everyone (96%) can catch a ball. Almost all teenagers (93%) can swim without aids and ride a tricycle, with 36% able to ride a bicycle. We did not ask about the range of other sporting activities that teenagers may be skilled in but we know that some teenagers are skilled at gymnastics, horse riding, diving, skiing, baseball and football and that these activities are an important part of their lives.

We would encourage all parents and teachers to support teenagers in a wide range of physical activities for two reasons, health and opportunities for social contacts and friendships. About half of all teenagers are considered to be overweight by their parents, and this tendency to weight gain, which is more significant after puberty, can be reduced by taking sufficient exercise as well as by healthy eating. Exercise will also improve gait and posture, breathing and general fitness. In addition, taking part in sporting activities can bring teenagers into contact with peers – both other peers with disabilities and typically developing peers. These sporting interests can continue to expand their social lives in their adult years.

Speech and language

The communication skills of most teenagers, that is their ability to get their message across, is very good. Almost all teenagers (96%) could start conversations, participate in conversations, talk about past and future events, ask questions and use the telephone. However, getting the message across can be supported by actions and gestures, facial expressions and tones of voice and the listener’s knowledge of the context and topic of the message. Almost all teenagers with Down syndrome have some speech delays and difficulties, that is, their speech is not as clear, fluent and easy to understand as that of their non-disabled peers. Some 33% of the total group were reported to have difficulty being understood by those unfamiliar with them such as assistants in shops or restaurants.

In addition to the effect of speech phonology and articulation difficulties, the intelligibility of their messages will also be reduced because they are often not able to produce grammatically complete sentences. All the teenagers in the 1999 study were talking whereas in 1987 there were 3 teenagers in a sample of 90 with no speech at all. There were...
The achievements of teenagers with Down syndrome

There were significant differences between the spoken language skills of the teenagers in mainstream education and those in special education settings. Most teenagers can improve their speech and language skills over the next ten years or more.

Number, money and time

Overall, the arithmetic skills of the teenagers educated in mainstream schools tend to be significantly ahead of the teenagers in the special schools but not their money skills. All the teenagers in the mainstream

Reading and writing

All the teenagers in mainstream education were able to read and could read short sentences and simple books – simple in the sense of containing simple sentence structures – but with age-appropriate content and interest. Almost all (94%) of the teenagers in mainstream schools could read more than 50 words and simple instructions, 83% could read items in the newspaper and 78% read for pleasure.

The reading achievements of the teenagers in special education were significantly behind those of their mainstreamed peers. Some 78% could read something and of this group, 83% could read their own name and some ‘social sight’ words (usually words with environmental and practical values such as ‘police’) and 60% could sound out words when reading and 60% could sound out words for spelling.

When writing skills are considered, 90% of all the teenagers could trace over and copy letters and words and almost everyone (93%) could write their name. Of the teenagers in the mainstream schools, 94% could write their family names, 83% could write simple sentences and 61% could write their own address, simple messages, simple stories and a short letter. Of the teenagers in the special schools, 48% could write their family names, 30% could write simple sentences and their own address, 17% could write simple messages, 4% could write simple stories and 22% a short letter.

The reading skills of most teenagers can be developed further during their teenage and early adult years and some may begin to read at this time.
Number for teenagers with Down syndrome contains a wide range of activities to develop number, money and time skills for teenagers

While more than half of the teenagers could recite numbers accurately to 10, half of this group could recite the numbers to 20 accurately and 4% could count objects to 20 and do simple addition with numbers within this range. Half of this group could recite the numbers to 50 and a third could count more than 20 objects accurately and recite numbers accurately to 100. While all the teenagers could add simple numbers, 78% could complete simple subtraction, 28% could complete simple multiplication and 17% could complete simple division.

For the teenagers in the special schools, the figures indicate that 69% could recite the numbers to 20 accurately and 52% could count objects to 20 and 61% could do simple addition. Some 26% of this group could recite the numbers to 50, 17% could count more than 20 objects accurately and 13% could recite numbers accurately to 100. While more than half of the teenagers could add simple numbers, 43% could complete simple subtraction, 4% could complete simple multiplication and 4% could complete simple division.

When we consider money skills, all but one of the teenagers relied on shop assistants to take correct sums of money. The special school teenagers tend to be doing better with 48% able to count simple amounts of money and 26% able to give an approximately appropriate amount in a shop, compared with 33% and 11% of teenagers in mainstream schools who could do these tasks.

When we consider general knowledge of time, only 20% of the teenagers could tell the time completely, all the teenagers in the mainstream schools could name the days of the week, and give their own name and age, 94% could say their own address, 89% their birthday, and 61% could name the months of the year. For the teenagers in the special schools 70% could name the days of the week, all could give their own name and 87% their age, 65% could say their own address and 43% their birthday and 35% could name the months of the year.

When we consider general knowledge of number, only 20% of the teenagers could tell the time completely, all the teenagers in the mainstream schools could name the days of the week, and give their own name and age, 94% could say their own address, 89% their birthday, and 61% could name the months of the year. For the teenagers in the special schools 70% could name the days of the week, all could give their own name and 87% their age, 65% could say their own address and 43% their birthday and 35% could name the months of the year.

Number for teenagers with Down syndrome contains a wide range of activities to develop number, money and time skills for teenagers (see Resources page 96). It encourages parents and teachers in both special and mainstream schools to continue to develop a basic understanding of the number system and simple calculations, as well as providing tips for supporting functional use of time and money.

Social and interpersonal development

Leisure interests

If we consider leisure interest and activities, watching TV was the favourite and some 80% of teenagers watched TV often, 55% were interested in pop-stars, 74% were interested in pop music. Some 40% of mainstreamed teenagers and 70% of those from special schools listened to pop music often. Some 44% of mainstreamed teenagers were interested in sports, 33% interested in the cinema and 22% in fashion, with 70% of those from special schools interested in sport, 65% interested in the cinema and 43% interested in fashion. If we consider more passive activities, some 35% read often, 38% played games often, and 27% of mainstreamed teenagers and 48% of those from special schools often enjoyed drawing. Some of the group differences may be due to the fact that there are more older teenagers (over 18 years) in the special school group. This list of interests and activities includes many that are age-appropriate but the teenagers tended to be engaged in these at home on their own, especially as many had TVs and computers in their own rooms. All but one teenager could operate the TV independently and 80% could operate computer games.

Friends

Some 58% of all the teenagers spend time with friends at least once a week. When we asked about these friends, 18% of the teenagers from the mainstream schools and 64% of the teenagers from the special schools had only disabled friends. Some 47% of the teenagers from mainstream schools and 9% of those from special schools had only non-disabled friends. About a third of all the teenagers had both disabled and non-disabled friends.

These figures indicate that about 50% of the teenagers educated in mainstream schools had no disabled friends and that 64% of the teenagers educated in special schools had no non-disabled friends.

The information provided on the sort of clubs attended partly explains these friendship patterns, as 55% of the mainstream teenagers and 43% of teenagers from special schools belong to ‘mainstream’ clubs, and 65% of the mainstream teenagers and 56% of teenagers from special schools belong to ‘special’ clubs. There was apparently the opportunity for more teenagers to have both disabled and non-disabled friends, as for example 65% of mainstream teenagers attended ‘special’ clubs but 18% did not make ‘special’ friends there.

However, the information suggests that 35% of the mainstream teenagers never had the opportunity to make friends with disabled peers in or out of school and that some 57% of the teenagers attending special schools had little opportunity to make friends with non-disabled peers in or out of school.
Information provided on going to parties and discos supports the above picture. While 69% of teenagers from mainstream education are invited to discos and parties organised for typical peers, only 16% of the teenagers from special schools receive such invitations. Some 80% of all teenagers go to discos and parties and some 40% go as often as every month, indicating that the groups of teenagers have equally active social lives but that those in mainstream education are more likely to go to ‘special’ events. The teenagers’ social world and friendships are being strongly affected by school placements.

In the authors’ view these findings have negative implications for both groups of teenagers. The teenagers being educated with their disabled peers seem to have little opportunity to socialise in inclusive or non-disabled settings and are less likely to have non-disabled friends. This is likely to put them at a disadvantage in feeling at ease with and being able to communicate with non-disabled peers when they attend inclusive further education colleges, when they are in the workplace and when they are out and about in the community.

In contrast, the teenagers educated in mainstream schools seem to be at risk of not having the opportunity to have friends with a similar level of disability for the close, special friendships and to find boy friends and girlfriends. Some 38% of the teenagers from the special schools had boyfriends or girlfriends yet no-one from the mainstream schools had a boyfriend or girlfriend at the time of the survey.

The effect of these social experiences during the early teenage years (11-16 years) seems to have negative consequences for some of them once they leave school. We only have a small number of older teenagers (over 17 years) who have left a mainstream school, but they seem to have more restricted social lives than the older teenagers from the special school system. It seems as though it may be more difficult for them to find friends or partners, and to settle into a social network, than it is for those from special schools.

The implications of these findings are that parents need to encourage friends with and without disabilities. The implications for schools and for an effective inclusive school system which can provide academic and social advantages have been discussed in the first article in the last issue.

Brothers and sisters

As has been indicated in other studies, brothers and sisters play an important part in the social lives of teenagers with Down syndrome as 83% of all the teenagers frequently join in social activities with their brothers and sisters. Only about 25% of the teenagers are reported to enjoy any of their social activities, without the support of a member of their family. As a consequence of limited independent travel skills, most teenagers are relatively socially isolated for their age.

Behaviour

Most young people with Down syndrome have socially acceptable behaviour and are sensitive to the needs of others and the personality and behaviour issues are discussed in detail in the first article. Behaviour difficulties do reduce during teenage years, however a small number of teenagers (12% in mainstream education and 32% in special education) are reported to have significant behaviour difficulties. If teenagers have significant difficulties, this is a significant cause of additional stress in families (see Issues for families with children with Down syndrome) and it interferes with the social and school lives of the young people. Most behaviour difficulties can be reduced with appropriate planning of a behaviour change programme. They do not have to be tolerated because the individual has Down syndrome and a plan to change them is in the interests of both the individual and the family (see Strategies for changing behaviour and developing social skills for individuals with Down syndrome).

In summary, the social and leisure interests of teenagers are age-appropriate, but they are relatively socially isolated compared to typically developing peers. Teenagers with Down syndrome have friends, but cannot meet up with them easily out of school, limiting the opportunities for close friendships.

The school placement of teenagers influences their opportunities for making friends with both disabled and non-disabled peers, and this may have longer term social and emotional consequences.

An overview of achievements at 16 years

Many teenagers with Down syndrome will be on the way to complete independence in personal care, able to choose their own clothes appropriately for the day, wash and bathe with minimum help, make a simple snack, answer the telephone and help with household tasks, but some will still need support for daily activities. Many teenagers will be quite socially confident in school and at clubs and only need minimal support to function in these settings. However, some young people with Down syndrome (15-20%) will still need a high level of support with their personal care and in social situations.

Many teenagers will be progressing with reading and writing, with some teenagers able to write short stories and record their work in lessons while others still need full support to do so. Some teenagers will be calculating with...
We need to have this vision of a right to an adult life and see our teenagers as on their way to adulthood – people first, like everyone else – if we are to help each one of them to achieve his or her full potential.

The achievements of teenagers with Down syndrome

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


numbers to 1000 or beyond but some will still be learning to count with numbers to 20. Teenagers will be progressing with their understanding of time and money at varying rates. It is possible for teenagers to benefit from access to the full school curriculum, differentiated to their needs, whatever their rate of progress, provided that there is adequate support in schools for this to be achieved.

Most teenagers will be enjoying music, dance, drama, art and sporting activities and developing their skills at varying rates. In these activities, the enthusiasm and creativity of teachers will have considerable influence on the way in which teenagers with Down syndrome progress. Participation in these activities is not dependent on good speech and language skills and individuals with Down syndrome can often show considerable talent if given the opportunity. Mime and dance activities, for example, allow teenagers to express their understanding of emotions and behaviour in a way they cannot do in daily life.

Most teenagers with Down syndrome can behave in an age-appropriate and socially acceptable manner, at home, at school and in the community, regardless of their level of ability, if they are expected to do so. This is a very important goal, as behaviour influences all aspects of teenagers’ lives, and the lives of their families. During teenage years, difficult behaviour causes stress in the family and reduces teenagers’ learning and social opportunities. In adult life, a person who can behave in a socially acceptable manner can participate fully in community and social activities. In the authors’ experience, less cognitively able adults with good social behaviour will be working and leading more fulfilling lives than more cognitively able individuals with poor social behaviour. Independence in the community will vary. Teenagers with Down syndrome who have been educated in fairly large mainstream schools will have had the opportunity to learn to find their way around a large site, to use the canteen for lunch (involving choices and the use of money) and they may be walking to school with friends, crossing roads or using the bus. Teenagers in special education may be part of much smaller communities (50 to 70 pupils rather than 1000-1500 pupils), with less opportunity to achieve these levels of independence. Out of school, teenagers’ opportunities will vary according to the resources of the areas in which they live. Some teenagers may walk to a local shop or club if they are very close to home, by the time they are 11 years old, but most children with Down syndrome will become more independent in their communities during their teenage years. Most teenagers will still be supervised when they travel outside the home, but they should be learning to walk to local shops and to cross roads safely.

In conclusion

Adolescence is a time for growth and progress for all teenagers, including those with Down syndrome, and there is much that we can do, as parents, teachers and carers, to continue to encourage independence and learning for our children. One of the most important issues is to recognise and respect the chronological age of each teenager with Down syndrome and to recognise that their social and emotional needs are largely age-appropriate, despite their language and cognitive delays. Their social understanding is usually more advanced than most people around them recognise. Teenagers with Down syndrome reach puberty at the same age as everyone else. They leave school and move on through life on the basis of their chronological age. As adults, they want the same things as everyone else, a home of their own with privacy, choice and dignity (even when it is only a bed-sitting room), useful employment and, friends, partners and a social life, and access to all community facilities. We need to have this vision of a right to an adult life and see our teenagers as on their way to adulthood – people first, like everyone else – if we are to help each one of them to achieve his or her full potential.
What do we know about the needs of children with Mosaic Down syndrome and their families?

Sue Buckley and Gillian Bird

Mosaic Down syndrome is rare and families feel lost when they receive this diagnosis – often weeks or months after the child’s birth. A new association will lead to progress.

In October 2003, the first international conference on Mosaic Down Syndrome will be held in Florida, USA, following the recent establishment of an International Mosaic Down Syndrome Association. The establishment of the Association is an important step, for both parents and professionals, as we do not know enough about the effects of Mosaic Down syndrome. The IMDSA website (see below) has provided parents with a chance to share experiences with other parents and if many families worldwide join the Association it will be possible to begin to gain more detailed information on the needs of these children and their families. At present, it is difficult to find enough children in any locality to study their development. The reader is referred to the personal case histories of children on this site as they make clear the uncertainty that families feel when they receive the diagnosis and the very varied developmental profiles of children with Mosaic Down syndrome.

A rare condition

It is estimated that 2 or 3 children in every 100 children diagnosed as having Down syndrome have the Mosaic form. Children with standard Down syndrome have an extra copy of chromosome 21 in every cell and this is the usual profile for some 96 in 100 children with the diagnosis. Children with Mosaic Down syndrome have some cell lines with the extra chromosome and some cell lines that are not affected and have the usual 46 chromosomes. A few children, 1 or 2 in a 100, have the translocation form of Down syndrome, when the extra chromosome 21 material is attached to another chromosome.

What are the effects?

Little is known about the development of children with Mosaic Down syndrome and how it may differ from the development of children with standard Down syndrome, which makes life very difficult for their parents. There are at least two published studies that suggest that, while they have a range of health and developmental difficulties which are similar to children with standard Down syndrome, these difficulties may be less severe. One American study of 30 children[1] and one Japanese study of 8 children [2] compared them with matched children with standard Down syndrome and their findings suggest that groups of children with Mosaic Down syndrome have a higher average IQ.

However, group averages are not very helpful when the variability of children within the group is large. For example, the average IQ score for the Mosaic Down syndrome group may be 64 [1] but some children may score 70 or more and some 40 or less. The average IQ for the standard Down syndrome group may be 52, but again some children will score 70 or more and some 40 or less. The range of scores for children with standard Down syndrome and those with Mosaic Down syndrome will, therefore overlap and some children with standard Down syndrome will score higher than some children with Mosaic Down syndrome, even if the averages indicate that the latter group may be less affected as a whole. This is illustrated in Figure 1.

These studies are rather dated and I do not think that IQ measures have much practical value, but I am using them to illustrate the issues facing parents. An individual child with Mosaic Down syndrome may show less developmental delay than a
What do we know about the needs of children with Mosaic Down syndrome and their families?

... if many families worldwide join the Association it will be possible to begin to gain more detailed information on the needs of these children and their families.

Are individual differences linked to cell pattern?

Children with Mosaic Down syndrome can have different patterns of Mosaicism. In order to try to find out why some children are more significantly delayed than others, some researchers have tried to investigate links between the degree of disability and the percentage of trisomic cells (those with 3 copies of chromosome 21) that the child has. For example, some children have only 25% of their cells with the extra chromosome while some have 50% and some have 75% affected cells. It has been suggested that children with a lower percentage of trisomic cells, are less affected by developmental difficulties, but larger studies are needed to explore this issue, before we can be confident that there is such a relationship.

Personal experiences and some difficult issues

We have had the experience of supporting a number of children with Mosaic Down syndrome in the past 20 years, and our evidence would support the view that these children have the same profile of speech, language, verbal short-term memory and learning difficulties but that their delays tend to be less than the children with standard Down syndrome.

A similar profile to a lesser degree

This study, like the earlier ones, gives the picture of very similar health and developmental difficulties for children with Mosaic Down syndrome but possibly to a lesser degree. The families have made use of the same range of services including speech and language therapy, physiotherapy and occupational therapy. All but two of the children had received early intervention services and of the 30 of school age or older, all but one had benefited from additional support in schools. One child was fully included without support, ten children were fully included with support and most had experienced some inclusion.

How are these children going to feel about their identity as adults? Will they want friends to know that they have Down syndrome?

... very similar health and developmental difficulties for children with Mosaic Down syndrome but possibly to a lesser degree.

Some of the children do not actually look as if they have Down syndrome.

Are individual differences linked to cell pattern?

... if many families worldwide join the Association it will be possible to begin to gain more detailed information on the needs of these children and their families.

The conference

If you are the parent of a child with Mosaic Down syndrome, do consider joining the Association. Details of how to join and of how to book for the conference can be found on their websites (see below). The conference is being held in Orlando, Florida so attending it could be combined with a visit to Disneyland! Dr. Colleen

The conference is being held in Orlando, Florida so attending it could be combined with a visit to Disneyland!
What do we know about the needs of children with Mosaic Down syndrome and their families?

Jackson from the Virginia research group will be speaking, as well as Dr Len Leshin, Cindy Knapp (a parent) and others. One of us will also be contributing and we hope to learn a great deal from meeting many families and individuals with Mosaic Down syndrome. We will report on what we learn in a future issue.

References

Useful sites
www.mosaicdownsyndrome.com
www.imdsa.com
www.ds-health.com

Appeal for HOT TIPS
Since my daughter was born with Down syndrome two and a half years ago, I have benefited many times from the tips and suggestions from those who have “been there, done it and got the T-shirt”. I have heard on many occasions parents say that they received a piece of advice from another parent or professional that really made a difference, sometimes quite substantially. Some parents have invented very creative solutions to meet a particular challenge. What I have wanted to do since my daughter was born is to collect as many of these wonderful tips as I can and collate them into one source for parents. I would therefore like parents to send in tips that have proved helpful on any issue of raising children with Down syndrome at any age. The tip can be very specific or general. The bottom line is that if a particular piece of information has helped you, then the chances are good that it will help someone else. I believe that parents have a wealth of experience and knowledge to share, so let’s do it!

Please send your top tips to:
Ann Haig or e-mail: annhaig@iol.ie
231 Grange Road
Rathfarnham
Dublin 16.

Please enclose name and contact address/phone number in case of query.
Thank you.

Special Needs and Families Research Project
University of Wales, Bangor
Sponsored by the PPP Foundation

Request participation on a research project in how family members, especially parents/parental caregivers, adapt to the care of children with special needs (specifically, Down Syndrome). We are interested in:

- What kind of positive experiences are there associated with the care of children with special needs, and how might these experiences help parents to adapt successfully?
- How do changes over time affect the adaptation of parental caregivers, and do various positive experiences help parents to maintain a sense of satisfaction in their caring role?

We are looking for 150 families of children with special needs in the NORTH WALES and ADJACENT areas to participate in our research project. Ideally, families will be willing to participate in our research now and also agree to be involved in a follow up data gathering phase in approximately 12 months time. The main benefits of this research relate to improving the knowledge that we have about families and how they adapt to caring for children with special needs. In particular almost nothing is known about parents’ positive experiences and how these might help families to cope more effectively. Also we appreciate that participation in research takes up valuable time. Therefore, we hope that families involved in the research will feel able to accept payment for participation.

If you are interested in taking part please contact Alexandra Beck at the University of Wales Bangor, Bangor, School of Psychology, Brigantia Building, LL592AS. E-mail: specialfamilies@bangor.ac.uk Telephone 01248 388436 for more information.
Can children with Down syndrome learn more than one language?

Sue Buckley

Does learning a second language affect progress in a first language? Some new evidence is beginning to indicate that children with Down syndrome can pick up a second language like other children, with no negative effect on their first language.

Can children with Down syndrome learn more than one language? Does learning a second language affect progress in a first language? These are questions that professionals are often asked but there is very little research evidence available on which to base advice. They are questions that are not easy to answer by designing a research study as, in many countries, so few children with Down syndrome are expected to learn more than one language. Parents could be very helpful in enabling us to answer these questions by recording the progress of their children with Down syndrome when they are in a bilingual situation and I hope that this article may encourage parents to write to me with information on their own children's progress with a second language. I am aware of many children and adults with Down syndrome who have achieved a functional level of competence in speaking a second and sometimes a third language, through contacts with families and professionals in many countries. I have also met children with Down syndrome who can read and write in more than one language but we need much more information about their level of general ability and on how they have achieved this in order to advise other parents. Case studies would be a good starting point for more research.

Learning a second language in school

In many countries, all children are expected to learn two or even three languages and they may begin to learn more than one language before starting full-time education or they may not be exposed to a second language until they are in school. For many of these children, only one language will be spoken at home and the other language may be used by some people in the community or only in school. Teachers and parents want to know if the child with Down syndrome should be included in second language learning. For example, should English speaking children with Down syndrome be included in Irish or Welsh lessons in primary school? Should children with Down syndrome learn a second language in secondary school when their peers begin lessons in the new language? As far as I am aware, there are no published studies of children's progress in these situations but I have met children with Down syndrome who have done well when learning a second language in both primary and secondary school. For example, I know children doing well in Irish language and Welsh language primary schools even though their first and home language is English. One lad in an English secondary school learned French in his first year as well as his

Learning two languages has had no negative effects on first language learning – no effects on vocabulary or on grammar in their spoken language

One lad in an English secondary school learned French in his first year as well as his non-disabled peer group – by going home and writing out everything he had to learn, as he knew that he had to see the French words to remember them. His mother commented that he was learning a second language in the same way as he had taught him his first language – by reading it. (For more on the benefits of early reading on speech and language development see 2)

The bilingual family

The other common situation that raises queries is the bilingual family. In a bilingual family, two languages will be used in the home because the first language of each parent is different and they wish their children to be able to speak both languages. If typically developing preschool children (under 5 years of age) are exposed to two languages used naturally they usually have no difficulty in becoming fluent in both languages.

Bilingual families are often advised not to speak two languages to babies and toddlers with Down syndrome on the assumption that, since children with Down syndrome have significant speech and language difficulties, they will be further disadvantaged by hearing two languages. There is actually no published evidence to support this view but there is one study in progress in Canada that suggests that there is no disadvantage. At least in the early stages, children with Down syndrome who are becoming bilingual are making the same progress in their first language as children with Down
syndrome who are learning only one language (monolingual). Preliminary findings from this ongoing study by Elizabeth Kay-Raining Bird and her colleagues were presented in July at a joint conference combining the Symposium on Research in Child Language Disorders held annually at the University of Wisconsin—Madison, Madison, USA with the IX International Congress for the Study of Child Language.[1]

Is bilingualism affecting their first language?
They are comparing the progress of 8 children with Down syndrome who are bilingual with a group of 15 who are monolingual, matched for mental age. All but one of these bilingual children are exposed continuously to both languages at home as well as in the community. The chronological ages of the bilingual children range from 4 years to 11 years. The two groups of children with Down syndrome do not differ in their English vocabulary sizes (English being the first or dominant language for all the children) or in their developing grammar as measured by Mean Length of Utterance (MLU). Learning two languages has had no effects on first language learning – no effects on vocabulary or on grammar in their spoken language.

Are they like other bilingual children?
When compared with typically developing bilingual children at the same stage of language development, the bilingual children with Down syndrome were making the same progress in vocabulary in both the languages. All the children with Down syndrome (both bilingual and monolingual) were using shorter phrases and sentences than the typically developing children, demonstrating the usual delay in mastering early grammar that is shown by children with Down syndrome.

This is an important study but, as the presenters emphasised, it is a small study which needs replicating and it is too early to see if bilingualism has any effect on the development of later grammar in one or both languages. However, they conclude that their study does NOT provide support for the advice to speak only one language to babies with Down syndrome – the advice that is usually given to parents at the present time. This research group are also looking at the way the bilingual children mix the use of the two languages and once they publish the findings of these studies we will publish the full references for our readers.

Other studies
There are two other published case studies of bilingual or multilingual individuals with Down syndrome, one of an Italian woman speaking Italian, English and some French [2] and one of twin girls who were bilingual in speech (English) and in sign, British Sign Language for the deaf (BSL) [3,4] as they had profoundly deaf parents, for whom BSL was the dominant language, and a hearing older brother. (Deaf sign languages such as BSL are full languages with fully developed grammars. Makaton is not a language, it is a set of signs used to support spoken language learning – without a grammar).

The Italian woman was reported as an exceptional case as she was seen to be particularly able, with an IQ of 71. She had standard trisomy 21 and she had good spoken Italian with better mastery of spoken grammar than is typical for a person with Down syndrome. She also had some competence in French and in English. She had been in Belgium until she was 6 years old on a NATO military base and therefore exposed to French. She learned English from a British sister-in-law and she was able to hold a conversation in English, watch English TV and speak on the phone. She had a full time job as an adult in an Italian advertising agency. Her abilities demonstrate that having Down syndrome does not prevent someone from learning several languages, as many parents and professionals know from their own experience.

Does language modality make any difference – is sign easier?
The bilingual twins, Sally and Ruthie, have Mosaic Down syndrome and normal hearing and they have been followed for a number of years by Bencie Woll and Nicola Grove in the UK. They were exposed to both BSL and speech in their home from birth and have become competent bilingual. At three years of age, the twins’ dominant language was BSL sign and their progress in spoken English was delayed relative to their sign language progress. They differentiated their language use like other bilingual children, signing to other signers and speaking to other speakers.

Vocabulary learning may be easier in sign
At ten years of age, their dominant language was spoken English. They still signed to their parents and other signers, but used speech to each other and to other speakers. Their sign vocabulary was more extensive than their spoken vocabulary. In sign, their vocabulary age for comprehension was at the same level as their mental age. In spoken English, their vocabulary comprehension level was approximately two years behind their mental age. This specific gap between mental age and language age is the usual pattern reported for children with Down syndrome learning a spoken language. The vocabulary advantage in sign might reflect that sign language was their parents’ first language therefore they may have experienced a richer vocabulary in sign. These findings could also reflect a sign advantage for learning vocabulary, supporting research that does indicate visual cues definitely support spoken word learning.

... a sign advantage for learning vocabulary, supporting research that does indicate visual cues definitely support spoken word learning

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http://www.down-syndrome.info/library/periodicals/dsnu/02/03/
learning and that spoken words alone are difficult for children with Down syndrome to learn.[3]

**Grammar learning is not easier in sign**

However, the twins’ development of grammar comprehension was equally delayed in both languages, sign and speech and it is disappointing to learn that they did not show an advantage in learning a sign grammar. This may be an important finding for our understanding of the cause of grammar difficulties. Most children with Down syndrome have difficulty mastering the grammar of their spoken language and have vocabulary knowledge that is ahead of their grammar by their teenage years. It has been suggested by a number of researchers that poor short-term verbal memory may be a major causal factor, limiting the children’s ability to process sentences and access the grammar, and also that speech-motor difficulties may affect the production of grammatical markers and complete sentences.[4,5]

If the main problem with learning grammar was linked to learning a spoken language from listening, then children learning a sign language might be less likely to show a grammatical difficulty and may have more fluent production in sign rather than speech. However the twins do show grammatical difficulties in both languages and use only short ‘keyword utterances’ in both speech and sign, suggesting a more fundamental language learning difficulty is associated with Down syndrome, regardless of the modality of the language. The girls are also now dominant in spoken English rather than in sign, despite sign being the dominant language of their parents. If sign was actually an easier language mode for children with Down syndrome, we might have expected them to prefer it and to have become more competent in sign than in speech.

What can we conclude from the available information?

The evidence from individual cases and from these studies indicate that children with Down syndrome can become bi-lingual and they seem to be doing so in the same way and as typically developing children of the same mental age and first language level. There is no evidence that learning two languages has any negative effects on the development of the children’s first language. The children with Down syndrome show difficulties in developing grammar in both languages, even if one language that they are exposed to is a full sign language such as BSL.

This suggests that the advice for parents should be to include their child with Down syndrome in ordinary family and community life like any other child. If their family is bilingual then they should use the two languages with the baby with Down syndrome in the same way as they do with their other children and he or she will be likely to cope perfectly well with this experience. Similarly, if other children in the family and local community are exposed to two languages in school, the child with Down syndrome can follow the same pathway.

I would offer two cautions to this advice based on my experience. Firstly, I would monitor the progress of the child with Down syndrome carefully as some children will experience more severe speech and language delays than others, and we do not have enough evidence to suggest that all babies with Down syndrome will cope with two languages. Secondly, all babies with Down syndrome need good language input to help them with their first language and I would concentrate all additional speech and language therapy and reading activities in the preschool years on the development of the main language the child will need in the family, community and in the school, if possible.

With regard to teaching grammar, the evidence we have at the present time suggests that the best way to teach grammar to children with Down syndrome is through appropriately planned reading activities in their first language, as we have argued in the first issue of this journal for 2002.[see 5,8] These reading activities are, of course, always accompanied by speech so that the visual and the spoken language forms have the same acquisition and seem to work together to support the learning of one language. We are exploiting the fact that visual short-term memory is better than auditory short-term memory for children with Down syndrome.

**References**

8. see articles on early reading in Down Syndrome News and Update, 2.1.

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http://www.down-syndrome.info/library/periodicals/dsnu/02/03/
Services and self-help groups – how do we ensure that everyone gets the help that they need?

Do we set up our own services or try to work in partnership with local providers?

The next two articles describe groups set up by parents to help their children's development. At the Trust we are receiving more and more requests to help groups to improve local services and this is the reason for beginning to develop Branches and Affiliated groups (see page 107). In the first article, from Ann Haig in Ireland, she describes the way in which she has set up a group with other parents. The group provides support and it aims to specifically promote the children's development through structured activities. The second article is from the founders of the Bristol Branch of The Down Syndrome Educational Trust – our first fully fledged Branch. Here parents have worked with the statutory services to provide speech and language therapy groups and they also offer a chance for parents to meet and talk over coffee. The speech and language therapist works for the local National Health Service Trust but the Bristol Branch pay for her time for one day per week.

If we were designing services to support children with Down syndrome and their families in the early years from birth to school age, how would we do it? What do families and children need? In my experience, we could describe their needs under three headings, information, support and practical help to promote their child's development.

Information
When we meet parents in the first days and weeks after their child's birth, they are usually looking for as much information as possible on the needs of their baby and their family. They have not had much contact if any with children with Down syndrome and are keen to learn all that they can about the new situation facing them.

Support
Most families find that meeting other families is helpful for the shared understanding of how they feel and for practical tips and information on how to cope and where to get services.

Practical help
Most parents are keen to do the very best for their child and want advice on how to help their children to progress as fast as possible. They require practical tips and activities which can become part of their daily routines. This practical help may be needed for health issues such as feeding, for motor skill development, for speech, language or cognitive development or social development and behaviour.

Parents and professionals
If we are going to meet these needs, we are going to require parent and professional partnerships if we are to be as effective as possible. Information to new families can be provided by parent organisations or by professionals. Opportunities to meet with other parents can also be provided by services or parents setting up groups. When we come to expert advice on how to help children progress then we will do best if we can work with experienced professionals. Not all professionals are experts in Down syndrome and often parents have more knowledge because they have read up on the issues or been on training courses. However, professionals will have skills that parents do not necessarily have and a partnership is likely to be the best way forward. For this reason we encourage parent groups who want better services in their area to try and work with local service providers to get these services going.

Training
Both parents and professionals may benefit from training. Running support groups will find themselves dealing with a whole range of personal and family concerns, as well as being asked about children's specific needs. They will need more knowledge and skills than they needed just to help their own child. Professionals also need training as we learn more about the most effective ways to help children with Down syndrome all the time. As we ask services to be inclusive, many staff in nurseries, schools and services have had no special training in the needs of children with developmental disabilities. Local parent groups can be effective in identifying the local training needs and bringing training to their area. This might be a workshop for health services, for speech and language therapists or for educators. The Trust is beginning to work with regional groups to plan and provide the training that they need in their area. We are expanding our expert team over the next six months in order to be able to provide this service.

Editor

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http://www.down-syndrome.info/library/periodicals/dsnu/02/03/
There are many reasons for wanting to set up a toddler group. You may want to meet other parents with similarly aged children, you may want to have some uninterrupted time with your child, or you may want to gain some ideas of ways that you can help facilitate your child’s development. For most of us, it’s all of the above. There is no doubt that there is a potent energy when parents and their children get together for positive reasons. I get asked a lot about why I set up my group and how I did it. I don’t think that there is any magic answer and I don’t think that there is one right way to do it. I think the starting point is clarifying with yourself and the other parents involved about what you want out of the group. Why do you want to get together? If you are wanting to have time to talk to other parents and share information, then you might want to consider what measures you can take to make sure that this can happen. Perhaps you take turns ‘minding the children’ for a short period of time so that the other parents can chat without distractions. It doesn’t matter how you do it, just make sure that you get out of it what you are looking for.

Once you have established what you want from your group, go to your community health nurse or social worker. They receive money for your child’s early services. What can they do to help? Before I established my group, I approached my local state-run service provider with a request for help. Some will accommodate your needs. They might provide you with a room or professional assistance. I have found that a number of service providers offer some sort of toddler group, which is fantastic. If what they are offering meets your needs then you are in luck. It’s when there is nothing on offer or it falls short of your needs that things become a bit trickier. Whatever the circumstances, I would discourage attacking service providers. I believe that we need to be assertive in stating what level of assistance we expect and then we should try to work with our service providers wherever possible to improve facilities. The thing is, while we are liaising and being assertive, the clock is ticking and our child is doing without. Personally speaking, that’s when I took matters into my own hands.

I wanted my daughter to learn to take turns with children and to have a peer group with whom she could learn and interact. I was doing the one-to-one intervention, but there were a lot of important skills that I could not target with just the two of us. Besides, it’s more fun for children to learn together and the adults support each other and keep the focus. Mainstream is important, but the activities offered at the toddler groups I’ve attended didn’t provide what I wanted. So, we started out just a pair of children
and a pair of parents, but soon there was a group of five children. At that point, I realized that we had a lot of strength and potential together. We all contributed monetarily and we started hiring in private therapists and buying specialist materials and equipment. The equipment is then loaned out to parents when they need it and we have access to resources that few parents would buy for their one child alone. There is always strength in numbers. But most importantly, we had a group of five children who were at a similar developmental level (very important) and I devised a developmental curriculum and led each session.

OK, I have a background in education and child development, but so do lots of people. If you want to run a group and none of the parents want or feel able to lead the group, then hire someone. Sound simple? It is. Recently I advertised in a local paper for a teaching assistant and I made it clear in the ad that our group was not-for-profit and we only needed someone part time. We had over a dozen replies, three of which were from state-qualified teachers with relevant experience! I was amazed by the response and the calibre of the respondents. No one was put off by the fact that we couldn’t offer much money. My advice to you is to go for it. If you want to hire someone, advertise. If you don’t ask then it won’t happen. When you do hire someone, if that is what you decide to do, then link them in to the research from The Down Syndrome Educational Trust and get them trained in sign language. I would also advise that you look for someone who doesn’t speak very quietly because a lot of our children have hearing difficulties. I use a microphone during our circle time to ensure that the children can hear me more clearly. You don’t need to blast the children, but you do need to be aware that the majority of our young children have ‘bad hearing days.’

What to look for in a toddler group leader

- Training in child development (e.g. NVQ, BTEC, NNEB)
- Experience with young children (special needs a bonus)
- Openness to learn

So, you have your group and someone to lead it. Now, what do you do in your group? Well, largely that will depend on what you want to get out of it. If you were looking to aid your child’s development, I would strongly urge you to think ‘holistically’. This means that you consider the whole child and not just one component of his or her development. We know that each area of development has an influence on all other areas and therefore it is difficult to isolate only one and give it sole consideration. That said, maybe you are only interested in enhancing communication skills in which case it would be entirely appropriate to give that your concentrated focus. If that is the case, please consider the child who has significant delays in this area of development and make sure that you allow him or her to feel success in the group through other means. There is nothing more soul destroying for the child and parent who see other children progress and succeed while all of their efforts seem to get nowhere. All children have strengths and it is important to recognize them. The self-confidence and esteem of the children (and parents!) is of as much importance as their skill development. When we feel good about ourselves, we learn better. I feel quite strongly about supporting a child’s self-esteem; it requires careful consideration in everything that you do with children.

Once you’ve found someone to lead your group, what do you do? Again, that depends on what you are wanting from the group. I recommend that you cover all areas of child development which are:
- Fine motor
- Gross motor
- Language/Communication
- Cognition
- Social skills
- Self help/Independence skills
- Emotional skills

In addition, I think our children benefit from work in the areas of sensory skills (how we perceive and process information from our environment) and oral-motor skills.

Toddler groups are usually for babies to three years of age. I run my group once a week for two and a half hours and I recommend to parents that from age two they attend a mainstream group at least once a week. From three years I would recommend a mainstream playgroup for the majority of children because the research from The Down Syndrome Educational Trust indicates the social and language advances that are made in this environment. That said, my group of three year olds will continue to meet next September alongside their mainstream experiences. I didn’t plan it that way; it’s just what was wanted. It makes good sense, though: the benefits of good modelling from typically developing peers alongside the tailor-made activities for children with special needs.

If you do set up a group, contact the PPA (the Early Childhood Organisation) for training opportunities, insurance and advice. You can also apply to your local council and enterprise board for grants. In conclusion, I would like to share with you some Web addresses that I have found useful. I wish you and your group every success and I include my Email address in case you wish to correspond. Enjoy the magic and potential of the early years!

www.downsed.org
www.ppa.ie
www.numicon.com
www.southpawenterprises.com
www.portageproject.org
www.pfout.com
www.wesco-group.com
www.tfhusk.com
www.nrs-uk.co.uk
www.collinseducation.com
www.talktoolstm.com
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Ann Haig is a behaviour analyst with a masters in early years education and has experience in mainstream as well as special needs education. Her early intervention group, S.K.I.P, was established in 2000. Ann’s contact information is on page 99.
The Bristol Branch of The Down Syndrome Educational Trust was started by two sets of parents living in Bristol who have children with Down syndrome, and who have been lucky enough to visit and be involved with The Down Syndrome Educational Trust in Portsmouth. The inspiration behind starting the group was seeing the work of, and meeting, Professor Sue Buckley and Gillian Bird. Having had this benefit for our children by travelling to Portsmouth, we felt we wanted to share it with other families who may not have had the same opportunity.

We have come to understand the importance of specialist speech and language therapy, and have launched the group by offering speech and language therapy groups for children from the age of 18 months. These are run by Sarah Coles, a Speech and Language Therapist with a special interest in Down syndrome, who has followed a training programme at Portsmouth. As from the October half-term, the groups will be extended to cover children of school age.

We are indebted to the Portsmouth team for their invaluable help, advice and enthusiasm for our venture. A special thank you goes to Sue Buckley for coming to Bristol for our opening. The Branch is presently funded by money raised by Jonathan Cook, one of the founding parents.

Groups take place every Monday at Henleaze and Westbury on Trym Community Church, who have kindly allowed the use of the premises free of charge.

If anyone is interested to know more please contact either:
Annabel Dixey on 0117 962 4735,
or Marie-Louise Cook on 0117 968 6893
Developing Branches of The Trust

In response to requests to expand work of the Trust to local areas, the Trustees are developing Branch and Affiliate guidelines and supporting local initiatives to develop Branches. The key points are set out below and readers will note that they reflect the service model outlined on page 103, and aim to provide support, practical help and information to parents and professionals in a variety of ways. We would welcome feedback on these proposals from any group interested in setting up a Branch.

Branches will operate under the charitable aims of The Down Syndrome Educational Trust, which exists to advance the development and education of children with Down syndrome. In particular:

- To promote research into the development and educational needs of people with Down syndrome and into the ways in which they may be most effectively educated.
- To disseminate the useful results of research, in accessible and practical format, to parents and professionals.
- To advise parents and others associated with individuals with Down syndrome on all matters related to their development and education.
- To organise classes, training workshops and other educational activities for the benefit of children with Down syndrome and their parents.

Branches of the Trust will enable families around the UK and abroad to have local access to the services, expertise, training and information available at The Sarah Duffen Centre in Portsmouth, supported by a team of professional staff based in Portsmouth, but able to visit Branch areas. Branches can decide which of the services they want to provide based on their assessment of local needs. Branches will operate under the Trust’s charitable registration – they do not need to become separately registered charities. Groups which are already registered as independent charities may wish to become Affiliated and work with the Trust to offer some of the same services.

Groups for practical help and support

A Branch may offer Early Development Groups in their area. The aims of these groups are to provide support to families from the first year of life, accurate information on the developmental and educational needs of children with Down syndrome and group activities for the benefit of children. The group activities may include speech and language groups, but advice and activities should cover all aspects of social, cognitive and behavioural development, not just speech and language development.

The Early Development Groups are likely to be run by parent volunteers who will receive training and ongoing support from the Trust’s professional staff team. A Branch may also employ the services of professionally qualified staff, provided the Branch has the funds to do so. Branches will be encouraged to work with the professionals available in their local statutory services whenever possible, as this will lead to permanently improved services for all families in the area over time – not just those who wish to join a Branch.

A Branch may also offer group activities for school age children. For example, school age groups could offer speech and language therapy or social activities. The standard of services being offered by Branches will be monitored by staff from the Trust’s professional team on a regular basis and should reflect the Trust’s values and philosophy (see page 124).

Consultancy and assessments

A Branch may also offer individual assessment and consultancy services to local children and families, either through individually booked sessions or an Open Day ‘drop-in’ access. The Trust’s professional staff team who will visit the Branch area to provide this service.

Training and information

A Branch may offer training events to parents and professionals in their area. The Trust will provide the staff and materials for these training events, and support the organisation of events. In this way, the Branch can ensure that the professionals in their area are kept up-to-date on current knowledge and best practice. The Trust will also support Branch activities intended to improve services in their area e.g. meet with key policy makers/ service providers to ensure appropriate services are in place. Branches will be able to make use of all the printed and web based information provided by the Trust.

Supporting research

Branches may take part in research projects as research is the core activity of the Trust and underpins the training and dissemination work of the Trust. For example, developmental records may be kept for children attending early development groups and this information may contribute to understanding individual differences in developmental profiles or to the evaluation of an intervention strategy.

Local decision making

Branches will be run by their own local committees supported by the Trust. At present, all Branch activities will be funded by moneys raised in the Branch area and the Branch will cover the costs of support from the Trust’s team. All money raised in a Branch area will be ring-fenced to be spent on Branch activities. Branch accounts and employment contracts will be managed centrally by staff at The Sarah Duffen Centre. Support can be provided centrally for printing of Branch stationery, notices, posters and tickets for fundraising events. Branches will be expected to work co-operatively with any other local groups working for the benefit of children with Down syndrome and their families.
Developing inclusion in Bahrain

Sue Buckley

I n September, I had the pleasure of spending ten days in Bahrain visiting schools and centres and speaking at a conference that attracted over 200 delegates from Bahrain and the neighbouring Gulf states. The visit was the result of co-operation between three families, the British Embassy, the British Council, the Bahrain Ministry of Labour and Social Affairs and the Bahrain Children and Mothers Welfare Society.

Two day conference
This Society made a major contribution to the visit by hosting the conference on The Development and Education of Children with Down syndrome in its headquarters and providing wonderful hospitality for myself and the delegates. I thoroughly enjoyed sampling a wide range of local cuisine. The President of the Society, Shaika Lulwa bint Mohammed Al Khalifa, was the conference host and personally made everyone feel welcome. The conference attracted a wide range of professionals and parents and they were welcomed by the British Ambassador, Peter Ford. I was introduced to the conference by Eman Rajaee, a 15 year old girl with Down syndrome, who addressed the audience in both Arabic and English.

We had lively discussions on some topics and some interesting misunderstandings as a result of translations – but fortunately many in the audience spoke excellent English and were able to help me out. I was impressed by the general enthusiasm for inclusion in the audience and a willingness to move forward in developing new services and changing schools.

Visits to schools and centres
During the ten days – in 45 degree heat! – I visited schools and centres providing a variety of services. Some centres were providing specialist care and education for children with profound and multiple disabilities and some were providing adult support and day services and, as in most countries, these had developed to provide services for children previously outside the education system.

Progress in inclusion
I visited the Hope Institute, an excellent special school providing high quality education for children with moderate to severe learning disabilities and started by the Children and Mother’s Welfare Society.

I visited individual children who were fully included in mainstream private schools and was able to provide advice for staff and parents. I also visited two of the government schools that have started classes for children with special needs during the last year. I believe that some ten schools are involved in this project to prepare schools for full inclusion. I was impressed by the enthusiasm of the Head teachers and senior staff for inclusion in these schools and their wish to gain advice and strategies for moving forward.

I met with senior officials from the relevant Ministries to discuss the issues facing them, spoke with students at the University, staff at the American Mission Hospital, which has provided medical services since pioneers started a clinic in 1880, and education professionals at the Bahrain Institute for Special Education.

Bahrain Society
I made two visits to the centre established by the Bahrain Down Syndrome Society and met with staff and families. The President of the Society, Dr Al Mannai, and his staff made me most welcome, translated for me so that I could converse with families, then showed me the valuable work that they are doing in speech and language therapy and early intervention.

I also visited a service provided by the Indian Ladies Association. I returned from this visit most impressed by the dedication of so many people and the work that they do on behalf of children with Down syndrome and their families. This is the case in most countries that I have the privilege to visit and, as current President of Down Syndrome International, it is one of our aims to develop an international network that can bring people together and pool expertise to enable countries to learn from each other. This is one of the functions of the International Congress held every four years (see page 111). The Congress usually attracts representatives from most countries and is a great way to exchange ideas.

Since I returned from Bahrain, I have received invitations from several neighbouring Gulf States that I look forward to visiting during the next year.
Hi there

I am Stuart Campbell, and I am 15 years old. I live with my parents at Ayrshire, Scotland. There are five of us in the family and I am the youngest, but all the others have grown up and left home. We were all away to France for our family holiday, including sisters in law and nieces and nephew, twelve in all. It was a good holiday, especially the cycling.

My hobbies are listening to music, for example S-club Seven and Top of the Pops, watching videos like Shrek, Cats, Joseph and the AmazTechnicolour Dream Coat and Chicken Run. I also go cycling, swimming, drama, I would like to be in a really good drama club. I go to Loudoun Academy in Galston and I get there by a minibus which picks me up at my house with our neighbours. I am in fifth year. My subjects are Art, English, Maths, Home economics, Technical and PE. I love them all. I used to be in a chess club for playing chess, a maths club and I still go to a Scripture Union group for learning about the Bible.

This is such an eventful year for me, first of all I was at my brothers wedding, I was the “best man.” I felt very excited. I made up a speech and told them I was “over the moon” when I was asked to be bestman. There were funny bits which made them laugh. After the meal there was Scottish dancing, a ceilidh.

Would you believe that a boy with DOWNS SYNDROME HAS BEEN DOING STANDARD GRADES AND PASSED ALL SIX!

EXAMINATION RESULTS TIME
French and Science - 3!!
English and Home economics - 4
Geography and Maths - 5
I was expecting these but everyone else was amazed and astounded!!

On the 5th September 2002 I became a PREFECT. There was a meeting for those who wanted to become prefects two weeks ago I was there because Mrs Hunter my Guidance teacher encouraged me to come.

And finally I am going to be baptised soon as I am a Christian, and that’s what we do in the Church I go to.
Inclusion update

Books:


Videos:

Workshops on inclusion at The Sarah Duffen Centre (spring/summer 2003)

Monday 27 January  Meeting the educational needs of children with Down syndrome in mainstream schools – Primary school
Tuesday 28 January  Meeting the educational needs of children with Down syndrome in mainstream schools – Secondary school
Monday 12 May  Meeting the educational needs of children with Down syndrome in mainstream schools – Secondary school
Tuesday 13 May  Meeting the educational needs of children with Down syndrome in mainstream schools – Primary school
Monday 16 June  Supporting the development and education of children with Down syndrome (Day 1/2)
Tuesday 17 June  Supporting the development and education of children with Down syndrome (Day 2/2)

See our Services brochure for details of these and other Workshops, or visit our website at: http://www.downsed.org

Seamless Transition
A series of workshops for teachers and support staff run by the Down’s Syndrome Association
Workshops for teachers and support staff working with children with Down’s syndrome at key stages 2, 3 and 4. Supporting transition to, and successful inclusion in, mainstream secondary schools.

• Effective Inclusion
• Accessing the curriculum at key stage 2 and 3 and alternative accreditation
• Strategies for effective inclusion: whole school planning
• Developing literacy and number skills at key stage 2 and 3

Tuesday 11th March 2003 - Plymouth, Devon
Wednesday 12th March 2003 - Stoborough, Dorset
Thursday 13th March 2003 - Axbridge, Somerset

Contact: Lucy Donnelly, SEN Regional Partnership (SW), Bishops Hull House, Bishops Hull, Taunton TA1 SE6
Fax: 01823 323388 for booking forms for the above.

Thursday 10th April - Fulford, York

Contact: Helen.upton@york.gov.uk for application forms

Friday 11th April 2003 - Carlton Park Hotel, Rotherham

Contact: 01326 311007 educate@downs-syndrome.org.uk for application forms.
• 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.

8th World Down Syndrome Congress
Suntec Singapore International Convention & Exhibition Centre, Singapore
1 – 5 October 2003

Down Syndrome: Global Progress in a Changing Era

Conference update: The 2nd announcement, call for papers and registration details are now being mailed. Note that the Early Bird rate for registration is before 1st April 2003.

A message from the President of DSI

This will be the 6th World Congress that I have attended and each one has been a wonderful experience. Most Down Syndrome Associations from around the world send representatives, many families attend, leading researchers and practitioners share the latest knowledge and good practice, adults with Down syndrome advocate for themselves and confront parents and service providers to rethink some of their attitudes and expectations and we all have a great social time as well! We see a new part of the world and we return home buzzing with new ideas, new friends, plans for collaboration with others, and with renewed enthusiasm for the task we are all engaged in – improving the quality of life for individuals with Down syndrome and their families.

Do join us in Singapore. These World Congresses have been maintained by the enthusiasm of a small international group – now formally established as Down Syndrome International. The main goal of DSI is to promote international collaboration, to promote the human rights of individuals with Down syndrome and to facilitate the sharing of information through the congresses, publications and the world-wide-web. Over the next year we will be having a membership drive and we will elect a new Board in Singapore. Do consider joining – membership will have some advantages at the Congress, we are negotiating member discounts on some international journals. We also need a significant membership if we are to speak out on human rights issues, such as discrimination in many countries’ immigration policies, an issue we are addressing at present. Visit the website for membership details.

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

Deutsche Down-Syndrom-Wochen
Awareness campaign in Germany

Cora Halder
German Down-syndrom Info-center

One of the projects of the German Down-Syndrom InfoCenter is the annual awareness campaign. Every single year, we notice again that it is an extremely good way to draw the attention of the press and the public to people with Down syndrome. I would like to recommend the idea of such a campaign to all others who are working in DS associations. It is not only a useful instrument to pass on information, it is also a lot of fun.

Educating and informing society has become an important part of our work. Through the years possibilities for children have improved as parents are well-informed and competent nowadays and there is a whole range of good facilities and qualified professionals supporting people with Down syndrome. But this on its own is not enough to improve the quality of life of individuals with Down syndrome. As long as others do not accept them and as long as they are discriminated against and refused by society, one of our main goals as advocates of our children, must be informing the public.

We knew from other DS groups in the USA, England and Italy that they organise awareness campaigns regularly and we decided to set up something like this in Germany as well. In 1996 we started with this idea in Bavaria. We contacted all the readers of our journal Leben mit Down-Syndrom and all the groups we knew of in Bavaria, to encourage them to take part in the activities. We decided to focus on the topic of mainstreaming, as this is something which burns on our nails.

We developed the poster series Down-Syndrom. Na und! (Down syndrome. So what!) and distributed it all over Bavaria. We compiled a list of ideas which parents could do in their communities, to spread general information and to draw attention to people with Down syndrome. The campaign was very successful.

We received enormous feedback: about 100 articles on Down syndrome were published in local newspapers; discussion evenings, photo exhibitions, information stands, visits to hospitals, lectures in schools, for students or other groups, and play-days for children with and without disabilities were organised. The goal of our campaign is not to raise money, but through the campaign and what was written in the papers, Down syndrome and the work of the Down-Syndrom-InfoCenter became more public and this triggered the effect that donations came in as well.

From the next year on (1997) the campaign was organised nationally, as a lot of groups were interested in taking part. Since then we have celebrated the Deutsche Down-Syndrom-Wochen regularly. After a few years, we found that this single week, (the first week in October)
did not give us enough time for all the different activities, so from 2001 onward we announced the whole month of October to be the “awareness month”.

During this month – now known as German Down-Syndrom-Month – parent groups (there are more than 200 in Germany) organise all kinds of activities in their own communities. The InfoCenter concentrates on a special topic each year, in 2001 the topic was “Prenatal Diagnosis”; this year the motto was “Down Syndrome and Art”. Every year we develop and produce posters, postcards or flyers. This information material can be ordered from the InfoCenter and used during the awareness month. Part of the campaign in 1999 was distributing the posters and handing them in the 100 largest railway stations in Germany. In 1998 we produced a cinema-spot with a very well-known and popular German quizmaster, which was shown in many cinemas all over the country. Moreover, we launched announcements in popular German newspapers. Parent groups became really inventive and carried out unusual activities focusing on Down syndrome. For example, one group baked the longest strawberry cake ever (Guinness book of records!), and sold it in slices, served by children with Down syndrome. Models with Down syndrome showed children’s clothes in a fashion show on the catwalk, many radio and TV programmes reported on Down syndrome, and children’s books on Down syndrome were presented as a gift to libraries, schools or kindergartens etc.

Awareness campaigns have proved to be a useful tool, not only to attract the attention of outsiders to our topic but also to do fund-raising. In Germany the parent groups who took part in the activities are very enthusiastic about the success they have had. They experienced that, step by step, society changes and becomes more aware of the needs of individuals with Down syndrome.

This year artists with Down syndrome are shown on our posters. We found that there are many adults with Down syndrome who work as artists. They are hired as actors in theatre groups, and work in film and television as well. There are many musicians, some playing in orchestras or pop groups. There are painters, sculptors and potters working in art workshops, making beautiful art and selling their products. They do things most people would never expect they would be able to.

The InfoCenter, which is situated in Lauf near Nürnberg, had two events on their programme this year. We invited the theatre group RambaZamba from Berlin, which has 40 actors with a disability, many of them with Down syndrome, to perform one of their successful plays in Nürnberg. On this occasion the Down syndrome “Moritz” prize will be handed over to the founders of RambaZamba. Every other year this award is given to a professional who has been exceptionally committed to working with persons who have Down syndrome.

Besides that the InfoCenter organised an exhibition with paintings by three artists with Down syndrome from a well-known Austrian art place. As the actors and the painters were all professionals of a high standard, they found a keen interest in the media and this provided us with the opportunity to spread a lot of information on Down syndrome.

Some examples of the ‘Down Syndrome and Art’ poster series. The message translates as ‘Art is based on Ability’
European Down Syndrome Association news

Conference on Medical Issues
30 November 2002, Bielefeld, Germany

Conference speakers and topics

- Prof. Dr. J. Perera, President of EDSA
  People with Down syndrome in Europe – Presentation of the Identity Document of EDSA
- Dr. A. Rasore-Quartino, President of the Scientific Committee
  Health Care Guidelines for Persons with Down syndrome (EDSA)
- Dr. M. Seidel, Bielefeld-Bethel
  Medical care for persons with mental disability in Germany
- Dr. B. Huber, Bielefeld-Bethel
  Epilepsy in persons with Down syndrome

The Inseparables – Ballet of the Chromosomes
G. Lederer, M. Haus, R. Ludwig, K. Menninger

- Dr. M. Šustrová, Institute of Preventive Medicine, Bratislava
  Immunological issues and research in Down syndrome
- Dr. M. Dierssen, Barcelona
  Genetical research: psychopedagogical implications

A full report from the conference will be included in the next issue
New magazine in Romania - update

The first issue of the new Romanian periodical “Trăind cu sindromul Down” (Living through Down syndrome) was published in September 2002. There will be four publications per year, and they will include a translation of EDSA news.

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photos from
Centrul Educational
Teodora, Dolj,
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Full membership details appeared in Issues 1 and 2 and will be updated in Volume 3.

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**SWEDEN**
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THE NUMICON APPROACH TO TEACHING NUMBER

Workshops presented by Vikki Horner at the Sarah Duffen Centre

The Numicon Maths Approach to teaching number has been designed for pre-school and primary level education. Children in secondary level education, who are struggling with number, are also using Numicon to help develop their basic number skills. This approach is suitable for children of all backgrounds and abilities and has huge potential for children with special needs and in particular children with Down syndrome. It is also suitable for children learning English as a second language. The games and activities are multi-sensory and the materials are colourful and easy to use. The Numicon system teaches children number through structured visual imagery using three strands, pattern, counting and arithmetic and provides tactile introductions to important concepts in arithmetic.

This approach draws on three of children’s key strengths because they learn through ‘seeing’ they learn through ‘pattern’ and they learn through ‘action’. In particular, it helps with counting, pattern, odd/even numbers, place value, estimation, addition and subtraction for example, and also provides the necessary maths language. This will become apparent during the demonstration of the materials. Extension games and activities to assist with generalisation of number skills will also be discussed in detail on the day. Teaching the time will also be covered using this approach.

Vikki will be offering Numicon training as part of the Down Syndrome Educational Trust’s workshop programme on:-

Wednesday, March 12th 2003
Wednesday, June 4th 2003
Wednesday, September 24th 2003

Each of these dates follows a 2 day workshop programme for either preschool, primary or secondary age children. Some delegates might wish to attend all 3 days – see the Trust Services catalogue. For further details and booking phone +44 23 9285 5330 or e-mail enquiries@downsed.org
Music day for children with Down syndrome

PROGRAMME

9.30  Arrival and Registration
      Refreshments
10.00 ROSIE CROSS
      Introduction and video presentation
10.30 Group music making for children
10.30 Guest Speaker
   LUCINDA MACKWORTH-YOUNG
   “Teaching and Learning through Feeling”
11.30 Coffee
11.40 WORKSHOPS
      An opportunity to discuss issues related to music
      and its availability for children with learning
      difficulties
1.15 LUNCH
      A light lunch will be provided
2.00 CONCERT
      Children with Down syndrome will show their
      skill on a variety of musical instruments.
      Volunteers are invited.
      We will see the result of the morning’s group
      music making.
3.00 Refreshments
3.15 Plenary session
4.30 Depart

For further information and booking form for the music
day, please contact:
   ROSIE CROSS
   52, WOODLAND ROAD
   NORTHFIELD
   BIRMINGHAM
   B31 2HY
   0121 628 3300
   Rosiepiano1@aol.com

Fees for the day include the cost of a light lunch and other
refreshments

Closing dates for applications:

£30  received before Dec 15th 2002
£35  received before Jan 31st 2003
£40  received during February 2003

These prices are per adult or per family which includes a
person with Down syndrome or other learning difficulty.

Lucinda Mackworth-Young MA (PsychEd) GTCL (Hons) LTCL
(Piano) LTCL (Clar).

Well known for her very entertaining and experiential
approach, Lucinda is a pioneering consultant in psychology,
 pianist and teacher who puts relevant psychology and psy-
chotherapy into practical forms for music teaching, learning
and performing. Shedding light on many of the problems
encountered daily, and offering a wealth of practical tips and
suggestions, she runs courses under her association Music,
Mind and Movement, in London and Norfolk, provides course
work for the professional development courses run by ABRSM,
ISM and EPTA and lectures widely for the major music teach-
ing societies, music colleges and universities in England and
abroad. She has had numerous articles and advice columns
published in music teaching magazines and journals (notably
in Music Teacher, Rhinegold Publications) and on the website
www.practicespot.com. Her highly successful and very read-
able book “TUNING IN: Practical Psychology for Musicians”
is also available from the Practicespot website.
Conferences

4 - 5 April 2003
Research Conference on Cognition and Behaviour in Down Syndrome. Joint NDSS/DSRF Science Meeting,
Denver, Colorado, USA - more details below
http://www.ndss.org
http://www.drsf.org

2 - 4 May 2003
13th Annual Roundtable of the IASSID Aging Special Interest Group (Theme: Aging, Intellectual Disabilities and
Quality of Care: A Picture of the Real World in 2003), Volos, Greece

1 - 5 October 2003
8th World Congress on Down Syndrome, Singapore. (Theme: Down syndrome: Global progress in a changing era)
Organised by Down Syndrome International
http://www.down-syndrome-int.org/congress/current/

31 October - 2 November 2003
International Mosaic Down Syndrome Association (IMDSA) Convention
http://www.imdsa.com/

14 - 19 June 2004
12th International Association of the Scientific Study of Intellectual Disabilities (IASSID) World Congress,
Montpellier, France

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National Down Syndrome Society (U.S.) & Down Syndrome Research Foundation (Canada)

**Research Conference on Cognition and Behavior in Down Syndrome**

When: April 3-5, 2003
Where: Denver, Colorado, United States • Hyatt Regency Denver
Why: To review the latest in research on cognition and behavior in Down syndrome and to determine
priorities in the specific areas of imaging, memory, mental health, mouse models, speech and
language and positive behavioral support.

Call for Posters – February 7, 2003 deadline. Poster submissions will be accepted for review in the
areas of cognition, behavior and other basic, clinical and applied research topics.

The Down Syndrome Medical Interest Group (DSMIG) will meet on Thursday, April 3, prior to the
conference. CMEs and CEUs will be available for the conference and DSMIG meeting.

For more information, please contact

National Down Syndrome Society
666 Broadway
New York, NY 10012
United States
Tel. (800) 221-4602 or (212) 460-9330
Fax: (212) 979-2873
E-mail: info@ndss.org / www.ndss.org

Down Syndrome Research Foundation
1409 Sperling Avenue
Burnaby, BC V5B 4J8
Canada
Tel. (604) 444-3773
Fax: (604) 431-9248
E-mail: info@dsrf.org / www.dsrf.org
The Down Syndrome Educational Trust at No.10

Howard Hurd
Development and Operations Manager, The Down Syndrome Educational Trust

Looking back over the past 12 months, one of the events that particularly stands out is the Trust’s visit to No.10 Downing Street. Cherie Booth hosted a special charity reception on 25th June 2002 to celebrate The Down Syndrome Educational Trust’s considerable achievements over the past 20 years.

The event came about through the actions of one of our supporters, Marilyn Holland, mother of a daughter with Down syndrome and a passionate advocate of our work, contacted Cherie Booth explaining about the Trust’s activities and asking her to support our work. In response to Marilyn’s letter, Cherie Booth offered to hold a special charity reception for the Trust at No.10 Downing Street. It was a major boost to a small charity like The Down Syndrome Educational Trust to be offered the opportunity to hold such a prestigious event.

We used the event to celebrate our achievements and thank a selection of key supporters. Guests at this event included some of our hard-working voluntary fundraisers and supporters, a selection of potential donors, our local city councillors, and several members of staff from the Trust.

We were also delighted that we were able to share this once in a lifetime experience with several children and young adults with Down syndrome. As you can tell from the photos, the atmosphere was relaxed and informal, and everyone had a great time.

During the reception we were able to highlight the considerable successes of 18 year old Francis Kenny. Francis was involved in one of the Trust’s first reading and language research projects in the early 1980s. He later went on to achieve 6 GCSEs and is now pursuing a career in agriculture. He has also just been awarded his Gold Duke of Edinburgh Award, and visited St James’s Palace on 27th November 2002 to meet the Duke of Edinburgh and receive his award. We hope to have a piece written by Francis about his experiences on the Duke of Edinburgh Award Scheme in the next issue of Down Syndrome News and Update.

Cherie Booth personally welcomed each guest to the State Rooms at No.10, and spent some time talking individually to everyone who attended. She then made a short speech, which she started by praising the vital work carried out by small and relatively unsung charities like the Trust. She then congratulated Francis on his achievements and went on to pay tribute to the Trust’s activities over the past 20 years. She highlighted our innovative research in using visual methods to teach talking, and the resulting benefits for language and cognitive development. She also praised our
pioneering efforts in promoting full inclusion for individuals with Down syndrome in education and in society. At the end of her speech, Ms Booth stressed the Trust’s desperate need for funding to continue our vital work.

After Ms Booth’s speech, Sue Buckley from the Trust gave a short talk in which she highlighted our future plans for research – including the need to investigate the crucial issue of social exclusion – and reinforced our constant struggle to attract sufficient funding. She also thanked our local Portsmouth city councillors for their backing in agreeing a new 50 year lease on our premises at the Sarah Duffen Centre. We’ve reproduced Sue’s speech below.

The event was an evening to remember for everyone who attended. All of our guests enjoyed the reception and the very impressive surroundings. We’re also pleased to report that several new fundraising activities were initiated as a result of the reception.

We’d like to thank Laura Hester (the event coordinator at No.10) and the other staff at Downing Street who went out of their way to make us all feel so welcome, and ensured that our younger guests felt at home. In particular, we would like to express our sincere appreciation to Cherie Booth for taking the time out of her busy schedule to host the event.

Sue Buckley’s speech

First, on behalf of everyone involved with the work of The Down Syndrome Educational Trust, I would like to thank Sue Booth for hosting this reception and I would like to thank all our guests for their interest in our work.

I have been involved in the work of the Trust since it started in 1980 and I am very proud of the achievements of the Trust, in particular the continuous research programme that we have been able to sustain in co-operation with the Psychology Department at the University of Portsmouth.

Research is our core activity – we have learned a lot but we need to continue to increase our understanding of the children's cognitive, speech and language, learning and social needs. We know much about the children's cognitive needs but in order for parents and teachers to be able to implement what we know, we need to develop more teaching programmes to support them, hence our plans for the See and Learn software project described in our Trust leaflet.

Inclusion is proving very successful but we still need to improve the social inclusion of the children in school and in the community and this is an area in which we wish to develop further research. Many children with Down syndrome find number difficult to understand – an area where we are about to publish an important study on their early understanding but we now need funds for further work.

As a research team, we are unique in that we are able to carry out longitudinal research studies over time and because the research is carried out by staff with extensive practical experience. The fact that the Trust’s staff both support children’s education directly and do research enables us to study the development of children who are well supported in their education and to whom we have regular access. Longitudinal work, following children over lengthy periods of time to evaluate teaching approaches, is scarce as it is expensive to do and does not produce a quick return in academic papers. Our ability to conduct longitudinal studies is a particular strength, as is our close contact with families and teachers. Working at the coalface strengthens our research and identifies the important issues to research. It also gives us much experience of the wide range of individual differences that exist among children with Down syndrome. The outcome is research findings which have real practical value and this is clearly recognised by the demand for our work all over the world, especially as trainers. I think that I can honestly say that we have not conducted any study which has not produced practical results and information which can improve life for individuals with Down syndrome. However, research is not always easy to fund.

In relation to our dissemination activities, many schools contact us as they still need training and support to enable them to be effective in inclusion and we need more experienced, professional staff to enable us to meet that training demand. Our new series of publications on development and education, Down Syndrome Issues and Information, designed for parents and teachers to access, is being very well received and the materials are already being translated into a number of languages.

We had a couple of difficult years in 2000/2001 when we were threatened with losing our building but with the support of Portsmouth City Council, a further 50 years in the building is now assured and we hope to go from strength to strength. However, we could not achieve any of the things that we have achieved without the full support of many families, their children and young people with Down syndrome and their teachers. We also could not have achieved without the support of fundraisers over the years – we can earn some of our income from training and publishing activities, but we depend on fundraising and donation for almost half of our annual income.

I would like to thank everyone here for your interest in and support for our work and we hope that we can answer further questions about what we do and our future plans as you all enjoy this reception. Thank-you once again to Cherie Booth for making this event possible and to all of you for attending.
Funding successes

£65,000 to recruit new Educational Psychologists

We have recently secured a major grant of £65,000 over two years so that we can expand our service delivery team by employing an additional Educational Psychologist. The grant – from a low profile UK charitable trust – will enable us to meet the increasing demand for our assessment, consultancy and training services.

The new Educational Psychologist will help to provide a comprehensive range of services including: consultancy services for families, detailed developmental assessments for individual children, expert advice for families, teachers and other professionals through our free AdviceLine service, and our growing outreach services for parents and schools across the UK, including new regionally-based Early Development Groups.

New grants for the Trust’s Early Development Groups

After an extensive fundraising drive aimed at local funders we have been able to secure grants totalling more than £22,000 towards the popular Early Development Groups we run for pre-school children with Down syndrome from Hampshire and surrounding counties.

Support came from: the Herbert and Peter Blagrave Charitable Trust (£15,000 over 3 years); the Tesco Charity Trust Community Awards (£5,000); the Hampshire and Isle of Wight Masonic Charity (£1,250) and several other local charitable trusts.

We are delighted to receive such significant funding for our Early Development Groups. These groups help to provide the best possible educational start for local pre-school children with Down syndrome, and enable us to develop practical techniques that we can share with other similar groups to benefit children all across the UK.

IT and web infrastructure

Many DSNU readers will be aware of the major problems we were having with our web, e-mail and document servers during the summer. Most of this equipment was over 5 years old, over-worked and increasingly unreliable. We were experiencing regular server failures, and over recent months these failures had become more and more frequent.

We had been planning to replace these servers with modern, faster, more powerful and more fault-tolerant machines during 2003, but the problems with the old servers came to a head early in September. Our main document servers suffered a hard-disk failure and, although all of data was fully backed-up, the computer was so old we could not easily obtain spares. In response, we immediately set about finding the funds to replace our servers.

Thanks to the generosity of two sets of parents we were able to replace our main document server and e-mail server within a few weeks. Then another parent, who works at the Vodafone head office in Newbury, suggested that we approach his employer for funding to replace our web-servers. We sent in an application for funding, and thanks to the parent’s very strong support, we were delighted to receive nearly £9,500 from the Vodafone UK Foundation in November. We are now in the process of installing these new web-servers.

Our new servers will enable us to continue providing 24-hour access to detailed information on Down syndrome for parents and professionals all around the world on our two main websites (http://www.down-syndrome.info/ and http://www.downsed.org/). We will also be able to continue providing free website hosting for several other key Down syndrome organisations: Down Syndrome International (http://www.down-syndrome-int.org/), the European Down Syndrome Association (http://www.edsa.down-syndrome.net/) and the Down’s Heart Group (http://www.downs-heart-down-syndrome.net/). We will also be able to implement our plans for an extensive online index of Down syndrome resources, an online shop, a secure website to allow on-line payment and donations, and e-visitors’ services so registered users can customise our websites to meet their needs.

However, the problems with our servers and the time taken to install the new equipment has delayed the launch of the online shop. Our online shop should now be up and running early in 2003. It will provide detailed information about the wide range of resources and services available from the Trust, along with online ordering, booking and secure payment facilities in £ sterling, US dollars and Euros.

Funding for new research

The Esmée Fairbairn Foundation has awarded us a grant of just under £17,000 so that we can investigate the benefits of using the Numicon system to help children with Down syndrome to understand number and to develop further activities to extend their use of number knowledge to everyday applications. This research project will be an extension of our usual support service to the children at schools in the Portsmouth area. The outcomes of this evaluation project will include new materials for parents and teachers about using the Numicon system with children with Down syndrome.

Our previous research studies indicate that number is more
difficult than literacy for most children with Down syndrome and we feel that the visual representation of number offered by the Numicon materials should help them, given their strengths in visual learning. For more details about the Numicon research, refer to the ‘Learning to count and to understand number’ feature in Down Syndrome News and Update Volume 2 Issue 1.

Over the coming year, we have plans to submit bids for research about new models for speech and language therapy, behavioural problems as a barrier to inclusion, and new techniques to overcome the social exclusion of teenagers and young adults with Down syndrome.

**DSii Adult and Health series**

Now we are close to completing the final books in the Education and Development series, we are currently seeking additional funds so we can produce two entire new series in our ambitious Down Syndrome Issues and Information publishing project. The new Adults with Down Syndrome series will provide detailed information and advice about the wide range of issues affecting adults with Down syndrome, and the Healthcare and Medical series will provide expert medical advice for professionals and parents. However, we have only secured £40,000 of the £100,000 we need to publish these exciting new publications and need to identify possible funders. If any readers can suggest sources of funding, especially from non-UK companies or foundations, we would love to hear from you.

**Trust membership**

Despite these successes in winning grants for specific activities and projects, we continue to struggle to attract core funding. We recently launched a new Trust membership scheme, and we are delighted that so many of our supporters and service users have joined up. By becoming a member of The Down Syndrome Educational Trust you help support our ongoing costs, and help us continue providing detailed expert information to parents and professionals through our free AdviceLine service and popular websites. Membership costs just £45 per year for individuals/families, and includes 4 issues of Down Syndrome News and Update. Existing DSNU subscribers can upgrade to Trust membership for just an additional £5.

For more details about Trust membership visit [http://www.downsed.org/membership/](http://www.downsed.org/membership/) or contact the Trust by email (enquiries@downsed.org) or by telephone +44 (0)23 9265 5330.

**Fundraising events**

Over the few months since the last issue of DSNU, we have received well over £50,000 from donations and fundraising events. The events are all organised by volunteers – usually parents – across the country, and they provide an extremely valuable source of core income with no outlay for the Trust. We would like to thank all our supporters who continue to fundraise for us, and devote their time and effort in organising events. While the work of the Trust continues to expand and we receive much feedback thanking us for our work, the task of funding our activities is a constant demand. We do not have any reserves – we use all our funds for active work. We rely on donations and grants for nearly half our income. So – if you have any ideas for fundraising events or activities that you’d like to discuss, please contact Howard Hurd or Linda Hall at the Trust. We can help with tickets, leaflets, advertising, posters and other advice.

**Services**

Our assessment and consultancy service is as busy as ever with a 4 to 6 month wait for families. This means that anyone wanting assessments and reports for Tribunals must contact us as soon as possible. We do try to respond to urgent issues including visits to schools in need of help with behaviour issues, as soon as we can. The AdviceLine is also very busy and many of you will have received letters highlighting the need for funding for this service and for the Information services on the website which we expect to develop considerably over the next few months, now that our new equipment is in place.

**Training**

Trust staff have been busy with training events around the country and at The Sarah Duffen Centre during the autumn. We have provided 14 days of training at the Sarah Duffen Centre covering issues relating to development and education from birth to secondary school age children for parents and professionals, including specialist days for speech and language therapists and senior education staff supporting the development of inclusion. We have also provided training days across the country in five locations in addition to seven days in Ireland and the visit to Bahrain described on page 108. Next year we will be providing workshops around the UK in Falkirk, Bradford, Norfolk, Wirral, Oxford, Derbyshire, Northants, Staffordshire, Jersey and Swindon. One or two more are in the planning stage and we will give dates, titles and contact details in the next issue and on our website. We are also travelling abroad to speak in Ireland, Spain, Singapore and the USA, visiting some of these countries more than once. We look forward to recruiting new staff to help us meet this demand as we have had to put off some bookings to 2004.

For more details about previous issues and information visit [http://www.downsed.org/library/periodicals/dsnu/02/03/](http://www.downsed.org/library/periodicals/dsnu/02/03/)
Standards

The Down Syndrome Educational Trust’s practising staff are all appropriately accredited with their respective professional bodies and all our services meet the standards required by the British Psychological Society. The Trust is committed to promoting the full inclusion of children with Down syndrome into mainstream education and into the life of the communities in which they live.

Values

Children with a disability are children first - with the same needs and rights as all children

- All children are of equal worth, whatever their disability, race, gender, social class or religion
- All children have the right to be fully included members of society
- All children should be enabled to achieve their full potential
- A child’s most valuable asset should be his or her family
- All families should have the support and services they need to enable them to promote the well being of all family members within a happy, healthy and secure family group
- All children should be enabled to take their place as valued adults and full citizens in society
- All adults with a disability have the right to live with independence, dignity and security and the right to exercise control over their lives

Principles

- Parents know their own children
- Parents and professionals are equal partners
- Parents should be empowered to enable them to make informed choices
- Professionals have no right to take control from parents
- Children and families will receive services of the highest professional standard
- All interventions should be based on a thorough understanding of the impact of the child’s specific disabilities on the process of development
- All interventions should be scientifically evaluated and clear evidence of outcomes, advantages and disadvantages provided to parents
- Parents and practitioners will receive information and advice that is based on a thorough knowledge of current research findings
- Research will be conducted and disseminated to a standard acceptable to the international research community
Aims and scope

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

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

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

Guidelines for contributors

Longer articles and reviews

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

Shorter case studies, resource reviews, and personal experiences

Accounts of personal experiences of parents, professionals and individuals with Down syndrome are welcomed. Ideally they should focus on a particular issue or concern. Both accounts of particular success and solutions, and accounts of difficulties or problems, are encouraged. Shorter or more general accounts of personal experiences may be submitted as correspondence. Reviews of books, teaching materials, educational computer software, as well as Internet and other electronic media resources, are all welcome. Full details of the subject of the review should be provided; e.g. publisher, source, ISBN, price, etc.

News

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

Correspondence

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

Editorial review

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

Submissions

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

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

Manuscript layout

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

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

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

Terminology and spelling: As this is an international and an inter-disciplinary journal the needs of readers from different backgrounds should be born in mind. Technical or other terms specific to a particular discipline should be avoided if possible; otherwise discrete explanations or a glossary might be added. Abbreviations, such as of journal titles, should be avoided. Authors should avoid the use of potentially devaluing terminology for people with a learning disability. The terms ‘children with a developmental disability’ or ‘with moderate/severe learning difficulties’ are acceptable. The terms ‘mental handicap’ and ‘mental retardation’ are not. The term ‘Down syndrome’ should be written in full, and ‘syndrome’ spelled 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
Light, P. (1985). The development of view-specific representa-

Article (World Wide Web reference):
Down syndrome. Down Syndrome Research and Prac-