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Cover picture: Arjan, age 9, playing football with his peers during break. Photo: Stichting Down Syndroom (SDS)
Editorial

Sue Buckley

New format

This is the second issue in our new format. We had some very positive feedback on the last issue and readers liked the new magazine format. Thank you for contacting us – feedback is most welcome and helpful.

International perspective

The international perspective which we wish to develop is illustrated in this issue with features from the Netherlands and from Australia, reports on the European Down Syndrome Association conference in San Marino and the plans for the 8th World Congress in Singapore supported by Down Syndrome International. We are also aiming to include resources from around the world, so please let us know of the activities and publications of your organisations.

Editorial and Review Board

We are still inviting offers to serve on the Editorial Board. As we said last time, we aim to have a Board that reflects the international focus and encourages contributions from around the world. Individuals with Down syndrome, their families and those who provide services across the world tend to face the same issues, even though there will be cultural variations. The more we can share examples of family experiences, of new activities and of new and successful services, the more we can benefit individuals everywhere. We would like the Board to reflect our readership – which is mainly parents, associations and practitioners – so please do think about offering your services.

Contributions

In this issue, we have contributions from parents, practitioners and researchers. We are keen to have 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 activities of associations and details of forthcoming conferences or publications, so that we can promote them in print as well as on our websites and the websites of EDSA and DSI. 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 readers to use these pages to debate issues. In this issue we have views on inclusion and on speech and language therapy which may be controversial – please write to us with your views.

The next issue will be mailed in late September, so copy by 6th September please.

Features

Topics featured in this issue are inclusion in mainstream school, independent living and employment for adults with Down syndrome and the provision of speech and language therapy.

• Inclusion in mainstream school

The feature on inclusion includes two contributions, one presenting the findings of a research study which compared the outcomes of two educational environments for teenagers with Down syndrome. The teenagers had been in either mainstream or special schools from the start of their full-time education at 5 years of age. The study reported is the largest and most detailed study of inclusion published and the findings have clear implications for the development of effective education. The findings should lead Education Authorities to work to end all segregated special education provision, and to also question the benefits of special classes and units. This does not mean that we do not need special education but that special educational support should be delivered within mainstream classrooms for the majority of children and for the majority of the school day.

• Independent living and employment for adults

Many parents worry about the future for their son or daughter with Down syndrome ‘after they are gone’. Meg’s story should go some way to allay the fears of parents, and brothers and sisters, as Meg continued to live happily in her parental home after the death of her mother. She had ‘live-in’ support but demonstrated an increase in skills and confidence as she gained more independence. There is a message here for most of us who are parents…..

In the second article, the experience of developing employment for adults is shared in the hope that it will encourage others to offer employment or to go out and seek employment opportunities. The supported employment agency describes their role in finding employees and supporting them and the employers through a training period. The employers have some tips for others, basically identifying how competent the workers are and how easy the project was to establish.

• Speech and language therapy

We are often asked about the provision of speech and language therapy – especially by parents fighting to get adequate provision – so we have tried to answer the question, based on research into the children’s needs and our own experience. The paper sets out the ideal service. It also highlights the need for speech and language therapists to know the research on Down syndrome and to take some specialist training. We would like to know what reactions parents receive if they ask for this level of service and we would like some feedback from therapists please.

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Inclusion in education – what are the benefits and how do we make it successful?

All over the world, more and more children with Down syndrome are going to mainstream schools – we need to evaluate outcomes and to share good practice

The first two articles in this issue focus on inclusion in education based on experience in the UK and in the Netherlands. In the last issue we shared the experience and advice of teachers in New Zealand and we hope to continue this international focus on inclusion as, while school systems vary from country to country, we suspect that the key principles which lead to successful inclusion are the same.

The drive for inclusion has been partly based on a human rights approach, which defends the right of all children to be full members of their communities – seen as children first and not segregated on the basis of disability, and partly on the belief that children will make better social, psychological and educational progress if educated with typically developing peers. All pioneers for change have a vision of what will be achieved but if we want to ensure that the benefits are being achieved then we need to be evaluating outcomes and identifying the factors which enable parents, schools and teachers to develop successful inclusion.

My first experience of being involved in major attitude and service change was during the move from institutional to community care for adults with intellectual disabilities in the 1970s. There was no doubt that to move people from long-stay hospitals to give them the chance to lead ordinary lives in the community was right – but it could be done well or done badly as we soon found out. If done well, the aims were achieved and people had fuller and more ordinary lives but if done badly, people were more lonely and isolated than they had been in institutional care. The same is true of inclusion in education – done well, everyone benefits and many case studies from schools and parents show this to be the case. However, there are also many reports of unsuccessful inclusion, where the child is probably not benefiting and is unhappy, while staff are stressed and feel they have failed.

The next two articles address these issues. The first describes a unique opportunity to evaluate the benefits and the disadvantages of special and inclusive education, unique because it was possible to compare the progress of teenagers of similar abilities and family backgrounds within the two school systems. Research like this will no longer be possible in the UK as now most children with Down syndrome start in mainstream schools and only those with more significant disabilities start in special education. Readers will see that there are some very significant benefits but that we also still need to work on social inclusion.

The second article links well with the first as it focuses on social inclusion and how parents and teachers can take practical steps to make sure that children are fully socially included – in and out of school. It is based on the author’s extensive professional experience of evaluating inclusion in the Netherlands and his experience as a parent. Gert de Graaf has provided some important and practical guidelines on how to give children with Down syndrome the best possible start in their preschool years and then how to ensure full and successful inclusion in school and in the community.

Both articles have relevance for parents and practitioners with children from preschool to secondary school age. At the end of the articles we provide a guide to resources to support teenagers in secondary education and to support inclusion in education. Inclusion is likely to be a regular feature in Down Syndrome News and Update so please send us your contributions – we would welcome both articles and letters.

We would like to provide a forum for discussion of the issues that we raise so we would particularly like to hear the views of those who disagree as well as those who agree with opinions expressed on our pages.

Editor
A comparison of mainstream and special education for teenagers with Down syndrome: implications for parents and teachers

Sue Buckley, Gillian Bird, Ben Sacks and Tamsin Archer

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

Inclusion in mainstream education has been expected to deliver many benefits – what does the evidence actually show?

In 1987, two of the authors of this article published information on the development and lives of a large and representative group of 90 teenagers with Down syndrome. In some ways, the progress of the teenagers was disappointing – very few had made any useful progress at all with reading, writing, number and money, and social independence skills such as crossing roads and travelling alone were very limited. Most led rather isolated social lives and only 42% had speech that was intelligible to those meeting them for the first time (for example in a shop or café). The authors commented that their findings should not be taken as indicating what teenagers with Down syndrome could achieve, but rather, that the findings may be due to the nature of the curriculum in special schools, low academic expectations, being bussed out of their own communities every day to school and social attitudes which did not allow children with Down syndrome into clubs and activities in their communities. In 1987 94% of the teenagers were in schools for children with severe learning difficulties (SLD), 6% in schools for moderate learning difficulties (MLD).

In 1988, as a result of this study and in line with legislative change towards inclusion in education in the UK, the Portsmouth team began to develop inclusive education in local mainstream schools for the children with Down syndrome starting school in the southeast part of the county of Hampshire. In the rest of the county most children with Down syndrome continued to be placed in special schools. The Down Syndrome Educational Trust funded a psychologist to work with the schools, parents and the Education Authority to develop successful inclusion. This work has provided a unique opportunity to compare the outcomes of special versus mainstream education for two groups of children with Down syndrome of similar backgrounds and ability. It enables us to test out our view that the teenagers in 1987 were under-achieving and socially isolated as a result of segregated special education. Are the teenagers who have been included in mainstream education showing the predicted benefits of going to school with their typically developing peers and that their academic achievements would improve. Does the evidence demonstrate these benefits?

In 1999 we repeated the survey that we had carried out in 1987 with the current group of teenagers, including some additional measures. This enables us to compare the benefits of mainstream and special education for the 1999 teenagers and also to ask if, as a group, they are benefiting from changes in social attitudes and better education when compared to the 1987 teenagers. Many of the results of the study were not as the researchers might have predicted, and the findings raise some important issues for parents and educators of teenagers with Down syndrome to consider.

The 1999 study

In 1999, information was collected for 46 teenagers, 28 in special schools (24 in SLD and 4 in MLD schools) and 18 in inclusive schools. The young people in the two groups
were placed in mainstream or special schools on the basis of where they lived; they were from similar social and family backgrounds and were likely to be of similar potential abilities when they started school. The results we report are unlikely to exaggerate any advantages of inclusive education for the following reasons.

1. When we compared the progress of the two groups, to ensure that we were comparing young people of potentially similar abilities, the 5 ‘least able’ teenagers from the special schools were taken out of the comparison group, before the two groups were compared. These 5 ‘least able’ teenagers are those with significantly more developmental delay and health problems than the rest of the group. Two of them have autism in addition to Down syndrome and 3 of the 5 have significantly high rates of difficult behaviours. These young people have had multiple difficulties since childhood, and children with this level of difficulty would not have been placed in mainstream classes in any part of the country at the time of the study.

2. The average age of the main-stream group is two years younger than the average age of the special school group. This would reduce the likelihood of finding higher scores on any measures for the total main-stream group, as we know from our 1987 study that the teenagers in all groups are likely to be progressing with age on the measures we used.

It is also important to note that the teenagers in the mainstream schools have been fully included in age-appropriate classes in their local schools, supported by a Learning Support Assistant for the majority of the day. They have not been in special classes or resource rooms in mainstream schools and, usually, they have been the only child with Down syndrome or a similar level of learning difficulty in school until they reached secondary schools. In secondary school, some have continued to be the only teenager with Down syndrome, but some have been with one or two others with Down syndrome.

In both 1987 and 1999, the information was collected by surveys. In both studies, parents completed a questionnaire designed by the authors, the Sacks & Buckley Questionnaire (SBQ). In the second study, additional standardised questionnaires were also used, the Vineland Adaptive Behaviour Scale (VABS)\(^2\) and the Conners Rating Scales (CRS).\(^3\) The two main questionnaires (the SBQ and VABS) both contain measures of personal independence skills – Daily Living Skills – which include measures of skills in dressing, toileting, bathing, cleaning, laundry and meal preparation, also time, money, telephone use and road safety. They also both contain measures of speech, language and literacy skills – Communication Skills, and measures of friendship, leisure and social skills – Socialisation Skills. The Vineland Adaptive Behaviour Scale provides normative data which allows scores achieved on the scales to be translated into age equivalent scores. This is useful because it allows us to compare the progress of the teenagers across different aspects of their development. We would expect progress to be even for typically developing teenagers, that is, all skills will be at approximately the same age-level. Previous research suggests that we will find an uneven profile for teenagers with Down syndrome, with Communication skills lagging significantly behind Daily Living and Socialisation skills. The age equivalent scores also allow us to identify the extent of progress with age during the teenage years and this is illustrated in the first set of histograms in Figure 1.

**Progress with age**

The first two histograms in Figure 1 indicate that Daily Living Skills and Socialisation Skills can be expected to improve significantly as young people with Down syndrome progress through their teens (though with the caution that these figures are for different teenagers in each age group, not the same teenagers as they get older). When we look at the third histogram in Figure 1, for Communication Skills, we see significant progress for the oldest group of mainstreamed teenagers but no significant progress with age for the teenagers in special education. These differences in progress in speech, language and literacy will be explored in more detail in the next section.

The first important conclusion we can draw from this piece of research is that we can expect significant progress in all areas of development during the teenage years. There is no evidence for a ‘plateau’ being reached, or even a slowing of progress.

The reader will also have observed that there are no significant overall differences in the Daily Living Skills or Socialisation Skills of the
teenagers educated in special or mainstream schools, though there is a difference on one measure which contributes to the Socialisation Skills score - the Interpersonal Relationships Scale. This difference may be important and is discussed in more detail in the next section.

**A more detailed look**

For each main scale on the VABS there are 3 subscales which contribute to that score and the information for these subscales is illustrated in Figure 2.

**Daily Living**

The first histogram illustrates that for Daily Living Skills the teenagers were performing at a similar level in personal and practical skills in the Domestic (e.g. preparing meals, cleaning, taking care of laundry), Personal (e.g. independence in toileting, bathing, dressing) and Community (e.g. staying at home alone, time, money, telephone and road skills) areas. It also illustrates that there were no significant differences in skills between the teenagers in the mainstream or the special school groups.

**Socialisation**

The second histogram, however, illustrates that for the Socialisation Skills measure there is a difference for the Interpersonal Relationships subscale, which covers social interaction, dating and friendship skills. There were no differences on the Play and Leisure (going to clubs, games, hobbies, leisure activities) or on the Coping skills (awareness of manners, social sensitivity and social rules) subscales.

On the Interpersonal Relationships subscale, the teenagers educated in the special schools scored significantly higher, largely due to differences in scores for the oldest age groups. The older teenagers in special education were more likely to have a boyfriend or girlfriend, a special friend and to belong to clubs than those from mainstream education.

This was the only measure of the many measures used in this research which showed a significantly better outcome for teenagers in special education.

The numbers of teenagers in the study are quite small - 18 in mainstream education and 23 in special education - so that further research is needed to explore the significance of this finding. However, one possibility is that the teenagers in special education have had more opportunity to develop mutually supportive, reciprocal friendships with peers of similar abilities and interests than those included in mainstream schools.

**Communication**

The third histogram in Figure 2 illustrates the results for the three subscales in the Communication Skills score. For the teenagers in mainstream schools, the results indicate that their receptive and expressive language is progressing at the same rate and that reading and writing is a specific strength and better than might have been predicted from their other language abilities. Their expressive language is 2 years and 6 months ahead of the special school group. Some 78% of the mainstream teenagers are rated as being intelligible to strangers compared with 56% in special schools in 1999 and 42% in 1987. For the teenagers in special education, their receptive language is at a similar level to those in mainstream school but their expressive language is more than 2 years behind their receptive language. Their reading and writing abilities are at the same level as their receptive language but significantly behind the reading and writing skills of the mainstreamed teenagers, the difference being more than 3 years.

It is possible that the improved expressive language of the teenagers in mainstream schools is linked to their reading and writing progress. Researchers suggest that expressive skills are delayed by hearing, speech motor difficulties, auditory memory and auditory processing difficulties.[5-8] Therefore, it may be easier for young people with Down syndrome to learn vocabulary and grammar from written language, than from spoken language. In addition, phonics work plus reading practice may improve speech-motor production skills and speech intelligibility.

The teenagers being educated in mainstream classrooms, with the individual help of a Learning Support Assistant, will have received daily literacy teaching with their typically developing peers. They will also have recorded their learning in all lessons by writing it down and reading it - with whatever level of support was needed to achieve this. Therefore the level of engagement in
literacy activities for all the teenagers in the mainstream classrooms will have been much greater than that experienced by teenagers in the special school classrooms.

**Overall profiles**

In Figure 3 the histograms show the overall results for the main developmental areas – Daily Living, Socialisation and Communication Skills. For the teenagers in the mainstream schools there are no significant differences in the progress being made in each of these areas of development. Communication Skills are good, largely due to their progress with expressive language and literacy. For the teenagers in the special schools, their Communication Skills are significantly delayed relative to their Daily Living and Socialisation skills.

As already noted, this special school profile is, in fact, the one that researchers would expect to see for teenagers with Down syndrome. A number of studies have found that speech and language skills, particularly expressive skills, are specifically delayed relative to both non-verbal cognitive abilities and to social and independence skills.\(^{1,4}\)

The results of our study suggest that it is possible to bring communication abilities in line with social and practical abilities for teenagers with Down syndrome, by including them in mainstream classrooms. The results indicate that a major factor may be the development of reading and writing and the use of literacy activities to teach and to support spoken language development.

Another major factor may be that the mainstreamed teenagers have been surrounded by typically developing competent spoken language users since they entered preschools at 3 years of age, and this spoken language and communication environment will have been very different to that experienced by the teenagers in the special schools. Almost all of the special school group have been in special schools for children with severe learning difficulties for their entire school career and this means that they have been with children the majority of whom have very significantly impaired language.

**Comparison with outcomes in 1987**

Perhaps the most surprising and important finding of this study was the lack of progress in special school education between 1987 and 1999. We confidently predicted that all teenagers would be doing better in the 1999 group as we know that the special schools have had higher expectations and more academic programmes in the past ten years than they did 15-20 years ago. However, we found no improvements in 1999, when compared with 1987, for spoken language skills, reading, general knowledge and overall school achievement – achievements were the same as in 1987. There were small gains in writing and number.

It is important to remind the reader that the children in the special schools were not less able than the earlier cohort. At the time that these children entered school there was very little mainstreaming where they lived and our data confirms this point, as in many areas of development their skills are the same as both the 1987 group and the 1999 mainstream group.

Our findings suggest that it is not possible to provide optimal learning environments in special schools and classrooms, however hard the teachers work. It suggests that learning within a typically developing peer group may be essential for optimal progress for two main reasons:

1. the typical spoken language of the peer group because this provides a stimulating language learning environment
2. the classroom learning environment and curriculum – the pace of learning has been much greater for those in mainstream because they have been in all academic lessons with individual support for their learning.

We can use the example of literacy to explore this further, the included teenager has had daily literacy lessons with his or her typically developing peers. The classroom curriculum is set for the mainstream children and their learning provides role models for literacy for the student with Down syndrome. He or she will be working with support within the class on individually set targets for literacy. A literacy lesson in a special school classroom will, of necessity, be very different. In the special school, the teacher will have perhaps 6 pupils, all with significant learning difficulties, and will design a literacy activity for this group – 2 of whom may be autistic, two with severe behaviour difficulties and 2 with Down syndrome – all have significantly delayed speech and language and only three are able to write their names. Sharing a story together may be an appropriate literacy activity for this group – to try and give a real picture of the different demands and resources of the two situations and to try to explain our findings.

The same comparison would apply to numeracy lessons in mainstream or special classrooms.

There were no gains between 1987 and 1999 in Daily Living Skills for teenagers in mainstream or special education and significant gains in Social Contacts and Leisure activities for both groups. We suggest that Daily Living Skills are mostly learned at home and therefore not influenced by school placement and, similarly, that the improvement in social inclusion reflects a general change in social attitudes and social acceptance in
the community rather than school placement effects. Social lives out of school are also more likely to be influenced by families than schools.

**Personality and behaviour**

Another major area of developmental importance that was looked at in these Hampshire teenage studies was the extent of behaviour difficulties, whether any behaviour difficulties change with age and if school placement has any influence on behaviour.

We were aware from our inclusion support work that difficult or disruptive behaviour is a major cause for the breakdown of mainstream school placements. We were also concerned to find out if the demands of coping in a mainstream classroom actually increased behaviour difficulties.

Significantly difficult behaviour affects the learning and social opportunities of a teenager with Down syndrome and can create considerable stress for teachers and for families. Conversely, teenagers who can behave in a socially acceptable and competent manner will be more likely to have friends, to have active social lives and to be successful in work as adults, than those who do not.

Difficult behaviours need to be considered in relation to the helpful and socially sensitive behaviour and the positive personalities that are characteristic of most teenagers with Down syndrome. Many references to the positive aspects of teenagers' personalities were made by parents during the recent Hampshire survey, for example:-

"J. is a happy and content girl, very understanding, helpful and has a great personality - she brings out the best in everyone."

"He is happy and outgoing and lots of people know him so we talk to more people because of him."

"She is a wonderful, happy and most loved member of our family. She is kind, caring, happy and thoughtful."

"A. has a positive approach to life and brings that to the family. His caring nature and enthusiasm are infectious. I think he has made the family dynamics easier than they would have been, especially the teenage years."

"She is good company, always happy, funny and content."

"Good point is, he is a happy lad who is good fun and has taught us a lot."

"Very loving, trusting and happy boy - enjoys life and is very sociable."

"Our daughter brings more love, fun and laughter to family life and though she will never be 'academic' there are other qualities she has which cannot be measured."

"He is popular, friendly and non-judgemental... he has added another dimension to our lives."

"Brings a lot of happiness to our lives. Her disruptiveness – being rude or awkward – can cause parents and sister to get cross and upset."

The last quote highlights the fact that difficult behaviours occur only sometimes and do not define the person's character. Someone with a positive personality can be difficult at times and this would characterise most of the teenagers in the survey. However, this does not mean the difficult behaviours are not distressing when they do occur and most parents and teachers are pleased to obtain advice on how to handle them.

Several measures were used to collect information about any behaviour difficulties that the teenagers had. There were behaviour questions on the original Sacks and Buckley questionnaire[1] and a Maladaptive Behaviour Scale on the Vineland Adaptive Behaviour Scales.[3] In addition, the Conners Behaviour Rating Scale[4] provides measures of several different aspects of behavioural difficulties, hyperactivity, cognitive problems or inattention, oppositional behaviour and Attention Deficit/Hyperactivity Disorder-ADHD.

All the measures illustrated that difficult behaviours tend to improve with age for most individuals, with only one teenager over 18 years in the mainstream schools comparison group having even a moderate level of difficulties. This strongly suggests that many of the behaviours reported for the younger teenagers may be linked to general cognitive delays and immaturity.

Our concerns about the demands of mainstream placements increasing behaviour difficulties were not confirmed. There was only one measure on which the teenagers from the different school systems scored significantly differently – The VABS Maladaptive Behaviour Scale – and these results are illustrated in Figure 4. The scores can be classified in terms of the severity of the behaviour difficulties. As the data below shows, significant behaviour difficulties only affect a minority. The teenagers in the mainstream schools were less likely to have difficulties, with 63% having no significant difficulties compared with 41% in the special schools, 25% having a moderate level of difficulties compared with 27% in the special schools and 12% (one in eight) having significant behaviour difficulties compared with 32% (one in three) in special schools.

The reader is reminded that the 5 'least able' teenagers in the special schools are not included in this comparison. Three of these 5 had very high scores for difficult behaviours and the remaining 2 had low scores. This means that in the whole sample of teenagers, and the whole sample is representative of the full range of teenagers with Down Syndrom...
syndrome, 26% (one in four) have some significant behaviour difficulties which will be probably causing problems at home and at school on a daily basis.

The Vineland Maladaptive Behaviour Scale predominantly includes questions about two main types of behaviour, those that may reflect anxiety and nervousness and those that reflect conduct disorder and poor attention.

On the Conners Behaviour measures, which focus on conduct disorders and attention difficulties, there were no significant differences between the levels of difficulties for the teenagers in mainstream or special schools. When the scores of the teenagers with Down syndrome are compared with norms for typically developing teenagers, the proportion of the total group who had serious difficulties was 16% on each of the Oppositional Behaviour, the Cognitive problems/inattention and the ADHD measure and 37% on the Hyperactivity measure. (The reader should note that some 5% of the typically developing population of teenagers of the same age will score in the serious difficulties range as defined by the Conners Scales).

The hyperactivity measures include, being always 'on the go', hard to control while shopping, runs about or climbs excessively in situations where it is inappropriate, restless in the squirmy sense, has difficulty waiting in line or engaging in leisure activities quietly. The high score here may reflect immaturity and improve with age, as similar findings have been reported by other researchers and interpreted in this way.[9,10]

The link between behaviour and poor communication skills

Similar to other studies, and the authors' 1987 study, there was a significant relationship between expressive communication skills and behaviour difficulties – the more limited a teenager's expressive language ability, the more likely he or she is to have behaviour difficulties. The implication here is that at least some difficult behaviours are the teenager's way of communicating when he/she does not have the language to do so. In addition, some behaviours may be the result of the frustration that arises when an individual is not understood.

Has inclusion achieved what we hoped for?

We stated at the beginning of the article that we hoped that included children would be more likely to have friends in the neighbourhood and better social lives as teenagers, with better social independence skills for getting around their communities, more friends and more involvement in clubs and activities, that their speech, language, behaviour and social development would benefit from being with typically developing peers and that their academic achievements would improve, when compared with the teenagers receiving special education in segregated schools. Does the evidence demonstrate these benefits? The answer is “yes” for spoken language, behaviour, social development and academic benefits and “no” for the social inclusion benefits.

The language and academic benefits were greater than we expected. The big gains for the included teenagers were for expressive language, literacy and, to a lesser degree, numeracy and general academic attainments. The average gain for expressive language was 2 years and 6 months and for literacy, 3 years and 4 months. These age-related scores are based on norms for typically developing children who are expected to progress 12 months on the measures in a school year. Children with Down syndrome usually progress about 4-5 months on these measures in a year – they are making progress but at a slower rate than typical children. Therefore, considered in relation to expected gains, the teenagers in mainstream school have gained the equivalent of 5-6 years progress in spoken language and literacy when compared to the teenagers educated in special classrooms.

There were some gains in social development and behaviour. The teenagers in mainstream schools were more socially mature, with more age-appropriate social behaviour and more social confidence. However, the social inclusion gains were not as great as we expected. On the standardised measures there were no gains for the included teenagers and the suggestion of a disadvantage. There were no significant differences in social independ-
enence skills, social contacts, leisure activities and community inclusion. Parents were as concerned about the social isolation of their teenagers as they had been in 1987, even though there was evidence of some improvements for everyone since that time.

The benefits of having daily contact with typically developing children and teenagers in the local area, during the school day, did not result in more inclusion and friendships during the teenage years. In addition, the included teenagers seemed to be less likely to have special friends, boyfriends or girlfriends and a social life of their own in their late teens, perhaps as the result of having less contact with peers with similar intellectual disabilities or peers with Down syndrome in school.

What are the implications for parents and for teachers?

1. That all children with Down syndrome should be educated within mainstream classrooms to ensure that they are able to develop their speech and language to the level that is optimal for each child.

   The importance of speech and language development for cognitive and social development cannot be over emphasised. Words and sentences are the building blocks for mental development – we think, reason and remember using spoken language, either silently ‘in our minds’ or aloud to others. Words provide the main source of knowledge about our world.

   Any child with speech and language delay will have mental delay (unless a signing baby in a deaf signing family, when sign will be as good as speech for mental development). In addition, speech and language skills influence all aspects of social and emotional development – the ability to negotiate the social world and to make friends, share worries and experiences and be part of the family and community.

2. That all children with Down syndrome should be educated in mainstream classrooms to learn alongside their peers and to access the academic curriculum adapted to their individual rate of progress.

   Full inclusion in the curriculum leads to much better literacy and numeracy skills, and general knowledge. The level of supported literacy experience across the curriculum also provides an important support for spoken language development.

3. Our research indicates that it is not possible to provide a maximally effective learning environment in a special education classroom.

   Children with Down syndrome need to learn with their non-disabled peers with the necessary individual support to make this successful.

4. The social aspects of inclusion need to be addressed.

   Children with Down syndrome in mainstream schools need more opportunities to socialise with a peer group of children with similar levels of intellectual disability. This can be achieved by closing special schools and classes and including all children with learning disabilities in mainstream school communities – at present many children who would provide this peer group in the UK are still in special schools. The children with Down syndrome have had a parent lobby and more of them are fully included than their peers with similar levels of intellectual disability. It can also be achieved out of school, by ensuring that children with Down syndrome have friends with similar disabilities out of school.

5. Friendships with non-disabled peers need more support within school communities.

   Teachers and parents need to do more to ensure that these friendships carry on outside school. We wish to see an improvement in understanding and support for teenagers and adults with Down syndrome in their homes, workplaces, shops and leisure activities as a result of inclusion. This is not yet happening and needs to be addressed within schools.

   These are statements supported by the evidence, and the evidence of earlier reviews of the benefits of inclusion.

   No study has provided evidence for any educational advantages of special education, only disadvantages, and the practical daily living and social skills are as good or better in mainstream education. The only benefit seems to be contact with a peer group of similar disability – and, considering the significant disadvantages of special education, that need is better met out of school, and in better planned inclusion.

   Our conclusions are uncompromising and if we are to achieve the full benefits of inclusive education for all our children we need to implement effective support and training programmes. We may also need some variety of provision. Most children with Down syndrome will benefit from the full classroom inclusion that we describe, sup-
ported by a learning support team. In many schools, a learning resource area which provides for small group work is needed for some children and can provide a place to meet the peer group with similar levels of intellectual disability.

If we include all children with Down syndrome and all children with intellectual disabilities, then some children may benefit from being in a resourced school. For those children with the greatest levels of disabilities, planning and providing for them may be best done within a specifically resourced school. This does not mean being educated in a special class or resource room — it means that we concentrate skills and human resources in some schools to develop the necessary expertise for successful inclusion of those with the greatest needs. It also means that the children have access to a similar ability peer group as well as benefiting from being included in the mainstream community.

There can be no single prescription for successful inclusion as the school systems in different countries and communities vary widely. The way to move towards full inclusion may be different in different communities and, importantly, different models may work equally well if the attitudes of the school community towards inclusion are positive and the aim is to seek the full inclusion of the child into the social and educational world of the school, while also meeting his or her learning and developmental needs.

**Postscript**

Some critics of our work have suggested that inclusion in Hampshire is ‘special’ and only successful because the Trust staff support the schools. In fact, from 1988, the teachers and the Trust’s psychologists learned together year by year. It was the teachers in the schools who showed us how to make inclusion successful. We did not visit more than once a term on average, unless asked to help with a problem. We did not start workshops on inclusion for teachers until 1993 and they were based on sharing what we were learning from the teachers. The children in the study differ widely in ability, behaviour, social needs and family backgrounds. The children studied have been spread through some 25 primary schools (infant and junior) and some 12 secondary schools, in inner city, urban and rural areas — these schools are likely to be representative of schools across the UK.

For the past 9 years, we have been running training for inclusion throughout the UK and across the world and we see many, many examples of similarly successful inclusion everywhere. Our schools experienced problems at times, like all schools developing inclusion, but the positive staff attitudes towards inclusion and the support of the Education Authority meant that problems were solved — not seen as a reason to move a child to a special school. At transition points from infant to junior to secondary it was assumed that the children would stay in the mainstream system and everyone planned accordingly. On the basis of parental choice two teenagers moved to MLD provision for secondary education and two moved to mainstream from MLD at this point!

It may be important to note that these teenagers were included before the introduction of IEPs (Individual Education Plans) or SENCOs (Special Educational Needs Co-ordinators) into UK schools. Schools are much better resourced to succeed now — though we do need to be sure that too much planning and special needs expertise does not result in lowered expectations.
We asked teachers to fully include the children in the class activities and told them we would help them to adapt once it was necessary. The children tended to surprise us all and fewer adaptations were needed in infant school than we had anticipated. There is the danger that an IEP could reduce expectations, depending on who writes it and their experience of working with children with Down syndrome in mainstream education. The children in this study also had no signing in their classrooms and, at first, no speech and language therapy service. They had to cope and make themselves understood in a spoken language environment and we encouraged teachers to use reading activities to develop their spoken language. We have no way of knowing how much this contributed to their significant speech and language gains, but we are very cautious about the current widespread use of symbols and signing in primary school years – for some children it is necessary and appropriate but not for all just because they have Down syndrome.

You might sum up our approach as focusing on children first – seeing children with Down syndrome as full members of the class and community and playing down differences. They do have special needs and teachers need to know how to address these but we still need to change public and professional attitudes so that they really do treat our children as children first. When we achieve this, we will really see the full benefits of inclusion.

References
Supporting the social inclusion of students with Down syndrome in mainstream education

Gert de Graaf
Stichting Down Syndroom (Dutch Down Syndrome Foundation)

Parents and families can work together to improve social inclusion

This article is written by Gert de Graaf. He is a free-lance researcher in the field of education for children with a developmental disability. In addition, he is the education officer of the Dutch Down Syndrome Foundation (Stichting Down Syndroom) and although bearing the same family name, he is not related to its director, Erik de Graaf. Finally, he is the proud father of a lovely twelve year old girl. She happens to have Down syndrome and is in the seventh grade of a mainstream school (the grade for ten/eleven year old children in The Netherlands).

During the last three years, on behalf of the Dutch Down Syndrome Foundation, Gert de Graaf has conducted several research projects in relation to the social inclusion of students with Down syndrome in mainstream schools. As such, he has made a thorough survey of the international literature. In addition, he has conducted a series of in-depth interviews of teachers, special educators, school administrators and parents of included children, and he has also made observations in the schools (both in the classrooms and in the playgrounds). On the basis of the findings of his research, he gives a list of practical recommendations for interventions aimed at improving the social inclusion of students with Down syndrome.

Dutch schools
Before presenting the findings it is necessary to set the scene with some remarks about the Dutch situation in relation to the inclusion of students with Down syndrome in mainstream education.

1. The Netherlands has an elaborate system of segregated special education. More than four percent of all children between six and seventeen years of age are taught in special schools. Since the seventies, the constant increase in the number of referrals to special schools for children with mild developmental disabilities and for children with specific learning disorders has worried educators and policy makers. Since the nineties, education policy, known as Weer Samen Naar School (Once Again Together at School), aims at reducing the number of children attending these types of special schools, with some success in recent years.

2. The integration into mainstream education of children traditionally placed in special schools for children with sensory or physical disabilities or severe learning disabilities (students with Down syndrome were traditionally placed in SLD-schools in The Netherlands) is largely due to the activities of parent organisations and was not the result of deliberate governmental policy. How-
ever, the Dutch government has followed this trend by changing rules and regulations in order to provide extra support in mainstream education. In grades 1 and 2 (4 to 6 year olds) schools qualified extra staff for half a day each week. In grades 3 through to 8 (6 to 13 year olds) schools receive extra staffing for one day each week. This means that, in comparison to, for instance, the United States, Italy or the United Kingdom, the amount of assistance for included children is rather low. Despite this fact, a growing number of schools agree to the parents' request to accept their child. Over the last ten years, the total number of students with Down syndrome in mainstream education has risen to almost 600 (which means slightly more than 25% of children with Down syndrome in The Netherlands in the age range from 4 to 14 years).

3. Due to the limited amount of assistance being provided by the government and due to the fact that mainstream primary schools in The Netherlands simply do not have to accept a student with a developmental disability, the inclusion is selective. This means that more able children with disabilities have more chance of being placed in a mainstream school and to continue their schooling there. New legislation is being prepared, but in this legislation there is no such thing as a clearly stated right to attend a mainstream school, though for schools a written policy in respect to inclusion will be mandatory and schools will have to give arguments if they refuse placement of a child.

4. In The Netherlands, since the late eighties, parents of children with Down syndrome have been encouraged (by the Dutch Down Syndrome Foundation) to use an early intervention programme to improve the development of their child. As a result, it is not unusual for some children with Down syndrome to be able to read before their peers. Unfortunately, there is a lack of professional support for parents working with early intervention. The Dutch government still has not given any

serious concern to implementing professional early intervention services and, in fact, is now breaking down the bit that existed. As promised, a list of practical recommendations will now be given for interventions aimed at improving the social inclusion of students with Down syndrome, especially those in mainstream education. However, many recommendations are also useful in situations other than mainstream school. Some of these interventions are directly aiming at social inclusion, some more indirectly.

Right from birth
Parents have an influence on the abilities, the behaviour and the social network of their child, right from birth. For young children with Down syndrome the following recommendations can be made:

1. Medical care should be based on an up to date medical checklist for children with Down syndrome.
2. Both hearing and vision should be checked regularly from an early age onwards.
3. An early intervention programme should be used to improve the child's abilities.
4. Teaching reading and number skills should be initiated before the child enters school.
5. Many children with Down syndrome misuse their social skills to avoid learning. Parents should not give in to this behaviour. Instead, they should try to make the task more interesting, to give the child more support and more encouragement and/or to build in smaller steps.
6. Language skills make an important contribution to social skills. In young children with Down syndrome expressive language is often lagging behind receptive language as well as behind overall development. Parents can strengthen their child's expressive language skills by:
   - encouraging the child to use words he/she already knows;
   - systematically teaching the child the words that fit to particular situations;
   - using signing and reading to support spoken language, thereby making use of the relative visual strength of children with Down syndrome.
7. For the development of social competence in their child, parents should combine emotional warmth and sensitivity with developmentally appropriate behavioural demands.
8. For the development of social competence and self-confidence it is important that a child experiences him/herself as an effective communicator. Due to a combination of motor, sensory and neurological problems, the communicative signals of many young children with Down syndrome are less clear, and their reactions often show a time delay. Parents of children with Down syndrome can learn (and often do learn) to take notice of smaller signals and to give the child more time to react.
9. Parents can help their child to learn pro-social behaviour by providing their child with examples, and by explaining and reinforcing pro-social behaviour.
10. Parents can help their young child with Down syndrome to gradually build up the ability to participate in longer interactions by imitating their child, by giving their child enough opportunity to take turns, by reacting to their child's initiatives, by extending their child's play (instead of switching to other activities too soon or too often).
11. Fantasy play is seen as a vehicle for social growth for young children. Many children with developmental disabilities do not spontaneously engage in elaborate fantasy play and/or are not very interactive in their play. Parents can help their child in this regard by engaging in their child's play as a playmate, thereby
elaborating on the child’s play theme.

12. Create opportunities for playing with other children. Playing together can be stimulated by giving children play suggestions, giving play materials which encourage playing together, encouraging and reinforcing playing together, getting play started by beginning to engage in a play situation yourself (and withdrawing when other children have joined in), helping children to resolve conflicts.

13. Building a social network starts right from birth. It starts by introducing the child to his/her parents’ social network and in the neighbourhood and can be extended by making use of regular services, like a regular day care centre.

14. When parents are feeling good about themselves, this has a beneficial influence on their child’s feeling of well-being and his/her behaviour. Parents should organise adequate support for themselves.

**Choosing a mainstream school**

Presently, under the ‘old’ legislation, more than half of the parents of children with Down syndrome in The Netherlands choose a mainstream school for their child:

- Many parents expect that their child, by going to a mainstream school, will have easier contacts with children in the neighbourhood.
- Many parents believe a mainstream class is a more stimulating social environment.
- Many parents think that a child in a school for children with severe learning difficulties (SLD) runs a greater chance of picking up inappropriate behaviour from his/her classmates.
- Some parents expect a better development of academic skills and criticise the curriculum and the way of teaching in a SLD school.
- Some parents believe educational inclusion can have a positive influence on the acceptance of people with disabilities in society.

Ideally, parents manage to find a school:
- with enough coping capacity (cooperation in the team; a strong school leader; some organisational stability; good social climate);
- in which differences in educational needs between children are being seen as normal;
- in which the school leader and most of the teachers see inclusion of a child with Down syndrome as a positive challenge.

From the viewpoint of social inclusion, a school in the immediate neighbourhood has one great advantage: the child meets the same children at school as in the neighbourhood, which greatly facilitates the building of a social network of playmates outside school hours.

**Getting into the school**

As has been stated before, in The Netherlands mainstream schools do not have to accept a student with a developmental disability. Consequently, parents have to ‘sell’ their own child.

It is important that the school makes a well informed decision about the individual child with Down syndrome and does not base its decision on prejudices with regard to children with Down syndrome in general. Psychological tests often give an underestimation of the abilities of children with Down syndrome in real life. To give the school an adequate picture, it is recommended that a videotape of the child’s functioning in daily life and in play and/or to use a checklist for skills from an early intervention programme is used instead.

The school director should see it as his or her responsibility to make sure the team is well informed and to create enough support in the team for inclusion.

**Some general conditions for success**

There is more chance for successful inclusion when teachers and parents cooperate well. This is more likely to occur when teachers and parents share basic ideas about the goals of inclusion, give each other enough positive feedback and make clear arrangements for regular consultations together.

Parents need support for themselves. Many parents experience the exchange of ideas and experiences with other parents of children with Down syndrome in a comparable situation as a strong support.

A positive attitude, with high expectations, is most important. A child should not be judged by his or her spoken language, because he/she will usually understand much more. In this respect the teacher’s attitude is an important factor.

Teachers are more likely to find solutions for problems, when they have an optimistic view, seeing problems as challenges and believing in the modifi ability of the child. Also teachers should learn to value small steps as success.

There should be enough assistance for supporting the child, the amount depending on the individual needs of the child. When the amount of extra assistance is limited, it is better to have many short periods of extra support during the week than accumulating all assistance on one day.

**Extending the child’s social network**

The school is not the only source of friends and playmates. Parents are recommended to invest in a broad and varied social network for their child, looking wider than the school and wider than same-age peers only.

Parents are recommended to be active in organizing opportunities for playing with peers. For parents of a child with a disability it is often necessary to start with actively inviting classmates to their home and to invest in good relations with the parents of classmates.

“At a meeting for the parents of his class, the first week after the holiday, we, the teachers and his mother, gave some information. The reactions were very positive. Other parents asked questions, like: ‘If he comes to play at our home, how can we be supportive?’” (teacher of Floris: 6 years, grade 1/2)

Teachers should keep the parents of the child with Down syndrome informed about which classmates he/she gets on well with at school.

Giving the parent of the child with Down syndrome an opportunity to explain his or her point of view to...
parents of classmates can help to take away possible fears and inhibitions on their side.

To prevent misconceptions (and possible envy about the extra assistance for the included child with Down syndrome) it is important that teachers give the parents of other children information about school decisions and its organisation with regard to the inclusion of children with disabilities.

In decisions about repeating a class, possible negative effects on the social network of the child should be taken into account.

Sometimes it is necessary to make use of a more deliberate method for creating and extending the social network of the child, such as ‘circle of friends’ or ‘making action plans’ (MAPs).

Social inclusion and social problems

The extent of social inclusion of individual children with Down syndrome is influenced by many different factors: child factors (for instance, social skills, speech, age), and environmental factors (for instance, social climate in the classroom, teacher’s attitude, behavioural management).

Interventions for improving the social inclusion of students with Down syndrome are more likely to be successful when they are aimed at different relevant factors simultaneously.

The social inclusion of a child with Down syndrome can evolve without any serious problems, with the child being well accepted and having friends.

However, social problems can occur. In this research three types of social problems were observed.

1. The child is more or less isolated.

Interventions could be: improving the child’s play skills, social skills and language/speech; creating play and learning situations which are more suited to the child’s abilities; inviting classmates to play at the child’s home; improving the social climate in the class; creating a ‘circle of friends’.

2. Classmates are dominating the child, smothering the child with too much help or overprotecting the child.

Interventions could be: giving classmates clear directions for their behaviour towards the child and, as a teacher, being a role model in this respect; diminishing the need for extra help by teaching the child more skills in self care; giving the child clothes, a bag and packed lunch that he/she can handle without assistance; creating situations in which the child can participate more as an equal or in which he/she can even excel.

3. The child is often behaving inappropriately or anti-socially. Sometimes it is classmates provoking these behaviours.

Interventions could be: making a thorough behavioural analysis of different relevant situations; ascertaining that inappropriate or anti-social behaviour is not unintentionally reinforced; reinforcing appropriate social behaviour; encouraging positive relations with classmates; giving classmates clear directions for their behaviour towards the child.

Creating situations

It is important to carefully observe situations in which the child has more positive interactions with his/her peers. Then, if necessary, similar situations can be recreated. Children with Down syndrome often have more interaction in situations with only a few other playmates. These situations can be arranged at school, whatever the total size of the class. Playing at home also gives opportunities to arrange adequate play situations.

Additionally, teachers and parents can organise ‘set-ups’. This means getting play sessions started by engaging in a play situation with the child, only to withdraw when other children have joined in.

“I in the beginning I helped play to get started by engaging children into fantasy play, because that is the kind of play Annelot likes and is good at. For instance, I give them a lot of clothes to use for dressing to represent all kind of fantasy figures.” (mother of Annelot; 8 years, grade 3/4)

Teachers can pair another child with the child with Down syndrome for certain activities (play as well as work).

Available extra assistance can be used for supporting a small group of students including the child with Down syndrome instead of only supporting the child with Down syndrome.

“The assistant tries to encourage Dorinde to play with other children. For instance, she starts an activity with Dorinde and then she invites one or two children to join in. She encourages them to play together. Or the assistant varies a round game, for instance a kind of colour-matching game.” (teacher of Dorinde; 5 years, grade 1/2)

Improving the child’s skills

Improving the child’s play skills, language, speech and social skills, can have a positive influence on the his/her social inclusion.

With regard to play skills, it is recommended that these are included as objectives in the child’s educational plan. Observe which games are actually (in that particular period of time) being played in the school’s playground and try to teach the child with Down syndrome the relevant skills and rules. Ask other children at school and in the neighbourhood if they want to assist. When the child is unable to play the game by the rules, for instance as a result of motor problems, make adaptations in consultation with the child and his/her playmates.

“In a subtle way the teachers do support him. For example, in grade 6 the sports games at gym get faster and more competitive. The teacher discussed this with Caspar: ‘You have less speed and ability with the ball’. And then she suggested that the team which wants to choose Caspar may choose an extra child, because the two together form a good team.” (mother of Caspar; 13 years, grade 8)

With regard to speech and language it is important to realise that in children with Down syndrome expressive language is often lagging behind receptive language. So, never
judge the child’s understanding by his spoken language.

Children with Down syndrome often have poor auditory processing and working memory. Therefore, make language visual by the use of signing and (early) reading. Do not speak in long sentences. Attract the child’s attention before telling him or her something.

Many children with Down syndrome have difficulties with extracting information from spoken language, searching their memory for information and words, and giving an answer. Give them enough time to react.

Some children with Down syndrome have difficulties in managing changes in activities (there is probably also a time-delay in inner speech). Make the day’s timetable visual and let them know if there is a change of activity some time before it actually occurs.

Teachers (and parents) can strengthen the child’s language and speech abilities by:

• encouraging the child to use words he/she already knows
• systematically teaching the child the words which fit to particular situations

“In the beginning he pushed other children away, because he didn’t talk at all then. This frightened the other children. We discussed this with the class, that he didn’t have the words and that we could teach him the right words together. For instance, one child told me: ‘Floris pushed me’. Then the two of us together went to Floris and told him that he could say ‘away’ or ‘no’. In this way he has learned that you don’t have to push, that there are other ways.” (teacher of Floris; 6 years, grade 1/2)

• using signing and reading to support spoken language, thereby making use of the relative visual strength of children with Down syndrome.

With regard to social skills the following is recommended:

• encourage the child, if necessary, to ask other children if he/she may join in their play. Practise this in role-play
• teach the child the ability to think up and/or accept compromises in conflict situations

“I asked her whether she sometimes wants to join in a play situation but does not succeed. Cornelijne said: ‘I don’t know how to ask’. Then we practised this in a role-play. I pretend I am a child and Cornelijne comes to me and has to ask: ‘May I join in?’” (teacher of Cornelijne; 9 years, grade 3/4/5)

• teach the child to stand up for him/herself in an appropriate way
• invest in teaching the child good manners
• make rules and routines in the classroom visible

“You repeat the rules, you demonstrate the rules, if possible with other children. Using other children as a model is often quite effective. ‘Look, Martin is showing how to hang up an apron for painting’. We also make use of cards which show all the activities of that particular day with images for the different activities. In the beginning he was saying ‘mama’ all the time. Now that we are using these cards he realises that first there is a work session and then snack time and then playing in the playground and then finally mama comes to fetch him. This supports him very well. It has proven to help some of the other children in his class as well.” (teacher of Floris; 6 years, grade 1/2)

• give the child clear directions for behaviour, for older children especially for showing friendliness, making physical contact and handling amorousness

“He has a tendency for kissing and cuddling. When he was six years of age, I thought ‘I don’t want this any more’. I really had a conflict with some of my family about this cuddling. Some of them said: ‘Oh, let him’. I then told them: ‘Yes, now it is still cute. But, if he is eighteen years of age, and he is still doing this, then he is the one who will have to pay.’ We drew clear lines for him. We told him that it is appropriate at a birthday party to give a kiss to the hero of the feast but that’s it. You have to make these social rules crystal clear for him.” (mother of Caspar; 13 years, grade 8)

• reduce inappropriate or anti-social behaviour by giving clear behavioural directions, by making sure unwanted behaviour is not unintentionally reinforced and by reinforcing good social behaviour
• take a long term perspective.

Informing classmates

In most cases classmates are well aware of the ‘specialness’ of the child with Down syndrome. Without adequate explanation, the chances are that classmates will form their own conclusions about Down syndrome founded on fragmented information. Thus it is recommended that teachers explicitly inform classmates about Down syndrome. As has been stated above, in many cases, it is also necessary to give classmates clear directions for their behaviour towards the child. In addition, an open discussion with the class gives the opportunity to explain to classmates ways in which they can be supportive to the child with Down syndrome (without being overprotective).
It is suggested that Down syndrome is discussed in the context of more general social themes.

**Improving the social climate**

A good social climate is essential for the social inclusion of a child with a disability.

Improvements in social climate are stimulated by:

- discussions with the class about the fact that all children are different
- discussions about social themes (e.g., friendship, feelings, discrimination)
- giving all children clear guidelines for social behaviour, reinforcing pro-social behaviour, intervening in cases of anti-social behaviour, encouraging all children to think up alternatives for inappropriate or anti-social behaviour
- explaining to all children the rationales for rules in the classroom or even making the rules in consultation with the children
- as a teacher, making plentiful use of positive methods for keeping order and managing behaviour.

**Stimulating self-confidence and a positive self-image**

Self-confidence and a positive self-image have a positive influence on social competence. Included students with Down syndrome are in a situation in which most of their classmates are more able in many areas. Although most children with Down syndrome, according to the parents and teachers interviewed, do not perceive this as a problem, it could be valuable for their self-esteem to place them in situations in which they are not the least capable, too.

The following recommendations are made:

- try to create situations in which the child can participate more as an equal or even in which he/she can excel
- not only school activities, but also hobbies can be a source of self-confidence
- make plentiful use of cooperative learning
- if possible, sometimes put the child in a leading position, for instance by making him/her the tutor of a younger child for certain activities.

It is essential that the parents give their child with Down syndrome adequate information about his or her own disabilities (and capabilities). For older children, contacts with others with a disability can be helpful in providing them with a frame of reference. Also with older children these contacts can eventually provide an opportunity for more equal friendships. Yet, such friend-
Participation can also be encouraged by:
- putting the child with Down syndrome near the teacher during lessons for the entire class
- making more use of visual presentation
- getting round the child’s speech difficulties, for instance by letting the child point to the right answer instead of having to speak
- making use of pre-teaching in an individual or small-group setting
- making plentiful use of cooperative learning and of peer-tutoring.

Many children with Down syndrome misuse social skills to avoid learning. Teachers should not give in to this behaviour. Instead they should try to make the task more interesting (for instance by contextualizing a ‘dull’ task in a more interesting activity), to give the child more support and more encouragement, to build in smaller steps, to give the child choices between tasks and during tasks, etc.

Working independently on an assigned task is a skill most children with Down syndrome have to be taught in a step by step fashion. Teachers should start with requiring the child to work independently for only very short tasks and then gradually stretch this out. For independent work, tasks should be chosen which the child has already mastered well.

The child should practise new tasks first with support and then repeat these independently in the classroom.

“Cornelijne and another girl are sitting at the computer. The girl asks: 'up to ten?' Cornelijne answers: 'yes'. The girl points to the screen and says: ‘here’. Cornelijne presses the mouse. It is a programme in which a picture appears with a particular amount of animals. The students have to choose the actual number corresponding with this amount from nine figures randomly scattered on the other side of the screen. Cornelijne and the girl are taking turns. They are speaking aloud to each other (‘how many?’; counting aloud, ‘good’, etc.). Now and then other children come and look what they are doing.”

(observation of Cornelijne; 9 years, grade 3/4/5)

Co-operative learning: Annelot reports the findings of her small group to the other groups

"To get him motivated enthusiasm and variation is essential. That is what he likes. He is very sensitive to the way you are presenting something to him. Sometimes, I’m just not original enough, then he finds it boring. What also works out very well with him and with things you want to teach him is letting him experience it. For instance learning to read the word ‘on’ as a flash word for him is much more interesting if we simultaneously climb on something.”

(remedial teacher of Arjan; 9 years, grade 4)

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http://www.down-syndrome.net/library/periodicals/dsnu/02/02/
It is important to invest in teaching the child to read and write. Mastering these skills opens up a much greater variety of tasks which can be done independently.

Even more than teachers, parents have the opportunity to search for meaningful applications of academic skills in daily life.

**Inclusion does not have to be perfect**

Many parents and teachers say that they, at times, feel dissatisfied with the inclusion of the child and with their own efforts, but most of them do also tone down these feelings: It is important to see a limited extent of social inclusion as valuable as well.

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**Annemot working one-to-one with a special educator outside the classroom**

“*He may choose from a few different activities and that makes him more highly motivated. Since some weeks I’m not hearing him saying all the time ‘I find it too difficult’. For instance, he now really wants to read and write series of words in which one letter is being changed. He also really enjoyed forming ‘dirty’ words from magnetic letters. It is part of this reading approach to let a child decide what words it wants to learn to read. Since I have started to work in this way, his motivation for reading has grown immensely.*” (teacher of Milan; 8 years, grade 3)

“*I’m trying to teach him to work independently. I’m now trying to stretch out the time he is doing this. I make very well structured and visually clear working sheets, but I do try to vary the way the sheet is ordered or the task is structured a little bit, for instance a picture has to be glued with a word instead of the other way around, because I fear that otherwise he would get stuck into one sort of frame. Before I let him work independently we first, the two of us together, look carefully at the material. I’m making sure that he knows the flashcard words and that he recognises the pictures. After doing this he puts the cards to the side of the sheet again and then he has to glue the cards on the right places all by himself. He now often corrects his own mistakes at the moment he is going to make them. In the beginning, if he was going to make a mistake, I said: ‘Look again’. But now I keep silent and more and more he proves that he can find out it himself. So now, also when I’m sitting next to him. I don’t correct mistakes immediately.*” (personal assistant of Timo; 7 years, grade 3)

“*The remedial teacher practises work with him in a one to one situation and then Caspar does the same work over again in the classroom. For instance with reading comprehension the two of them together fill out worksheets with multiple choice questions about a text and then later in the week Caspar does the same sheets over again in the classroom, all by himself.*” (teacher of Caspar; 13 years, grade 8)
Inclusion resources

Books:


Videos:

Workshops on inclusion at The Sarah Duffen Centre (autumn 2002)
- Monday 16 September: Meeting the educational needs of children with Down syndrome in mainstream schools – Infant school
- Tuesday 17 September: Meeting the educational needs of children with Down syndrome in mainstream schools – Junior school
- Monday 23 September: Meeting the educational needs of children with Down syndrome in mainstream schools – Secondary school
- Monday 04 November: Supporting the development and education of children with Down syndrome (Day 1/2)
- Tuesday 05 November: 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

Including Children with Down's Syndrome in Mainstream Schools
A conference and workshop programme for professionals in education
Presented by the Down's Syndrome Association

Infant and Primary Schools
- Friday 11th October 2002
  The Dennison Centre, University of Hull, Cottingham Road, Hull, HU6 7RX
- Thursday 7th November 2002
  Royal National Hotel, Bedford Way, London WC1H 0DG. Contact: Education Information Officer Tel: 01326 311007, or email: educate@downs-syndrome.org.uk for application forms

Transition to and inclusion in Secondary Schools
- Thursday 10th October 2002
  Brantingham Park, Elloughton, East Yorkshire, HU15 1HX. Tel: 01482 392430 for application forms
  Gt Baddow Centre, near Chelmsford, Essex. Email: senaps.inset@essecc.gov.uk or fax: 01245 436588 for booking forms
- Thursday 14th November 2002
  Haringey Professional Development Centre, Downhills Park Road, London N17 6AR. Contact: Sue Rush. Tel: 0208 489 5028, fax: 0208 8489 5001 or email: sue.rush@haringey.gov.uk
- Friday 15th November
  Curriculum & Teachers’ Centre, London Borough of Richmond upon Thames Contact: Tina Cruise. Fax: 020 8891 7516 or email: t.cruise@richmond.gov.uk, by 1 November 2002
- Friday 22nd November
  Bestwood Lodge Hotel, Bestwood Country Park, Arnold, Nottingham Contact: Education Information Officer. Tel: 01326 311007, or email: educate@downs-syndrome.org.uk for application forms
Independence and employment for adults with Down syndrome

Gaining an adult status – the importance of independence and of having a job

The next two articles discuss aspects of life for adults with Down syndrome. The first, Meg’s story, has been written by Meg’s sister, Ann, and describes how Meg and the family coped after their mother’s death. Two important themes come out in this story – the way in which Meg, at the age of 48 years, took more charge of her own life and developed new confidence and independence after her mother’s death and the issues for brothers and sisters of adults with Down syndrome. Meg’s mother had assumed that she would live with one of her sisters after her death and they were happy to arrange this but, in fact, Meg stayed in the family home as it became clear that, with support, this would be possible. While many adults with Down syndrome do move to independent living facilities before their parents die, more do not – they continue to live with parents because everyone feels this gives them the best quality of life or because a suitable alternative does not exist.

Meg’s story may encourage families to plan for their family member with Down syndrome to stay in the family home, if suitable support can be organised. This could be on the lines of Meg’s example – carers living in the house, or it could be achieved by inviting other adults with learning disabilities to share the accommodation, again with appropriate support available to them. In the UK, national charities such as Mencap have schemes to enable this to happen but there is an issue about ownership of property to be considered, as schemes such as this may require the property to be transferred to the charity.

Meg’s story reminded me of another story shared with me by a family member recently. After the death of her parents, she felt that she should take her brother with Down syndrome, a gentleman in his forties, into her home. Instead, she found him a place in a residential care facility but felt extremely anxious and guilty about this decision. She visited at all hours to check that he was OK but as the weeks went by, it became clear that he was really enjoying his privacy and independence and he made clear to his sister that he preferred his own home to living with her. He also gained new skills and became more independent. There is a message in here about the self-esteem and self-identity of adults and about how difficult it is for those of us who are parents to let go!

The second article describes the development of an adult employment scheme to encourage other employers to think of offering employment. While, in the UK, the disability benefit rules restrict the amount of money that can be earned, employment within these rules can still make a significant difference to the income of an adult with Down syndrome – it may double their weekly ‘spending’ money available for leisure activities, clothes and holidays. Some of the workers on this project opened their own bank accounts for the first time, all were very positive about joining the pay roll and one made clear he was now at work, just like his older brother. One of the staff already working in the organisation commented ‘these employees with Down syndrome are far more competent at the work and far better behaved than teenage work experience trainees that I worked with in a previous job’.

Adult employment resources

Education, training and employment services:
Rathbone - a charity and voluntary organisation which provides education and training for young people and adults with special needs. http://www.rathbonetraining.co.uk/
The Shaw Trust - is a national charity that provides routes to work for people who are disadvantaged in the workplace due to disability, ill-health or other social circumstances. http://www.shaw-trust.org.uk/index.php
Mencap - employment services, including advice and training. http://www.mencap.org.uk/html/jobs/jobs.htm

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http://www.down-syndrome.net/library/periodicals/dsnu/02/02/
Meg’s story

Ann Barry
Queensland, Australia

A story in two parts: in 1994 I wrote describing the background of my sister with Down syndrome and the way in which she and I had coped with her care after the death of our mother. I hoped that our experience would be useful to parents facing the prospect of their handicapped child being left without parents. The second part describes the present situation and includes our plans for the future.

Part I: 1994

Margaret Judith Hooper was born 6 May 1946, when our mother was 36. Meg was the fifth and last child in the family. We older children were all born before the war. I think that Meg would have been assessed as having a fairly high IQ for a person with Down syndrome. How accurately indicative that was I have no idea.

Meg was among the first children to be educated by the (then) Sub Normal Children’s Association, first at our home, 170 Old Cleveland Road Coorparoo and later at Bowen House. At age 15, as was the system, she underwent prevocational training at Bowen House; I remember hearing about the flat there. She made morning teas and Christmas cakes and learnt other life skills. Making up orders of fruit and vegetables from produce bought at the markets was another activity. This gave her experience in handling money, a skill I notice Meg has lost now.

At age 18 she started at the sheltered workshop at Coorparoo, and recently moved with the workshop to Yeerongpilly.

Our mother died in 1988. It might be useful to describe Meg’s skills at that time.

Our mother taught Meg to iron at an early age. For as long as I can remember she always washed and ironed at home for my mother and herself. She also took in ironing for neighbours.

She routinely made her own lunch for work. This was done methodically and neatly. She was not interested in cooking (though she has always loved food and is grossly overweight), but was quite capable of making my mother cups of tea, and of making a light dinner for them both occasionally. She kept her own room quite tidy, making her bed every day, even at weekends.

She had few friends. Some women friends of my mother’s were very nice to her, always turned up with birthday and Christmas presents, but it was all one way, Meg did not reciprocate. That would have been done by my mother. She loved to join in family celebrations, and always kept a birthday book. She knew when family birthdays came around, though Mother would be the one who rang to say happy birthday. I remember her 21st birthday, a little dinner party, Meg made a very nice speech. (She is now planning her 50th birthday party!)

She was not keen on holidays, went away only if Mother took her, and did not seem to get particular pleasure from whatever it was. She came away with my family on very rare occasions. In 1988 my mother and I went to the US and Meg stayed at home, but I forget what arrangements we made for her care. My sister Marie lived opposite so she probably supervised. When my mother went away overnight, Meg stayed at home alone, and was happy to do so.

With the encouragement of Mrs McConnell (Principal at Bowen House), Meg learnt to use public transport at a fairly early age. I remember Mother having qualms about it, but there were few problems. Meg has a good sense of direction and sometimes when out with me she obviously knows better than the driver.

She attended monthly socials at the YWCA and Saturday bus trips.

“We whilst Mother lived, it was Mother’s life, Mother’s home, and Meg was very much an appendage, she just went along with everything and was looked after.”

So while Mother lived, it was Mother’s life, Mother’s home, and Meg was very much an appendage, she just went along with everything and was looked after. But Meg has always been a very caring, sympathetic and completely unselfish person, to the extent that she was an example to the rest of us.

I know our mother expected that, when she died, Marie or I would take Meg to live with us in a specially built granny flat. Both husbands were agreeable. However, on the night of the funeral, a cousin turned up with her nightie and said she
would like to stay with Meg for a few days. Other help materialised. Before long Meg then took charge herself, drew up a roster, and wrote down a person's name for each night – these included my cousin, a sister-in-law and a number of nieces and nephews. (I have to say that this roster took a bit of supervision. Meg could be a bit dictatorial and nominate nights, rather than ask for offers.) After a few months we found this was working so well that we decided to look for someone to live permanently with Meg. Since then we have had sometimes one, sometimes two young women who live there and go to work. Their responsibilities are to cook for Meg and socialise with her. In return we provide free board.

I explained to Meg early on that she was now the woman of the house. It was her home and she should be responsible for it. She writes things on the shopping list, things she needs for her lunches usually. She conscientiously changes her sheets, and when visitors leave, it is Meg who strips the beds and remakes them. She still loves the bus trips and socials. When I was responsible for transport she would always ring a day or so ahead to remind me. Later she took to asking for my son whom I had been delegating to do the job. The girls now living there both have cars and they do this job now.

One year Marie and I as usual did the flowers in church for our mother's anniversary. This was not discussed with Meg. The service had just started, and there was Meg at the door. Without a word to anyone, she had got dressed and walked the couple of blocks. After that we included her.

When Marie was ill in 1992, Meg called in every afternoon after work and they drank tea together. Then Marie went to Mt. Olivet. When Meg was taken to visit, she just sat quietly, caring but composed. She seemed to know what was going on without being told. Marie died of cancer in August 1994. We talk about Marie sometimes, but Meg avoids using her name.

At Christmas time it is now Meg who gets out the decorations. She reminds me about doing her cards, and she has a list of recipients. She makes up her mind about who should receive presents; sometimes she has definite ideas about what the present should be.

She has taken up new hobbies. One is patchwork, initiated by our neighbour Margaret Bell. Another is embroidery, initiated by an aunt. Meg has made step by step progress to the stage where she now arranges with this aunt (in Yarraman) a convenient time to visit, and can go both ways by bus. The aunt belongs to an embroidery group, and when Meg visits she is included in the sewing days. She also does long stitch embroidery. Incidentally this aunt and her husband describe Meg as a dignified woman.

Meg now does ironing for three neighbours. Ironing is always done at weekends, and even if she has been out on a Sunday, Meg will always get straight into the ironing when she returns home. If she will be away for a weekend, she herself contacts the women and lets them know when she will be back. Her arrival is always confirmed by telephone.

She is starting to become interested in cooking, prompted by another aunt who visited and taught her a few things. The girls who live there insist that she cleans up her own mess in the kitchen and she can do that.

At an early stage of her new life, Meg took over Mother's telephone book. She keeps in close contact with a small group of people, most of them are relatives. Others receive calls on important occasions only, such as a birthday, the arrival of a new baby, or when someone goes to hospital etc.

She recently organised afternoon tea for the birthday of my niece Naomi, who lives with her. Meg rang a few people, relatives and neighbours, and, with the help of a neighbour, requested a plate of food from some of them.

There is a wonderful group of neighbours there. Immediately next door is Margaret Bell who is a good friend. The back doors are very close, and the families have been in close contact for years. Margaret O'Brien lives a few doors away; she visited my mother every Wednesday for afternoon tea. When my mother died, Margaret O'Brien continued to come, did not miss a week, and now routinely has tea with Meg whenever she goes away, and invites her for dinner whenever they are having a roast. When I was away for her birthday last year, I received a phone call from Meg and Marg O'Brien (on a Wednesday, of course) asking if they could organise a tea party at Meg's to celebrate.

When I was away recently, Meg developed a very painful leg at work and thought she would not be able to walk to the bus. She had the workshop phone a friend who lives in Yeerongpilly, who drove her home.

Since Mother's death, relatives and friends from out of town still ring and ask for a bed, and people still pop in. One girl who was to fill in as a carer for a few weeks could not handle the fact that people would visit without first phoning, would even wander right in and say hello. She left. These people are in fact now visiting Meg as a person, she is no longer an appendage. These visits do two things: they provide continuity with her past, which was important at first, and they provide an opportunity for social intercourse, which is important in everyone's lives. I could go on and on with background, but enough is enough. I come now to what I see as the most impressive or conspicuous things Meg has accomplished since our mother died.

Meg has become more positive in so many ways. 'Positive' was a key word which someone gave her when she was first grieving. Meg wrote little notes for herself, some of them would be stuck on the fridge. They always said 'Be positive'. She would often say it to me with a smile. Even now she still brings it out occasionally.

She has developed her own circle of friends with whom she keeps in regular contact. I notice that this circle is growing.
the telephone calls – people call, and Meg visits. I notice that some have been dropped from the telephone routine, and I am sure that is because she did not get a positive response, these people did not keep up their side of the relationship.

She reminds me when she has to go for her 2-yearly checks with physician or ophthalmologist. She makes her own appointments with the local hairdresser, is not upset by change of ownership or change of premises – she just phones me to make sure I will send in the money. She handles the dentist completely independently, going monthly to have her gums checked. Dental care involves a nightly fluoride application using an appliance like a mouth guard, which she does herself, more reliably than most of us would be.

She knows when she needs new clothes: I am summoned to discuss her wardrobe twice a year at the change of seasons, and at other times to discuss underwear, nightwear etc. We have replaced her old sewing machine and typewriter, but she now thinks she would like a word processor!

I suppose to sum it up, we could say she has grown up a lot, she has matured and become quite independent. Sadly, this could not happen while our mother lived, her death opened the door for Meg to become much more adult, a separate identity. But this development depended on the training and example which our mother had provided. Mother was a quite remarkable person, admired, respected and loved by all who knew her.

I believe that her recent development was facilitated by two factors: first, keeping her in her own home and second, the support of relatives and friends.

Part 2: 2002

Meg is now nearly 56 years of age. She still lives in our mother’s home, still with a carer. In 1996 we celebrated her 50th birthday with a gathering of about 35 friends and relatives here at our home. She had long anticipated this event and had the event planned for a long time. She was happy and taken part in deciding the menu and planning the event. She made a nice little speech. Afterwards she told me she was looking forward to her 60th. She still attends the monthly socials and bus trips though I notice she misses one occasionally through forgetfulness. She is still fond of the telephone, though she has little to say and the calls are short.

One significant change is in her weight. She was always inclined to being overweight, and our doctor warned me that in time her knees would become troublesome. So we instituted a diet program and she has lost 30 kilos, down from 95 to 65. She has an exercise bike and a walking machine. She is very methodical about using the equipment, making ruled pages for each day and marking off the time she sets for herself. She is still very fond of food and I am sure that weight control will be an on-going consideration.

The biggest change since 1994 is that Meg has gradually become too conscious of her own health. She is not a very cheerful person now, though some people have a happy knack of carrying on with a bit of nonsensical banter that she does enjoy. She talks about herself too much, wanting people to take her pulse, complains about little pains here and there. She talks to anyone who will listen about whether or not she should take tablets as prescribed. And having read that Alzheimers disease is common in older people with Down syndrome, we have decided to consult a psychiatrist, the idea being that we may be able to pick up early signs. We still accept that the time might come when Meg would need a paid carer.

To sum up the situation now, I am still satisfied that we made the right decision in keeping Meg in her own home. I do not think that the gradual decrease in her cheerfulness is due to her domestic arrangements, but rather part of her aging process. We have been fortunate in being able to find thoughtful and conscientious carers. We have to face retirement from the workshop and finding other suitable occupations.

“I believe that her recent development was facilitated by two factors: first, keeping her in her own home and second, the support of relatives and friends.”

“Meg is not only well and happy, but has matured and become independent to an extent we would never have believed possible.”
Employing adults with Down syndrome

A partnership between The Down Syndrome Educational Trust and a supported employment service backed by the European Social Fund has created part-time jobs for five young people.

The Trust’s Sarah Duffen Centre, in Portsmouth, teamed up with Southern Focus Trust’s Supported Employment Service to provide the work opportunities. The five employees, who all have Down syndrome, started working at the centre earlier this year as production and administration assistants following successful job trials.

Each employee works for a total of four-and-a-half hours every week on a range of tasks. Initial job coach support from Southern Focus Trust, to help the five settle in and learn their tasks, has now faded to on-the-job support from other staff at the centre.

Three of the employees work together on Mondays. The two other workers are employed on Wednesdays. Centre Trustees pay for taxis to and from work for all five under an arrangement set up by the Supported Employment Service.

All five employees, four in their early 20s and one in his 40s, are carrying out Supported Permitted Work under regulations laid down by the Department for Work and Pensions. Their weekly wage does not affect their welfare benefits because it is within a disregarded limit set by the Benefits Agency for people receiving means-tested Income Support.

One of the workers, Ellie Hardy, aged 21, said: “I love my job. It’s absolutely brilliant and means a lot to me. I like doing different things at work and talking to the other people.”

Southern Focus Trust’s Supported Employment Service was set up in 1997 to help people with learning disabilities find work. Since then, the service, which has financial support from the European Social Fund and Hampshire County Council, has helped people find employment, both paid and voluntary, and training opportunities. The service also runs three businesses employing people with learning disabilities. In summer 2000 the service set up a shop in Leigh Park, Hampshire, selling donated pre-owned clothing and toys. The shop currently employs 16 part-time retail assistants who work with job coach support.

Further jobs have been created in the two other business ventures, a gardening service and a catering operation providing lunches for staff and service users at a Day Service for people with learning disabilities.

Steve Henwood
Supported Employment Services

A partnership between The Down Syndrome Educational Trust and a supported employment service backed by the European Social Fund has created part-time jobs for five young people.
The employer’s perspective

When the Trust took the decision to set up its own publishing and printing facilities, we realised that we would be able to offer employment to adults with Down syndrome. We were planning to install digital printing equipment and the finishing equipment necessary to produce our own publications, such as this periodical. With employees with intellectual disabilities in mind, we chose equipment that was as safe and as easy as possible to operate. Easy does not necessarily mean simple to operate, but it does mean that machinery can be set to run in a relatively trouble-free manner by staff. The finishing equipment includes a cutter for cutting covers to size, a booklet maker to fold and staple books (see both photos on this page) and a driller, to drill holes in books intended for ring binders. Books being sold as packages have to be put into binders. In addition our mail order service requires stuffing of envelopes, sticking on address labels and franking mail through an automated in-house franking machine. It also requires the assembly of plastic boxes and then putting in the right contents for each of four teaching packs (see photo on opposite page). In other words, we have a range of tasks which our employees enjoy and do with considerable competence.

We were careful to plan the start of the employment project at a time when we felt we were sufficiently organised and experienced with the production work, and when we had enough work and enough staff in place to ensure that we could offer a quality work opportunity. We started production in December 2000, but we did not start the employment project until September 2001. We then asked Southern Focus Trust to guide us and to set up work training for the first 3 workers. They visited to discuss what we could offer and they then offered work trials to adults whom they were in contact with. They also provided advice for us and a job coach to work with our staff to train the workers. The first 3 employees settled in and learned the work tasks much quicker than we anticipated. They all enjoyed the work and wished to become employees. As the first 3 moved onto the pay roll, we then took another group of 3 on a work trial. We have 6 adults working for us but only 5 on the payroll as the 6th person has paid work elsewhere, so chooses to come to us as a volunteer. (The UK Disability Benefit system prevents her from being paid in two jobs – she would exceed her earnings limit).

The second team of three settled in as quickly as the first group, though one individual has rather more significant intellectual disabilities than the rest and it has taken him longer to learn all the tasks. He also has additional personal care needs and we asked for support for him for longer than the rest of the group, but he is now working without the additional support.

When we first met the prospective employees, they seemed to have quite varying skills – that is, some had better spoken language than others, and some had better motor skills than others – and we predicted, wrongly, that their competence on the job would vary. All the employees have become very competent and capable of a much higher level of productivity than we anticipated. Ability as an employee is certainly not linked to speech and language skills – which vary significantly from one adult with only a few words to one who is a very competent talker. The adult with additional physical needs, a mild hemiplegia, has been determined to master all the tasks – even stuffing envelopes. The employees vary in age from early twenties to late forties and they can work unsupervised on almost all the tasks. However, we do have another member of staff supervising their work schedule for the day – keeping an eye out for them even though she does not need to be with them all the time. They know what to do if a machine breaks down or jams – or if they run out of work. Their time-keeping is excellent and we have had very little time lost to sickness.

All the employees have fitted into the work team and to the social life of the work at the Trust. We have been clear that socialising with staff is done at coffee breaks and lunch breaks. We have worked as a group to encourage appropriate work behaviour, for example, pointing out that interrupting staff for a chat is not appropriate and ensuring clear guidelines are followed by all staff. We have had far fewer issues than we anticipated in settling our new employees into work. They are a pleasure to have in the work team and we all look forward to the days when they work. If the publishing output continues to increase, we will take on another team of three. They work in two teams, at present each coming for one day a week and this seems to work well.

The main reason for writing this article is to share our experience with others to encourage more employers to offer work to adults with Down syndrome. We also wish to encourage parents to seek work for their adults and not to underestimate the work competence of even those who have more significant disabilities. Our advice to prospective employers, based on our experience to date, would be:

- Work with an employment agency if you can – they will advise on suitable work tasks for individuals, provide job coaches, deal with Benefit issues and advise on Health and Safety issues.
- Plan ahead to ensure your organisation is clear about the work it can offer – we did not want to be trying to find tasks each week, enough suitable work must be available.
- Discuss the social and support issues with current employees – to ensure that a positive atmosphere exists among employees and that all employees treat those with intellectual disabilities as equal members of the work team.
- Do not underestimate the work abilities of adults with Down syndrome.

Jackie Dixon
Speech and language therapy for children with Down syndrome

Guidelines for best practice based on current research

Sue Buckley and Patricia Le Prévost

The provision of speech and language therapy services for children with Down syndrome is a controversial issue and families receive different services depending on where they live and the knowledge and interest of local speech and language therapists in the specific needs of children with Down syndrome. This article is an attempt to provide guidelines for speech and language therapists based on the best evidence of the children’s specific speech and language needs currently available. It is a summary of the key facts about their speech and language profile and needs, followed by recommendations for service provision. References to further reading are included to support the points made in this brief overview.

Parents are encouraged to draw these guidelines to the attention of their therapy providers. They may be copied for individual use.

Language is vital for mental and social development

It can be argued that speech and language therapy is the most important part of intervention services for children with Down syndrome if we wish to promote their cognitive (mental) and social development.

Cognitive development - In our view, speech and language development are absolutely central to the cognitive development of all children. First, words equal knowledge and the faster a child learns vocabulary, the faster he or she is acquiring knowledge about the world. Therefore vocabulary development is very important – the number of words that a child knows when he or she enters school at five years will have a very significant influence on progress. Secondly, language supports thinking and reasoning. The human brain has evolved a remarkable ability to learn spoken language with amazing ease and then to use that spoken language for mental activities. Thinking, reasoning and remembering, for example, are usually carried out in mind as ‘silent speech’. It follows, therefore, that any child with significant delay in acquiring language will be delayed in the ability to use these cognitive processes. Although delayed, almost all children with Down syndrome will use spoken language as their main means of communication. The use of signs in early years will help them to progress but for most children signs are used as a bridge to talking, not to teach a sign language.

Social development - Language is equally important for children’s social development as it enables them to negotiate their social world and to control their behaviour. For example, as children acquire language, they can ask for what they want, explain how they feel, describe what they have been doing and share thoughts and worries with friends. Children are able to begin to control their behaviour by using silent speech to instruct themselves and to plan their actions.

The more we can do to help children with Down syndrome to learn to talk, the faster they will progress in all areas of cognitive and social development.

The speech and language profile associated with Down syndrome

Specific speech and language difficulties - Children with Down syndrome usually have an uneven profile of social, cognitive and language development – they do not have a profile of equal delay in all areas, they have a profile of strengths and weaknesses. For example, social development and social understanding is typically a strength, while spoken language development is a weakness. There is now consistent evidence that these children have a profile of specific speech and language delay relative to their non-verbal mental age. There are considerable individual differences in rates of progress but the overall specific profile is usually evident for all children with Down syndrome. [1,2]
An uneven profile within the language domains - While the speech and language skills of children with Down syndrome are delayed relative to non-verbal mental abilities, different aspects of speech, language and communication skills are not equally delayed.

Communication skills are a relative strength with good understanding and use of non-verbal communication skills and good use of gesture. [1, 2]

In language, the children show delayed development of vocabulary in infancy, with comprehension ahead of production, but by the teenage years, vocabulary is a relative strength with vocabulary 'ages' ahead of grammar 'ages'. In grammar, there is evidence of specific difficulties in both comprehension and production. [3-5]

In speech, there is considerable difficulty at all levels from planning to articulation and phonology. Most teenagers still have significant intelligibility problems. [4, 5]

Individual differences are seen within the typical profile, with some children having more speech difficulties than others, relative to language comprehension and some children having larger differences between comprehension and production than others, for example. Therefore, each child with Down syndrome should receive an individualised therapy programme but the principles for effective practice upon which this should be based is the same for all children with Down syndrome.

Possible primary causes
Research is beginning to provide some useful information on the underlying causes of the speech and language profile associated with Down syndrome. Working memory - Children with Down syndrome have specific impairment in the phonological loop component of working memory relative to their non-verbal abilities, and this is now thought to be a major cause of their speech and language difficulties. [6, 7] For all children, the phonological loop is thought to play a critical role in learning a spoken language as it holds the sound pattern of the word to enable the child to both link this with meaning and to store it to support production of the spoken word. Phonological loop difficulties will affect both vocabulary learning and grammar learning. [8, 9]

Visual short-term memory is not impaired relative to non-verbal mental abilities and is described as a relative strength. In addition, research has indicated that visual coding of verbal information may be used by children with Down syndrome in short-term memory tasks. [6, 7]

Hearing - Most children with Down syndrome (at least 80-90%) suffer from conductive hearing loss and auditory discrimination difficulties which will compound the phonological loop difficulties. However, the phonological loop difficulties are thought to exist independently of any hearing impairment. [9]

Speech-motor difficulties - speech sound and word production difficulties also have physical causes. These are linked to the motor skill difficulties associated with Down syndrome and the oral-motor difficulties demonstrated from the first year of life, which affect feeding and chewing patterns. For all children, first words can be predicted from the speech sounds that they can make in babble – in other words early spoken vocabulary is influenced by existing articulation and phonological skills, not the reverse. [8]

Possible secondary causes
Slow vocabulary acquisition - The development of early grammar has been shown to be linked to total productive vocabulary for typically developing children as well as for children with Down syndrome. Therefore, the very slow rate of productive vocabulary development that is typical for children with Down syndrome may mean that the development of grammar is delayed beyond the optimal period for grammatical acquisition (1-6 years) – for a full discussion of this issue see [24].

Speech-motor effects - Delayed output of first words and unintelligible utterances may reduce or change the language input to the children. Difficulties with speech production probably compound the grammar learning and grammar production difficulties. [10]

Principles for effective interventions
There is considerable agreement among international experts on the principles that should guide speech and language therapy for children with Down syndrome, based on research into their difficulties and into effective interventions. [11-13]

Targets for all four domains
All experts identify the need to have separate targets for the four components of speech and language skill - communication, vocabulary, grammar and speech work, for each child.

Targets for comprehension and production
In addition, for vocabulary and grammar separate targets will be needed for comprehension and for production. [13]

Use of signing - There is agreement on the use of sign systems to promote spoken language with benefits for both comprehension and production.

Use of reading - There is agreement on the importance of using reading activities to teach spoken language for those of all ages. In particular, the benefits of using early reading in preschool years as an explicit language teaching activity are recognised.

Parents are the main therapists
All experts identify that language is learned all day, every day, as children are involved in communication with their families and friends and therefore the focus of effective therapy must be to share skills with parents because they will be their child’s best therapist.

Implications for a comprehensive therapy programme
Preschool services
Specialist training for work with children with Down syndrome will be helpful and up-to-date knowledge of the research literature is essential. The needs of children with Down syndrome tend to be different from the needs of other children with learning difficulties. Their hearing, phonological loop impairment and
Speech and language therapy for children with Down syndrome

Knowledge and skills

- to have up-to-date knowledge of the specific research literature on speech and language development, working memory and effective therapies for children with Down syndrome
- to understand the significance of the specific impairment in the phonological loop component of working memory for the speech and language profile associated with Down syndrome

Models of delivery

- to understand the importance of reading work to support the development of vocabulary, grammar and speech clarity, using strengths in visual memory
- to understand the importance of auditory discrimination for speech sounds, phonics activities, phonological awareness training and speech work in order to improve working memory function as well as speech.

First year of life

1. Encourage a good communication environment at home and ensure that parents understand the speech and language needs of their child, and how speech and language develops.
2. Provide support for feeding and activities for oral-motor development.
3. Encourage all communication skills, eye-contact, turn-taking, pointing and joint-referencing by the end of the first year.
4. Target auditory discrimination for speech sounds to improve auditory discrimination in the phonological loop.
5. Target auditory discrimination for speech sounds in order to support the development of babble (typical babies tune their babble to the language they are hearing by 12 months – in other words they are setting up the speech-motor skills for talking).
6. Encourage the use of gesture and sign primarily to aid comprehension.

The Swedish therapist Irene Johansson has evaluated and promoted this type of programme for infants with Down syndrome for a number of years and others have stressed the need for speech as well as language work to begin early. [4,5,9]

Second year

1. Encourage a good communication environment at home and ensure parents understand the speech and language needs of their child, and how speech and language develops.
2. Continue with targeted work in support of hearing and producing speech sounds – single sounds and reduplicated babble (for speech and for auditory

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3. Teach comprehension and production of early vocabulary with games using objects, pictures and actions to supplement the daily language exposure of the child. This approach is currently recommended by the Hanen programme for children with Down syndrome. [10,13] They recommend targeted teaching and practice of words, then two and three word constructions, as they do not believe that the quality language immersion approach is sufficient for children with Down syndrome. They advise that the words chosen for imitation are chosen with initial consonant sounds that the child can already make, highlighting the need to address speech sound production skills in advance of vocabulary and language progress. Keep a record of words understood and words signed or spoken.

4. Teach two and three word constructions through play and encourage imitation by child.

5. Address communication skills if necessary (3-5% have autistic spectrum difficulties).

**Third to fifth years**

1. Encourage a good communication environment at home and ensure parents understand the speech and language needs of their child, and how speech and language develops.

2. Continue with targeted work in support of hearing and producing speech sounds – as single sounds and in whole words (for speech and for auditory memory development). [13,14] Keep a record of speech sound progress. [see 25]

3. Continue to teach vocabulary and develop early grammar and syntax. This can be done through play and by making books with the language to be learned in print. [see 25]

These reading activities will be an aid to parents to support the teaching and practice of vocabulary and grammar, but there is also increasing evidence that seeing words as well as hearing them is a significant aid for many children with Down syndrome. Indeed, the research evidence indicates that the most effective interventions for speech, language and working memory development for children with Down syndrome is to place them in mainstream preschools and schools, and to teach them to read. This leads to very significant gains in expressive language structure, speech intelligibility and verbal and visual short-term memory spans by the teenage years. Significant gains are seen by 10 years of age. [15-21]

The benefits of reading may come initially from the ability to store the whole printed word image more accurately than the spoken form – and the former then supports the learning of the latter. As letter sounds are learned, auditory discrimination for speech sounds will improve and then phonological awareness – the ability to hear sounds in words. Longitudinal studies demonstrate this happening for children with Down syndrome as they learn to read and to spell. [29]

All reading activities are planned to ensure the children understand, or are taught to understand, what they are reading otherwise no language benefits would be seen. If observers complain that children with Down syndrome read but do not understand what they are reading, this is the fault of the teacher not the child. [see 25]

4. Records of vocabulary comprehension and production should be kept [25] and therapists should be aware of the important link between productive vocabulary size and the development of grammar in production, which has been demonstrated for typically developing children and children with Down syndrome. [24, 20] This means that at least some of the grammar delay seen in children with Down syndrome is the result of delay in learning vocabulary. Further there is evidence of a critical period for learning grammar (to about 6 years) when the brain is maximally receptive and there is evidence that mastering grammar significantly effects phonological development in children. All these findings have significant implications for our understanding of the speech and language profile usually seen in children with Down syndrome and significant implications for early and continued therapy.

5. Address communication skills if necessary (3-5% have autistic spectrum difficulties).

**Primary school years**

Ideally all children with Down syndrome should receive speech and language therapy in school but access to this service will vary considerably from place to place.

Progress at five years will vary widely between children, with some having quite clear production of 3 or 4 word sentences but with grammatical markers missing, the majority at a 2 or 3 word stage in production, much of this difficult to understand, and some with very few words or signs. Most children will have significantly better comprehension than production.

Reading activities will be an important support for speech and language development throughout the school years.

Detailed information on the range of progress of children can be found in the books in the DSii series on Development and Education – see Resources.

**Goals for speech and language therapists working with 5-11 year olds with Down syndrome**

**Knowledge and skills**

- to have up-to-date knowledge of the specific research literature on speech and language development, working memory and effective therapies for children with Down syndrome
- to understand the significance of the specific impairment in the phonological loop component of working memory for the speech...
Speech and language therapy for children with Down syndrome

and language profile associated with Down syndrome
- to understand the importance of reading work to support the development of vocabulary, grammar and speech clarity, using strengths in visual memory
- to understand the importance of auditory discrimination for speech sounds, phonics activities, phonological awareness training and speech work in order to improve working memory function as well as speech.

Therapy plans
1. to have clear targets for 4 areas of work, speech, vocabulary, grammar and communication skills and to keep detailed records of progress
2. for vocabulary and grammar, to have separate targets for comprehension and for production, as comprehension in both domains is typically significantly ahead of production
3. for speech work, separate targets may be needed for articulation, phonology and intelligibility (pacing, voice etc)
4. to assist teachers in using reading to teach language and to incorporate speech and language targets into literacy activities
5. to review oral-motor function, feeding, chewing and drinking patterns and advise accordingly
6. all targets should be shared with parents, teachers and assistants
7. encourage a good communication environment at home and at school, and ensure parents, teachers and learning support assistants understand the speech and language needs of their child, and how speech and language develops.
8. address communication skills if necessary (3-5% have autistic spectrum difficulties).

Models of delivery
- children with Down syndrome should be seen at least monthly in school, targets reviewed and activities set for parents, teachers and assistants to include in their daily routines
- these activities should be modelled with the child by the speech and language therapist, so that parents and assistants can confidently enable the child to practice daily. Therapy sessions will not change speech and language development unless they lead to an increase in daily teaching activities and appropriate styles of communication at home and at school.
- some children with Down syndrome of primary school age may need weekly individual or group sessions of speech and language therapy with a therapist who has the specialist knowledge and the skills to address their profile of difficulties, particularly for speech and intelligibility work.

Secondary school years
Speech and language therapy should continue for all teenagers with the same list of key objectives and targets as for the primary age group, but adapted to focus on age appropriate language needs and activities.

Some teenagers with Down syndrome will be making good progress and talking in reasonable sentences, others will still have fairly limited spoken language. The range of individual differences is very wide. Many secondary school pupils with Down syndrome will have small productive vocabularies (800 words or even less) and limited productive grammar.

Reading activities will still be an important way to help all teenagers. Most will still have phonological and intelligibility difficulties that should be targeted, and the social use of language, particularly the ability to initiate and maintain conversations, may need addressing.

Goals for speech and language therapists working with 11-16 year olds with Down syndrome

Knowledge and skills
- to have up-to-date knowledge of the specific research literature on speech and language development, working memory and effective therapies for children and teenagers with Down syndrome
- to understand the significance of the specific impairment in the phonological loop component of working memory for the speech and language profile associated with Down syndrome
- to understand the importance of reading work to support the development of vocabulary, grammar and speech clarity, using strengths in visual memory
- to understand the importance of auditory discrimination for speech sounds, phonics activities, phonological awareness training and speech work in order to improve working memory function as well as speech.

Therapy plans
1. to have clear targets for 4 areas of work, speech, vocabulary, grammar and communication skills and to keep detailed records of progress
2. for vocabulary and grammar, to have separate targets for comprehension and for production, as comprehension in both domains is typically significantly ahead of production
3. for speech work, separate targets may be needed for articulation, phonology and intelligibility (pacing, voice etc)
4. to assist teachers in using reading to teach language and to incorporate speech and language targets into literacy activities
5. To review oral-motor function, feeding, chewing and drinking patterns and advise accordingly.

6. All targets should be shared with parents, teachers and assistants.

7. Encourage a good communication environment at home and at school, and ensure that parents, teachers and learning support assistants understand the speech and language needs of their teenager, and how speech and language develop.

8. Address communication skills if necessary (3-5% have autistic spectrum difficulties).

Models of delivery

- Teenagers with Down syndrome should be seen at least monthly in school, targets reviewed and activities set for parents, teachers and assistants to include in their daily routines.

- These activities should be modelled with the teenager by the speech and language therapist, so that parents and assistants can confidently enable the young person to practice daily. Therapy sessions will not change speech and language development unless they lead to an increase in daily teaching activities and appropriate styles of communication at home and at school.

- Some teenagers with Down syndrome of secondary school age may need weekly individual or group sessions of speech and language therapy with a therapist who has the specialist knowledge and the skills to address their profile of difficulties, particularly for speech and intelligibility work.

Adult life

A recent study in the UK and work in the USA has indicated that speech and language skills can be improved with therapy during the adult years. However, speech and language therapy services for adults are even scarcer than those for children. This is an area for further work and an article on work with adults will be published in next year’s issue of this journal written by a practitioner in this field.

References


20. See parents’ accounts and research on early reading in DSNU 2 (1).


23. See Record Keeping checklists in Resources list.


Record keeping

Six checklists to enable parents and therapists to plan activities and to keep a record of children’s progress in vocabulary, grammar, speech and communication are available from The Down Syndrome Educational Trust:


Practical Activities

Three age specific guides to practical activities to encourage speech and language development are available from The Down Syndrome Educational Trust. They should be helpful to parents and classroom assistants:


Books


For detailed reviews of the relevant literature see the following Overview modules from the Down Syndrome Issues and Information Development and Education Series:


Teaching Materials

Four early language games are available from The Down Syndrome Educational Trust, sold either separately or as a set, saving 15%.

- DownsEd picture lotto, illustrating first words with full colour photographs.
- DownsEd picture dominoes, for picture matching and teaching vocabulary.
- DownsEd consonant sound cards, with picture prompts for 20 English consonant sounds to encourage toddlers to listen to and to imitate the sounds.
- DownsEd language cards, with colour photographs illustrating a selected set of first words.

For details of these and specialist courses for speech and language therapists, see the websites at http://www.downsed.org

Videos


Acknowledgements

The authors would like to thank Leela Baksi and Margaret Wright, Speech and Language Therapists, for feedback on an earlier draft of these guidelines. However, the opinions expressed, and any errors or omissions, are the responsibility of the authors.

Speech and Language workshops at The Sarah Duffen Centre (autumn 2002)

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See our Services brochure for details of these and other Workshops, or visit our website at: http://www.downsed.org
Increasing Expressive Vocabulary Through Parental Recognition

- an update on the techniques of the Love and Learning method featured in Issue 1

Joe and Susan Kotlinski
Michigan, USA

In addition to using audio/video tapes and books with our daughter we also developed a technique to help her extend her vocabulary and stimulate her expressive language. We called it “Oh! - That’s A New Word!” It was very simple to do and made a dramatic difference in her spoken language. After a time, it was something she would initiate and which always produced the desired response from us.

If your child has a very limited vocabulary (less than 100 words) we suggest you use this method to help stimulate expressive language. You’ll need a 8.5” by 11” sheet of paper taped to the refrigerator or other prominent place, a thick black marker and some blank 5” by 7” cards. When your child says a new word or a word you have not heard for a long time, stop whatever you are doing and say in a very expressive way, “Oh! That’s a new word! I have to write it on the list.” Go to the refrigerator list and write down the word. Then use a black marker and print the word in lower case letters on a 5” by 7” card. Show and say the word one time to your child. Later in the day when you read to your child show him or her the card again and say the word. What makes this method so effective is that when you hear a new word from your child, you stop what you are doing, get very excited about the word, praise your child and then go to your list to write down the word. Your actions will give your child positive feedback that you value his accomplishment. Although things may be slow at the first, with time it can become a game for your child. He or she will listen for new words and more readily attempt to say the word himself in order to make Mom or Dad excited about another new accomplishment.

“Your actions will give your child positive feedback that you value his accomplishment.”

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(313) 581-8436
http://www.loveandlearning.com
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

Part I Medical, Biochemical, Genetic, Research, Developmental Disability Medicine: 1/2 October 2003

Part II Education, Social, Recreational, Legal, Para-Medical, Family, Adolescence, Sexuality, Employment: 3/5 October 2003

Dynamic speakers being sought for Keynote and Plenary Sessions

Part II will incorporate

- Panel discussion by people with Down syndrome

In conjunction with the Congress programme, other activities such as the following are planned:

Sub Theme: “Family Quality of Life”
- Workshops and discussion groups

Awards
- People with Down syndrome who excel in education, theatre, music, arts, sports and other fields
- Research work related to Down syndrome
- People who have significantly volunteered their time and promoted advocacy

Executive Directors/Administrators Round Table Session (If adequate response.)

Display Talent Area
- A display area for photographs and artwork will be available for people with Down syndrome

Exhibition
- An exhibition for both commercial companies (such as vendors and educational products) and non-profit Down Syndrome Organisations will be held during the congress

Email service
- Email service will be made available for delegates

Special Vouchers/Gifts for DSI members
- Special vouchers/gifts will be given to all DSI members

Exchange of experiences
- Delegates will be given the opportunity to show their videos / CDs on Down syndrome

Special Interest Focus Group
- The Congress Organising Committee will convene and help to facilitate Special Interest Focus Group discussions if there are any such proposals and interest.

DSI General Assembly will be convened on 5 October 2003

The next host of the 9th World Down Syndrome Congress will be announced
**Target Audience**

- Persons with Down Syndrome and their families
- Special Educationists, Psychologists, Social Workers
- Researchers, Academics and Practitioners
- Medical and related Healthcare Professionals
- Rehabilitation Specialists such as Physiotherapists, Occupational, Speech and Vocational Therapists
- Members of Down Syndrome Associations and sister organisations
- Government Officials and Civil Servants from ministries/agencies in Social and Community Services, Health and related departments

**Registration Fees**

<table>
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*Currency Exchange Rate: USD 1.00 : SGD 1.743 EUR 1.00 : SGD 1.745*

The Congress is supported by Down Syndrome International, KK Women’s and Children’s Hospital (Singapore), Singapore Tourism Board, Singapore Airlines and Down Syndrome Medical Interest Group. The Congress Organising Committee will arrange for attractive airfares and hotel rates for the congress delegates and accompanying persons.

**About Singapore and the Congress Venue**

Singapore is a thriving and a safe city-state, with something for everyone. Singapore is a culturally diverse melting pot, where you could explore a variety of cuisines, heritage sites and tourist attractions. The Congress venue is Suntec Singapore International Convention and Exhibition Centre, one of the best facilities in the region. The 8<sup>th</sup> World Down Syndrome Congress will provide a not-to-be-missed opportunity for all. We will see you in Singapore in October 2003.

**A message from the President of DSI**

This will be the 6<sup>th</sup> 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.
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.

European Down Syndrome Association news

San Marino conference report

The European Down Syndrome Association held a very successful scientific meeting in San Marino in May, under the chairmanship of Dr Alberto Rasore-Quartino, from Italy. San Marino provided a spectacular venue for the meeting which attracted several hundred delegates from all over Europe and some from further afield, including the USA. The focus of the conference was ‘The adult with Down syndrome – a new challenge for society’. The conference covered medical, genetics, social, family, employment and independence issues, with a high standard of contributions from speakers from many different countries. One theme was ageing, with a particular concern to update delegates on current research into Alzheimer disease from both the genetic and clinical aspects. While the actual incidence of Alzheimer disease in adults with Down syndrome is less than was once thought, they are still at greater risk for age over 40 years than the rest of the population. This has also drawn researchers into looking at many aspects of the effects of ageing in individuals with Down syndrome and some important longitudinal studies are being carried out in the USA. Presenters from Italy drew attention to mental health issues for adults and the risk of depression, which can be confused with the onset of dementia but is, of course, treatable. A group from the USA highlighted increased risks of osteoporosis and bone fractures in post-menopausal women with Down syndrome. This work should lead to improved quality of life for ageing individuals with Down syndrome.

Another theme was inclusion in education and in employment, with contributions from a number of countries including Italy, the UK and the Netherlands. A common theme was a concern about inclusion in secondary education. In many countries, inclusion in primary education is working reasonably well, but inclusion at secondary level is more problematic. One tension is the demand of the curriculum – with questions being raised about the difficulty of offering an appropriate curriculum to teenagers with Down syndrome if just drawing on what is available in the schools. This may not offer practical life skills and vocational training opportunities, and the need to continue to develop basic literacy and numeracy skills may also need special planning. There were presentations on memory and language development, with one paper indicating that speech and language therapy will continue to bring benefits to adults and that it can be implemented by staff in day services under the guidance of a speech and language therapist. There were papers on independent living and also an important discussion of the experiences of brothers and sisters. The conference organisers hope to publish a book of proceedings and some of the presenters have been approached to contribute to future issues of Down syndrome News and Update.

Next EDSA meeting

The next EDSA meeting will be held on 29 - 30 November in Bielefeld-Bethel, Germany. Bethel is the largest centre for epilepsy in Germany. To close the festivities of the jubilee of the Arbeitskreis Down-Syndrom there will be a congress, concentrating on medical issues, the official presentation of the EDSA-medical checklist and identity document, a ballet of The Inseparables (the chromosomes 21) and organ concerto. Further details will be in the next issue and on the EDSA website.
Join the European Disability Forum now!

2003 will be the European Year of People with Disabilities, a unique opportunity to advance the disability agenda in Europe.

The Year should also contribute to a strengthening of the disability movement in Europe. EDF is the voice of disabled people at European level and the more representative this voice is, the more impact its requests will have. It is therefore important that as many relevant disability organisations in Europe as possible become members of EDF. The membership fee structure is designed in a way that the fee should not be an obstacle to becoming an EDF member.

2003 is also the great opportunity to establish permanent alliances with other stakeholders that have in common with disabled people their commitment to promote the rights of disabled people. These organisations can also become members of EDF. Some examples of these organisations are:

- Local authorities
- University departments
- Research and rehabilitation institutes
- Companies
- Trade unions
- Foundations

If you know any of these organisations which could be interested in becoming an EDF member, contact them directly or provide their contact details to EDF, so that EDF can approach them.

EDF is also open to receive individuals as members. Many individuals are members of other NGOs, so why not become a member of EDF. It is just 60 Euros a year.

The benefits of becoming a member of EDF are of many kinds:

- Direct access to all relevant European information via the EDF Weekly Mailing.
- Possibility of influencing the work of EDF with your expertise.
- Possibility to disseminate information about your own organisation through the EDF website and other information tools.
- To establish contacts with other EDF members, to exchange information or to undertake joint projects.
- A copy of the EDF annual report.
- Access to the membership-only website of the EDF.
- To participate at the General Assembly as observer.

If you are interested in becoming an EDF member, visit the EDF website (http://www.edf-eph.org) for more information or contact the EDF Secretariat at membership@edf-eph.org

EDSA Board meeting

The Board was able to meet in San Marino and it was very rewarding to note that the membership of EDSA has grown considerably. Organisations in twenty countries are now members with a particularly welcome growth of members from Eastern European countries. All member countries are represented on the Board by a parent and a professional representative. This reflects the spirit of EDSA and the belief that individuals with Down syndrome, their families, service providers and researchers need to work together within one community to achieve maximum benefits for all. At the Board meeting an EDSA identity document was approved, setting out the philosophy, values and aims of EDSA. The Board also approved a European Down Syndrome Medical Checklist. We hope to publish these in future issues. The Board discussed ambitious plans to address a number of issues including the support of families, human rights issues for adults, promoting a positive image of individuals and their lives and tackling discrimination in insurance provision. EDSA is playing an increasing role as a member of the European Disability Forum and other international disability groups.

EDSA Website: http://www.edsa.down-syndrome.org

New magazine in Romania

I am very pleased to let you know that we have got a grant for a periodical magazine about Down syndrome, named “Traind cu sindromul Down” (Living through Down syndrome). There will be 4 publications per year, and the first one will be published in August. We shall be translating and adapting EDSA News for our magazine.

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

The Trust has commissioned a series of books on adult issues in its Down Syndrome Issues and Information series under the editorship of Professor Roy Brown in Vancouver, Canada. Roy recently retired from being head of the Disability Programme at Flinders University in South Australia and he is well known for a life time of work promoting quality of life issues for adults with intellectual disabilities. Some twenty authors from six different countries have agreed to contribute and the topics include health and ageing, including women’s health issues, education, vocational training and employment, independent living, leisure and recreational activities, art and drama, relationships, marriage and sexuality, the family, mental health and emotional well-being, the elderly person, international and cultural issues, the law and human rights, advocacy, and the spiritual needs of adults.

Grants and research plans

The Trust is seeking grant money to support an action research project with other agencies – education, social services and leisure services – to look at ways of improving the social inclusion of teenagers and young adults with Down syndrome. It is also actively seeking funds to support further evaluation of the Numicon approach to teaching maths and to support the planned See and Learn software project. The first stage of the software project will go ahead with existing Trust resources in order to produce and trial an example of the teaching software. Once funders see what we intend to develop we may have more success in finding grants. Meanwhile any contributions towards this work will be appreciated.

DSii Development and Education series

We are completing the last books in this series during August and September. Some of us are still writing the final topics and we are able to give more time to this when the schools are on holiday and all our term time work ends. Thank-you to subscribers who have shown such patience as the writing and production of these books has now taken more than two years to complete. We have had much positive feedback on the materials and hope to have web versions available in 2003.

Online shop

While some of the Trust staff are having a few quiet weeks writing, others are busy with programming and we hope to have an on-line shop and booking system operating in the autumn. This should be particularly helpful for those using our services from overseas.

Down Syndrome Educational Trust - Bristol branch

The Bristol branch of the Down Syndrome Educational Trust will be opened by Professor Sue Buckley at its first meeting on Monday 9th September 2002. The branch has been formed by two parents in Bristol and will initially be offering group speech and language therapy sessions for children with Down syndrome from the age of 18 months onwards. The sessions will take place on Monday mornings at Henleaze and Westbury Community Church, Eastfield Road, Westbury on Trym, and it is hoped to extend this to sessions for school age children within a short time. The sessions are being taken by Sarah Coles, a speech and language therapist who has a special interest in Down syndrome, and who has been on a training course at The Down Syndrome Educational Trust in Portsmouth.

Would anyone interested please call any of the following for further details:

Sarah Coles at Southmead Hospital, tel: 0117 959 5680
Marie-Louise Cook (parent), tel: 0117 968 6893
Annabel Dixey (parent), tel: 0117 962 4735

Good news for the Centre

Our future in the Sarah Duffen Centre is now assured for the foreseeable future as we have agreed a new 50 year lease on our Victorian property with Portsmouth City Council. We appreciate the support of the City as our property is ideal for our purposes, with easy access by sea, road, air and rail, ample car parking and enough space for our activities. It is a valuable site in a prime location and the City has chosen to continue to support our work rather than use the site for other purposes when our current lease ends next year. We will be applying for grants to upgrade the interior of the building and to improve specific facilities for conference and consultancy work over the next few years.

Fundraising

We would like to thank all our supporters who continue to fundraise for us and we will be sending out a Fundraising News in September with details and photos of many events organised for us by individuals and groups over the past 6 months. 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 the donations and events organised by individuals to provide nearly half our income. So-if you have any ideas for fundraising events please contact Howard Hurd or Linda Hall. We can help with tickets, leaflets, advertising and other advice.
Parent and family weekend

31 August - 1 September 2002

Weekend conferences offer the opportunity to attend a range of sessions covering a variety of topics. Speakers from different professions provide the opportunity to share information and discuss parents concerns, with each session lasting one-hour. The weekend also offers chances for families to meet with each other and is relaxed and informal. A crèche for a limited number of children is available.

A weekend conference for families with babies and children up to 8 years of age

Programme

Saturday:

• Early language development: Activities to promote the development of early language and communication skills from birth to first words, and an opportunity to discuss any problems or difficulties that may arise.

• Teaching children number - The Numicon approach: The steps to be mastered in understanding number at home and at school, and how to use the Numicon materials to support the development of number skills.

• Teaching reading to teach talking: The ways in which reading can be taught in pre-school and school years, identifying the benefits for speech, language and memory development, and giving practical examples.

• Priorities for early intervention from birth to 3 years: An overview of the specific developmental profile associated with Down syndrome and the priorities for effective early intervention and for the family.

• Medical issues: Medical issues of particular relevance to children with Down syndrome with an opportunity to discuss individual questions.

• Education: Beneficial teaching methods and strategies appropriate for children of all ages, discussion of school placement and models of good practice for early intervention, nursery and primary education.

Sunday:

• From first words to sentences: Ways of helping children to expand their vocabulary and the use of grammatical sentences.

• Computers as an aid to learning: Introducing children to the computer and demonstrations of useful and motivating software for the child with Down syndrome.

• Teaching children number - The Numicon approach: The first steps in understanding number for preschoolers, using the Numicon materials.

• The statementing process: the various stages involved, how to develop a positive relationship with a child’s school, and the role of the statement in relation to legislation on special educational needs.

• How do we change children’s behaviour? The factors which affect human behaviour and special issues affecting children with Down syndrome. Some practical strategies for managing difficult behaviours.

• Working memory skills: The importance of working memory for language processing and learning, and techniques for supporting children's development of memory skills.

Session leaders and speakers:
Professor Sue Buckley, Gillian Bird, Professor Ben Sacks, Pat Le Prévost, Vikki Horner and Bob Black.

Still some places available for this weekend

Order Reference | Description                              | Excl. VAT | Incl. VAT |
---------------|-------------------------------------------|-----------|----------|
CNF/20020831   | Family conference - delegate Aug/Sept 2002| 59.15     | 69.50    |
CHE/20020831   | Family conference - crèche place Aug/Sept 2002 | 29.36     | 34.50    |

(fee includes buffet lunches, tea and coffee on both days)

Dates for next year’s Parent and Family weekends:
3/4 May 2003 and 23/24 August 2003
New Internet resource aims to get medical students “into the right ways of thinking” about learning disabilities


What they say…
The new Learning about Intellectual Disabilities and Health website was created by the UK Down’s Syndrome Association in collaboration with the Department of Psychiatry of Disability at St George’s Hospital Medical School (SGHMS).

It aims to provide a broad range of information to medical students and practitioners about learning disabilities, and the factors they need to consider when treating patients with learning disabilities. There is a clear need for this type of resource, as most of the 26 medical schools in the UK currently have little or no formal teaching on learning disability.

At the launch, Carol Boys, Chief Executive for the UK Down’s Syndrome Association, said: “We hope that medical schools across the UK will encourage their students to use the site to improve the currently patchy provision of training in this area. Boosting the training of future health professionals is vital to eradicating discrimination. We also hope to encourage existing health professionals to use the site, particularly those involved in primary care.”

The Rt Hon Jacqui Smith MP - the Minister responsible for people with intellectual disabilities in the UK Department of Health – commented: “It is important to get medical students into the right ways of thinking about people with learning disabilities at the outset of their careers… It is also important to get messages across to current practitioners to ensure that the clinical culture that the students of today will move into in years to come is increasingly competent in relating to people with learning disabilities.”

What we say…

A promising start
The website certainly succeeds in providing a range of useful resources on learning disabilities for medical students and practitioners. There are two main types of information provided – articles advising how to provide effective care for people with learning disabilities and articles on specific health care topics.

We were particularly impressed by the articles about providing effective care for people with learning dis-
As it currently stands, the Room for development medical teaching and practice. The articles also give parents a very useful insight into current influence medical students’ ways of thinking, these articles also give parents a very useful insight into current medical teaching and practice.

The articles on specific health care topics provide useful, short summaries from a range of sources, especially in health issues relating to individuals with Down syndrome. These articles include information to help treat patients with Down syndrome who have impaired hearing or vision, heart problems, cervical spine problems, and so on. There are also some useful summaries of the history and genetics of Down syndrome.

For all articles we would have liked to know more about the authors – for example if they are medical professionals and the organisations where they work. It would also be useful to have hyperlinks at the end of the article to access further information or linked resources on the Internet.

The website is well illustrated with positive photographs of individuals with learning disabilities in a range of real life settings. There were also a couple of case studies written by people with learning disabilities and their families. More case studies such as these would help medical student and practitioners appreciate that individuals with learning disabilities are individuals first and foremost – with their own fears and needs just like any other patient.

Room for development
As it currently stands, the Learning about Intellectual Disabilities and Health website is a good starting point, but we feel that it needs considerable development to meet its true potential as an effective learning tool for medical students.

In particular, the number of specific areas of learning disability covered are extremely limited. The website could be improved by providing a basic list of the main types of learning disability, their effects, their prevalence, and suggested websites for further information. The website’s authors do recognise, however, that it needs further development to include more causes of learning disability and their related healthcare concerns.

At present, the majority of the articles on the website relate to the health care of individuals with Down syndrome, and many of these are already available on the Down’s Syndrome Medical Interest Group’s website (http://www.dsmig.org.uk/).

There are also a few terminology issues – the website also uses the term Down’s syndrome, instead of the more widely accepted Down syndrome, and is inconsistent in its use of ‘intellectual disability’ and ‘learning disability’ as a key term.

The website also aims to provide a range of potentially useful ‘interactive’ learning resources for medical students and practitioners, including a bulletin board and an ‘Ask a question’ facility. At the moment, however, the bulletin board does not seem to be up and running, and only two answers to questions have been posted since the website’s launch in February 2002.

The links to other resources could be better organised into related groups, with descriptions about the information available at each link. The links could also be more comprehensive – for example, there are no links to some of the key journals that publish the latest research on learning disabilities, including Down Syndrome Research and Practice from The Down Syndrome Educational Trust.

Usability and accessibility issues
One of the most serious faults for a resource website of this nature was that it had no search facility. This will become a particular problem if the website expands to include a much larger number of articles about a wider range of learning disabilities. For example, you can’t conduct a quick search to find all articles on Down syndrome or on autism.

- We also found the structure of the website to be a little confusing and navigation could also be improved, as there is no quick way to move from section to another without going via the home page.

- It is also a shame that there are some accessibility issues with this website, when it is compared against the ‘industry standard’ – the Web Content Accessibility Guidelines from the World Wide Web Consortium (http://www.w3.org/tr/wai-webcontent/).

Summary
We agree with the DSA-UK that making our future doctors more aware of the issues surrounding the treatment of people with learning disabilities will help them provide better health care for these individuals. The Learning about Intellectual Disabilities and Health website has the potential to become a very useful learning resource for medical students and practitioners, and the general information it currently provides on caring for individuals with learning disabilities is extremely interesting. However, at present the website suffers from a restricted range of information and some usability problems. Nevertheless, we hope that this website is able to develop to become a major source of medical information about the entire spectrum of learning disabilities.

At present, for detailed information on specific health issues relating to individuals with Down syndrome, we would also recommend Dr Len Leshin’s extremely comprehensive ‘Down syndrome: health issues’ website (http://www.ds-health.com/).

Joanna Nye, Assistant Editor, Down Syndrome News and Update
Conferences

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

26 - 29 September 2002
Molecular Biology of Chromosome 21 and Down Syndrome, 10th International Meeting, Sitges (nr. Barcelona), Spain
http://www.crg.es/chr21meeting/

11 - 13 October 2002
Celebrating the Past: Envisioning the Future, A conference to mark 50 years of the Fred and Eleanor Schonell Special Education Research Centre, Brisbane, Australia
http://www.tandf.co.uk/journals/carfax/Schonell.pdf

13 - 16 November 2002
37th Annual National Conference of the Australian Society for the Study of Intellectual Disability, Hobart, Tasmania, Australia

3 - 5 April 2003
Research Conference on Cognition and Behaviour in Down Syndrome. Joint NDSS/DSRF Science Meeting, Denver, Colorado, USA.
http://www.ndss.org
http://www.dsrfr.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)
http://www.dpa.org.sg/DSA/DS8Congress.htm

14 - 19 June 2004
12th International Association of the Scientific Study of Intellectual Disabilities (IASSID) World Congress, Montpellier, France
http://www.iassid.org/communication/12th.htm
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

Article (World Wide Web reference):