Down Syndrome
News and Update
Volume 1 No.1 - June 1998

Contents

Editorial
3

Education
Including children with Down syndrome
5
Review: Children with Down syndrome
14
Review: An evaluation of educational placements in Devon
15
Research: The social development of children in special school
16

Health
The thyroid and Down syndrome
20
Nutritional supplementation - controversy and further comments
22

Speech and language
Bilingualism and Down syndrome
29

Information technology
Getting started on the Internet
31
Educational software reviews
34

Research updates
The National Down Syndrome Society’s 11th Research Conference
37

News
The Foyle Down Syndrome Trust
41
News from The Sarah Duffen Centre
42
Diary dates
43

Supplement
The Down Syndrome Educational Trust Review of Activities during 1997
45
Down Syndrome News and Update

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

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

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

For further guidelines for submissions, please see pages 53-55.

Editor
SUE BUCKLEY
Professor: Psychology of Developmental Disability
Director: Centre for Disability Studies,
University of Portsmouth, UK.
Director: The Down Syndrome Educational Trust, UK.

Assistant Editor
DR ANGELA BYRNE
Psychologist
The Down Syndrome Educational Trust, UK.

Editorial Board
GILLIAN BIRD
Director of Consultancy and Training Services,
The Down Syndrome Educational Trust, UK.

Professor BEN SACKS
Consultant Developmental Psychiatrist and Medical
Advisor, The Down Syndrome Educational Trust, UK.

FRANK BUCKLEY
Director of Operations and Finance,
The Down Syndrome Educational Trust, UK.

BOB BLACK
Development Officer (South West Region),
The Down’s Syndrome Association

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

We would particularly welcome advisors from a variety of countries.

Address for correspondence
Editor.
Down Syndrome News and Update.
The Down Syndrome Educational Trust.
The Sarah Duffen Centre, Belmont Street, Southsea, Hampshire PO5 1NA England.
Tel +44 (0) 1705 824261 Fax +44 (0) 1705 824265 Email news-update@downsnet.org
EDITORIAL

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

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

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

In this issue
In this issue, the focus is on successful inclusion in education for children with Down syndrome, with the leading article addressing the issues of attitudes, whole school culture and successful planning on a school level. The second part of this article, addressing the implications of the specific learning needs of the children for adapting the curriculum, will be in the next issue. Both articles are based on our experience of placing and supporting children in mainstream schools over the past ten years and they cover material that we regularly share at our education workshops. In our view, we are still not planning for inclusion at the appropriate levels in the UK, i.e. at the policy, authority or whole school levels. Too often a school only thinks of inclusion when a child is about to arrive and all the arrangements focus on individual support for that child to help them to fit into a culture and an educational environment not designed for them. Since all the evidence is that the schools that are best at inclusion are the best for all the other pupils in them, we hope that our article will encourage some debate in staff rooms and some whole school planning for change.

As more and more children with Down syndrome are being included, it is essential that we objectively evaluate the effectiveness of inclusion. We provide readers with summaries of the findings of two studies, one by Denise Dew Hughes of Oxford, looking specifically at social effectiveness and the other by Jane Beadman of Devon, comparing the progress of children in mainstream and special schools. Educators will also be interested in Gillian Bird’s review of a new book on including children with Down syndrome by Stephanie Lorenz containing much practical advice for teachers and support assistants in mainstream schools and the guides to useful software in the classroom.

Access to information on every conceivable topic is undergoing a revolution with the advent of the World Wide Web. Frank Buckley and Angela Byrne have written a introduction to getting connected to the Internet, and will present a guide to the information resources available on the Internet in the next issue. The Down Syndrome Educational Trust is continuing to develop a web site (at http://www.downsnet.org/). We hope that it will become a comprehensive information resource on Down syndrome and be recognised for the standard of its contents. We will only be including material of a standard generally accepted by peer review in the scientific community. We are also developing host sites for several other organisations including the European Down Syndrome Association and the Down’s Heart Group.
While we welcome the potential of the Internet for providing the possibility of rapid exchange of information and expert advice, we also worry about the amount of misleading and inaccurate information that is also available on the Internet. One of the topics in our health section, ‘Targeted Nutritional Intervention’ (‘TNI’), is an example of this. Many sites and newsgroups contain misleading information, some just wrong and some making wild claims for effects for which they cannot produce any acceptable evidence.

In a recent issue of our Newsletter (issue 1.4, November 1997) we published an article on the issue of such supplements and the lack of evidence of positive benefits plus the very real risks of harmful ones. The article provoked a number of positive and negative responses and we publish one of the letters received and our reply in this issue. We will be dealing with these issues further in future issues. In the Health section, we also include an article on the thyroid by Len Leshin and the details of a very useful resource pack on heart defects produced by the UK Down’s Heart Group.

The Research Update in this issue comes from the meeting held in the USA by the National Down Syndrome Society. The topics were wide ranging, covering issues from infancy to adult life, and from genetics and biomedical research to practical living and care issues.

International News will cover the activities of organisations around the world and we welcome contributions from individuals and groups from all countries.

We hope you find this new publication interesting and informative. Please let us have your comments and ideas or contributions for future issues.

Sue Buckley
Getting the culture right

Why inclusion?

Why should you, as a headteacher, school governor, teacher or parent, be concerned about how well your school is meeting the needs of children with significant special educational needs?

Firstly, because the evidence is that the individual schools who are the most successful at including and educating these children are also the best schools for all the other children in them (1).

Secondly, where whole education systems have shifted to be fully inclusive and to provide for all children within mainstream schools, they report that the quality of education has improved over time for all children (2).

The implication of these statements is that if we want our schools to provide the best possible education for all our children we need to explore what makes the inclusion of children with significant special educational needs successful. We also need to ask why mainstream school systems improve when changing to successfully meet the challenge of educating these children.

The first part of the article provides guidelines to good practice in developing the inclusive school, considering the importance of the role of the Headteacher and managers in developing school philosophy, values and culture, school organisation, staff training and the management of resources. We then consider the role of the teacher in developing inclusive classrooms and finally the role of all the pupils in developing peer support.

Developing inclusive schools

For us, the opportunity to go to a school in the community in which you live, with the other children who live in your neighbourhood, regardless of disability or special educational need is a human rights issue. We do not expect all readers to agree with us but we do hope that this article will challenge some of the current assumptions about the roles of schools in our society and that it will provoke discussion with your staff and colleagues.

In this article we will explore these issues, sharing the experiences that we have gained from developing inclusive placements for children with Down syndrome in the UK over the last ten years - children who would otherwise have been placed in special schools. During this time we have learned a great deal about the school factors which lead to success or failure. With other colleagues in The Sarah Duffen Centre and in the Department of Psychology, University of Portsmouth, we have also been studying the cognitive, social and behavioural progress of these children in inclusive placements in some detail. This work has relevance to a wide range of children and will be reviewed in part 2 of this article.

We are psychologists specialising in working with children with moderate to severe learning difficulties and between us we have some 45 years of experience. However, until we became involved in the implementation of the 1981 Act in the late 80’s, all our experience had been in special education settings.

Promoting mainstreaming

The last ten years have been the most rewarding and exciting of our careers. We have been most impressed by the ways in which children with Down syndrome and significant special needs have been welcomed in the majority of mainstream schools and by the skills, enthusiasm and professionalism of the majority of mainstream teachers with whom we have worked. We have seen successful placements and great progress for the majority of the children during most of their school years. Some have had good and bad experiences as they have moved up the school and we will return to the reasons for this later in the article.
We have been involved in the direct support of many individual children from the start of their school careers through to secondary school. We have also provided INSET training around the country and offered advice on individual placements at particular points in time. Much of the content of this article draws on our extensive opportunities to learn alongside the teachers who are successfully including and educating children with significant learning difficulties or disabilities in their classrooms (3).

At the start of our involvement with mainstreaming, we made links with research groups and education programmes in other countries in order to learn from their experience. We are confident that our experience is valid as success or failure in our placements has been the result of the same criteria reported by others in places where they are further down the road towards fully inclusive education systems.

We use the term mainstreaming deliberately to describe our early experience. When we began to ask schools to accept a child with severe learning difficulties in their school, we were asking them to take a child with the support of an untrained Learning Support Assistant (LSA) into the regular classroom environment with little or no preparation. The teacher had to try to meet this child’s needs without time to think about changing the classroom environment or teaching styles or to learn new skills. This is what our American colleagues in Madison, Wisconsin call the “dump and hope” phase! In Madison they closed their last segregated special school site in 1976 (4) so they have more than twenty years of experience to draw on.

Moving to inclusion
Inclusion is more than mainstreaming. It is the result of rethinking the role of education and usually requires a change in school and classroom culture and organisation.

Over time we have seen a shift in the UK towards the development of inclusive school cultures but this is still mostly because individual schools have developed their skills and changed their beliefs about the role of schools. It is rarely the result of planning for an inclusive system by Local Educational Authorities. In these inclusive schools there is more awareness of the individual needs of all children, more flexibility in the curriculum and a valuing of diversity. This shift has been particularly noticeable over the last few years, since the establishment of SENCO’s and the implementation of the Code of Practice, following the special needs legislation in the 1993 Education Act.

There are very few UK Education Authorities that have actually embraced an inclusive philosophy and actively managed change. The London Borough of Newham is one example where an inclusive policy is in place. It has received much of its impetus from effective lobbying by parents of children with disabilities and special educational needs. The Wisconsin changes were also driven by parent pressure in the early years. In both the Newham and the Wisconsin situations, change has progressed in the same way. Both replaced segregated special schools with special units or special resources on some mainstream sites. Both found that these could be phased out over time as all teachers increased their range of skills and all schools became more confident at meeting a variety of needs. The specialist skills of the teachers who used to work only on segregated sites become available to all children in the system and to colleagues and this helps the process of change as well as benefiting many more children.

Whole school issues and the role of the headteacher

School philosophy and culture
The schools that we would rate as the most successful have established an inclusive culture. They have thought about and explicitly embraced a philosophy that values all children equally and celebrates the diversity of the human population. They believe that the role of education is broad and would accept Lou Brown’s definition that it is the task of schools “to prepare children to live, work and play in an inclusive society”. (Lou Brown is the Professor of Special Education, University of Wisconsin, Madison(3)).

Schools as agents of change
A school has the opportunity to establish a community that demonstrates the values that we might wish to see expressed in the wider society outside school.

We can use the example of disability to explore this argument further. It is common for adults with disabilities to observe that their lives are far more restricted by the attitudes of the non-disabled majority towards them than by the limits actually imposed by their disability. One reason for this may be the lack of contact with people with disabilities that most of the non-disabled population have as a result of mainly segregated schooling and
segregated services for children and adults with disabilities. This has lead to a society where the majority of individuals do not understand the needs of people with disabilities nor feel at ease in relating to or working with them.

The decisions that are made about the design of our schools, work places, transport and communication facilities take little account of the needs of those with physical or sensory impairments. Access to the daily opportunities that the rest of us take for granted is therefore denied to most children and adults with disabilities. Until recently, all children with identifiable disabilities experienced this lack of access from earliest childhood, when they were denied the opportunity to benefit from the same educational experiences as other children. This resulted in two main disadvantages - a restricted access to the curriculum and no opportunity to be part of the ordinary social world of childhood. In other words, most children with disabilities experienced both social and educational deprivation during childhood, leading to social isolation, under achievement and impoverished lives as adults.

*If all children are able to grow and learn together, the child with special needs has the optimal opportunity to reach his or her potential, to make friends and to become fully integrated into mainstream society.*

The other children have the opportunity to learn to understand the effects of disability and to learn how to care for and support children with a variety of needs. They will learn that all children with disabilities are children first, with the same psychological, emotional and social needs as all other children. Like the rest of us, significant relationships with others are central to their well-being as children and adults and the opportunity to establish and maintain friendships during childhood is important preparation for successfully developing these relationships in adult life. The non-disabled students will become better friends, neighbours, workmates and bosses for people with disabilities in their adult lives.

*This may require schools to recognise that social development should be an explicit part of the curriculum, giving children the opportunity to think about friendships, loneliness and social isolation (5).*

The experience of communities who have had fully inclusive education systems for a generation is that these gains do occur. Attitudes do change throughout the community and opportunities become more equal. More young adults with significant disabilities are able to work, live independently, establish their own families and enjoy the same leisure facilities as everyone else. More of the young adults who, though not disabled, were in the less able third of the mainstream school population in terms of academic progress, also do better in these inclusive school systems. The skills developed by all teachers as they are required to meet the educational needs of those with the most significant difficulties benefit many others who have always been in the mainstream but not always had their needs met. Teachers learn how to address social and behavioural needs more effectively and to extend access to the curriculum to a wider range of children.

*However, these benefits will only be the outcome if inclusion is done well.*

The individual educational needs of all children must be met as well as they would be in separate facilities. Mixing with children with significant disabilities can result in other children becoming less tolerant and sympathetic if the experience is unpleasant for any reason, so how do we move forward successfully?

**Strategies for success**

**Valuing diversity and building self-esteem**

_The successful schools see all their pupils as individuals and value them equally. They encourage their students to recognise that we are all individuals and to recognise that we all have strengths and weaknesses._

Healthy adjustment in adult life is likely to come from a realistic appraisal of oneself, therefore setting goals that are achievable and appropriate and which lead to a positive self-concept - feeling good about oneself. Building positive self-esteem in all pupils should be a primary goal for all teachers (6). This is no easy task. It means helping all students to identify their strengths and their limitations so that they choose to develop their strengths. It means that those schools with authoritarian cultures need to change, and that ridicule and humiliation of children should have no part in the school culture or in any teacher’s repertoire. One of us (SB) has had the opportunity to travel extensively and experience the atmosphere in schools where building self-esteem is a primary goal. We do experience this in some of our UK schools, but not to the extent that is common in parts of
North America and Canada.
Our experience in the UK is that the culture and philosophy in schools can be very different, even in neighbouring schools. We can illustrate this with a real example. The student’s name has been changed to preserve confidentiality in this and later case examples.

Several years ago one of us (SB) received a phone-call from a distressed parent, asking if one of us could attend a review meeting with her and her husband, as she feared that the school no longer wanted her daughter as a pupil. Her daughter Sally was 13 years old and had Down syndrome. She had received all her education to that time in mainstream school with full time non-teaching support provided. She was nearing the end of her second year in secondary education and the school were expressing considerable concern about her progress both educationally and socially.

SB arranged to arrive at the school in time to meet Sally and to talk with the staff before the review meeting. It was quickly apparent that the staff had no positive commitment to meeting this student’s needs. The Head of Learning Support made clear to SB that she and her staff did not have the time to differentiate work for Sally, seeing this as an inappropriate use of their time. They were also concerned that she was becoming increasingly socially isolated. They did not want advice from us on how they could change this state of affairs and make the placement successful.

This would of course mean accepting that the school might be failing Sally. Their perception of the situation was that Sally should not be in their school. All the difficulties they were experiencing were the result of her disability and she should be in a special school. They even expressed negative views about her in her presence and seemed to have no sensitivity to the probable effect of their attitudes towards her on her progress or happiness within the school.

The review meeting was a formal affair involving the Headteacher, Head of Learning Support and five other professionals from local and county LEA’s and chaired by the Deputy Head. The Head was visibly annoyed by SB’s presence and did his best to prevent her from contributing to the discussion. The meeting had clearly been called with one aim - to agree to remove Sally from the school and put her where this Head made plain he thought that she belonged - in a school for children with severe learning difficulties. He seemed to have little understanding of the social influences on any child’s performance and progress. He saw Sally’s present difficulties in his school as entirely her problem, the result of her disability. He certainly did not want any advice. For him, the last straw was when SB secured the agreement of the LEA to continue to the same level of LSA support for Sally if we found her another mainstream placement as this clearly implied that she believed this school was failing Sally.

With Sally’s parents, SB approached another mainstream school near her home. This school expressed a willingness to accept her and a visit was arranged. The contrast in the two school’s philosophies and cultures was extreme. The Headteacher of the new school greeted SB warmly and informed her that he would be delighted to accept Sally in his school. He explained that this was a community school - in name and in philosophy. He wanted all the children in the neighbourhood to be welcome in his school and had been developing his learning support resources accordingly, since coming to the school as Head four years earlier. He then took SB to meet the Head of Learner Support. She explained that she had no previous experience of teaching a child with Down syndrome but that she had given some thought to our request and was looking forward to supporting Sally in the school. She added that she had considered what she would have wanted if Sally had been her daughter and knew that she would have wanted an education with mainstream peers within her own community for her.

At this point SB knew that this placement was going to be a success. She was then asked about Sally’s achievements in literacy and numeracy and was told that there were other students of her age working at the same level so she could join their groups. The Head then asked SB what year group Sally should join. SB said that she was unsure as Sally was probably less socially and emotionally mature than other girls of her age. The Head laughed and said that some girls of her age were more like 18 year olds in social and emotional development, others more like 9 year olds - he felt sure she would be fine in her correct year group!

At this time, we had little experience of secondary schools and this case made us feel that we were on a steep learning curve! SB was quite shaken by the contrast in the attitudes and beliefs of the two headteachers and their staff. One school had told her that Sally could never fit in, as she was so different from their other pupils. Another school just down the road had no problem seeing Sally as happily fitting in to their school community and pointing out that her needs were not different from those of some of the other mainstream
pupils in the school, either academically or socially. Could the populations of children in the two schools really be that different or was it the way the staff perceived their children that was different?

The evidence on the school intakes supported the latter view. We cannot help worrying about the educational experience of many of the other children in the first school, not just those less academically able, but also those with social and emotional needs. In both these schools it seemed that the Headteacher was determining the culture and values of the whole school, for good or ill.

We would ask all Heads and managers to reflect on their own personal attitudes to disability and to children with special needs. It is likely that your personal attitudes and your emotional reactions to disability will be influencing the decisions that you are making and will be apparent to your staff and to your pupils. You might also reflect on what educational and social opportunities you would want for your own child, if you had a child with a disability.

**Staff attitudes**

In our experience, the single most important predictor of success for placements is staff attitude. If the staff believe that the child is appropriately placed in their school, the placement will be a success. We have seen very disabled children, with significant dependency needs, flourish in schools were they are wanted. We have seen children with obvious disabilities but academic progress within the norms for their age, fail in schools that do not want them - or should we say failed by schools that do not want them.

The evidence in favour of the importance of staff attitude is particularly striking when a pupil flourishes in one school but has a miserable time in the next school.

We have had this experience with several children whom we know well. One young friend of ours, Gerry, is now 11 years old. Gerry has Down syndrome. He went to the same mainstream nursery as his brother and then into the infant school where he made extremely good progress. The school had given much thought to meeting his needs and the staff were rightly proud of his achievements.

In Gerry’s last year in this school, his class teacher was sharing her experiences at a training day at our Centre. She described how, as Gerry’s strengths were his literacy skills and his computer skills, he was spending some time each week helping children in the reception class and in Year I, listening to them read and showing them how to use the computer. This teacher had deliberately constructed opportunities to build Gerry’s self-confidence and self-esteem. These situations also showed the other children that, despite his disability, Gerry had strengths and could help others as well as benefit from their help at other times. His literacy skills were within the range of his classmates.

Imagine our concern when he moves to the junior school with these peers the very next term and the new class teacher phones us expressing the view that he has no place in their school - he should be in a school for children with severe learning difficulties!

Before long Gerry was showing his distress by bedwetting, something he had not done since the age of three years. We were able to improve this situation somewhat but it continued to be less than satisfactory by our standards.

At this time, we were supporting another lad with Down syndrome of the same age and with a very similar profile of abilities and special needs in a nearby school. The contrast was dramatic. This junior school had two children with Down syndrome on the school roll and all the staff were immensely proud of the progress of both of them. We would observe that the two schools had different atmospheres and different attitudes to all their children, confirming what we had read and have stated at the start of this article.

The schools that are best for all children are the best for those with very special needs.

Some headteachers might reflect further on the significance of this as it implies that schools who are not good at meeting the needs of special students may not be the best schools for all the other children in them either.

We could give more examples of this kind, where a child has made very different progress after a school move and has been perceived and described very differently by Headteachers and teachers in the two schools.

The message from this section is threefold. Firstly, successful schools clearly recognise the wide range of educational needs present in any year group in any school population and they acknowledge that it is their job to meet this wide range of educational needs. Secondly, successful schools develop a culture that is caring and supportive of all in the school
community, aiming to value diversity and to build positive self-esteem for all its pupils. Thirdly, successful schools appreciate the effect of being valued and feeling liked by staff and other pupils on the progress of all children.

School organisation and the use of resources

*If schools are to succeed in meeting this wide range of needs successfully, there needs to be flexibility within the classroom, within the year group and across year groups.*

Flexibility in the classroom is easier to achieve in the primary years when small group working is often the norm within the class. This enables children to work at their own pace within the class. A statemented child in the class with the support of an LSA can provide a bonus for other children in the class. This was one of the things that we learned as soon as we began to place children with Down syndrome in infant schools with a full-time LSA. The LSA could often work with a group of children, all of whom benefited from the extra help.

After a year, we suggested to our LEA that it would be cheaper to give every reception class an additional LSA than bother to try assessing children for Statements before they were in school. There are only a finite number of different special educational needs and we argued that all schools should be able to meet the needs of the four and five year olds in their community, with an LSA in the class and appropriate peripatetic advisory or teaching input. We also argued that assessing the child’s educational needs once they were in a school environment might lead to more valid and useful Statements. Our advice was not taken!

We are not in favour of special classes or units as we feel these are not usually necessary and carry the risk of segregating children again. They also do not recognise that all children are children first, regardless of disability or other special needs. There is no reason why any child cannot be a member of an ordinary class, in the correct year group, even if his or her educational programme has to be provided on an individual or small group basis.

This is the model that we see working well in many secondary schools. All children are members of ordinary classes and ordinary tutor groups even when they have considerable special educational needs. Their educational programme is then worked out for them as an individual, just as it for the other pupils as they make their choices of subjects that they wish to study. It then becomes no more stigmatising or isolating to have a lesson in the Learning Support Centre than it does to study Spanish rather than physics. Nor is it any more difficult to staff an expert Learning Support Centre than an English or Mathematics Department.

In Wisconsin, regular schools not only have expert special educators on their staff but also speech and language therapists, physiotherapists and occupational therapists as well. This means that their expertise is available to all children in the community, in a much more accessible way than in the UK at present.

While we try to support children’s learning within the classroom in the early years, to ensure maximum social integration and access to the curriculum, there should be no rigid rules about this. Every school, especially every junior school, would benefit from a learning resource centre, where children can have the benefit of individual or small group work.

One of the best examples of planning such a centre that we have come across was in a secondary school, where the learning resource centre had been deliberately sited right in the centre of the school. In addition to providing for those with special educational needs, it housed the school’s best computer resources so that it really was a learning resource for all pupils. This meant that any pupil could use the centre without embarrassment and that one was as likely to find a gifted child working there as a child needing special additional teaching or adapted resources.

The role of Learning Support Assistants

The success of many of the placements that we have supported has been due in large part to the skill and commitment of the LSA assigned to support the child. However, many of the schools that we have worked with do not know how to support and make full use of their LSAs. While recognising that the work of LSAs is critical to the access to mainstream school for many children in the UK at the present time, we are building a system on the cheap as most are poorly paid, have minimal training and no career progression open to them.

This situation highlights the lack of real policy commitment to or planning for inclusion in this country. Some other countries, Italy for example, provide extra training for qualified teachers so that they can become facilitators for inclusion. This recognises the importance of changing the whole philosophy and culture in
many schools and in classrooms, if they are to become truly inclusive communities. Is there a message here for our SENCO’s and their training?

Many of our children would not have made the academic progress that they have without the one-to-one teaching provided by their LSA. However, striking the right balance between supporting the child and encouraging independence is not easy. Too much one-to-one support for learning can make the child dependent on adult support. The child needs to learn as part of a group and to work independently. Too much adult support can also make the child seem more different to the other children than is necessary and prevent them offering support to the special child in ways that may come quite naturally to the children.

In some schools, LSA’s have a very difficult time. They have no professional training or status and are sometimes not treated well. We have been to schools asking for advice for a child, where the LSA was not allowed to talk with us, the clear message being that she could not have any useful views and must not be allowed to get above her station! More commonly, we find LSA’s who are given too much responsibility for the education of the child they are supporting either because the school feels no commitment to the child or because they do not know how to plan an educational programme for them. The class teacher must recognise that he or she has the responsibility for the education of a statemented child and that they have the same right to be a full member of the class as any other child.

Another difficulty an LSA can encounter is the responsibility of knowing that a child is not receiving an appropriate educational programme in the school but not having the status to do anything to change the situation. They may also be the main link between school and family, party to the concerns of both sides but without the power to solve any conflicts of opinion. This can be very stressful for the LSA.

These are matters for the Headteacher to be alert to and in many schools the status of the LSA’s has improved. Many are highly valued and well supported by their SENCO’s. Training programmes for LSA’s are improving.

Working with parents
Many parents of children with special educational needs have become experts. They will be experts in their knowledge of the effects of the child’s disability on their development and experts in teaching their own child. Parents of children with identifiable disabilities often join parent support groups and quickly access a wide range of information on their child’s condition.

Parents are likely to have been actively recruited into early intervention programmes by the time their child was one year old. In these programmes they will have been treated as equal partners by the professionals and expected to be their child’s main educator. Most early intervention programmes recognise that home is the most significant learning environment for any child’s development and that parents can be the child’s best teachers, so they actively pass on their skills and knowledge to parents. Parents choose learning goals and set priorities based on their view of the child’s needs and their awareness of the whole family’s needs and resources.

This parent-professional partnership approach has been very successful in pre-school years but parents often find that schools do not know how to form the same effective partnerships. Teachers in the mainstream are not always good at forming a positive relationship with parents of children with special needs. Teachers do not always recognise the contribution that parents can make in helping the teacher to realise the child’s full potential, if only teacher and parent could work together.

Most parents know that their child will benefit if they continue to teach them or help them to consolidate skills out of school hours, but they need to know the teacher’s current goals for the child. They may also need materials or ideas for activities to be provided from school, though often parents could supply materials for use in the classroom. We know many who create wonderful learning materials and games at home that children in the class would all benefit from. Bringing in such games can raise the self-esteem of the special child, as they are used and enjoyed by others in their class.

Many parents have valuable specialist knowledge of their child and their condition to share with their child’s teacher if given the opportunity. We often meet frustrated parents who cannot offer the information they know the teacher would find useful because the teacher will not accept it. It seems that many teachers do not know how to establish a partnership with parents. Too often, we come across situations where the teacher seems to feel threatened and to fear loss of face if he or
she admits that parents could know some things that she does not. This is an important issue which may need to be addressed by training and staff development in many schools.

**Peer support**

*In our experience, many schools fail to realise that the biggest resource that they have available to them to support children with special educational needs is the other children in the school.*

If a child needs more help, the first reaction is to send for another adult, either an assistant or external specialist. The use of strategies such as peer tutoring, cross-age tutoring, co-operative group learning and team projects is not as widely developed in the UK as in North America. All children benefit from these activities as they all learn how to teach and to co-operate with others. These are very valuable skills to take to the adult work place (7).

Explicit use of peers to prevent social isolation and to build circles of friends increases all children’s sensitivity to how others feel if ignored or actively rejected. Many academically able children do not make friends easily, so all children in the school will benefit when involved in projects to help friendships. Most teachers would benefit from some training in the techniques of developing peer support systems for teaching and for social support.

**Behaviour**

Effective behaviour management is another area where some staff training would be beneficial in the majority of schools we visit. While children with learning difficulties may be particularly at risk for developing behaviour problems as a result of frustration or failure, any child can present such difficulties. In the past few years, a variety of good written resources to support good behaviour management have become available.

Like developing the school culture and values, this is a whole school issue. All staff need to have consistent, positive behaviour management strategies, not just the special needs staff.

**Staff training**

We have mentioned staff training a number of times already. Staff development is clearly the responsibility of the Headteacher and in most schools, teachers are able to access a variety of training opportunities. However, if you want to change the school culture and become an inclusive school, creating the optimal learning environment for all, then some whole school training will be necessary. *You must have your whole school staff signed up to creating the social culture you are aiming at (8).*

In our experience, training sessions for the whole staff team are extremely valuable in giving an opportunity to debate these issues and make them explicit in everyone’s thinking. You will be very fortunate if all your staff have positive attitudes towards a truly inclusive culture, but it is useful for the whole staff team to be aware of the attitudes and prejudices of colleagues. It can also be salutary for those with negative views to realise that they are in a minority. In addition to a programme of training for your whole staff aimed at developing an inclusive culture throughout the school, for the benefit of all your pupils, it is important to consider the preparation of staff and other pupils for the arrival of a pupil with a particular disability.

We find that a session on Down syndrome, for example, for the whole staff team, before the child arrives at school, is very helpful in preparing the way for successful placement. We can answer questions about the condition, often clearing away myths, and we can explain how and why this placement will really benefit this child. It is not appropriate to expect the special needs staff to educate the rest of the staff team or to expect them to succeed in an atmosphere where a majority of staff do not think that they have any responsibility for children with special needs in the school.

Preparation of pupils is also important if a child with obvious special needs is coming into a school with no other similarly disabled pupils. We would suggest both a whole school approach and a class approach. The whole school approach might use an assembly to make clear to all children the welcome and support expected for the child, and therefore reinforcing explicit awareness of the school’s values. The class approach can include discussion of explicit strategies for welcome and for peer support for the child as well as giving children an opportunity to be informed about the specific disability so that they can understand the child’s needs and respond sensitively.

**Financial Resources**

We have deliberately left the issue of costs until the end of the article as, while we recognise that additional support for children with special needs costs money, our value system would lead us to argue that children
with special needs have the same right to share
in the community’s resources as all other
children. They have a right to be part of the
ordinary world of childhood in their
community - and that means a right to go to
school with the children in their
neighbourhood.

On a national, or on an area education
authority scale, it does not cost more to put
the resources into mainstream rather than
special segregated school. In fact many would
argue that it is a fairer use of specialist
resources (since, when specialist teachers and
therapists are moved to mainstream sites, their
expertise is available to many more children).
But this requires a full commitment to
inclusion and a total reorganisation of the
education system. It certainly costs more to
include statemented children while still
maintaining special schools.

We would argue that the challenge for an
education authority or a school is to make the
best use of its resources in an equitable way for
all its pupils. Lack of money should never be
an excuse for not allowing access to a
statemented child - this amounts to
discrimination on the basis of disability (as do
the other clauses allowing exclusion in our
legislation!).

Conclusions
In this article, we have emphasised the effect
of social opportunities on the development of
all children and the role of the school in
providing a social world that promotes the
values we would like to see expressed in our
society at large. We have argued that such a
school will provide the environment for all
children to flourish, socially, emotionally and
academically.

References
Gruenewald, L. & Jorgensen, J. (1989) Should students with severe intellectual disabilities be based in regular
or special education classrooms in home schools. Journal of the Association for Persons with Severe
Handicaps, 14(1), 8-12.
handbook for teachers. University of Portsmouth.
Down Syndrome. Orlando, USA.
There a Desk with My Name On It? The Politics of Integration. London: Falmer

Bibliography
Improvement. London: Fulton
Pupils with Learning Difficulties. London: Fulton
Chapman Publishing Limited.

The Authors:
Sue Buckley is Professor of Developmental Disability at the Department of Psychology at the University of
Portsmouth, UK. She is also Director of The Centre for Disability Studies at The University of Portsmouth and
Director of Research and Information Services and at The Down Syndrome Educational Trust. She also serves as
a Non-Executive Director of the Portsmouth and South East Hampshire District Health Authority and on the
boards of the European Down Syndrome Association and the International Down Syndrome Federation.

Gillian Bird is Director of Consultancy and Education Services at The Down Syndrome Educational Trust and
has been been supporting children with Down syndrome in mainstream school placements for the past 10 years.
Both Sue Buckley and Gillian Bird regularly provide consultancy and training for schools and LEA’s through
The Down Syndrome Educational Trust.
Stephanie Lorenz has produced an excellent new resource for mainstream schools with pupils with Down syndrome, written to be useful for children of all ages and suitable for secondary as well as primary schools.

Chapter 1 includes a description of the causes of Down syndrome and the effects the syndrome may have on children’s physical development, learning and behaviour.

Chapter 2 explains the history of inclusion to practitioners with models for including pupils in their community schools and details of sources of support and advice for the teacher and other school staff. This leads into a more detailed Chapter 3 focused on models of support, with recommendations for including the child in school life, planning IEP’s, and discussion of types and levels of support for the pupil and the teaching staff.

Chapter 4 will help teachers to understand the children’s and families pre-school experiences. Typical stages of children’s motor skill development, self help skills and language development during the first few years at school are described. Difficulties remembering and sequencing information, due to poor short-term memory function, particularly for information that has been heard rather than seen, are highlighted with practical techniques for aiding and improving memory.

Chapter 5 provides clear, straightforward guidance for differentiating the curriculum, followed by advice for the teacher on how to include the child with Down syndrome in whole class instruction. A summary of effective teaching approaches for presenting information, in addition to repeated or simplified verbal instruction, for example, the use of overheads, flipcharts, objects, modelling by other pupils, written lists and other visual supports is likely to be particularly useful to teachers and assistants. Methods for overcoming recording difficulties that typically hold back the children’s abilities to demonstrate their understanding are included.

Chapter 6 focuses on developing literacy and numeracy. These are vast subjects across the age and ability range the book covers but sufficient information is included to encourage teachers to develop teaching programmes for their individual child with Down syndrome, whatever his or her age, level of skill and understanding. Chapter 7 discusses behaviour management, including causes, prevention and sexual development.

Chapter 8, entitled ‘working with the whole school’, offers reassuring information to parents and teachers, with guidance for the whole school. It offers useful information for parents, LEA’s, teachers, assistants, and mainstream peers, including establishing circles of friends, peer tutoring and student support teams. Chapter 9 is dedicated to working with parents and with outside agencies and includes descriptions of the roles of the speech and language therapist, the learning support teacher and the educational psychologist.

Chapter 10, a vision for the future, comments on the inequalities for children’s access to mainstream education across the country, the need to improve provision and the need for accurate and up-to-date information for all concerned, with implications for training and LEA policy. This book is essential for schools new to mainstreaming children with Down syndrome and will offer encouragement and fresh ideas for teachers and learning support assistants that have been educating children in their community mainstream schools successfully for a number of years.

The Author: Gillian Bird is Director of Consultancy and Education Services at The Down Syndrome Educational Trust and has been supporting children with Down syndrome in mainstream school placements for the past 10 years.
REVIEW: AN EVALUATION OF EDUCATIONAL PLACEMENT FOR CHILDREN WITH DOWN’S SYNDROME IN THE SOUTH DEVON AREA

Gillian Bird

This 90 page document provides detailed information about the abilities, skills, educational attainments, placement and inclusion of children with Down syndrome in south Devon. 13 children with Down syndrome attending their local mainstream primary schools were reviewed to evaluate educational attainments and levels of integration. 9 children with Down syndrome, in the same primary age range, who attend schools for children with learning difficulties (severe and/or moderate) in the same geographical area, were also reviewed to look at educational attainments and levels of learning abilities. A comparison of the achievements of both groups is reviewed and proposals to enhance future inclusion in mainstream schools for this group of pupils are made.

This publication will be of particular interest to educational psychologists, advisers and teachers. It provides them with descriptions for a sample group of children from one area placed in mainstream and special schools, using a range of measures for assessing intellectual ability, reading, communication, academic skills, behaviour, differentiation and integration. As well as useful data, there is information from structured interviews with teaching staff, categorised into areas of success and areas of difficulty, and from interviews with parents. Parents with knowledge of assessment and descriptive attainment terminology will also find the report interesting. For all readers, the report provides information that can be used as a form of ‘benchmarking’. Although the size of the group is small there is little else like it, hence its particular value for psychologists, especially when combined with the assessment and attainment information from Dr Angela Byrne’s longitudinal research on 24 children educated in mainstream schools in Hampshire, West Sussex and the Isle of Wight (University of Portsmouth, 1997, details and related publications available from The Down Syndrome Educational Trust).

The research cannot be taken as a direct comparison between types of school provision - such research would be inappropriate in the light of current legislation as the children should be in mainstream schools, within certain flexible parameters and parental choice. Jane’s information offers supports for this in South Devon at least, in that the majority (but not all) of the children attending special schools were functioning within the lowest ability range for children with Down syndrome, and that 6 out of 7 of these children had significant medical problems. However, the report later states that in the special schools the children with Down syndrome were generally part of the groups of children with most advanced play skills (in the special school population), organising games and activities with other children and playing in a similar way to their counterparts in mainstream. Many of the other children in the playground had very limited play skills, were often isolated in their play, did not interact with other children and were often involved in repetitive, ritualistic behaviour, involving no interactions with other children. The special schools had lower academic expectations with consequences for teaching and lower performance. This is not a new finding, but replicates those from studies conducted in earlier days of mainstreaming, when children’s achievements (with Down syndrome) in different types of school placement were investigated.

Jane Beadman describes the needs of the mainstream schools, their strengths and weaknesses, with a clear summary and detailed, specific recommendations. These cover the areas of resources, equality of opportunity (for children with Down syndrome and for children with similar learning difficulties who do not have Down syndrome), training for staff, support services, teaching resources, monitoring, working with parents and the whole school and managing behaviour. Educational psychologists and others interested should read the report for themselves and recommend it to education authorities as they provide a useful checklist for helping to develop good practice.

‘An evaluation of educational placement for children with Down’s syndrome in the south Devon area” is published by Devon County Council, 1997. It is priced at £6.00 per copy +£1.00 postage and packing. Make cheques payable to Devon County Council and send, with order, to Mrs J Beadman, Educational Psychologist, Psychological Service, New Devon South, Kennicott Lodge, Ashburton Road, Totnes, Devon, TQ9 5JY

The Author: Gillian Bird is Director of Consultancy and Education Services at The Down Syndrome Educational Trust and has been supporting children with Down syndrome in mainstream school placements for the past 10 years.
RESEARCH SUMMARY: THE SOCIAL DEVELOPMENT OF CHILDREN IN SPECIAL SCHOOLS

Denise Dew-Hughes

A research project commissioned by the Teacher Training Agency as part of the Teacher Research Grant Scheme 1996/97

Aim
To investigate the social development of children with severe learning difficulties in special schools as compared with those in mainstream schools.

Summary of findings for this case study
- Children with severe learning difficulties (SLD) on a mainstream site showed an ability to work co-operatively and autonomously for up to 300% longer than their peers in a special school.
- They were able to form groups and pairs spontaneously, distinguishing appropriately between companions for work and recreation.
- They changed to a self-determined activity within an agreed academic range after completing a given task.
- They had a classroom-day over two hours longer than their peers in special schools, whose timetables are constrained by difficulties of movement and physical care.
- A comparable group in a special school were seen as being less mature than their peers and more dependent on adult help.
- They were given little responsibility for their own belongings and equipment, or opportunities to make choices, take risks or determine activities.
- They had a complex, individualised curriculum with frequent changes of activity and groups often determined by the least able in the class.

Analytic framework
The framework for analysis was a set of readily available indicators of social maturity:
- co-operating with a partner or group;
- playing co-operatively during leisure time;
- being aware of different adult roles;
- reducing reliance on the teacher or learning support assistant (LSA);
- looking after belongings and equipment;
- working independently at a set task;
- maintaining appropriate work behaviour to finish a task;
- concentrating and avoiding distractions;
- choosing activities, food and personal care.

For analysis, these indicators were categorised as:
- the social maturity of the children;
- social relationships with the staff;
- attitudes and practices of the staff.

Staff were asked to comment on these indicators and to anticipate educational outcomes.

Classroom observation
Social maturity
Most noticeable were the duration and frequency of children working co-operatively at a set task. Most children on the mainstream (M) site managed several periods of 30 minutes, but in the special (S) school intervention by the teacher was usually required after 10 minutes.

Spontaneous interactions between children were rarer in S. M Children paired or grouped naturally, choosing different peers for recreation and work. There were some highly co-operative interactions.

Appropriate self-employment between tasks was rare on S site. Children usually chose solo play with toys. Three children in S school exhibited uncooperative behaviour, and one on M site.

Opportunities for self-help and independence were almost never offered to the S children, while the M group had to look after their own belongings and tidy work materials. Both groups chose their food, but S children ate lunch in an appointed seat; the M children ate lunch with chosen companions.
“S staff had not considered that close personal relationships could restrict social development”

Playtime on S site presented few opportunities for organised, interactive or exploratory play, and children were not exposed to risk. M school play areas were more amenable to both active games and sociable chatting. Undirected interactions between children were frequent.

Social relations with staff
On M site there was a clear teacher-pupil relationship, with formal use of titles. The LSA was less didactic but still not maternal. Mutual respect was noticeable and children’s permission was requested before inserting their names into the story-time reading. S children called everyone except the headteacher by their first name.

Almost all the S children had physical contact with the staff during observations, for comfort, physical care, help with dressing, hand-holding or pats for praise. No M child had contact with the adults, although the close physical proximity was the same.

Practices and attitudes
The S school spent time on transport, physical care regimes, therapies and slower-moving members of the group, which reduced the classroom day to three hours and 20 minutes. The M school had five hours and 25 minutes of available class time.

Much of this difference was accounted for by the M children’s taking personal responsibility for moving themselves into, about and from the school - unaccompanied and with their own equipment.

Teaching activities were frequently interrupted in S school by changes to individual timetables, medical visits to the classroom, withdrawals for therapy and visitors. The M school established a practice of non-interruption during teaching time which delivered a clear message to the children on the priority of teaching and learning.

The M classroom language was more sophisticated. S laid much more emphasis on spoken praise; language was simple and direct, allowing for comprehension by the less fluent members of the class, and was often accompanied by signing. M language was more challenging; the following terms were used freely:

Maths take away, subtract, higher than, difference between, minus, total;
Science vitamins, vibrations, flexible;
D&T recite, recall, consider.

Staff impressions
Staff showed they were aware of the differences site placement made to education, particularly to the sensitive issue of outcomes at later Key stages.

Social maturity
All staff believed that children in special schools:
- were “quite a lot less” socially mature than mainstream peers;
- became more mature when included in mainstream schools, responding “quite dramatically to the behaviour of other children”;
- had a flexible curriculum, allowing time for extra interpersonal and social skills teaching.

Teachers initially said social immaturity was located in the disability. They then explained that it was probably caused by a lack of early social interaction and a more protected home situation.

“It can be both... they’re not given the same social interactive opportunities.”

“Parents probably expect less of children in a social sense... they don’t interact as much at pre-school.”

All agreed that adult expectations were a contributing factor, as were the atmosphere and structure of the school. Several declared that they made unconscious assumptions about social maturity which delayed development. All recommended encouraging children to take responsibility for their own actions as a move towards maturity.

“Treat them age-related, and have expectations of their social and academic achievement, because I think we’re aiming too low.”

Attitudes and practices
All staff interviewed agreed that special schools:
- had a family atmosphere;
- combined the roles of teacher and parent, resulting in some confusion for the child;
- treated pupils as if they were less mature and capable than mainstream peers;
treated children closer to their academic than chronological age.
offered few opportunities for independence, self-responsibility and risk-taking;
made fewer demands on parents;
had attitudes and practices which affected outcomes, as they could be the deciding factor for senior school and post-16 placement.

Reasons for this were given as:
- the lower social maturity of pupils on entry;
- the lack of peer-group role models;
- the influence of “Nursery Nurses” practice;
calling staff by their first names;
staff being unaware of the children’s true capabilities or potential;
over-protectiveness in social situations;
convenience - it is quicker to help than to wait for children to help themselves;
the constraints of children with more severe difficulties in the same group.

S Staff considered the family atmosphere a bonus - a strong ethos of personal care appealed to parents. Unlike M staff, they did not consider it might cause delay in social maturity and independence. They assumed that social and academic levels were related. M teachers believed all children wished and had the right to behave like their peers; staff would facilitate this if a child were experiencing difficulties. Having peer groups for constant comparison raised the priority of social development as an educational outcome. They saw the children’s social capabilities in general as outstripping their academic ability.

Social relationships

Children in M school:
- had no role confusion; they saw staff as professionals, not family, and used titles;
- were cuddled if distressed, but “talking about the problem and helping sort it out” was usual.

On the S site:
- children were cuddled for reasons relating to social needs - “If they want it there must be a reason for it” and to “feel that someone really cares about them”;
- some were seen as needing “to have a close relationship with a teacher”;
- children were touched all the time, although “part of the staff training should be about how we handle children... is it always necessary?”;
- staff: “We’re like an extended family.”

S staff had not considered that close personal relationships could restrict social development; M staff were sensitive to establishing a professional relationship and valued their role as teachers.

“Whose needs are you satisfying?”

“Would I like someone to do this to my own child... or even to me... Sometimes in special schools, [they] do things to children that they wouldn’t like done to themselves or to their own children.”

“Maybe they need [cuddles] in mainstream and don’t get it because people have different perceptions of what touching a child is.”

Outcomes

Teachers who had given educational outcomes full consideration were adamant of the importance of social maturity in the following areas:
- Choices of senior school or access to employment and FE. It has “quite a lot” of influence on choice of secondary school and ability to cope.
- Children who transferred successfully to M were “socially mature although they may have been slightly less academically able.” “They can cope socially and ask for help at an academic level.”
- Socially mature young people were “more likely to find jobs” even if “academically behind”, “Over the years... it has always (been) a real worry for us.” “We’ve never got this right.”

Teachers also commented:
- Professional concerns invited them to treat children closer to their academic ability.
- Close physical care activities for older children maintains attitudes “we’ve normally left behind with infants. We still carry the idea of them as babies.”
- Different adult roles became blurred by extended care regimes, delaying secondary socialisation where distinctions between home and school fall into place.
- Children with SLD, included in mainstream schools at whatever age, change their social behaviour. “There’s no other factor: They came on by leaps and bounds almost the minute they walked through the door of M.”
“They’ve got more choices.”

“If we haven’t encouraged them from the earliest opportunity to take responsibility... to learn the hard way, then I don’t think we’ve done them any good service.”

About the project
This study looked at Key Stage 2 children with SLD in two Oxfordshire schools with a long-standing integration link. Staff were invited to comment on how a range of observed classroom practices might contribute to the development of social maturity and affect education at Key Stages 3 and 4.

The sample
Six children were selected from a larger class group on each site. They were:
- all on the role of the special school;
- supported by its staff;
- matched for age, gender, ability, levels of learning difficulties and sensory impairment.

Methods
Structured, timed observations took place during lessons and lunch and play periods. Field notes were collected to set the data in context. Teachers, LSAs and headteachers on each site were interviewed.

Further reading
Tomlinson, S., The Social Construct of the ESN(M) Child, Special Education.

The Author:
Denise Dew-Hughes is a doctoral student at Oxford Brookes University, School of Education, Wheatley, Oxfordshire.
THE THYROID AND DOWN SYNDROME

Len Leshin

Normal Function
The thyroid gland sits at the base of the front of the neck and makes thyroid hormone from iodide, thyroglobulin and tyrosine. This results in the production of thyroxine (T4), which is a “prohormone” (it’s inactive but just one step away from becoming a real hormone), and the actual thyroid hormone, T3. Both T3 and T4 are secreted by the thyroid into the blood stream. T4 is converted to T3 by the thyroid, kidneys and liver. It is the T3 that’s so important for normal growth and development of infants and children, and normal metabolism of all ages.

So where does the Growth Hormone fit in? The GH, synthesized in the pituitary, appears to be the mediator between the thyroid hormone and the individual tissues. You can also include somatomedins, a group of proteins under the control of GH, as mediators between T3 and body tissues.

Thyroid function is controlled by Thyroid Stimulating Hormone (TSH), a hormone made in the hypothalamus and pituitary. If the brain detects that T3 levels are low, more TSH is made which tells the thyroid to make more T4 and T3. If levels are too high, the brain slows down making TSH.

Hypothyroidism
This is the state of not making enough thyroid hormone, and is the most common thyroid problem associated with DS. This can be present at birth (congenital) or may occur at any age (acquired). Every state in the US and many other countries routinely screen all newborns for hypothyroidism. In newborns and infants with DS, the most common reason for hypothyroidism is that the thyroid did not form correctly in the foetus. In acquired hypothyroidism, the most common reasons in toddlers and older children with DS is (1) autoimmunity (where the body makes antibodies against its own thyroid) and (2) thyroiditis (where the thyroid tissue becomes replaced with white blood cells and fibrous tissue).

The symptoms of low thyroid hormone are difficult to pick up, especially in infants. They include decreased growth, decreased development, an enlarged tongue, decreased muscle tone, dry skin and constipation - all of which might be expected in an infant with DS. So, it is recommended that all infants with DS be checked at birth, 6 months of age, 1 year of age, and once a year thereafter for thyroid function, regardless of their growth.

Screening for thyroid function in infants usually involves only a TSH level; if the TSH is elevated, then the T4 will be checked. In older infants and children, a T4 and TSH is recommended, and some doctors include a measurement of T3 as well. Typically in hypothyroidism, the T4 will be low and the TSH will be elevated (as the brain is trying to tell the thyroid to get going).

Treatment is the replacement of thyroid hormone with synthetic thyroxine. The dose is managed by watching sequential blood tests to see how the thyroid responds. Treatment is usually needed for life. It should be noted that if the parents have become used to a calm, sedate child who is hypothyroid, the replacement will look as if the child has suddenly become hyperactive, when in fact the child is returning to his or her natural (ahem) state.

Hyperthyroidism
While not as common as hypothyroidism, this does occur. The usual cause is, again, autoimmune disease, but in this disease, the immune system cranks up the thyroid. (This is called Graves Disease.) Symptoms include rapid heart rate, nervousness, sweating, decreased attention span, flushed skin, always feeling hot and loss of hair. Often these children will have a noticeably enlarged thyroid. Testing here includes TSH (low), T3 (elevated) and T4 (elevated).
Treatment is aimed at blocking the action of the thyroid hormone on body tissues. Antithyroid drugs are often the first course of action. However, almost all of these drugs can cause significant side effects. Surgery is sometimes used to remove part of the thyroid, and then the child or adult is begun on thyroid replacement if needed. In adults, the most common treatment is destroying the thyroid by drinking radioactive iodide, and the patient then takes replacement thyroid hormone. However, radioactive iodide is not often used in children because of the risk of thyroid carcinoma, especially in children with DS, where leukemia is more common.

**Thyroid, DS and Controversy**
Before the genetic reason of Down Syndrome was known, many people thought that DS was caused by hypothyroidism. In 1896, 20 years after Langdon Down first described “mongoloids” (ugh), Telford Smith reported that giving thyroid therapy improved physical and mental conditions of these children. For decades later, researchers argued whether all children with DS had hypothyroidism or not. With improved laboratory tests, the true picture of most children having normal thyroids emerged.

There have been many claims for giving all children with DS thyroid hormone replacement, regardless of their blood tests. Dr. Turkel included thyroid hormone in his “U” series, Harrell’s paper in 1981 on vitamin and mineral replacement included thyroid hormone therapy, and one researcher, Clemens Benda, advocated giving all children with DS a mixture of thyroid and pituitary gland. However, there is no known benefit from giving thyroid hormone to children with DS who have normal thyroid function, and it could be detrimental.

Some researchers have claimed that there is a “low-borderline” thyroid state, and the tests could be normal as the body is able to partially compensate. However, research shows that giving thyroid replacement to individuals with DS and low-normal thyroid tests had no cognitive improvement.

**The Author:**
Len Leshin is a paediatrician in Corpus Christi, Texas, and father of Avi (a 4 year-old with Down syndrome) and is a member of the American Down Syndrome Medical Interest Group. His website, “Down syndrome Health Issues” can be found at http://www.davlin.net/users/lleshin/ and contains a wealth of useful information on a range of health matters.
Dear Professor Buckley

I am writing with concern to the article written in your November magazine, namely “Our View on Mega Vitamin Therapies”. Since our son Alexander was born 15 months ago with Down’s Syndrome, we have come to greatly admire the work you have done and continue to do in helping children like mine obtain the most of their potential from an educational standpoint.

The most important things for any parent for their child is their health and happiness. With a child with Down’s Syndrome, we have the added wish that they should be able to support themselves when we are no longer around for them. As a new mum, I can look relatively objectively to the work that has been going on in helping children like our own. I was quite surprised and extremely disappointed to see the lack of work that has been going into researching our children’s health. Whenever it is asked “why is my child more prone to chest infections/heart problems/leukaemia etc”, it is because they have this extra chromosome. But when you ask why, nobody has any answers.

However, the research surrounding ‘TNI’ has at least gone some way into looking at the reasons why our children suffer more. It is proposed that Down’s Syndrome is not a static genetic disorder, but a progressive degenerative disease. Certainly evidence produced to date would concur with that hypothesis.

If your research had been done correctly you would have found that ‘TNI’ is not a megavitamin therapy and it was only developed in the 1990s. You have “sweepingly” referenced it in your article, you have not got into the theory behind it and therefore not provided both sides of the story. You have just mentioned Piracetam in passing, though it is not a vitamin, it is a drug. This is totally unclear in your article, and this could be quite misleading.

If you had listened to the evidence produced by Dr David Swenson at the ‘TNI’ conference held in London recently, you would have heard about the work that is going on in identifying the genes on chromosome 21. The theory put forward is that the extra genes are causing oxidative stress in the body, so causing cell damage and ill-health. It has certainly been proved that our children are subjected to more oxidative stress than average. This in turn is damaging cells in their body including brain cells which in turn, it is theorised, could be one of the reasons why our children are more prone to Alzheimer’s Disease when they reach their mid-thirties.

‘TNI’ is not the megavitamin theory, though it is believed by giving our children antioxidants (including vitamins) it can help relieve this oxidative stress and so lessen cell damage and improve their health in general. It was developed in the early 1990s by a lady called Dixie Lawrence Tafoya after she adopted a child with Down’s Syndrome. Nutrichem used to work with her and now she has joined forces...
with a company producing Nutrivene. Neither company to my knowledge has pushed their products at all in the UK to date.

A lot of the references you use in your article are very old, and much before the time of 'TNI' as it exists today.

Again, if you had attended the conference you would have heard from Dr Leichtmann, a paediatrician in the US who has done controlled studies on children/adults with DS taking the 'TNI' formula as against those just taking multivitamins. The results showed that those with 'TNI' had far less infections, and their development was several months ahead of those not in similar social circumstances. As an experienced paediatrician specialising in DS, he is certain that 'TNI' has a positive effect. He is currently undertaking a double blind study but I certainly would not be prepared to submit Alexander to it!

Like a growing number of other parents in the UK and over 6,000 in the US, I can testify that the 'TNI' therapy has been successful for my son. Until I started Alexander on the 'TNI' therapy (without Piracetam), he was continuously ill, he had very blotchy bad skin, and his development was very slow indeed. Not a week went past without my getting a call from nursery to say he was ill yet again.

In August last year, we decided to try the therapy to see how he got on. We asked our GP and paediatrician before we did so, and both were reluctant to prescribe Piracetam, so we used the formula without. We haven't looked back since. His skin is clear, his health is much better (one day off nursery since September), and his general development has been on an upward trend.

I am sorry I cannot agree with your assertion that I was biased in favour especially as I was paying for it. I would quite welcome the excuse not to pay for it. It costs a lot of money, and I would rather not have to pay. But my child's health and development is more important and I have evidence for myself that it has benefited my son.

We are traditionally very conservative in the UK, and we will not try something until it has been around for years. I have not got time to waste on my son. I want to be sure I am doing everything I can to lessen the cell damage in his body.

Nobody is saying “stop giving your child Portage/educational input, because 'TNI' will cure them”. No parent would be silly enough to do so. But they can exist side by side. 'TNI' can improve their health so that they are able to develop more from the greater educational opportunities they are given. There is no way giving 'TNI' lessens the importance of the work you have done and continue to do.

Nobody doubts at all your assertion that social, educational and family environment have significant development on intelligence. But also most important is that your child is healthy to be able to take a lot of your teachings on board!

I had heard about a programme on television and contacted your Ben Sacks back in April to try and find out about it. Without being asked, he gave me his opinion on vitamin therapies and told me they were a waste of time. I lost several precious months as a result of conversations with both him and Sarah of the DSA. Were you not representing my child in other ways, I would have been tempted to sue the Centre! It wasn't until reading Chris Wills' article in the DSA newsletter that I was able to find out more.

It is very sad that you have used your newsletter as a forum for a subject that you clearly know very little about. What you have done is very dangerous, as you could be depriving some children whose parents were on the verge of giving them help, who take your word as gospel!

I hope you can publish this letter in your newsletter to let some parents know that there is a very positive side to 'TNI'. In the meantime, I implore you to refer on any parents who enquire about 'TNI' to the Down's Syndrome Research Foundation who specialise in researching the physical side of Down's Syndrome and seem to know an awful lot more about it!

Yours sincerely,
Gillian Barrett
RESPONSE


Dear Mrs Barrett,

Thank-you for your letter regarding our article on megavitamins, published in DownsEd News issue 1.4 and for your kind comments regarding our educational work. Although your letter was addressed to me, this reply has been written by Professor Sacks and myself, as was the article you question.

We would like to respond to some of the particular concerns that you express and do so under topic headings.

Health and prevention of infection

We would share your view that it is most important to work to ensure that our children are healthy, happy and as independent as possible in adult life and our work has been dedicated to this end.

You state that you were surprised and disappointed to see the lack of research that has been conducted into our children's health problems. We would not agree with the accuracy of this statement and would point out that over the past twenty years, considerable clinical research by paediatricians has led to the documentation of the increased risk of certain illnesses (and the reduced risk of others) resulting in Health Care Checklists (1) and many books of guidance for paediatricians, general practitioners and parents (2,3,4). In addition many geneticists and biochemists in laboratories all over the world have been and still are trying to understand the mechanisms that may be altered by the presence of the extra genes on chromosome 21. Advances in the methods available have been so great in the last ten years that the possibility of being able to solve some of the puzzles and find at least some effective and safe pharmacological interventions in the next ten years is now very real.

Increased life expectancy

The efforts of the medical profession and the scientific community over the past 50 years can already be seen in the increase in health and life expectancy for people with Down syndrome. Before World War II, of those people with Down syndrome who survived infancy, a majority would have died from infectious disease during adolescence. Unfortunately antibiotics are not effective in treating viruses, for which no effective treatment has yet been identified. At present there is no known intervention that will substantially effect the incidence of infective diseases in people, including those with Down syndrome, who are not otherwise ill or have a normal adequate mixed diet. Forty percent of children with Down syndrome did not survive infancy because of congenital heart disease. Currently, this figure has been reduced by more than half by developments in modern paediatric surgery.

The average life expectancy of people with Down syndrome has increased from 12 years in 1947, when few lived to adult life and only 6% lived to 30 years (5). Now the estimates are 44% will reach their 50’s and 14% their 60’s (6). At the present time, the fact that in the developed countries the majority of children born with Down syndrome survive and are likely to live beyond fifty years of age is entirely due to the progress in health care available to them.

‘TNI’

Targeted nutritional intervention is not a new concept and it is based on the mostly the same theories as previous mega-vitamin therapies. It is just a change of name and a variation of some of the contents. All the previous mega or multi vitamin, mineral and amino acid supplements from the time of Turkel onwards have claimed to be specially formulated to meet the particular needs of people with Down syndrome. This has been the reason for not recommending the proprietary brands available in the local pharmacy. We understand that, by calling a product a ‘nutritional intervention’ rather than a ‘therapy’ of any kind, the proponents in the USA avoid the risk of prosecution if it proves harmful.

We are not aware of any published research on the current ‘TNI’ formulas which substantiate any of the benefits claimed by their proponents, let alone any that has been published in a reputable, peer reviewed scientific journal. There are many doctors and scientists all over the world working on the possibilities of treatments and regularly discussing our current state of knowledge. A significant number of them are also parents of children with Down syndrome so they have even more reason to seek effective treatments.

We are aware of the hypotheses behind some of the recommended supplements. Some may be on the right lines and lead to effective therapies some may not. The fact that we know of a biochemical or metabolic abnormality at the cellular level does not mean we yet understand the cause nor how to return it to normal. If a cell seems to have a lower than normal level of a particular substance,
there is no reason to assume that simply taking more of it in the diet will lead to a return to normal levels in the cells. If a metabolic process is abnormal it may well go on being abnormal regardless of the quantity of chemical substances available to it. We discuss below the kinds of issues raised in the Wills article and on ‘TNI’ sites on the Internet such as that of Drs Leichtmann and Swenson. I am sorry to say that, in our opinion, the information on both these sites is not of a standard that would be accepted by most in the scientific community. Both contain many assertions of benefit for which they do not cite any evidence. It is accepted practice that if you make a statement such as ‘this will increase growth’ you reference it to an article or articles containing research based evidence to support that statement.

**Progressive degenerative disease**
We feel that the suggestion that Down syndrome is a ‘progressive degenerative disease’ is misleading and designed to alarm parents unnecessarily and we cannot agree with your statement that evidence supports this as an accurate model for the syndrome. The accepted use of this phrase is to describe conditions in which there is progressive loss of function usually leading to premature death.

The majority of children with Down syndrome enjoy life and make steady progress in all areas of their development, from birth to adult life. A substantial proportion (not exactly known) now live into their fifties without clinical evidence of Alzheimer disease or loss of skills. This suggests that, although documented biochemical abnormalities do occur in Down syndrome, they do not cause a progressive degenerative disease. Some of these biochemical abnormalities may turn out to be the reasons why the rate of progress for most areas of development is slower than is typical. However, we are not yet able to be precise about which of the described abnormalities in biochemical function, if any, lead to particular delays in development.

**Piracetam**
We are aware that Piracetam is a drug and that possibly its main action is to activate AMDA/kainate receptors in cells, changing the calcium ion balance within the cell. The effects of this action are widespread and not fully understood but it is known that excessive stimulation of glutamate receptors may be toxic. It is important to point out that Piracetam has not been approved in either the UK or USA for use with children with Down syndrome. It is therefore not surprising that your GP and paediatrician were not willing to prescribe it for Alexander.

**Oxidative damage**
The suggestion that people with Down syndrome show evidence of lipoperoxidation is at least thirty years old. Unfortunately, despite continuous research efforts since that time, the mechanisms for this are still not fully understood. It is known that one of the 3 types of SOD is over expressed in people with Down syndrome but there is no direct evidence that this is responsible for any of the reported oxidative stress. Oxidative stress has been and is the subject of a great deal of research. It occurs in the cells of every human and animal organism (7). It is known to be influenced by age and amount of daily calorie intake. Whether dietary use of ‘antioxidants’, such as vitamin C, selenium and other substances, has any effect on oxidative stress still remains to be proved.

**Alzheimer disease**
The causation of Alzheimer disease is also unknown. As recently as January 1998 two articles were published, one in Nature and one in Science (8,9), reporting completely new findings about this puzzling condition. At present it is likely that more research groups are working on Alzheimer disease than on any other disorder and many of them are including patients with Down syndrome in their studies. I should point out that the early claims that everyone with Down syndrome will get Alzheimer disease were wrong.

Until recently it was assumed that the early occurrence of beta amyloid plaques in the brains of people with Down syndrome led to the development of Alzheimer disease in everyone with the syndrome. However, the results of a number of studies over the last decade have consistently failed to detect dementia in the majority of adults with Down syndrome over 30 years old, and there is no evidence of increased risk for decline in adaptive functioning before 50 years of age. It is possible that not all plaques have the same significance. Some may be more benign than others. It is probable that the plaques seen in people with Down syndrome are not associated with dementia in the way they appear to be in other people (10). A survey in the USA found that Alzheimer disease was more prevalent in older adults with other types of learning disabilities than in those with Down syndrome. These findings are reassuring and make clear that the majority of adults with Down syndrome can expect to enjoy healthy lives into their fifties and sixties (11).
London conference, October 1997

With reference to the conference on ‘TNI’ held in London recently, both I and Professor Sacks would have attended in the hope of hearing some new and scientifically acceptable evidence, but we had accepted an invitation to lead a residential conference for parents of teenagers in Holland that weekend some six months before we received an invitation to the ‘TNI’ meeting. We would be very pleased to receive copies of the papers presented or the video that I believe was made. We have already asked the organisers for this information but have not yet received it. We would also be interested to see the published results of any of Dr Leichtmann’s current research.

Scientific v anecdotal evidence

I am happy to know that you are convinced that Alexander is healthier on the formula. Unfortunately this is known as anecdotal evidence does not, by itself, help the debate. How are you measuring change? Can you be sure that his development is going faster than it would have without ‘TNI’? Do you know that he is doing better than would he on a healthy balanced diet or with the addition of ordinary children’s dietary supplements? Even if he is doing better, do you know which of the ingredients may be having a positive effect? Any benefits may be due to only one or two substances. Can you be sure that other substances in the formula are not harmful in the short, medium or long-term? These are all the questions we need answers to before we could support the use of such treatments. They can only be reliably answered by controlled double-blind studies of adequate numbers of children, as we pointed out in our article. If any of the ingredients do turn out to be beneficial, and some may be proven to be so in the light of proper clinical trials, it is likely that others may be useless but harmless and that some may be harmful.

This is why every large national association for people with Down syndrome is not supporting the use of ‘TNI’ at present and no Scientific Committee at the national or international level is recommending their use either. It’s not that we are simply conservative in the UK, it is because the vast majority of doctors and scientists world-wide do not consider the evidence of either efficacy or safety to be available.

Unfortunately, the history of medicine provides countless examples of treatments that were promoted as miracle cures and received testimonials of efficacy from many that tried them but turned out to be ineffective or toxic when subject to scientific evaluation.

Referring parents for expert advice

On your last point, I am afraid that I could not refer parents to the Down’s Syndrome Research Foundation, without knowing more about their scientific advisors in the UK. It is my understanding that it is run at present by well meaning parents who do not have enough medical or scientific knowledge to be able to understand or review the theories or the evidence, let alone suggest treatments.

Professional standards of practice

We, personally, do not have any prejudices or hidden agendas. As responsible professionals, it is our duty to examine and evaluate the evidence available to support claims of effectiveness as objectively as possible in order to provide the best possible advice. If we know that there is published evidence that a therapy works and is safe, then we would recommend it. If we believe that there is the possibility that a newly devised treatment might work because it is based on a credible hypothesis, then we would encourage a proper evaluation study to test the treatment.

In our own work at The Sarah Duffen Centre we have been doing exactly this with our research programme for the past eighteen years. At the start, many of our ideas were considered to be wrong by a majority of our colleagues. We have designed studies to test our hypotheses and, by producing evidence to support them, have influenced change in educational practice.

Until recently, the values and principles that guide our practice at The Sarah Duffen Centre were set out in our literature a copy of which I enclose. They include the statement ‘all interventions should be scientifically evaluated and clear evidence of outcomes, advantages and disadvantages provided to parents’. We hope that this letter is helpful in explaining more fully our position and the reasons for it. We realise that these are complex issues and if you would like to discuss them further, why not consider coming to The Sarah Duffen Centre where we would be pleased to meet with you?

With kind regards
Ben Sacks, Sue Buckley
References

Recommended web references:

The Authors:
Professor Ben Sacks is Consultant Developmental Psychiatrist and Medical Advisor at The Down Syndrome Educational Trust with more than 40 years clinical experience. He has recently retired from the Chair in Developmental Psychiatry at Charing Cross and Westminster Medical School, University of London, UK.

Sue Buckley is Professor of Developmental Disability at the Department of Psychology at the University of Portsmouth, UK. She is also Director of The Centre for Disability Studies at The University of Portsmouth and Director of Research and Information Services and at The Down Syndrome Educational Trust. She also serves as a Non-Executive Director of the Portsmouth and South East Hampshire District Health Authority and on the boards of the European Down Syndrome Association and the International Down Syndrome Federation.
REVIEW: INFORMATION PACK ABOUT HEART PROBLEMS FROM THE DOWN’S HEART GROUP

Ben Sacks

The incidence of congenital cardiac disorders in people with Down syndrome is rather high and the fraction of those that are amenable to cardiac surgery and other forms of treatment is now very much higher than it used to be. The relatively recent changes in attitude towards providing these treatments has resulted in increasing numbers of children with Down syndrome undergoing cardiac surgery.

The Down’s Heart Group is an organisation which was established to help the parents of children with Down syndrome and a heart condition. Their aim is to supply information about the heart conditions found in people with Down syndrome in a straightforward and easily understood form.

The Group has published an Information Pack containing fifteen A5 sized cards each covering a separate topic and a video tape. The cards describe virtually all of the cardiovascular conditions which occur in people with Down syndrome as well as topics such as The Heart Team, Medical Terminology, drugs used in cardiology and cardiac catheterisation.

The topics are covered in a straightforward, factual and easily understood style while maintaining a supportive tone. Concerned parents will be able to find information about almost all the general questions they are likely to ask in this pack. The companion videotape graphically illustrates some of the same topics as well as demonstrating some of the concerns that parents expressed during group discussions. These materials are highly recommended.

Review by Professor Ben Sacks, Consultant Developmental Psychiatrist and Medical Advisor to The Down Syndrome Educational Trust.

The Information Pack is available from the Down's Heart Group, National Office, 17 Cantilupe Close, Eaton Bray, Dunstable, Bedfordshire, LU6 2EA.
BILINGUAL CHILDREN WITH DOWN SYNDROME

A letter
Our seven year old boy with DS is in primary one of our local school and is being educated through a second language - Gaelic. Our home language is English. I would be interested to hear about anyone with DS that is in a similar situation (i.e. being educated in a language other than that of the home) for a university dissertation that I am preparing on this subject as well as for our own benefit.

Many thanks
John Charity.

Comments
This letter requesting information on children with Down syndrome learning a second language has prompted me to summarise my experience and the advice that I give in the following notes. I would also welcome any information that readers have either by post or to the Speech and Language 'bulletin board' (newsgroup) at news://news.downsnet.org/downsnet.public.topics.speech-language

I am frequently asked for my advice on bilingualism by parents and professionals and I give the following response:

1. There is no research literature or systematic study of bilingualism in people with Down syndrome to inform decisions on this issue to my knowledge.

2. In my frequent travels around the world over the past fifteen years, I have met a significant number of children and adults with Down syndrome who are competently bilingual. Some are able to speak three languages and many are able to read, write and speak to a functionally useful level in two languages. The levels of achievement vary between individuals, but my experience is sufficient to enable me to reject the view that a bilingual situation at home or at school is necessarily going to be too difficult for a child with Down syndrome.

3. The bilingual children and adults with Down syndrome that I have met have had a variety of experiences.
   a) Some have been in bilingual homes and exposed to two languages from birth. They have learned the two languages at the same time, though usually have more productive vocabulary in the one most frequently used in the family, while showing good comprehension of the other. Where signing is being used with speech, the sign seem to help the child to learn the word for something in both languages - it acts as a 'bridge'.
   b) Some have learned a second language outside the home as a result of going to school in a community that uses a different language from the child’s first language. The first bilingual children that I met had both had this experience. One young lady whose first language was English, from an English speaking family, had learned Welsh in the village school from five years of age. When I met her at ten years old, she could read and write equally well, at a functional level, in English and in Welsh. Her parents informed me that she was going to pursue her secondary schooling in the Welsh language school as that was where her friends were going. The second bilingual child with Down syndrome that I met had moved to France with her family at ten years of age, from the UK. She had learned French at this point, taught by her mother, and had continued her education in French, able to read and write in French as a teenager. I recently met a young Japanese woman with Down syndrome in her early twenties who could read and speak English, although neither of her parents could do so to the same level of competence. I also know twins with Down syndrome whose parents are both profoundly deaf. These girls are bilingual in British Sign Language and in English. They can switch from one to the other when they are in the company of both deaf and hearing people at the same time. The progress of these twins has been documented and they have found grammar difficult in both languages. Grammar, of course, is well known to be more difficult for children with Down syndrome to master than vocabulary.
Advice

On the basis of my experience, I advise any bilingual family to treat a baby with Down syndrome like any other child in their family i.e to expose them to both languages naturally, for the following reasons.

• I think that it is important that family life continues as normally as possible for all family members and is distorted as little as possible by the arrival of a baby with Down syndrome, for the well-being of everyone in the longterm.

• If there other children then parents will want them to have the advantage of being bi-lingual.

• The extended family are likely to speak different languages and the child with Down syndrome will be part of a bilingual world so it is not possible or desirable to suggest he or she is only brought up in one language.

• It is rather cruel in my view to tell a parent or grandparent that they cannot communicate with a baby in their first language.

However, I suggest that specific language teaching activities, including reading activities, focus on teaching the child the language that he or she will use in school.

I also emphasise the importance of a good language learning environment e.g one in which the baby is talked to as much as possible, in a child centred way i.e is talked to about what he or she is doing or interested in, by all family members as they spend time with the child.

Caution - I see young children who are doing well in bilingual situations, developing competence in both languages and doing as well in their first language as most children with Down syndrome. I also sometimes see children who have very little first or second language if they are not being talked to at home, and this can be a particular risk if the child is cared for by a nanny who speaks little of the family’s first language. What matters is the quality and quantity of the language experience of the child.

As I have made clear, these are personal views based on my practical experience. I would welcome comment and experiences from others.

Sue Buckley
Introduction
Few people can not have heard about the Internet. The amount of news and hype surrounding the “Information Super-Highway” has grown dramatically over the past couple of years. Millions of people now use the Internet daily for communication, information and entertainment, and use is growing exponentially. It is estimated that around 55 million people currently have access to the internet and that this will increase to around 550 million over the next three years (Source: International Data Corporation/The Economist).

This article is the first of a two part series on the Internet. This instalment aims to explain a little about the Internet, and the practicalities of getting connected. The sequel will focus what do with the Internet once connected, how to find the information that you are looking for, and will offer a number of pointers to sites with interesting information about Down syndrome, health, disabilities in general, research and more.

About the internet
What is the Internet?
Essentially, the Internet is a large network. In principle, it is similar to any local area network (LAN), as might be found in many offices or academic departments, where computers are linked together in order to be able to share data. The key difference is scale - the Internet includes thousands of smaller networks that are inter-connected via telecommunications systems.

The Internet began around 20 years ago as ARPA net (a U.S. Defence Department research network) and other radio and satellite networks. Since then, it has developed to include numerous networks around the world. These include the National Science Foundation Network (NSFNET), the Australian Academic and Research Network (AARNet), the NASA Science Internet (NSI), the Swiss Academic and Research Network (SWITCH), and about 10,000 other commercial and research networks.

The Internet currently extends to over 50 countries and continues to expand rapidly. Eastern European countries are rapidly becoming connected and many developing countries are investing in connections as a means to improving education. Western Europe is comparatively well connected, and accounts for around 25% of all hosts connected to the Internet. (1)

What is the World-wide Web?
Defining the “World-wide Web” is not an easy task. In a sense, it is no more than a huge collection of documents stored on computers around the world in a standard format that makes them easily accessible to any computer with the necessary software to read them. What draws these documents together into a “web” is the method of navigating them through “hyperlinks”. “Hyperlinks” are a lot like references in a book or journal article, except that instead of having to visit a library to find the referenced document, they take you straight to it (Figure 1). “Hyperlinks”, together with text, graphics, video and sound, make up “Hypertext”, the format of the “web”:

“Hypertext” is text with links. Hypertext is not a new idea: in fact, when you read a book there are links between references, footnotes, and between the table of contents or index and the text. If you include bibliographies which refer to other books and papers, text is in fact already full of references. With hypertext, the computer makes following such references as easy as turning the page. This means that the reader can escape from the sequential organisation of the pages to pursue a thread of his or her own. This makes hypertext an incredibly powerful tool for learning. Hypertext authors design their material to make it open...
to active exploration and in doing so communicate their information and ideas more effectively." (Berners-Lee, 1991-2)

The World Wide Web was invented in late 1990 by Tim Berners-Lee. Tim Berners-Lee, a graduate of Oxford University, was a consultant in hardware and software system design, real-time communications graphics and text processing, and a principal engineer with Plessey Telecommunications in Poole. In 1989, he commenced consulting for CERN, the European Particle Physics Laboratory in Geneva, Switzerland. The Web was originally developed for CERN to allow information sharing among teams of scientists who were spread around the globe. During 1990, Tim Berners-Lee wrote the first WWW client along with most of the communications software.

Since then, software companies have assumed the role of browser software development. The continuing development of the standards that bind the web together has been assumed by an organisation called W3C that was founded in 1994. W3C is an international consortium, jointly hosted by the Massachusetts Institute of Technology Laboratory for Computer Science [MIT/LCS] in the United States; the Institut National de Recherche en Informatique et en Automatique [INRIA] in Europe; and the Keio University Shonan Fujisawa Campus in Asia. Initially, the W3C was established in collaboration with CERN with support from DARPA and the European Commission.

What other facilities are available on the Internet?
Other facilities on the Internet, besides the World Wide Web, include electronic mail (e-mail), and newsgroups. (2) Electronic mail allows you to send messages, documents, pictures and even video and audio clips to anyone who also has access to the Internet. Messages and documents can be delivered to the other side of the world in a matter of minutes, for simply the costs of being connected. A considerable amount of The Down Syndrome Educational Trust’s correspondence is now conducted by e-mail, saving paper, fax, telephone and postage costs.

Newsgroups are public discussion forums, where anyone can post or read messages. Newsgroups tend to be divided by subject or interest. There are currently around 30,000 newsgroups with an estimated 20,000,000 readers at 80,000 sites world-wide.

Getting connected
A detailed discussion of computer hardware and software is outside the scope of this article, and what follows is only a summary of the key factors relating to Internet access. If you are considering purchasing a computer for home use, other factors will be important beyond simply Internet access.

If you would like further information, please feel free to contact us, or contact your local computer dealer. Some contact information is available at the end of this article.
Getting started on the Internet

What is required for access?
Any computer that can run a “browser” application, access to a telephone line, a modem and an Internet Service Provider are required. Any mainstream “IBM-compatible” personal computer with a “486”, “Pentium”, “Pentium Pro” or “Pentium II” processor (or compatible) will be capable of running the software necessary for Internet access. Also, Apple Macintosh PC’s and Acorn (32-bit) computers can access the Internet.

Any ordinary telephone line is adequate for connecting to the Internet. It need not be a dedicated line. Other options include ISDN lines, though these are relatively expensive to install and only worth it if you intend to spend a lot of time on-line. Generally, if the modem is fast, then you spend less time on-line (keeping telephone bills lower) and gain a smoother browsing experience. However, modems claiming speeds of above 33.6 kilobits per second are dependent on Internet Service Providers with special equipment, and rely on data compression techniques that will not always achieve these rates.

What is required for browsing the web?
In order to read Web pages, a browser is required. There are a number of browsers available, but for most personal computers the two most popular are Microsoft’s “Internet Explorer” and Netscape’s “Navigator”. Both are available in various versions for Windows 95, Windows NT 4.0, Windows 3.1, Windows NT 3.51, Mac OS and UNIX. If you are signing up with an Internet Service Provider, you will usually be provided with a browser and software for email, newsgroups, and other functions. The latest browsers are usually distributed on the free CD’s with most computer magazines and are available for download on the Internet. (3)

What is required for other Internet services?
Access to email and newsgroups requires additional software. Again, this will usually be provided by an Internet Service Provider. Both Microsoft Internet Explorer and Netscape Navigator also come with packages for email and newsgroups.

In the next part
In the next issue of Down Syndrome News and Update we will present a review of a number of information resources about Down syndrome and related subjects.
A frequent concern that I hear expressed by parents using computers regularly with their children is the lack of good programs to help with gaining number skills. This is partly due to the child’s difficulty with getting to grips with numbers and partly because there are very few simple programs to help with each stage of the learning process. Part of the problem is identifying where the child is at and therefore what to be practising or developing at any given time.

In order to deal with numbers a child needs two things, the skills to use the numbers and the opportunity and motivation to use the skills that they do gain. Early on the best exercises could well be those that deal with ‘spatial awareness’ rather than specifically with numbers and later it could be just as important to work on sequencing and categorising objects as well as developing memory skills to help with having ‘a place to put the numbers’ before actually tackling numbers at all. Good examples of these programmes are Blob 1, Blob 2, Make It Happen and Count with Blob from Widget Software, Touche from Le Computer and The Switch On and Touch Games 1 & 2 series from Brilliant computing. Worth a mention also are People Matching, Amazing One Bear Band and Amazing Animals from Hornmead Software, the latter being an excellent colour and number programme even if it does look a bit dated.

In my experience the best computer programmes for dealing with all these pre number skills come from software by Brilliant Computing and Widget Software. As for the second need, opportunity and motivation, life should provide these if only in terms of counting, playing shops, counting items and using money in the real world, to get things they like. A child will need plenty of opportunity to make mistakes.

Two programmes that have proved particularly useful recently for some children are Number Pics and Talking animated numbers. Both are designed for schools but equally useful at home. Number Pics offers practice with counting objects and recognising the number. At its easiest level it offers error free learning by speaking the number as the objects appear, leaving the child who has difficulty with counting objects the verbal clue as well as the visual clue, as below it would say the word 4 as the picture opens. The child would then select the number from the choices at the bottom and if correct the number would be spoken again and then appear on the window next to the objects. You can choose whether to work on numbers from 1-5, 0-9 or 1-10. As the child gains confidence the sound can be switched off leaving them no choice but to physically count the objects to know the correct number to select. Alternatively the child can be presented with a multiple choice option where the number is written in the centre and there are 4 pictures to choose from, only one of which contains the correct number of objects. As with the first exercise you can choose whether to give the verbal clue or not.

A great programme with numbers from one to ten is Animated Numbers from Sherston software, which really makes the numbers come alive with super pictures and animations and has some exercises looking at simple number concepts which are entertaining and exciting for people to use.

For more advanced number work, like introducing adding and subtracting, there are quite a few gamey programmes designed for young children that can have valuable contents, many of them however do not simplify activities enough and assume a more complex knowledge of numbers than children may have. Many like the Funschool series may only have a small number of activities that prove to be of much value. Funschool 4, has good exercise’s in finding a missing number, requiring the child to count from 1 in order to identify the missing number. For serious number work the slightly less lively educational programmes will prove much more valuable if time can be spent working with a child.

Number tiles is a plain programme that allows a child to practice adding and subtracting using either real numbers or by counting objects or domino style tiles. It may take a while to work out how to change from one type of display to another and to alter the level of difficulty, but once the teacher or parent has mastered it it becomes a good teaching resource with a fair variation of presentations for the child to work from counting objects towards doing sums with real numbers.
Once working with real numbers, children of all abilities need to spend a lot of time practising sums, a dull activity at the best of times and even more so for children who find it difficult. *Maths Book* offers children an on screen variation that doesn’t require so much hand written work and helps to offer a way to learn how to do sums as they practice, pointing out many of the common errors as they occur. The sums are presented in a very formal text book format that will be familiar to children doing sums at school but it offers help with all the common mistakes and helps to remind children of the rules of carrying tens and so on. It also speaks it’s help to assist those with poor literacy. The added bonus is that it will allow you to print out worksheets at the child’s own level and these will automatically include any sums that were done wrong on screen, offering paper and pencil exercises away from the computer.

The level of help that is given can be altered in line with the child’s confidence and ability. The difficulty of the sums can be altered from adding two figure numbers to each other to using hundreds, tens, units and two places of decimals, offering even monetary style sums to work on. The upper levels are beyond the scope of most of the children that I have worked with, but the introductory levels are fine.

Of course, numeric practice often requires some literacy and speech skills which is why there are some simple error free sections in *Speaking for Myself*. These allow a child to just practice learning the written, spoken and visual clues to the numbers from 1 to 12 as described below.

*Speaking for Myself* also has a wide range of literacy and language development sections: first words for visual sight vocabulary, simple talking books which practice putting two and three words together, and a series of exercises which help with speech and language/communication development, spatial awareness, listening skills and placement. This has been developed in association with The Down Syndrome Educational Trust and the Down’s Syndrome Association as it has long been apparent that the range of new CD-ROM, multimedia computer programmes for early years and specifically relevant to children with Down syndrome, has been very limited.

The author: Bob Black is the Down’s Syndrome Association’s Development Officer for the South West and author of “Speaking for Myself”, a multimedia software package that offers a range of activities designed to assist early language and reading development in children with learning difficulties.

### REVIEW: SOFTWARE TO START WITH

**Bob Black**

At The Wessex Computer Workshop at The Sarah Duffen Centre in October there was a great deal of interest in computer programmes that did not require the child to use the mouse on the computer. The co-ordination required to use the mouse with the hand to move the object on the screen is complex, just watch any adult without difficulties doing it for the first time. As well as the hand to eye co-ordination that is required there are those buttons which have to be pressed at the appropriate time as well, and depending on the type of computer you have there can be 1, 2, or 3 buttons all performing different tasks. So as an introduction to using the computer it is well worth finding programmes that do not require mouse control.

There are plenty of companies out there who will sell you a variety of alternatives, touch screen, concept keyboards, roller balls and the like but while using an alternative of these kinds may be relevant in a school situation to carry out particular tasks for short periods, most parents want to work towards enabling their children to use the same tools as everyone else. These alternatives can actually create a barrier, not only limiting the amount of software that children can use but making it unnecessary to learn the skills that will be of most value to them later on.

I shall describe a couple of programmes that use just one or two keys on the keyboard (mainly the space bar, which is the nearest and biggest, and the return key, which is next biggest) and then go on to list a few others that have been popular with children in my area.

Probably the longest serving and most used programme in the history of early years computing is Blob and although this programme is long in the tooth its relevance is still as good today as it was
when it was originally written for the old BBC computers. It is now available for the more modern computer and offers a wide range of exercises and a wide range of options for how to run it. If you choose “keyboard” from the list of options and then choose “spacebar” a whole range of simple exercises can be carried out just by pressing the spacebar.

Another long-standing favourite is Facepaints. This simple little programme is extremely versatile and offers choices from simply pressing the spacebar, through using the mouse and on to having to type in simple choices using the standard keyboard, so the range of ages and abilities is extremely wide. It allows the child the opportunity to create faces from a large combination of features, sex, colour, shape, eyes, noses, ears, hair and even glasses, moustaches and a choice of hats. There have been times, when demonstrating software to children that this particular programme has had to be removed from the choices because children have just wanted to keep on playing with all the combinations that can be achieved.

And it doesn't stop there, when the picture is complete it can be given a name, printed out or even made to speak by using a microphone connected to your computer. This software not only offers choices of how to use it but gives children an opportunity to develop computer skills, skills in making choices, observation skills and speech practice as well as offering the chance to keep a printed record of their work and have a lot of fun into the bargain.

The author: Bob Black is the Down’s Syndrome Association’s Development Officer for the South West and author of “Speaking for Myself”, a multimedia software package that offers a range of activities designed to assist early language and reading development in children with learning difficulties.

Software contacts
The Down Syndrome Educational Trust has recently begun stocking recommended educational software through its subsidiary, DownsEd Limited. A selected range is held in stock (normally supplied within 2 working days) and other titles from Semerc, Topologika, Sherston and Widgit can be supplied to order (normally within 4 working days). For further information, call +44 (01705) 824261 or e-mail sales@downsnet.org

To contact suppliers direct:
Brilliant Computing; Hornmead software: available from Semerc. 1 Broadbent Rd, Watersheddings, Oldham OL1 4LB +44 (0161) 627 4469

Widgit software available from Widgit. 102 Radford Rd., Leamington Spa, Warwickshire, CV31 1LF

Topologica software (Number Pics, Number tiles and Maths book) Waterside House, Falmouth Rd, PENRYN, Cornwall TR10 8E Tel +44 (01326) 377771 Fax +44 (01326) 376755 Email brian@topolgka.demon.co.uk

Animated numbers is from Sherston software Angel House, Sherston, Malmsbury, Wiltshire, SN16 0LH +44 (01666) 840433

Web references:
Educational software suppliers
Sherston - http://www.sherston.com/
Topologika - http://www.topolgka.demon.co.uk/
Widgit - http://www.widgit.com/
Inclusive Technology - http://www.inclusive.co.uk/
The National Down Syndrome Society held its 11th International Down Syndrome Research Conference on Cognition and Behaviour in Florida in November 1997. I was invited to participate in the 3 day meeting, giving me the opportunity to share this summary with readers. I have attempted to review the main points from most of the papers. Many of the presenters have published some or all of their work, so if any reader would like more information on any topic please contact me and I will provide references or put them in touch with authors. I have grouped the papers into topic areas, starting with infancy and moving to adult issues, with medical/genetic research at the end.

Infancy
The first presentation by Dr Rathe Karrer and Dr Jennifer Hill Karrer of the Smith Mental Retardation Centre, University of Kansas outlined their research on attention and cognition in infants. They explained how they are using measures of the electrical activity of the brain called event-related potentials (ERPs) to study cognitive development in infants. ERPs are measured by electrodes placed on the baby’s scalp. It is a harmless and non-invasive technique that can be used to measure brain responses to stimuli presented to the baby. They are looking at responses to visual stimuli such as attention, response to novelty and recognition memory in infants with and without Down syndrome. They are engaged in longitudinal studies and may be able to relate the ERP data to different rates of progress in the children.

ERP measures are being widely used in other centres in the UK and USA to study brain development in infants and children with Down syndrome and to chart the effects of different rates of functional development on specialisation in the brain. It is even argued that the technique can be used to evaluate the effects of different types of intervention or input on the development of the brain.

Speech and language
The next presentation by Dr Carolyn Mervis of the Department of Psychology, University of Louisville, Kentucky, reviewed her research on vocabulary acquisition and on children’s ability to master category concepts. She pointed out that the ability to form concepts and to categorise is critical to a child’s ability to understand and to organise their experience of the world. She has collected detailed longitudinal data on five children with Down syndrome and they showed two rates of progress with two children progressing like typical children and three progressing more slowly, highlighting the variability to be expected in their development.

A second paper on language development was presented on the second day by Dr. Libby Kumin, Department of Speech/Language Pathology, Loyola College, Maryland. She has collected data on 115 children from two to five years by asking their parents to complete the McArthur Communicative Development Inventory. This asks parents to identify the words and sentences that their child is using from a checklist. Mean vocabularies grew from 55 words at age two by approximately 100 words per year to 391 words at five years. However, variability at each age was very large (from 8 to 226 words for different children at two to 62 to 611 at five years). She also reported on the emergence of early grammatical markers such as plurals, possessives and past tenses. These also showed wide variation in the age they were achieved by different children.

Both the papers on language illustrated the very different rates of language development seen in different children with Down syndrome. Research which identifies the reasons for these different rates of progress is
needed if we are to become more effective with individually targeted interventions matched to children’s specific needs.

**Early communication and later social skills**

Dr Marion Sigman, from the School of Medicine, University of California Los Angeles, reported the findings of a longitudinal study of 70 children with Down syndrome followed from pre-school to middle school years. In the pre-school years, the children’s ability to initiate interactions and to share in joint attention situations (e.g. to attend to same object or activity with a communication partner) correlated highly with verbal language development. Followed up eight to ten years later, those with better interactive skills as infants were better socially integrated in the school playground. Dr Sigman therefore emphasized the importance of following the baby’s lead and talking about what he or she is looking at to encourage these joint interaction skills. She also observed that schools do not use playtimes as positively as they could to teach and foster social interactions between children.

**Reading and language**

There were two papers on reading and speech and language development. In the first, Dr Anne Fowler of the Haskins Laboratories, New Haven, Connecticut reviewed the research on language development, considering variation and progress in the four different aspects of language skill. These are 1) phonology - how words are pronounced, 2) grammar, syntax and morphology - how sentences are constructed, 3) lexical knowledge or vocabulary - the names and meanings of words 4) pragmatics - the rules governing the way that conversations are conducted. Dr Fowler pointed out that not only is there wide variation in overall language skill between children and adults with Down syndrome, but there is also variation in the levels of difficulty experienced within the four aspects of language for individuals. She also pointed out that current research findings needed to be interpreted with caution as we have only just begun to tap the full potential of persons with Down syndrome. With these caveats in mind, she reported that typically, children with Down syndrome have more difficulty with grammar and phonology than with vocabulary and pragmatics. She argued that phonological memory (auditory short-term memory - often measured by digit span tasks) is a core problem affecting language learning. For example in one study of young adults, correct use of verbal auxiliaries (e.g. is and are in he is running, they are running) was predicted by digit span, those with better digit spans having more correct use of grammar. She also pointed out that some individuals achieve good language and some good literacy skills also, the good readers also having better digit spans than most people with Down syndrome.

My paper on stimulating reading and language through the school years addressed some of the issues raised by Dr Fowler. Drawing on two longitudinal data sets collected with colleagues here at The Sarah Duffen Centre and in the Department of Psychology, University of Portsmouth, I argued that the better digit spans and better speech and language skills of readers may be the consequence of learning to read rather than causal factors. Studies of typically developing children would support the view that this may be the case and that progress in either short memory, or speech and language or reading skill will have a beneficial effect for the other two skills - this is referred to as reciprocal causation or ‘bootstrapping’. I also illustrated the range of reading, spelling and comprehension progress being made by children in our ongoing longitudinal study and the rate at which they are becoming alphabetic readers (e.g able to use phonic knowledge to ‘sound out’ an unfamiliar word). It appears that they move from relying on logographic (relying on visual memory of whole words) to alphabetic strategies once they reach the reading levels of a typical seven year old on our tests. This is very encouraging especially as the children with Down syndrome are likely to have less good sound production and sound discrimination abilities to support the learning of phonics.

**Short-term memory**

One of the factors thought to be causally linked to some of the language learning difficulties is poor auditory (or verbal) short-term memory development in children with Down syndrome. Dr Chris Jarrold, Dr Alan Baddeley and Dr Alexa Hewes, of the University of Bristol, UK, presented their recent research on this topic as a poster presentation. They compared the performance of children with Down syndrome, children with moderate learning disability and typically developing children, all matched for vocabulary comprehension, on verbal and visual spatial short-term memory tasks. The children with Down syndrome have equivalent visual-spatial spans but significantly lower verbal spans when compared to the other two groups of children.
This difference was not related to hearing loss or speech articulation rate for the children with Down syndrome and they also showed no ‘primacy’ effect e.g. relatively good performance on the first item in a list. The authors conclude that their results suggest a problem in the phonological loop component of the working memory system - perhaps rapid trace decay or increased interference from subsequent items entering memory. This is an important area for further work as this system is critical for the support of all learning.

Adolescence and early adulthood
Three papers discussed the needs of adolescents and young adults with Down syndrome. Dr Don Van Dyke from the University of Iowa Hospital and Clinic, Iowa City presented an overview. He identified that the major task of adolescence is separation from the family. In early adolescence the main preoccupations for young people are growth and puberty. For young people with Down syndrome puberty is usually reached at the usual age, the growth spurt may be earlier and less and obesity may be a risk. This is a time when appearance and self-image become important, so it is important to encourage good hygiene, a pride in appearance and fashionable clothes. Friendships and the peer group become important and leisure interests and social competence will help the young person to be included. Dr Van Dyke emphasised the need for good health care, including sex education, contraception and sexual health care to be available to adults and adolescents with Down syndrome.

In a paper entitled Living in the Community, Dr Siegfried Pueschel discussed the needs of adults if they are to participate fully in the community. He pointed out that we need to consider planning for the transition from adolescence to adulthood, for post-secondary education, for living and recreational options. We need to consider social skills, relationships and sexuality, medical care and mental health issues. Dr Pueschel emphasised the need for forward planning to build up self-esteem and the social and practical skills that will be needed for meaningful participation in the community. He also discussed employment and living options and the need for preparation for relationships. He particularly stressed the value of leisure and recreational activities, arguing that they can build self-confidence, improve motor skills and physical fitness, increase independent functioning, nurture creativity and self expression and provide opportunities for friendships.

Adult mental health
Dr William Cohen from Pennsylvania Children’s Hospital, Pittsburgh, shared his experience of treating behavioural problems of young people with Down syndrome at his specialist Centre. About one third had some difficulty. The most common problems were defiant or aggressive behaviours and adjustment difficulties - typical adolescent difficulties. One person had depression, one panic attacks and another an eating disorder. For all adolescents with disabilities, adolescence is a particularly difficult time as they come to realise the real impact that their disability is having on their lives when they see peers and siblings moving on in ways that they are unable to achieve. In the young adults, less than one third had any problems and none were aggressive. Depression, anxiety, eating disorders and obsessive compulsive disorder were the type of problems seen, again problems occurring in a minority of the rest of the population of this age. Dr Cohen gave examples of responses to treatments for his patients and drew attention to one important issue. People with Down syndrome may be inclined to talk to themselves when under stress. You and I will be worrying silently in our heads, they are doing this worrying out loud and it is important that it is not misinterpreted as a psychotic symptom.

A further paper on psychiatric disorders in adults with Down syndrome was presented by Anna Mies and Kendra Moses of Southern Illinois University School of Medicine giving similar outcomes in their clinic population. They pointed out that some 20% to 30% of adults with Down syndrome may suffer from a mental disorder at some time. They are less vulnerable than adults with learning disabilities from other causes, but may be more likely to have depression or dementia in later life. It is important that doctors and carers realise that a mental illness can occur and can be treated, especially as some folk will have limited communication skills and their difficulties be misinterpreted, so go untreated or be treated inappropriately.

Issues for older adults
Dr Dennis McGuire and Dr Brian Chicoine, from the Lutheran General Hospital, Glenview, Illinois shared the results of their experience of working with some 600 adults at their Adult Down Syndrome Centre. They had information on their self-help, social and communication skills as well as their healthcare needs. Some 10% of adults needed help
with all daily living skills and a further 5% needed prompts. Of the rest 38% were mostly independent, 40% needed some support in their lives and 7% were able to manage selfcare but were not socially or practically independent. While 75% of adults had communication which was understood by caregivers most of the time, only 28% could be understood most of the time by unfamiliar others. When it came to expressing feelings, 78% could express them well non-verbally but only 39% verbally and so many caregivers found it difficult to interpret the expressed emotions of the person with Down syndrome that they were caring for. Especially vulnerable in this respect were those with mental health problems (about 30% of the group).

The most common health issues were sensory deficits - of 602 people, 312 had impaired vision and 247 had a significant hearing loss and 351 had impacted wax in their ears! Overweight was an issue for 423 people, 222 were hypothyroid, 6 had vitamin B12 deficiency and 11 were diabetic. 41 had developed seizures and only 33 suffered from sleep apnoea suggesting it is less common in adults with Down syndrome than in children. Of the 300 women in the study, 49 had passed the menopause and 89 suffered from dysmenorrhea.

Of those with mental health problems, 87.5% were described as having a ‘reversible’ or treatable disorder and only 12.5% had Alzheimers dementia. (This meant that only 26 of the total of 579 had dementia and they were all over 40 years of age). This study also drew attention to the frequent occurrence of self-talk, which was reported as used by 79% of the adults. Eighty percent were friendly and social, with only 20% described as anti-social or inappropriate in their behaviour at times.

Medical/genetic research
There were two papers in which the progress in understanding the genetics of Down syndrome was reviewed. One emphasized the search for links between genetic profiles and cognitive profiles, the other explained the potential of trisomic mouse models for testing some of these hypotheses. Both these speakers gave similar presentations at the Vancouver conference in April 1998, which I will be reporting on in the next issue, so I will include a little more detail then.

Two papers discussed the search for effective pharmacological treatments for some of the abnormalities in biochemical functioning and the health risks associated with Down syndrome. One was presented by Dr Alberto Costa of the Jackson Laboratory, Bar Harbor and the other by Dr George Capone of the Kennedy Krieger Institute, Baltimore. These were both speculative papers, discussing the areas in which research might be worthwhile based on our current knowledge and the enormous methodological difficulties facing such research. Dr Capone pointed out that there is a need to develop a valid and reliable protocol for accurately measuring the development of children with Down syndrome before the effectiveness over time of any interventions can be reliably evaluated.

The American Down Syndrome Medical Interest Group, which includes many of the most expert medical practitioners, biochemists and geneticists in this field, had its meeting at this conference. (A number of these experts are also parents of children with Down syndrome themselves). This meant that there was discussion of health guidelines, areas that need further research and exchange of good practice. (There was also extensive discussion of the problems being caused by the promotion of Targeted Nutritional Interventions (‘TNI’) despite the lack of evidence for the wild claims being made for its efficacy by those selling it or those using it in their private practices). The view of this expert group, which is to not recommend the use of ‘TNI’, can be found on the NDSS website.

My views on this are made clear elsewhere in this issue and on our website. The most distressing aspect of this whole sorry debate is the unnecessary stress and anxiety being caused to new parents by the conflicting information that they are being bombarded with at present.

The Author:
Sue Buckley is Professor of Developmental Disability at the Department of Psychology at the University of Portsmouth, UK. She is also Director of The Centre for Disability Studies at The University of Portsmouth and Director of Research and Information Services at The Down Syndrome Educational Trust. She also serves as a Non-Executive Director of the Portsmouth and South East Hampshire District Health Authority and on the boards of the European Down Syndrome Association and the International Down Syndrome Federation.
The Foyle Down Syndrome Trust opens its centre

Congratulations to all those in Londonderry, Northern Ireland, who have worked so hard over the past three years to get the Foyle Down Syndrome Trust launched, especially Gerry Craig who had the original vision and the fundraising talent to make it a reality. It is modelled on the constitution of The Down Syndrome Educational Trust and is providing professional services to children and teenagers with Down syndrome and their families in the area. They now have 2 teachers, a director and secretary in post and a centre of their own.

The Down Syndrome Educational Trust is helping with advice and training from The Sarah Duffen Centre. This may be a model that others would like to develop expert services in their area - if so contact us to discuss the ways in which we could help you from Portsmouth.

“We are absolutely delighted to announce that the Foyle Down’s Syndrome Trust has now opened its centre for educational and social inclusion.

“There was great excitement and a wonderful sense of achievement in Thursday 5th March, 1998 as her Excellency Jean Kennedy Smith, United States Ambassador to Ireland, officially unveiled the plaque especially commissioned for the occasion. There were representatives from the parents and children participating in the project, a number of adults who have Down’s syndrome, members of trustees and invited guests.

“We are delighted to have the centre up and running and to see the hard work and effort that went into the pilot programme beginning to bear fruit. The new Director, Kay Devine, paid tribute to the crucial preparatory work done in the past two years stating “I would like to acknowledge the tremendous work which the trustees and Ann Breslin put into the early years and I look forward to the challenge ahead as our vision is further realised. This is a truly exciting time for the Foyle Down’s Syndrome Trust.

“On behalf of both the children and families, the Trustees would like to acknowledge the invaluable assistance of Professor Sue Buckley and the staff of The Sarah Duffen Centre.”

Photo: Trustees of the Foyle Down’s Syndrome Trust
From left to right - Front row: Dessie Boyle, Her Excellency United States Ambassador to Ireland, Jean Kennedy Smith, Gerry Craig, Chairperson F.D.S.T - Back row: Kay Devine, Director, Maureen Heatherington, Sandra McCallian, Margaret McSorley Development/Outreach worker, Joe Duggan, Sean O’Kane and Noleen Dawson.
NEWS FROM THE SARAH DUFFEN CENTRE

New programme of training events 1998-9
A new range of workshops has been planned for the 1998/9 school year. The education workshops will continue to run, with an increase in training events for staff from Secondary schools. In addition, we have developed a range of new training opportunities for trainers, including training for school outreach service workers, special educational needs co-ordinators, health visitors and social workers. Other events are planned for psychologists, speech and language therapists and pre-school home visiting teachers.

For parents, we have introduced a series on development for children aged 0-2, 2-4, 5-8 and 9-12, covering all aspects of development and education. We also have workshops specifically for parents on how to work effectively with schools, including how to assess and describe children’s needs, advocate and approach placement and transition issues with increased knowledge and confidence. Specialised workshops on teaching reading, behaviour and social development will be held during each term.

We look forward to continuing to welcome visitors from around Europe to these events. If you would like further information, please contact The Down Syndrome Educational Trust.

Book now published in full on DownsNet
The text of the book Meeting the Educational Needs of Children with Down Syndrome, by Gillian Bird and Sue Buckley, has been added to The Down Syndrome Educational Trust’s web site. This book is now out of print and will not be reprinted until we have had a chance to revise and update it. For the time being, it may be found at http://www.downsnet.org/library/books/meeting_needs/

Open day dates
The summer Open Day is on August 26th. Open days offer opportunities for parents and professionals to use our library, look at and try some of the resources and discuss individual children’s needs with our professional staff. Those of you without access to the Internet can look for yourselves at the range of information available on web sites from around the world if you are to attend on either of these dates.

Computer morning, 27th June
The library has been extended to include computers and software for children, developed in liaison with the DSA, for which computer tables have been donated by IBM. If you are able to visit Portsmouth on June 27th you will be able to use the children’s software yourself as we are inviting parents and children on this date, in association with the DSA. Please contact the Centre for further details.
DIARY DATES

Conference: The Future Is Ours:
1998 National Down Syndrome Society Conference
9th - 11th July 1998 - Lake Lawn Lodge, Delavan, Wisconsin, USA.
For further information contact:
NDSS. 666 Broadway, 8th Floor. New York, NY, USA. 10012-2317.
Tel: +1 (212) 460-9330. Fax: +1 (212) 979-2873. E-mail: info@ndss.org

Family Weekend Conference
5th & 6th September 1998 - at The Sarah Duffen Centre, UK

Reading and writing for beginners
14th September 1998 - at The Sarah Duffen Centre, UK

Understanding development from 0-2 years
21st September 1998 - at The Sarah Duffen Centre, UK

Assessment and planning for placements
28th September 1998 - at The Sarah Duffen Centre, UK

Meeting educational needs in infant schools
5th October 1998 - at The Sarah Duffen Centre, UK

Meeting educational needs in junior schools
12th October 1998 - at The Sarah Duffen Centre, UK

IV European Symposium - Early Intervention:
Equal opportunities and quality of life for families with a young disabled child.
14th-17th October 1998 - Worriken-Center, Butgenbach, Belgium.
For further information contact:
Office for Disabled People of the German-speaking Community of Belgium,
Aachenerstrasse 69-71, B-4780 St. Vith.
Tel: +32 (0) 80 22 91 11 Fax: +32 (0) 80 22 90 98 E-mail: dpb@euregio.net

Developing social skills and behaviour
16th October 1998 - at The Sarah Duffen Centre, UK

Understanding development from 2-4 years
19th October 1998 - at The Sarah Duffen Centre, UK

Fourth European Down Syndrome Conference: Creating Challenges
10th - 13th March 1999 - Malta
Organised under the auspices of the European Down Syndrome Association (EDSA) and the
International Down Syndrome Federation (FIDS) by the Down Syndrome Association of Malta in
collaboration with the Department of Psychology at the University of Malta.
The Conference aims at bringing together persons with Down syndrome, parents, professionals
and others interested in the field in an atmosphere of mutual respect and collaboration. The
programme will consist of a number of plenary and specialist sessions, which may either focus on
issues for particular groups or issues of general interest. Papers are invited for presentation at the
Conference, as well as proposals for themes for symposia, thematic sessions and plenary sessions.
For further information contact:
Conference Secretariat Down Syndrome Association, 45 South Street, Valetta VLT11, Malta.
Tel: +356 235158 Fax: + 356 236197 E-mail: johnpeel@waldonet.net.mt
OR: Scientific Secretariat, Dr Mark G. Borg, Department of Psychology, University of Malta, Msida MSD06, Malta. Tel: +356 32902269

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

The conference aims to provide an opportunity for people with Down syndrome, their parents, carers and families, and interested professionals to address the major issues and hear the latest developments from international experts.

For further information contact:
Congress Secretariat, Seventh International Down Syndrome Congress, GPO Box 2609, Sydney, Australia 2001
Tel: +61 2 9241 1478, Fax: +61 2 9251 3552, E-mail: down@icmsaust.com.au

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

The 11th World Congress of the IASSID plans to bring together more than 1,500 people for an international exchange of knowledge and ideas. Participants will be able to develop networks of colleagues which can lead to collaborative research and consultation. One of the major benefits of the World Congress is the opportunity for colleagues working in different parts of the world to become acquainted with each other’s research, innovations and exemplary practices. Attendees will also be able to consider ways in which these research advances can have a beneficial effect upon supports for individuals with an intellectual disability and their families.

For program information contact:
Dr. Neil Ross, President-elect, Association de Villepinte (IASSID), 28 rue de l’Eglise, Villepinte 93420, France.
Tel: +33 1 43 85 12 06, Fax: +33 1 49 36 11 54, E-mail: njross@compuserve.com
IASSID Homepage Address: http://www.waisman.wisc.edu/iassid/

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

For information about any of the events at The Sarah Duffen Centre, please call for a copy of our Training Events brochure.
SUPPLEMENT: THE DOWN SYNDROME EDUCATIONAL TRUST, REVIEW OF ACTIVITIES, 1997

Research activities
In collaboration with the University of Portsmouth, The Down Syndrome Educational Trust supported seven postgraduate research programmes during 1997. Its support ranged from full funding (two projects) to support through assessment and library resources, family contacts, advice and conference funding. In addition, the Trust assists projects undertaken by BSc and MSc students. During 1997, these included a study of phonological awareness in children with Down syndrome and a study of self-concept in adolescents with Down syndrome in special and inclusive school settings.

Reading, language and memory development in primary school age children
The Down Syndrome Educational Trust continued a longitudinal study of language development in children with Down syndrome in mainstream schools during 1997. This study has now been in progress for four years in conjunction with Centre for Disability Studies at the University of Portsmouth. The first three years’ data formed the basis of a successful PhD thesis by Angela Byrne, and had funding from the University of Portsmouth. Further study has been funded by The Down Syndrome Educational Trust.

The investigation showed that the majority of the children with Down syndrome had acquired some useful reading skills during their early school years and that reading is typically a strength for these children compared to their other cognitive skills. Most of the children with Down syndrome relied upon visual strategies to learn a sight vocabulary. The most able readers who had achieved reading ages of 7 and above were also able to make use of their alphabetic skills to extend their reading vocabularies.

DownsEd Limited supported the presentation of a paper based on this research, by Angela, at the 6th World Congress on Down Syndrome in Madrid in October. Since completing her PhD, DownsEd Limited has employed Dr. Byrne to support services and publishing activities. During 1998, Angela will oversee further data collection and analysis.

Education in mainstream schools
Collection and dissemination of examples of good practice in meeting the educational needs of children with Down syndrome across the age range continued throughout 1997. Individual differences, transition to secondary school, behaviour management, and different models of support have been of particular interest.

Information collected has been of value for training events and individual consultancy. Application of research into cognitive development applied to classroom practice was documented for this purpose but has yet to be written for publication.

Hampshire’s mainstream school placements have enabled research into peer relationships to be successfully undertaken for BSc projects in 1996 and published in the journal Down Syndrome Research and Practice.

Reading and language in pre-school children with hearing impairments or Down syndrome
A comparative investigation of reading and language development in children with hearing impairments, children with Down syndrome, and children without disabilities recommenced in the autumn of 1997. The Down Syndrome Educational Trust is funding Michele Whitcombe, as a part-time PhD student, to complete this study.

Numerical skills
The study, started in 1995, is investigating the development of early number skills, including counting and conceptual knowledge, longitudinally in a group of children with Down syndrome. Joanna Nye is carrying out this research for a PhD with the Department of Psychology at the University of Portsmouth. The project was wholly funded by the Portsmouth Down Syndrome Trust in the first year. It is currently supported by a bursary and expenses budget from the University of Portsmouth, and by The Down Syndrome Educational Trust through use of facilities including rooms, video-recording equipment, test materials and contacts with families.
During 1997, the first year of data collection for this longitudinal project was completed. In total 55 children with Down syndrome and their families were seen for pilot and main studies, 26 of whom have been invited to return for follow-up assessments in Years 2 and 3. Analysis is ongoing.

DownsEd Limited supported Joanna’s attendance to present a poster based on part of the data collected in the first year at the 6th World Congress on Down Syndrome in Madrid in October.

Speech and language intervention
This study, started in 1994, is evaluating the effectiveness of early intervention for speech and language development. Pat Le Prevost is carrying out this research for an MPhil with part-funding from Oxford NHS Trust. A comparison of two groups of 5-7 year olds who had experienced different interventions was completed in 1997 and a longitudinal study of infants was continued. A focus of this project is to explore the individual variation in language progress between children and the uneven profile of development of language.

Data from the first study was presented by Pat at the 6th World Congress on Down Syndrome in Madrid in October. This study should provide information that will enable speech and language therapy to be tailored more effectively to individual need.

Cognitive and social development in infancy
During 1997, Brickshand Ramrattan continued a project exploring the links between visual recognition memory, cognition and social communicative skills in infants with Down syndrome. A paper on this work has recently been accepted for publication in Down Syndrome Research and Practice. The Down Syndrome Educational Trust is continuing to offer library and computing resources in support of this project.

Social skills and peer relationships in inclusive education
Mary Ramrattan continued an investigation of the social interactions of children with Down syndrome and their mainstream peers in inclusive education settings. This work developed from a study identifying the limited social lives of adults with learning disabilities living in the community.

Reading and language development in adults
In September 1997, Christine Jenkins, an experienced speech and language therapist, was awarded a full-time research bursary by the NHS Executive (South and West) Research and Development Directorate. Christine is a part-time lecturer at the Department of Psychology at the University of Portsmouth. Her three-year project will investigate the effectiveness of teaching reading to improve the spoken language skills of adults with Down syndrome.

Support and advice services
Supporting children in mainstream schools in the south England area
The Down Syndrome Educational Trust has been supporting children with Down syndrome in local schools since 1986. The Trust provided regular support for 38 children and schools in Hampshire during 1997. The Trust provided 56 visits to schools in Hampshire and surrounding areas. These visits often coincided with attendance at children’s annual reviews. The Down Syndrome Educational Trust has additional links, through research projects, with children attending schools in West Sussex and the Isle of Wight. In April 1997, Portsmouth City Council awarded a grant of £17,000 over 12 months towards the Trust’s advice and support service for local mainstream schools with children with Down syndrome.

During 1997, schools from across the UK and abroad also maintained links for advice on classroom practice and research information. There have been meetings between The Down Syndrome Educational Trust’s staff and teaching advisory services in Surrey, Oxford, Northern Ireland, Ireland and West Sussex.

The Trust provides advice and information to Infant, Junior, and Secondary schools. This includes information about the children’s learning strengths and weaknesses, teaching reading and writing, language and memory development, speech and communication, handwriting skills, numeracy and social development and behaviour. All advice is based on current research and is individually applied to the child’s profile, class, and school characteristics. The provision of individual advice benefits the children, their families and schools, through the continuation of placements in mainstream school. This service also provides examples of good practice for use in training and for wider dissemination.
In addition to school visits and attendance at annual reviews, schools have accessed services, library and teaching resources through training at The Sarah Duffen Centre, at ‘Open Days’ and through individual consultations and the advice line. Many LEA’s have received training in their own localities.

Schools in Portsmouth received a higher level of services and provision of training for school staff and parents in fulfilment of the Portsmouth LEA grant.

**Early Development and Speech and language groups**

Two ‘Early Development’ groups and a ‘Speech and Language’ group are provided by The Down Syndrome Educational Trust. These groups offer support, information, and structured teaching activities to families who are within regular travelling distance of Portsmouth. ‘Early Development’ groups have been provided in since 1983.

During 1997, two ‘Early Development’ groups met during school terms for two hours on alternate weeks. One group is for children aged 18 months to 2.5 years, and the other group is for children aged 2.5 to 5 years. The first hour is informal for mutual parent support and discussion of individual concerns with professional staff. The second hour offers structured activities to assist the children with their language, speech, communication, and social learning needs.

Advice and structured teaching activities are informed by current research and proven models of good practice. Families attend the structured activities on a regular basis to gain maximum benefit for their children’s development.

Parents of new babies are welcome to attend the groups for support and advice, and 26 regular attendees for the structured learning group came from Hampshire, Berkshire, London, Surrey, West Sussex, Devon and Hertfordshire.

Since September 1997, Children in Need have been contributing to the costs of running the ‘Early Development’ groups and the costs of additional groups. This has enabled the provision of a regular group focused on speech and language development.

The ‘Speech and Language’ group meets weekly during school terms. The group provides one hour of work in a group for the child and his or her parent in attendance, with additional weekly ‘speech’ homework. The group commenced in September 1997 and is attended by 5 children, aged 4 to 7 years, with particular speech and communication difficulties. The children have shown improvements in speech, work habits and behaviour and the format of the group is already being used as a model by other Speech and Language therapists around the country.

At the end of 1997, there was a waiting list for attendance at the early development groups and the speech and language group.

**Open Days**

Four Open Days ran at The Sarah Duffen Centre during the school holiday breaks in April, May, August and October. They offer parents and professionals an opportunity to meet The Sarah Duffen Centre’s professional staff and to learn about the resources and services available at The Sarah Duffen Centre. A total of 55 adults and 43 children attended the Open Days.

The Trustees plan to run five Open Days during school holidays in February, April, May, August and October 1998.

**Psychological assessment and individual consultation service**

The Down Syndrome Educational Trust provided 59 assessments and 37 individual consultations during 1997. Individual psychological assessments offer an opportunity for families to consider their child’s developmental history, development and skills in detail, with assessment of skills and abilities led by a psychologist. They then receive advice on how to promote the cognitive, social and behavioural development of their child through educational and family activities.

Assessments and consultations fall into three categories. Assessments for pre-school children examine all areas of development, with an emphasis on speech, language and cognitive development, and often to contribute to LEA statements identifying educational needs. Assessments for school children aid progress in Infant, Junior and Secondary schools, in special as well as mainstream schools. Assessments for children with atypical development offer highly individual and specific advice. These can focus on, for example, behaviour that challenges their families and those working with them in school, lack of speech and poor
communication skills, including autistic spectrum disorders, or more severe developmental delay. The Trustees recognise this third group as being in particular need of high quality assessment, services and family support.

A fee of £300.00 for a full assessment and written report is requested for the assessment service and full written report, and £200.00 for an assessment without full written report. Fees of £37.50 per hour are requested for the individual consultation service. For detailed written reports, particularly for reports that are required for Tribunals, the costs often exceed the fee. When this occurs, the Trust subsidises the difference. When resources permit, The Down Syndrome Educational Trust does not request fees from families on Income Support. The Trustees of The Down Syndrome Educational Trust and the Directors of DownsEd Limited anticipate having to increase these fees from September 1998.

Advice Line
The Down Syndrome Educational Trust provides an AdviceLine service for parents and professionals. While families with new babies will be spoken to as soon as is possible, school and parents requiring a detailed response were directed towards a telephone AdviceLine during two half-day slots per week. During 1997, The Down Syndrome Educational Trust responded to over 1,500 telephone calls, 350 letters and 140 e-mails for detailed, individual advice. This service is freely accessible and supported from general charitable funds, including proceeds from trading activities.

The Trustees of The Down Syndrome Educational Trust realise that this service is highly valued by those who utilise it. However, it consumes considerable time and resources, and is therefore expensive to provide. In order to meet growing demands on this service, The Down Syndrome Educational Trust will need additional funding during 1998. It will also seek ways of increasing the efficiency of advice delivery. Measures that increase efficiency will undoubtedly involve reducing the amount of individual advice, and greater use of ‘standard’ advice sheets. The challenge will be to identify when individual advice is necessary, and when ‘standard’ advice sheets will suffice.

Information Service
The Down Syndrome Educational Trust responded to 90 queries from researchers studying, researching or interested in the development and education of children with Down syndrome during 1997. Responses included specialist bibliographic searches, reference lists, and article reprints.

Teaching and training activities
Weekend conferences for parents

Fees to cover the costs of these events are kept to minimum thanks to the voluntary attendance of most of the expert speakers. However, the Trustees of The Down Syndrome Educational Trust and the Directors of DownsEd Limited anticipate having to increase these fees from May 1999.

Regular workshops for parents and professionals
DownsEd Limited provided 20 one-day and two-day workshops at The Sarah Duffen Centre throughout 1997. These were attended by around 300 parents, teachers, educational psychologists and speech and language therapists. The workshops covered a variety of educational and development subjects, including meeting educational needs, early development, speech and language development, psychological assessment and needs, reading, social development and behaviour. A small but successful day dedicated to meeting educational needs in the secondary school was piloted as a new training development in 1997 and similar training days are now fully booked for 1998, and planned with increased frequency for 1999.

Evaluation records by participants for all training events were very positive. As with comments about other services, these evaluations are monitored by the Trust’s professional team and by a ‘Services Advisory Committee’ of parent representatives. However, there were comments from teachers who felt that The Down Syndrome
Educational Trust should keep schools better informed of training events, and its other services. Most of these teachers had heard about the workshop from parents who subscribed to the Trust’s newsletter, and felt that other teachers would benefit from knowing about the workshops.

This issue was addressed by a significant direct marketing initiative in the autumn of 1997. Following this initiative, enquiries and bookings for workshops during 1998 have increased considerably.

**Specialist teaching materials**

In order to fill a gap in the range of commercially available teaching materials particularly suitable for younger children, the professional staff at The Sarah Duffen Centre devised five teaching packs. Four of the packs teach language and speech using pictures, and each set has a particular additional function.

The **Language Cards** can be used to teach, reinforce, and extend first vocabulary. This pack includes 54 colour photographs, with written words on the reverse of each card for teaching nouns, verbs, early adjectives and prepositions. The written words also function to introduce the reading of single word items and short phrases. The pictures and words help develop signed and spoken language. Each picture is a colour photograph, with the verbs demonstrated by young children with Down syndrome and their parents.

The **Lotto** pack teaches matching, beginning with two familiar items, and progressing to a larger lotto board for matching six pictures. A **First Picture Dominoes** teaches side by side matching of pictures, with the adjacent pictures facing in the same direction. When children have mastered the lotto and dominoes they are then able to succeed with the more typical commercially available matching and domino games.

The **Sound Cards** help to develop early listening and perception of individual consonant sounds and enable the child to practice saying the sounds. A clear colour picture represents each sound, and the corresponding sign symbol is on the reverse of each card. The picture helps the child to remember the sound and the sign. The child can also ‘make’ the sound and join in the game by signing at a stage when he or she may not be able to produce the sound clearly without visual and gestural support. Perception and production of sounds are fundamental building blocks for learning to speak clearly.

The more practice young children receive the more automatic these abilities become, thus assisting the more difficult job of saying a series of sounds in succession to create spoken words. While all children benefit from such practice, some children require this type of activity to be able to progress forward in learning to speak.

The Down Syndrome Educational Trust received grants to assist with the production of these materials from the Down’s Syndrome Association (£15,000) and Portsmouth City Council (£3,500). The overall cost of the production of the first four packs was £52,000 and DownsEd Limited has funded the balance of £33,500.

Sales of these materials have been solid, but not as much as initially hoped. However, the Trust has received plenty of positive comments from the families and teachers using them. Unfortunately, the slow sales have delayed the production of the fifth pack, to teach language through reading.

**Information dissemination activities**

**Lectures and workshops - overseas**

Trust staff presented 18 lectures and workshops outside of the United Kingdom during 1997, of which 5 were keynote presentations at international conferences. Apart from a number of presentations at the 6th World Congress on Down Syndrome, these overseas engagements were conducted by Professor Sue Buckley and Professor Ben Sacks.

Professor Buckley presented lectures and training on reading, language, cognitive development and meeting educational needs in Malta, Ireland, Jersey, Holland, the United States, Australia, Norway and Spain. Professor Sacks presented lectures on health, behaviour, sexuality and adolescent issues, in Holland, Spain, and Jersey. These presentations will have reached around 4,000 delegates, including parents and professionals.

Engagements during 1998 already include presentations in Canada, Australia, New Zealand, Singapore, Fiji, Portugal, Holland, Ireland, and Norway.

**6th World Congress on Down Syndrome, Madrid**

In October the 6th World Congress on Down Syndrome was held in Madrid. The Down
Syndrome Educational Trust was exceptionally well represented, with five staff making presentations, including 2 keynote speakers. Most of these speakers presented research conducted by The Down Syndrome Educational Trust in conjunction with the Centre for Disability Studies at The University of Portsmouth. The subjects discussed included cognitive and academic attainment in children, early intervention programmes, number development, behaviour management in adults, and practical implications of psychological research.

DownsEd Limited organised an exhibition stand at the congress. This stand distributed information about the work of the Trust, and its services and products. The display included the new teaching materials and the full range of books and periodicals. A display and mobile demonstration of the web site content also featured on the stand.

Visiting lectures and workshops - UK
Staff led 13 workshops and training days around the United Kingdom during 1997. These included events in London, Surrey, Essex, Wales, Cambridge, Sussex, Norfolk, and Suffolk. The majority of these workshops were provided for teachers and education professionals, though many included parents. With an average attendance of 80 people per day, these workshops reached about 1,000 people. In 1998, 24 training days are booked for UK venues.

2nd International Conference on Language and Cognitive Development in Down Syndrome
In April 1997, the Portsmouth Down’s Syndrome Trust and the Down’s Syndrome Association (England, Wales, N.Ireland) sponsored the 2nd International Conference on Language and Cognitive Development in Down Syndrome, which was hosted by the University of Portsmouth. Seven of the world’s leading researchers in this field gave presentations and some 80 participants attended.

Regular periodicals published for a world-wide audience
DownsEd continued to publish DownsEd News during 1997. The launch of a new periodical, DownsEd Update, was delayed until early 1998. This new publication, which is to published four times per year, seeks to offer more detailed practical advice for teachers, speech and language therapists and general practitioners, as well as parents, than is provided in the newsletter.

Similarly, the journal, Down Syndrome Research and Practice was delayed due to lack of submissions. Down Syndrome Research and Practice is a peer-reviewed academic journal, with an independent editorial board, that is published by The Down Syndrome Educational Trust. The editorial board includes many of the world’s leading researchers into Down syndrome. The final issue of volume 4 (originally due in late 1996) was published in December. However, Down Syndrome Research and Practice was nominated as the official journal for the 6th World Congress on Down Syndrome and many submissions have been received since October. The Down Syndrome Educational Trust is thus confident that all six issues of volumes 5 and 6 will be published during 1998.

Subscribers to these periodicals include both parents and professionals involved in the care of people with Down syndrome from around the world.

Internet information resources for a world-wide audience
Having established a presence on the Internet in mid-1996, DownsEd continued to expand the range of information available on its web site (http://www.downsnet.org/). By the end of 1997, this included all the key articles from DownsEd News and Down Syndrome Research and Practice that had been published up until early 1997.

Around 20,000 visits were made to the web site during 1997, equating to approximately 8,000 different users.

Visits to the site grew steadily as content was added during the early part of the year. This growth accelerated during last few months of 1997, following a display and demonstration of the site at the 6th World Congress on Down Syndrome in October. Currently the site receives an average of 1,000 visitors each week.

Expanded range of recommended literature offered through mail-order service
To promote the dissemination of information to parents and professionals, DownsEd Limited expanded the range of books and teaching
materials stocked by its mail-order business during 1997. The Trust’s professional team selected these items to represent the best of the available literature and teaching materials for assisting children with Down syndrome. The range complements the books, periodicals, and teaching materials published by The Down Syndrome Educational Trust.

This expanded range was launched in conjunction with new services and training events for the 97/8 academic year in the autumn, and promoted at the 6th World Congress on Down Syndrome in October. The mail order service has been used by over 2,000 customers over the past year.

Resources expansion plans
In December 1996, the National Lottery Charities Board and the Single Regeneration Challenge Fund pledged capital funding of projects to expand The Down Syndrome Educational Trust’s physical resources. Both projects sought to refurbish parts of the Victorian school building that The Down Syndrome Educational Trust partly-occupies.

The first project was to develop expanded resources for Family Services in the north-west wing of the building, including additional playrooms and observation facilities, and a family resource room. Coupled with additional furniture and observation equipment, this was to enable the provision of additional educational groups and assessment services. The National Lottery Charities Board awarded £354,000 to fund this project in December 1996.

The second project was to develop new resources for teaching teenagers and adults in the east wing of the building, including multi-purpose teaching rooms, and a sports and arts hall. These facilities were to enable the Trust to develop its research beyond early intervention and education, and to develop educational services and models of best practice in partnership with the local Further Education provider. £764,000 was awarded in December 1996 through the Portsmouth and South East Hampshire Partnership bid to the UK government’s Single Regeneration Budget (III) Challenge Fund.

As 1997 progressed, plans were further developed and negotiations over the property commenced. The Victorian school building is held under a charitable Trust. Until April 1997, this Trust was managed by Hampshire County Council. From April 1997, responsibility for management of the property passed to Portsmouth City Council as part of wider changes involved in its becoming a unitary authority.

By December 1997 The Down Syndrome Educational Trust and Portsmouth City Council had not been able to agree the necessary lease terms that were required to fulfil the projects’ objectives. The offer from the National Lottery Charities Board was limited to one year and thus lapsed in mid-December.

The Trust is currently investigating alternative options for the development of these additional resources and seeking additional funding to compliment the offer from the Single Regeneration Budget (III) Challenge Fund which still remains.

Relationships with other organisations
Down’s Syndrome Association (England and Wales)
Down’sEd has a positive working relationship with the Down’s Syndrome Association (based in London and serving families in England, Wales and N. Ireland). The two organisations have different and complementary aims:

- The Down’s Syndrome Association’s main aims are to support parents through parent networks and the provision of information and to change public awareness/attitudes to Down syndrome.
- The Trust’s main aims are to promote the development and education of children with Down syndrome. The Trust achieves these by conducting original research and by providing professional advice and training to the parents and professionals who care for those with Down syndrome.

The Directors of both organisations meet regularly to ensure that they work together and maximise their resources. The Down’s Syndrome Association provides funding for some of the Trust’s projects, including £15,000 towards the production costs of teaching materials during 1997.

During 1997, the Down’s Syndrome Association appointed regional Development Officers to serve and develop membership of the national organisation.
Wessex DSA
The Wessex Branch of the DSA held its October meeting on computers at The Sarah Duffen Centre in October 1997. The Chichester Down Syndrome Group also visited The Sarah Duffen Centre for an evening meeting and use of library facilities.

The University of Portsmouth
The Down Syndrome Educational Trust’s historical links with The University of Portsmouth have developed into an alliance promoting scientific research and disseminating quality advice.

The research conducted by this partnership has earned international acclaim. DownsEd now has research links with all the other major international researchers in the field.

The Pro-Vice Chancellor, Dr. Michael Bateman, of the University of Portsmouth became a Trustee of The Down Syndrome Educational Trust in May, 1997.

European Down Syndrome Association (EDSA)
Professor Sue Buckley, is a Vice-President of EDSA and regularly contributes to EDSA scientific meetings in Europe. In October she was appointed Chair of EDSA’s Scientific Advisory Board. The Trust is hosting a web page for the European Down Syndrome Association on its website and is planning to start a Bulletin Board for researchers to encourage European collaboration.

International Down Syndrome Federations (FIDS)
Sue Buckley is a member of the Board of the newly established international federation. FIDS has adopted the academic journal published by The Down Syndrome Educational Trust, as its official journal for its members.

Down Syndrome Associations worldwide
The Down Syndrome Educational Trust is used as a resource by the parent associations in many countries. In 1997, the Trust was invited by parent associations to provide training in Ireland, Jersey, Holland, Norway and Spain. In 1998, the Trust is booked to provide 38 days of training by 19 associations/professional groups abroad.

The Trust’s publications and research findings are being used all over the world to help parents and to support practice. The Trust’s website has become a particularly valued resource in many other countries.

In 1997, the publication Meeting the Educational Needs of Children with Down Syndrome was translated into Spanish and Dutch.

The Trust is being used as a model for the development of similar organisations in the UK and in other countries. The Foyle Down Syndrome Trust in Northern Ireland is the first to be established and the Down Syndrome Educational Trust is providing consultancy and staff training for the Foyle group. Discussions are in progress with four other groups planning similar ventures.
Aims and scope
Down Syndrome News and Update aims to provide information to meet the needs of a variety of professionals and parents caring for individuals with Down syndrome around the world. It covers a range of subjects including early cognitive development, speech and language, general health, medical issues, education, behaviour, numeracy, social skills, and issues in adolescence and adulthood. Information is presented through detailed articles, reviews, research summaries, case studies, news, and by correspondence.

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

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

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

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

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

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

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

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

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

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

Manuscript requirements for longer articles and reviews
Please send four copies of your manuscript, which should be typewritten and double-spaced on A4 paper, with any tables or illustrations. At the same time, please submit your article on a 31/2-inch floppy disc in PC format. Word processors’ file formats that can be supported are (in order of preference): Word for Windows 97, Word for Windows 95, Word for Windows 6, Word for Macintosh 5.1, WordPerfect 6, WordPerfect 5, Works for Windows 4.0, Works for Windows 5.0, or Rich Text Format (RTF). Tables and graphs may be submitted in the following spreadsheet packages’ file formats (in order of preference): Excel 97, Excel 95, Excel 6.0, Lotus 1-2-3, or Quattro Pro. Graphs and diagrams that are submitted as ‘graphics’ file formats should be saved as (in order of preference): Graphics Interchange Format (GIF), Portable Network Graphics (PNG), Corel PhotoPaint (CPT), TIFF Bitmap (TIF), Adobe PhotoShop (PSD), or Windows Bitmap Format (BMP).

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

Format
The suggested title should appear on the first page of the manuscript. The name(s), title(s) and affiliations of the author(s) should appear on the second page. Where there is more than one author, indicate who should receive correspondence. All papers should be in English and spellings should be British.

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

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

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

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

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

ADVERTISING AND SPONSORSHIP
If you, your organisation, or even the company you work for would like to support this publication, you may like to consider advertising or sponsorship.

Organisations may become sponsors by committing to a regular contribution to the production’s overheads. Sponsors will be acknowledged for their support.

Organisations may wish to advertise services, products or events. Although we are happy to publish brief information about events and reviews of products, organisations may wish to display more information.

For further information about sponsorship or advertising in Down Syndrome News and Update, please contact Frank Buckley at The Down Syndrome Educational Trust, or email news-update@downsnet.org

The Down Syndrome Educational Trust currently underwrites the costs of this publication. Receipts from sponsors and advertisers will help to keep subscription prices down and ensure that the publication reaches the widest possible audience.